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Perceptions of Risk and the Management of Miscarriage Among Under-served Populations and Health Providers in Indiana: A Case-study Perspective

BY

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Executive MPH

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PERCEPTIONS OF RISK AND THE MANAGEMENT OF MISCARRIAGE AMONG UNDER-SERVED POPULATIONS AND HEALTH CARE PROVIDERS IN INDIANA: A CASE STUDY PERSPECTIVE

BY

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An abstract of
A Thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements of the degree of
Master of Public Health in the Executive MPH program
2014

Abstract

Perceptions of Risk and the Management of Miscarriage Among Under-served Populations and Health Care Providers in Indiana: A Case Study Perspective

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The purpose of this study is to determine what behavioural or environmental factors are perceived by individuals in this rural area as contributing to their experience of miscarriage or subsequent unexplained fetal loss. In addition, interviews with local care providers will help to ascertain and assess the extent to which community health care providers are equipped to discuss and provide information to under-served populations in rural communities in Indiana with respect to reproductive health and fertility outcomes. This assessment allows for the identification of gaps to initiate targeted remediation, as well the identification of strengths in order to reinforce successes in provider services. It also raises awareness of miscarriage as a significant reproductive and public health problem and suggest ways in which supportive programming could be implemented into current provider services in rural communities.

Recent research indicates that the experience of miscarriage is both ubiquitous and under-recognized by patients, providers and the public writ large. Miscarriage, or fetal death prior to the 20th week of gestation, is an experience, which while common goes largely un-discussed in contemporary culture or public health discourse. Statistically, miscarriage occurs in approximately 10 to 15 percent of clinically recognized pregnancies under 20 weeks of gestation often before a woman even knows she is pregnant. In this study I investigate perceptions of risk based upon socio-cultural behavior and environment among women and men who knew of the pregnancy and experienced miscarriage in the first trimester or who experience recurrent (consecutive) pregnancy loss.

A qualitative approach was utilized to assess perceptions by individuals and providers of the risk and subsequent management of miscarriage. Recruitment of individuals via snowball sampling methodology provided the basis for the case study participants. Open-ended qualitative interviews provided the basis for the case study analysis. Transcribed narrative data were analyzed using standard coding procedures and MAXQDA software.

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Table of Contents

Chapter 1

Introduction

Background of the Problem

The medical definition of miscarriage is the spontaneous loss of a pregnancy before 20 weeks' gestation, when the fetus has a chance of survival outside the womb. Perhaps surprisingly, miscarriage is the most common reason for gynecological admissions into hospitals in the United States and studies suggest that as many as 50% of pregnancies miscarry before implantation in the womb occurs (Stirrat 1990) often before a woman even knows she is pregnant and before the pregnancy is clinically recognized.

Chromosomal abnormalities account for over half of early miscarriages and are described in the medical literature as "chance events" with no known or necessarily discernible cause, and are typically not detected as pregnancies. A "missed" miscarriage or loss of fertilized egg in the womb occurs several weeks later, when a pregnancy may have been detected but implantation into the uterine lining could or did not occur (ibid).

Recent research (Cecil 1996; McCreight 2004) indicates that the experience of miscarriage is both ubiquitous and under-recognized by patients, providers and the public writ large and across cultural contexts. Miscarriage is an experience, which while common, goes largely un-discussed in contemporary culture or public health discourse and is rarely seen as a significant public health problem.

Over the past century, and with heightened attention to both reproductive health care and assisted reproductive technologies and against a backdrop of increasing age of childbearing (for both men and women), researchers have discovered particular risk factors for miscarriage. Commonly cited risk factors include the age of the mother: miscarriage risk rises as maternal age increases. For women under 35 the clinical miscarriage rate is 6.4%, at 35-40 it is 14.7%, and over 40 it is 23.1% (cf. Murphy & Philpin, 2010; Pregnancy Loss, n.d.). Cigarette smoking, certain drugs (prescribed drugs such as aspirin or illicit substances), multiple pregnancies such as twins or triplets, poorly controlled conditions such as diabetes, and auto-immune disorders such as Lupus may also increase the risk of miscarriage. More recent studies focus on caffeine intake, exercise, weight, the presence of phospholipid antibodies in the bloodstream, thyroid concerns and socio-environmental factors as significant contributors to potential miscarriage.

If "[m]iscarriage is the most common adverse outcome in pregnancy, it unfortunately remains one of the least understood and discussed phenomena. For many women it is a traumatic experience and one with little broader social and cultural support or recognition. Previous research has identified shortcomings in the emotional and social support provided for miscarriage sufferers but, personal accounts of pregnancy loss remain relatively under-explored" (Simmons, Singh, Maconochie, Doyle, & Green, 2006) Studies suggest that anxiety and emotion support among couples can aid greatly in the "treatment" of grief, isolation and even of the understanding the health problem, but do little to ameliorate the individual perceptions of risk or management of identity that individuals experience as a result of miscarriage (ibid).

Statement of the Problem

Understanding the socio-cultural context and perceptions of adverse pregnancy outcomes is important for informing the best approaches for public health programs.

Understanding local and individual, patient as well as provider, perceptions of health, stigma, and disclosure is essential to improve access to health services and for patient uptake of behaviors. However, women's perceptions, client's and service provider's understanding and attitudes towards adverse pregnancy outcomes, and how these affect health-seeking behavior, have received scant research attention. This thesis describes the results from a qualitative study that explores the perceived causes of miscarriages and congenital anomalies, stigma associated with these adverse outcomes, and issues around disclosure and health-seeking behavior.

The study was conducted in rural areas of the Midwest, in two of the poorest counties in the state of Indiana where access to provider care for ob/gyn services, in particular, is low. The state in general ranks low on nationwide and overall health statistics, where obesity, tobacco use and diabetes are considered the most pressing health concerns (Indiana State Department of Health Burden Report 2014).

Purpose of the Study

The purpose of this study was to determine what behavioural or environmental factors are perceived by individuals in a rural area as contributing to their experience of miscarriage or subsequent unexplained fetal loss. In addition, interviews with local care providers helped to ascertain and assess the extent to which community health care providers are equipped to discuss and provide information to under-served populations in rural communities in Indiana with respect to reproductive health and fertility outcomes. This assessment allows for the identification of gaps to initiate targeted remediation, as well the identification of strengths in order to reinforce successes in provider services. It also raises awareness of miscarriage as a significant reproductive and public health problem and suggest ways in which supportive programming could be implemented into current provider services in rural communities.

Research Questions

Relevant study questions include: How do men and women understand and describe the experience of miscarriage? How do men and women differ in their responses to miscarriage and pregnancy loss? What are the significant factors that account for the different narratives individuals give to miscarriage and pregnancy loss? Do these shift depending upon whether it is the first or subsequent miscarriage experience? Are there significant socio-economic or other socio-behavioral factors that affect the experiences of miscarriage and pregnancy loss (such as education, income, occupation, religion)? Do the experiences and narratives of miscarriage and perceptions of risk vary across racial/ethnic groups? Given the relative dearth of support services or provider care for the experience of miscarriage, what are the strategies that men and women employ to manage the experience of unintended pregnancy loss? How can these qualitative understandings better inform a provider/patient experience?

Significance of the Study

Understanding individual beliefs and attitudes about miscarriage from patient, as well as provider perspectives, is important to determine better health care support and outcomes. Ultimately the study of the perceptions of risk based upon socio-cultural behavior and environment among women and men who experienced miscarriage in the first trimester or who have experienced recurrent (consecutive) pregnancy loss can help inform and empower patients and providers grappling with treatment options. This qualitative study will help to understand individual knowledge and perceptions of miscarriage in contemporary rural contexts in the United States.

Health professionals promote the importance of reducing miscarriage risks in general ways. Rarely however is miscarriage discussed with patients as a significant public health or reproductive problem prior to pregnancy loss. Better communication strategies and shared understandings of cultural context and significant variables such as gender can lead to better health care, particularly for women in under-served populations. This study will illuminate gaps in knowledge in the understanding of patients and providers that could influence how to promote or culturally contextualize important preventative health messages. These gaps could help lead to more effective communication between health care professionals and the general public about miscarriage, which could augment efforts aimed at increasing access to safe gynecological care and assisted reproductive technologies. This study will provide insights that will lead to hypotheses for future additional qualitative and quantitative research, and will inform decision makers in the allocation of care for those experiencing pregnancy loss.

Chapter II

Literature Review

Introduction

While miscarriage is an ubiquitous experience, the systematic study of miscarriage, perceptions of and management of it has been relatively understudied (Darney, Weaver, VanDerhei, Stevens, & Prager, 2013). The majority of studies have tended to focus on causal factors and links, and several psycho-social studies exist that examine the experience of grief, impact upon family dynamics and relationships, and mental health after miscarriage. Again however, the majority of any in depth, qualitative or quantitative analysis has remained largely focused on the meaning of miscarriage as related to the physiological ability to carry subsequent pregnancies to term rather than emotional or socially constructed responses Some studies, albeit few, focus upon male factors influencing miscarriage outcomes and few, if any, interrogate questions of male perceptions and experiences of pregnancy loss (Abboud & Liamputtong, 2005). Little data exist to situate miscarriage in contemporary discourse about assisted reproductive technologies, the implications of miscarriage, on both patients as well as providers, and how perceptions of and the management of miscarriage occurs in resource-poor areas (and under-served areas such as Indiana) of the United States where ob/gyn services are limited.

This literature review will focus on the three specific facets – the perceptions of miscarriage as a public health problem, the perceptions of miscarriage as a result of individual actions and/or decision-making or environmental factors, and provider perspectives on miscarriage that are available in the context of the United States. I include studies of miscarriage in other cross-cultural contexts in the effort to provide a springboard for my own future work on these issues in global health contexts. The literature review will provide the context for the analysis conducted in this thesis, and how the subsequent results will contribute to continuing guidance for patients, providers, and the general public in preventing and managing early pregnancy loss.

Miscarriage as a Public Health Problem

Reproductive "disruptions" such as infertility, pregnancy loss and fetal genetic disabilities can be tremendously anxiety-producing for those who experience such events. Scholars have situated recent discourse on reproduction in debates over what may be considered "normal" reproduction given advances in technology and assisted reproduction, as well as what the global, political and policy implications of those debates may be (cf. Inhorn 2007). Despite a long social history and feminist scholarship on the phenomenon of miscarriage, pregnancy loss remains largely a medicalized issue for those in health care and sciences.

Regan (2003) notes that in the United States, for example, the phenomenon of miscarriage and pregnancy was long documented in women's lives and yet is rarely discussed in medical texts or manuals. Up until the 1960s and 1970s in this context, miscarriage and pregnancy loss remain shrouded and relatively unexamined as a public health problem – remaining solely an individual concern and an issue for an individual patient and their provider in minimal ways. More recently however, public health awareness movements (Macaluso et al., 2010) and greater attention to pregnancy loss as part and parcel of reproductive health (Brady, Brown, Letherby, Bayley, & Wallace, 2008; Simmons, 2006; Smith, Frost, Levitas, Bradley, & Garcia, 2006) have meant that women have been encouraged to acknowledge grief over pregnancy loss and that that acknowledgement and attention has occurred beyond the boundaries of women's health magazines.

Regan (2003) traces the analysis of miscarriage and pregnancy loss in medical, social science and even popular journals to demonstrate the representations of this public health problem that both men and women encounter over the course of the last century. Regan's argument rests on the notion that awareness of miscarriage has come about in public health in part as a result of discourse over abortion, feminism and medical control over reproductive bodies. In this work it is also clear that an uncritical adoption of definitions and language used to describe miscarriage by hospitals, health professionals and therapists have contributed in part to the arguably still shrouded, stigmatized and complex problem of pregnancy loss.

Socio-cultural, Individual and Environmental Factors

The majority of Americans inaccurately believe miscarriage is rare and misunderstand its causes, creating an often isolating and guilt-ridden experience for those who experience it. These are the findings in the first-ever national survey to assess attitudes and perceptions towards miscarriage (Albert Einstein College of Medicine, 2013). Over one thousand participants (both women and men) believed miscarriage is rare (about 65 percent), when as noted previously, it occurs in one in four pregnancies. This study reinforces the statistic that the majority of miscarriages (60-80 percent) are due to chromosomal abnormalities; however, survey respondents most commonly cited a stressful event (76 percent), longstanding stress (74 percent) and lifting a heavy object (64 percent) as causes. Additionally, respondents inaccurately thought that having the following would cause miscarriage: a sexually transmitted disease (41 percent), an abortion (31 percent) or use of implanted long-term birth control (28 percent). In this study, nearly 23 percent of respondents erroneously believed a miscarriage may be caused solely by the woman not wanting the pregnancy or feeling ambivalent toward the outcome (ibid).

While knowledge of miscarriage rates was low, respondents accurately assessed that it is traumatic, with 66 percent believing the emotional impact is severe and potentially equivalent to the loss of a child; the language used to describe both miscarriage and stillbirth are captured in medical literature as "pregnancy loss" and arguably create perceptions and attitudes toward treatment, social responses and care that stigmatize and shroud miscarriage in clinical (rather than patient driven) terms; ultimately hindering effective communication or treatment of miscarriage and risks as public health problems. Research shows understanding the cause of miscarriage can reduce feelings of guilt or blame; however, currently the origin is only identified in 19 percent of patients (ibid; Murphy & Philpin, 2010; Rajan & Oakley, 1993; Rowlands & Lee, 2010).

Interestingly, public disclosure of a miscarriage by a celebrity or public figure had a positive influence on the feelings of those who had suffered miscarriages (Albert Einstein College of Medicine, 2013). As one researcher states, "[t]he false perceptions and lack of understanding about miscarriage are significant in the U.S., and contribute to many women and couples feeling isolated and alone after suffering from a miscarriage [and] widespread education is needed to reduce stigma and help those who have suffered an early pregnancy loss. Patients should work closely with their doctors to understand the causes of their miscarriages and to work towards successful future pregnancies." Yet provider perspectives arguably remain limited to a medical model of the body (cf. Martin, The Woman in the Body, 1987) and may overlook significant socio-cultural, demographic factors. This may be particularly true in the case in rural, resource-poor communities, both in the U.S. and in any work abroad.

Increasingly too, with later age of childbearing among women in the United States, age related complications and factors related to pregnancy loss have taken center stage in discourse surrounding miscarriage and assisted reproduction. According to the Albert Einstein College of Medicine study, a recent investigation in the Journal of Obstetrics and Gynecology (2013) finds that "sub-fertile" women who are using assisted reproductive technologies experience greater psychological trauma after miscarriage than others, they expect to be able to achieve fertility with more reliability given the utilization of technology. Reliance on assisted reproductive technologies and presumptions about access (not all socio-economic and demographics will have equal access to costly interventions/technologies), on the part of both patients and providers can hinder investigation into miscarriage itself as a significant and socially relevant public health problem.

Provider Perspectives on Miscarriage

As noted previously, approximately15% of recognized pregnancies end in miscarriage, or spontaneous abortion; the proportion increases with the sensitivity of pregnancy diagnosis to a range of 20%-62%. Using a conservative incidence estimate of 10%, there may be half a million spontaneous abortions each year in the United States. *Quality* health-care for miscarriage typically means that women are seen in physician's offices, uterine aspiration is typically conducted and in particular cases, emergency room visits are necessary if resources are available and patients need to be (or should be) seen after miscarriage (for D & C procedures or general follow up). As Harris, Dalton and Johnson (2007) point out, surgical management, in the case of early pregnancy failure is often the norm for those who have access and resources and little discussion between patient and provider is considered necessary (see also Cecil, 1994), miscarriage follow up (D & C procedures primarily) are seen as standard treatments and follow up. For those in this study, not all sought or were able to seek clinical care immediately after miscarriage, but were aware of services through the hospital or alternative care centers.

There are significant studies regarding the question of compliance in reproductive health, and specifically when talking about the meaning of miscarriage. For many providers, women's willingness and ability to comply with provider recommendations, care, and "well-pregnancy" goals become contested and the source of frustration for many. For women in rural and resource-poor areas, the ability to adhere or comply with particular guidelines suggested by physicians or "well-baby" initiatives to reduce the risks of pregnancy are not part of cultural perceptions of health. For example, several studies note the role that cultural context and the influence of culture can play on women's decision making while pregnant, and these studies mirror much of what individuals in this study discussed when talking about patient versus provider care for reproductive health and pregnancy loss. Root and Browner (2001) discuss in detail about knowledge and the ways in which both women and their providers talk about "knowing" about pregnancy and pregnancy loss and contest over the authoritative voice in reproductive loss and grieving/management of loss. Largely absent from discussions of knowledge and awareness of miscarriage is any mention of the role of men and/or systematic study of perceptions or responsibility in compliance or complicity in adherence to drug regimens prescribed for pregnancy. Much of what the provider perspective rests on is the desire of providers to see patients adhere to particular "healthy" pre-natal strategies.

Responses to Miscarriage – Public Health and Political Implications

Regan argues that an emphasis on grief and grieving may easily be seen as apolitical (2003: 370) – certainly grief and an increase in awareness of the necessity for sensitivity to grief and pregnancy loss has been put into place as a means to ameliorate structural and societal inattention to the meaning and management of miscarriage. Nevertheless, attention to and public health responses to miscarriage can have certain politicized implications. As Regan notes, "public fixation on miscarriage as a personal tragedy rather than a public-health problem is certainly politically advantageous for American pharmaceutical, chemical, manufacturing, and agricultural industries, that might otherwise face restrictions" (ibid); if the onus and responsibility for the pregnancy loss is at the individual and behavioral level, than other structural, community and policy level factors need not be explored or addressed. If environmental factors contribute directly to increases in miscarriage incidence (cf. de la Rochebrochard & Thonneau, 2002; Kline, 1989; Triche & Hossain, 2007) then they may have larger implications, unless it remains an individual level health problem.

As Regan (2003) and others (Bansen & Stevens, 1992; Rowlands & Lee, 2010) note too, the insistence on viewing miscarriage as an individual health problem (rather than a public health one) also deflects attention away from inequities in health care, socio-economic and racial and ethnic disparities that produce higher infant mortality rates among some populations (such as among African-Americans in the United States or among cultural groups in cross cultural contexts). Lastly, as medical institutions legitimate and support individual responses and factors as the sole contributors to miscarriage and pregnancy loss, it serves to reinforce anti-abortion, anti-feminist perspectives that suggest ideological stereotypes of woman as mothers, conventional gender norms of gender and family, the primacy of motherhood in defining women as persons and ultimately, the need for less attention by those working in public health to address miscarriage as a serious issue. The assumptions that undergird these perspectives are that women grieve and are sad at pregnancy loss and that is the sole, expected or appropriate reaction – obviously this will vary by life cycle stage, and other socio-cultural factors, but Regan (2003) and others argue that those are secondary factors, miscarriage remains cast as an individual "problem" and not a public health one.

The Health Belief Model

The Health Belief Model is useful in thinking about perceptions of and management of miscarriage in a case study. Specifically, the model can help predict behavior and potential uptake of health care, services and practices (cf. Orji 2012 for discussion of the extension of the model) and more recently, the role that knowledge and perceptions play in personal responsibility. While the model was designed to predict behavioral response to the treatment received by chronically ill patients, in more recent years the model has been used to predict more general health beliefs and practices (Glanz et. al. 1997, 2002) and in the case of this study, it will be used to assess the knowledge and attitudes that patients and providers have about miscarriage.

Chapter III

Methodology

Study Design

This study utilized a case study perspective of qualitative data in Putnam and Hendricks counties in Indiana from 2012 – 2014. These data are results of participant observation and qualitative and in-depth interviewing with participants drawn from a larger study conducted on the meaning and management of miscarriage among men and women in the rural Midwest. In addition to these methods, and at the suggestion of those in the case study, informal group discussions were used for this study too because they allowed for the collection of in-depth data of perspectives on a range of dyadic relationships (patient-provider, women-men, those who miscarry-those who carry pregnancy to term). Further, informal group discussions were beneficial because they fostered open communication about pregnancy loss across a range of constituents, were seen as a means of support and were driven by study participant concerns and initiatives.

I have framed this thesis as an investigation of the lives of several women and men with whom I have worked since the inception of this project several years ago. I have interviewed three women, two men and two providers at great length and have been fortunate to have been granted access to observe care for these individuals at provider offices. The larger context and project from which these data are drawn include far more individuals but I have chosen to focus on the lives of these several individuals to be able to provide a more nuanced, in depth, qualitative assessment of the perceptions of miscarriage over a longer period of time with limited numbers of individuals. I have been able to re-interview and follow the lives of these select participants for this study.

The protocol for this study was determined to be exempt from the IRB review given the use of case study approaches and the small sample size (cf. IRB Guidelines http://www.irb.emory.edu/eirb/index.html). I completed CITI training through Emory and received the IRB letter from Scott Katz stating that "No IRB Review is Required" for this study based upon the sample size and guidelines.

Study Context

This study was conducted in the rural and under-served communities in Putnam and Hendricks counties in central Indiana. These two counties were initially selected for their ease of accessibility to the researcher and an attempt to reflect some diversity in study population. Putnam county is significantly less wealthy as a county than Hendricks county with one hospital serving approximately 38,000 people throughout the 483 square mile region. The majority of individuals live in rural areas and contrasts are sharply divided between those who are farmers and those who work for larger corporate distribution centers (Walmart, Chiyoda, Toyota). Greencastle is the county seat where the largest employer is a residential liberal arts university and is the site of the Putnam county hospital and clinical ob/gyn resources. Unemployment in 2010 for Putnam county was 6.5% and the county is 97.3% white, 4.1% identify as African-American and the remainder Latino or mixed ethnicity according to the U.S. Census (2010). Hendricks county, by contrast, had a larger population of 150, 400 people in 2010, spread over 409 square miles with an unemployment rate of 4.9%. The county seat is the community of Danville which is host to a growing community of midwives and doulas, and the Hendricks county hospital system is one of the most extensive in the state (second only to the Indiana University medical system). Hendricks county also has a slightly more diverse racial/ethnic demographic (although not much) where 89.8% of the population identifies as white, 5.8% as African-American and 3.4% as Latino and the remainder consisted of two or more ethnicities (U.S. Census, 2010). The study counties were therefore largely white, rural and poor communities and the study participants reflective of the demographic snapshot of these areas.

Study Population

This study is a study of primary data collected by the researcher over a two-year period from 2012-2014. Individuals included in this case study were eligible to participate if they were of childbearing age (18-45) and had experienced at least one miscarriage or pregnancy loss. All socio-economic groups were eligible to participate in the study. Having more than one miscarriage was a common phenomenon among study participants but was not a requirement for either inclusion or exclusion in the study. Male partners were included in the case study in order to examine the perceptions, as well as the experience of miscarriage from a male partner perspective.

Data Collection

The primary method of data collection included interview and longitudinal participant observation with the case study participants. Additional and periodic informal conversations were held with case study participants in order to discover common themes in the understanding and perceptions of miscarriage – and included both patient and provider perspectives. To recruit participants, a snowball sampling method (for the larger study) was utilized and participants were asked if they would be amenable to further follow up and participation in this case study project focused on perceptions and management of miscarriage. Both men and women were recruited and consented by the researcher throughout the various stages of these projects. The interviews, case study narratives, and participant observations were not anonymous, but all coded notes have been cleaned of any confidential or identifying information so that no data can be linked in those ways. All transcripts of interviews and follow up conversations have been recorded and transcribed by the researcher with themes and codes compiled in a codebook included in the Appendix.

Data Analysis

The qualitative analysis software package MAXQDA was used to manipulate the textual data for analysis. Thematic analysis is used to analyze the textual data and analysis has involved reading each of the interviews and subsequent interviews and annotating the main themes raised in the data. Initially, this has all been done by hand and notes taken while transcribing. I have done all of my own transcription for this project – largely as a way to become most familiar with these data while simultaneously protecting the identities and life stories/reproductive histories of the individuals involved. A codebook was developed where themes were listed and defined with examples and are included in an Appendix. The codes were developed and defined based upon the main issues raised in the transcripts. The codes were validated for inclusion in the codebook if they were repeated across transcripts or emphasized to be of importance to the participants. For example, if an issue led to a detailed discussion, it was deemed valid for inclusion in the codebook. Both inductive and deductive codes have been developed (discussed in more depth in the Findings/Discussion chapters). The analysis plan was developed, therefore, in conjunction with the core research questions given that each research question should have a core set of associated codes that help to elucidate various dimensions of those questions. Thick description adds to the analysis and connection of data, questions and coding.

Data Quality and Study Limitations

A strength in using the case study approach to collect data is that it allows the participants to have authority, agency and a real 'voice' as individuals, even while tackling a public health and population level problem. Using mixed methods approaches, where individual stories (captured in qualitative data) as well as background facts and statistics that emerge from quantitative approaches that provide a springboard for more in-depth ethnographic approaches are needed to inform policy and play on media interests. Different forms of data may be needed too, to reach different audiences and a more mixed methods approach could better inform future studies on a larger and potentially more representative scale and for comparison (CBPR, n.d.). While great value lies in qualitative data and case studies in particular, there are certain limitations to their use, specifically, the sensitivity and integrity of the researcher, and any biases that may hinder accurate interpretation of these data. There were no language barriers or translation issues to limit accurate interpretation of these data. Limitations that are specific to this thesis are the relative dearth of diversity in the sample, the potential for certain strong voices to be heard over others in conversation and observation and case study related fears over lack of generalizability of findings. These potential limitations were minimized in this study by the researcher's skills in qualitative study design, length of study and as Hamel (1990) suggests, the ability of case study data to emphasize nuance, depth and difference in ways that allow ethnographic data to tell a more complete narrative while using quantitative and statistical data as a backdrop.

Chapter 4

Findings

In this chapter the findings of the data analysis are reported. The results of the study are broken down by analysis of individual patient and provider perspectives and data gathered through participant observation are included as part of the larger social context in which the meaning of miscarriage is mediated. Themes and significant outcomes from MAXQDA appear in the Appendix in tables for both patient and provider responses. Public perception and perspectives as gathered through ethnographic observation are also included as relevant.

Patient Perspectives

Individual responses to questions about the meaning of miscarriage and the management of the body varied but could be organized according to certain salient themes. Specifically, narratives of patients as well as providers coalesced around ideas of miscarriage as particularly gendered, control over the body, clinical constructions of the body, environmental factors and public/private dichotomies. The data in this section are presented in thematic ways and draw upon various cases to highlight how these themes emerged from the qualitative data.

Gender & Identity

Perhaps the most significant theme that emerged throughout this study is the idea that miscarriage and pregnancy loss are inherently gendered experiences. They are not simply reproductively different experiences for women and men, rather the social construction of the experience of miscarriage itself was understood as "naturally" and inherently different according to gender and societal expectations that surround the meaning of pregnancy and loss. The case of Karen and Steven Glazer[1] offers insight into some of the gendered differences in responses to miscarriage.

Karen and Steven describe themselves as "active, busy people, always on the go" and as "people who find it hard to leave people behind", they have moved around a considerable amount for education and employment but each stressed the importance of keeping in touch with friends in each of the places they have lived. Middle-class, white and dual-earners at present, Karen and Steven met when they were both in graduate school in the 1990s in Boston. Karen was several cohorts ahead of Steven in their graduate program in literature and a native of the East Coast. Steven was from the Midwest, he had been married before and had children from that marriage. The two married while in graduate school and as they each described it, "made the decision to finish our degrees, get good jobs together and then think about starting a family when we had more stability". After several temporary and term positions at colleges and universities in the Midwest, the two found themselves in the fortunate position with full-time academic jobs at the same institution.

It was several years still before Karen and Steven planned to have children but as Karen put it, "we felt like we had checked off the first two steps, we had done our degrees, we had the perfect jobs together...of course we kinda felt that the next step in the plan would just fall into place". The two decided to wait until Karen had completed her first interim (pre-tenure) review but both agreed that waiting until tenure would be "pushing it". As Steven described, "I think we both acknowledged that we weren't getting any younger, we felt confident but I think these days you'd also be foolish to look around and

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[1] All names used in this study are pseudonyms unless otherwise noted

not realize that people our age who were not in academia already had kids". Both worried too that when they had children that "the kids wouldn't have anyone to play with in the family...my brother has children already and Karen's brother and sister all have kids and we really didn't want ours to be without that cousin network", Steven relayed.

Once Karen's interim review was complete and successful, the couple began planning and trying to conceive. Karen described how "it wasn't much planning [laughs] we didn't really worry too much, we just thought it was pretty nice to not have to think about birth control, it felt like a relief!" and reflected on how "naïve" she felt they were then, "we didn't even think about the possibility that something would happen that would be a barrier to conception that **we** hadn't been responsible for".

After trying to conceive for several months, it was a relief too when Karen finally became pregnant. Karen described the increasing anxiety and feelings of failure that she had begun to experience (prior to pregnancy) and reflected on the intersections between gender and reproduction:

> "I was getting really anxious...like sex wasn't even as fun anymore, we were completely trying....having sex all the time it felt like...but not in the way that we used to like on vacation...[laughs]...this was beginning to feel like a job and then the hard part for me anyway was that the job was something that I was turning out not to be very good at...it was ironic because I had just gone through such a successful review but I felt like such a failure in everything related to my body...I've always been able to just kinda say, 'oh, I do x, y, z' and then once I say it, I'll get it done...this was completely different, completely out of my control at first so I wanted to make it something that I could tackle and 'get done'...I know how awful that sounds...[laughs]...but to be honest, back then I had no idea of the kind of work that we were going to have to do. I just felt like this is something that a woman should be able to do. And I'm a feminist you know! But if I'm being honest with you, that's how I felt...like, I should be able to get pregnant and when it took a while, I really seriously began to feel like maybe I wasn't a good wife, a real woman...all the stuff that I would seriously gag on if I heard someone else say....that's exactly how I felt and I know for sure that Steven wasn't even internalizing all this

> failure stuff back then, its never really been about failure for him as a person, as a body...I think that is the main difference between men and women on this one".

Karen's description of the challenges in getting pregnant a first time resonated with Steven but as she correctly summarized, his interpretation of what was happening and how they were each experiencing this early frustration was less about failure as an individual and more grounded in sympathy for his partner. Steven talked about how he had his own expectations that "things would eventually work out" and described how when Karen finally became pregnant:

> "I think I just expected that it would work out all along, maybe that's a guy thing, I don't know, I'm not sure what other guys would have to say about that but I do think that the expectation for men is far different than for women. I mean nobody, nobody at all who knew we were trying ever even questioned me about what I was eating or drinking or doing and Karen got those questions all the time, she was constantly monitored even in informal ways, we used to joke about it like the pre-pregnancy panopticon [laughs]...we were expecting that people would monitor a pregnant Karen, like no-alcohol, no caffeine, stuff like that, but this fertility monitoring was tough! It felt like we might as well be having sex in public sometimes...I would get a call, email or text from Karen during the day if she was ovulating and we'd have to rush home or find some way to plan to have sex if not then, later in the day. Crazy. Anyway, once it all worked out it was something I wanted to tell everyone but Karen didn't want to...she wanted to wait the full three months, she was really worried...she was excited but worried because as she told you, she was beginning to think she couldn't do anything right. And yeah, that's what she thought, that **she** couldn't do anything right, not us, she always made it seem like there was nothing wrong with me then".

At twelve weeks into the pregnancy and at the third physician's visit, after which Karen and Steven had planned to tell people their news, it became clear that the pregnancy was not viable. Karen described the experience this way:

> "the doctor was looking and looking for a heartbeat, and he was looking and looking and not finding it and it was this terrible, like, 'I have to leave the room'....and then he came back with different equipment, the ultrasound and

> then there was nothing there. And the title he gave was blighted ovum, very medieval, and some of the terminology is real interesting, really kinda coarse and harsh....so...blighted ovum [pause] basically it had never developed a heart but....my body hadn't rejected the placenta....it was attached maybe? ...the uterine wall, it was there, everything was still there and kinda operative....and I was three days from leaving for a trip with students and they had to do a D & C right away and so we scheduled the D & C for the next morning. And I remember coming home just sort of shocked and you know, the shock of it all..."

Karen described feeling devastated and "like all those old feelings of failure came right back up" for her. She described feeling tension between her own internalization of failure as she stated as "literally a failed reproductive body" but also the frustration that "this wasn't happening to Steven...it was one of the things that we couldn't totally share, I mean he was there and sharing in it and was sobbing, but it was happening to me, to me as a woman". For Steven the experience of that first miscarriage was profound but in ways that he reflected upon as a "learning experience". He stated, "I really felt like it was a learning by doing kinda process and here we were totally crushed, I mean just so, so sad and it was so painful for Karen, but we learned from it and moved on, we cried alot and hurt, but yeah, it made us optimistic".

For Katrina and Paul Roberts, who describe themselves as well-educated "but struggling to make ends meet", the experience of miscarriages highlighted the tremendous differences in public responses to failed pregnancy in terms of gender. Specifically, the difficulty that many men experience in talking about their experience of miscarriage or even the difficulty in getting others to recognize that the miscarriage was a shared experience. For several men, it was clear that while pregnancy was seen as something that happened to the couple, miscarriage was something that was culturally understood as happening to women. Paul, in talking about their first experience stated,

> "The first miscarriage really hit us both hard, it was really difficult, I just couldn't express it to anyone how hard it was hitting me, it felt like it was something that was totally taboo. People at my office were asking how Kat was and I just felt like screaming sometimes so they'd hear me too...you know? Like nobody ever, ever, ever asked me how I was doing, like its completely taboo to ask a guy about it. It was weird, like when we announced we were going to have a baby it was something that was about ***us***, but when people found out it was a miscarriage, it was about ***her***".

Paul noted too that his identity as a "father" was subject to scrutiny as well. Whereas his wife was "seen" as having experienced pregnancy and therefore motherhood to some extent, Paul described feeling invisible and subject to some debate over whether or not he could claim any legitimate identity as a father and observed that the same simply was not true for his wife.

> "Yes, its true, not very many people go out of their way to talk to me, ask me how I'm doing, they ask about Kat but its almost like miscarriage makes men invisible, or maybe people assume we are impervious to the pain of it, the loss is something that Kat experiences but nobody thinks that I would, it's really sad and that just makes it worse, I feel as if who I am as a man, as a father has been lost too but absolutely no one, not even our doctor recognized that. I'm not going to have any Father's Day in the future you know but nobody thinks about how this is for men, what this does to us, I don't want to sound like a terrible guy, I know how hard this is for Kat but what about men? My brother Doug for example, he talks about all his kids and is one of those proud soccer dad types, and here I am feeling completely sad but also, and I'm not real proud of this, but like less of a man and like everyone would laugh if I suddenly whipped out the ultrasound photos we got early on or talked about my kids who died, that would not be cool and is not the kind of thing that guys do".

The results from this research clearly indicate that, where pregnancy loss is approached as a gendered event, which requires reflection, explanation and the development of an appropriate ritual, there is increased opportunity for parents to articulate their *own* interpretation of the experience (cf. McCreight 2004). Yet gender remains a powerful influence on the perception of who can "claim" the miscarriage experience and how others might interpret the meaning of that experience for men and women. For example, when a baby is stillborn, that is, where a baby dies after 23 weeks gestation, a stillbirth certificate is required, which McCreight notes, "serves as a ritualistic affirmation that bereavement has taken place" (2004, p. 336). Fathers, however, who are not married to the mother, are excluded from registering the stillbirth. One man in the study expressed how his grief was heightened when he tried to register his stillborn daughter only to find that, since he was not married to the mother he was unable, legally, to register the stillbirth, although the parents, siblings of the mother and of course the mother herself are able to do so. For many men such as Paul Roberts, social interaction and lack of more formal, legal acknowledgement of miscarriage and pregnancy loss reinforces the idea that these are inherently gendered experiences and that they cannot claim a "miscarriage" identity in the same ways as women.

Gender and Age

For several individuals the theme of miscarriage as a wholly gendered experience was also complicated by age. While Karen and Steven ultimately described at times, very different interpretations of the miscarriage, these descriptions were grounded heavily in gendered discourse about the body and age and ultimately how age matters more for women than men when thinking about reproductive ability. Their experience mirrored those of others in this study; specifically, the older the couple or individual who experienced the miscarriage, the greater the urgency and frustration expressed. For those who were younger or who had only experienced one miscarriage thus far, the responses were more positive, more optimistic. Steven elaborated several times during one of our early discussions together on how he would have been happy to wait even a bit longer to have children although he was cognizant of the fact that Karen's fertility was at risk the longer they waited. As he described at one point:

> "well for me of course, this is not something I would be doing if we weren't together..[laughs] its like having the dog, I probably wouldn't have the dog, or any dog, like I wouldn't have thought about that as an idea if I was just a single guy, on my own and all that...[laughing] which when I think about it is ridiculous because most of my adult life I've been married, but I mean, I'd had my two kids in my first marriage, pretty early on and now they're grown up...and so no, I don't think that at this stage in my life this would be something that I'd be doing...you know you don't see men who go to sperm banks or whatever and really want to be single fathers later in life you know, it is such a gendered thing that is for sure...and in a weird way that is a lack of power [laughs], I know that you will laugh at that and think otherwise...but you know, you know what I'm saying here, that men lose some of that power to have those choices, like if you really wanted to be a single father later in life...anytime in life maybe, you don't have those same options, its completely skewed....."

As he later put it too, "men just have that luxury, we really don't have to think about it in the same ways but we had been so focused on Karen's job that I think it was easier to forget that the clock was ticking". It was easier and it did "make sense" to both Karen and Steven when I talked with them about their decisions to delay childbearing in order to focus on career goals they each had. The problem raised by the miscarriage however was that the pressure was on to fulfill their fertility desires in ways that their work lives and decisions had limited.

Lastly too, the public and private performance of fertility and the challenge to gendered identity became heightened after the Glazer's miscarriage experience. For Karen she described a sense of relief again over the decision "not to tell" others about the pregnancy even though they had "almost made it" to the three month point. She talked about how she "didn't want other people to then have to say something or feel sorry for me or to not talk about their own pregnancies or kids, I think that happens all the time and it would've just added to the sense of failure". Interestingly for Steven, as many men who are willing to talk about the meaning and experience of miscarriage, the response was the opposite. As Steven described,

> "there was this one time, I was in the gym, and this was right after it happened, maybe about a week or so after and this guy is in the locker room, I mean it's a real guys guy type scene and I'm almost embarrassed to talk about it, but it was, it was so testosterone-filled...anyway, this guy from a different department is in there and he was talking smack with this other guy, they're part of the noontime basketball crowd and that's pretty competitive as a group...so this guy shouts at one point, and I mean he didn't even know, ***nobody*** knew what we had just gone through, but he shouts 'oh at least I can get my wife pregnant, knocked her up again!'...like it was a challenge or a one up [coughs, clears throat] and part of the point you know, he is an older guy so it was like this double thing, double message about how virile or whatever he was...you know that's the stuff I wouldn't think twice about before but all of a sudden I took it personally and was thinking about what a complete asshole that guy was".

Throughout my conversations with Karen and Steven, it was clear that the meaning of their miscarriage was complicated by expectations of success in the workforce and as gendered bodies that were subject to biological realities such as age; Karen felt as though she needed to establish a career before starting a family but that control over work and family was challenged by the experience of miscarriage. In this sense the idea of control over the body was another salient theme in the research.

Control

Both men and women in this study talked about the "loss of control" that having a miscarriage presented in their lives. McCreight (2004) notes that for many men, pregnancy loss signaled a profound shift in the expected future plans and direction of their lives. As she notes "when a pregnancy ends there is not only the loss of the baby, but also a loss of future hopes and dreams" (p. 336). Attendance a grief support groups and participation in on-line discussion and blogging groups was something that both men and women in this study did, largely, as Nicole Reitman suggested "as a result of that feeling like everything else was out of control...I felt like I'd lost everything in an instant, in that short span of time I went from being a mom to being nothing...and I had absolutely no say whatsoever, it was all out of my hands". As Dave Forester, a self-described "working class and regular guy", explained too,

> "I've always been a 'take charge' kinda guy, you know I was the first one to organize a team in the neighborhood growing up, or to do the office betting pool for March madness these days and I just have always been someone who likes to be in control [laughs] I admit it, but that was the thing when we had the next miscarriage it just felt like everything was spiraling out of control....like I suddenly had no say in anything that happened...I couldn't stop the first one and obviously I couldn't stop the next one...it was awful. This friend of mine, a guy I've known from work, he took me aside one day and asked me for a beer, we were out and he said something like 'hey man I think you're probably somebody who has gotten everything he always wanted, everything's always worked out for you and this has to be pretty fucking tough'...it was the one and only time that anyone ever acknowledged what happened and that it wasn't my fault".

The lack of control over public recognition or the acknowledgement of death was also significant. Given that stillbirths (death after 23 weeks of gestation) receive certification in a hospital and miscarriages and pregnancy loss prior to that do not, many individuals voiced frustration and sadness over their lack of ability to control that social recognition of the loss. Certification can serve as a ritual and symbolic affirmation that pregnancy, "birth", and bereavement have taken place. If there are remains to be buried as in the case of stillbirth, the loss can feel more complete and individuals spoke about having more control over their bodies and the outcomes if this was the case. For many, control and management of the miscarriage was a way in which management of the alienation that they felt could be handled. Specifically, many women in particular spoke of feeling ostracized from others, alienated from their bodies and at a loss as to how to explain the pregnancy loss. As Carol Byrnes said, "I felt as if I had done everything right, everything in my power and then I had none, no power, no ability to make sense of anything that had happened". Amanda Brown offered a similar observation and said,

> "I was trying really hard to be healthy, take control over my diet, something that I never really did before, I was doing everything 'right' you know, really paying attention because I was aware enough of all the things that could go wrong and I was really worried this was genetic...I knew enough about what happened with my mom and grandma, this was something that they went through but nobody ever talked about. Actually nobody talked about this until much later when I finally was talking about our experiences...my mom was over and we were just sitting around talking one day and she brings this up, like all about her miscarriages and I'm was like 'whoa, what? How come I never knew about this?' and she said people just didn't talk about it, there was nobody to talk to. So anyway I was really careful and my friend totally called me out, she saw me refusing coffee and not drinking and just having decaf or whatever and not going out....[laughs] it was hard to hide and I wasn't even showing yet! Yeah but so I was trying hard to control when information got out, I was trying to control my body and in the end it just didn't matter..."

As Amanda noted and others discussed, the idea of failure and in particular of failed, overly medicalized bodies was present throughout the data.

Medicalization

For Karen Glazer, the way that the clinical personnel and hospital staff medicalized the miscarriage was disturbing. Not only was the miscarriage seen as a "failure" in clinical terms but the overly emotional nature of their traumatic experience led to very few interpersonal interactions with physicians or others who she felt "steered clear of the topic, it was **just** a procedure to them, nothing more" when she had returned for the D & C. For others too the description and categorization of miscarriage as clinical (and individual) failure was pervasive in how they talked about loss and how they had begun to initially understand their pregnant body. Amanda Brown described how,

> "I was totally getting prepared for childbirth, I was online constantly, there are sites that will show you and tell you exactly how big your baby is at that moment, so some days I'd be at work and cruising around the internet and I'd think 'oh, my baby is the size of a blueberry or chickpea'....it is kind of weird too, everything is about the size of a food [laughs] and it's all very happy and benign and nothing is ever very clinical at all, its pretty happy and I'd say, maybe this is going to sound wrong, but it's really presented nicely, its like women or people I guess are taught that being pregnant is something everyone can understand but not something that is ever negative or technical....its watered down and made 'happy'...babies equal blueberries that sort of thing ....well all of that disappears when you miscarry...that "blueberry" becomes a "blighted ovum", a "group of genetically mutated cells" or of course, the old standby..."your body's mistake"....all very medical, all very technical".

I illustrate more of the medicalization and clinical language that surrounds perspectives on miscarriage in the provider perspectives in the sections that follow.

Self-blame & Isolation

Grace, a quiet woman in her mid thirties spoke to me about her three miscarriages. One of Grace's miscarriages occurred in her first marriage and she has had two more recently with her current marital partner. Grace's story epitomizes the stigma and subsequent self-blame that many women (and men) experienced as a result of failed pregnancy. For Grace, her first miscarriage occurred when she and her first husband were young and newly married, as she described,

> "It took us by surprise for sure, I mean I'm not sure that we really wanted to have a baby then, we had been using birth control but not [laughs] very well I guess...we were in our early twenties I guess then, I got married when I twenty two and so I'm not really sure we were prepared, we definitely weren't ready financially or any of that...anyway, so it was a shock but I think we were getting used to it. So one day I was with my friend who was visiting and we were downtown, we had gone to an art show there I think, something

> free but that made us feel grown up you know? I was going to tell her during her visit about the pregnancy but hadn't gotten that far when I had to go to the bathroom...I was cramping, agony....worse than any period pains that I had ever even thought of, I think I knew what was happening to be honest, but I kept telling myself 'oh maybe this is just part of pregnancy'...like it was something that I didn't know about yet...wishful thinking. So I went to the bathroom and my friend followed me, I guess I didn't look well, but she said she had to go too and we are side by side in the stalls, she is peeing and asks me if I'm okay and I said finally 'no, I'm having a miscarriage'....and just like that I'm crying and realizing how awful this is and I have to have it in the bathroom..."

Numerous descriptions of the miscarriage experience illustrate how women feel to blame for the loss. In Grace's case, she went on to describe how she felt that she had even caused it intentionally, "I had this thought that maybe I had wished it, that we weren't ready, it was too soon and I had hoped for this outcome...I know that sounds silly, but I really had that idea that I had made it happen, I was really afraid that I just hadn't wanted it enough". Grace also described a response that many women noted, that she somehow "deserved" it and that the stigma associated with having a miscarriage was warranted. As she said,

> "I had an abortion when I was much younger, in my teens, I guess I thought that maybe that had caused the miscarriage, that first one anyway. I thought I was being punished...the funny thing is, we're not at all religious, I didn't grow up in a religious family really, we went to church occasionally but the punishment thing just came from me thinking about all the times I hadn't wanted to get pregnant and then I was finally feeling happy about it and it felt like someone pulled the rug out from underneath my feet, like I wasn't a happy, married woman anymore, I was back to being a kid who was in trouble, so I deserved it".

Again, Grace's responses in interviews and discussions indicated the individual level of culpability that many who experience miscarriage describe. Other reasons that women gave for miscarriage as a direct result of their own behavior include: drinking too much coffee or consuming too much caffeine, working out too much, or getting "stressed out" at work and trying to "do too much". All of these kinds of responses point to how women internalized and experienced miscarriage as a result of some individual transgression.

Keri Peterson spoke about the ways in which she felt that her miscarriage was her fault. She described both how she "was thrilled to find out about the pregnancy" but simultaneously "nervous because I wasn't sure it was a good time for me to be having a baby". Keri described how she continued to eat and drink whatever she typically did prior to finding out she was pregnant and said, "it included a lot of coffee...[laughs] I have times when I think that I should just have drunk a lot of coffee in my younger days because it seemed to prevent pregnancy from sticking...I could've avoided a lot of stupidity over getting the pill you know?" Keri blamed herself and her "coffee drinking habit" for her miscarriage and while there is some clinical evidence to suggest that caffeine intake can increase risk for miscarriage (Weng, et. al. 2008) as a manifest explanation, the latent explanation, or the self-blame that Keri revealed, was a ubiquitous theme in all of the interviews. All individuals talked about how at some level they felt "to blame" for the pregnancy loss – either through their own actions or inattention to their bodies. As Keri put it, "I could never tell anyone just how much I felt it was my fault...at the hospital when I went that first time to make sure all the baby was gone, I basically felt like I was there for an abortion and everyone was judging me...they knew why I was there, but acted like it was my fault somehow for losing this baby".

Men too talked about ways in which they felt miscarriage was their fault or they were to blame for failed pregnancies. Aaron, whose baby was stillborn said, "at the hospital we were pretty invisible, ignored totally...honestly it felt like we had some kind of disease and everyone, even the hospital staff was worried that it was catching". Aaron also echoed the statements of other men and described feeling "responsible" when his wife was in pain, and for his lack of knowledge, "it is just hard to know what's going on and I felt like I should have known more".

Narratives of individual fault were reinforced in the language of others as well. Specifically, when others learned of a miscarriage, it was not uncommon to either deflect blame away or to create additional stigma. As Grace described,

> "So when I was having that first miscarriage, in that public bathroom and my friend is asking if I'm okay and yeah, yeah I was...it was gross and hurt but I was okay, it was probably still pretty early...again, I didn't really know what was going on back then...it was just my first [laughs, sniffs]...anyway we left the art show and we were walking downtown along the river and my friend is just talking nonstop sort of and says 'oh this happens to everyone I think' and stuff like 'oh you can try again right away' and 'I'm sure it just meant that that baby wasn't going to be right'...like it was some kind of **good** thing...you know she might have been right but on the other hand that was not really what I wanted to hear...she just made it seem even more like my fault, like I was not very good at making a baby, I made a bad one and so she just dismissed it".

For many women and men, relatives' responses echoed what Grace experienced. Todd, the partner of one of the women in the larger study population I interviewed, described how his mother responded when she'd heard that her daughter-in-law had had a miscarriage. He said, "she just kind of brushed it off, she said it happened to everyone and that we shouldn't worry, it probably was meant to be, she said something about how a woman's body always knows and just got rid of it". For Todd and his wife and the myriad others who talked about the language of miscarriage this kind of response was typical. Perhaps not surprisingly however, very few ever talked about the experience of miscarriage outside of their most intimate relationships. Grace poignantly described how she thought that the problem of miscarriage "was just *my* problem, not a *real* problem or something that others would really want to know about, after a certain amount of time too, nobody, even those people who you tell, none of those people want to hear about it anymore...and there certainly aren't any Hallmark cards at Krogers to send to someone who has a miscarriage". Grace's friend, Brittany Neel described how she and her husband got to the point where they were,

> "'Faking infertility' or problems getting pregnant because that was easier than trying to explain how many freaking times we 'failed' and had to mourn, exhausting to think about these as deaths you know, I think that is a protective mechanism in a sense, that I don't allow myself to think too much about it. I don't want to be one of those women who dwell so much on this – I just couldn't take that, I don't know who those people are, why do you want to celebrate those little deaths over and over again? I don't get it".

Brittany also talked about the failure she felt that was symbolized in the material items that surround pregnancy.

> "I think the hardest part for me was the clothing, the stuff – you know I wasn't very pregnant yet and I sort of secretly bought a maternity dress...I mean secretly because I just ordered it from the Gap and it came online and nobody would know...I didn't want to count chickens or jinx it somehow...maybe I was already worried, but anyway, I went ahead and bought this dress and it doesn't really look all that different from other dresses, but I knew it was a maternity dress, so I hung it up and kept waiting, I was really excited to wear it and then the first miscarriage happened and then the second and now its just pushed to the back of the closet...I didn't get rid of it yet, but some days I wonder how long I have to keep that damn dress..."

In Grace's case too, her subsequent miscarriages reinforced what she felt was the cultural assumption that women were most responsible as individuals for pregnancy losses even if those losses are due to environmental and less individual factors.

Environmental Factors

Again, one of the themes that emerged most saliently across the interviews and observations that I conducted was the tension between individual and environmental culpability. For many participants in this case study analysis, it was clear that while they did not necessarily feel "failure-free" in the sense that many (particularly women) reflected feelings of responsibility and failure akin to the descriptions that Karen Glazer gave for her problems becoming pregnant and the subsequent miscarriage; but rather that there were other factors that might be pinpointed as contributing to pregnancy loss. For Vanessa Nelson-Ramirez, who described herself as a Midwest native, originally from Chicago who had moved to Indiana for an old boyfriend's job, environmental factors were the leading cause of her miscarriages in her mind.

When I met Vanessa, she had just had her second miscarriage although this pregnancy had progressed further than her first. She felt extremely successful in many ways and relayed that to me, saying:

> "With this second pregnancy I did so many things correct...it is still a frustration, don't get me wrong, I don't want you to think I'm not upset about this, but I guess what I'd want people to know, the things that I didn't know when I had my first miscarriage was all the stuff that you have to do to keep healthy and to keep everything around you healthy...I mean literally, like just not breathing in second-hand smoke made a huge difference I think, I got my boyfriend and his friends to quit, at least smoking in the house and car and I really think it made a difference. I read about how important vitamins are and now, as I'm thinking about taking baby aspirin to try again, that's supposed to make it 'stick' somehow. I was also a lot more careful about what I ate, no fast food and in between I lost some weight, it is supposed to make it easier to get pregnant so I tried to just create a healthy me, a healthier environment for all of us and I think it worked, well....it worked to a point, now I have to figure out what else went wrong and try to fix that".

For Vanessa, the understanding of the body as mechanical and as subject to external environmental factors was particularly salient. Hers was not the only narrative to describe the experience of miscarriage in these ways, many women talked about "fixing whatever was broken" and "making certain that the environment was healthy". Even when there was disagreement over precisely what "healthy" meant in the focused and follow up discussions with women, most agreed that being "healthy" was inextricably linked to both individual and environmental behaviors and contexts. Individual explanations for miscarriage were less significant for those who talked about the role that environmental factors played.

While no women in this study had been exposed to radiation or had had chemotherapy of any sort, several pointed out that they were aware that exposures to chemicals and toxins of any kind (one woman worried about drinking from an old Nalgene water bottle made from BPA after she had a miscarriage) could lead to pregnancy loss and miscarriage in addition to birth defects among live children. Sarah O'Brien and her boyfriend Tyler Moore both mentioned awareness of how environment and health were related in terms of pregnancy outcomes. Sarah, a high school graduate who is working while taking courses at the local community college in preparation for nursing school described how "people are more aware of the way what we do to the environment can affect our health, I don't think that is surprising, but when I was pregnant I was suddenly way, way more aware of breathing in smoke, or pollution or [laughs] I became one of those people who *actually* read nutrition labels"! Tyler confirmed a similar shift in his perception of the environment, "I learned about toxins in school [college] and was always aware of that stuff, how bad it can be for you but when Sarah was pregnant we even got the app [for the smart phone] so you can click on a food and see what's in it".

Provider Perspectives

Medicalized Bodies

Provider perspectives on the experience of miscarriage highlighted several themes that intersected in various ways with the meanings that individuals gave to the experience. Specifically, providers spoke in gendered ways about miscarriage and reinforced the idea of body as machinery and as something to be fixed, maintained and repaired. Several providers noted too that despite their frustration that patients were not aware of the frequency of miscarriage across the population, they were unwilling to talk about the possibility or potential of miscarriage, or pregnancy complications with their patients; often deflecting questions during initial, routine pre-natal visits and suggesting that "typically patients do not want to hear the negative, the possible bad stuff, we are way more accustomed to focus on the positive and not on the realistic". Overall provider perspectives suggested both individual and environmental factors were to blame for miscarriage.

As Kerry Maynard, a self-described "rural doctor through and through" and someone who finally found her role in being able to care and spend time with underserved populations, noted, "a lot of times I wish I had pointed out the potential problems, the things that can go wrong and the ways to be careful during pregnancy". Kerry is an ob/gyn who sees a great deal of the women in Putnam County. She moved to the area over ten years ago and as her reputation for being a caring doctor has grown, so has the waiting list to become one of her patients. Kerry talked about how she was taught to think about miscarriage and pregnancy loss in medical school and reflected some of the same themes that patients such as Grace Kaufmann and others highlighted. Kerry described,

> "When I was in school you pretty much learned about the weeks of gestation, what happens when and the nuts and bolts of fetal development. We learned about hormone levels and at the time the hot thing to study was fetal alcohol

> syndrome so we were all pretty immersed in learning about that...but now that I think about it, so much of what we were taught was about the problems that patients brought onto themselves, their behaviors and that miscarriage was a kind of 'natural' outcome of some of these things".

For Kerry, it became clear that with the rise of assisted reproductive technologies, wealthier women too were the ones who would increasingly have access to healthy and successful reproductive outcomes in ways that those with fewer socio-economic advantages did. For her, working as a health care provider, the issue of miscarriage is inextricably linked to cultural and demographic factors that affect fertility outcomes. She said, "one of the hardest things here is to convince people to eat more healthily, to reduce sugar in the diet and sodas...oh my god...don't get me started on coke sizes and refills...diabetes, keeping a healthy weight and no tobacco, those are the things I emphasize" she said. But in rural Indiana, numerous women who Kerry attended to and saw throughout their pregnancies or miscarriages, did not have the financial resources or easy access to better food options.

Importantly however, when thinking about provider perspectives on the management and medicalization of miscarriage, no provider spoke of miscarriage or pregnancy loss as something other than an *individual* level, or *personal* problem. In fact one provider argued when I described this study that, "miscarriage is just *not* a public health problem, there is no way you are going to make people believe that not being able to have children or keep a pregnancy is on the same playing field as AIDS or the flu". While others provided more nuanced insight, suggesting for example that larger structural inequalities in women's health and the value of feminist perspectives could help illuminate the reasons for neglect of miscarriage in the field, and into how and why miscarriage might not be seen as a public health problem. Miscarriage is cast as "failure", as one physician put it, "as amped up menstruation, the body is just getting rid of unwanted, unusable material" and such assumptions can potentially influence policy or attention and funding given to dissemination of information or care and support to those who suffer miscarriage. The physician's statement above is an important reflection on assumptions about where funding and public health education and information are disseminated in general and with respect to pregnancy loss in particular.

While Kerry Maynard recognized the significance of the socio-cultural and environmental factors that influenced miscarriage, she readily admitted that she was, "still wedded to that medical model...I really have a hard time talking about miscarriage as something other than reproductive failure or to use terms like 'blighted ovum' when I'm trying to explain what happened". Kerry echoed precisely what patients such as Karen and Steven experienced and reinforced the notion that the language of miscarriage is grounded in medical, technical and mechanical metaphors. For Kerry too, she described the desire on her part to reassure her patients that in fact miscarriage was common and perhaps not the devastating news they so often assumed. She stated that "I know it is difficult, no doubt about it, but I at least try to remind women, and men too I guess, that miscarriage happens a lot, it is just that people don't go talking about it that much...most people go on to have successful pregnancies". She spoke on several occasions about the need to improve her own provider practices and to include some acknowledgement of the potential for miscarriage in early pregnancy. As she put it however, "I think I'm just hesitant to talk about it, loath to talk about it really, because I have this fear that if I talk about it, it will jinx the pregnancy, the patient will think I had something to do with it and I'll lose their trust".

Trust

Trust is an essential part of John Foulkes' narrative about himself. As a physician who has long practiced in Indiana, Kentucky and Michigan, John described himself as someone who has had a "good deal of experience" with the experience of pregnancy and loss and added "miscarriage should be seen as just part and parcel of pregnancy, but nobody ever wants to hear that, no patient wants to talk about it". John has had an unique approach to talking to patients about miscarriage – he encourages them to talk candidly with him about the experience and he is a vehement critic of the language used to describe miscarriage if it is anything other than clinical and descriptive. By this he means that both patients and physicians should be using language that describes precisely what is going on, insisting on as he said, "correct medical terminology" and he is an avid critic of popular culture and magazines that "focus on that damn culture of the baby bump but never say a word about the speed bumps along the way". John believes that patients should be empowered with knowledge about their experience but his own beliefs suggest that that experience is a largely clinical one. As he puts it,

> "I want patients to know what is going on in their own body...it is not mystical, its not magic, it is science and there are things that can be done to control that science and the outcomes, just like any other experiment I guess and that makes it an easy way to explain what happened to a lot of these women. I tell them not to smoke, don't drink, eat good food and take vitamins and that things will work out".

While John's explanation at times echoes the blame and deflection that Vanessa and Todd experienced, John argued that it was not about "lessening" the experience of miscarriage, but trying to actively teach women about their bodies and help inform others as to what to do to have a healthier outcome. John is known in his practice and in the reproductive health community nearby for suggesting to women and their partners that it might be useful and informative to collect the products of miscarriage in order to learn (if patients bring the fetal product to him he will help them look at it and discuss it, he will even give one instructions about how to collect blood and material from the toilet without contaminating the 'specimen') about the reproductive process.

Not all providers in all communities around the country or globe are like John in his straightforward use of clinical language and follow-up with individual patients and families. For the most part when asking women and men about their experiences with providers during or after a miscarriage, most suggested that they prefer that their providers were not "so involved" and most noted that their care providers did not have much interaction at all.

As Jodi, a woman who had just had her third miscarriage said to me, "they [providers/physicians] just expect you to dust yourself off, pick up and start all over again, its like they want to get it right and so they expect that you want the same thing...sometimes it is exhausting...I had days where I felt like a puppy mill but without the puppies...". Others noted too that the kind of "over-involvement" or "attention" that their miscarriages received just served to heighten the sense that they (the patient) were to blame. As Jodi continued, "I kept feeling like I was being coached, if I just kept practicing enough, I'd finally get it right and then everyone would be pleased with my work".

For John and other providers however, the idea of "fixing" or having control over the reproductive body was paramount. From the language he chose to use to the emphasis he placed on empowerment of patients (although again, how that experience was empowering for women was subject to some debate among women I talked to as some felt strongly that

John "couldn't possibly know what it was like for a woman, even as a doctor, he just won't know what it is like" according to Jodi), John was an interesting example of provider perspectives on pregnancy loss. By no means is John typical, but his narrative does illustrate some of the intersections between gendered expectations, language and control over the body. For John and many others too, these intersections can also create tensions in how they treat patients who are seeking care or explanations for miscarriage. As John explained on one occasion,

> "I'd say the hardest part about having to do a D & C after a miscarriage, if its not a clean miscarriage, a natural one, is that feeling that you are actually performing an abortion...don't get me wrong, I'm pro-choice, I have grown daughters, I have always wanted them to be have a choice over their bodies...control...but when you are actually performing this action, something they teach you in medical school...all of a sudden there's this conflict, at least if you are a thinking physician, if you are paying attention to what you are doing and how complex a moment that is...the same is true when I have to tell a woman and her husband or boyfriend about the process of miscarriage...I can get tongue tied, even when I insist on using the 'right' language, I find it hard to talk about stillbirth versus miscarriage versus pregnancy loss...it all runs together but when you stop and think about it, they all have meaning".

It is also clear that in examining patient and provider perspectives, several useful themes emerge that help to situate and explain the meaning of miscarriage. From language to individual and contextual culpability to risky health behaviors, miscarriage can be interpreted through a variety of lenses. One lens through which miscarriage is rarely considered however is as a substantive public health problem, one that removes blame and stigma from women themselves and situates reproductive health in a larger socio-economic and political milieu. In the following chapter I draw upon some of these data to explore the implications of such a study.

Chapter 5

Discussion and Implications

A lack of knowledge about miscarriage was mentioned multiple times throughout each interview, focused discussion or even in participant observation of casual conversation. Clearly miscarriage has real social and personal meaning for individuals, but it remains largely shrouded from public or contemporary discourse about the meaning and multiple avenues available for reproduction. Women are not receiving health communication materials or having conversations with health professionals about miscarriage (either before or after such a loss) nor the ubiquity or potential manageability of pregnancy loss in terms of public health. It seems imperative that women (and men) understand the potential significance of a myriad number of factors – both individual as well as environmental – that can contribute to the potential for miscarriage.

It is the responsibility of healthcare professionals to educate women patients on the potential risks of certain behaviors but it would be erroneous to suggest that placing the onus of responsibility and ultimately blame for miscarriage on women is a sound public health strategy. As Murphy and Philpin (2010) point out in their study of clinical attitudes toward miscarriage, that pregnancy loss, at any stage of gestation, poses a threat to the social order and presents health care professionals with an "ambiguous" situation – miscarriage and bodily products that result are seen as "matter out of place" (cf. Douglas, 1977 for additional discussion of pollution and purity) and as in conflict with more traditional public health or clinical practices.

For some women, the conversation about miscarriage with a health care professional came only after a first miscarriage (and no discussion occurred when pregnancy was first confirmed) and belied clinician's fears of presenting information that might seem contradictory to positive pregnancy experiences and narratives. Others described how discussions about miscarriage often came couched in ICD-9 codes that further alienated the experience of miscarriage from the individuals themselves. ICD-9 codes that read "unexplained infertility" or "recurrent spontaneous abortion" are descriptive in a medical billing and insurance sense but do little to help explain or adequately capture the experience from the patient's perspective.

In his now pivotal work *The Illness Narratives* (1989), Arthur Kleinman spoke of the importance of understanding insider or emic (patient) perspectives on the illness experience. In the case of miscarriage in contemporary rural parts of the United States (and arguably other cultural contexts as well) understanding beliefs and patient perspectives on the meaning and management of miscarriage appears essential if patients and providers are going to have a more fruitful experience. An honest conversation about the potential for miscarriage could affect a woman's likelihood of participating in other health behaviors and would increase public awareness of miscarriage on the whole, dispelling myths from informal sources.

By placing miscarriage in larger cultural discourse about pregnancy and public health, the stigma and social suffering of many could be ameliorated. While studying miscarriage may not directly change behaviors of patients and/or providers directly, using the Health Belief Model as illustrated below can capture the implications of this work:

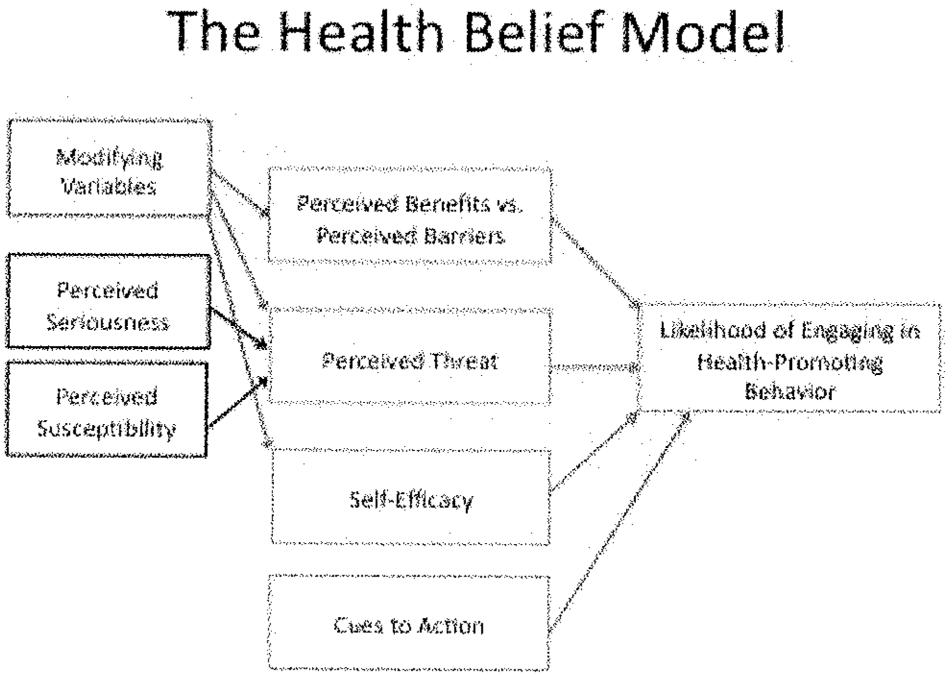

Figure 1: The Health Belief Model (adapted from AFMC Primer)

Historically, the model was utilized to help predict and explain whether patients would change their patterns of behavior based when provided with additional knowledge and influence from health care providers. It seems particularly useful in thinking about the illness narratives and discourse on miscarriage (from all perspectives) as it can help to explain the significance of the **perception** of a condition and consequent behaviors/responses. In the case of miscarriage as these data illuminate, patients who have experienced miscarriage talk about their perceptions of *failure*, of the *body as mechanized* and *inherently gendered* in ways that affect how they respond to pregnancy loss. In addition, *environmental* factors and external influences play a large role in the experience and explanation of miscarriage from the perspective of both patients and providers. For providers too, the perception that some individuals (based on age, or health behaviors such as smoking or drinking alcohol) are more or less susceptible is significant. In placing these ethnographic data from this study into the model, it is possible to see that there is not one model or experience of miscarriage, but rather that certain themes emerge that make it both a public health and political problem.

Specifically, as Regan (2003) suggests that if the onus and responsibility for miscarriage remains at the individual or even behavioral level, then other structural, community and policy level factors need not be explored or addressed. Inequities in access to care and information about reproductive health in rural Indiana are not unique. Patients and providers are often operating with different assumptions about the meaning of reproduction in everyday lives and may talk past each other. Patients should feel empowered to talk about miscarriage in ways that do not reinforce self-stigmatization or blame and should have access to information about miscarriage prior to such an event. Providers should consider the relevance of the experience in the context of their patient's lives; like Kleinman, seeking to place the patient's own experience in broader context. Unfortunately the lack of consistency in medical information given to women creates mystery, doubt and misinformation about miscarriage. Popular culture presents miscarriage and pregnancy loss as inherently devastating but uncommon. The lived experience of women and their partners who experience miscarriage suggests a more complicated analysis.

In interviews, focused and follow up discussions as well as participant observation in the lives of women and men in this study, it was clear that support groups (online and in person) and as discussed via themes of isolation, were effective in the management of miscarriage. One woman suggested that a mobile application could be developed that would increase connectivity among those who experience miscarriage, continuing conversations about the experience beyond the clinical or caregiver context. Another woman pointed out that there are multiple "apps" that facilitate conversations and monitoring for reproductive success (tracking ovulation for example) but none exist that either acknowledge or connect the lives of those who have had a miscarriage. The potential downside to such connectivity however is, as Grace Kaufmann's story suggested, is that once a healthy pregnancy outcome is achieved, the desire to return to a miscarriage or pregnancy-loss support group is lessened.

There is still a lot that remains unknown about women's experience, understanding and the management of miscarriage. Linda Layne, a leading scholar in the study of pregnancy loss suggests "the care given to women who undergo miscarriage or still birth would be greatly improved by applying the principles of the women's health movement to pregnancy loss" (in Inhorn 2007, p. 80). For Layne, models of "prepared childbirth" offer interesting insights into the dearth of information or follow up care that women receive with respect to pregnancy loss. She argues that one of the reasons that women are aware of pregnancy and birth is the plethora of information available; from clinical care to mass marketed media and books on the subject of pregnancy. Popular culture reminds us daily of "baby bump" watches of celebrity bellies and "What to Expect When Expecting" genres of books now occupy entire sections of bookstores. But as Layne asks, "what would 'prepared pregnancy loss' look like?" (p. 81) and is such a model feasible given cultural barriers to understanding the miscarrying body as anything other than "failed" or "invisible". Miscarriage is not routinely considered a public health problem either, seen as an individual and even uncommon experience despite scientific evidence and literature to the contrary (cf. Freedman et. al. 2008; Pregnancy Loss, n.d.; Trinder et. al. 2006). While this study provided important context about patient and provider perspectives on the meaning of miscarriage, using qualitative research, additional qualitative studies are needed to add depth to the issues. Qualitative research seeks to explain more fully human behavior and beliefs. With quantitative data that confirms the ubiquity of miscarriage and pregnancy loss across socio-economic strata, additional qualitative data are needed to understand the context of the meaning of miscarriage for both patients and providers and the recognition of pregnancy loss as a broader public health problem.

This study design did not stratify participants by age group, race or socio-economic status given the case study analysis; so various demographic differences in the perceptions of miscarriage are not observable. In order to identify potential patterns by these features, future long-term ethnographic research should be conducted to stratify focus groups, interviews and observation by socio-demographic or cross-cultural characteristics. Future research too should examine current knowledge of physician's and health professionals about miscarriage and seek ways in which patient narratives and experiences could help inform better management and care practices.

Chapter 6

Conclusion

There is limited recognition of the ubiquity of miscarriage in reproductive life in the contemporary United States. Increasingly, in a world with ever-shifting fertility technologies to help people fulfill reproductive desires, the idea of control over the body and of female reproductive bodies in particular has come into sharp relief. Management of the body (cf. Martin 1987) continues to be a central trope in our everyday lives – one only need peruse the aisles of any grocery or tune into any media source and we learn from an early age of the products and industry designed to keep the female body controlled, managed and healthy. Contemporary corporations such as Facebook and Apple (Tran, 2014) are now investing in the future reproductive potential and childbearing desires of female employees; offering to pay for egg freezing and other ARTs as awareness of the tensions between workforce participation, delayed childbearing and increasing technologies come center stage. Miscarriage is an important aspect of the larger cultural discourse on reproductive decision-making.

Yet the meaning and management of miscarriage remains stunted in relative comparison to other aspects of reproductive life. It has remained shrouded from both everyday public as well as scientific discourse. Literature and popular culture have acknowledged that pregnancy loss may cause emotional distress, discomfort and offer a challenge to family building and planning but rarely are ethnographic investigations of the experience conducted or the cultural meaning of miscarriage explored. At the same time the majority of Americans inaccurately believe miscarriage is rare and misunderstand its causes, creating an often isolating and guilt-ridden experience for those who experience it.

Given that "miscarriage is a traditionally taboo subject that is rarely discussed publicly – even though nearly one million occur in the U.S. each year, making it the most common complication of pregnancy" (Albert Einstein College of Medicine, 2013) it is not surprising that the meanings of miscarriage for both patients and providers have long been seen as individual health concerns.

In order to achieve better patient care and women's reproductive health care in particular, attention to seemingly individual level experiences such as miscarriage must be paid. Miscarriage must be understood not simply as a facet of individual health beliefs or behaviors but rather in terms of greater public health concerns, social inequalities and gender expectations.

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Appendix A

Table 1. Codebook Table of Significant Themes using MAXQDA Analysis

Code	Description	Example
Gender	Use this code when informant describes the role or impact of gender on experience of miscarriage	Popular assumptions, provider assumptions and patient assumptions that miscarriage is a "women's" issue, inattention to male experience of miscarriage
Age	Use this code when miscarriage is described related to age	Miscarriage as linked to later age of childbearing, age of women versus age of men
Medicalization	Use this code when body is referred to in purely clinical terms or as machinery, failed reproduction	Clinical language about failed reproduction, "blighted ovum", "now I know what went wrong and I need to 'fix' it"
Environment	Any information related to environmental factors, knowledge about healthy behaviors and environments	Healthy foods, drinks, lack of tobacco use; changes in behavior as a result of knowledge of pregnancy and environmental factors, "I was very careful with what I ate or drank", "I know there are toxins in the environment that can affect the baby", environmental or illness conditions mentioned in conjunction with pregnancy and/or miscarriage
Control	Use this code when there is mention of individual assertion of control over the body or circumstances surrounding miscarriage, any mention of power	Management of the body and outcomes, "I felt like I had no control over my body", "I had done everything right but had no ability to stop it", "I was a take charge kind of guy but things went spiraling out of control", lack of sharing with others to keep information private, public/private dichotomy
Self-blame	Use this code when individuals refer to miscarriage as their fault, any individual culpability or when blame is mentioned	"I feel as if I did something wrong", male partners blaming selves for not being as supportive as possible, failing to recognize any problems, women blaming themselves for poor behaviors or beliefs that they didn't want the pregnancy
Isolation	Use this code when there is mention of being alone, miscarriage as an alienating experience	"Miscarriage is lonely", "there are no Hallmark cards to buy when someone has a miscarriage", lack of registration of miscarriage vs. stillbirth
Trust	Information related to trust between patient/provider, trust between partners, trust of medical system or of the body	"I want patients to know what is going on with their body", openness, willingness to talk about potential of miscarriage as part of pregnancy