Fear of the Childbirth Experience

by

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Abstract

For many women having a generalized level of fear and anxiety about the childbirth experience is a normative response. This emotion, for some women, translated into a sense of fear that can become so overwhelming that it influences obstetric outcomes, as well as a woman's ability to access and maintain medical care.

Research has been constrained by a lack of a reliable and valid instrument that measures fear of childbirth (FOC) in the context of the maternity care system in the United States. The purpose of this study was to organize the phenomenon of FOC in the United States, and to adapt a gold-standard instrument to accurately measure it. The adaptation of the instrument was guided by Ecological Systems Theory.

In the first part of this project a diverse sample of women were recruited to participate in three focus groups in order to conceptually organize the phenomenon of FOC and to develop language for use in instrument adaptation, the Revised Wijma Delivery Expectancy Questionnaire (R-WDEQ). The findings of the focus group indicated that FOC is a complex phenomenon grounded in fear at the individual, provider, birth setting, and societal level. Content validity of the revised instrument was determined using a panel of six experts resulting in a Content Validity Index of .93. Through item reduction and content validity testing the R-WDEQ was reduced to 10 items and renamed the WDEQ-US. Factor analysis was performed using principal component analysis with oblique rotation revealing three factors, identified as External Fears, Fear of Death, and Internal Fears. The three factor solution explained 63.1% of

the variance. Further testing is needed to ensure that the instrument is accurately measuring FOC across a diverse population of pregnant women.

CHAPTER 1

Introduction

Approximately four million women give birth annually in the United States. They experience their births within the context of a dominant maternity care system that assumes women will be safe, well cared for, and can expect to have a healthy baby. The experience is personal, intimate and unlike any other for women. It represents the rare intersections between major physiological change, intense psychological meaning and vulnerability as a psychosocial event. Although it is a universal transition, childbirth is not only influenced by a pregnant woman's circumstances and expectations but it is also significantly influenced by the broader context of societal and cultural values and norms (Etowa, 2012). Despite what is generally framed as an experience of growth and even a defining event in a woman's life, there are women for whom the experience of childbirth generates a high level of fear.

The general fear about impending childbirth is recognized as normative while there is evidence that an excessive fear of childbirth (FOC) can also be present that extends beyond this normative state. Little is known about how this is expressed and how it might intersect with other pregnancy health outcomes. Studies in other countries have found that FOC is associated with increased use of pharmacologic pain relief (Adams, Eberhard-Gran, & Eskild, 2012; Alipour, Lamyian, & Hajizadeh, 2011; Sjogren & Thomassen, 1997), longer times to accomplish delivery (Adams, Eberhard-Gran, & Eskild, 2012), higher rates of operative vaginal delivery

(Adams, Eberhard-Gran, & Eskild, 2012; Heimstad, Dahloe, Laache, Skogvoll, & Schei, 2006), emergency cesarean section (Nilsson, Lundgren, Karlstrom, & Hildingsson, 2011; Ryding, Wirfelt, Wangborg, Sjogren, & Edman, 2007), preference for elective cesarean section (Nieminen, Stephansson, & Ryding, 2009; Waldenstrom, 2004), self-reported negative birth experience (Nilsson, Lundgren, Karlstrom, & Hildingsson, 2011; Ryding, Wirfelt, Wangborg, Sjogren, & Edman, 2007), higher rates of induction (Sjogren & Thomassen, 1997), increased used of synthetic oxytocin to promote labor progress (Sjogren & Thomassen, 1997) and decreased 'normal' delivery diagnosis (Sjogren & Thomassen, 1997).

Despite the significance of FOC, the definition and description of it in the literature is often conflated with definitions of anxiety or other interpersonal psychopathology. Labor anxiety, pregnancy anxiety, or fear of childbirth are all interchangeable terms used to describe similarly identified phenomena. Fear of childbirth was chosen in order to separate it from the individual psychopathology of anxiety. Historically, fear in pregnancy was a symptom regarded, by care providers, as a fairly unambiguous entity that could be solved by the promise of pharmacological pain relief. However, the existing literature defines FOC as a serious concern about the well being of the child, the labor process, loss of control, distrust of own competence, and lack of trust in the staff present to support the process, elements not necessarily amenable to being alleviated with pharmacological pain management (Sjogren & Thomassen, 1997).

While this is a fairly broad definition, it still places the origin and pathology within the individual realm of the woman. I argue that FOC is a more intricate feeling with an individual and sociocultural pattern of contributing factors. Expanding the definition of FOC to examine the interplay between woman, provider, identity, and culture allows for a deeper interpretation of the

origins of FOC and a more rich understanding of how interventions can be structured to reduce fear and improve outcomes.

Childbirth in context

The culture of birth in the United States is grounded in technologically advanced obstetrics. Women receive the message from their providers and culture at large that pregnancy is a state of unrest where disasters are narrowly avoided through the use of technology and medicine (Davis-Floyd, 2003). This increased acceptance of and reliance on the technocratic model of childbirth has given rise to fears of medical interventions, the fear of being at the mercy of medical technology and providers, as well as the fear of giving birth without medical intervention (Geissbuehler & Eberhard, 2002).

In a similar effort to expand definitions, feminist scholars have attempted to look at childbirth from a psychosocial point of view, asserting that motherhood is a meaningful status for many women, across all cultures. As a result, birth becomes a symbolic moment in this important transition and is richly engaged in cultural understandings of 'womanhood'. Anthropologist Robbie Davis-Floyd (2003) argues that childbirth is a rite of passage into motherhood. She states that the purpose of the various hospital rites organizing medicalized birth is to socialize women to the culture's main beliefs around birth and womanhood (Davis-Floyd, 2003). Alternatively, Emily Martin (1987) argues that relations of childbirth mimic the class relations of industrial production under capitalism in that women's bodies are seen as more or less efficient machines, women as unskilled workers, and doctors as managers (E. Martin, 1987). Despite these analyses of the cultural context as it shapes the social relations of childbirth, their analysis of childbirth directs attention to the level of the individual and to women's lack of trust in, and alienation from, their bodies. While providing an important reason why women acquiesce

in the medical takeover of childbirth, their arguments fail to develop a full understanding of the social context within which birth occurs.

Fox and Wort argue that the social relations that shape the birth, especially the amount of support a woman receives and can count on receiving from family and her providers, influences the decisions she makes during the course of her labor and delivery, and thus her experience of childbirth (Fox & Worts, 1999). As a result, when care providers act upon a definition of childbirth as hazardous and intervene on what is essentially a natural process, they decrease the control available to the birthing woman and potentially alienate women from an empowering experience as well as instilling a sense of fear. Women are expected to accept this legitimacy of biomedical authority and trust that their care providers will take care of their family. Although American women have, for the most part, accepted since the early part of this century biomedical authority and its associated technologies in childbirth, many continue to remain uncertain about its importance (Davis-Floyd, 2003). In reality, much of prenatal care can be seen as a process of medical socialization, in which providers attempt to teach pregnant women their own interpretation of the signs and symptoms the women will experience as the pregnancy proceeds and the significance that should be attached to them (Browner & Press, 1996). As indications for "high risk" pregnancies proliferate and more links are suggested between maternal behavior and negative fetal outcomes, women find themselves expected to accept intensifying prenatal surveillance that is grounded in fear. In stark contrast, historically, childbirth took place in the home under the care of trusted family members or community members. This removal of power and control from the hands of women or trusted community members places women with the undue burden of having to seek trust and alliance with a care system that has historically inflicted numerous abuses upon women, particularly marginalized women. Medicalization of childbirth

has dehumanized its potential as a deeply significant life event for women. Medical practitioners are exerting a greater degree of social control, as well as ever-increasing biomedical instrumentation, over what was once viewed in most societies as a woman-centered, non-medical event (Fisher, Hauck, & Fenwick, 2006). The consequences of medicalized childbirth extend beyond the individual experiences of individual women to the broader issue of societal norms surrounding pregnancy and birth. That is, they not only affect an individual woman's image of herself, but also importantly, tend to generate feelings of incompetence in all women (De Koninck & Parizeau, 1991). Gaining a better understanding of childbirth fear is an important strategy for health care professionals if we are to improve the quality of care afforded women and their families during the normal, but significant life event of childbirth (Fisher, Hauck, & Fenwick, 2006)

Women are also being told that they need to integrate conflicting information from providers, family, friends, and culture and incorporate it into their own self-care because ultimately, when things go awry, as a culture, women are often blamed for not listening to the "right" advice or for making "bad" choices and become the sole vessel for all behaviors and bad outcomes. Thus, the biomedical model has transformed the act of birth from that of a normal, social, intimate event to one where women are isolated and expected to rely solely on a provider with whom they have very little relationship and to fend off or sort through conflicting information about a process they are told is inherently risky and in need of continual surveillance.

There is a need for a greater sensitivity to the broader social context within which women make this transition to motherhood-especially women's privatized responsibility for children's health and well-being. The combination of a powerful life transition, alienation from support,

and reliance on a provider and system that fears the birth process serve as the building blocks of fear of childbirth. For many women this fear is amplified by a historical earned mistrust of the health care system and providers. I argue, it is in this disconnect of responsibility, control, and mistrust that FOC emerges, thus we need to move the definition beyond one of individual psychopathology to an experience contextualized in the sociocultural context of the U.S. Maternity care system.

The need for an expanded definition

Childbirth has a compelling uncertainty in a world enmeshed with dilemmas of power and control. The culture a woman gives birth in has profound effects on her own personal sense of power and control within an unknown and foreign institution. Culture not only specifies the perinatal care available to the perinatal family, but it also socializes and educates thereby instilling the desire for a particular style of care (Williamson & Harrison, 2010). As a cultural phenomenon, human childbirth is a unique process involving highly systematized patterns of care and diverse perspectives so that members of one culture might not recognize care in another culture as care (Etowa, 2012). Practitioners need to be familiar with cultural issues related to childbirth since they constitute the context within which women have children in a community. They should understand the different ways in which mothers conceptualize, explain, and report symptoms of fear and how their own interactions reinforce these fears either directly or indirectly (Dennis & Chung-Lee, 2006).

Even though mothers have various interactions with health professionals in the perinatal period, they are often reluctant to obtain professional assistance and to disclose emotional problems, particularly depression, anxiety, and PTSD (Seng, Low, Sparbel, & Killion, 2004a; Whitton, Warner, & Appleby, 1996). The lack of knowledge about perinatal mental health

concerns or the acceptance of myths is a significant barrier and renders some women unable to recognize the signs and symptoms of what may differentiate normal fear versus problematic fear of childbirth. Furthermore, perceived social pressures hinder women from taking the initiative to obtain assistance due to shame and the fear of being labeled mentally ill (Dennis & Chung-Lee, 2006). For example, the fear of losing custody of one's baby emerged as a major help-seeking barrier in a study of barriers to disadvantaged women seeking help for postpartum depression (Templeton, Velleman, Persaud, & Milner, 2003). This fear is not without basis. Despite the fact that there is not racial difference in substantiated abuse cases, African American children are disproportionately represented in child welfare services populations compared to their numbers in the overall family or child populations and compared to white children living in similar circumstances (Courtney & Skyles, 2003). In addition, reticence resulting from cultural mistrust may be interpreted as evidence of paranoia, resulting in misdiagnosis of major individual psychopathology such as schizophrenia (Hunter & Schmidt, 2010).

The prenatal care relationship between a patient and practitioner is an essential component in minimizing the impact of FOC. Prenatal care is also an excellent opportunity to support women in behavior changes that could improve the prenatal and early postpartum experience (Tough, Siever, & Johnston, 2007). This may be especially true for women with psychosocial risk factors that are challenging to address, including mental health, domestic violence, or substance use problems (Wu et al., 2012). An alliance with health care providers could also have a positive impact on women's integration and processing of a complicated birth in which they needed to trust their practitioner to manage an emergency situation (Berg & Dahlberg, 1998). In addition, this relationship and sense of support has a positive influence on birth confidence, responsiveness to newborn babies, postpartum depression symptoms, and

breastfeeding outcomes (Hodnett, Gates, Hofmeyr, & Sakala, 2003). If care providers' screening for FOC moves beyond the model of FOC as individual psychopathology, they remove the burden of mental health concerns from the woman herself and instead place her within the context of her provider, her birth setting, and her culture at large.

Project purpose

In the literature, FOC has been viewed as either a normative response to an unknown experience or an experience of psychopathology in need of therapeutic response. In actuality, the fear of the childbirth experience is a more complex phenomenon deeply imbedded in the culture in which a woman exists. The experience is influenced by complex phenomena such as social support, alliance with health care providers, and understanding of the system in which she is giving birth.

The vast majority of research done on the experience of FOC has been done in Scandinavian countries by psychologists and obstetricians with largely homogenous populations giving birth in a very different maternity care system. There is a lack of research that contextualizes FOC as an experience that is influenced by larger structures and a need to look at FOC among a more diverse sample of women. Looking at FOC from a global perspective allows us to disentangle the various elements so that the resulting knowledge moves beyond symptom management and toward a need to challenge how the system and structure influence the personal experience. Examining FOC among a diverse sample of women not only provides a deeper understanding of their experience with FOC but also provides an example of how to frame FOC as a phenomenon deeply embedded in cultural expectations and interactions with macro systems. Focusing on diverse populations provides a means to hone a critical understanding of the phenomenon by eliciting an emic perspective from both dominant and non-dominant groups.

This gap in the literature creates increased missed opportunities for care and also underestimates the potential impact of the FOC on obstetric outcomes. A similar example in the literature studied at the University of Michigan is the pathway between stress and increased risk for preterm delivery (Lu & Chen, 2004; Seng, Low, Sperlich, Ronis, & Liberzon, 2009). Women who report high pregnancy related stress levels have an increased risk of preterm birth. This relationship is more striking for African American women compared with Caucasian women suggesting that the role of identity within a larger social structure may have an impact on the phenomenon (Dole et al., 2004). Stress factors such as fear, poverty, the role of perceived racism, life experiences with racism, as well as living in especially segregated residential areas, increase the risk of adverse birth outcomes indicating that the factor of stress is larger than an individual psychopathology and more deeply rooted in systemic or institutionalized phenomena (Collins, David, Handler, Wall, & Andes, 2004; Paul, Boutain, Agnew, Thomas, & Hitti, 2008).

This project seeks to fill the gaps in the literature and expand the concept beyond individual psychopathology with an understanding of how the culture of the woman, provider, and birthing environment serve to reinforce or ameliorate fear of childbirth. The aims of this project are:

- Specific Aim 1: Examine all extant FOC measures in relation to the proposed conceptual framing and consider their empirical adequacy for US research.
- Specific Aim 2: Elucidate and conceptually organize the components of childbirth related fear in a diverse sample of US women
- Specific Aim 3: Adapt an existing instrument to demonstrate the components of a theoretically informed instrument for use in the United States.

As approximately four million give birth annually in the United States, having a more thorough understand of the experience of fear of childbirth fills a necessary gap in the literature. If the conservative estimate holds true that 10% of women experience FOC to such an extent that it interferes with their ability to access or maintain care, elucidating the concept has the potential to influence the outcomes for many women. Examining how the phenomenon is experienced differently in the United States allows researchers and clinicians to being making connections between FOC and problematic obstetric outcomes. Additionally, exploring how structural variables, such as care provider and place of birth, affect FOC offers further critique of the current maternity care system and offers tangible examples of how these systems impact outcomes. Approaching this analysis as a midwife with a background in public health, my hope is to begin to engage in research which pulls from critical theory and aims to produce research findings which are emancipatory by challenging oppressive practices and structures as well as promoting health and well-being.

CHAPTER 2

Review of the Literature

Pregnancy and childbirth are normal physiological processes and significant social and emotional events in the life of any woman and her family. The experience of childbirth, even though inherently unpredictable should be a positive life-affirming event associated with minimal risk of an adverse outcome (Fisher, Hauck, & Fenwick, 2006). Research demonstrates, however, that there is a high prevalence of fear associated with the childbirth experience. Although up to 80% of women identify common concerns (Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001), just over 20% (Hofberg & Ward, 2003; Zar, Wijma, & Wijma, 2001) report more specific or intense worries with between 6–10% of women experiencing severe fear of childbirth that creates dysfunction or is otherwise disabling (Wijma, 2003). The purpose of this chapter is to present the state of the literature reviewing the phenomenon of severe fear of childbirth (FOC).

Fear of childbirth

The prevalence of FOC cited in the literature ranges from 5-52%. The prevalence has been reported at 52% in a sample of 280 women in the US (Lowe, 2000), 10% in a sample of 2,662 Finish women (Waldenstrom, Hildingsson, & Ryding, 2006), and 5% in a sample of 8000 Swedish women (Geissbuehler & Eberhard, 2002). Zar, Wijma, and Wijma (2001) reported 20% of women in developed countries, such as Sweden and Australia, experience childbirth fear

(Hall et al., 2009). Twenty five percent of the one sample reported high levels of fear, while 54% reported moderate, and 21% low levels of childbirth fear (Hall et al., 2009). Women expecting their first child report higher levels of fear than women who have given birth before (Alehagen, Wijma, & Wijma, 2006). The overly broad conceptualization of fear and variation in the time of its measurement contribute to the inconsistency across findings of prevalence and effect on outcomes (R. C. Johnson & Slade, 2003). For example, a highly statistically significant difference was found in the occurrence of complications between anxious and nonanxious women, as measured by the IPAT Anxiety Self Analysis Form (Crandon, 1979). However, in a subsequent study, depression and anxiety subscales were found to be unrelated to obstetric complications using the General Health Questionnaire (Bhagwanani, Seagraves, Dierker, & Lax, 1997) Additionally, the broad range in prevalence reinforces the hypothesis that FOC is deeply grounded in culture and context and supports the need for further research in the United States, particularly among marginalized populations with additional psychosocial risk factors.

Fear of childbirth can be far reaching with adverse physiologic and emotional consequences for mothers, infants and families. Fear of childbirth, as defined in the introductory chapter, is a complex phenomenon with an individual and sociocultural pattern of contributing factors. Previous studies have indicated that the antenatal presence of FOC leads to an increased risk for the pregnant woman having a negative experience during the birth. A woman's FOC, especially intense fear, influences how the pregnancy proceeds, the course of the birth and postpartum bonding (Geissbuehler & Eberhard, 2002).

In some women the fear is specific, and only concerns the event of childbirth. In others, FOC exists in parallel with other types of anxiety disorders. For example, women who fear the physical symptoms of anxiety may be fearful of childbirth given the numerous somatic

sensations associated with even the most medicated of childbirth experiences (R. C. Johnson & Slade, 2003). For those who fear the consequences of anxiety symptoms, such as dismissal or embarrassment, FOC is a natural segue because they are afraid of how they will present themselves during the birth. Women may be afraid of anxiety symptoms appearing during the birth experience and as a result, fear the birth by proxy. Women who are afraid of the end psychological state associated with symptoms of anxiety may experience FOC because of other fears of losing control or of being unable to cope with the birth (Spice, Jones, Hadjistavropoulos, Kowalyk, & Stewart, 2009).

Traditionally the difference between a fear and a phobia is in the level of avoidance a person feels compelled to enact (Ost & Hugdahl, 1981). People with phobias control their situation by means of avoidance. But a pregnant woman with a childbirth phobia cannot avoid what she fears and therefore can feel captured by the situation (Wijma, 2003). The difference in FOC compared with other phobias is that, in many women, FOC increases to a phobic level after they have become pregnant. As in other phobias, the fear gradient increases when the individual approaches the feared situation.

While there is no one picture of who struggles with FOC, previous research indicates that there are certain characteristics that are likely to predispose women to FOC. Of note is that none of the studies included in the summary table presented below were done in the United States.

Table 2.1.

Factors predisposing women to FOC

Predisposing Factor	Reference
Young maternal age	(Standley, Soule, & Copans, 1979)
Low education	(Rofe, Blittner, & Lewin, 1993; Standley, Soule, & Copans, 1979)
Low socio-economic status	(Rofe, Blittner, & Lewin, 1993; Standley, Soule, & Copans, 1979)
Psychological distresses before pregnancy	(Areskog, Kjessler, & Uddenberg, 1982; Sjogren, 1998)
History of sexual abuse	(Areskog, Kjessler, & Uddenberg, 1982)
Low self esteem	(Engle, Scrimshaw, Zambrana, & Dunkel-Schetter, 1990; Lowe, 2000; Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001)
Fear of pain	(Areskog, Kjessler, & Uddenberg, 1982; Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001)
Feelings of vulnerability	(Lowe, 2000; Melender & Lauri, 2001; Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001)
Psychological problems during present pregnancy	(Areskog, Kjessler, & Uddenberg, 1982; Saisto, Salmela-Aro, Nurmi, & Halmesmaki, 2001)
Lack of social support	(Engle, Scrimshaw, Zambrana, &

	Dunkel-Schetter, 1990)
Great number of daily stressors	(Paarlberg et al., 1996)
Previous operative birth	(Ryding, 1993; Ryding, Wijma, Wijma, & Rydhstrom, 1998; Sjogren, 1998)
Previous adverse obstetric outcome	(Ryding, 1993)
Lack of knowledge about childbirth process	(Engle, Scrimshaw, Zambrana, & Dunkel-Schetter, 1990)

From the above table we can ascertain that FOC appears to exist alongside many other psychosocial vulnerabilities, such as lack of social support, young maternal age, low socio-economic status, etc. In addition, the list of predisposing factors is almost identical to a list that could be created for risks of postpartum depression or posttraumatic stress disorder following delivery indicating that FOC shares many qualities with other psychosocial concerns of the childbearing process. Additionally, many of the predisposing factors shown to be of concern in the research, such as younger maternal age or low socioeconomic status may not be inherent risk factors but instead may be indicative of how the imbalance of power between provider and patient informs FOC.

In summary, the review of the risk factors or characteristics for women at risk for FOC is limited in being generalizable to women in the United States as all of the studies have been done outside the United States. Additionally, no studies have looked at all the major variables at once making it difficult to create a picture of which women may be more predisposed to FOC. A limitation of the creating a picture of risk factors and predisposing factors is that some variables may be based solely on the population studied or the variation in analysis that may or may not have included the same variables of interest.

Clinical significance of fear of childbirth

This review will systematically integrate the literature focused on FOC from the past 20 years and address methodological problems in the literature that may blur our understanding of the impact of FOC. A search was conducted for published English language reports of randomized control trials, uncontrolled studies, and observational reports that assessed FOC and obstetric outcomes. The search used a combination of the key words anxiety, fear, tocophobia, pregnancy, labor, and childbirth. Relevant studies were identified by searching PubMed, CI-NAHL, PsychINFO, and EMBASE. A hand search of references cited in the studies pulled through electronic searches was also reviewed to identify additional studies not previously located. A summary of the search process is provided in Table 2.2

Table 2.2

Literature review search process

Total studies pulled	Total studies hand pulled from references	Number excluded	Total number of studies included
172	11	131	52

For the purposes of this review studies that did not conceptually define FOC as a distinct entity were excluded. The isolation of pregnancy anxiety from a background of indices of general anxiety and depression enables clinicians and researchers to address issues of identification, prediction, and prevention and risk reduction more precisely and perhaps more effectively in the future (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004). The significance of focusing on FOC distinctly is highlighted by the following investigation. In a follow up of the children from the pregnancies studied in one report, pregnancy fears were among the strongest predictors of lowered cognitive development and temperamental problems at 8 months of age. In contrast, measures of general anxiety and neuroticism failed to predict

development and temperament at 8 months. In addition, this same study found that only 8-27% of the variance of pregnancy anxiety was explained by general anxiety and depression (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004). The implications of this indicate that assessment of general anxiety during pregnancy may underestimate fear specifically related to pregnancy or childbirth. In addition, case reports were excluded, as were articles where there was no English translation available.

There are a number of different ways a review of the FOC literature could be undertaken. The first would be to organize the studies based on physiologic outcomes such as the relationship between FOC and preference for cesarean section or increased risk for induction. While this approach to the review would present a solid case for the influence of FOC on obstetric outcomes, it places the significance of FOC solely on the physiologic outcome of the individual birth and, as a result, fails to address the larger social structures hypothesized to be significant in understanding FOC. The review that follows is organized by study location. Location was chosen as the organizing construct for this review because of the underlying hypothesis that culture has a significant impact on how women experience FOC. In addition, organizing the review highlights how concentrated the literature has been in the Scandinavian countries making generalizability and comparisons to other countries, particularly the United States, extremely difficult.

Scandinavia

In one cross sectional study in 2001, 74 women were selected from a University Hospital to participate while in active labor. They were given the Delivery Fear Scale (DFS) once prior to receiving any pain relief. The Delivery Fear Scale is a short instrument with ten statements that are answered on a ten-point scale that takes 30-90 seconds to complete. The higher the score, the

higher the fear (Alehagen, Wijma, & Wijma, 2001). Differences in fear were assessed by comparing women who had or who have not had babies previously. Fear during birth was also explored as a predictor of duration of labor, amount of pain relief received and risk of instrumental vaginal birth and emergency cesarean section. Women who had not had a baby previously had higher scores on the DFS than women who had experienced birth before $t(74)=3.91$, $p<.001$). The amount of medication for pain relief received and the duration of labor, but the not the occurrence of instrumental birth and emergency cesarean section, were significantly correlated with fear during the first phase of labor (Alehagen, Wijma, & Wijma, 2001). According to the authors, a likely explanation of the findings is a process of negative feedback in that fear may increase the experience of pain, and that pain may increase fear, which leads to requests for more pain relief (Alehagen, Wijma, & Wijma, 2001).

In a prospective study in Norway, women were recruited prior to a routine ultrasound appointment to assess background information, estimation of fear of childbirth, and estimation of anxiety. Fear of childbirth was measured by the Wijma Delivery Expectancy Questionnaire (WDEQ), translated from the original Swedish version to Norwegian by persons fluent in both languages. The WDEQ is a validated 33-item questionnaire, with scores ranging from 0 (minimum) to 165 (maximum). Chart review was completed after birth to assess mode of birth. A trend was noted towards more frequent operative vaginal birth ($p=0.067$) in the high fear group; however, there was no relationship between fear of childbirth and planned or emergent cesarean section (Heimstad, Dahloe, Laache, Skogvoll, & Schei, 2006).

A cross-sectional study of 1635 pregnant women in Sweden was performed to assess the relationship between FOC and mode of birth preference. The WDEQ questionnaire, described above, was completed as well as demographic and obstetric data including preference for

cesarean section. In a multivariable analysis of the group of nulliparous women, fear of vaginal birth was the only factor that predicted preference for cesarean section (Nieminen, Stephansson, & Ryding, 2009).

A recent longitudinal cohort study of 3189 Swedish women found that those reporting severe FOC were more likely to give birth by elective cesarean section. Six dimensions of FOC were identified by the authors in this study. Women who reported "lack of positive anticipations", one of the six identified dimensions, were more likely to request elective cesarean delivery (Ryding et al., 2015) A dose-effect pattern was observed between level of fear and risk of emergency cesarean section in both primiparous and multiparous women (Ryding et al., 2015).

One segment of a quantitative, longitudinal population-based study in Sweden explored FOC at two time points, one during pregnancy and again one year after birth and its association to birth experience and mode of birth in 1506 women. Participants were recruited prior to a scheduled ultrasound midway through pregnancy and given the first questionnaire with investigator developed questions about FOC. Each questionnaire had one question about FOC, 'Worries and fears are common feelings among men and women facing childbirth. To what extent do you experience worries and fear?' The question was assessed on a 4-point rating scale ranging from 'not at all' to 'very much'. Subsequent questionnaires were sent to the women's home that continued to measure FOC and then also postpartum feelings about the birth. Prenatal FOC was significantly associated with FOC 1-year postpartum, self-reported negative birth experience, and emergency cesarean section (Nilsson, Lundgren, Karlstrom, & Hildingsson, 2011).

In a prospective case-control study women who had sought help from a fear of childbirth team and a group that did not self identify as having FOC were compared. Self-report questionnaires were completed once prenatally and at one-week postpartum. One component of the questionnaire was the 'Fear of Childbirth Questionnaire' that consists of 19 items with the 'yes' or 'no' answers. Comparisons were made between 85 women on fear of childbirth, personality variables (i.e. anxiety prone, more short tempered etc.) and experience of childbirth. The women who had sought help tended to be more anxiety prone and shorter tempered. They also had a more negative experience of their recent childbirth (Ryding, Wirfelt, Wangborg, Sjogren, & Edman, 2007).

A case-control study in Sweden of 1,981 women retrospectively compared FOC scores from the WDEQ for the women with the end result of emergency cesarean section and compared them to controls, matched for age and parity. The odds ratio for emergency cesarean section was 3.0, indicating that women who have a serious fear of childbirth were three times more likely to have an emergency cesarean section (Ryding, Wijma, Wijma, & Rydhstrom, 1998)

A small case-control study in Sweden compared women referred to a psychosomatic outpatient clinic because of FOC with a matched reference group. Women were referred to the outpatient clinic because their physicians identified them as having a high level of fear about the upcoming birth, however no standardized questionnaire was used. Women referred to this clinic with FOC had higher rates of induction, increased usage of epidurals and pudendal blocks, increased use of oxytocin, shorter duration of labor, and decreased 'normal' birth diagnosis when compared women with low levels of FOC. Of equal importance the women in this study who were referred for psychosomatic support for severe FOC had a 50% reduction in cesarean section

for psychosocial indication and vaginal deliveries similar to a reference group indicating that FOC could be modulated using this intervention prenatally (Sjogren & Thomassen, 1997).

A large prospective study using between-group comparison of 2662 women across 600 antenatal clinics in Sweden was conducted to address FOC. Women filled out questionnaires at 16 weeks gestation and two months postpartum. Women were identified as having fear of childbirth if they answered 'very negative' to the question 'How do you feel when thinking about labor and birth?' Women with FOC were compared with those in the reference group without this characteristic. FOC increases the rate of elective cesarean section and may have a negative impact on the subsequent experience of childbirth (Waldenstrom, Hildingsson, & Ryding, 2006)

A more recent prospective study performed in Norway followed 2206 pregnant women with a singleton pregnancy. FOC was assessed using the WDEQ at 32 weeks and then correlated with labor duration, use of epidural analgesia and mode of birth. The prevalence of FOC was 7.5%. Labor duration was significantly longer in women with FOC compared with women with no fear using a linear regression model (Adams, Eberhard-Gran, & Eskild, 2012).

The research done in the Scandinavia countries represent the most comprehensive of the literatures describing FOC and looking at the potential impact on the outcomes. As a summary, increased amount of pain relief, longer duration of birth, more frequent operative vaginal birth, preference for cesarean section, emergency cesarean section, self-reported negative birth experience, higher rates of induction, increased used of synthetic oxytocin, decreased 'normal' birth diagnosis have all been associated with FOC, although the measures used varied substantially when identifying FOC. Taken together FOC is a significant health concern and has a clear impact on outcomes for women in the Scandinavian countries. The research in the Scandinavian countries is also the most comprehensive in terms of looking at fear of childbirth

during pregnancy and during birth and looking at how the experience differs for women having their first baby or a subsequent baby.

Iran

A prospective study by Alipour et. al. was designed to assess the predictive value of antenatal state and trait anxiety and fear of childbirth as independent risk factors for the occurrence of severe postpartum depression. One hundred and sixty nulliparous women in Iran were administered the State-Trait Anxiety Inventory (STAI) and Childbirth Attitudes Questionnaire (CAQ) instrument measures at two points during pregnancy. Depression was measured 45 days and 3 months after birth. High state anxiety was associated with a significantly higher risk for postpartum depression. Higher risk of postpartum depression at the 45th day and third month after birth were independently predicted by trait anxiety. After controlling for age, education level and satisfaction with living conditions, fear of childbirth was found to be unrelated to postpartum depression (Alipour, Lamyian, & Hajizadeh, 2011). This study is unique in that it looks at FOC in a non-European country and examines the interrelationship between depression, anxiety, and fear. However, the study has limitations in definition used for FOC and the method of measurement for FOC. No specific FOC measurement was used and anxiety and depression that developed after 28 weeks was not compared to anxiety or depression identified in early pregnancy or prior to pregnancy.

United Kingdom

A prospective study using between-group comparisons was completed in the United Kingdom with 453 women recruited via mailed questionnaire booklets at 32 weeks gestation. No other inclusion or exclusion criteria were applied. Women gave consent for researchers to receive a copy of her birth summary sheet. The WDEQ and the Speilberger State Trait Anxiety

Scale (STAI) were used to measure FOC. Participants with high fear of labor were not more likely to have an instrumental or cesarean birth (R. Johnson & Slade, 2002).

This study lies in contrast to the numerous other similarly designed studies that did find a relationship between FOC and a problematic obstetric outcome in other countries. First, the study in the United Kingdom only had a 35% response rate, compared with >80% in most of the Swedish studies. Another concern is the use of the WDEQ, which was originally designed and tested in the Swedish language. It is possible that translation of the measure into English has caused some dilution in the meaning of the words identifying fear or alternatively may not capture the features of FOC that are potentially unique within this population. The non-significance findings in this study could also be due to insufficient sample size. Lastly, the study in the United Kingdom chose only to examine the influence of FOC on emergency cesareans and not other obstetric outcomes, many of which have been identified in the Scandinavian investigations.

Australia

A prospective correlational study conducted in Australia measured FOC at 36 weeks gestation and again at 6 weeks postpartum. Data on obstetric outcomes and mode of birth were abstracted from the health record after the woman gave birth. Fear of childbirth was measured using the W-DEQ and was not associated with mode of birth, however, high perception of risk as measured by total score on the W-DEQ was associated with elective and emergent cesarean deliveries (Fenwick, Gamble, Nathan, Bayes, & Hauck, 2009).

Canada

Using a prospective design, a study in Canada was carried out to assess prenatal predictors of postnatal symptoms of PTSD and depression. Women were recruited through

prenatal education classes and completed questionnaires containing the WDEQ by mail prenatally and one month following the birth. Medical chart review was completed to assess for mode of birth, episiotomy, perineal trauma, duration of labor, and Apgar scores. Obstetric outcomes were used to predict postnatal depression and PTSD only. The relationship between the obstetric outcomes and their relationship to prenatal anxiety were not reported. FOC was a small, but statistically significant, predictor of postnatal symptoms of both PTSD and depression (Fairbrother & Woody, 2007).

Work by Stoll et al. is being done in Canada and represents some of the beginning work examining FOC a socio-cultural phenomenon. The first study done by the group was a secondary analysis of an online survey aimed to identify university students' (n=3680) attitudes towards pregnancy and birth, with a focus on fear of childbirth and preferences for obstetric interventions (Stoll, Hall, Janssen, & Carty, 2014). The authors developed a six-item scale to measure FOC. This analysis found that students who were more fearful of birth preferred epidural anesthesia and elective cesarean birth. Worries over physical changes during pregnancy and birth, favorable attitudes towards obstetric technology, and exposure to pregnancy and birth information via the media were also significantly associated with a preference for cesarean birth. An important finding of this study was that fear of birth scores were highest among students who reported that the media had shaped their attitudes towards pregnancy and birth (Stoll, Hall, Janssen, & Carty, 2014).

A follow up study of the same database was done on the open-ended questions of the online survey. Content analysis was performed on women's open-ended responses about their feelings towards birth and comments were analyzed for women with high and low fear of childbirth. Students with high FOC described birth as a frightening and painful process and were

more likely to view obstetric interventions favorably. Students with low fear of childbirth were more likely to view interventions critically (Stoll & Hall, 2013).

United States

Lowe (2000) performed a secondary analysis looking at the relationship between self-efficacy for labor and childbirth fears in healthy nulliparous women. The study contained 280 predominantly white, well-educated, middle class women who were enrolled in childbirth education classes. The Childbirth Attitudes Questionnaire was used as the primary measure of FOC. The sample was divided into a low-fear and a high-fear group and significant differences were found between the groups. Women in the high fear group were characterized by significantly high learned helplessness, poor health locus of control, and significantly lower self-esteem and generalized self-efficacy (Lowe, 2000).

In another United States investigation, a longitudinal, descriptive study was carried out among a convenience sample of 35 English-speaking, predominantly white nulliparous women who were partnered and enrolled in a childbirth education program. Women were interviewed in person and given three self-report instruments to complete upon enrollment, 4 hours after labor onset and after birth. The Prenatal Self-Evaluation Questionnaire II (PSEQII) was used to evaluate pregnancy and childbirth-related anxiety. Medical records were obtained to extract perinatal data regarding labor and birth. Prenatal anxiety was significantly related to decreased self-efficacy for childbirth, labor pain, number of hours at home in labor, and a greater admitting cervical dilation (Beebe, Lee, Carrieri-Kohlman, & Humphreys, 2007). Interestingly, the women being admitted with greater cervical dilation can be assume to have delayed hospital presentation. Based on the studies in Scandinavia countries, this lies in contrast to what might be expected for women with anxiety and fear about the childbirth process who may be thought to

want to be in the professional care of others. It begs the question of whether the fear expressed by women in the United States matches the fear of women in other countries. If the fear for women in the United States lies within the hospital structure as opposed to the process of childbirth itself it would make sense that women would present at later dilation. These findings support the need to examine issues of alliance and safety with care providers as an important contributor to FOC and also reinforce the need to look at FOC from a systemic view as opposed to only considering it from the perspective of individual psychopathology.

A prospective study in Cleveland, Ohio was conducted with 88 nulliparous women to assess for anxiety levels. The Spielberger State-Trait Anxiety Inventory was delivered three to four times during pregnancy and the scores were averaged for correlation with perinatal outcome. The information regarding perinatal outcome was obtained from the medical records. A positive correlation was present between anxiety scores and postdates birth, thick meconium, and neonatal congenital abnormalities (Bhagwanani, Seagraves, Dierker, & Lax, 1997).

The study of FOC in the United States has been limited generally but especially for marginalized women. The three studies done in North American included a total of 28 non-white women compared to 403 white women. In addition, none of the studies sought to examine how the context of birth differs for women in North America and how the technocratic model of birth adds to the prevalence of FOC or how it might influence outcomes particularly in marginalized women where the phenomena may be heightened by issues of mistrust of care providers and the daily experience of racism. In order to accurately measure FOC in the United States,a measurement is needed that includes the contextual features of diverse women with very different histories and experiences with the health care system. In addition, the highly medicalized care that is so pervasive in the United States may impact women and previous

studies have not disentangled these type of care practices or have assumed that care practices do not have a significant impact on the experience of FOC as a phenomena that extends beyond individual psychopathology.

Treatment approaches

As much of the previous research on FOC has come from psychology and obstetrics, the overall theoretical framework is one of individual psychopathology. As a result, the majority of treatment approaches to FOC have been counseling with the long-term goal of reducing women's fear. For example, in Sweden, the standard care for women with FOC is usually counseling with specially trained teams of midwives and obstetricians (Ryding, Persson, Onell, & Kvist, 2003; Saisto, Toivanen, Salmela-Aro, & Halmesmaki, 2006). However, there is a lack of detailed guidelines that describe how the counseling teams should work and a lack of consensus about the best way to perform treatment. In addition, the research published about the outcomes of such counseling shows minimal to no effect on even soft outcomes such as reduced fear or a positive birth appraisal.

One of the first studies that looked at the influence of counseling on FOC was done in Sweden in 1998. Women with severe FOC were placed into psychotherapy during pregnancy and compared with matched references who received standard, brief counseling at prenatal visits. In spite of the social support women still identified the birth experience as stressful and have similar appraisals about the experience as women who did not receive counseling (Sjogren, 1998). Saisto et al. compared cognitive behavioral therapy and conventional prenatal care and found that while both methods reduced unnecessary cesarean sections; neither was effective in reducing women's FOC (Saisto, Salmela-Aro, Nurmi, Kononen, & Halmesmaki, 2001). A follow up study explored 14 sessions of group therapy combined with relaxation in nulliparous

women and found that women in the intervention group had a small but statistically significant lower rate of emergency cesarean section (Saisto, Toivanen, Salmela-Aro, & Halmesmaki, 2006). Another study in Sweden followed a group of 62 women identified as having high FOC who underwent counseling with specially trained midwives. The women who underwent counseling actually identified their birth experience as more frightening than the control group despite being satisfied with the counseling process (Ryding, Persson, Onell, & Kvist, 2003).

A similar trend was found in a Swedish study of 936 women. Women who underwent counseling reported higher FOC for up to a year after birth, had a more negative birth experience that did not change over time and preferred cesarean section to a greater extent in the case of another birth (Larsson, Karlstrom, Rubertsson, & Hildingsson, 2015). Another recent study in Sweden used Internet based cognitive behavioral therapy (ICBT) to attempt to alleviate fear in women identified prenatally as having severe fear of childbirth. The study interviewed 15 women who completed eight weeks of weekly ICBT sessions. The study found that after the counseling the women had a more "realistic" sense of childbirth and perceived their partners and care providers as more supportive, but had little effect on their FOC or outcomes (Nieminen et al., 2015).

The limited effect of these counseling approaches suggests either FOC extends beyond an experience of individual psychopathology or that the counseling approach requires greater definition to accomplish an effect. Approaching FOC as a phenomenon that can be resolved with symptom treatment or simple relaxation exercises, as was done in the treatment studies reviewed here, appears to be inadequate. It is possible that the interventions were not helpful. But it is also possible that the conceptualization of FOC as an individual psychopathology is incorrect or only a partial understanding of a more complex issues. Sociocultural factors were

not considered but, as argued above, may represent an important unmeasured component of FOC that may warrant changes in practice rather than treatment of women experience fear.

Summary of previous research

In summary, the vast majority of studies about FOC have come out of the Scandinavian countries and have taken place almost exclusively with Swedish women. Among these studies FOC has been associated with a greater desire for pain medication, higher rates of induction, preference for cesarean delivery, emergency cesarean section and a negative self-reported birth experience. A variety of scales have been used in these studies. These studies are similar to the work done in Australia that also found women with fear to have higher levels of elective and emergency cesarean and work done.

Studies in the United States and Iran correlated FOC with higher rates of postpartum depression, anxiety and PTSD. The few studies that were done in the United States also found that women with high FOC had lower self-esteem, lower self-efficacy in health settings, and a higher prevalence of post dates pregnancy and thick meconium during the birth process.

Studies done in the United Kingdom stand in contrast to many of the Scandinavian studies where no relationship was found between FOC and emergency delivery or cesarean delivery. The studies done in the United Kingdom used an English translated version of the Wijma Delivery Expectancy Questionnaire (WDEQ), which begs the question of if the study population actually did have lower rates of emergency or cesarean delivery or if the problem lies in the measurement of FOC and the translational concerns of the WDEQ.

The few studies done in Canada were some of the first to address the issue of sociocultural concerns informing FOC. These studies found that FOC was associated with PTSD

and depression in pregnant women. The study in Canada that surveyed non pregnant women found that women who had a generalized fear about the birth process had a preference for epidurals and elective cesarean sections. This is one of the first studies that looked at FOC as a phenomenon that exists outside of just pregnant women.

Limitations of previous research

There are a number of important conclusions that can be drawn for understanding FOC of women in the context of the US maternity care system from an overall assessment of this literature review. The first is the complexity of applying research conducted in other countries to the context of care and women in the United States. As described above, research on FOC is limited outside Scandinavian countries. Low rates of intervention, homogenous populations and a publically funded universal health care system create a very different environment for studying FOC than in the United States (Fenwick, Gamble, Nathan, Bayes, & Hauck, 2009). As Lowe states, the sociocultural climate in which women in the United States develop their impressions about childbirth deserves attention. The technocratic model of childbirth in the United States has fostered the medicalization of virtually all childbirth so that the conceptualization of birth as a normal life event has been lost (Lowe, 2000). Young American women develop their view of birth in the context of the fear and emergency based, predominant model of hospital birth as seen on television shows like ER, Maternity Ward, and Baby Story. These overly dramatized depictions of birth in combination with an increasing access to information about maternal morbidity and mortality create a culture in the United States that is reliant on and encourages FOC. The significance of these larger structural informants of FOC is seen in some of the more recent Canadian research (Stoll & Hall, 2013; Stoll, Hall, Janssen, & Carty, 2014). External conditions that generate childbirth fears often relate to the context or environment in which

women give birth and the interactions and actions shared with health care professionals. Examining the linkages between FOC, health care providers, birth setting and larger social constructs is essential in understanding the phenomena of FOC.

Additional challenges are noted that affect the ability to apply what is known about FOC from international studies to women in the United States. The lack of statistically significant findings in many studies can be attributed to weaknesses in the designs employed in the studies (R. Johnson & Slade, 2002). For example, in one study multiple regression was done with 16 variables which would require an n=560 for adequate analysis (Tabachnick & Fidell, 2007). In this particular study there were only 93 participants (Clifford, Weaver, & Hay, 1989). In another example, several studies used large numbers of potential obstetric outcomes collapsed into one composite score and participants were then considered a "complicated" case if they had one or more of the possible outcomes (Clifford, Weaver, & Hay, 1989; McCool & Susman, 1994; Rizzardo, Magni, Cremonese, Talamo Rossi, & Cosentino, 1988). The range of results that vary by country speak to the need to have country or context specific studies to explore how FOC impacts outcomes. There are many issues specific to the manner in which researchers have measured or defined obstetric outcomes. Researchers have measured obstetric complications inconsistently and without a systematic look at overall impact. For instance, many of the studies have a small number of women and may be underpowered to explore some of the less common outcomes such as preterm birth, low amniotic fluid, or low birth weight. Other studies just focus on one or two outcomes that usually involve a combination of a number of factors, such as emergency cesarean sections. Studying outcomes that conceptually match the current understanding of FOC, such as length of labor, use of analgesia, satisfaction with birth process, etc. may provide a more rich understanding of how FOC affects women. In addition, the

development of a many new instruments that have not been subject to psychometric evaluation, including reliability or validity offer challenges for researchers seeking to tease out the difference between generalized anxiety and anxiety specific to childbirth (R. Johnson & Slade, 2002).

In summary, despite numerous studies seeking to understand the impact of FOC on obstetric outcomes we have limited information specific to women giving birth within the United States. This is particularly true when we are seeking to apply the previous research to women's experience of pregnancy and childbirth in the U.S. system of maternity care. The complex system of biomedical care that encompasses maternity care in the United States is a very likely contributor to fear and studies of FOC need to take place within the system to fully understand its depth. Additionally, we have no instrument that has been confirmed appropriate for use with US populations generally and specifically not with the populations at greatest risk or that warrant greater focus.

Conclusion

Despite its framing as a positive life event, the process of pregnancy, labor and birth is a physiologically and psychologically stressful event even when all aspects of it result in a positive outcome. There is limited information about the experience of FOC in the United States. However, the limited research that has been done in other countries has demonstrated a link between FOC and limited, problematic obstetric outcomes. Without being able to adequately identify FOC in U.S. women there is option for potential interventions on the individual or structural level. The cultural context of birth in the United States and the medicalized approach to care may actually increase risk for women to experience FOC. This is a particular concern for marginalized population that come to the experience of birth with a potential history of poor care

or perceived discrimination from their health care providers. Therefore, the purpose of this project is to gain a better understanding of how FOC is experienced in the United States by using a broad cross section of women as participants.

Women's psychological experiences during the actual process of labor and birth are an essential part of obstetrical care. The findings of this integrated literature review and the review of the limitations of the current research highlight the importance of finding the fearful women during pregnancy. In terms of reducing FOC, further research to investigate the nature of fear and the efficacy of interventions is therefore warranted (R. C. Johnson & Slade, 2003). In order to do so attention is needed at both the individual level but also must consider the environment in which the birth takes place and the practitioners providing care to women. Lastly, gaining a greater understanding of how disadvantaged women experience FOC and how levels of FOC interact with other complex psychosocial elements, such as mistrust of care providers and perceived racism provides insights into how psychosocial phenomena impact obstetric health disparities. The following chapter offers support for the use of an ecological model to understand FOC. The proposed model can aid in a multidimensional investigation of FOC in the context of today's maternity care setting.

CHAPTER 3

Conceptual Model of Fear of Childbirth

Introduction

In the literature reviewed in the previous chapter, fear of childbirth (FOC) has been centered as an individual psychopathology. Little attention has been paid to contextualizing the experience by culture and social context. The dominant approaches to childbirth in the US maternity care may likely contribute to fear and need to be considered when looking at the phenomena. The social context in which women live their lives may also contribute to questions of fear and may be activated throughout women's lives as they experience institutionalized discrimination in the form of systematic oppressions. To fully conceptualize these aspects of FOC, a conceptual model should encapsulate the sociocultural context the woman lives in and consider how it interacts with the added structural aspects that may lead to FOC. The purpose of this chapter is to re-conceptualize FOC as an complex phenomena grounded in individual experience but informed by larger structural issues related to immediate social support, care providers, and the setting in which a woman gives birth.

The dominant contributions to the literature on fear of childbirth (FOC) have been from psychology. The result is that the understanding of the phenomenon has tended to emphasize the individual experience. However, the ideology of individual responsibility inhibits understanding of the phenomenon and substitutes instead an unrealistic behavioral model that many argue supports a victim-blaming ideology (McLeroy, Bibeau, Steckler, & Glanz, 1988). The

individual model instructs people to be individually responsible at a time when they are only one contributor to a complex birthing environment. This focus on the individualized experience is often at the expense of action needed to change organizational, institutional, environmental conditions that shape a woman's experience and her perception of birth (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Systems models remove the unreasonable attribution of responsibility to the individual by recognizing many forces shape each woman's perceptions of pregnancy and childbirth. Systems models can enhance human dignity by moving beyond explanations that hold individuals solely responsible, and even blame them for, problematic feelings or outcomes (Sallis, Owen, & Fisher, 2009). Systems models have long been considered the most appropriate way to view development and change in individuals, families, and organizations (Sword, 1999). They offer a way to conceptualize the interdependence among people, their behavior and their environment (Carlson & Chamberlain, 2005).

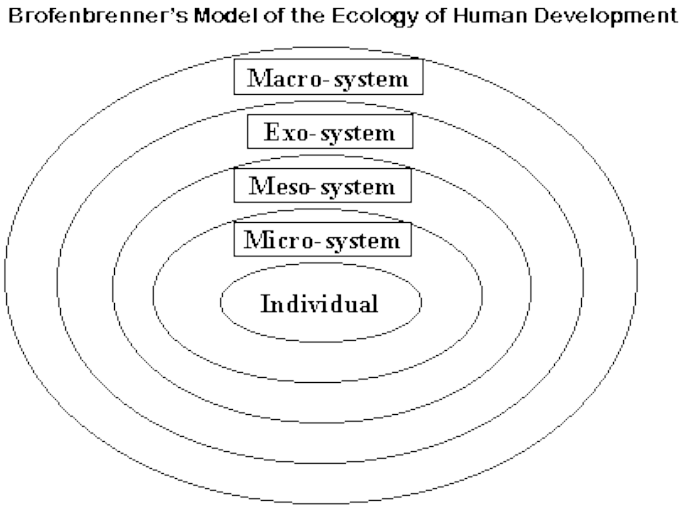
One commonly used system model is Bronfenbrenner's Ecological System Theory (EST), which offers an approach to understanding how multidimensional levels interact and influence health behavior. The model specifically considers the interdependence of the biologic, psychological, and sociologic systems at work in many health behaviors. The purpose of this chapter is to provide an overview of the EST model as it applies to FOC in women in the United States. The multilevel perspective that the EST provides offers a promising approach in health promotion efforts because it offers researchers a chance to look at multiple influences on one health phenomena, in this case FOC.

Ecological Systems Theory

Ecological Systems Theory (EST) is a conceptual model developed by Russian born psychologist Urie Bronfenbrenner. Bronfenbrenner developed the model to focus on the interplay between research and policy related child development. Bronfenbrenner adapted EST from the physical sciences to apply to human behavior. He discussed the different systems levels as (1) the microsystem-including the roles and characteristics of a developing individual, (2) the mesosystem-the settings with which the developing person interacts, (3) the exosystem- settings with which the individual does not interact directly but that nonetheless have an effect on the individual's development, and (4) the macrosystem- cultural values and variables that affect individuals (Corcoran, Franklin, & Bennet, 2000). Bronfenbrenner viewed the individual's experiences as a "set of nested structures, each inside the next, like a set of Russian dolls." His model stresses the importance of interactions between characteristics of people and their environments and holds that 'the main effects are in the interaction' (Franklin, 1988a). Although the ecological model was developed to describe factors that influence individual differences in child development, such a model is applicable to other interactive systems (Logsdon & Davis, 2010).

Figure 3.1

Bronfenbrenner's ecological model



The term *ecology* is derived from biological science and refers to the interrelations between organisms and their environments. Ecological models, as they have evolved in behavioral sciences, public health and nursing, focus on the nature of people's transactions with their physical and sociocultural surroundings (Sallis, Owen, & Fisher, 2009). The environmental levels of influence distinguish ecological models from behavioral models and theories that emphasize individual characteristics, skills, and proximal social influences such as family and friends, but do not explicitly consider the broader community, organizational, and policy influences on health behaviors (Sallis, Owen, & Fisher, 2009). Thus, an ecological perspective implies reciprocal causation between the individual and the environment, sometimes referred to as a transactional model (McLeroy, Bibeau, Steckler, & Glanz, 1988).

A key strength of EST is its focus on multiple levels of influence that broaden options for understanding and intervention (Sallis, Owen, & Fisher, 2009). Health policy groups rely increasingly on multi-level interventions to solve the most pressing health problems. Based in part on the success in reversing the epidemic of tobacco use, there are high expectations that

interventions based on ecological models can address other complex phenomena (Sallis, Owen, & Fisher, 2009). EST assumes that appropriate changes in the social environment will produce changes in individuals, and that the support of individuals in the population is essential for implementing environmental changes (McLeroy, Bibeau, Steckler, & Glanz, 1988). Bronfenbrenner's EST addresses the complex and multidimensional nature of the social problem of FOC with its conceptualization of the individual as being affected by the larger systems levels (Corcoran, Franklin, & Bennet, 2000).

Ecological models offer multiple levels that are inclusive of factors that influence health behaviors and beliefs. Ecological models specify that factors, including intrapersonal, interpersonal, organizational, community, and public policy, can influence health behaviors, and particularly health beliefs. A single level intervention may only focus on a set behavior whereas a multi level intervention would consider the context, values, and beliefs about the role of that behavior in the individual, family, environment or community. Inclusion of multiple levels of influence distinguishes ecological models from theories that primarily focus on one or two levels. A direct implication of ecological models is that single-level interventions are unlikely to have powerful or sustained population wide effects (Sallis, Owen, & Fisher, 2009). For example, a review of randomized controlled trials seeking to prevent sexually transmitted infections compared single-level interventions with multi-level interventions and population level interventions. While HIV transmission rates were uniform across the three groups, multi-level interventions were significantly more likely to prevent transmission of all other sexually transmitted infections (Manhart & Holmes, 2005).

Many examples of interventions targeting individuals have shown short-term effects. Educational interventions designed to change beliefs and behavioral skills are likely to work

better when policies and environments support the targeted behavior changes. Similarly, environmental changes by themselves may be insufficient to change behavior. For example, putting more fruits and vegetables in all convenience stores may have little impact unless the environmental change is supported by communication, education, and motivational campaigns (Sallis, Owen, & Fisher, 2009).

In the United States one of the best examples of the successful implementation of a health promotion program using Ecological Systems is the case example of tobacco use. The magnitude of America's continuing tobacco related illness, combined with the success of the nation's multifaceted smoking control endeavors, make tobacco control an excellent candidate for examining why a multilevel approach to health and disease is essential (Smedley, Syme, & Institute of Medicine Committee on Capitalizing on Social Science and Behavioral Research to Improve the Public's Health, 2000). The tobacco companies have been using multilevel marketing to attract smokers for over a century. Advertising and other forms of marketing seduce young people into experimenting with cigarettes and keep adults hooked who may otherwise quit. Individual level intervention to increase quit rates were fundamentally ineffective because they were no match for the multilevel marketing capabilities of the tobacco industry. It is only when prevention interventions addressed smoking at numerous levels, including policy, culture and intrapersonal health, that there was a reduction in the prevalence and incidence of smoking in the United States (Smedley, Syme, & Institute of Medicine . Committee on Capitalizing on Social Science and Behavioral Research to Improve the Public's Health, 2000).

Ecological Systems Theory in pregnancy & childbirth

Recognizing that most public health challenges are too complex to be adequately understood and addressed from single level analyses, the EST includes a more comprehensive approach that integrates multiple levels of influence to impact health behavior and ultimately health outcomes (Robinson, 2008). EST advocates health promotion programs that focus on behavioral change through educational activities or other intrapersonal level change strategies alone, often neglect the social and environmental context in which those behaviors occur and are reinforced (Robinson, 2008). The same extrapolation can be made when considering interventions to address a woman's sense of fear when approaching childbirth.

The interactions between person, event, and environment define the dynamic relationship between individual and community and form, for each individual, a unique context for fear of childbirth. Attending to a woman both as a new mother and as a person who is depressed or anxious is not sufficient. In order to provide adequate care for women with fear of childbirth, providers must also recognize that fear evolves within a complex life context (Locicero, Weiss, & Issokson, 1997). Each of the factors known to contribute to FOC can be located within one of the levels identified by ecological theory. Through application of the ecological theory to FOC, its complexity and interacting features have a greater potential to be considered within the research context.

The utility of adapting the ecological model for use in describing influences on childbearing women is that it provides a reminder of the multiple levels at which health care providers influence the health and well-being of the women and their infants and families (Sword, 1999). EST has been used to design smoking cessation programs for pregnant women (Lemola & Grob, 2008), prevent teen pregnancy (Suner, Nakamura, & Caulfield, 2003),

increase sustained breastfeeding practices (Tiedje et al., 2002), and to change hospital practices to become more family centered in an effort to decrease child maltreatment (Garbarino, 1980). Additionally, systems theories have been a guiding framework to understand the persistence of racial disparities in preterm birth. A 2010 paper presented the factors that contribute to racial health disparities utilizing EST to underscore the importance of their interaction and impact on birth outcomes. Using this model, the authors conclude that the historical context of Black women in the United States was a missing facet that had not been previously discussed in other work and was a contributory factor to negative birth outcomes (Alio et al., 2010).

The EST as applied to the issue of fear of childbirth offers a way of exploring factors that operate on different levels facilitating a more complete understanding of the interaction among factors within and across levels. It also allows for the analysis of direct and indirect causal explanations of the phenomenon. Thus, attention to the social conditions prior to, after, and during childbirth is essential, in addition to concern with the psychological conditions during and immediately following childbirth (Garbarino, 1980).

Ecological Systems Theory and anxiety

In addition to its use in looking at health issues specific to childbearing women, EST has also been used to address anxiety and stress. Using EST to explore mental health concerns expands the rhetoric of mental health as an interpersonal problem and instead looks at the large context in which mental health occurs. Seyle (1956) was the first to propose that chronic stress may have a cumulative damaging effect on human physiology. In his theory of a general adaptation syndrome, he attempted to explain physiological responses to environmental stressors. Accordingly, distressing ecological factors ranging from interpersonal style to mainstream discrimination practices, group marginalization, limited social support, and private family

dynamics act as an ecological undercurrent to the phenomena of anxiety and fear. The ecological approach seeks to understand these variations of individual physiology within the context of the social environment (Carlson & Chamberlain, 2005).

Ecological models encompass risk factors that are linked to an individual's self and surrounding environment, such as developmental history, coping mechanisms, modeling and vicarious learning, and interpersonal support systems. Ecological factors can also reflect a host of other environmental and personal variables, including accumulated psychosocial effects of previous trauma that may predispose individuals to respond to subsequent events in detrimental ways. This perspective suggests that psychological attributes of human beings are best understood in the ecological context of human community, and that individual reactions to events are best understood in light of the values, behaviors, skills and understandings that human communities cultivate in their members (Carlson & Chamberlain, 2005).

Support for an ecological model in psychology is also found in the growing empirical research on oppression and its caustic effects on wellness and development (Greenleaf & Williams, 2009). Traditionally, intrapersonal or deficit-oriented approaches to mental health care and the use of culturally biased diagnostic criteria worked to perpetuate various forms of social injustice and cultural oppression within the therapy relationship. Solomon (1992) cited research indicating that various diagnoses, such as depression, anxiety, and oppositional defiant disorder are social indicators of the stress experienced by populations that lack power; thus, care providers should expect the oppressed and underprivileged to show more signs and symptoms of stress and psychopathology. Additionally, research has shown a correlation between marginalized populations and the under, over, and misdiagnoses of psychopathology within the health care profession (Solomon, 1992).

An EST response to intrapersonal mental health care is frequently referred to as social justice counseling. Ecologic models in counseling address contextual inequities that curtail clients' development; the ecological perspective provides practitioners with a solid conceptual foundation to support advocacy as the means and tool for social action (Greenleaf & Williams, 2009). This stands in contrast to previous counseling approaches that have been largely unsuccessful but have framed FOC as an individual psychopathology in need of cognitive behavioral therapy or other types of interpersonal counseling (Saisto, Toivanen, Salmela-Aro, & Halmesmaki, 2006). Therefore, an ecological perspective, which recognizes the wellness of the individual as inextricably linked to the wellness of his or her environment, provides a basis for professionals to address the inequitable social, political, and economic conditions that impede individuals, families, and communities from optimizing their potential (Greenleaf & Williams, 2009).

Proposed model

Bronfenbrenner's EST has been so broadly used in health research in the United States that considering multiple eco-social levels is becoming an essential component of examining a health phenomenon. The increased popularity of EST stems from a growing recognition that most health challenges are too complex to be understood adequately from single levels of analysis and, instead, require more comprehensive approaches that integrate psychological, organizational, cultural, community planning, and regulatory perspectives (Stokols, 1996). The proposed EST offers an alternative to previous conceptualizations of fear of childbirth (FOC) and a more comprehensive orientation to understanding multiple influences on FOC. In addition to acknowledging the variables that influence the birthing woman as an individual, the model

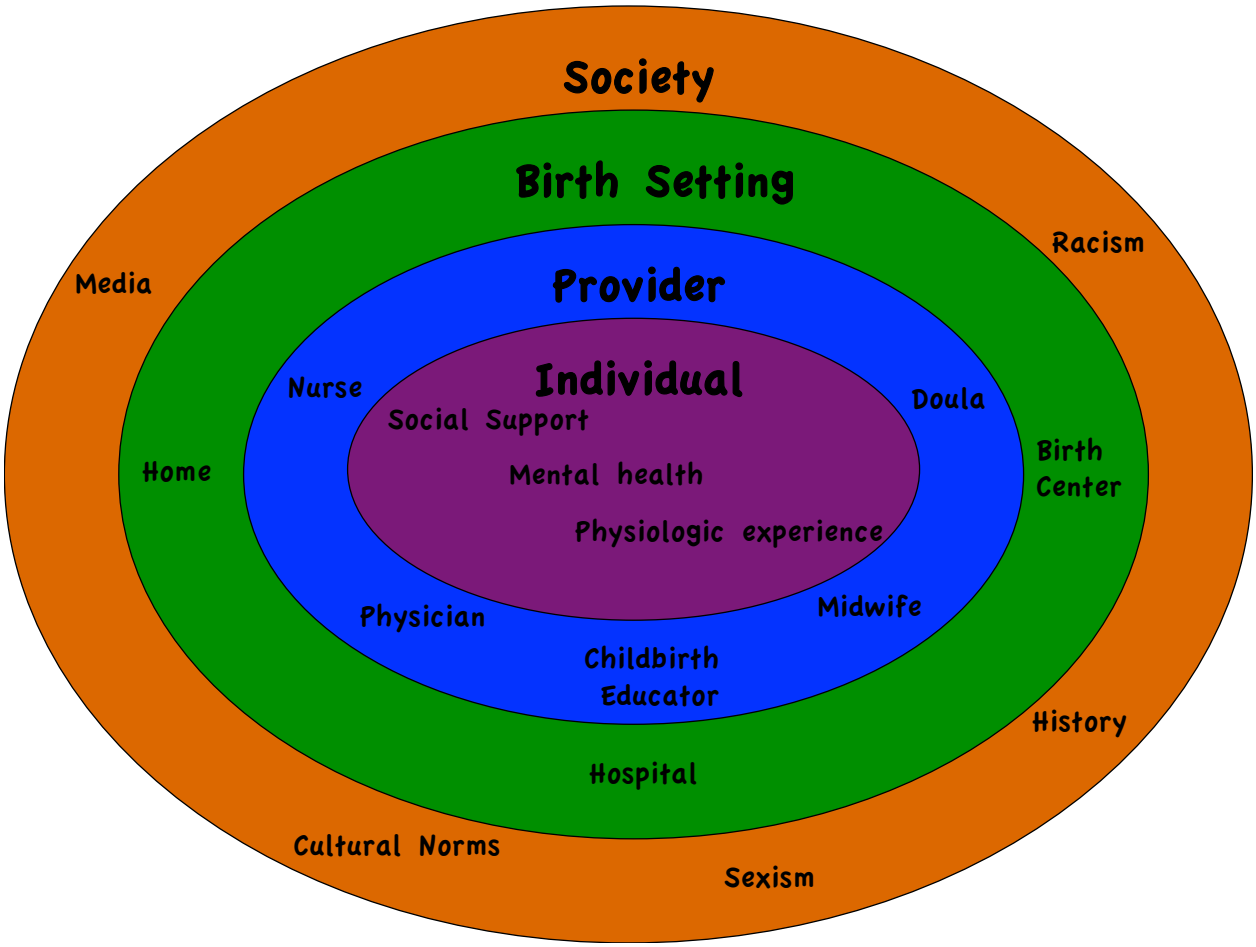
directs attention to the factors that determine health care provision, structure, and atmosphere for the health care system as a whole.

The model proposed to guide this project attempts to situate FOC within the complex, dynamic relationship of a woman and her birthing environment and the larger chronosystem that informs these relationships. The model is based on the EST but also takes into account the deeply personal nature of childbirth and the intricate and complex relationship between a woman and her provider through examining issues of perceived discrimination and self-efficacy within the health care system. Childbirth is a changeable, complex, and multifaceted moment in a woman's life and the experience of fear can alter the health of the mother and may influence health outcomes for the mother and her baby.

The model will explore what was learned in the literature review regarding risk factors for FOC but will place it within the context of a cultural phenomenon rather than a woman specific psychopathology. For example, a woman's experience with racism is not just influenced by her own personal integration of racism but instead recognizes the impact of racism as experienced within a culture grounded in institutionalized racism. The proposed model offers a comprehensive approach for analysis of the varied factors relevant to FOC within an institution of maternity care. The model starts with the foundation of the individual woman and the social support available to her as well as her mental health and feelings of self-efficacy in the health care system. The next layer builds on the individual experience by including the relationship the woman has with her care providers. The next layer is the institution in which the woman gives birth, whether it is in a hospital or a birth center or home setting. Lastly, the model includes larger structural issues of sexism and racism and contextualizes these issues as informants of FOC.

Figure 3.2

Proposed fear of childbirth model



Limitations of EST

A weakness of EST is its lack of specificity about some of the most important hypothesized influences on the phenomenon. There can be a lack of information about how the broader levels of influence operate or how variables interact across levels (Sallis, Owen, & Fisher, 2009). Thus, there is a risk that in broadening the perspective of FOC, the specificity of the measured variables becomes dilute. In addition, with a broadened perspective tangible interventions become harder to develop, implement, and measure. So at the intervention level,

where the goal is to isolate an intervention from the effects of its context, there is a risk that the intervention may be conceptually at odds with the ecological emphasis on studying how intervention components are influenced by their context (Sallis, Owen, & Fisher, 2009).

In order to address these limitations of working with ecological models it is important to develop more sophisticated operational models that lead to testable hypotheses and useful guidance for interventions. Research based on ecological models is, by definition, more demanding than behavioral research at a single level. Developing and collecting measures of influences at multiple levels, conceptualizing and implementing interventions at multiple levels, and using more sophisticated statistical strategies place substantial demands on research projects and interventions informed by EST.

Lastly, there is the critique that placing the individual at the center of the theoretical framework still maintains an emphasis on the behavior of the individual. In the case of FOC, there is the concern that, with the woman at the center of the model, emphasis of individual psychopathology may prevail.

Conclusion

This chapter critically examines the utility of the Ecological Systems Theory in the literature and suggests an expanded orientation to more fully appreciate its complexity. This alternative approach not only takes into account factors and processes relevant to the individual, but also acknowledges influences on the design and delivery of maternity health care (Sword, 1999). An ecological model is proposed that compels health care practitioners and researchers to acknowledge the many influences on fear of childbirth. The ecological approach is more useful than one-dimensional ways of viewing FOC and can serve as a basis for future empirical investigations. It enables the researcher to move from a reductionist view of the issue to a more

holistic perspective. For example, on the individual level, attention should be given to the intrapersonal enactment of FOC with special attention paid to the uniqueness of birth as a woman's event. This framework enables us not only to identify the characteristics of women who experience FOC; but also to describe the type of social environment most likely to produce women with high levels of FOC. An analysis of structural conditions and constraints additionally contributes to our knowledge of how these fears are maintained from generation to generation in populations that are socially dislocated (Franklin, 1988b).

CHAPTER 4

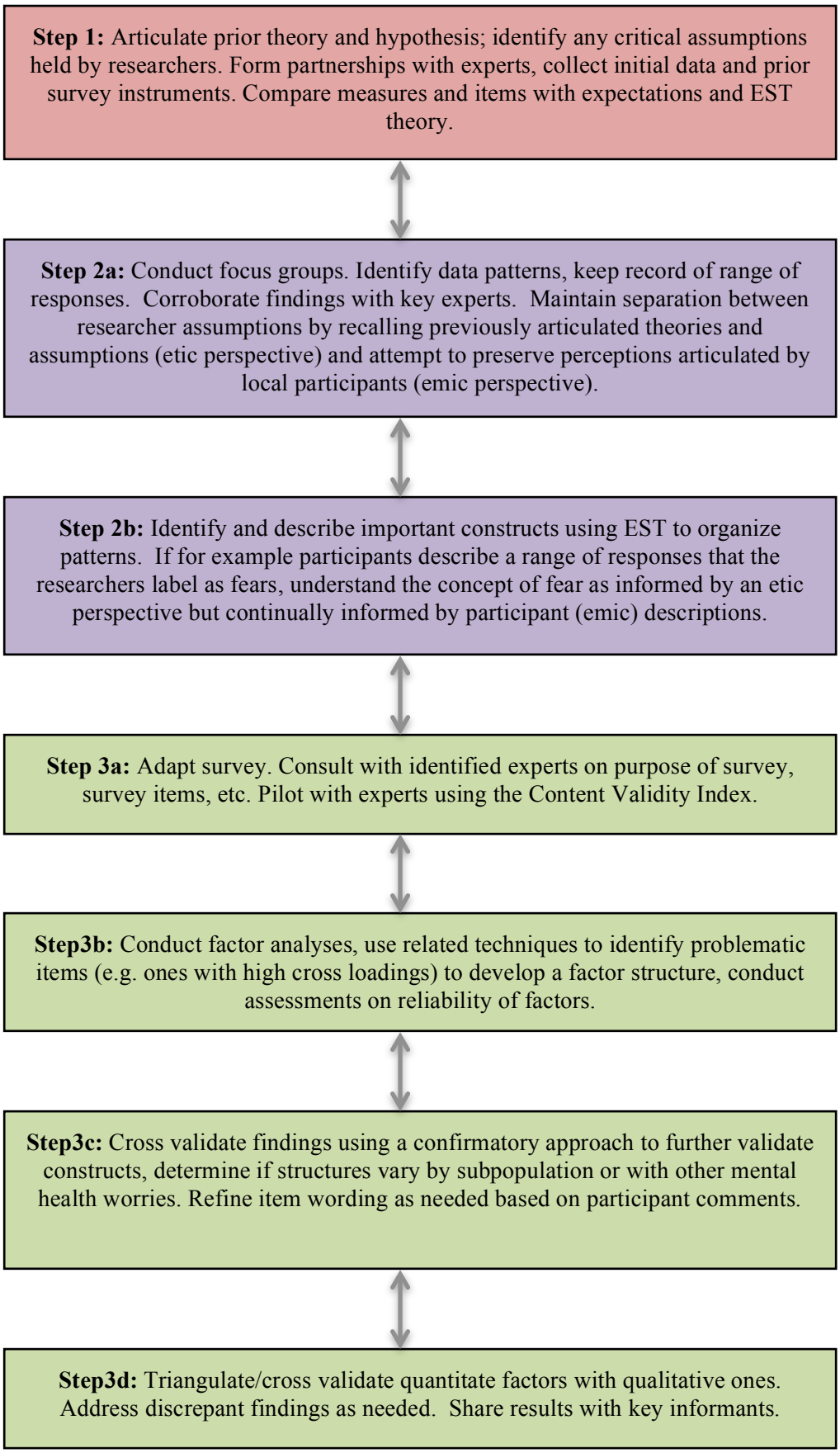
Methods

The purpose of the proposed project is to use a mixed-methods approach, grounded in Ecological Systems Theory (EST) to advance knowledge of fear of childbirth (FOC) by adapting the current gold standard instrument to be a comprehensive and culturally informed survey instrument for use in clinical practice in the United States. The aims of this project are:

- Specific Aim 1: Examine all extant FOC measures in relation to the proposed conceptual framing and consider their empirical adequacy for US research.
- Specific Aim 2: Elucidate and conceptually organize the components of childbirth related fear in a diverse sample of US women
- Specific Aim 3: Adapt an existing instrument to demonstrate the components of a theoretically informed instrument for use in the United States.

The figure below offers a step-by-step process for completion of the three major aims of this project and reflects the steps in quantitative-qualitative data collection and analysis to address the challenges of cultural factors during survey development and construct validation. The figure is a series of text boxes with bi-directional arrows between each of the steps to reflect the idea that the approach to this project is an iterative process and revisiting any stage may be necessary depending on developments in subsequent work. The figure is based on previous research by Hitchcock et. al. in using a mixed methods approach to develop a culturally expansive survey

instrument (Hitchcock et al., 2005). Following the figure is a detailed rational and description of the proposed approach to addressing these three aims.


Step 1: Articulate prior theory and hypothesis; identify any critical assumptions held by researchers. Form partnerships with experts, collect initial data and prior survey instruments. Compare measures and items with expectations and EST theory.
Step 2a: Conduct focus groups. Identify data patterns, keep record of range of responses. Corroborate findings with key experts. Maintain separation between researcher assumptions by recalling previously articulated theories and assumptions (etic perspective) and attempt to preserve perceptions articulated by local participants (emic perspective).
Step 2b: Identify and describe important constructs using EST to organize patterns. If for example participants describe a range of responses that the researchers label as fears, understand the concept of fear as informed by an etic perspective but continually informed by participant (emic) descriptions.
Step 3a: Adapt survey. Consult with identified experts on purpose of survey, survey items, etc. Pilot with experts using the Content Validity Index.
Step3b: Conduct factor analyses, use related techniques to identify problematic items (e.g. ones with high cross loadings) to develop a factor structure, conduct assessments on reliability of factors.
Step3c: Cross validate findings using a confirmatory approach to further validate constructs, determine if structures vary by subpopulation or with other mental health worries. Refine item wording as needed based on participant comments.
Step3d: Triangulate/cross validate quantitate factors with qualitative ones. Address discrepant findings as needed. Share results with key informants.

Specific Aim 1: Examine all extant FOC measures in relation to the proposed conceptual framing and consider their empirical adequacy for US research.

Although there are a number of measures that have been created to measure FOC, many of these instruments have not undergone adequate psychometric testing or do not conceptually match the proposed, expanded definition of FOC for this project. A thorough comparison of existing measures is necessary in order to identify a psychometrically sound, conceptually coherent measure of FOC that is relevant for use within the context of the US maternity care system and for use within diverse populations of women. As noted through the review of the literature provided in Chapter 2, there are a number of instruments currently in use.

- Primary Care evaluation of Mental Disorders
- Spielberger State-Trait Anxiety Inventory (STAI-T)
- Anxiety Sensitivity Index (ASI)
- Fear of Childbirth Questionnaire (FOCQ)
- Prenatal Self-Evaluation Questionnaire (PSEW)
- Pregnancy Related Anxieties Questionnaire (PRAQ)
- Oxford Worries about Labour Scale (OWLS-9)
- Pregnancy Anxiety Scale (PAS)
- Delivery Fear Scale (DFS)
- Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ)
- Tilburg Pregnancy Distress Scale (TPDS)
- Cambridge Worry Scale

The five most commonly used scales and a comparison of their features are listed in Table 4.1 in Chapter 2 and below.

Table 4.1

Commonly used fear of childbirth scales

Instrument	Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ)	Delivery Fear Scale (DFS)	Fear of Childbirth Questionnaire (FOCQ)	Childbirth Attitudes Questionnaire (CAQ)	Prenatal Self-Evaluation Questionnaire II (PSEQII)
Year of development	1996	2002	1982	2000	1979
Country of origin	Sweden	Sweden	Sweden	United States	United States
Item source	Derived from the first two authors' clinical experiences of women with fear of childbirth	Authored piloted 60 words with pregnant women, 10 words were chosen.	No explanation of development available	Adapted from the FOCQ	No explanation of development available.
Number of items	33	10	19	15	79
Style of Measurement	6-point Likert scale	10-point Likert scale	Yes or No	Likert scale	4-point Likert scale
Advantages	*Based on Lazarus' theory *Extensive reliability and validity testing * Gold standard	*Strong piloting *Well tested	*Straight forward to administer *Developed by field experts	*Developed in the United States *Reported reliability	* Developed at the University of Michigan
Disadvantages	*Problematic language	*Meant to be delivered in labor *Too many scale steps	*No recent validity or reliability *Problematic language	*No information on how or why it differs from the FOCQ	*Instrument length *Anxiety small component of factor structure

In addition, a search will be conducted to confirm that all available measures have been identified. Existing measures will be found using a combination of the key words including anxiety, fear, tocophobia, pregnancy, labor, and childbirth. PubMed, CI-NAHL, PsychINFO, and EMBASE will be searched to identify relevant measures. The references of studies identified by electronic searches will also be searched to identify additional studies. Available measures will be obtained from published research and intervention articles. Their potential will begin to be evaluated for use in the context of the United States from a theoretical and psychometric stance towards the goal of exploring the utility of varied aspects of the available instruments within focus groups

Instruments that will undergo analysis will be ones developed for the specific purpose of studying FOC as an entity separate from generalized anxiety or other perinatal mental health psychopathology. Many instruments may include a few questions that seek to query fear of childbirth as a domain or a component of a related domain. While these instruments may be valuable for a particular area of study, the purpose of this Specific Aim is to analyze and compare measures specific to the purpose of FOC. Therefore, measures whose purpose is to measure a number of constructs, as opposed to solely FOC, will be excluded from analysis.

All of the available measures that meet these criteria will be compared in the following manner. First, the study author(s), name of the survey instrument and details on the origins of the survey instrument will be identified in addition to the type and number of respondents from whom the instrument was designed to collect data. Second, the contents of the survey instruments will be described. The number of items in the instrument will be noted, excluding demographic and other background questions as well as the basic domains if they are identified in a particular survey instrument. The type of rating scale used in the instrument will be

identified and the response scale categorized in terms of whether it is open-ended or close-ended, the number of close-ended response options (dichotomous or multiple categories), and the nature of the response scale: evaluation (e.g., poor, fair, good, very good, excellent); frequency (e.g., none of the time to all of the time); satisfaction (e.g., very satisfied to very dissatisfied); or, visual analog.

Third, characteristics of how the survey instrument was used will be presented—that is, implementation characteristics. For example, whether any information is provided as to when the instrument was given to respondents (e.g., 2 days after delivery, prenatally, etc.). How the survey was administered, i.e. by in-person interviews, telephone, mail, or drop-box, will be reported. Lastly, the performance characteristics of the survey instruments will be documented. This includes the response rates and whether information about the reliability (internal consistency, test–retest, and inter-rater) and validity are reported, what analyses were used to assess the instrument's performance, what the distribution of scale is, and whether any other instrument assessments were undertaken.

In keeping with the Ecological Systems Theory conceptual model that is the basis of this project, an overall theoretical evaluation of the instruments will need to acknowledge the variables that impact the individual as a birthing woman, but also direct attention to the factors that determine health care provision and structure and atmosphere for the health care system as a whole. Particular attention will be placed on whether the available instruments contain questions that address all levels of the FOC concept, and not just the microsystem of individual psychopathology. The instruments will be assessed for language specific to the domains as well as the ordering of questions to see if there is a logical rhythm that moves through the fears as a personal experience to fear as a phenomenon influenced by external sources. The resulting

information will be used to determine which existing instrument is best suited for adaptation for use in the United States.

Specific Aim 2: Elucidate and conceptually organize the components of childbirth related fear in a diverse sample of US women

Qualitative methods expand the ways in which we develop and validate quantitative instruments and contribute to an understanding of how well the instrument measures the domains of interest. For the purpose of this project, focus groups will be used to generate qualitative data allowing the researcher to directly hear respondents' comments and probe their exact meanings. Such exchanges allow both researchers and respondents to raise and explore issues in order to validate the relevance of certain items, to hone wording, and to generate additional ideas.

The proposed study would use a qualitative content analysis approach to conceptually organize the phenomena of FOC in the United States. Focus groups will be conducted to not only derive new knowledge or evaluate services or programs but also to seek opinions, values and beliefs in a collective context (Krueger & Casey, 2000). The underpinning assumption of this method is that individuals are valuable sources of information and are capable of expressing their own feelings and behaviors (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). Focus groups generate information through interactions between participants, which tend to reveal concepts that no single participant could fully articulated alone (Kitzinger, 1995).

This is a particularly useful method for elucidating the features of phenomena across a diverse population. An increasing number of studies demonstrate the utility of the focus group method in conducting health-related research in culturally and linguistically diverse populations (Devlin, Roberts, Okaya, & Xiong, 2006; Huer & Saenz, 2003). For this study, focus groups were chosen because of their advantage in exploring multifaceted and complex phenomena. In

this type of setting, private or stigmatized feelings are more easily discussed because responsibility for the idea can be diffused among the other participants (Stevens, 1996). Shy, unresponsive, or marginalized participants may find solidarity in shared experiences and be emboldened to speak more candidly (Kitzinger, 1995). Finally, focus groups are in keeping with oral traditions of communication in many marginalized populations (Devlin, Roberts, Okaya, & Xiong, 2006).

While the purpose of this investigation is to develop a richer understanding of the phenomena of fear of childbirth, this project will apply a content analysis approach as opposed to a phenomenological approach. On the surface, it appears that phenomenology shares with feminist analysis a commitment to grounding theory in lived experience, and in revealing the way in which the a world view is produced through constituting acts of subjective experience (Butler, 1988). However, the phenomenological focus on the "essence" or the generic lived experiences often fails to take into account the intersectionality of women's identities as influential on their experience. The absolutism and exclusion of phenomenology fail to take stock of the ways in which oppressions and privileges structure the ontological categories through which identities are conceived and is not in keeping with the theoretical basis of this project (Butler, 1988). Content analysis, on the other hand, focuses on the characteristics of language as communication with attention to the content or contextual meaning of the words people choose to use (Tesch, 1990).

Content analysis is defined as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns (Hsieh & Shannon, 2005). Initially content analysis dealt with 'the objective, systematic and quantitative description of the manifest content of communication' but, over time,

it has expanded to also include interpretations of latent content (Graneheim & Lundman, 2004). Latent content is an analysis of the text and also involves an interpretation of the underlying meaning of the text (Graneheim & Lundman, 2004). Content analysis is generally used with a study design whose aim is to describe a phenomenon. This type of design is usually appropriate when existing theory or research literature on a phenomenon is limited, as is the case for the phenomenon of FOC within the United States (Hsieh & Shannon, 2005). The main strength of a directed approach to content analysis is that existing theory can be supported and extended. In addition, as research in an area grows, a directed approach makes explicit the reality that researchers are unlikely to be working from the naive perspective that is often viewed as the hallmark of naturalistic designs such as the phenomenological approach (Hsieh & Shannon, 2005).

The goals of the focus groups would be to explore the construct validity of FOC by thoroughly operationalizing and defining the construct. At the very base level, what counts as low and high FOC is essential to analyze if we are to understand how participants are interpreting items on any scale. It is also important to understand how responses relate to the social and political conditions of individuals particularly when working with marginalized populations (McClelland, 2010). Another advantage of content analysis is that it can capture participants' word choices that may inform item development. In addition, the focus groups will seek to explore which constructs appear significant in informing FOC with a diverse population of women in order to develop a scale that more adequately measure the phenomena.

The focus groups will start with a generalized discussion of FOC using questions like "Please tell me what you think about when you think about giving birth." and "When you envision your birth what things come to mind that make you feel afraid or worried?" and "What

things do you think would be important to ask women about if we were looking to identify women with significant fears or worries?" If issues of identity and relationships with the health care system do not get addressed using this approach other open-ended questions will be used to situate FOC within the larger socio cultural environment. The focus group will conclude by asking each participant to provide three 'bullet points' with the 'take home messages' about what fear of childbirth means to her. This technique will serve to validate that the most crucial points that the participants want to convey have been understood by the facilitator and are conveyed in her own words (Seng, Low, Sparbel, & Killion, 2004b). This approach of 'funneling' from the larger phenomena, to working through specific topics that may be useful in developing an instrument, to creating 'bullet points' of key items is useful in that it represents a compromise between the various levels of structure, allowing for a wider perspective of individual experiences in the initial stages, followed by specific questioning in the subsequent stages of the discussion to directly answer the research question of developing an accurate and representative measure (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007)

Inclusion criteria for the focus groups will be women who are over 18 years old who identify as having worries or concerns about the experience of childbirth. All women will be included, regardless of if they have had a child or are currently pregnant, in order to tap into the experiences of women who may have such significant fear that it progresses to phobic levels of avoidance of pregnancy. The number of focus groups conducted and the composition of the focus groups will depend on sampling and the necessity of ensuring an adequate mix of identities in the overall study population. Women will be recruited through flyers in obstetrician and midwife offices, local community centers and health centers, and larger churches in the Detroit and Ann Arbor area. The number of participants in each group will vary from 5 to 7 in order to

keep the environment intimate. The time spent in each group will depend on when the obtained data becomes redundant and when the women themselves identify that the topic has been thoroughly explored. Particular attention will be paid towards creating an overall diverse sample based on race, ethnicity, class, and socioeconomic status. However, groups will be loosely organized in order to create groups with relatively similar demographics. The literature describes a need to ensure that each focus group is comprised of relatively homogeneous participants in terms of the nature of their experience of the issue to avoid the generation of potential power issues between participants and promote the comfort of participants (Clark et al., 2003; Krueger & Casey, 2000; Morgan, 1998). To address this possibility, the co-facilitator of focus groups will be as ethnically similar to participants as possible, thereby diffusing some of the challenges of having a primary facilitator who is not demographically similar and could be considered an outsider who is unfamiliar with cultural context (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). This perceived similarity may assist in reducing communication barriers (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007).

Focus groups will be transcribed into text from the audiotape of the group. Once the text has been condensed, it will undergo abstraction in order to emphasize descriptions and interpretations on a higher logical level. The resulting meaning units will be organized into categories that share commonality but are exhaustive and mutually exclusive, as much as is possible when describing emotion specific to the human experience. The resulting themes will be used to inform the adaptation of the instrument. The summative bullet points will be extracted from the transcript and used as an audit tool to increase rigor in the analysis phase of the project (Seng, Low, Sparbel, & Killion, 2004b). Emerging themes will then be coded using NVivo

qualitative software. In addition, the information about dissenters will be analyzed and interpreted in order to increase descriptive validity, interpretive validity, and theoretical validity.

Keywords-in-context will be used to determine how words are used in context with other words. This technique is well suited to content analysis and to work through an under explored phenomena as well as the challenges of translated instruments in order to capture what words might be more appropriate to measure the chosen construct in a newly developed instrument (Kronberger & Wagner, 2000). Keywords-in-context represents an analysis of the culture of the use of the word. The major assumption of this approach is that people use the same words differently, necessitating the examination of how words are used in context. This approach will be used in order to identify the most prominent, thematic dimensions of FOC.

Specific Aim 3: Adapt an existing instrument to demonstrate the components of a theoretically informed instrument for use in the United States.

After extensive comparison of the existing measures, as described in detail in Chapter 6, the Wijma Delivery Expectancy Questionnaire (WDEQ) was chosen as the instrument best suited for adaptation for use in the United States. The WDEQ has been used most extensively in the literature and is currently considered the gold standard instrument for measuring FOC (Wijma, 2013). The process for adapting the WDEQ is described below as part of Specific Aim 3.

Applying Ecological Systems Theory to something as complex as human emotion suggests the need for defining and measuring fear within all levels of the model. Human emotion in combination with culture provides an even more challenging scenario. Many forms of assessment that explicitly contend with cultural issues are rife with validity concerns due to inconsistency of constructs across culture (Hitchcock et al., 2005). Item content for the newly

adapted instrument will be derived from the previously described focus groups and based on the described item content of the original WDEQ instrument being adapted. Use of qualitative data provides a strong foundation to enhance content validity and to delineate the content domain (Tilden, Nelson, & May, 1990). A precise definition of the domain is a crucial first step. Content validity is extremely dependent on appropriate operational definitions, which should flow directly from the conceptual definitions identified during the qualitative component of this study (Gable & Wolf, 1993). The identified conceptual definition will be based on a combination of theory, a comprehensive literature review, results of the qualitative investigation, and this researcher's experience working with a diverse population of childbearing women in clinical practice. The conceptual definition defines the universe or domain of content that will be measured (Beck & Gable, 2001). Operational definitions bring to life the domain by defining it in terms of the observations and/or activities that measure it (Waltz, Strickland, & Lenz, 2010).

Once the dimensions of the adapted instrument are decided upon, the next step is to focus on generating adapted items for each of the identified dimensions (Beck & Gable, 2001). Items from the original WDEQ that match the identified dimensions will be kept. To ensure the qualitative meaning during item development, new instrument items will be written to correspond with the specific verbatim quotes extracted from the qualitative data in order to create meaningful instrument items (Fleury, 1993).

The adapted survey instrument will have two to three questions for each dimension of the conceptual framework in order to provide a rich understanding of how that dimension is experienced by women but not be so item heavy that the instrument becomes burdensome in clinical practice. In order to make it useful for clinical practice the goal will be to adapt the WDEQ into an instrument that has fewer than 20 items and function at a fifth grade reading

level. Additionally, the goal is to have a final instrument whose factor structure taps into all levels of the conceptual model and creates a normal distribution in which FOC that is severe can be differentiated from the normative response to a major life event.

The first step in testing the developed instrument would be an analysis of the content validity of the measure. The assessment of content validity is one of the most critical steps in instrument development. Content validity addresses the degree to which items in an instrument adequately represents the domain of content (Beck & Gable, 2001). Since content validity is a prerequisite for construct and criterion related validity, it should receive the highest priority during instrument development. Content validity should be assessed while the instrument is in the development phase rather than evaluating it after the instrument is in its final form (Waltz, Strickland, & Lenz, 2010).

The Content Validity Index (CVI) is a recommended approach to quantifying the instruments content validity (Lynn, 1986a; Waltz, Strickland, & Lenz, 2010). The CVI is calculated from content experts' ratings of the content relevance of the items on an instrument. A 4-point Likert scale is used where 1 equals not relevant to 4, very relevant. The CVI represents the proportion of items on an instrument that achieved a rating of 3 or 4 by the content experts (Beck & Gable, 2001). Six to ten content experts will be used to calculate the CVI for the resulting instrument as described by Waltz and colleagues (Waltz, Strickland, & Lenz, 2010) These content experts will be a combination of practicing midwives with extensive experience working with a diverse population of pregnant women and psychologists or social workers with a research or practice specialty in anxiety. Each content expert will be given the conceptual definition and identified dimensions of FOC developed from the focus groups in order to make editorial changes that they feel are necessary to improve any of the items (Beck & Gable, 2001)

After necessary revisions are made to the draft instrument a series of cognitive interviews will take place with willing participants from the focus groups. Beginning in the 1980's, cognitive interviewing has emerged as one of the more prominent methods for identifying and correcting problems with survey questions (Beatty & Willis, 2007).

After a final draft of the survey instrument is created, the instrument will undergo reliability and validity testing in order to validate its use with a diverse sample of women in the United States. The goal will be to recruit 200 women since that is the general rule of thumb that is required in order to perform factor analysis testing of a new instrument (Tabachnick & Fidell, 2007). If a sample of that size is not feasible, then 10 women per item number will be recruited (Nunnally, 1978). Oversampling of minorities will be attempted in order to achieve a sufficient sample size for ethnicity-specific analyses and data presentation (Yancey, Ortega, & Kumanyika, 2006).

Women will be recruited through prenatal care centers by setting up a table to encourage face-to-face interactions with study participants. In a review of the literature seeking to recruit adequate representation of minority women in studies, it was found that face-to-face recruitment produced the highest yield of eligible and willing participants among African Americans, Latinas, and Caucasians (Yancey, Ortega, & Kumanyika, 2006). Word-of-mouth dissemination was second in recruitment yield so each participant will be given a flyer about the study with contact information in order to give to friends and family who also might be eligible for participation. Research supports that familiarity may be more important than ethnic matching in recruitment so the table will be set up on the prenatal care day every week until recruitment meets capacity (Yancey, Ortega, & Kumanyika, 2006). The continued presence of the

researcher will hopefully establish trust and familiarity with women who have been historically exploited or disenfranchised.

Inclusion criteria will be any pregnant woman, greater than 18 years of age who are pregnant and self-identify as having any worries or concerns about childbirth. Exclusion criteria will be kept to a minimum in order to assure that the sample is diverse and representative of prenatal care clinics in the United States. Women will be asked to complete the survey instrument packet which will include a basic demographic and general health history, the current gold-standard instrument used to measure FOC (Wijma Delivery and Expectancy Questionnaire), the revised Wijma Delivery Expectancy Questionnaire (R-WDEQ), a brief measure of depression (Patient Health Questionnaire -2), a gold-standard anxiety instrument (Generalized Anxiety Disorder -7), a brief PTSD screening measure (PTSD Checklist-Civilian Version), a measure of perceived discrimination in the health care setting (Discrimination in Medical Settings Scale), and a measure of self-efficacy in a medical setting (Medical Social Self-Efficacy Scale). The survey will be confidential and participants will be given a nominal cash incentive for their participation. Any participant who would like to receive a copy of the final analysis will be asked for their mailing or email address in order to send reports and/or links to publications that come out of the research. (IRB approval was obtained from the University of Michigan as well as all major health centers in which the research took place.)

Reliability will be measured using Cronbach's alpha statistic. This statistic uses inter-item correlations to determine whether constituent items are measuring the same domain. If the items show good internal consistency, Cronbach's alpha should exceed 0.70 for a developing questionnaire (Rattray & Jones, 2007). The face validity of the instrument will be evaluated by the women who are filling out the questionnaire packets by asking all of them to comment on the

questionnaire, and urging them to write down their comments throughout the instrument (Garmy, Jakobsson, & Nyberg, 2012).

When developing a questionnaire it is important to include additional established measures with proven validity against which to test the developing questionnaire. Construct validity relates to how well the items in the questionnaire represent the underlying conceptual structure. Factor analysis is one statistical technique that can be used to determine the constructs or domains within the developing measure. This approach can, therefore, contribute to establishing construct validity (Rattray & Jones, 2007). Therefore, exploratory factor analysis will be done on the instrument to see how it performs and if the theoretically developed domains are representative in the factor structure of the instrument. Further tests of validity will be done in comparison with the other instruments delivered in the survey pack.

Table 4.2

Scales used for validity testing

Instrument Name	Conceptual Model Level	Rationale for Inclusion
Wijma Delivery Expectancy Questionnaire (W-DEQ)	Individual	Analysis of concurrent validity
Patient Health Questionnaire – 2 (PHQ-2)	Individual	Analysis of discriminant validity
Generalized Anxiety Disorder – 7 (GAD)	Individual	Analysis of discriminant validity
PTSD Checklist – Short Form	Individual	Analysis of convergent validity
Discrimination in Medical Settings Scale (DMS)	Provider, birth setting, society	Conceptual analysis of the role of discrimination
Medical Social Self-Efficacy Scale (MSSES)	Individual, provider, birth setting, society	Conceptual analysis of the role of self-efficacy

Based on the information obtained from the previous analysis basic parametric testing of the instrument will be performed. Tests of normality such as the Kolmogorov-Smirov and Shapiro-Wilk statistics would be performed as well as an examination of the standardized residuals in order to meet assumptions for parametric statistical analyses. Inter-item correlations will be examined for conceptual redundancy and lack of fit. The correlation matrix will be inspected for values that are lower than .30 (Pallant, 2007). After examining the inter-correlations, the internal consistency reliability of the items will be examined to verify that the reliability would not improve by eliminating an item. Lastly, before performing a factor analysis the Kaiser-Meyer-Olkin measure of sampling adequacy will be examined to ensure that it is above .60 as suggested as the minimum value for a good factor analysis (Tabachnick & Fidell, 2007). If factor analysis is considered appropriate exploratory and confirmatory analysis with both rotations will be performed in order to find the best factor solution. The criteria used to determine the number of factors, and the number of items with a factor, where the point of continuity is on the screen plot, and eigenvalue of greater than 1, and item factor loading greater than .40 (Tabachnick & Fidell, 2007).

CHAPTER 5

Review of Existing Instruments

Specific Aim 1: Examine all extant FOC measures in relation to the proposed conceptual framing and consider their empirical adequacy for US research.

Recent decades have seen an increase in biopsychosocial approaches to enhance the study of pregnancy and birth outcomes and how those outcomes are influences by perinatal mental health. There is a considerable research that has accumulated from the Scandinavian countries on the relationship between fear of childbirth (FOC) and adverse birth outcomes. Many new instruments have been introduced with this research, however, many of these new measures that have not been subject to theoretical grounding or psychometric evidence, resulting in serious questions about the quality and direction of research on FOC (Alderdice, Lynn, & Lobel, 2012). This review provides a summary of evidence on the reliability and validity of measures of FOC currently available in order to support the development of a high quality, theoretically driven, psychometrically robust measure of FOC.

In addition to comparisons on development, use, content, and psychometrics, the measures will be analyzed using the Ecological Systems Theory conceptual model that is the basis of this project. This is to ensure that the measures acknowledge the variables that impact the individual as a birthing woman, but also direct attention to the factors that determine health care provision and structure and atmosphere for the health care system as a whole. This means

paying particular attention to whether the available instruments have questions that attempt to query all levels of the FOC concept, and not just the microsystem of individual psychopathology. This perspective suggests that psychological attributes of human beings are best understood in the ecological context of human community and that individual reactions to events are best understood in light of the values, behaviors, skills and understandings that human communities cultivate in their members (Carlson & Chamberlain, 2005).

Fear of childbirth

Historically, fear in pregnancy was a symptom regarded, by care providers as a fairly unambiguous entity that could be solved by the promise of pharmacological pain relief. The existing literature defines FOC as a serious concern about the well being of the child, the labor process, loss of control, distrust of own competence, and lack of trust in the staff present to support the process (Sjogren & Thomassen, 1997). Despite this broad definition, it still places the origin and pathology within the individual realm of the woman. Instead, FOC is a more intricate feeling with an individual and sociocultural pattern of contributing factors. Expanding the definition of FOC to examine the interplay between woman, provider, identity, and culture allows for a deeper interpretation of the origins of FOC and a more rich understanding of how interventions can be structured to reduce fear and improve outcomes. For this project FOC is defined as a unique, complex phenomenon with an individual and sociocultural pattern of contributing factors. This expanded definition allows for a more in depth analysis of the topic.

For women, FOC may represent a converging of various feelings of anxiety during pregnancy into one, socially and psychologically acceptable entity. In some women, the fear is specific and only concerns the event of childbirth. In others, FOC exists in parallel with other types of anxiety disorders. However, for most, FOC is a distinct phenomenon that differs from

generalized anxiety and depression. In fact, in one study, only 8–27% of the variance of FOC was explained by general anxiety and depression in early and mid pregnancy and during late pregnancy no linear association was found between general anxiety or depression and FOC. Therefore, the authors concluded that FOC and general anxiety be regarded as different entities (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004).

Many studies of FOC have chosen to use standard measures of generalized anxiety to assess the correlation between FOC and obstetric outcomes such as the Primary Care evaluation of Mental Disorders, Spielberger State-Trait Anxiety Inventory (STAI-T), and the Anxiety Sensitivity Index (ASI). While these measures have a long history of accurately measuring generalized anxiety and have extensive psychometric data with a diverse sample of women in many settings, attempting to measure FOC using generalized anxiety instruments fails to capture women where FOC and generalized anxiety do not overlap. For this reason, general measures of anxiety, even if they were used to study FOC specifically, are not included in this analysis.

Methods

Search strategy

A literature search was conducted to identify reliability and validity data for fear of childbirth (FOC) measures. Terms such as 'fear of childbirth', 'worries about childbirth', 'childbirth anxiety', 'pregnancy anxiety' were used to search five computerized databases (PubMed, PsycInfo, CINAHL, HAPI, and Google Scholar). Filters were put in place in order to limit searches to publications available in English. Because of the limited amount of results no time filter was placed on the searches. The initial search was conducted in November 2011 with a final update carried out in May 2012 where only one more instrument was identified.

Selection

The abstracts of 433 publications were screened to determine those that were likely to include information on the measurement tools used to evaluate FOC. Exclusion criteria were: studies that did not use a measure designed specifically to study FOC; those that sought to measure FOC in partners or support people as opposed to women; those that were not available electronically through the University of Michigan library or InterLibrary Loan; and, duplicate references. Subsequently, the full texts of 132 publications were obtained and assessed for eligibility. Eleven measures were found in these 132 publications that are assessed below.

Results

Pregnancy Anxiety Scales

The first grouping of scales that were found in the literature were scales that focused specifically on anxiety during pregnancy. For some of these scales, fears about childbirth are embedded within the measure but the primary focus is assessment of anxiety during pregnancy, not specifically about the childbirth experience.

The *Pregnancy Related Anxieties Questionnaire* (PRAQ) was originally developed in 1990 by Van den Bergh in a study seeking to explore the relationship between maternal anxiety and neonatal behavior (Van den Bergh, 1990). The scale was not used again until 2000 where it was revised for the purposes of a doctoral thesis studying a similar phenomenon (Huizink, 2000). This revised scale (PRAQ-R) was later published in a study seeking to differentiate prenatal anxiety as a distinct phenomenon from generalized anxiety and depression (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004). This shortened 34-item version, the PRAQ-R, was derived from the original version by retaining the items with the highest factor loadings on each of the five subscales: ‘fear of giving birth’ (8 items), ‘fear of bearing a

physically or mentally handicapped child' (5 items), 'fear of changes and disillusion in partner relationship' (6 items), 'fear of changes' (8 items) and 'concern about one's mental well-being and the mother–child relationship' (4 items) (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004).

The items in the PRAQ-R are answered on a 5-point Likert-type scale ranging from 'never' to 'very often.' The Cronbach alpha of the summed score was .73 in a study by the author of the revised version (Huizink, de Medina, Mulder, Visser, & Buitelaar, 2002). A copy of the revised instrument was requested from the author but no response was received.

The literature reveals two scales; both named *Pregnancy Anxiety Scale* (PAS). Unfortunately for this analysis, the two scales are often conflated in the follow up research using one of the scales and so it is unclear if they are both reformatted versions of an original PAS scale. The first was developed in a study of 61 pregnant women in Montreal in the early 1970s (Burstein, Kinch, & Stern, 1974). For the purposes of this analysis, this scale will be referred to as PAS-1 in order to differentiate it from the other Pregnancy Anxiety Scale. Originally, the PAS-1 consisted of 25 dichotomous items adapted from those created in an earlier study on anxiety in pregnancy (Pleshette, Asch, & Chase, 1956)) .

The items in the original PAS-1 were developed for physicians to use in clinical practice based on the clinical observations of Pleshette and colleagues (1956). It was intended to be a diagnostic tool, but has only been used to study pregnancy anxiety retrospectively (Levin, 1991). A factor analysis of the instrument chose 13 of the questions from the original 25. The resulting analysis identified three dimensions including 'anxiety about being pregnant', 'anxiety about childbirth', and 'anxiety about hospitalization' (Levin, 1991). Multiple other articles site an alpha of 0.81 as presented by Levin, however, the original article does not report an alpha at

all so it is unclear where the alpha of 0.81 originates. No other psychometrics are available for the PAS-1.

A unique attribute of the PAS-1 is that it is one of the only scales examined that seeks to gather information about the societal influences of FOC by asking questions like "Did any one frighten you about having a baby?" or "Did you read anything that frightened you about having a baby?" In addition, the scale explores worries about if the doctors or nurses "might not be friendly". Unfortunately, the scale is more limited when looking at the individual level by asking questions such as "did you ask for pain medicine before childbirth?" as a way to gauge FOC. While this may be applicable for some women, it assumes a level of knowledge about options available for women that may not be as readily known throughout a diverse sample of women. In addition, questions such as "Did you fear that you would fall and hurt your baby?" have such a level of specificity that they may fail to identify women with more open ended worries or fears about childbirth.

The second Pregnancy Anxiety Scale (PAS-2) was created as part of a dissertation project seeking to compare the way women who have had perinatal loss and those who have not attempt to resolve tasks of pregnancy (D. Y. Cote-Arsenault, 1995). The scale is based on the work of Theut et al. and the instrument (Pregnancy Outcomes Questionnaire) (Theut, Pedersen, Zaslow, & Rabinovich, 1988). The PAS-2 was originally a six-item measure that included two items directly from the POQ and four others that were developed for the dissertation study using the POQ as a guide (D. Y. Cote-Arsenault, 1995). The PAS-2 used a visual analogue format where each item consisted of a stem and a 100mm horizontal line on which to mark the response between the two end anchor points of "definitely No" and "Definitely Yes" (D. Y. Cote-Arsenault, 1995).

Discriminant validity of the PAS-2 was determined by comparing the scores with women who experienced pregnancy loss and women who had not experienced pregnancy loss. The mean pregnancy anxiety scores for the loss group and the no loss group was 48.70 and 35.03 respectively. A varimax rotation factor analysis revealed two factors, pregnancy concerns and concerns for baby. Internal consistency of the scale was alpha = .7051. Individual item-total correlations ranged from r=. 25 to 62. Construct validity of the PAS-2 was found in moderate correlation with state anxiety (STAI) (r=.645, p=.00) (D. Y. Cote-Arsenault, 1995). The most recent use of the PAS-2 describes it as a 9-item scale, however there is no information on what items were added from the original 6-item scale or how they were developed. The internal consistency of the 9-item PAS-2 was alpha =.74-.83 (D. Cote-Arsenault, 2007).

The 6-item scale is included in an article by the original author (D. Cote-Arsenault, 2003). The 9-item scale is not available in any published source. The advantages of the PAS-2 is that it is a short, concise scale with available psychometrics. In addition, the visual analogue scale (VAS) offers a unique approach of scaling FOC. The VAS approach is thought to provide a greater measurement of subjective phenomena because it allows more freedom to express a uniquely subjective experience from a set of categories (Pritchard, 2010). Another advantage of the scale is the lack of specificity in the questions. The scale asks questions such as "I feel confident that this baby will be fine" as opposed to other scales which tend to list specific conditions that some women are afraid that babies will have. The openness of the questions allows women to interpret their fears and worries subjectively while still providing a quantitative, diagnostic outcome measure that can be used clinically or in research. The major disadvantage of the scale is that the 6-items only tap the individual level of the proposed model and do not query what fears women may have that are at the provider, setting, or societal levels.

The *Tilburg Pregnancy Distress Scale* (TPDS) was constructed after extensive focus group study in order to measure distress during pregnancy and how that influenced obstetric outcomes. The first focus group consisted of six midwives and six maternity nurses, the second group consisted of three primiparous and three multiparous pregnant women, and the third group consisted of six women who had recently delivered. The primary topic of the focus group was what issues were most relevant to pregnancy distress (Pop et al., 2011). The authors analyzed the resulting text and they then created a 22-item scale for pilot testing. The TPDS uses a four-point Likert scale ranging from 0 (very often) to 3(rarely/never). This scale was then distributed to 11 community midwife offices to examine its psychometric properties. After this analysis, a more refined version of the TPDS was distributed to an additional 10 community midwife offices in order to perform factor analysis and to determine the concurrent and construct validity (Pop et al., 2011).

All assumptions for conducting principal components analysis were met. The Kaiser-Meyer-Oklin value was 0.81 and the Bartlett's test of sphericity was significant ($p<0.001$). Catell's scree test suggested a two-component solution ('negative affect' and 'partner involvement'). After oblimin rotation, 34% of the variance was explained by these two factors. Six of the items did not have a loading above 0.40 and were deleted from subsequent analysis. The resulting 16-item TPDS showed good internal consistency (alpha = 0.78) (Pop et al., 2011). Concurrent validity was measured using the Edinburgh Postnatal Depression Scale and the Generalized Anxiety Disorder Anxiety Scale and found to be significantly correlated with the TPDS (p's <0.05). Construct validity with the same two comparison scales was performed using a series of single logistic regressions. These regressions showed that women with a previous diagnosis of depression and/or anxiety were also at increased risk for TPDS scores over the 90th

percentile for the overall TPDS score and 'negative effect' subscale, but not the 'partner involvement' subscale (Pop et al., 2011).

The primary advantage of the scale is that the first version of the TPDS originated from direct consultation with pregnant women, new mothers and clinicians. The limitations of the scale, similar to many other scales, is that the scale was only tested with Dutch Caucasian women. The item content of the TPDS does a good job exploring how partners and/or social support is key to FOC but fails to examine how the provider, birth setting, or societal levels of interest influence FOC. Even within the individual level of interest, many of the questions are focused on body dysphoria in pregnancy as opposed to specific fears or worries about the birth experience. While these dysphoric concerns may be relevant and significant, they most likely represent a surface manifestation of deeper fears around the body's ability to perform the tasks of childbirth.

Some instruments used in the field were not specifically developed to measure FOC but have components that apply to fear and anxiety. One such example is *Lederman's Prenatal Self-Evaluation Questionnaire* (PSEQ). The PSEQ was developed as a component of Lederman's larger research on the relationship between psychosocial conflicts during pregnancy and selected complications that arise during labor. The book that lead to the development of the instrument was an attempt to explicate the dimensions of maternal role development that are paramount during pregnancy, and to illustrate adaptive and maladaptive responses within each of the identified dimensions (Lederman & Weis, 2009). The dimensions, or psychosocial tasks of pregnancy, include well-being of self and baby, acceptance of pregnancy, identification of a motherhood role, preparation for labor, fear of helplessness and loss of control in labor,

relationship with her mother, and relationship with husband or partner (Lederman &Weis, 2009).

Within each dimension cluster factor analysis was performed. Three separate anxiety factors were identified during this process. The three anxiety subscales were (1) COPING: maternal coping behavior during and between contractions, (2) SAFETY: concerns about safe maternal and fetal outcomes, and (3) PAIN: fears and concerns about pain labor. The internal consistency of the three anxiety scales ranged from 0.70 to 0.90 as measured by Cronbach's alpha (R. Lederman, Weis, & SpringerLink, 2009).

The resulting instrument is a 79-item instrument that are scored on a 4-point Likert-type scale with agreement responses ranging from 'very much so' to 'not at all'. The PSEQ is scored as seven scales corresponding to the developmental tasks. Higher scores indicate greater conflict and more difficulty in accomplishing the task. The acceptance-of-pregnancy scale contains 14 items, identification with motherhood role contains 15 items and all other scales contained 10 items. The instrument has been used in nursing research with pregnant women with the scales' reliability ranging from 0.73 to 0.94 Cronbach's alpha (Beck, 1999).

The actual instrument is not available at the University of Michigan library or through any online database. A request was made to the original author for a copy for the purposes of this evaluation; however, the instrument is only available for a substantial fee and, therefore, is not likely to be taken up for use in clinical practice and could not be analyzed for conceptual fit. As a whole the instrument is not useful for researchers seeking to study FOC as an independent construct. Multiple other dimensions are included in the scale that are not applicable and the scale in its entirety is lengthy and time consuming with 79-items. In addition, the factor structure of the anxiety components continues to support the understanding of FOC as individual

psychopathology as none of the three factors seek to query the provider, setting or societal levels of interest.

Worry scales

A number of scales originating in the United Kingdom seek to explore FOC but conceptualize the phenomena as 'worry' as opposed to 'fear'. The *Oxford Worries About Labour Scale* (OWLS) was created using a list of worries about birth that arose in a qualitative study looking at women's experience of care (Garcia, Redshaw, & Fitzsimons, 1998). After key items were identified, a small number of cognitive interviews were held for women to think about their responses to the question and to insure that the language was understood and that the 10 items reflected their worries during this period. In order to further validate the instrument, a psychometrics study of the OWLS was performed with a random sample of 2960 women who had recently given birth in England (Redshaw, Martin, Rowe, & Hockley, 2009).

Exploratory factor analysis (EFA) was performed on the full 10-item OWLS using an oblimin non-orthogonal factor rotation. Before factor extraction, the Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy and the Bartlett Test of Sphericity (BTS) were conducted to ensure that the characteristics of the data set were suitable for factor analysis. KMO analysis yielded an index of 0.87. Following factor extraction and oblimin rotation, three-factors with eigenvalues <1 emerged from analysis of the 10-item OWLS and together accounted for 51.93% of the total variance. The factor loadings were named OWLS – pain and distress, OWLS – uncertainty, and OWLS – interventions (Redshaw, Martin, Rowe, & Hockley, 2009).

Divergent validity was determined by correlating OWLS scores with a composite measure based on five questions asking about the information received: at the booking appointment, 'I was given the information I needed'; confirmation of receiving a copy of the

Pregnancy Book; confirmation of contact details of named midwife and communication with staff 'doctors talked to me in a way I could understand' and 'midwives talked to me in a way I could understand' during pregnancy. Higher scores on this composite score indicate greater agreement. No significant correlation was observed between the OWLS-9 score and the information and the communication composite score (Redshaw, Martin, Rowe, & Hockley, 2009).

An internal consistency analysis of the OWLS was conducted to ensure that the measures satisfied the criteria for clinical and research purposes using the Cronbach coefficient alpha statistical procedure. Calculated Cronbach's alpha of the OWLS-9 was 0.85. The mean OWLS score was 25.15 (SD 6.72) with a median of 25. The range of scores was 30 with a minimum of 10 and a maximum of 40 (Redshaw, Martin, Rowe, & Hockley, 2009). Discriminant validity was evaluated by comparing differences between OWLS scores in and the index of multiple deprivation (IMD) (Office of the Deputy Prime Minister, 2004). This index is a measure of multiple deprivation and provides information about the social and economic context of the locality in which the women were living in England. A significant difference between groups was observed, $F(4, 2690)$ 3.90, $p>0.01$ (Redshaw, Martin, Rowe, & Hockley, 2009). Predictive validity was evaluated using logistic regression. OWLS scores were regressed onto groups categorized by either agreement or disagreement with statements related to experiencing 'baby blues' at 10 days postpartum. The OWLS and each factor sub-scale scores were found to be significant predictors of 'baby blues' at 10 days postpartum (Redshaw, Martin, Rowe, & Hockley, 2009).

The OWLS has many advantages. The measure is short, robust, and respondent derived in its development. The instrument is easily administered for self- completion and is easily

scored without the requirement of complex scoring algorithm or score weighting. The scale measures a distinct domain of worry associated with birth and may be helpful in separating birth specific worry, fear of childbirth and more generalized maternal anxiety (Redshaw, Martin, Rowe, & Hockley, 2009). In addition, it is the only FOC instrument that was specifically tested for use with a diverse population. In the unadjusted models, women from non-white backgrounds had higher odds of being worried about each worry outcome, apart from having a forceps or cesarean delivery. The higher odds in the non-white group were most marked in relation to worries about pain and discomfort, not knowing how long labor would take, embarrassment and having more worries overall (Redshaw & Heikkila, 2011). This finding supports the overall premise of this dissertation project that marginalized identities have significant impact on women's FOC.

The challenge in this finding is that the work was done with women in England who are largely non-English speaking and non-citizens and therefore represents a different phenomena to women in the United States who hold positions as minorities despite shared language and citizenship status. Additionally, the context of the research dictated that the women's responses on the measure were retrospective. However, the value of the instrument is more likely utilized among women in the antenatal period (Redshaw, Martin, Rowe, & Hockley, 2009).

The *Cambridge Worry Scale* (CWS) was developed for use in the Cambridge Prenatal Screening study to examine women's concerns about the health of their baby within the context of other concurrent worries, both pregnancy related and more general (Green & Kafetsios, 1997). The scale was developed after critique of a standard, generalized anxiety instrument as being a scale that only measures extent of worries and not the type of worries (Green, Kafetsios, Statham, & Snowdon, 2003a). Responses to the CWS are made on a six-point Likert-type scale

(0 ‘not a worry’ to 5 ‘extremely worries’). The scale has 16 questions and concludes with an open-ended question that allows respondents to discuss worries not on the list (Green, Kafetsios, Statham, & Snowdon, 2003a).

The CWS was tested with women at three points during pregnancy and exhibited satisfactory internal consistency at all three times points (time 1 = .79, time 2 = .79, and time 3 = .76). Principal components analysis with oblique rotation at time 1 yield four factors that account for almost 57% of the total variance. Items were adequately correlated (Keiser Mayer Olkin adequacy = .87). Factor 1 had a component loading of 27.75% and had to do with socio-medical aspects of having a baby, such as giving birth, going to the hospital, internal examinations, and coping with the new baby. Factor 2 had a component loading of 12.22% and had to do with socio-economic issues such as money, employment problems, housing and the law. Factor 3 had a component loading of 9.28% and included items concerns with the health of the mother and baby including miscarriage, something being wrong with the baby and the mother’s own health. Factor 4 had a component loading of 7.72% and concerned relationships with partner, family and friends (Green, Kafetsios, Statham, & Snowdon, 2003a).

Comparing scores on the CWS measured Criterion/concurrent validity with certain sub-groups of women based on previous childbearing experience. Repeated ANOVAS were conducted with reproductive experience as the main between-subject factor and age and level of education as model covariates. As expected, previous reproductive experiences had an impact on factor 1 (socio-medical) and factor 2 (health), age was predictive of differences in factors 3 (socio-economic) and 4 (relationships) (Green, Kafetsios, Statham, & Snowdon, 2003a). Convergent/discriminant validity was measured by comparing scores on the CWS with the State Trait Anxiety Index (STAI). A multiple regression was carried out with state anxiety and worry

scores at time 3 as predictors of concurrent EPDS score, a measure of antenatal dysphoria. State anxiety had a correlation of r= .63 but the CWS score also had significant predictive value (r = .15, R2 = 0.14, F(1,1181) = 34.31, p<.001) (Green, Kafetsios, Statham, & Snowdon, 2003a). Similar psychometric testing was done with the CWS translated into Swedish, German, and Spanish (Carmona Monge, Penacoba-Puente, Marin Morales, & Carretero Abellan, 2012; Jomeen & Martin, 2005; Petersen, Paulitsch, Guethlin, Gensichen, & Jahn, 2009).

An advantage of the CWS is that there are questions that query how women are integrating external concerns such as 'housing', 'money problems', or 'problems with the law' into worries about the birth. However, the focus of the scale was worry about something being wrong with the baby. The authors were concerned that if there was undue emphasis on this topic it would heighten women's awareness that something could be wrong with the baby and generate additional worry (Green, Kafetsios, Statham, & Snowdon, 2003b). Therefore, the authors embedded questions about worry about something being wrong with the baby with a list of other items. Despite the addition of other items the conceptual focus of the scale remains on the individual psychopathology of the woman and fails to conceptually capture 'worries' or 'fears' at the provider or birth setting level of the proposed model.

The primary challenge of both the 'worry' scales (OWLS & CWS) is in the conceptual understanding of 'worry' and its incongruence with the proposed EST model. Worry is described by the authors as a predominantly cognitive activity involving negative thoughts and images about possible events and their outcomes. These worries are usually temporary and resolve when an event is over and are usually considered a normal feature of psychological functioning (Hirai et al., 2008). Therefore, worry describes the normative process of engaging in a new, significant activity, such as birth and motherhood, but fails to capture when the worry

crosses over into a phenomena like fear or anxiety. In addition, the scale fails to capture fear, or even worry, about interactions with the health care system or provider as supported by EST. Questions on both 'worry' scales are rooted in the individual level and do not capture fears that extend in from the provider, setting, or societal level.

Another grouping of scales that were analyzed for this evaluation were measures that were designed to be used while a woman was in active labor. The *Self-Evaluation in Labor Questionnaire* (SELQ) is a 21-item, 4-point Likert-type scale that provides measures of state anxiety (anxiety), confidence in ability to handle labor (confidence), concern regarding the outcome of labor for self and baby (concern), and fear of pain (fear) (Lederman, Lederman, & Kutzner, 1982). Conceptualized within a general framework of maternal anxiety and stress during labor, higher scores on each subscale are associated with increased stress so that higher scores represent increased state anxiety, decreased confidence in ability to handle labor, increased concern regarding the outcome of labor, and increased fear of pain. Alpha coefficients computed for the study data were reported in another article as 0.77 for state anxiety, 0.85 for confidence, 0.55 for concern, and 0.83 for fear (Lowe, 1989). No record of the scale is currently available in order to analyze the questions and which domains they measure of the EST. However, the scale was meant to measure specific anxiety-related variables during the process of labor as opposed to being a prenatal screening or diagnostic tool (Lowe, 1989). In addition, the items that measure anxiety were not generated specifically in relation to the situation of labor but were instead taken from generalized anxiety measures. Lastly, the instruments validity and reliability has never been published in a peer-reviewed journal (Wijma, Alehagen, & Wijma, 2002).

The items for the *Delivery Fear Scale* (DFS) were developed by the original three authors based on their clinical experience with pregnant and birthing women (Wijma, Alehagen, & Wijma, 2002). They composed a list of positive and negative items, expressing fear-related appraisals and their contrasts that were characteristic of women in labor. Eight experienced midwives were then asked to comment on the items. These comments and suggestions were used to compose a final list of 60 items that women could grade on a scale between 1 (do not agree at all) and 10 (agree totally). These items were then piloted with 92 women while in active labor in order to identify the items with the highest item-total correlations (Wijma, Alehagen, & Wijma, 2002). The final ten items were then administered to a new group of women in labor with subsequent semi-structured interviews to make an inventory of the women's descriptions of the content of each of the ten items. The alpha coefficient for the test was 0.88 in both phases of the study (Wijma, Alehagen, & Wijma, 2002).

An advantage of the scale is that half of the items are negatively worded and the other half are positively worded in order to not bias women's thoughts in a negative direction (Wijma, Alehagen, & Wijma, 2002). Another interesting component of the DFS is that the construction was guided by the item-total correlations as opposed to factor analysis. The authors chose to construct the scale in this way because ideally the scale should be measuring Fear as a single component and so factor analysis may not be as useful. However, this also speaks to the fact that the authors were only trying to measure the individual level of the proposed model. The other challenge of the scale is that is meant to be administered while a woman is in active labor and, therefore, offers limited diagnostic value for clinicians and researchers seeking to develop interventions prior to the onset of labor. Using the instrument in labor offers challenges as the researcher has to contact the woman many times during labor which runs of the risk of creating a

'doula effect' where even minimal contact with a seemingly supportive person could reduce a woman's fears and worries (Kenner, Klaus, & McCrath, 1991).

Fear of childbirth scales

The *Fear of Childbirth Questionnaire* (FACQ) was one of the first instruments developed to examine fear of childbirth (Areskog, Kjessler, & Uddenberg, 1982). The Questionnaire consists of 19 items with the answers 'yes' or 'no'. The instrument has been used in nine studies of fear of childbirth and has been the basis for the development of similar instruments. No published information about the factor structure or other psychometric performance of the instrument is available. One study that used the instrument did indicate that a score of five was used as a cut-off point for moderate fear and 10 for severe fear (Ryding, Wijma, Wijma, & Rydhstrom, 1998).

The 1982 article looked for congruence between women who identified FOC in the scale and those who identified FOC during individual interviews. The 'anxiety about delivery' was examined by both methods independently (Areskog, Kjessler, & Uddenberg, 1982). The degree of correspondence between the results obtained by the two methods varies with the number of affirmed statements in the questionnaire. Seventy five percent of women who had affirmed >8 items also verbally admitted fear of childbirth during the personal interview. The specificity of the questionnaire was found to be 96%, but the sensitivity was only moderate (38%) (Areskog, Kjessler, & Uddenberg, 1982).

The challenge with the instrument largely resides in the use of pre-formulated statements to be affirmed or denied. These type of questionnaires are often criticized for being leading and not having a clear cut off for what would be for a 'yes' versus a 'no' answer. Some of the questions in the instrument rely on the woman having a great deal of knowledge about the birth

and potential complications, for instance 'I am afraid of rupturing during the delivery'. The other challenge resides in problematic translation issues where the instrument uses words like 'phantasies' and 'prick' to describe what can be assumed as 'anxieties' and 'needles' respectively. There are two questions specific to the midwife, or care provider, but no questions that attempt to query feelings about the environment of the birth of the influence of societal expectations and norms.

The *Childbirth Attitudes Questionnaire* was adapted from a questionnaire designed to measure fear of childbirth by Areskog and colleagues (Areskog, Kjessler, & Uddenberg, 1982). It was initially presented by Harman at the Annual Meeting of the American College of Nurse Midwives in 1988 (Harman, 1988) and later published by Lowe (2000). The scale is a 15-item Likert scale that has a possible score range of 15-60 with higher scores indicating greater fear. In the initial study the scale had an internal consistency reliability estimate of 0.83 (Lowe, 2000). The instrument has been used in 14 other studies in some variation of its original form. One study deleted two items ("I have nightmares about the delivery" and "I have difficulty relaxing when thinking of the coming birth") at the request of the care providers because they worried that the items were scary, hence that by filling in the questionnaire women would become more anxious about the upcoming birth (Tanglakmankhong, Perrin, & Lowe, 2011). The relationship between PTSD and fear surrounding medical activities and procedures is an essential avenue to explore for women with fear of childbirth. Eliminating questions that trigger the somatic experience of trauma or fear negates this connection and could have biased the identification of women with FOC who may have preexisting and or/concurrent PTSD. Despite these weaknesses, in this particular study the instrument had a Cronbach's alpha of 0.81, and its

averaged total scores were significantly correlated ($r=0.55$; $p<0.001$) (Tanglakmankhong, Perrin, & Lowe, 2011).

Dr. Lowe was willing to share a copy of the instrument for the purposes of evaluation. The directions written on the scale indicate that it is meant to be self-administered. The instructions state that the scale is comprised of a list of fears that pregnant women have had in the past. Women are reassured that some women may have all of the fears and others may have none and are asked to answer as honestly as possible without consulting anyone else. Most of the questions concern specific procedures or events that are common in hospital deliveries including bleeding too much, 'painful' injections, being left alone, having a cesarean section etc. There is one question that addresses the general hospital setting and one question about not getting the kind of care that the woman wants.

The CAQ offers a concrete, easy to administer, basic review of fears that women may identify to their clinicians. This scale was used originally by Lowe to examine the relationship between FOC and self-efficacy for birth (Lowe, 2000). Within this context the scale offers a valuable assessment of what particular individual level fears decrease or increase the phenomena of self-efficacy for birth. However, with the broadened perspective of this study and the proposed model grounded in EST, the scale fails to adequately address all levels of the model.

The scale offers a relatively comprehensive view of the individual level of the proposed model, but lacks a thorough assessment of the other components of the model. In addition, while the questions that appear on the CAQ may be very real concerns for women, the specificity of the questions leaves little room for women to identify fears that may fall outside of the individual level and also does not allow for women to express other fears within the individual level if they are not identified within the scale. The question concerning the Provider level (I have fear of not

getting the kind of care that I want) assumes that women have enough understanding of what type of care options are available to make a judgment of whether they are receiving the type of care they would prefer. While this may be true for many women, women who have a history of marginalization within the health care system may not be familiar with the concept 'preferred care' to make a clear judgment of how that may affect their own fear.

Perhaps the most widely used measure of FOC is the *Wijma Delivery Expectancy Questionnaire* (W-DEQ). The W-DEQ was developed from the theory that the expectations a pregnant woman has about the anticipated delivery are highly relevant for both her experience of and behavior during the delivery. Similarly the woman's appraisal of a past delivery will strongly indicate the degree of anxiety associated with her last childbirth, offering an estimate of the fear she may experience during a future delivery (Wijma, Wijma, & Zar, 1998a). The instrument was developed in parallel with Lazarus' theory of stress and coping that states appraisal processes are a principal factor in determining how people react to environmental stressors (Lazarus, 1982). Thus, the W-DEQ was developed to measure FOC during pregnancy (version A) and after delivery (version B).

The 33 items in the scale were derived from the first two authors' clinical experiences of women with FOC. The content of FOC was operationalized by means of items comprising statements concerning intensities of emotions and magnitude of cognitions regarding the delivery (Wijma, Wijma, & Zar, 1998a). During its development the questionnaire was tested and women's remarks concerning convenience and comprehensibility were incorporated into the final form.

The authors used the internal consistency reliability (Cronbach's alpha) and the split-half reliability for estimating the reliability of the W-DEQ. Split-half reliability estimates were

obtained by dividing the items in an even numbered and an odd-numbered group. The Spearman rank correlations with statistical correction was then calculated to obtain the reliability coefficient for the whole test (Wijma, Wijma, & Zar, 1998a). The W-DEQ version a administered in pregnancy at week 32 had a split-half reliability of 1.00 and a Cronbach's alpha of 0.93 (n=196).

The measure uses a 6-point Likert scale with the end points marked 'not at all' and 'extremely' (minimum score = 0,maximum score = 165). The validity of the W-DEQ has been tested in several studies (Zar, Wijma, & Wijma, 2001). Unlike any of the other instruments presented the W-DEQ did extensive construct validity testing with multiple other instruments. The W-DEQ correlated respectively r=0.54 (nulliparous group) and r=0.55 (parous group) with the STAI, meaning 30% overlap. This level of common variance indicates that the W-DEQ measures in the domain of anxiety, and, at the same time, that enough variance is left for the measurement of another dimension not explained by generalized anxiety (Wijma, Wijma, & Zar, 1998a).

The W-DEQ has been used extensively in the literature exploring anxiety and worries in pregnancy, making it a useful instrument when replicating other studies in order to increase understanding of FOC within the context of American women at high risk for obstetric complications. However, the scale was originally written in Swedish and has some significant translation challenges. The scale consistently refers to 'fantasies' when a more appropriate term might be 'worries' for women in the United States. In addition, some of the words, for example 'desolate', are translated into a higher reading level than might be appropriate for a lower SES, urban population such as the one in this study. The scale only measures the individual level of the EST model. None of the questions query worries or fears that have to do with the provider,

birth setting, or societal influences. Lastly, preliminary data from a qualitative instrument validation study indicate that the concepts the W-DEQ attempts to query as well as the translational problems throughout the scale make it an ineffective scale for women in the United States (Roosevelt, under review).

Discussion

This systematic review of the reliability, validity, and conceptual match of FOC measures identified 11 metrics that met the original criteria for evaluation. Although the quantity and quality of psychometric data were variable, the review provides important summative information for use in future research and clinical practice. As discussed in previous studies (Huizink, Mulder, Robles de Medina, Visser, & Buitelaar, 2004) the convergent validity data suggests that FOC and generalized anxiety are related constructs. However they are not so highly correlated as to be the same construct, thus providing added value for measuring FOC specifically.

The dominant contributions to the literature on fear of childbirth (FOC) have been from psychology. The result is that the understanding of the phenomenon has tended to emphasize the individual experience and at times can support a victim-blaming ideology (McLeroy, Bibeau, Steckler, & Glanz, 1988). The complexities of social causation are only beginning to be explored. The ideology of individual responsibility inhibits that understanding and substitutes instead an unrealistic behavioral model where women are the sole contributors to the FOC phenomena. This conceptual understanding instructs people to be individually responsible at a time when they are becoming less capable as individuals of controlling their birthing environment (McLeroy et al., 1988). Examining measurement instruments using EST as a theoretical framework offers an alternative to previous conceptualizations of FOC and a more

comprehensive orientation to understanding multiple influences on FOC. In addition to acknowledging the variables that impact the individual as a birthing woman, the model directs attention to the factors that determine health care provision, structure and atmosphere for the health care system as a whole.

Recommendations

A thorough comparison of existing measures was necessary in order to identify if a psychometrically sound, conceptually coherent measure of FOC relevant for use within the context of the US maternity care system and for use within diverse populations of women was available. This review has identified 11 measures currently being used internationally. Many of the measures are not well developed and consideration needs to be given to the research question being addressed before deciding which existing measure to use. Although there are a number of measures created to measure FOC, many of these instruments have not undergone adequate psychometric testing or do not conceptually match the proposed, expanded definition of FOC based on the EST model. After comparison of all the instruments, the Wijma Delivery Expectancy Questionnaire was chosen for adaptation not only because it is the current gold standard, but also because it has some of the most comprehensive language of all the instruments queried and, therefore, has the greatest potential for conceptual fit with the chosen framework.

Like many perinatal mental health issues, FOC measures appear to be largely limited to country of origin and this lack of international collaboration imposes a number of restrictions on current research knowledge (Alderdice, Lynn, & Lobel, 2012). Certain aspects of fear may have specific cultural relevance and may not translate well across cultures. The ability to identify FOC in a diverse sample of women will add considerably to the complex nature of FOC and what aspects best predict adverse birth outcomes. While pregnancy anxiety or fear is typically

presumed to be a global construct, it has identifiable dimensions on all levels of the EST model. A more dimensionally comprehensive measure with situationally specific referents is needed if we are to adequately measure FOC in women in the United States.

CHAPTER 6

Results of the Qualitative Phase

Specific Aim 2: Elucidate and conceptually organize the components of childbirth related fear in a diverse sample of US women

Chapter six describes the qualitative data gathered as a result of conducting focus groups with a sample of women in Southeast Michigan. As described in chapter three, the initial phase of the sequential study was to conduct focus groups with a broad section of women not historically represented in the study of fear of childbirth (FOC). The purpose of this first phase was fourfold: (1) Identify data patterns within a range of responses; (2) describe important constructs of FOC using Ecological Systems Theory (EST) to organize patterns; (3) generate an adapted survey; and, (4) corroborate findings with key experts. Analysis of the focus group data will be used to adapt the Wijma Delivery Expectancy Questionnaire for use in the United States. Qualitative methods can expand the ways in which we develop and validate quantitative instruments and can contribute to an understanding of how well the instrument measures the domains of interest. For the purpose of this project, focus groups were used to generate qualitative data that will allow the researcher to directly hear respondents' comments and probe their exact meanings. Such exchanges allow both researchers and respondents to raise and explore issues in order to validate the relevance of certain items, to hone wording, and to generate additional ideas of emerging practices.

This chapter discusses the recruitment and sample of women who participated in the focus groups, the procedures used to collect and analyze data, the results of the focus groups, the rationale to amend an existing instrument, the methods used to estimate the credibility of the results, and the integration of the data to revise the instrument a second time prior to performing confirmatory testing.

Sample and recruitment

Purposive sampling was used to recruit 22 women into three focus groups. The first focus group took place at a women's art and music festival in Michigan. Flyers were posted inside the bathrooms and the first aid tent. Any woman of childbearing age was invited to participate. A total of six women participated. The second focus group took place at an urban health clinic that serves primarily Spanish speaking clients in Detroit. Nine women participated in the focus group at this clinic. The last focus group took place at a family planning clinic in Detroit. Seven women participated in the focus group at the family planning clinic.

Deliberately, each focus group had a unique demographic makeup. The focus group that took place at the music/art festival was predominantly white, educated, and identified as a sexual minority (i.e. queer, lesbian, dyke, etc.). The focus group that took place at the health center was almost entirely made of Latina women who had experience with birth personally, as well as professionally within their community and knew each other well. The final group at the family planning clinic was mostly black women who were part of the prenatal program that takes place at the health center. All 22 participants were women 18 years old or over who provided consent to participate in the focus groups. The demographic characteristics of those women who agreed to participate are shown in Table 6.1.

Table 6-1

Demographics of focus groups

N=22	Overall N(%)	Focus Group 1 N(%)	Focus Group 2 N(%)	Focus Group 3 N(%)
Ethnicity				
White	7(32%)	5(83%)	1(11%)	1(14%)
Latina	8(36%)		8(89%)	
Black	6(27%)			6(86%)
Asian	1(5%)	1(17%)		
Age				
18-25	7(32%)	1(17%)	3(33%)	3(43%)
26-34	10(45%)	3(50%)	4(44%)	3(43%)
35-45	5(23%)	2(33%)	2(23%)	1(14%)
Household composition				
Single	5(23%)		3(33%)	2(29%)
Married/partnered	14(64%)	5(83%)	5(56%)	4(57%)
Divorced	2(8%)	1(17%)	1(11%)	
Separated	1(5%)			1(14%)
Education				
Some high school	2(8%)		1(11%)	1(14%)
High school/GED	6(27%)		4(43%)	2(29%)
Some college	5(23%)	1(17%)	2(23%)	2(29%)
Trade/technical	1(5%)			1(14%)
Associate degree	1(5%)			1(14%)
Bachelor's degree	4(19%)	2(33%)	2(23%)	
Master's degree	2(8%)	2(33%)		
Professional degree	1(5%)	1(17%)		
Employment				
Employed for wages	17(77%)	5(83%)	9(100%)	3(43%)
Student	3(14%)	1(17%)		2(28.5%)
Unemployed	2(9%)			2(28.5)
Childbearing history				
Never been pregnant	3(14%)	1(17%)	2(23%)	
Currently pregnant	4(18%)	1(17%)	1(11%)	2(29%)
Given birth in past 5 yrs	15(68%)	4(66%)	6(66%)	5(71%)
Healthcare provider				
Certified Nurse Midwife	8(36%)	1(17%)	2(23%)	5(71%)
Homebirth midwife	1(5%)	1(17%)		
Obstetrician	12(54%)	3(50%)	7(77%)	2(29%)
Family physician	1(5%)	1(17%)		

Data collection and procedures

The first step was to clarify the study purpose orally when participants called to request more information. The focus groups were scheduled after participants who stated they had some FOC agreed to participate and consent was obtained. The first focus group took place in a quiet gathering area at a music festival. The second focus group took place in a conference room at the health clinic in Detroit and the third focus group took place in a conference room at family planning clinic in Detroit. All focus groups were recorded using a digital voice recording application on an iPhone. The principle investigator (PI) kept handwritten notes in addition to recording the interviews. The purpose of the written notes was twofold. First, the PI added notations and highlights to indicate the necessity to probe for clarification and second, the notes provided a backup copy in case there was a problem with the recording.

At the start of the focus group participants were informed about the purpose of the group and the protocol. During the first part of the group participants were given an opportunity to discuss what fear of childbirth has meant to them and what type of things came to mind when they thought about birth. After FOC was discussed more generally the PI then probed each of the themes discussed with open-ended questions in order to situate FOC within the larger socio cultural environment. Each focus group was concluded by asking each participant to provide three 'bullet points' with the 'take home messages' about what fear of childbirth meant to her (Seng, Low, Sparbel, & Killion, 2004b).

After all three focus groups were completed the PI transcribed the focus groups while reviewing written notes to ensure that all things discussed in the notes were audible in the recordings. The transcribed focus groups were then imported into NVivo qualitative software in order to organize quotes from the focus groups into levels of the Ecological Systems Theory

Focus group findings

The findings from the focus group discussions and content analysis process are grouped according to the proposed model based on Ecological Systems Theory: individual; providers; birth settings; and, society. Some of the themes that emerged could be applied to two or more of the levels and a decision had to be made based on the context of how the theme emerged in all three groups as to which level to put it in. This speaks to the reality of using EST in which the levels represent more of a continuum as opposed to four distinct levels.

Women expressed an immense amount of relief about being asked about their fears. As one woman said "We all have those fears and they are really real and they take up so much mental energy. So much. I don't think I ever went more than a few hours without revisiting a new fear" (Group (G) 1). They expressed fears reminiscent of PTSD that lingered on for years even after giving birth. "But you know, he's three now and I can be right back into that place of the fear swallowing me up and not being sure that I would ever make it to the other side" (G1). Despite the universality of the fears and the recognition that some fear is a normative part of the experience, many women felt that it wasn't okay to express their fears to other people. "The verbalizing of the fears might make them real or I might get an answer that is worse than the fear itself" (G2).

Individual fears

The first set of fears discussed in this chapter are fears that focus around the woman's individual experience of fear as a psychological construct. Many of the themes that emerged from the focus groups reiterated themes seen in previous research, such as fear about the pain of childbirth or fear that the woman or her child may die during the birth process. However, many of the fears discussed in this section are new themes and relate to the woman in the context in which she sees herself giving birth. Fears such as feeling out of control during the process or feeling vulnerable suggest a strongly relational component to FOC that has not being discussed in previous literature. These themes are included in Table 6.2 below.

Table 6.2

Individual themes

Emerging Themes Informed by Ecological Systems Theory	
Individual	Feeling vulnerable Choosing support people Obligation to family Feeling out of control Being disrespected Pain Fear of dying

Women felt in a vulnerable position when giving birth. "I hated that feeling of being totally at the mercy of these strangers and trusting that they would treat me and my baby good" (G3). They adjusted who they had around them to account for feeling vulnerable. "When you are feeling vulnerable you don't want people around you who don't care about you? You want people around you who will help you and be there to support you, and make you feel safe, and make it easier, not harder" (G2).

For many women the choosing of who attended the birth was a key modifier of how fearful they felt. This desire to choose who was in attendance at the birth was a common theme among all three focus groups. “I felt so loved and supported at my births with my family around” (G2). Many women discussed the desire to have women friends and family around and how the presence of someone who had been through birth before felt reassuring and comforting. “I wanted my mom and my grandma and all my aunties there even though I knew I wouldn’t be allowed to. I just felt like if I could look up and see a bunch of people who had done this that I would remember that I could do it too” (G3). One of the women in the focus group who also works as a doula talked about discussing with her clients who will be at the birth encouraging them to find people “…who will make them feel safe and supported and they are really thinking about the female family members or doulas. They want their husbands there but they know they aren’t really going to know what to do” (G2).

While having supportive women around was a common theme through much of the discussion, other women felt obligated to have their family. “I had my neighbor with me and she was great but my mother came and she was terrible to be there. She was so worried the whole time and kept rubbing my back all hard” (G2). Particularly with family members they were not close to “My cousin came up and kept talking and trying to take pictures of me to post on Instagram and I was ready to smack her the whole time. I knew my whole pregnancy that my family was going to try and make this a scene and then they did. The nurse ended up asking her to leave, thank god.” (G3).

Struggles with family support was a common theme, but many women also really wanted the birth to be a private experience with their partners and had fears of their partners not being present or other people trying to trump the role of their partner as primary support person. “But

for me I just want my husband and my doula there. I don't want any family around. I feel like they would bring their own set of expectations and it just feels like it should be this private experience for our own little family. I was afraid my mother or mother-in-law would come in and take over and it wouldn't be this fantastic bonding experience that my husband that I had planned on."(G2). One of the women told the story of a doula client she worked with whose husband was on the other side of the state for work and did not have a car and how the woman's labor was long and hard because of how abandoned the woman felt without her husband there. "I really think she was waiting for her husband or someone else to come and help her so she didn't feel so alone." (G2).

Feeling out of control in the process of giving birth was a fear for many women. "I know I see that with the ladies we work with (participant is a doula) and being that out of control of my own body feels like it would be terrible. It makes me not want to ever have babies of my own."(G2). For other women the fear of being out of control was also wrapped up with being worried about being disrespected based on identity. "For me it is about feeling out of control and what would or could happen to my body having a baby and being treated like shit because I was a dyke."(G1). A big theme in group three was the actual physical loss of control of bodily functions. Women worried about having bowel movements in front of their partners or yelling too loudly and being told to be quiet. "I worked for a while as a house keeper at X hospital and I remember cleaning the delivery floor and nurses sitting around talking about how so and so was acting the fool and couldn't get a grip so then being that patient became one of my biggest fears like what if the pains was too bad and they couldn't get me no epidural and then I was the patient that was hollering on and people would laugh at me."(G3). The feeling of being out of control was invariably linked to fears about the pain and whether women had the strength to handle the

hard work of birth. “I just didn’t think I could do it. I hate being in pain and everyone talked about birth as the most pain you ever had and I felt like maybe the pain would be so bad that I would lose my mind.”(G2). The discussion about how painful birth was became such a fear that it deterred women from actually getting pregnant. “…and I was like ‘are you kidding? Why would I be excited? You just made it sound like a nightmare. I’m fucking panicked!’ ” (G1). For many women how they handled the pain and whether they chose to utilize pain medication was a fear. “Like if they can’t handle it and need to get an epidural that their mother will say they aren’t really moms because they didn’t do it without drugs and couldn’t handle the pain.”(G2). While the pain of birth was a major fear for many women, other women tried to transform the experience as moving from a place of fear to a place of united triumph after the birth. “When my little girl came out and cried and the pain stopped I just felt like this little person and I had been through this dark path together and survived and how amazing is that that we did that together.”(G1).

The last major theme that appeared for women related to individual fears about childbirth is the fear of dying during birth or something going catastrophically wrong. The “what ifs” of the birth process took up a lot of space in women’s minds. “It is just so hard and so much could go wrong that I get scared thinking about having my own kids.”(G2). The concept of birth being a risky event came up when women discussed weighing the decision to go through the birth process. “I know it isn’t really risky but because I’ve seen those things and heard those things they’re stuck in my head and then I think about them happening to me and I just don’t know if I could do it. Like maybe it is my intuition telling me I shouldn’t and I should listen to it like maybe having a family isn’t worth dying or having to have your child die.”(G2). While this

theme is frequently discussed in the previous literature it had significantly less emphasis in the focus groups than other themes.

Some of the women worried about the babies getting sick or dying and their partners not having access to them for legal reasons. “The biggest thing I have fear about this time around is that something will happen to me and or the baby and my partner won’t have access to us.”(G1). For a lot of women the fear of dying was wrapped up in their ability to get through the process. “I was just sure I wasn’t that strong and that I would die all alone.”(G3). That responsibility felt singularly on the women themselves as if they alone held the weight of whether they and their babies survived the process. “It is all on you and your body to make things go along and holy shit is that a lot of responsibility.”(G1).

Provider fears

In addition to personal fears about their own birth experience women in all three focus groups expressed a number of fears about their providers and the interactions they would have with them during the delivery. For the purposes of the focus group we defined providers as their doctors, midwives, nurses, or doulas. However, the themes that came out of the focus groups were almost entirely focused on their experiences with their primary birth providers, meaning their doctors or midwives. Table 4-3 summarizes the fears women reported related to their providers.

Table 6.3

Provider themes

	Emerging Themes Informed by Ecological Systems Theory
Provider	Being a "good" patient Assumptions by providers Seeking out providers with shared identities Desire for respect Desire to be heard Being dismissed

Women expressed fears and worries about not being a "good" patient. They had a lot of expectations for themselves during the delivery and a lot of fear that they would let down their providers if they didn't behave appropriately. "I was afraid I wouldn't be a good patient and then they would talk about me."(G3). When probed about what being a good patient meant women talked a lot about not being out of control with their providers. "I don't want to be the woman that kicks her doctor when things get hard at the end and then that doctor talks forever about the moron he delivered who gave him a black eye."(G1). Other women were worried about being too demanding. "Like I know they're all busy up there and so I didn't want to go in and out of the hospital not sure if I was in labor and have my doctor come in over and over again and then have to be there forever if I'm taking too long."(G2). This worry, that the intensity of birth or their own capability, would interfere with how they were viewed by their providers was a theme among all three groups and taps into the work previously done critiquing the phenomena of "compliance" in the health care system. Compliance is an ideology that transforms providers' theories about the proper behavior of patients into a series of research strategies, research results, and potentially coercive interventions that appear appropriate, and instead reinforce a provider's authority over health care (Trostle, 1988). The phenomena of therapeutic compliance is a

problematic concept with its own social history but has deep roots in women's fears about childbirth.

Some women felt the need to represent their whole demographic so as not to give a bad name to other women. "We are such a small minority of patients, especially in the pregnancy world, that there is this need to live up to the expectation of being awesome parents and really good at the whole pregnancy gig or the doctor might think we aren't doing it right and then you get into the whole do they respect me thing."(G1).

Many women translated this fear of having to live up to expectations based on their identities into choosing providers that shared their identity. "I'd imagine if you're like me it is really both, you like them, and you share life experience with them so you can feel a little more confident about the whole birth process."(G1). And "It was really nice to just be able to talk about our identities in a way where we didn't need to educate, we could just, you know, coexist and feel understood." (G1). For those who chose to work with providers with whom they didn't share a common identity, women talked about how important it was to have a provider that was able to be open and kind and how much the attitude of their provider alleviated their fears. "Then we met her and felt like it was all going to be okay. She just exuded this kindness and acceptance and we didn't have to explain ourselves."(G1). Even if the provider wasn't familiar with their culture, having a provider that was open to learning about a woman and what she values lessened fear and worries. "She was really patient and asked about me and how my culture feeds a baby and was asking if I had other women in my family who breastfed and she was really cool. Like she cared about who I was and what I brought to the experience."(G2). While this desire for shared understanding was alluded to through other themes in all three groups, it particularly resonated with the group of women who largely identified as lesbian or

queer and who were predominantly white. While all groups discussed the differences in identities between themselves and their providers, it was largely the white women who discussed seeking out alternative providers to meet this need indicating a potential race difference in the experience of agency within the health care system.

Women in the focus groups talked a lot about assumptions on the part of their providers that made their fears worse and increased their anxiety about the birth process. "Like the doctors assume they will just be able to do it because Mexicans don't like pain meds and then if they can't maybe there is something wrong with them."(G2). Many women talked about experiencing micro aggressions from their providers that they felt came from being of a different class or race than their provider. "I know a lot of the women who have babies with those doctors use Medicaid and that is all I had too but I just knew if I could get some private insurance, like some Blue Care Network or something like that than they would see me different and probably treat me different. I was never able to get different insurance and I still wonder if maybe they would have listened to me more when I was having all those early pains and maybe my baby girl wouldn't have come so early. Like they would have respected what I had to say more if they thought I had more money or if I looked more like who they are."(G3).

The theme of being treated respectfully by their providers came up in all three groups. "The feeling of being out of control when I'm potentially naked and trusting some doctor, or you know doula or midwife or whatever, to treat you well when you are naked, out of control, in pain, and in a public space? I wanted them to respect me. I hoped they would respect me."(G3). For many women differences in dialects and language added into their fears if they would be respected or not. "I knew I need to learn the words and the language and the, you know, how things work so I could help other ladies not be afraid and to feel like someone understood them

and respected them and would be on their side."(G2). "But really my English didn't seem like it helped when I was there with my sister because the doctors still just talked fast and used medical language that I didn't understand them or I think they thought maybe I didn't speak English either so why bother slowing down."(G2). Even when providers did slow down enough to try and help patients understand what was going on, many women felt like the way they were being spoken to was condescending. "I mean I speak English better than that doctor did but he got all slow and curt because he thought I was some young stupid girl who didn't understand jack. But I understood just fine what was wrong with my baby; I had done lots of research. He just wasn't being respectful and I didn't like that."(G3).

In a similar theme to a fear of disrespect women also expressed a fear of not being listened to by their providers. "I really love my OB but I have never felt so patronized as when she told me that I didn't need to worry so much."(G1). This came up especially when women expressed their fears and worries about the birth process. "I made a joke once about now knowing how much it was going to hurt this time and I was looking for some reassurance or something and instead I felt really sort of dismissed and shamed by his answer. Like of course it is going to hurt, you're having a baby, what did you think would happen, everything would be all fantastic?"(G3). This feeling of dismissal tended to vary by type of provider. Women who birthed with midwives felt that they were able to discuss their fears and have them be heard. "This is again why I loved our midwife. I felt like we could bring our fears to the table anytime and she would sit with them and could really hear my concerns."(G1). The feeling of being listened to extended to how women felt like their pain would be managed by their providers. One woman discussed how she chose a midwife to attend her birth because she felt like her birth plan would be accommodated. "I liked how my midwife told me once during my prenatal visit

that if I didn't want an epidural she would do the best she could to help me get through that birth without that needle in my back. She talked about how I just needed to let all the people know what I wanted and that she would help make sure that I got it, even if I forgot that I didn't want the medicine and started asking for it she would remind me of my plans and wishes and help me see if they had changed or if I was just feeling scared."(G3). This stands in contrast to another woman who spoke about her own birth and the births she has attended as a doula. "They think they can fix it if we are in pain and maybe we don't want it fixed. Maybe we want to go through our rite of passage without being told we are doing it wrong or not normal." (G2).

However, perhaps the most distressing fear for many of the women in relation to not be listened to is whether they feel included in their own health care decisions and in the birth process. For women who do not have English as a first language this is a poignant fear. "They just assumed because she was young and Latina that she wouldn't speak the language and so they didn't feel the need to tell her things or include her and they also just assumed that she would have the baby just fine with no help because her mom was there."(G2). This role of language and being listened to extended to women with a lower education level as well. "I don't claim to be the smartest woman and I don't have a bunch of degrees and school stuff but what I do know is my own body. I knew something was wrong with that baby. I just knew it. I really really knew it and they still didn't listen to me."(G3).

Birth setting fears

The setting in which a woman chooses to give birth reflects a lot of women's fears and worries about the process. In these focus groups there was much discussion about giving birth at home versus in the hospital in terms of women's own experiences as well as the experiences of their family and friends. The themes are summarized in Table 4-4

Table 6.4

Birth setting fears

	Emerging Themes Informed by Ecological Systems Theory
Birth Setting	Included in decisions Feeling safe/unsafe Pressure for hospital birth

For some women, giving birth at home felt like where they would feel safest and least afraid. The women who actually had homebirths in the focus groups were all from group one and were primarily a well-educated, partnered, and white. Women in the other two focus groups discussed homebirth as something they had heard about or who had relatives who had given birth at home, however, none of the participants in groups two or three gave birth at home. "Homebirths are safe and if I was going to have go through the hell process of birth I wanted to do it on my own terms with people I chose and not some resident or medical student I never met."(Group 1). For these women homebirth felt like a refuge from the perceived chaos of hospital birth. "See I grew up an athlete so I had lots of sport injuries as a kid and college student and was in and out of the hospital a lot and met a lot of really crummy providers with no skills. I feel like some of the pain that I have now is because they didn't really take me all that seriously or give me good care or respect me and I hated it."(Group 1). For this woman, if she was going to give birth, it was going to be in a place where she felt safe and supported by the providers that she chose to interact with. "Some neighbors of ours had the baby at home and if I wasn't going to get it wham bam cut out all neat and clean than I sure as hell wasn't going back to the hospital. I would have been so pissed to go back to the hospital."

For many of the women in group two, homebirth was something that they had heard about and were interested in but still had their babies in a hospital. "One of my grandmothers

had all her babies at home and she was the only one that didn't complain about the whole thing."(G2). Another woman connected the experience of being afraid with planning a hospital birth. "My mama had all of us at home too in Mexico. She had some bad stories and she talks a lot about the pain but she never seemed afraid or unhappy. It seems like the women who are afraid are the ones that go to the hospital."(G2). Some women in all three groups, regardless of where they chose to give birth, challenged the idea that hospital birth was safe at all. "Everybody just goes to the hospital because they think they will be "safe" there and then the stories are terrible and they are so unhappy."(G3) Despite the perceived benefit of homebirth women felt social pressure to give birth in a hospital setting, even if they were not completely comfortable in the environment. "There is a lot of pressure to do things like other Americans and here you have your babies in the hospital."(G2).

In contrast, many women in the focus groups felt like the hospital was the safest place to be and had fears and worries about the idea of having a baby in an out of hospital setting. "I can't imagine having no baby at home. What if something goes wrong with you or the baby?"(G3). For these women the process of birth felt so inherently risky that, even if they didn't like their providers, they still felt a hospital was the safest place to give birth. "It's funny because I didn't like the people at the hospital but I felt safer being there. I would be too afraid to have a baby at home without an operating room nearby."(G1). The hospital provided a network of safety for a potentially unpleasant and risky life event. "Oh man, I barely wanted to have a baby the normal way. I really wanted to have a cesarean but they don't let you do that unless there is something wrong. I was like oh there is something wrong all right. I don't want no baby stretching and tearing open my stuff. Now that's just wrong."(G3).

Societal fears

The vast majority of what was discussed during the focus group related to an individual woman's personal experiences, her interactions with her provider, or the system in which she is choosing to give birth. However, in all three focus groups women alluded to larger societal constructs that affected their birth experience and contributed to what made them fearful. The themes related to societal influence are summarized in Table 4-5.

Table 6.5

Society fears

Emerging Themes Informed by Ecological Systems Theory	
Society	Media compliance Stories from friends and families Sexism Racism

The role of the media and what women see on television and in the movies had an impact on how they experience their own births and what types of things they feared. "I feel like in the beginning I wasn't that afraid and then when I actually was pregnant myself I started noticing that every birth on TV or in the movies was a disaster and it started feeling like wow maybe that is what it really looks like."(G1) Women felt like the images that they saw in the media about birth affected how they felt about their own bodies and their ability to give birth. "You have the most intense relationship of your life with your body during pregnancy and instead of doing that in a world that honors it all we do it as a terrifying made for TV lifetime movie."(G1) This constant barrage of images of birth as an emergency and a dramatic event was linked by many women to why there is pervasive cultural fear of birth. "Like we make birth this huge horrible thing and we see it on discovery health and dateline and it is always a big dramatic event. We've

lost the ability to think about birth as normal. My partner and I talked a lot about that, how the root of that loss of normality is fear."(G1)

Many women discussed how their own cultural understanding of birth contributed to their attitudes as well as their worries. "We live in Mexican neighborhoods, we get our health care here with people we know and (who) understand us, we work with other Mexicans, our children are cared for by neighbors. So we get to be ourselves. But when you go the hospital, for anything really but I guess I'm talking about birth because that is the only time most of us have been to the hospital, so when you go to the hospital you have to meet this other world, a world that doesn't like understand us or how we do things."(G2). Women talked about hearing stories from their relatives and how those stories added significantly to their anxiety about how hard the birth was going to be. While some women felt these stories added to their fears, other women felt they were a necessary part of preparation for the experience. "I think for our culture a lot of those stories are made for preparing girls. Like you have to be tough to do it and if you're tough you'll enter mamihood (motherhood) and if you're not, well, it's like you're not a real mother."(G2).

Women linked their fears about birth and pregnancy to larger social constructs of sexism and racism. One woman talked about how one of her biggest fears about pregnancy and birth was having her body be further on display in a world that already commodifies the female body. "Why I won't do it?…. hmmm…well at the top of the list is the gendered idea of pregnancy and birth. I'm a big fat butch and so is my partner, we aren't girly and pregnancy is so gendered and the body is so public and I've tried my whole life to make my body not a public commodity."(G1).

For women from a racial minority the influence of racism contributed to their fears about pregnancy and birth. “Race absolutely matters in birth. It matters in everything. Some of it is the way the doctors treat us but I think it is also just the whole system. It’s not set up for us to understand or be able to navigate and of course that is going to make us afraid.”(G3). Women from group three talked a lot about the disparities in infant and maternal health and how scared they felt going into the process knowing that just by nature of being Black their children had a higher chance of dying during birth. “I don’t want to be one of those people that makes everything about race because I know most of it is just how people treat each other but I agree, racism affects the way we are treated in birth. How can it not with how often our babies die and only like a few people even looking at that to see why that happens. If white babies be dying people going to stand up and take notice.”(G3).

Summary of focus group findings

All three focus groups were concluded by asking each woman to identify three bullet points that they wanted the researcher to take as key points regarding the discussion. In the first and third group the bullet points were all consistent with the information that had been shared previously in the group and supported the structure of themes that emerged. In the second group the use of the bullet points prompted an entirely new discussion about the role of race and ethnicity as informing FOC. It was brought up by one woman who had spoken very little throughout the group. As we moved on from her bullet points, women started to respond to her feelings of having fear about performance during delivery being uniquely related to identifying as a Latina and a mother and an additional 40 minutes of discussion occurred. When the group closed after this discussion and women were given a chance to revisit their bullet points of take

away messages almost every woman in the group who identified as Latina included race and ethnicity as a key take home message.

The findings from the focus groups provided valuable information in relation to the purpose of this study: to understand how women experience fear of childbirth (FOC) within diverse samples of women. Women experience FOC as a complex phenomenon that extends far beyond fear of the pain of childbirth or other individual level fears.

Table 6.6

Emerging themes informed by Ecological Systems Theory

Emerging Themes Informed by Ecological Systems Theory	
Individual	**Feeling vulnerable** **Choosing support people** **Obligation to family** **Feeling out of control** **Being disrespected** **Pain** **Fear of dying**
Provider	**Being a 'good' patient** **Assumptions by providers** **Seeking out providers with shared identity** **Desire for respect** **Desire to be heard** **Being dismissed**
Birth Setting	**Included in decisions** **Feeling safe/unsafe** **Pressure for hospital birth**
Society	**Media compliance** **Culture** **Ethnicity** **Sexism** **Racism**

On the individual level women have fears about feeling vulnerable during the birth process. For some women these are alleviated by getting to choose which social support people they have by their sides. Women have fears about feeling out of control of the process to the

point that the fears extend to their babies dying or even dying themselves during the birth process. These fears are consistent with previous research on FOC.

Women in the focus groups talked extensively about the role of their provider and how providers can ameliorate their fears and worries or make them worse. Women are concerned about being viewed as a good patient by their providers. Many women have concerns about not having a shared identity with their provider and how that lack of shared of identity leads to be treated with a lack of respect or just not being listened to and included in health care decisions. For some women these provider concerns lead them to choose out of hospital birth setting where they have more control over their environment and who cares for them. Interactions with their providers and the desire for approval and to be "good patient" were persistent themes in all three groups. This continued attention to providers' perceptions and feelings as much as or more than their own lead to a tremendous amount of fear.

However, some of the most compelling findings from the focus groups were the discussions about social constructs of identity and how those influenced whether a woman feared the birth process or not. The images of birth in the media lead a lot of women to fear parts of the process that they hadn't heard about or didn't even realize might happen. Women talked about cultural understandings of birth and how their cultural identity lead to them feeling misunderstood or disrespected in the health care setting. This extended to interpretations of sexism and racism within the larger society and how those constructs played out during the childbirth experience. One woman summed it up best when she said: "We live on the border between two cultures and that affects our health, our work, our children. Everything. Birth just brings it out more because it combines all the things we do, our family our bodies, everything,

into one time. And when you live in a place that involves balancing two worlds, well maybe the birth is the thing that tips that balance and we fall."(G2).

Study limitations

As with all focus group research, the study was not without limitations. First, generalizability from focus groups is limited and this may be especially true when extending the results to other minority populations. Another common limitation of focus group methodology is selection bias; most of the participations thought the location and time were convenient. In contrast, women who met the criteria, but may have had other constraints, such as no transportation or no child care, were not able to participate. Despite these limitations, focus group methodology remains a viable way to gain information that is not easily obtained through quantitative methods. Additionally, because of the open-ended nature of questions, important issues may have been omitted from the focus group discussions. Further research with these, and an expanded demographic of women, is necessary to elucidate additional factors and determine whether the issues identified here are shared across demographic groups.

Conclusions

The findings of these focus groups provide evidence that women's birth experiences and their experiences with fear surrounding childbirth are regulated by many other social mechanisms including race, class, gender, and ethnicity. As with all significant events, birth is something to which we bring our social interpellated selves (Martin, 2003). It is a social event that involves intensive and significant relationships with the people and institutions that surround us. Earlier analyses around childbirth experiences tended to universalize women and their experiences. However, there is evidence to support the notion that social constructs such as race, class, sexual orientation, and gender have an impact on the subjective evaluation of the

experience of birth and even on the actual character of the birth itself. There has been little work that systematically analyzes the differences between women in terms of their attitudes, desires, and their differential access to and use of power in childbirth to construct a context for giving birth that makes them feel safe.

The results of these focus groups indicate that how we measure FOC in our research needs to be expanded to include things that women in the United States identify as key contributors to their fears and worries. The results also support the use of EST as a theoretical framework for examining FOC. Viewing women as intrapersonal units of study as opposed to deeply rooted within the culture in which they live fails to recognize the way women gain power and active control over their birthing experience within the confines of a 'technocratic' birth. We need to measure not just the individual woman's fears but also how her provider, birth setting, and society at large contribute to integration of the birth experience and her fears and worries around the process.

CHAPTER 7

Analysis of Survey Data

Specific Aim 3: Adapt an existing instrument to demonstrate the components of a theoretically informed instrument for use in the United States.

Content validity

Content validity concerns the degree to which a sample of items, taken together, constitutes an adequate operational definition of a construct (Beck & Gable, 2001). The process generally involves two distinct phases; a priori efforts by the scale developer to enhance content validity through careful conceptualization and domain analysis prior to item generation, and posteriori efforts to evaluate the relevance of the scale's content through expert assessment (Beck & Gable, 2001).

This first phase of the content validity process was undertaken during scale development. Fear of childbirth (FOC) was conceptualized as an intricate feeling with an individual and sociocultural pattern of contributing factors using Ecological Systems Theory and the information gained during the focus group portion of this project. As the Wijma Delivery Expectancy Questionnaire is considered the gold standard instrument for FOC, a decision was made to adapt this existing instrument for use with women in the United States as opposed to developing an entirely new scale (Wijma, 2013). The existing structure of the scale was kept involving a 6-point Likert scale that included emotions and sentiments regarding the childbirth

experience on either side of the scale. The focus groups were used to generate a pool of descriptors that explore the construct. Words that were used repeatedly during the focus groups that were clear, concise, readable and distinct were chosen. Words were chosen that articulated the construct well so as not to introduce sources of error variance, which would reduce the strength of correlations among items in the factor analysis process. In some cases, if the words exceeded a 5th grade reading level, synonyms were chosen that would reflect the construct while maintaining the integrity of the instrument for use with a majority of women. In addition, the words were placed purposively throughout the scale so that the flow of the scale reflects the theoretical model developed for this project (i.e. individual, provider, birth setting, and culture). Table 7.1 shows the flow of items retained, revised, or added based on the information from the focus groups.

Table 7.1

Item retention and development

WDEQ	Retained from WDEQ	Focus group revisions	Focus group additions
Fantastic	Fantastic		
Strong	Strong		
Confident	Confident		
Afraid	Afraid		
Safe	Safe		
Abandoned	Abandoned		
Fantasies of child dying		Baby death or injury	
Frightful		Scary	
Lonely		Alone	
Deserted		Supported	
Pain		Painful	
Happy		Unhappy	
Panic		Panicked	
Totally lose control of myself		Out of control	
Longing for the child		Excited	
Dangerous			
Weak			
Independent			
Desolate			
Tense			
Glad			
Proud			
Composed			
Relaxed			
Hopelessness			
Self confidence			
Trust			
Behave extremely badly			
Dare to totally surrender control of my body			
Funny			
Natural			
Self-evident			
			Respected
			Understood
			Maternal death or injury

The content relevance of the resulting scale was assessed using procedures recommended by Polit & Beck (2008). In order to compute the item-level content validity index (I-CVI) a panel of content experts is asked to rate each scale item in terms of its relevance to the underlying construct. The expert participants were sent a letter explaining the process and provided with a Content Validity Index. The letter is included as Appendix A and the content validity form is included as Appendix B. In addition to the quantitative scoring in the CVI, content experts were asked to share qualitative comments regarding the items as well as the overall questionnaire.

Table 7.2

Characteristics and qualifications of content validity experts

Content Expert	Title	Research focus	Credentials
1	Nicole Fairbrother Assistant Professor University of British Colombia Department of Psychiatry Director Mother-Infant Wellness Lab British Colombia Women's Hospital	• Psychiatric epidemiology • Perinatal mental health	Ph.D. Psychology
2	Wendy Hall Professor University of British Colombia School of Nursing	• Transition to parenting • Infant sleep • Breastfeeding	Ph.D., RN Nursing
3	Kathrin Stoll Postdoctoral Fellow University of British Columbia School of Nursing Midwifery Program	• Childbirth fear • Refugee women's attitudes about childbirth • Childbirth education	Ph.D. Nursing Midwifery Epidemiology

4	Cheryl Beck Professor University of Connecticut School of Nursing	• Postpartum mood disorders • Impact of trauma on childbirth and postpartum	DNSc, CNM Nursing
5	Penny Simkin Author, Doula, Childbirth Educator, Birth Counselor Senior Faculty Simkin Center for Allied Birth Vocations Bastyr University	• Childbirth education • Birth support • Impact of trauma on childbirth	Physical Therapist
6	Gloria Davy Adjunct Professor Berkley College School of Liberal Arts & Sciences	• Applied psychology • Postpartum mood disorders	Ph.D., MPH Public Health
7	Meghan Eagen-Torkko Assistant Professor Seattle University School of Nursing	• Trauma and childbirth • Breastfeeding relationships	Ph.D., CNM Nursing

Several different labels have been used to describe the item-relating continuum that content experts used. For the purposes of this evaluation the content experts were asked to rate the items based on the most frequently used scale in the literature: 1=not relevant, 2=somewhat relevant, 3=quite relevant, and 4=highly relevant (Davis, 1992). Then, for each item, the I-CVI is computed as the number of experts giving a rating of either 3 or 4, thus dichotomizing the ordinal scale into relevant and not relevant, divided by the total number of experts. If the CVI is utilizing six or more judges to create an I-CVI the recommendations is to discard an item if that I-CVI is less than .78 (Lynn, 1986b). All items had an I-CVI of over .80 except for one

question.. That question, regarding how "independent" a woman would feel during birth had an I-CVI of .50, therefore it was deleted from the final scale.

In addition to the I-CVI a scale level content validity index (S-CVI) was also calculated. The S-CVI is calculated by summing the I-CVIs and dividing them by the total number of items (Polit & Beck, 2006a). The S-CVI calculated for the scale was 92.5% indicating the measure as a whole was successful in measuring the construct of fear of childbirth. While one item was deleted from the scale based on scoring low on the I-CVI, one item was added based on the comments from the content experts. The original scale includes a question about frequency of fears regarding the death of the baby during birth (retained in the revised scale). Three of the six content experts suggested adding in a question about women's fears that she may die during the birth process. As this was a theme that came up during the focus groups as well this question was added into the final scale.

Survey packet

The final survey packet that was administered to pregnant women consisted of the Revised Wijma Delivery Expectancy Questionnaire as well as the following instruments that were used to test the reliability and concurrent, convergent, and discriminant validity of the revised instrument. The survey pack is included as Appendix C.

Patient Health Questionnaire -2

The Patient Health Questionnaire- 2 (PHQ-2) was chosen for assessment of depression. The PHQ-2 has been used in numerous studies to assess the point prevalence of depression among obstetric patients (Andersson, Sundstrom-Poromaa, Wulff, Astrom, & Bixo, 2004). The PHQ-2 is a shortened and validated version of the standard depression screening tool the Patient Health Questionnaire – 9. The PHQ-2 includes the first two items of the PHQ-9. The stem

question is “Over the last two weeks, how often have you been bothered by any of the following problems?” The two items are “little interest or pleasure in doing things” and “feeling down, depressed, or hopeless.” For each item the response options are “not at all,” “several days,” “more than half the days,” and “nearly every day,” scored as 0,1,2,3 respectively. The, the PHQ-2 score can range from zero to 6. A PHQ-2 score greater than or equal to 3 has a sensitivity of 83% and a specificity of 92% for major depression among pregnant women (Kroenke, Spitzer, & Williams, 2003).

Generalized Anxiety Disorder – 7

The Generalized Anxiety Disorder – 7 item scale (GAD-7) was chosen to assess for preexisting, generalized anxiety. The scale has been used extensively to assess for point prevalence in pregnant populations (Andersson, Sundstrom-Poromaa, Wulff, Astrom, & Bixo, 2004). The GAD-7 is a one dimensional scale designed to assess the presence of the symptoms of generalized anxiety disorder referred to in the DSM-IV. It is self-administered and the total score is calculated by addition of the answers for each items. The scores of all seven items range from 0(not at all) to 3(Nearly every day), identical to the PHQ-2. The total core ranges from 0-21. The total score may be categorized into four severity groups: minimal/no anxiety (0-4), mild (5-9), moderate (10-14), or severe (15-21) with an optimum cut off value for generalized anxiety disorder at 10 points (Spitzer, Kroenke, Williams, & Lowe, 2006).

Short Screening Scale for PTSD

Previous research has examined the link between PTSD and anxiety about the childbirth experience. Therefore, a brief screening of PTSD was necessary in order to look at the relationships between PTSD and FOC. The PTSD Checklist -6 (PCL-6) is an abbreviated version of the PTSD Checklist – Civilian Version (PCL-C) that is used as a brief screening tool in

primary care. The PCL-C is a 17-item self report measure mapping directly onto DSM-IV criteria. The PCL is a well-established self-report measure of PTSD symptoms with good reliability and validity (Wilkins, Lang, & Norman, 2011). The response options are: '1-not at all', '2-a little bit', '3-moderately', '4-quite a bit', or '5-extremely'. Cutoff for screening for PTSD and thresholds for reliable and clinically significant PTSD is 14 for the PCL-6 (Lang et al., 2012).

Medical Social Self-Efficacy Scale

The Medical Social Self-Efficacy Scale (MSSES) is one of the only scales that has been developed to look at self-efficacy specific to the health care setting. The instrument was selected to reflect the sociocultural context of women within the maternity care system. The MSSES is used to assess social self-efficacy within a medical context for patients of diverse cultural and linguistic backgrounds. The items in the scale relate to confidence in a person's ability to communicate with and maintain a social interaction with a health care provider. The scale contains 11 items which are rated on a 7 point scale of agreement where one indicates that the state is 'not at all true', 3 indicates that the statement is 'somewhat true', and 7 'very true'. There are no published cut offs for scoring the MSSES, however, the mean score across populations were 61.03 (Caltabiano, Costin, & Ochiai, 2015). For the purposes of this evaluation, scores below the mean were considered to be low social self-efficacy within the health care setting.

Discrimination in Medical Settings

The proposed model seeks to understand how larger social structures such as race, class, and gender impact the experience of FOC. The Discrimination in Medical Settings (DMS) scale was adapted from existing discrimination scales based on prior studies of health care

discrimination (Peek, Nunez-Smith, Drum, & Lewis, 2011). It modifies items from the Everyday Discrimination Scale, an instrument that asks about the frequency of experiences with everyday mistreatment (Williams, Neighbors, & Jackson, 2008). The resulting seven-item instrument assesses responses with a 5-point Likert scale (1-never, 2, rarely, 3-sometimes, 4-most of the time, 5-always). It then asks people to mark the identities that people felt were at the basis of the discrimination if they had marked '3-sometimes' to any of the questions.

Wijma Delivery Expectancy Questionnaire (Version A)

The Wijma Delivery Expectancy Questionnaire – Version A (WDEQ) is considered the current gold standard for measuring FOC. The WDEQ was developed to measure a construct of fear related to childbirth during pregnancy (Wijma, Wijma, & Zar, 1998b). The scale has 33-items that rate personal feelings and cognitions on a six-point Likert scale with the endpoints marked with 'not at all…' and 'extremely…'. The minimum score is 0 – and the maximum score is 165. The higher the score, the greater the fear of childbirth evidenced. Women who scored greater than or equal to 85 on the WDEQ were considered to have 'severe fear of childbirth' (Ryding, Wijma, Wijma, & Rydhstrom, 1998)

Factor analysis of the Revised Wijma Delivery Expectancy Questionnaire

The aim of this portion of the analysis was to determine the underlying structure of the Revised Wijma Delivery Expectancy Questionnaire (R-WDEQ) and to identify the number of subscales or factors. As the R-WDEQ is a new scale no previous factor analysis had been done. Consequently an exploratory factor analysis where there are no predetermined hypotheses about the relationships between the items was undertaken.

Participants

Women who were 18 years old or older and currently pregnant were recruited from three prenatal care clinics (Hurley Medical Center, Providence Hospital, and University of Michigan Health Center) as well as online through social media. Women at the health centers were given an information sheet to read over regarding the study and women who elected to participate were then given a paper copy of the survey packet with a pen and clipboard to complete while they waited for their appointment. Women who found the study through social media were directed to a Google survey document which started with the initial information sheet and, if a woman checked that she elected to continue, she was then transferred to an online Google survey which was identical to the paper copy women completed in the health centers. A total of 329 women participated in the project. A diverse sample of women completed the survey packet. Most of the women were white or black, with only a few other racial identities represented. The majority of the women lived in households with less than $30,000/year income and had given birth previously. Demographic and obstetric characteristics for participants are reviewed in Table 7.3 and Table 7.4.

Table 7.3

Demographic characteristics of participants for factor analysis

Characteristics	Total Sample (N= 329)	
	N	%
Race		
Black	108	33.5%
White	192	59.6%
Latina or Hispanic	15	4.7%
Middle Eastern	2	0.6%
Asian/Pacific Islander	2	0.6%
Other	3	0.9%
Age		
18-22	47	14.6%
23-27	104	32.2%
28-32	86	26.1%
33-37	68	21.1%
38-44	17	5.2%
45+	1	0.3%
Marital Status		
Single	85	25.8%
Partnered	45	13.9%
Married	183	56.5%
Widowed	1	0.3%
Divorced	8	2.4%
Separated	2	0.6%
Family Income		
Less than $30,000	131	42.8%
$30,000-$49,000	57	18.6%
$50,000-$99,000	61	19.9%
More than $100,000	57	18.6%

Table 7.4

Obstetric Characteristics of participants for factor analysis

Characteristics	Total Sample (N= 329)	
	N	%
Parity		
Primaparous	96	30.3%
Multiparous	221	69.7%
Trimester		
First trimester (0-13 weeks)	84	25.8%
Second trimester (14-26 weeks)	118	36.3%
Third trimester (27-42 weeks)	123	37.4%
Care Provider		
Midwife	108	36.7%
Physician	186	63.3%

Suitability of the scale for factor analysis

The 18 original items of the Revised Wijma Delivery Expectancy Questionnaire (R-WDEQ) were subjected to Principal Components Analysis (PCA) using SPSS version 22. Prior to analysis, negatively worded items were reverse coded. The full data set was then analyzed for its suitability for factor analysis. The Kaiser-Meyer-Olkin value was .816 exceeding the recommended value of .6 (Kaiser, 1974) and Bartletts' Test of Sphericity was highly significant ($p<.001$), supporting the factorability of the correlation matrix.

Item reduction

Removing items from the R-WDEQ scale could potentially strengthen the validity of the instrument. Additionally, reducing the number of items on the R-WDEQ without compromising

the usefulness of the scale would decrease participant burden and make the scale more useful for clinical practice as well as research purposes. The correlation matrix was examined and revealed six items whose correlations were <.30, suggesting that they should be removed (Pett, Lackey, & Sullivan, 2003). These items were: 1) Fantastic, 2) Scary, 3) Painful, 4) Strong, 5) afraid, 6) excited, and 7) unhappy. These items were removed from the final scale.

Two items were highly correlated with one another (r>.75) suggesting multicollinearity, or duplication of items (Pett, Lackey, & Sullivan, 2003). These items were 1) respected and 2) understood. The item with the highest commonality "Respected" (.697) was retained and the other was removed.

The final refined R-WDEQ included 10 items that met criteria for content validity, were sufficiently correlated with other items without exhibiting multicollinearity, and exhibited communalities of .30 or greater. The refined R-WDEQ will be referred to as the WDEQ-US.

Factor analysis of the WDEQ-US

A new factor solution with the remaining 10 items was then undertaken. A comparison of the items retained is presented in Table 7.5.

Table 7.5

Comparison of R-WDEQ and WDEQ-US

R-WDEQ	WDEQ-US
Fantastic	
Scary	
Painful	
Strong	
Confident	Confident
Afraid	
Out of control	Out of control
Panicked	Panicked
Excited	
Baby death or injury	Baby death or injury
Maternal death or injury	Maternal death or injury
Alone	Alone
Supported	Supported
Abandoned	Abandoned
Respected	Respected
Understood	
Unhappy	
Safe	Safe

The revised factor analysis had a Kaiser-Meyer-Olkin sampling adequacy value of .778 with a highly significant ($p<.001$) Barlett's Test of Sphericity supporting the factorability of the WDEQ-US. Principal Components Analysis of the WDEQ-US revealed the presence of three factors with eigenvalues exceeding 1, explaining 36.5%, 16.0%, and 10.6% (for a total of 63.1%) of the variance respectively. An inspection of the scree plot revealed a clear break between the third and fourth factor supporting a final three-factor solution.

Confirmatory factor analysis was conducted using a three-factor solution and the 10 remaining items on the WDEQ-US explaining a total of 63.1% of the variance. To aid in the interpretation of the factors an oblique (Oblimin) rotation was performed. The three-factor solution rotated in four iterations with five items loading on the first factor, two on the second,

and three on the third. The pattern matrix is presented in Table 7.4. Most item-to-factor loadings were .60 or greater, indicating very good or excellent shared variance (Pett, Lackey, & Sullivan, 2003).

The three-factor solution was interpreted and the factors were named by identifying the theme common to the items loading on those factors. The first factor was made up entirely of items on the scale that represented external sources of fear in the theoretical model such as fear of abandonment from social support networks, fear of providers, and fear of the birth setting. This factor was named "Fear of how others would behave". The second factor, identified as "Fear of death and injury", involved two questions asking about fears the woman may have had in the last month that she or her baby will die or be critically injured during the birth. The items loading on what comprised the third factor were descriptors about the woman's interpretation of her own characteristics that would impact upon FOC; therefore, it was named "Fear of how she herself would feel".

Table 7.6

Pattern matrix

Item	Factor 1: Fear of how others would behave	Factor 2: Fear of death or injury	Factor 3: Fear of how she herself would feel	Commonality
Confident			-.569	.384
Out of control*			-.878	.736
Panicked*			-.857	.724
Baby death or injury*		.883		.776
Maternal death or injury*		.830		.692
Alone*	.818			.656
Supported	.874			.683
Abandoned*	.749			.616
Respected	.625			.514
Safe	.603			.530

* reverse coded items

The Correlation Matrix for the three factor solution revealed correlations ranging from .109 to .446 indicating an appropriate amount of correlation and confirming the appropriate use of an oblique rotation solution (Pett, Lackey, & Sullivan, 2003). However, both an orthogonal and oblique rotation were conducted and analyzed using a three-factor solution resulting in items loading identically.

Possible scores for the WDEQ-US ranged from a low of 10 to a high of 60, with lower scores indicating less fear of childbirth. Means, standard deviations and ranges for the WDEQ-US as well as subscales are reported in Table 7.5

Table 7.7

WDEQ-US: means, standard deviations, and ranges

	N	Mean	Standard Deviation	Range (possible score)
WDEQ-US	303	24.08	8.43	10-52 (10-60)
Fear of how others would behave	310	10.30	5.23	5-27 (5-30)
Fear of death or injury	325	4.58	2.53	2-12 (2-18)
Fear of how she herself would feel	314	9.02	3.39	3-18 (3-18)

Factor to factor correlations and factor to scale correlations were measure by the Pearson product-moment correlation for the three factors and ranged from r= .125 to r=.861. Results of these correlations are summarized in Table 7.6. The Pearson product-moment correlations between all subscales were significant at the p=.01 level. The significance level indicates that the observed values are not likely to be the result of chance (Portney & Watkins, 2008; 2009).

Table 7.8

Pearson product moment correlations for factors and WDEQ-US

	Fear of how others would behave	Fear of death or injury	Fear of how she herself would feel	WDEQ-US
Fear of how others would behave	1	.125	.494	.861
Fear of death or injury	.125	1	.239	.476
Fear of how she herself would feel	.494	.239	1	.786
WDEQ-US	.861	.476	.786	1

WDEQ-US scores and demographic correlates

Statistical analysis was performed to identify if there were differences in WDEQ-US scores related to demographic and obstetric history characteristics. Correlations were not significant between age, education, marital status, employment, and income between the RWDEQ and the WDEQ-US as presented in Table 7.7. Age, education, marital status, employment, and income were all measured as continuous variables in the demographics section.

Table 7.9

Correlation comparisons between RWDEQ and WDEQ-US

	RWDEQ	WDEQ-US
Age	r = .127	r = .275
Education	r = -.100	r = -.087
Marital Status	r = -.069	r = -.041
Employment	r = -.071	r = -.081
Income	r = -.075	r = -.030

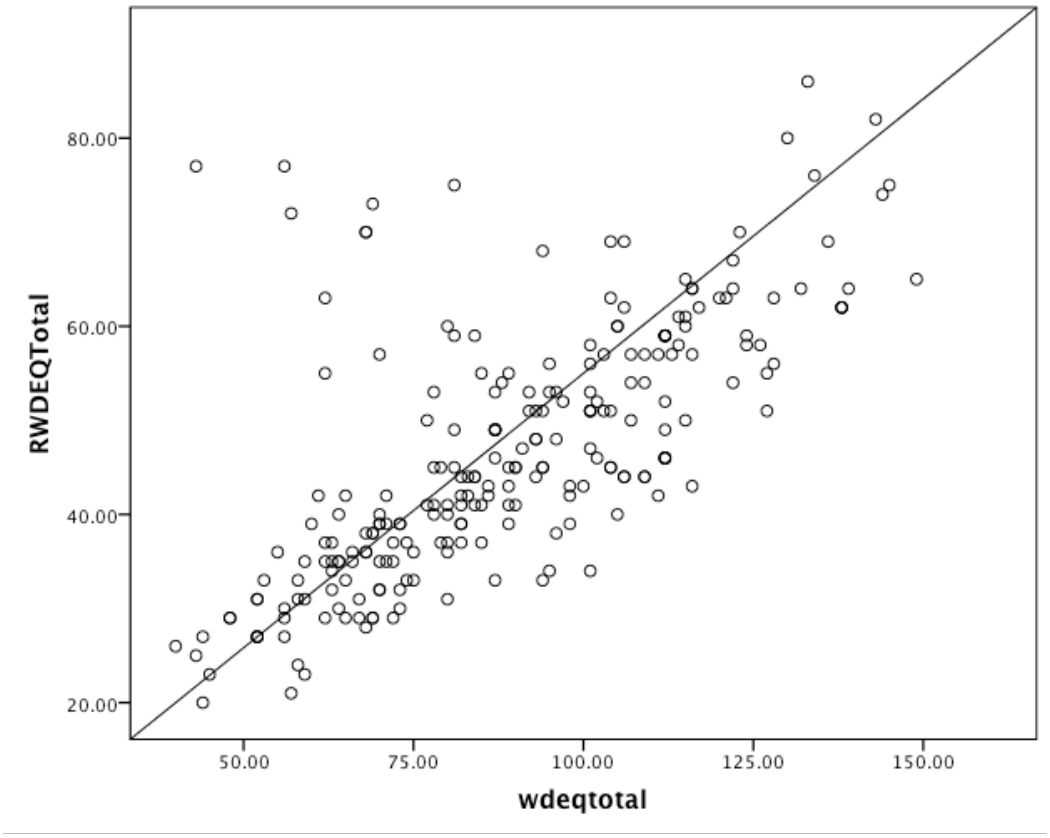
Additionally, one-way ANOVA for comparison of the RWDEQ and the WDEQ-US indicated there was not a statistically significant difference in scores by ethnicity. Independent t-tests indicated there was not a statistically significant difference in RWDEQ or WDEQ-US scores between primaparous and multiparous women, nor was there a statistically significant difference between those women with a history of cesarean section or vaginal birth.

Concurrent validity

Concurrent validity tests how well the instrument measures against another reliable measure of the same concept. Pearson's product moment correlation was used to measure the concurrent validity of the WDEQ-US and the original WDEQ, the current gold standard. Concurrent validity of the WDEQ-US was supported by a large positive correlation between the WDEQ-US and the WDEQ (r=.667). These results indicate that women who had high levels of FOC on the gold standard instrument, the WDEQ, had similarly high scores on the WDEQ-US. Figure 7.1 graphs the results to show the similar trend in scores on both instruments.

Figure 7.1

Correlation between WDEQ and WDEQ-US



Discriminant validity

Discriminant validity is based on correlation and is an assessment of the relationship between tools that measure theoretically different constructs (DeVillis, 2003). A means of examining discriminant validity was to correlate scores on the WDEQ-US with scores on existing, psychometrically sound instruments (Polit & Beck, 2006b). Preliminary analyses of these data were completed to ensure no violation of the assumptions of normality, linearity, and homoscedasticity (DeVon et al., 2007) Normality and linearity were assumed. The assumption of homoscedasticity was assessed by examining the shape of the scatter plots as well as by using

a linear regression model and examining the residual plot for rectangular shape and a lack of funneling. No violations were found.

While the WDEQ-US includes a component of anxiety, the underlying assumption of this project is that, while there may be some overlap between FOC and generalized anxiety, ultimately, they are conceptually different from each other. Respondents' scores from the WDEQ-US were compared with scores on a generalized anxiety scale, the GAD-7. Anxiety tends towards being a state trait meaning that, if people tend towards an anxious state, this anxiety will be exhibited in other high anxiety events, such as childbirth (Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007) It was anticipated that for this research, women who exhibit higher levels of anxiety, as determined by the GAD-7 would also have unrelated levels of FOC. First, internal consistency reliability coefficient for the GAD-7 scale was examined ($\alpha = .88$, $n = 325$). There was a statistically significant, fair positive correlation between the WDEQ-US and the GAD-7 ($r = .36$, $p<.001$, $n=300$). In order to analyze the significance of these numbers, the construct validity coefficients were accepted as: $r \geq 0.81–1.0$ excellent, 0.61–0.80 very good, 0.41–0.60 good, 0.21–0.40 fair and 0–0.20 poor (Feise & Michael Menke, 2001). This supports the assumption that FOC may share attributes of individual psychopathology but is not ultimately correlated with generalized anxiety.

Convergent validity

Convergent validity is based on correlation and is an assessment of the relationship between tools that measure theoretically similar constructs (DeVillis, 2003). Previous studies have reported a relationship between fear of childbirth and PTSD symptoms (Fairbrother & Woody, 2007; Wijma, Soderquist, & Wijma, 1997; Wijma, Alehagen, & Wijma, 2002) The relationship between FOC and PTSD may be due to individual differences in anxiety sensitivity and fear of

anxiety-related bodily sensations (Fairbrother & Woody, 2007). Internal consistency reliability coefficient for the PTSD scale was examined ($\alpha = .83$, $n = 328$). There was a statistically significant, moderate positive correlation between the WDEQ-US and the PTSD scale ($r = .58$, $p<.001$, $n=300$). These findings indicate that women with higher FOC also had higher levels of generalized anxiety. Similarly, women with higher levels of FOC had higher levels of PTSD.

Internal reliability of the RWDEQ

The reliability estimates for all measures in the survey packet are presented in Table 7.8. The internal reliability of the RWDEQ was determined using Cronbach's alpha coefficient. The original RWDEQ had a Cronbach's alpha coefficient of .846 indicating good internal consistency (reliability) of the RWDEQ. The revised WDEQ-US yielded a Cronbach's alpha coefficient of .797 indicating the WDEQ-US also has good internal consistency among participants. As can be seen from the table, the alpha coefficients are well above the .70 criterion for the internal consistency reliability for all of the scales but the Patient Health Questionnaire -2. This could possibly be because there were only two questions in the Patient Health Questionnaire.

Table 7.10

Reliability estimates of all questionnaires

	r (n)
Revised Wijma Delivery Expectancy Questionnaire	.85 (294)
Wijma Delivery Expectancy Questionnaire -US	.80 (302)
Wijma Delivery Expectancy Questionnaire	.92 (254)
Patient Health Questionnaire – 2	.55 (329)
Generalized Anxiety Questionnaire - 7	.88 (325)
Post Traumatic Stress Disorder Checklist	.83 (328)
Discrimination in the Medical Setting	.85 (324)
Medical Self Efficacy Scale	.96 (320)

Further reliability testing was also done on the WDEQ-US to confirm reliably across racial groups and among primaparous and multiparous women. The results (Table 7.9).

Table 7.11

Reliability of WDEQ-US across racial and obstetric demographics

	r (n)
Race	
Black	.71 (97)
White	.81 (178)
Latina	.78 (15)
Parity	
Primaparous	.78 (91)
Multiparous	.78 (204)

Post hoc analysis

Several items included on the questionnaire provided opportunity for post-hoc analysis of questions not previously conceptualized in the psychometric testing of the WDEQ-US. First, does perceived discrimination influence FOC? If yes, what type of discrimination is most insidious in creating an environment for FOC? Second, is self-efficacy within the medical system protective in relationship to fear of childbirth? Finally, do women seeing a midwife for care have more or less FOC than women seeking care from a physician?

Perceived discrimination and fear of childbirth

Overall perceived discrimination in the health care setting is moderately correlated with FOC as measured by the WDEQ-US ($r = .34$, $p<.001$, $n=299$). Women who responded 'sometimes', 'most of the time', or 'always' to at least one question were then asked to identify which characteristics about themselves they felt lead to that discrimination. The characteristics are broad concepts and do not indicate direction of discrimination. For example, when a woman indicates that her age was a source of discrimination from health care providers the scale does not indicate if this is because she perceives herself as older or younger. As seen in Table 7.10

age, education, and weight discrimination were most highly associated with a higher score on the WDEQ-US indicating more FOC.

Table 7.12

Perceived discrimination and fear of childbirth

	Discrimination		No Discrimination		Statistic	
	M	SD	M	SD	t(df)	p
Age*	27.75	8.80	23.37	8.19	3.36(300)	.001
Ancestry*	16.60	3.21	24.20	8.43	-2.01(301)	.045
Sexual Orientation*	31.40	9.32	23.95	8.37	1.98(301)	.050
Disability	22.88	5.72	24.11	8.49	-.41(301)	.683
Gender	25.95	8.05	23.80	8.45	1.49(301)	.137
Religion	23.00	5.66	24.08	8.44	-.18(301)	.856
Education*	27.87	8.47	23.61	8.37	2.92(291)	.004
Race*	26.93	5.71	23.60	8.71	2.42(301)	.016
Weight*	27.75	9.48	23.45	8.08	3.18(301)	.002
Income*	27.11	8.39	23.77	8.38	2.01(301)	.045

*significant at $p<.05$

Self-efficacy and fear of childbirth

Overall scores on the Medical Self Efficacy Scale were high with a mean of 64.20 out of a possible score of 77.00 indicating that the sample felt that they had high self-efficacy within a medical setting. The relationship between self-efficacy (as measured by the MSSE) and fear of childbirth (as measured by the WDEQ-US) was investigated using Pearson product-moment correlation coefficient. Preliminary analysis was performed to ensure no violation of the

assumptions of normality, linearity, and homoscedasticity. There was a small, negative correlation between the two variables, r = -.26, n=303, p,.001, with high levels of self-efficacy associated with lower levels of fear of childbirth.

Care provider and fear of childbirth

In order to assess whether FOC differed by type of provider, an independent samples t-test was conducted to compare the scores of the WDEQ-US. Women who were cared for by midwives had lower FOC (M=22.49, SD=8.60) when compared to women who were cared for by physicians (M=24.60, SD=7.91); t (286)=-2.10, p=.037 [two tailed]). The magnitude of the differences (mean difference = -2.10, 95%CI: -4.08 to -.13) was small (eta squared = .02).

Prevalence

In the original WDEQ women who scored greater than 83 (out of a possible 165) were considered to have FOC (Ryding, Wijma, Wijma, & Rydhstrom, 1998). It is unclear from the published literature if this is the halfway point or the median split. In the study sample the median split for the WDEQ was 88 and the halfway point is 82.5 therefore a decision was made to use the halfway point for determining FOC in the WDEQ-US. Women were considered to have FOC if they scored above 30 (out of a possible 60) on the WDEQ-US. Overall point prevalence of FOC across the entire population of women surveyed with the WDEQ-US was 21.9%.

Summary

The WDEQ-US is the end result of a thorough psychometric testing process. The instrument was found to be valid and reliable. Additionally, the factor structure of the WDEQ-US is consistent with the theoretical framework of its development indicating that FOC is a

phenomenon that extends beyond individual psychopathology and has overlap with complex social structures. The following chapter offers a summary of the study as a whole as well as presenting conclusions and recommendations for next steps.

Chapter 8

Summary, Conclusions, and Recommendations

The proposed project sought to fill gaps in the literature and expand the concept of fear of childbirth (FOC) beyond individual psychopathology with an understanding of how the culture of the woman, her provider, and the birthing environment serve to reinforce or ameliorate fear of childbirth. The aims addressed were:

- Specific Aim 1: Examine all extant FOC measures in relation to the proposed conceptual framing and consider their empirical adequacy for US research.
- Specific Aim 2: Elucidate and conceptually organize the components of childbirth related fear in a diverse sample of US women
- Specific Aim 3: Adapt an existing instrument to demonstrate the components of a theoretically informed instrument for use in the United States.

The end result of this investigation was to revise, test, and validate a quantitative self-report, Likert-type scale, that measures pregnant women's fear of childbirth (FOC) in order to have a scale that would be useable in the United States and potentially other English speaking countries. After extensive literature review, the Wijma Delivery Expectancy Questionnaire was chosen as the scale used most in the literature and, therefore, the scale that was most appropriate to adapt for use in the United States. Focus groups were used to generate descriptors that a broad cross section of women in the United States used to describe their experience with FOC. The original 33-item WDEQ was then adapted into an 18-item instrument. Initially, the revised scale was sent

to a panel of experts in order to undergo a content validity index process. The resulting revised WDEQ (R-WDEQ) was administered to 329 women in order to test the scale and begin the establishment of psychometric properties for this revised version of the WDEQ. A factor analysis process was conducted to confirm its psychometric properties and functional capacity as a measure of FOC in the United States. The work was guided by the use of the conceptual framework informed by Ecological Systems Theory and the qualitative results were continually referred to when decisions were made regarding item addition, deletion, or revision. The WDEQ-US is a shortened version of the revised WDEQ and is the outcome of this inquiry. The purpose of this chapter is to interpret the results of the study, discuss strengths and limitations, provide conclusions, and propose recommendations for future research.

There are five sections within the chapter. Section one discusses results of the findings of the study. Conclusions related to validity testing, reliability assessment, and ancillary findings are explicated. The second and third sections discuss strengths and limitations of the study. Section four reviews implications for midwifery and nursing practice. The final section explores recommendations for further research.

Discussion of study results

Characteristics of samples

A convenience-sampling framework was used for both the qualitative and quantitative portions of this study. The populations were relatively similar between women who completed the qualitative component of the project and women who completed the quantitative component of the project. The demographic information of both groups is provided in Table 8.1. Oversampling for race and class diversity was deliberate in order to create an instrument that would be generalizable for many populations and because, historically, very little research has

been done looking at FOC within minority populations. The goal of the project was to have relatively similar populations in both phases of the study in order to increase generalizability. With the exception of parity, the populations were similar.

Table 8.1

Demographic comparison for qualitative and quantitative phases

Demographic	Qualitative Project	Quantitative Project
Race/Ethnicity		
Black	6 (27%)	108 (33.5%)
White	7 (32%)	192 (59.6%)
Latina	8 (36%)	15 (4.7%)
Middle Eastern	0 (0%)	2 (0.6%)
Asian/Pacific Islander	1 (5%)	2 (0.6%)
Age		
18-25	7 (32%)	151 (46.8%)
26-34	10 (45%)	154 (47.2%)
35-45	5 (23%)	18 (5.8%)
Household composition		
Single	5 (23%)	85 (25.8%)
Married/partnered	14 (64%)	228 (70.4%)
Divorced	2 (8%)	8 (2.4%)
Separated	1 (5%)	2 (0.6%)
Childbearing history		
Never been pregnant	3 (14%)	0 (0%)
Primaparous	2 (9%)	96 (30.3%)
Multiparous	2 (9%)	221 (69.7%)
Given birth in past 5 years	15 (68%)	0 (0%)
Healthcare provider		
Midwife	9 (41%)	108 (36.7%)
Physician	13 (59%)	186 (63.3%)

Conclusions of validity testing

All three specific aims for this project were intended to lead to the goal of creating a reliable and valid instrument for use in research and practice that measured FOC among a diverse group of US women. Construct validity for the WDEQ-US was examined through the use of content validity, exploratory factor analysis and convergent validity**.**

The original set of items on the R-WDEQ was derived from focus groups that underwent a rigorous content analysis process and using words-in-context to develop descriptors that emerged from all three groups that described women's experience with FOC. The descriptors were then organized using Ecological Systems Theory to develop a pilot instrument. The items that comprised the R-WDEQ were subjected to critical review by a panel of experts using a Content Validity Index process to ensure the scale had content validity. As a result of this process, eighteen items, within the four content domains of the conceptual model, were included in the pilot version of the scale. Although it was recognized the experience of FOC is a changeable and highly individualized experience, the content domains were named in sequential fashion in consideration of using a stepwise approach to asking women to explain their FOC.

The three content domains were 'Fear of how she herself would feel', 'Fear of death or injury', and 'Fears of how others would behave'. Fears of how she herself would feel contained items related to a woman's description of her own feelings about the birth process. This content domain uses words like "confident", "out of control", and "panicked" to ask a woman to describe what feelings she had about how she would feel during the birth process.

The fear that a woman or her baby may die or be injured during the birth process was the second content domain. This domain contained items related to how often thoughts of dying interrupted a woman's daily experience. The original WDEQ scale asked a question about fear

of the baby dying. Using feedback from the focus groups and the Content Validity Index process a question was added about persistent fears of the woman herself dying.

Fears related to how others would behave was the third content domain of the R-WDEQ. Items, which comprised this domain related to fears about limited support from the woman's social support network. This domain also was linked to the expected support from the woman's clinical care team and her feelings about the location of the birth.

The three domains that appeared in the instrument are applicable to the theoretical model used to inform its development. While each domain does not correspond directly to a level of the model, the model was key in determining the word choices used in the final instrument. In general, the domain of Fear of how she herself would feel and Fear of death or injury related to the first level of the model. Fear of how others would behave is related to the second and third levels of the model indicating providers and the birth place. The fourth level of the model, larger system issues of racism, sexism, and media expectations appear in all three domains of the instrument and are represented by the words chosen for the final instrument. This was a deliberate decision in order to maintain the dynamics of the focus groups where issues of privileges and oppression were a pervasive component of all levels of birth fear.

The Exploratory Factor Analysis for the revised scale, the R-WDEQ revealed a stable three-factor solution for both the R-WDEQ and the final WDEQ-US. The three factors of the scale were labeled: (1) Fears of how other would behave, (2) Fear of death and injury, and (3) Fears of how she herself would feel.

Eight items were reduced from the R-WDEQ to create the WDEQ-US based on Exploratory Factor Analysis results described in chapter seven. The reduced items were primarily from the first content domain, but some were also from the third content domain. No

items were deleted from the second content domain. 'Fantastic', 'scary', and 'painful' were deleted from the first content domain and 'understood' and 'unhappy' were deleted from the third domain. Interesting to note that fear of pain did not pull through as a relevant component of the final analysis. This reinforces the idea that pain management may serve to keep the woman manageable but may not serve to actually alleviate fear or worry. The final ten-item scale was named the WDEQ-US for the purpose of this analysis.

The examination of relationships between the WDEQ-US and three established psychometrically sound scales addressed concurrent and convergent validity. Scores on the WDEQ-US correlated with scores on the WDEQ scale demonstrating concurrent validity. Scores on the WDEQ-US correlated with scores on the GAD-7 and the PTSD scale demonstrating convergent validity.

The researcher anticipated a positive correlation of >.50 between the WDEQ-US and their respective established scales. When considering concurrent and convergent validity, a positive correlation in the range of .50 is respectable for a newly designed scale ((Waltz, Strickland, & Lenz, 2010). It is recognized that the level of statistical significance is influenced by sample size (Polit & Beck, 2006b).

Results of these computations revealed a strong, positive correlation between the WDEQ-US and the WDEQ with the Pearson *r* exceeding the goal of >.50. Women with higher levels of FOC on the WDEQ-US also had higher amounts of FOC on the WDEQ. This was an anticipated finding and provided evidence to support the concurrent validity of the WDEQ-US.

Pearson *r* computations to assess the relationship between the WDEQ-US and GAD-7 scale revealed a weaker, less positive correlation with the Pearson *r* falling short of the >.50 goal supporting discriminant validity. One study reviewed in Chapter 3 found that only 8-27% of the

variance of FOC was explained by generalized anxiety and depression indicating that FOC is a broader concept that anxiety and the need for a FOC specific instrument (Huizink, de Medina, Mulder, Visser, & Buitelaar, 2002). The weaker correlation between the WDEQ-US and the GAD-7 in this study indicates that in this population FOC remains a different phenomenon from generalized anxiety and supports the need for a separate instrument to measure FOC.

In order to establish convergent validity Pearson *r* computations to assess the relationship between the WDEQ-US and PTSD was performed. The analysis revealed a stronger, more positive correlation with the Pearson *r* exceeding the goal of >.50. Women with higher levels of FOC were more likely to indicate higher symptoms of PTSD. Many studies have discussed the relationship between FOC and PTSD so this was an anticipated finding and provided evidence to support convergent validity of the WDEQ-US (Fairbrother & Woody, 2007; Wijma, Soderquist, & Wijma, 1997; Wijma, 2003).

Conclusions of reliability testing

The alpha coefficient was used to assess the reliability of the WDEQ-US. Scale development experts agree than an alpha of .70 is acceptable for a newly designed affective scale (DeVillis, 2003). The alpha coefficients met psychometric criteria for newly designed instruments. High alpha coefficients for all three domains in the WDEQ-US indicated that variance in scores was attributed to the measurement of true score and not the measurement of error (DeVillis, 2003). Such findings lend support to a high degree of internal consistency and suggest the WDEQ-US and the three domains of the scale do in fact measure the constructs of FOC. No appreciable change in alpha was noted if any item was deleted.

Ancillary findings

The conceptual framework for this study sought to move beyond viewing FOC as an individual psychopathology. As a result issues of discrimination were looked at as informants of FOC. Pearson *r* correlation analysis were run to explore the relationship between women who exhibited high FOC and women who perceived high levels of discrimination in the health care setting. Age, education, and weight discrimination were most highly associated with a higher score on the WDEQ-US. Race, income, and sexual orientation were also associated with a higher score on the WDEQ-US. Further analysis using Pearson *r* correlation indicated that women with high levels of self-efficacy in the health care setting had overall lower levels of FOC. An independent t-test was also performed in order to assess whether FOC differed by type of provider. There was a significant difference in fear scores for women who were cared for by midwives versus women who were cared for by physicians.

Results of the study provide evidence to support the role of discrimination women experience in influencing FOC for women. Based on comparisons between groups, findings reveals that younger, heavier, and poorer women experienced greater discrimination from health care providers and this increased their scores on the WDEQ-US. Furthermore, the findings indicate that improving self-efficacy among women could be an effective strategy for decreasing FOC among pregnant women. Lastly, as the mean scores on the WDEQ-US were lower for women who were being cared for by midwives it creates a question as to whether women with lower fear self select into midwifery care or if the type of care midwives provide is protective against FOC.

While race was a strong variable of interest from the qualitative findings, it did not come through as strongly in the quantitative findings. There was a significant relationship between

discrimination based on race and FOC, but it was less significant than issues of age, class, and weight. This could be because the scale did not clearly indicate that women could choose multiple selections regarding perceived discrimination and women felt that other areas were more salient at that moment in time. Another reason for the discrepancy might be that the qualitative groups were addressing larger theoretical concerns allowing for deeper discussion on the role of systemic racism while the scale speaks more directly to tangible experiences with health care providers. However, the most likely reason is that there was a racial difference between the researcher recruiting participants and the participants themselves. The sensitive nature of the topic of race and racial discrimination has implications for the accuracy of reports of discrimination (Williams, Neighbors, & Jackson, 2003). Recent research on the race-of-interviewer effects indicates that black participants are reluctant to reveal their true racial beliefs on race sensitive questions when talking to white interviewers. This holds true for in person interviewers and self-administered interviewers (Williams & Mohammed, 2009). In fact, the strongest effect of black participants being deferent to white interviewers was for perceptions of racial discrimination as opposed to other measured variables such at race-associated politics, pace of civil rights, etcetera. (Krysan & Couper, 2003).

Open-ended question on the WDEQ-US scale

During the testing phase, at the end of the scale women were asked one open-ended question intended to address fears they have not addressed in the scale. Many of the women who answered the open-ended questions related fears related to specific interventions. As exemplars, one woman commented "I'm scared things won't move along and I'll need a section". Another wrote, "I don't want to be induced and need an epidural".

The importance of these comments must be acknowledged. The WDEQ-US is intended to measure women's FOC in a broad or aggregates sense related to individual emotions. Despite this, women felt compelled to include comments about specific interventions that inform their fears in very specific ways. Such remarks related to specific interventions suggest linkages to the significance of the model of maternity care in the U.S. and the potential effect of the of how the technocratic model of birth may inform women's fears.

Strengths of the study

Experts in the area of instrument development assert quantitative assessment tools should be reliable, valid, standardized, and free from bias (Rust & Golombok, 2009). In order to accomplish these goals, it is imperative methodological studies be conducted to test newly designed instruments to ensure they have strong rational scientific designs.

The use of a mixed methods approach is likely the biggest strength of this study. Mixed methods research is emerging as a dominant paradigm in health care research (Doyle, Brady, & Byrne, 2009). The goal of mixed methods research is to move beyond the binary of quantitative versus qualitative and instead focus on recognizing the usefulness of both paradigms and identifying how these approaches can be used together in a single study to maximize the strengths and minimize the weaknesses of each other (Rust & Golombok, 2009)

Using mixed method research to conceptualize and then quantify a phenomenon has many benefits. The first is the use of triangulation that allows for greater validity by seeking corroborations between quantitative and qualitative data. Mixed methods also provide a more complete and comprehensive picture of the study phenomenon by using a combination of research approaches (Doyle, Brady, & Byrne, 2009). In nursing, where researchers often seek to study complex phenomena, mixed methods offer a range of perspectives. This can aid in

hypotheses development - using qualitative research that can then be followed up with quantitative research (Doyle, Brady, & Byrne, 2009). For this study, the qualitative component of the study was essential in generating items for inclusion in the final survey instrument. In addition, the diversity of the sample that participated in the focus group project was a strength for the qualitative component of the study.

Another strength of the study was the face-to-face presence of the primary researcher at all three sites. An issue associated with electronic surveys is the response rate that will be achieved and the potential for selection bias among respondents. Level of internet use is related to family income, with almost 80% of those having a family income of >$75,000 using the internet while only 25% of those with incomes of <$15,000 using the Internet (Hayslett & Wildemuth, 2004) In addition, racial differences in internet use persist, with Whites and Asian/Pacific Islanders having higher rates of Internet use than Blacks and Latinas (Hayslett & Wildemuth, 2004) This disparity in internet participation was seen in this survey as well. The women who responded to the online survey via social media were 88% white and 67% had incomes greater than $75,000. This compares to 59.6% white and 37% with incomes greater than $75,000 for the overall sample.

The problem with the differences in these samples is that some of the words that were included, based on an extremely diverse focus group sample, may not have pulled through as relevant to survey participants who were more representative of dominant groups. The sampling frame for this project sought to seek information about FOC among underrepresented women in order to develop a representation of FOC in the United States. While collecting survey data online happened rapidly (100 in under 24 hours) the sample exhibited a skew towards white, upper middle class, well educated women. Sampling from prenatal clinics at the three research

sites was more time intensive (229 in six months); however, it lead to a more diverse and generalizable sample for analysis.

Continued presence at all three prenatal sites also allowed the researcher to build a strong rapport with staff in the clinics who then encouraged women to participate in the survey. Many women asked the researcher about the survey over a period of a few weeks prior to agreeing to participate ensuring that women who might be otherwise unlikely to participate in research were sampled. The study population was also fairly evenly distributed across pregnancy trimesters allowing for more complete investigation of how FOC may evolve throughout the pregnancy.

Limitation of the study

The largest limitation of this study is the use of a convenience sample. Results from studies using convenience sampling are not as generalizable to other settings, given the narrow focus of the technique (Polit & Beck, 2006b). The researcher attempted to sample from diverse sites throughout southeast Michigan however having only three final sites participate limited the generalizability of findings.

Another limitation intrinsic to study design is that some women were called into their appointments while completing the survey and were unable or unwilling to take the packet with them to complete. As the WDEQ and the demographic information were at the end of the survey packet these were the two areas with the largest amount of missing data (n=36).

Other limitations of the study is the role of social desirability. Many women were in the waiting room with family or friends who were watching as they completed the survey. Gable and Wolf (1993) argue that if the purpose and intent of the research, as well as practical uses of study results are explained to respondents and if the study situation is non-threatening, subjects should answer honestly. While all of these issues were taken into account as women approached the

table, the presence of family and friends and the discussion about what the participant should or should not be feeling was not anticipated.

Other potential limitations of the study were the competing forces of influences on the final instrument that all had significant influences. The first influence was the need to maintain the format of the original gold standard instrument. The original instrument is based on emotional responses to FOC and while the revised instrument attempted to move away from this phenomenon, ultimately, the WDEQ is an instrument designed to measure an individual psychopathology and the format reinforces that assumption of FOC. The second major influence was the use of the theoretical model that posits that FOC is a more complex phenomenon understood on multiple levels. The third influence was the panel of experts. While the panel had extensive experience in perinatal mental health and childbirth related concerns, with the exception of two experts, all of their own works functions from a position of perinatal mental health as individual psychopathology that ultimately influenced how they approached revisions to the instrument. The last major influence is the two competing groups of participants. The focus groups participants represented were a diverse sample of women who were almost all part of an underrepresented minority. While the quantitative group participants were fairly diverse the presence of many social majorities may mean that some of the themes that were brought to the surface in the focus groups may not have carried through to the final instrument, particularly around issues of oppression.

The final limitation of the study was layout of the survey. A decision was made a priori to revise the gold standard instrument as opposed to developing an entirely new survey. In practice, the layout of simpler instruments such as the PTSD checklist and the GAD-7 had lower levels of missing data and fewer comments about the repetitiveness of the questions. The

WDEQ tends to be a long and repetitive instrument, which is standard in a lot of psychological surveys. Because the final instrument is designed for use in brief, clinical encounters the length of the survey and the layout increased participant burden and make the instrument potentially more cumbersome to complete in a clinical encounter. Pilot testing of the shortened WDEQ-US is necessary to see if the length of the survey decreases the number of non-responders and incomplete surveys.

Implications for midwifery and nursing practice

The current state of the science regarding FOC for women within the US maternity care system is limited. Investigations of FOC and associated obstetric complications have been measured inconsistently and/or without a systematic look at overall impact on maternal or fetal/newborn well being. The purpose of this study was to revise and validate the gold standard instrument for measuring FOC with women in the United States. The revision of the WDEQ represents a quantitative measure from which considerable knowledge can be gained about women's experience with FOC. This section presents implications of study results for midwifery as well as nursing and physician practice.

The WDEQ-US scale is designed for a number of intended uses. It was deliberately written in a readable and accessible manner to allow for utilization among different women in a variety of health care settings. On a practical level, the scale is a shorter, easy to administer instrument that provides clinicians with a sense of women's perception of the birth experience and how fear may be affecting that perception. The information gleaned from the instrument on a clinical level may allow clinicians to alter their care approaches to ease women's fear in order to promote a better birth experience. In the case of FOC in pregnant women, easing fear is different than removing the thing that is feared. Information gained from what fears women

express as a population could be used to make home birth a more viable option for women with fears of the hospital setting. It could be used to promote accessible doula programs for women with fear of lack of support from their immediate family friends. The information can be used to enact changes in the staff level to improve performance around respectful delivery of information and more gentle approaches to physical contact. Lastly, the information gained can provide important information to perinatal care providers of how larger structural issues of racism, classism, and sexism affect the way patients experience their birth. An essential goal for the use of the scale is to not merely focus on the individual expression of FOC. If the translation to use ends up being just another scale to identify FOC as a problem located in the woman herself, then the scale is not being used as intended and instead colludes to reinforce FOC as individual psychopathology.

Future research directions

Empirical inquiry answers posed questions; it also generates new questions. This methodological study was no exception. Results of the study support the reliability and validity of the WDEQ-US scale and have begun the establishment of sound psychometric properties. Scientific inquiry, however, cannot end there. Three areas for further research are presented that would continue to build strong psychometrics for the scale. The first would be continued validation and reliability studies of the WDEQ-US. The second area related to research, would utilize the scale to explore the relationship between fear of childbirth and experiences of discrimination in the health care setting among marginalized women. The third would be using the WDEQ-US to explore the relationship between FOC in the United States and adverse obstetric outcomes. The last would be to explore whether system changes might provide a less

fearful, healthier and satisfying experience that is well within the standards of safety demonstrated in outcomes studies.

Further validation of the WDEQ-US

This dissertation research revised and validated a quantitative self-report- 6-point Likert scale that measures women's experiences with FOC. Over 300 women in the southeast Michigan area participated in that validation process. Scale development experts agree the use of different samples to test measurement tools adds to establishment of psychometric properties (DeVillis, 2003). To be ready for use in further research the resulting WDEQ-US scale needs further investigation as a scale that may offer potential to better address the challenging concern of FOC.

In order to offer continued support for the reliability and validity of the scale, another sample should be used to test the 10-item final version of the WDEQ-US scale. The recommendation would be that this sample is recruited from a different geographic region of the United States. Data from the third sample would be analyzed and compared with results from the presented sample to assess similarities and differences. Congruent findings would provide further evidence for the psychometric soundness of the WDEQ-US.

A second recommendation is conduct a research study to ensure the WDEQ-US has predictive validity. Predictive validity is the extent to which a score on a scale or test predicts scores on some other criterion measure (DeVillis, 2003). In addition, research to determine norm references or standardization of the WDEQ-US scale is important. It is not necessary for all research instruments to be standardized or norm referenced; however, such referencing increases interpretability and meaningfulness of the scale. Norming the WDEQ-US would allow

clinicians and research to compare the scores of women they are working with scores from other practices or other geographical regions.

Fear of childbirth and perceived discrimination

An expected finding of this study is that women who had high levels of FOC, specifically around 'external fears' also had high levels of perceived discrimination from health care providers. A theoretical underpinning of this project was that fear of the childbirth experience extends beyond the individual psychopathology and is instead a reaction to fear of the process, the people that are caring for them during the process, and where the process takes place.

Experiences with discrimination are associated with delays in seeking medical care and poor adherence to medical care recommendations independent of need, enabling and predisposing factors (Casagrande, Gary, LaVeist, Gaskin, & Cooper, 2007) Many studies have focused on race-based discrimination encountered in health care settings and have found that such discrimination is associated with worse health outcomes (Hausmann, Jeong, Bost, & Ibrahim, 2008). While race discrimination was an expected finding in this study, an unexpected finding was the number of women who listed weight as the descriptor they felt lead to discrimination during their health care visits.

There is compelling evidence that heavier persons are stigmatized and these stigmatizations transcend negative evaluations of others. Heavier people are often the target of multiple forms of discrimination which has implications for their psychological as well as physiologic well being (Carr & Friedman, 2005). None of the research on perceived discrimination around weight has been specific to the prenatal period. The prenatal period is a time where women's weight is the focus of almost every visit and where women are given strict guidelines by their clinicians and lay people about the 'appropriate' amount of weight to gain

during pregnancy. Research looking at how that advice translates into discrimination and informs a fear of the childbirth experience is crucial in order to develop language and programs to support health pregnancies without invoking discriminatory practices.

Fear of childbirth and obstetric outcomes

Extensive studies have been done in the Scandinavian countries looking at the impact of FOC on obstetrical outcomes. In these countries, FOC has been associated with increased use of pharmacologic pain relief (Adams, Eberhard-Gran, & Eskild, 2012; Alipour, Lamyian, & Hajizadeh, 2011; Sjogren & Thomassen, 1997), longer times to accomplish delivery (Adams, Eberhard-Gran, & Eskild, 2012), as well as higher rates of operative vaginal delivery (Adams, Eberhard-Gran, & Eskild, 2012; Heimstad, Dahloe, Laache, Skogvoll, & Schei, 2006), emergency cesarean section (Nilsson, Lundgren, Karlstrom, & Hildingsson, 2011; Ryding, Wirfelt, Wangborg, Sjogren, & Edman, 2007), preference for elective cesarean section (Nieminen, Stephansson, & Ryding, 2009; Waldenstrom, 2004), self-reported negative birth experience (Nilsson, Lundgren, Karlstrom, & Hildingsson, 2011; Ryding, Wirfelt, Wangborg, Sjogren, & Edman, 2007), induction (Sjogren & Thomassen, 1997), increased used of synthetic oxytocin to promote labor progress (Sjogren & Thomassen, 1997) and decreased 'normal' delivery diagnosis (Sjogren & Thomassen, 1997).

Replicating these studies in the United States would allow for a deeper understanding of the connection between FOC and obstetric outcomes as well as health disparities in obstetrical outcomes. A similar example in the literature studied at the University of Michigan is the pathway between stress and increased risk for preterm delivery (Lu & Chen, 2004; Seng, Low, Sperlich, Ronis, & Liberzon, 2009). Women who report high pregnancy related stress levels have an increased risk of preterm birth. This relationship is more striking for Black women

compared with White women suggesting that the role of identity within a larger social structure may have an impact on the phenomena (Dole et al., 2004). Stress factors such as fear, poverty, the role of perceived racism, life experiences with racism, as well as living in especially segregated residential areas, increase the risk of adverse birth outcomes indicating that the phenomenon of stress is larger than an individual psychopathology and more deeply rooted in systemic or institutionalized phenomena (Collins, David, Handler, Wall, & Andes, 2004; Paul, Boutain, Agnew, Thomas, & Hitti, 2008).

Conclusion

Taken together, the empirical chapters that compose this dissertation offer insight into fear of the childbirth experience. Although each investigation is relatively narrow in scope, the analyses takes important steps in advancing the study of fear of childbirth while also illuminating ways that larger social structures influence perinatal mental health. To inform specific recommendations for practice changes, additional research is needed looking at the influence of fear of childbirth on obstetric outcomes and, in turn, demographically informed disparate health outcomes.

Appendix A – Content validity index letter

Good afternoon,

My name is Lee Roosevelt and I'm a doctoral candidate at the University of Michigan working with Dr. Lisa Kane Low and Dr. Julia Seng. Part of my dissertation project has been modifying an existing instrument used to measure fear of childbirth for use with women in the United States. The Wijma Delivery Expectancy Questionnaire is the most widely used fear of childbirth scale, however it has never been validated in the United States and initial focus group research indicated that the scale did not fully incorporate how women describe their own fear of childbirth. *I'm contacting you as an expert in the field of maternal mental health to see if you would be willing to review the attached revised instrument and score each question as part it's validation process.*

The revised scale was developed based on extensive focus group research with a broad cross section of women in the United States. The general layout and design of the scale is similar to the W-DEQ and some of the constructs were carried over, however many of the questions are new constructs identified by women in the focus groups.

For part of this validation process I am using the Content validity index (CVI). CVI is the degree to which an instrument has an appropriate sample of items for the construct being measured. Basically, it involves looking at each question and rating the question using a Likert scale to rate how relevant each question is to the big picture of understanding fear of childbirth.

If you would be willing to take a few minutes to look at the scale and participate in the content validity process I would appreciate it tremendously. *If you open the attachment you will see the scale with a purple shaded box on the far right where the question can be scored as 1=not relevant, 2=somewhat relevant, 3=quite relevant, or 4=highly relevant.*

Thank you so much for your consideration. I am hoping to have this portion of the validation process complete by May 14. Please let me know if you have any questions or concerns.

Sincerely,
Lee Roosevelt

Appendix B – Content validity index

This questionnaire is about feelings and thoughts women may have about childbirth.

Please complete each question by drawing a circle around the number belonging to the answer that most closely corresponds to how you imagine your birth will be.

Please answer how you **imagine** your birth will be – not the way you **hope** it will be.

I. How do you think your birth will turn out as a whole?						**CVI Score** 1=not relevant 2=somewhat relevant 3=quite relevant 4=high relevant
1 Extremely fantastic	2	3	4	5	6 Not at all fantastic	
1 Extremely scary	2	3	4	5	6 Not at all scary	
1 Extremely painful	2	3	4	5	6 Not at all painful	
II. How do you think you will feel in general during the birth?						
1 Extremely strong	2	3	4	5	6 Not at all strong	
1 Extremely confident	2	3	4	5	6 Not at all confident	

						CVI Score 1=not relevant 2=somewhat relevant 3=quite relevant 4=high relevant
1 Extremely independent	2	3	4	5	6 Not at all independent	
1 Extremely out of control	2	3	4	5	6 Not at all out of control	
1 Extremely panicked	2	3	4	5	6 Not at all panicked	
1 Extremely excited	2	3	4	5	6 Not at all excited	
III. During the last month have you had worries that your baby will die or be seriously injured during birth?						
1 Never	2	3	4	5	6 All the time	
IV. How do you think you will feel about your support people (significant other, family, friends) during the birth?						
1 Extremely alone	2	3	4	5	6 Not at all alone	
1 Extremely supported	2	3	4	5	6 Not at all supported	
1 Extremely abandoned	2	3	4	5	6 Not at all abandoned	

						CVI Score 1=not relevant 2=somewhat relevant 3=quite relevant 4=high relevant
V. How do you think you will feel about your care providers (nurses, midwives, doctors) during the birth?						
1 Extremely respected	2	3	4	5	6 Not at all respected	
1 Extremely understood	2	3	4	5	6 Not at all understood	
VI. How do you think you feel about the place you give birth?						
1 Extremely unhappy	2	3	4	5	6 Not at all unhappy	
1 Extremely safe	2	3	4	5	6 Not at all safe	
VII. What other thoughts do you have about your upcoming birth?						

Appendix C – Composite survey packet

Thank you for your willingness to participate in this research and further our understanding of what type of fears and worries women have about childbirth. Your participation in this study is voluntary. If you decide to take part in this study, you are still free to withdraw at any time and without giving a reason. You are free to not answer any question or questions if you choose. All responses are anonymous in order to protect your confidentiality.

When you have completed the survey packet please hand it back to the researcher assistant or by email to the principle investigator, Lee Roosevelt, at Lkrmidwife@gmail.com. We would like to offer women a $10 thanks for their participation in the project. If you are returning this packet via email and would like to receive this gift please include your mailing address in the message.

Are you 18 years old or older?

Are you currently pregnant?

Do you have some fears or worries about childbirth?

If you answered YES to all three questions above please continue on with the survey packet.

This questionnaire is about feelings and thoughts women may have about childbirth.

Please complete each question by drawing a circle around the number belonging to the answer that most closely corresponds to how you imagine your birth will be.

Please answer how you **imagine** your birth will be – not the way you **hope** it will be.

I. How do you think your birth will turn out as a whole?					
1 ☐ Extremely fantastic	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all fantastic
1 ☐ Extremely scary	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all scary
1 ☐ Extremely painful	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all painful
II. How do you think you will feel in general during the birth?					
1 ☐ Extremely strong	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all strong
1 ☐ Extremely confident	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all confident
1 ☐ Extremely afraid	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all afraid
1 ☐ Extremely out of control	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all out of control

1 ☐ Extremely panicked	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all panicked
1 ☐ Extremely excited	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all excited
III. During the last month how often have you had worries that your baby will die or be seriously injured during birth?					
1 ☐ Never	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ All the time
IV. During the last month how often have you had worries that you yourself will die or be seriously injured during birth?					
1 ☐ Never	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ All the time
V. How do you think you will feel about your support people (significant other, family, friends) during the birth?					
1 ☐ Extremely alone	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all alone
1 ☐ Extremely supported	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all supported
1 ☐ Extremely abandoned	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all abandoned
VI. How do you think you will feel about your care providers (nurses, midwives, doctors) during the birth?					
1 ☐ Extremely respected	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all respected

1 ☐ Extremely understood 7.	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all understood
VII. How do you feel about the place where you will give birth?					
1 ☐ Extremely unhappy	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all unhappy
1 ☐ Extremely safe	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all safe
VIII. What other thoughts do you have about your upcoming birth?					

Please continue to the next page.

Over the last two weeks, how often have you been bothered by the following?				
	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	☐	☐	☐	☐
2. Feeling down, depressed, or hopeless	☐	☐	☐	☐
Total = _____				

Please continue to the next page.

Over the last two weeks, how often have you been bothered by the following?				
	Not at all	Several days	More than half the days	Nearly every day
3. Feeling nervous, anxious or on edge	☐	☐	☐	☐
4. Not being able to stop or control worrying	☐	☐	☐	☐
5. Worrying too much about different things	☐	☐	☐	☐
6. Trouble relaxing	☐	☐	☐	☐
7. Being so restless that it is hard to sit still	☐	☐	☐	☐
8. Becoming easily annoyed or irritable	☐	☐	☐	☐
9. Feeling afraid as if something awful might happen	☐	☐	☐	☐
Total = _____				

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ☐
Somewhat difficult ☐
Very difficult ☐
Extremely difficult ☐

Please continue to the next page

The next questions are about problems and complaints that people sometimes have in response to stressful life experiences. Please indicate how much you have been bothered by each problem in the past month. For these questions, the response options are: "not at all", "a little bit", "moderately", "quite a bit", or "extremely".

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Repeated, disturbing memories, thoughts, or images of a stressful experience from the past?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Feeling very upset when something reminded you of a stressful experience from the past?	1 ☐	2 ☐	☐	4 ☐	5 ☐
Avoided activities or situations because they reminded you of a stressful experience from the past?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Feeling distant or cut off from other people?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Feeling irritable or having angry outbursts?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Difficulty concentrating?	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Total = _____					

Please continue to the next page.

How often do any of the following things happen to you?

	Always	Most of the time	Sometimes	Rarely	Never
You are treated with less courtesy than other people.	5 ☐	4☐	3☐	2☐	1☐
You are treated with less respect than other people.	5 ☐	4☐	3☐	2☐	1☐
You receive poorer service than other people.	5 ☐	4☐	3☐	2☐	1☐
A doctor or nurse acts as if he or she thinks you are not smart.	5 ☐	4☐	3☐	2☐	1☐
A doctor or nurse acts as if he or she is afraid of you.	5 ☐	4☐	3☐	2☐	1☐
A doctor or nurse acts as if he or she is better than you.	5 ☐	4☐	3☐	2☐	1☐
You feel like a doctor or nurse is not listening to what you were saying	5 ☐	4☐	3☐	2☐	1☐
Total = _____					

If you checked "Sometimes" to at least one question, what do you think is the main reason for these experiences? (check all that apply)

You Ancestry or National Origin ☐ Your Gender ☐ Your Race ☐

Your Age ☐ Your Religion ☐ Your Weight ☐

Your Sexual Orientation ☐ Your Education ☐ Your income ☐

Your disability ☐ Other (specify) ☐ _____

Please continue to the next page.

1. I feel confident in asking the doctor questions about my illness.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
2. I feel confident in asking the doctor questions about my medication	1 ☐ Not at all true	2 ☐	3	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
3. I feel confident in asking the doctor questions about my treatment.	1 ☐ Not at all true	2 ☐	3	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
4. I feel confident in asking the doctor to repeat information.	1 ☐ Not at all true	2 ☐	3	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
5. I feel confident in telling the doctor that I did not understand what was said about my illness.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
6. I feel confident in telling the doctor that I did not understand how to take my medication.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
7. I feel confident in asking the doctor to explain the purpose of medical tests.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
8. I feel confident in questioning the doctor's advice/recommendation.	1 ☐ Not at all	2 ☐	3 ☐	4 ☐ Somewhat	5 ☐	6 ☐	7 ☐ Very true

	true			true			
9. I feel confident in telling the doctor that I have had side-effects from the medication.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
10. I feel confident in telling the doctor that I have not followed her/his recommendations.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true
11. I feel confident in telling the doctor I want to change my medication.	1 ☐ Not at all true	2 ☐	3 ☐	4 ☐ Somewhat true	5 ☐	6 ☐	7 ☐ Very true

Please continue to the next page.

Instruction:
This questionnaire is about feelings and thoughts women may have at the prospect of labor and delivery.

The answers to each question appear as a scale from 1 to 6. The outermost answers (1 and 6 respectively) correspond to the opposite extremes of a certain feeling or thought.

Please complete each question by drawing a circle around the number belonging to the answer which most closely corresponds to **how you imagine** your labour and delivery will be.

Please answer **how you imagine** your labor and delivery will be – not the way you hope it will be.

I. How do you think your labour and delivery will turn out as a whole					
1 ☐ Extremely fantastic	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all fantastic
1 ☐ Extremely frightful	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all frightful
II. How do you think you feel in general during the labour and delivery?					
1 ☐ Extremely lonely	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all lonely
1 ☐ Extremely strong	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all strong
1 ☐ Extremely confident	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all confident
1 ☐ Extremely afraid	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all afraid
1	2	3	4	5	6

☐ Extremely deserted	☐	☐	☐	☐	☐ Not at all deserted
1 ☐ Extremely weak	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all weak
1 ☐ Extremely safe	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all safe
1 ☐ Extremely independent	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all independent
1 ☐ Extremely desolate	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all desolate
1 ☐ Extremely tense	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all tense
1 ☐ Extremely glad	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all glad
1 ☐ Extremely proud	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all proud
1 ☐ Extremely abandoned	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all abandoned
1 ☐ Totally composed	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all composed
1 ☐ Extremely relaxed	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all relaxed
1 ☐ Extremely happy	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all happy
III. How do you think you will feel during the labour and delivery?					
1	2	3	4	5	6

☐ Extreme panic	☐	☐	☐	☐	☐ No panic at all
1 ☐ Extreme hopelessness	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ No hopelessness at all
1 ☐ Extreme longing for the child	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ No longing for the child at all
1 ☐ Extreme self confidence	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ No self-confidence at all
1 ☐ Extreme trust	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ No trust at all
1 ☐ Extreme pain	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ No pain at all
IV. What do you think will happen when labour is most intense?					
1 ☐ I will behave extremely badly	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ I will not behave badly at all
1 ☐ I will dare to totally surrender control of my body	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ I will not dare to surrender control to my body at all
1 ☐ I will totally lose control of myself	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ I will not lose control of myself at all
V. How do you imagine it will feel the very moment you delivery the baby?					
1	2	3	4	5	6

☐ Extremely funny	☐	☐	☐	☐	☐ Not at all funny
1 ☐ Extremely natural	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all natural
1 ☐ Extremely self-evident	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all self-evident
1 ☐ Extremely dangerous	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Not at all dangerous
VI. Have you, during the last month, had fantasies about the labour and delivery, for example:					
…fantasies that your child will die during labour/delivery?					
1 ☐ Never	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Very often
…fantasies that your child will be injured during labour/delivery?					
1 ☐ Never	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐ Very often

Please continue to the next page

Demographics: The information below helps us as researcher to make sure that we are surveying a wide range of people so that everyone's voice is represented in the research.

Gender
- Female ☐
- Male ☐
- Transgender ☐

Family Income
- Less than $30,000 ☐
- $30,000-$49,000 ☐
- $50,000-$99,000 ☐
- More than $100,000 ☐

Race
- Black/African American ☐
- White ☐
- Latina or Hispanic ☐
- Middle Eastern ☐
- Asian/Pacific Islander ☐
- Other ☐

Education
- Some high school, no diploma ☐
- High school graduate, diploma ☐
- Some college, no degree ☐
- Trade/technical/voc. Training ☐
- Associate degree ☐
- Bachelor's degree ☐
- Master's degree ☐
- Professional degree ☐
- Doctorate degree ☐

Age
- 18-22 years old ☐
- 23-27 years old ☐
- 28-32 years old ☐
- 33-37 years old ☐
- 38-44 years old ☐
- 45+ years old ☐

Marital Status
- Single ☐
- Partnered ☐
- Married ☐
- Widowed ☐
- Divorced ☐
- Separated ☐

Employment Status
- Employed for wages ☐
- Self-employed ☐
- Out of work ☐
- Homemaker ☐
- Student ☐
- Military ☐
- Retired ☐
- Unable to work ☐

Prior Pregnancies
- Number of total pregnancies _____
- Number of live births _____
- Number of premature births _____
- Number of miscarriages _____
- Number of voluntary abortions _____
- Number of living children _____

What trimester of pregnancy are you in?
- First trimester (0-13 weeks) ☐
- Second trimester (14-26 weeks) ☐
- Third trimester (27-42 weeks) ☐

Obstetric History
- Number of Vaginal births _____
- Number of cesarean sections _____
- Reasons for cesarean _____
- Number of births attended by midwives _____
- Number of births attended by doctors _____

Have you ever been diagnosed with?

Depression ☐ Bi Polar (Manic Depression) ☐ Schizophrenia ☐ Personality disorder ☐

Anxiety	☐	Obsessive-Compulsive Disorder	☐	Psychosis	☐	Other	☐
Panic attacks	☐	Substance Abuse/Dependency	☐	ADD/ADHD	☐		

Thank you for taking the time to complete this survey packet.

Please return this completed survey pack to the researcher. If you are not returning this survey pack in person please be sure to include your mailing address in the message so that we can offer you a gift of appreciation for your time. Your address will not be sold and will not be used for any other purposes.

For further information, please contact the Principle Investigator: Lee Roosevelt MPH, CNM at Lkrmidwife@gmail.com.

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