CE 1.5 ANCC Contact Hours

FACTORS AFFECTING UNCERTAINTY IN WOMEN

with High-Risk Pregnancies

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Abstract

Objective: To evaluate the state of the science on uncertainty in high-risk pregnancy and identify factors that influence uncertainty in women diagnosed with a high-risk pregnancy.

Data Sources: Primary research articles from CINAHL, Ovid, MEDLINE, Scopus, and PsycINFO written in English, without date restrictions.

Study Selection: Nineteen articles were identified, including 14 qualitative studies and 5 quantitative studies.

Data Extraction: This integrative review was guided by Whittemore and Knafl's methodology. Studies were graded on level and quality of evidence as per Dearholt, Dang, and Sigma Theta Tau International.

Data Synthesis: Studies were synthesized by using constant comparative methods according to factors influencing, outcomes of, and management of uncertainty.

Conclusion: Uncertainty is a prominent theme in women experiencing a high-risk pregnancy. Uncertainty is influenced by various personal, pregnancy-related, demographic, and healthcare-related factors. Findings may offer insight and empathy for healthcare professionals. Nurses who understand significance of uncertainty in adjusting to two conflicting life events have the opportunity to help women in their understanding of a high-risk diagnosis during pregnancy through anticipatory guidance. Future research is needed to explore factors affecting uncertainty and to understand the experience of high-risk pregnancy to develop interventions aimed at mitigating uncertainty in high-risk pregnant women.

Key words: High-risk pregnancy; Integrative review; Uncertainty.

One in four women is diagnosed with or considered to have a high-risk pregnancy (HRP). High-risk pregnancy may be defined as "one in which a condition exists that jeopardizes the health of the mother, her fetus, or both," (Ricci, 2016, p. 648). Although research has focused largely on the physiological maternal, fetal, and neonatal outcomes, research on how women process and experience HRP is limited. Women with HRP may experience a wide range of emotions, occurring simultaneously on opposite ends of the spectrum. Faced with both the threat of illness and the joy of pregnancy, women may experience intense feelings of uncertainty and loss of control, accompanied by anxiety and psychological distress (Giurgescu et al., 2015; Höglund & Dykes, 2013).

Uncertainty is inherent in the human experience but is even more significant in the context of illness. Uncertainty in illness has been defined as "the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225). Uncertainty occurs due to inability to assign meaning to illness-related events, assign probability to or predict outcomes (Mishel, 1988). The experience of uncertainty is deeply rooted in the individual's perception, influenced by both cognitive and precognitive ways of knowing (Penrod, 2007). When an event is perceived as uncertain, appraisal of risk or threat occurs as the individual considers the event in a positive or negative light (Mishel, 1988).

The concept of uncertainty in the context of illness has been examined extensively among nurse scholars (Cypress, 2016; Mishel, 1988; Penrod, 2007; Zhang, 2017), although study of uncertainty in high-risk pregnant women has been limited. While uncertainty is often unrecognized or misinterpreted by healthcare providers (HCPs) during pregnancy, the experience of uncertainty appears to be universal. Uncertainty is a common experience during pregnancy regardless of risk (Borrelli, Walsh, & Spiby, 2018; Hui Choi et al., 2012), as the outcome is not ultimately known until after birth. As the clinical focus is shifting from patient- to family-centered care, current extensions of the concept of uncertainty have encompassed both the individual and caregivers (Zhang, 2017).

Uncertainty has been associated with higher levels of distress, anxiety (Cypress, 2016), and diminished quality of life (Zhang, 2017). Prenatal stress (i.e., stressful conditions endured by mothers) has been associated with poor birth outcomes including preterm birth and low birthweight (Staneva, Bogossian, Pritchard, & Wittkowski, 2015), and long-term consequences such as poor neurodevelopmental outcomes, insulin resistance, and cardiovascular disease (DeSocio, 2018). Given the relationship between lower psychological well-being and poor perinatal outcomes, more study is needed on prevalence of uncertainty in HRP. Factors affecting uncertainty and outcomes of uncertainty in HRP must be identified to develop targeted interventions aimed at mitigating uncertainty.

The purpose of this review is to provide an overview of existing literature on uncertainty in HRP and gain a better understanding of the role of and factors affecting uncertainty in HRP including: (1) what is known about uncertainty in HRP and what factors influence uncertainty; (2) the quality of what is known; (3) what should healthcare professionals know about uncertainty in HRP; and (4) next steps for research and/or practice.

Uncertainty exists both in pregnancy and in illness separately; however, uncertainty associated with a high-risk pregnancy is likely exaggerated by an illness with an often-unpredictable course.

Method

The review method by Whittemore and Knafl (2005) was used to generate an integrated synthesis of existing research on uncertainty in HRP. A computer-assisted search without date restrictions to April 2019 was conducted for research publications indexed in English in CINAHL, Ovid, MEDLINE, Scopus, and PsycINFO using the search terms high-risk pregnan* or pregnan* complication* AND uncertain* (See Figure 1 for flow diagram of article search and selection process). Inclusion criteria were primary quantitative or qualitative studies published in English on the target population of high-risk pregnant women and measured or described presence of uncertainty. Articles that included *diagnostic* or *clinical uncertainty* were excluded.

Final sample included 19 studies with similar methodologies. Each study was evaluated based on inclusion of both the target population and measurement or description of uncertainty. Although uncertainty was not always mentioned explicitly in the title or study purpose, uncertainty was measured in correlation with other concepts in quantitative studies. In qualitative studies, uncertainty, factors affecting uncertainty, role of uncertainty, or ways of coping with uncertainty were inherent in findings and discussion sections. Constant comparative methods (Whittemore & Knafl, 2005) were used to permit iterative comparisons of findings on presence of and factors influencing uncertainty.

Results

Description of Included Studies

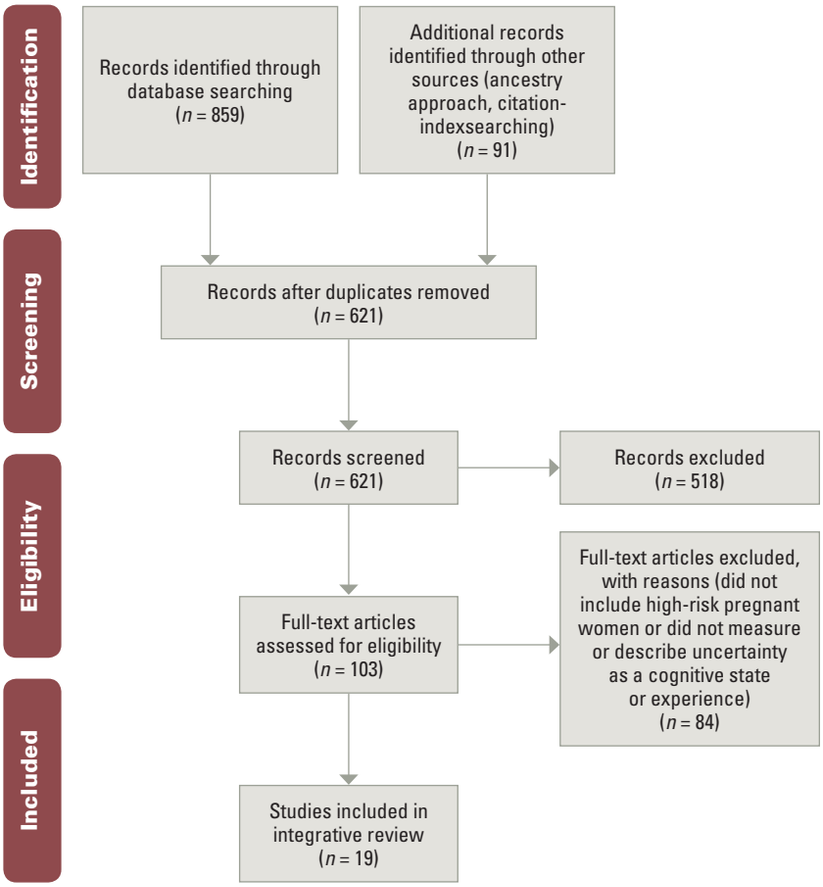
Studies were conducted from 1994 to 2018. Fourteen of the 19 studies used qualitative methodologies guided by unspecified qualitative methodologies (n = 7), grounded theory (n = 2), or phenomenology (n = 2). Most qualitative studies included a single interview (n = 10) and included sample sizes from 7 to 30 participants. Of the 19 studies, 5 were quantitative, of which 3 were cross-sectional. Sample sizes in quantitative studies ranged from 20 to 342. Two of the five quantitative studies identified a theoretical framework: the transactional model of

stress and coping and a combination of Snyder's holistic model of the childbearing experience and Mishel's uncertainty in illness theory.

Most studies were conducted in either the United States (n = 7) or Canada (n = 4). Participants' ages ranged from 18 to 43 years, although not all studies reported age ranges for participants. Of studies reporting race (n =10), the majority, if not all of the participants were white with the exception of Giurgescu, Penckofer, Maurer, and Bryant (2006) and Shannon and Lee (2008) who included an ethnically diverse sample, Sun et al. (2008) and Tseng et al. (2008) who included only Taiwanese women, and Giurgescu et al. (2015) and Patterson (1993) who included only African American women. Ten of the studies reported on educational level. Most participants had completed high school, and many had at least some college. Of 11 studies reporting marital status, all but one study (Giurgescu et al., 2015) included mainly or all married participants.

Studies included women with a variety of HRP conditions (n = 5) or singular conditions (n = 14) including risk for or preterm labor, fetal conditions, advanced maternal age, thrombophilia, pregnancy after fetal loss or risk for miscarriage, multiple sclerosis, prenatal depression, preeclampsia, and maternal HIV infection. Gestational age at time of data collection ranged from the first trimester to 39 weeks gestation to 14 months postpartum. Of studies reporting on gravidity and parity, most studies included more multiparous women (n = 5).

Figure 1. Flow Diagram of Article Search and Selection Process



Quality of Included Studies

Studies were graded on level and quality of evidence per Dearholt et al. (2012). All studies were level III (nonexperimental and qualitative studies). Most studies were of good quality (n = 16), providing reasonably consistent results, adequately powered given study design, and recommendations consistent with current scientific literature, one was rated as high quality and two studies were of low quality. Studies rated as low quality were graded as such due to insufficient sample sizes or inconsistent results.

Level of Uncertainty

Across studies quantitatively measuring uncertainty, researchers reported, on average, low to moderate levels of uncertainty. Although Clauson (1996) reported low to moderate uncertainty on admission for most participants, 23% reported quite high levels of uncertainty. Uncertainty was significantly lower at discharge (Clauson, 1996). Giurgescu et al. (2006) reported overall low levels of uncertainty in their sample, although the researchers speculated the high level of social support reported in this sample may have mitigated uncertainty.

Cevik and Yagmur (2018) used the Intolerance of Uncertainty Scale to measure reactions to uncertain situations in women at risk for pregnancy loss, finding a significant difference between women at risk for miscarriage and those not at risk. Giurgescu et al. (2015) reported in a small pilot study no significant differences in levels of uncertainty between low-risk pregnant African American women and African American women with preeclampsia.

Researchers used several tools to measure uncertainty in HRP: Mishel Uncertainty in Illness Scale (n = 2), Uncertainty Stress Scale-High-Risk Pregnancy Version (n = 1), Intolerance of Uncertainty Scale (n = 1), and Parental Perception of Uncertainty-Diagnosis (n = 1). Of key concern is that most of the instruments were not designed for use in pregnant women (See Table 1 for brief summary and Supplemental Digital Content, http://links.lww.com/MCN/A54, for detailed findings).

Findings from qualitative studies indicated uncertainty as a frequent situational stressor (Gupton, Heaman, &

Table 1. Studies on Uncertainty in High-Risk Pregnancy

Author (Year)	Design	Sample Size	Key Findings
Carolan & Nelson (2007)	1, 4	22	Dealing with uncertainty emerged as one of the risk-related themes. Coped by seeking out more information or by emotionally distancing themselves from the pregnancy.
Cevik & Yagmur (2018)	2, 3	342	Higher uncertainty associated with lower psychological well-being and increased stress and anxiety.
Clauson (1996)	2, 4	58	Higher uncertainty associated with increased stress, perception of threat, and LOS and earlier GA.
Currie & Cornsweet Barber (2016)	1, 3	12	Pregnancy overshadowed by unpredictability and the need for control. Relationship with HCP, disempowerment in the hospital, and the role of support was evident.
Giurgescu et al. (2015)	2, 3	49	Higher uncertainty associated with increased psychological distress. No differences in uncertainty between women with HRP and low-risk pregnancy.
Giurgescu et al. (2006)	2, 3	105	Higher uncertainty associated with increased avoidance as a coping strategy and decreased social support, psychological well-being, and positive interpretation.
Gupton et al. (1997)	1, 3	24	Situational stressors included uncertainty and lack of control. Social support and coping aided in mediating stress as a result of situational stressors, including uncertainty.
Höglund & Dykes (2013)	1, 3	15	Unpredictable symptoms led to uncertainty over when to take symptoms seriously. Support from their partners and HCPs aided women in achieving balance.
Jones et al. (2005)	1, 4	7	Uncertainty was among the three aspects of emotional turmoil identified.
Lou et al. (2016)	1, 3	16b	HRP screening results generate worry and uncertainty. Coped by gathering information, social withdrawal or distraction, and focusing on the positive versus uncertainty.
Martens & Emed (2007)	1, 3	9	Uncertainty over the treatment outcome and labor and birth. Coped by taking control of uncertainty through a conclusive diagnosis, information, and maintaining perspective.
Moore & Côté-Arsenault (2018)	1, 4a	19	The metaphor of navigating an uncertain journey emerged as the main finding. Women dealt with uncertainty through both negative and positive emotions.
Patterson (1993)	1, 3	17	Uncertainty over inability to determine the outcome incongruence with women's projections of a typical pregnancy experience. Sought out advice from other women.
Price et al. (2007)	1, 3	12	HRP was a challenge with fear, uncertainty, and stress. Spiritual beliefs and practices aided women in their search for meaning as they moved through the experience of HRP.
Shannon & Lee (2008)	2, 4	20	Higher uncertainty associated with lower social support and increased perceived stress, interpersonal social conflict, psychological symptom distress, and depressive symptoms.
Smeltzer (1994)	1, 3	15	Uncertainty over an unpredictable illness with incongruence in expectations of illness and pregnancy-related symptoms, labor and delivery outcomes, breastfeeding, and long- and short-term parenting and lack of information from HCPs. Social support was key.
Sun et al. (2008)	1, 4	20	Prevailing sense of uncertainty was the core category.
Tseng et al. (2008)	1, 3	12	Future uncertainty was among five of the recurring subthemes. Previous negative experiences and HRP conditions beyond depression intensified uncertainty.
Weiss et al. (2002)	1, 3	30	Uncertainty emerged as a complex mix of hope, worry, and denial over recognition of symptoms and the threat or risk attributed to the cause of the symptoms.

Note. 1, qualitative design; 2, quantitative design; 3, cross-sectional; 4, more than one time point; GA, gestational age; LOS, length of stay; HCP, healthcare provider; HRP, high-risk pregnancy.

[a]Review of pregnancy diaries

[b]Study included couples

Ashcroft, 1997; Price et al., 2007; Smeltzer, 1994) related to having a high-risk condition during pregnancy that only time can resolve (Lou et al., 2016; Patterson, 1993; Tseng et al., 2008). Uncertainty was often central to the experience of HRP (Jones et al., 2005; Moore & Côté-Arsenault, 2018; Sun et al., 2008; Weiss, Saks, & Harris, 2002) and something that had to be dealt with (Carolan & Nelson, 2007; Martens & Emed, 2007). Uncertainty emerged as a complex mix of hope, worry, and denial (Lou et al. 2016; Moore & Côté-Arsenault, 2018; Weiss et al., 2002) that for some extended to future possibilities (Jones et al., 2005; Smeltzer, 1994; Sun et al., 2008; Tseng et al., 2008)

Figure 2. Uncertainty in High-Risk Pregnancy

Factors Contributing to Uncertainty

Making sense of the symptoms. Women struggled to correctly identify the cause of physical symptoms when faced with chronic illness during pregnancy. Having pregnancy-related symptoms on top of their illness-related symptoms lead to uncertainty (Smeltzer, 1994). Women were uncertain over which symptoms required action (Weiss et al., 2002). Unpredictable contractions perpetuated a lack of control and uncertainty over when to take them seriously (Höglund & Dykes, 2013). For some, this led to hypervigilance in monitoring symptoms (Moore & Côté-Arsenault, 2018). Some high-risk pregnant women struggled with lack of symptoms in certain conditions and not being able to predict if and when they will occur (Currie & Cornsweet Barber, 2016; Martens & Emed, 2007). Unpredictability of symptoms and duration of symptoms were among the top items that elicited the most uncertainty in high-risk hospitalized pregnant women (Clauson, 1996). Some physical symptoms, such as fetal movement were perceived as reassuring and aided in reducing uncertainty (Moore & Côté-Arsenault, 2018) (See Figure 2).

Familiarity and congruence in events. Lack of familiarity with the HRP experience was evident as women were thrust into medicalized care (Currie & Cornsweet Barber, 2016) and to some, a foreign world (Price et al., 2007). A positive relationship was noted between levels of uncertainty and length of stay in hospitalized high-risk pregnant women (Clauson, 1996). In women at risk for preterm labor, early detection of contractions was more difficult in primigravida women as they had no familiarity with pregnancy-related symptoms (Patterson, 1993). Women in Weiss et al.'s (2002) study actively sought ways to make their experiences with preterm labor familiar by comparing knowledge from previous experiences and experiences of others.

Receiving an HRP diagnosis was often perceived as an unanticipated event. Uncertainty surrounded the condition itself, treatment, labor and birth, and neonatal outcomes (Clauson, 1996; Jones et al., 2005; Martens & Emed, 2007; Smeltzer, 1994; Sun et al., 2008; Tseng et al., 2008). Women who had previously been pregnant constantly compared the current pregnancy with their previous pregnancy experiences (Martens & Emed; Patterson, 1993) and chronic illness experiences (Smeltzer, 1994). When these comparisons were incongruent, uncertainty occurred. In women with prenatal depression, previous negative experiences tended to intensify their uncertainty surrounding unpredictable pregnancy outcomes (Tseng et al., 2008).

Education and knowledge. Women with more education experienced lower levels of uncertainty (Clauson, 1996). Lack of information or knowledge about the condition or pregnancy was related to higher uncertainty (Carolan & Nelson, 2007; Lou, et al., 2016; Martens & Emed, 2007; Smeltzer, 1994).

Social support. The role of social support in levels of and experience of uncertainty was evident across studies (n = 10). Women with higher uncertainty reported less social support (Giurgescu et al., 2006; Shannon & Lee, 2008) and a higher incidence of interpersonal social conflict (Shannon & Lee, 2008). In pregnant women with multiple sclerosis, receiving mixed support from family, friends, and providers about their pregnancy intensified their uncertainty while having an impact on their overall well-being (Smeltzer, 1994).

Healthcare team. Healthcare providers either helped or hindered the distress about uncertainty in HRP (Currie & Cornsweet Barber, 2016; Weiss et al., 2002). Women sought clarification of symptoms or validation in their interpretation of symptoms from HCPs (Weiss et al., 2002). When women felt there was a lack of information or a shared definition of the condition, it had a negative impact on their ability to perceive an accurate risk level (Smeltzer, 1994), whereas women who reported receiving a conclusive diagnosis had less uncertainty (Höglund & Dykes, 2013; Martens & Emed, 2007). Patterson (1993)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Certain pregnancy-related complications may invoke less or more uncertainty depending on severity of disease or intensity and frequency of symptoms.

reported that black women's HCPs were the last consulted when attempting to make sense of symptoms and risk; this finding may be attributed to racial differences in engagement with the healthcare system.

Other factors affecting uncertainty. Certain demographic, illness-related, and psychosocial factors have been linked to uncertainty in high-risk pregnant women. Clauson (1996) found no differences in uncertainty levels based on parity, but earlier gestational age was associated with higher levels of uncertainty. This finding, however, was not replicated by Giurgescu et al. (2006), although the mean gestational age was greater in the latter study.

Uncertainty was increased in women who had more severe disease (Price et al., 2007). Women with chronic, progressive illnesses, such as multiple sclerosis experienced uncertainty not only related to the pregnancy, but to future parenting concerns related to progression of their disease (Smeltzer, 1994). Uncertainty was closely tied to appraisal of maternal and fetal risk (Weiss et al., 2002) and increased in women who perceived higher levels of stress and threat (Clauson 1996; Price et al.; Shannon & Lee, 2008).

Outcomes Associated with Uncertainty

Research on outcomes of uncertainty has been largely limited to psychological outcomes. Higher uncertainty was associated with higher levels of psychological distress (Giurgescu et al., 2015) and lower psychological well-being (Cevik & Yagmur, 2018; Giurgescu et al., 2006). Higher incidence of psychological symptom distress and depressive symptoms was also noted in women with more uncertainty (Shannon & Lee, 2008). Only one study reported the relationship between uncertainty and birth outcomes. There were no differences in level of uncertainty between full-term and preterm births (Giurgescu et al., 2015).

Coping with Uncertainty

High-risk pregnant women coped with uncertainty in a variety of ways. In addition to affecting the level of and experience of uncertainty, social support also played a role in coping with uncertainty. Some women attended to the uncertain situation ahead by withdrawing socially with their partners as they came to their own understanding, whereas others used social engagement as distraction (Lou et al., 2016). Social support aided in regaining a sense of balance (Höglund & Dykes, 2013) and mediated women's stress (Gupton et al., 1997). Sharing stories with others (Patterson, 1993) and engaging with the healthcare system were also helpful in mitigating uncertainty (Martens & Emed, 2007; Weiss et al., 2002).

Women dealt with uncertainty by seeking more information (Carolan & Nelson, 2007; Lou et al., 2016; Martens & Emed, 2007; Patterson, 1993; Weiss et al., 2002) and attempting to maintain perspective (Martens & Emed). Positive coping strategies were used to mitigate situational stressors such as uncertainty (Gupton et al., 1997). Spirituality and prayer helped women in search for meaning in HRP (Price et al., 2007). Lower uncertainty was related to more positive feelings (Price et al.) and positive emotions such as anticipation, excitement, confidence, and happiness were a focus in women with a previous fetal loss (Moore & Côté-Arsenault, 2018). Other women coped with uncertainty by embracing negative emotions such as anxiety and fear (Moore & Côté-Arsenault, 2018) or by emotionally distancing themselves from the pregnancy (Carolan & Nelson, 2007). Women with higher levels of uncertainty were more likely to report less positive interpretation and more avoidant coping strategies (Giurgescu et al., 2006) such as distraction (Lou et al., 2016).

Discussion

Uncertainty exists both in pregnancy and in illness; however, the uncertainty associated with a pregnancy compounded by illness is likely exaggerated. An outcome unknown until birth in many cases; lack of support from family, friends, and HCPs; and insufficient knowledge were all factors that influenced not only high-risk women's interpretation of illness-related events, but overall uncertainty surrounding their pregnancies. Similar results have been reported in women with low-risk pregnancies (Hui Choi et al., 2012). Findings suggest that uncertainty is a regular occurrence in women facing HRP and that uncertainty is either heightened or diminished by various personal, pregnancy-related, demographic, and healthcare-related factors.

Suggested Clinical Nursing Implications

- Uncertainty associated with high-risk pregnancy is likely exaggerated by an illness with an often-unpredictable course. The outcome remains unknown until after birth.
- Some pregnancy-related complications may invoke less or more uncertainty depending on the severity of disease or the woman's appraisal of risk or threat surrounding the condition. The intensity, frequency, incongruence, or unpredictability of symptoms may intensify uncertainty.
- Nurses must explore and seek to understand the individual concerns and factors contributing to uncertainty in women's experiences of high-risk pregnancy.
- Understanding individual concerns and factors contributing to uncertainty allows nurses to offer clinical and emotional support and tailored coping strategies helpful in reducing uncertainty during high-risk pregnancy.

Results suggest this body of knowledge is clearly in the descriptive phase. All studies were level III evidence and mainly good-quality studies (Dearholt et al., 2012). Most studies were cross-sectional and correlational, only offering data at a single point in time. This type of design does not allow for examination of how uncertainty and uncertainty factors may have varied over time. No studies were found on uncertainty management intervention for women with HRP. Uncertainty management interventions have been successful in other nonpregnant populations, including HIV (Brashers, Basinger, Rintamaki, Caughlin, & Para, 2017) and diabetes (Amoako, Skelly, & Rossen, 2008), both of which have an impact on pregnant women.

Few studies included a diverse sample, and uncertainty was not examined by specific pregnancy-related conditions in studies that included more than one high-risk condition. Some pregnancy-related complications may invoke less or more uncertainty depending on the severity of disease or intensity and frequency of symptoms that may partially explain variations in uncertainty levels. Most studies were subject to sampling bias related to demographic characteristics, namely race, educational level, marital status, pregnancy-related illness, or single site or city location limiting the external validity of findings.

High-quality descriptive studies examining uncertainty in HRP with larger and more demographically and geographically diverse samples are needed to further explore factors influencing uncertainty in high-risk pregnant women. Identification of factors that are associated with higher uncertainty will allow for development of more targeted and tailored interventions.

Clinical Implications

Occurrence of uncertainty is well documented in HRPs; however, degree of uncertainty experienced by high-risk pregnant women and the factors that influence uncertainty are less clear, especially when compared with low-risk pregnant women. Although it is likely that uncertainty will exist to some degree throughout pregnancy until the outcome is known, nurses and other healthcare professionals may be able to mitigate uncertainty in high-risk pregnant women based on findings. At the bare minimum, qualitative findings may offer insight and empathy (Kearney, 2001) to the experience of HRP. Nurses who understand the significance of uncertainty in adjusting to two conflicting life events can help women in their understanding of a high-risk diagnosis during pregnancy through anticipatory guidance. Healthcare professionals can offer anticipatory guidance (Kearney) to women facing uncertainty by sharing how other women in similar situations have described uncertainty. Nurses may be able to share how other women have coped with their uncertainty in HRP. ✣

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