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A metasynthesis of risk perception in women with high risk pregnancies

Abstract

Introduction: Risk perception in women with high risk pregnancies affects their decisions about perinatal care and is of interest to anyone involved in the care of pregnant women. This paper provides a metasynthesis of qualitative studies of risk perception in women with high risk pregnancies.

Methods*:* A systematic search of eight electronic databases was conducted. Additional papers were obtained through searching references of identified articles. Six studies were identified that reported qualitative research into risk perception in relation to high risk pregnancy. A metasynthesis was developed to describe and interpret the studies.

Results: The synthesis resulted in the identification of five themes: determinants of risk perception; not seeing it the way others do; normality versus risk; if the baby is ok, I'm ok; managing risk.

Conclusions: This metasynthesis suggests women at high risk during pregnancy use multiple sources of information to determine their risk status. It shows women are aware of the risks posed by their pregnancies but do not perceive risk in the same way as healthcare professionals. They will take steps to ensure the health of themselves and their babies but these may not include following all medical recommendations.

Keywords: High risk pregnancy, risk perception, risk management, communication.

A metasynthesis of risk perception in women with high risk pregnancies

Introduction

High risk pregnancies are those complicated by a factor which threatens the wellbeing of the mother and/or fetus. Women whose pregnancies are diagnosed as high risk may experience many emotions including fear, anger, loneliness, frustration and hope (Leichentritt et al 2005; Loos and Julius 1989; McCain and Deatrick 1994). Exactly how they feel about the pregnancy will be affected by how they perceive the level of risk. Studies of risk perception show an individual's perception of risk is a subjective response based on previous life experiences, coping strategies, the context in which the risk occurs, the degree of perceived control, and the weight attached to information about the risk obtained from a variety of sources (Alaszewski and Horlick-Jones 2003; Edwards et al. 2002; Gray 2006). This is also true of risk perception in pregnancy (Jordan and Murphy 2009; White et al. 2008).

How women with high risk pregnancies perceive their risks will affect their behaviour in pregnancy and their decisions about perinatal care. Knowledge of women's risk perception is therefore important for professionals involved in their care. However, a systematic review of seven quantitative studies of risk perception suggests pregnant women and healthcare professionals do not perceive pregnancy risk in the same way. The review found results were inconsistent for the association between women's perceived risk scores and healthcare professionals' ratings of risk for women with high risk pregnancies (Lee et al 2012). Qualitative research can provide a more detailed understanding of the complex factors which influence women's perception of risk. A metasynthesis will provide a comprehensive study of work in this area.

Differences in perception of risk may result in misjudged and misinterpreted communication between healthcare professionals and pregnant women and a subsequent lack of satisfaction with healthcare provision (Searle 1996). This is an issue of concern as women with high risk pregnancies represent a group with which professionals may already have difficulty communicating. For example, in a qualitative study of 17 healthcare professionals involved in the care of women with high risk pregnancies, 15 reported experiencing communication difficulties for reasons including powerlessness, anxiety and lack of time (Pozzo et al 2010).

Differences in risk perception between women with high risk pregnancies and health care professionals may occur for several reasons. Women may lack knowledge e.g. Chuang et al (2010) found non-pregnant women suffering from diabetes, hypertension or obesity were not aware of all of the risks these conditions posed during pregnancy. Women may choose to rely on their own understanding of their symptoms rather than medical diagnoses. Thus pregnant women diagnosed with hypertension, a condition which increases risks to the mother and fetus, but without symptoms of the condition, reported feeling fraudulent accepting medical care and found it difficult to follow treatment plans (Barlow et al 2008).

What women with high risk pregnancies want from their relationship with health professionals may also not coincide with what professionals think is important or possible in the relationship. In a study by Pozzo et al (2010), professionals who reported difficulties communicating with women also noted that women had asked for greater emotional closeness and empathy. In another qualitative study of women with high risk pregnancies and professionals involved in their care it was found that women placed a great deal of emphasis on hope (Roscigno et al 2012). They wanted realistic information and did not think they were denying the risks of the pregnancies but hope was viewed as a positive source of strength in difficult circumstances. In contrast the professionals thought it was important to

realistically portray potential negative outcomes. Whilst they stated they did this in a non-directive manner, this was not the women's interpretation of the experience. Similarly, in a qualitative study of what constituted quality of care in pregnancy, women cited three requirements from information from midwives: that it helped them to prepare for parenthood; it enabled them to make informed choices; and was a source of reassurance. Midwives identified the first two of these needs as important to women but not the need for reassurance (Proctor 1998).

How women use the information they are given during pregnancy may also reflect their priorities, which may be different to those of healthcare professionals. In a qualitative study of decision making in pregnancy, Levy (1999) found a key activity for women was maintaining equilibrium. This meant decisions had to balance the needs of the fetus with the needs of the woman and her partner, other children and wider sphere of life. Women prioritised the needs of the fetus but they also weighed up the effects of recommended treatments on their existing families. They then modified treatment plans according to what they believed best for their individual circumstances. Women generally prefer a process of shared control of their care with medical professionals and value this when it is offered (VandeVusse 1999). If it is not offered, women utilise a variety of strategies including challenging health professionals, negotiation, and appearing to accept recommendations during the consultation but then modifying them as they feel appropriate (Levy 1999; VandeVusse 1999). Their responses may also differ with time. Durham (1999) found women with high risk pregnancies would initially comply with treatment plans when their condition was newly diagnosed and anxiety levels were high. However, after some time elapsed and their conditions had not notably worsened, the women negotiated modifications to their treatment in order to accommodate what they felt were realistic adjustments within the context of their circumstances. Thus women in these studies were aware of the risks as

described by healthcare professionals but did not necessarily respond to them in the way the professionals recommended.

Although women may not adhere to recommended treatments they do want to be informed about the risks they are facing. In the study by Pozzo et al (2010), 92% of participants wished to be kept informed even if there was uncertainty about what was going on. Levy (1999) found women wanted information about their pregnancy although they would avoid information they were unable to act on or they perceived as irrelevant. Women also wish to be involved in making decisions about their care. A qualitative study of women with high risk pregnancies showed 30 of the 47 participants wished to be involved in decision making. Following the birth of their children, five of the remaining 17 women said that in future pregnancies they would also want to take a more active role in their care (Harrison et al 2003). Shared decision making in pregnancy is also associated with more positive emotions on the part of women (VandeVusse 1999).

Women with high risk pregnancies may therefore not perceive risks in the same way as healthcare professionals or act on them in the way professionals recommend. This discrepancy may cause frustration on both sides if not dealt with sensitively. Professionals may not be able to judge which patients are less satisfied with the care they are receiving as doctor satisfaction levels following consultation are not correlated with patient satisfaction levels (Zandbelt et al 2004). There is also no correlation between doctors' perception of patient satisfaction and patients' actual satisfaction scores (Merkel 1984). Patient satisfaction is an important consideration because it is associated with adherence to treatment (Schneider et al 2004). If women feel their concerns are unacknowledged they may be less willing to engage with healthcare services, potentially increasing the degree of risk.

Perception of risk is therefore a factor which strongly influences the care high risk women receive during their pregnancy. It affects the decisions a woman makes about her pregnancy, her relationship with healthcare professionals and attitudes towards treatment. Comparatively little research exists in this area. Lee et al (2012) found available quantitative research is inconsistent in definitions of high risk pregnancy and in what questions are addressed. A consideration of qualitative studies will add depth and clarity to the existing knowledge.

This paper provides a metasynthesis of qualitative studies of risk perception in women with experience of high risk pregnancies in order to develop a greater understanding of their concerns and their feelings toward their care. It is hoped this will improve communication with these women and so enhance satisfaction with healthcare provision. The paper examines the existing qualitative research on the subject, develops a synthesis of these studies to build on existing knowledge and provides a foundation for future research to improve care. It will inform the clinical management of high risk pregnancy by providing a clearer understanding of how women with high risk pregnancies perceive risk. This will be of use to any professionals involved in the care of women with high risk pregnancies.

Method

Search strategy

A systematic search of medical and psychological literature was conducted up to July 2012 in order to identify studies of the perception of risk in women with experience of high risk pregnancies. No start date was specified for the search so each database searched its maximum range of papers. It was decided not to reject studies on the basis of age so as not to exclude any potentially relevant papers. A wide ranging definition of high risk pregnancy was used that encompassed conditions either predating or developing during pregnancy

which have the potential to cause harm to the mother or fetus in order to ensure as many articles as possible would be identified. Eight databases were used for the search: Medline, PubMed, PsycINFO, PsycARTICLES, Web of Science, Scopus, Embase and CINAHL. Broad search terms reflected the described definition of high risk pregnancy. These included key words related to common pregnancy-related conditions: "complicated", "high risk", "diabet*", "VBAC", "caesarean", "twin", "hypertens*", "high blood pressure", "pre-eclamp*"; which were crossed with "birth", "pregnan*", "antenatal", "antepartum", "intrapartum", "deliver*"; and then with "risk" *and* "perception" *or* "perceived". As key authors were identified, searches were also conducted under their names and reference sections of all relevant papers were inspected.

Search outcome

The search yielded 2024 citations. Review of the titles to exclude those clearly not relevant to the synthesis reduced the number of citations to 103. Abstracts of these papers were then examined to determine eligibility for inclusion. Studies were included if they reported qualitative research into perceived risk in women with experience of high risk pregnancies either as the main focus of the study or as a substantial element of it. Studies that did not fulfil this inclusion criteria were excluded (n=69). Studies were also excluded if they only reported a quantitative assessment of perceived risk (n=9), studied risk perception in non-pregnant women (n=5), were not published in English (n=7), or were meta-analyses and review papers (n=0). Studies on specific populations where perceived risks are likely to differ substantially were also excluded. This included studies from developing countries (n=5) and studies of adolescent pregnancies (n=2). This resulted in a total of six studies being included in the metasynthesis (Corbin 1987; Heaman et al 2004; Jackson et al 2006; Patterson 1993; Simmons and Goldberg 2011; Stainton 1992). Suitability for inclusion was

agreed on after discussion among the team and where necessary authors of studies were contacted if further information about studies was required.

Definition of high risk pregnancy differed between the studies and included pre-existing medical conditions likely to affect the health of the woman and fetus during pregnancy (Corbin 1987), conditions developing during the pregnancy (Heaman et al 2004), and conditions where the onset was not stated (Jackson et al 2006). The other studies defined risk in terms of conditions which would only affect the health of the infant. These were previous perinatal loss (Simmons and Goldberg 2011) and risk of preterm labour (Stainton 1992; Patterson 1993). Two of the studies (Corbin 1987; Stainton 1992) included interviews with women who had given birth following high risk pregnancies as well as with women who were still pregnant. Studies therefore did not all compare women with the same conditions or define high risk pregnancy in the same way. Thus assessments of perceived risk in the included studies will be derived from various circumstances and comparisons between studies does not exactly compare like with like. However, whichever definition of high risk pregnancy is used, it will entail a degree of risk to mother and/or baby caused by a medical condition meaning there are potential similarities between studies in terms of attitude towards and perceptions of risk.

A full description of the included studies is provided in Table 1.

Quality assessment

There are no widely agreed criteria against which to judge the quality of qualitative research (Atkins et al 2008), nor is there agreement as to how or whether quality should be reported within a metasynthesis (Dheensa et al 2012). Quality of studies included in this paper was assessed using a checklist but no studies were excluded on quality grounds. This decision was supported by the work of Sandelowski et al (1997) who argue the lack of

agreement on what constitutes good quality in qualitative research means the exclusion of studies on such grounds could not be justified and studies which may not satisfy a quality assessment checklist may still contain valuable findings. A checklist, based on that of Atkins et al (2008) was used to indicate the range of quality of studies and provide a means of testing the contribution of papers to the final metasynthesis (Malpass et al 2009). No new themes were introduced into the metasynthesis if they only featured in a study with a lower quality score. The checklist and results are shown in Table 2.

Analytic strategy

The synthesis was constructed using the process of meta-ethnography described by Noblit and Hare (1988). The papers were read and re-read and key themes were identified. Tables were constructed for each paper showing first and second order constructs for each theme. The definitions of these constructs was taken from Malpass et al (2009) where first order constructs are considered to be participants' "views, accounts and interpretations", i.e. direct quotes from participants. Second order constructs are considered to be "authors' views and interpretations... of patients' views", i.e. analytic commentary on the first order constructs.

Using these tables, studies were then translated into one another using the processes of reciprocal and refutational translation (Noblit and Hare 1988). Reciprocal translation is the process of identifying commonalities in themes across the studies so that similar themes may be grouped together. Refutational translation is the identification of disagreement between themes. The presence of apparent contradictions between themes does not undermine the reliability of the metasynthesis, rather their presence acknowledges the diversity of responses permitted by the nature of qualitative research (Walsh and Downe 2005). Therefore both first and second order constructs were used to construct the

metasynthesis. Themes, or second order constructs, were identified in the original papers and translated across the studies. Quotes from participants, or first order constructs, were used to support the credibility of the new themes and to demonstrate their traceability back to the originals.

The aim of a metasynthesis is to bring fresh insights and new understandings to a subject (Walsh and Downe 2005) rather than to merely summarise or reduce. To this end, a line of argument synthesis was carried out so that the translated themes were organised into a logical and coherent order which provided a new description of women's experience of risk perception in high risk pregnancy. This stage is described by Malpass et al (2009) as the development of third order constructs, that is the "views and interpretations of the synthesis team".

Each stage of the synthesis process was discussed within the team until a consensus was reached. In order to ensure validity of the synthesis, quotes from original studies were used to illustrate and support the third order constructs (Jensen and Allen 1996). Auditability was maintained by keeping tables to show how themes came to be linked to one another.

Results

Nineteen themes were initially identified across the studies. These were then organised into five key themes: (1) determinants of risk perception; (2) not seeing it the way others do; (3) normality versus risk; (4) if the baby is OK, I'm OK; and (5) managing risk. Table 3 shows which themes were drawn from which studies.

Determinants of risk perception

One of the main factors which influenced women's risk perception was their interactions with healthcare professionals. They used information gained from professionals in assessing their degree of risk:

> I was influenced in making this rating after having all the necessary information and knowing what are the consequences of being an outside patient or hospitalized. (Heaman et al 2004 p.114)

However reactions to information could vary. For some women increased contact with doctors was a source of reassurance:

> Anxious in a way, because you think, 'Oh, if, you know, your midwife wants you to go there could be potential problems' but on the other aspect, you'd sooner know, you know, earlier on and have it, close, more closely monitored so, a bit anxious but also a bit relieved if that makes (laughs) sense. (Jackson et al 2006 p.912)

> It doesn't upset me to be classified as 'high-risk'. In some ways I like it because I get to come to the doctor more often, and when you're my age and it's your last chance to have a baby, you know you want to be reassured, so that's good. Yeah, so I enjoy that part. (Simmons and Goldberg 2011 p.456)

Other women felt less able to rely on the information they were given:

> I don't know how bad it is because the nurses try to save you the heartache. I don't know whether they hold back or whether they're telling you the whole truth. (Stainton 1992 p.41)

Other factors women utilised when determining their degree of risk included test results and fetal monitoring. These were often a source of reassurance:

> I know that there is some risk if the baby is born too soon, but I don't feel the risk is high because the fetal assessments show that the baby is strong. (Heaman et al 2004 p.114)

Advice from friends and family (Patterson 1993) and poor obstetric history (Heaman et al 2004; Jackson et al 2006) also influenced risk perception:

> I asked a cousin of mine, because I got a little strange feeling in my navel, like something on the other side was pulling my navel, and so I didn't want to call emergency or anything like that. So then I just call on my cousin and asker her, 'Do you remember having this pulling in your navel? What is it?' She said, 'It's just the baby growing, you know.' She's had two and I figure, I'm sure she's felt it at least once or twice. (Patterson 1993 p.282)

> Pleased yeah. Cos I mean because I've lost a, a, previous baby... I was very nervous this time round anyway so, it was a bit reassuring for me that they were gonna keep a close eye on me, so, if anything I was more than happy to be checked out. (Jackson et al 2006 p.911)

However, another study (Patterson 1993) contradicted the idea that obstetric history is important and stated participants "did not seem to expect past reproductive losses to directly influence the current pregnancy" (Patterson 1993 p.281). However no quotations from participants were offered in support of this assertion.

Not seeing it the way others do

Women's assessment of risk did not always concur with that of medical professionals. At times women thought professionals overstated the risks of the pregnancy:

> I thought the assessment they were making was too strong. I wasn't as sick as they thought, and if the baby was only 33 weeks, then obviously he wasn't prepared to come, so why put the baby under stress by having it so quickly? (Stainton 1992 p.42)

> I think if you're feeling fit and well, and you turn up at the hospital you feel a fraud but I think you're gonna feel that if you feel fine, there's nothing really they can do really. (Jackson et al 2006 p.911).

They also reported feeling hopeful and focussing on the positive but thought healthcare professionals took the opposite view:

> People would rather be negative than positive. If there is one little thing that goes wrong, that's all they want to talk about, not all that's going right. (Stainton 1992 p.40)

This did not mean women were unaware of the degree of risk associated with their pregnancies and they rejected the view they were denying the seriousness of the situation (Stainton 1992).

Women weighed up the risk factors associated with high risk pregnancy in the context of other important elements of their lives – primarily their husbands, other children and careers:

> They want to put me in the hospital to regulate me, but I can't go because my husband yells at me about who will take care of our little boy. When I come home, he makes it very difficult for me for several days. It just isn't worth it. (Corbin 1987 p.332)

Women felt torn between competing demands when making decisions about the management of their pregnancies. The pregnancy was given priority but this often involved difficult

choices (Corbin 1987). Positioning the risk in the context of daily events also served to normalise events and so function as a coping strategy (Patterson 1993).

Disagreement over the perception of risk levels could lead to conflict between women and healthcare professionals. This could occur when women felt their views were not being acknowledged:

> They tried to convince me that I was having some kind of stress episodes. I said, "I know what an insulin reaction is, I've had diabetes for years. I know what it is, either that or I am losing my mind." They almost convinced me that I was going crazy... I guess it upset me because I know what is going on with my diabetes and nobody would listen to me... Even though I knew what was going on, nobody would listen to me. (Corbin 1987 p.333)

Conflict also arose when women felt healthcare professionals were not responding adequately to a situation which for them was a cause for concern:

> You know, I wanted to be referred to an obstetrician, which I felt at 37 and having experienced a miscarriage was within a perfectly legitimate kind of request and she really didn't seem keen on that... My attitude was... so ___ what! I do not give a ___ if the ultrasound booking clerk is unhappy with you! (Simmons and Goldberg 2011 p.455)

It could also occur in the postnatal period if women felt distrusted by professionals and were denied physical access to their infants:

> One day they would let me do mouth care and maybe change his diaper, and the next time I came in there would be a different nurse and she wouldn't let me do anything. (Stainton 1992 p.44)

Potential conflict could stem from women feeling the risks their infants faced were not acknowledged or understood by others who had not faced similar situations:

> None of my friends understand. They think the baby is three weeks old and has been doing great so it can't be that bad… They don't understand that when a little baby has a setback it can be dangerous. (Stainton 1992 p.41)

Normality versus risk

Although women often focussed on the positives in their situation and on the potential for achieving their goal of motherhood (Stainton 1992), they also recognised their high risk status as one of the defining features of their pregnancies:

> You're not in here because you're having a baby. You're in here because you have a problem. (Stainton 1992 p.40)

Other studies referred to women's reactions to realising they were at increased risk:

> Like getting a time bomb thrown in your face. (Heaman et al 2004 p.113)

Being allocated high risk status was not always seen in a negative light if the diagnosis permitted access to an increased degree of medical care regarded as potentially beneficial to the pregnancy:

> For me, being 'high-risk' has actually been positive because I find that the care I have received has been amazing. I really feel better taken care of than an individual who wouldn't be considered 'high-risk', so in a way I consider this a blessing or a benefit. (Simmons and Goldberg 2011 p.455)

Some women expressed the view that pregnancy was never free of risk and that unknown factors also posed a degree of threat to their pregnancies:

> Because we are taking time to monitor myself and my baby, I feel somewhat safe. However, there is always the doubt of the unknown and uncontrolled problems. (Heaman et al 2004 p.114)

While women acknowledged their high risk status, this was still viewed in the context of other elements of their lives. Thus attempts were made to normalise symptoms:

> Sometimes I might not feel great in the afternoon, but I'd say that's normal, so I don't, you know, let it get me down. I just rest for a little while, and come here and do what I gotta do. (Patterson 1993 p.282)

If the baby is OK, I'm OK

Women reported finding reassurance in feeling fetal movements and in the intuitive knowledge that things were well with their baby:

> Regardless of what they [health team] are telling me, as long as I feel movement, I know it [the fetus] is okay. (Corbin 1987 p.331)

> They thought that the baby, in terms of his length and size, was a bigger gestation than my date, but I'm sure of my date, so [laughing] I just have a big baby. That's what I think. (Stainton 1992 p.43)

Women also regarded this intuition as central to their caring role for their infants when they were at risk. They believed it differentiated them from healthcare professionals:

> They don't have time to look for hours at a time. We get to know him better than they do, and what we have to say may not make sense to them, but it's important that they hear it anyway. (Stainton 1992 p.43)

However, despite this focus on the babies' wellbeing, women were at times fearful of developing too deep an emotional attachment during pregnancy in case things did not end well:

> The more things we have, the more I would have to get rid of, if the baby were stillborn or something... I think what really hurts is when you have gone through all of these plans and then they fall through. I'll wait until the baby is born, then if everything is all right, I'll get the clothes and emotionally put myself into the baby. (Corbin 1987 p.331)

Women also considered the consequences of attachment to their babies in the postnatal period if there was still a risk to the infants' health:

> You just have to think she will make it. If you think that way and then if she goes, it's going to be hard too. It's always in the back of your mind. (Stainton 1992 p.41)

Managing risk

Women described differing attitudes to following advice from healthcare professionals. They were prepared to follow advice but carefully assessed it according to what they felt was best for their own and their babies' health based on their experience of their medical conditions. If they felt advice was not helpful they would modify it accordingly:

> When I went to the dietician for counselling, the foods she cut out were the ones with protein. I was concerned about that because I know in pregnancy you are supposed to increase your protein intake. So I added some extra milk and an egg to my diet. (Corbin 1987 p.329)

However other women reported a greater willingness to adhere to recommended treatment programmes believing this was a way to reduce risks (Heaman et al 2004). These women welcomed medical care:

> It is not that I think my prenatal care with my previous [pregnancy] by no means was poor or anything like that. But you can see that there is so much more that can be done that you just want it all. Why there is no reason why we shouldn't be able to have all the support and all this, um, care. You know it's just so, like I say how can people consciously have children without all these resources. (Simmons and Goldberg 2011 p.455)

Women reported using hope as a strategy for coping with the perceived risks of the postnatal period when their babies' prognosis was still uncertain:

> You can't live every day as if she's going to go. You'd be crying all day. (Stainton 1992 p.41)

Discussion

This metasynthesis analysed six studies of risk perception in women with experience of high risk pregnancies to provide a new overview of how women determine risk, make decisions and act on the degree of risk they perceive. It identifies the multiple sources of information women use in determining their risk status. It demonstrates women do not perceive risk in the same way as healthcare professionals which can potentially lead to conflict. It shows that women want to be informed of the risks posed by their pregnancies and will take the steps they believe necessary to ensure a healthy outcome for themselves and their infants. However these may not include following all aspects of treatment recommended by professionals.

In determining risk, women used information from a variety of sources. Information from healthcare professionals was considered useful but women were frustrated if they sensed information was being withheld or was inconsistent in nature. The work of Pozzo et al (2010) suggests that women will tolerate uncertainty from healthcare professionals when a definite prognosis cannot be given. Further research is therefore required to examine communication in high risk pregnancy situations where the outcome is uncertain. This will help establish how professionals can best communicate concerns which may change over the course of the pregnancy so they acknowledge the dynamic nature of the concerns without sounding inconsistent. Training interventions have been shown to improve communication by healthcare professionals (Davis et al 2003). Despite the fact that time may be perceived as a barrier by professionals to improved communication (Pozzo et al 2010), research shows consultations with patients by professionals who have undergone communication skills training do not take longer (van Dulmen and van Weert 2001).

Professionals should also acknowledge that women base their perception of risk on information from a variety of sources. The research in this synthesis would suggest pregnant women do not necessarily attach more weight to advice from professionals than they do to that from trusted family and friends. This should also be considered during discussions with women with high risk pregnancies in order that concerns on both sides can be fully explored and understood. Advice from others appeared more reliable if women believed they had experience of similar situations. Comments from those who had not could generate conflict. Further research is required to understand how women make decisions about which advice they will follow and how they deem an information source to be trustworthy.

The synthesis shows there may be disagreement over the degree of risk involved in pregnancies between women and health professionals. This is consistent with a review of quantitative research (Lee et al 2012) which showed women may perceive risk as higher or

lower than professionals do. Again this should be sensitively acknowledged and addressed in order that communication about pregnancy risk can be open and realistic on both sides. Disagreement may also arise because women are likely to perceive their pregnancy risk in the context of other aspects of their lives including family and employment while healthcare professionals are more inclined to view medical risks in isolation.

The metasynthesis demonstrates that women do not deny the risks presented by high risk pregnancies even if their perception of risk is different to that of healthcare professionals. This is illustrated by the fact that women may be reluctant to develop a deep emotional bond until they are certain that their babies will be well. High risk pregnancy is a process characterised by ambivalence. Women simultaneously experience anxiety and hope - they both want a baby and yet fear the risks of the pregnancy (Leichentritt et al 2005). Women in the studies displayed such ambivalence, describing using both hope as a coping strategy in high risk situations and the fear of developing a deep attachment when there was still a chance of losing their infants. Women's attitudes to medical care were not uniform. Women expressed various responses to care including feeling reassured, willingness to follow the treatment they felt was appropriate, and modifying treatment they felt was not applicable to their circumstances.

These different responses to the management of high risk pregnancy are not necessarily contradictory. Women with high risk pregnancies may adopt different approaches to care recommended by professionals over the course of their pregnancies. It may appear paradoxical that women can at times not follow medical advice and at others welcome more intensive medical care but individuals may alternate between these stances according to circumstances (Lupton 1997). These behaviours may include openly negotiating how much of a recommended regime they are prepared to follow, appearing to follow the regime but not doing so in reality, or entirely following the regime (Levy 1999; VandeVusse

1999). Entirely accepting a treatment regime is most likely to occur in an emergency situation but may also result from a desire to avoid confrontation (Levy 1999). Healthcare professionals should consider this last point in interactions with women with high risk pregnancies as a lack of shared decision making is associated with more negative emotions for pregnant women and, as discussed in the introduction, professionals may not recognise which patients are dissatisfied with their care.

Health professionals working with women with high risk pregnancies should be aware that different attitudes to the management of the pregnancies can mean that women will not always comply with all recommended aspects of treatment. Women are more likely to contextualise the risks within their life circumstances, whereas doctors may view them as isolated medical issues (Lyerly et al. 2007). Thus women may adapt their treatment so that it is manageable within their situation. Noncompliance with medical treatment is not unique to women with high risk pregnancies. Up to half of the general population do not comply fully with recommended treatment regimens so such behaviour cannot be considered a minority or deviant reaction (Donovan and Blake 1992). Women with high risk pregnancies are committed to achieving good outcomes for themselves and their babies so professionals should not regard non-adherence to a treatment programme as evidence of recalcitrance or a lack of care (Durham 1999). Realistic discussions about what aspects of treatment women feel able to accept may increase overall compliance (Durham 1999). Women respond positively to professionals who support them to make decisions about their healthcare (Levy 1999). Future research should address the responses of healthcare professionals to patients who do not comply fully with recommended treatments.

This metasynthesis is the first paper to bring together qualitative studies of risk perception in women with experience of high risk pregnancy to widen the understanding of the ways in which women define and act on risk. Limitations include the different definitions

of high risk pregnancy used in the studies included, for example, medical conditions predating pregnancy, conditions developing during the pregnancy, and conditions affecting only the baby. This means participants were not all facing the same risks. However all the women face some degree of risk to themselves and/or their babies and so will face similar concerns. The detailed and specific nature of qualitative research permits the recognition that participants will always come from a variety of circumstances. Further research is needed however to identify whether there are differences in the way women perceive and act on risks if the threat posed is only to their babies' health, e.g. in premature labour, or if their own wellbeing is also at stake. Studies of women from developing countries were excluded from the metasynthesis. The increased health risks of giving birth in these countries means perceived risk of women there may not be comparable with that of women from developed countries. This is another area for future research.

A final issue is the inclusion of studies which included postnatal data. Some of the data included in the metasynthesis came from retrospective reports from women who had already had their babies. The extent to which knowledge of pregnancy outcome affects the way women describe their perception of risk during pregnancy is not known. Women do have very good recall of the factual events surrounding pregnancy (Tomeo et al 1999). However their recall of more subjective aspects of the birth experience may change over time (Waldenstrom 2003). Research in non-pregnant populations has found people utilise a process of retroactive pessimism, a form of hindsight bias, to convince themselves bad outcomes were more inevitable than they initially believed before they outcome was known (Tykocinski 2001; Tykocinski et al 2005). Further research is therefore needed to ascertain whether women report their perception of risk during pregnancy differently after they have given birth and know whether their babies are healthy or not. This could be clarified by prospective research that compares women's perceptions of risk in pregnancy and after birth.

In conclusion, this metasynthesis contributes to the literature on risk perception by providing clarity and greater understanding of the ways in which women with high risk pregnancies perceive the risks of their pregnancies and respond to these risks. It shows women with high risk pregnancies do recognise the increased risks they face but may not perceive risk in the same way as healthcare professionals. Women's determination of risk is based on information from a variety of sources. Healthcare professionals represent one of these sources and the information they impart will not always be prioritised over other sources. Women do regard high risk status as a defining feature of their pregnancy but will not always view this in a negative light if it enables them to access additional medical care. However women's attitude towards medical care is mixed with some women feeling that aspects of medical care will lead to increased risks. Women prioritise the wellbeing of their babies, even though this may be difficult in the context of the other life events, and take the steps they believe will best secure the wellbeing of their babies. The clinical implications of the metasynthesis include the need to manage differences in risk perception with sensitivity and respect if women are to feel supported by healthcare professionals as they deal with the challenges of high risk pregnancies. Improved communication with women is likely to enhance their satisfaction with healthcare. Further research is recommended to determine how this can best be achieved by establishing how women prioritise information and how healthcare professionals react when women do not share their perceptions of risk.

References

Alaszewski, A., Horlick-Jones, T., 2003. How can doctors communicate information about risk more effectively? British Medical Journal 327, 728-731

.

Atkins, S., Lewin, S., Smith, H., Engel, M., Fretheim, A., Volmink, J., 2008. Conducting a meta-ethnography of qualitative literature: lessons learnt. BMC Medical Research Methodology doi:10.1186/1471-2288-8-21.

Barlow, J. H., Hainsworth, J., Thornton, S., 2008. Women's experiences of hospitalisation with hypertension during pregnancy: feeling a fraud. Journal of Reproductive and Infant Psychology 26, 157-167.

Chuang, C. H., Velott, D.L., Weisman, C. S., 2010. Exploring knowledge and attitudes related to pregnancy and preconception health in women with chronic medical conditions. Maternal and Child Health Journal 14, 713-719.

Corbin, J. M., 1987. Women's perceptions and management of a pregnancy complicated by chronic illness. Health Care for Women International 8, 317-337.

Davis, R. E., Dolan, G., Thomas, S., Atwell, C., Mead, D., Nehammer, S., Moseley, L., Edwards, A., Elwyn, G., 2003. Exploring doctor and patient views about risk communication and shared decision-making in the consultation. Health Expectations 6, 198-207.

Denzin, N. K., 1989. The Research Act: A Theoretical Introduction to Sociological Methods 3rd ed. Prentice Hall, New Jersey.

Dheensa, S., Metcalfe, A., Williams, R. A., 2012. Men's experiences of antenatal screening: a metasynthesis of qualitative research. International Journal of Nursing Studies doi.org/10.1016/j.inurstu.2012.05.004.

Donovan, J. L., Blake, D. R., 1992. Patient non-compliance: deviance or reasoned decision making? Social Science and Medicine 34, 507-513.

Durham, R. F., 1999. Negotiating activity restriction: a grounded theory of home management of preterm labor. Qualitative Health Research 9, 493-503.

Edwards, A., Elwyn, G., Mulley, M., 2002. Explaining risks: turning numerical data into meaningful pictures. British Medical Journal 324, 827-830.

Gray, B. A., 2006. Hospitalization history and differences in self-rated pregnancy risk. Western Journal of Nursing Research 28, 216-229.

Harrison, M. J., Kushner, K. E., Benzies, K., Rempel, G., Kimak, C., 2003. Women's satisfaction with their involvement in health care decisions during a high-risk pregnancy. Birth 30, 109-115.

Heaman, M., Gupton, A., Gregory, D., 2004. Factors influencing pregnant women's perceptions of risk. MCN The American Journal of Maternal and Children's Nursing 29, 111-116.

Jackson, C. J., Bosio, P., Habiba, M., Waugh, J., Kamal, P., Dixon-Woods, M., 2006. Referral and attendance at a specialist antenatal clinic: qualitative study of women's views. British Journal of Obstetrics and Gynaecology 113, 909-913.

Jensen, L. A., Allen, M. N., 1996. Meta-synthesis of qualitative findings. Qualitative Health Research 6, 553-560.

Jordan, R. G., Murphy, P. A., 2009. Risk assessment and risk distortion: finding the balance. Journal of Midwifery and Women's Health 54, 191-200.

Lee, S., Ayers, S., Holden, D., 2012. Risk perception of women during high risk pregnancy: a systematic review. Health, Risk and Society 14, 511-531.

Leichentritt, R. D., Blumenthal, N., Elyassi, A., Rotmensch, S., 2005. High-risk pregnancy and hospitalization: the women's voices. Health and Social Work 30, 39-47.

Levy, V., 1999. Maintaining equilibrium: a grounded theory study of the processes involved when women make informed choices during pregnancy. Midwifery 15, 109-119.

Loos, C., Julius, L., 1989. The client's view of hospitalization during pregnancy. Journal of Obstetric, Gynecologic and Neonatal Nursing 18, 52-56.

Lupton, D., 1997. Consumerism, reflexivity and the medical encounter. Social Science and Medicine 45, 373-381.

Lyerly, A. D., Mitchell, L. M., Armstrong, E. M., Harris, L. H., Kukla, R., Kupperman, M., Little, M. O., 2007. Risks, values, and decision making surrounding pregnancy. Obstetrics and Gynecology 109, 979-984.

Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., Kessler, D., 2009. "Medication career" or "moral career"? The two sides of managing antidepressants: a meta-ethnography of patients' experiences of antidepressants. Social Science and Medicine 68, 154-168.

McCain, G. C., Deatrick, J. A., 1994. The experience of high-risk pregnancy. Journal of Obstetric, Gynecologic and Neonatal Nursing 23, 421-427.

Merkel, W., 1984. Physician perception of patient satisfaction: do doctors know which patients are satisfied? Medical Care 22, 453-459.

Noblit, G., Hare, R., 1988. Meta-Ethnography: Synthesising Qualitative Studies. Sage, New York.

Patterson, K. A., 1993. Experience of risk for pregnant black women. Journal of Perinatology 13, 279-284.

Pozzo, M. L., Brusati, V., Cetin, I., 2010. Clinical relationship and psychological experience of hospitalization in "high-risk" pregnancy. European Journal of Obstetrics and Gynecology and Reproductive Biology 149, 136-142.

Proctor, S., 1998. What determines quality in maternity care? Comparing the perceptions of childbearing women and midwives. Birth 25, 85-93.

Roscigno, C. I., Savage, T. A., Kavanaugh, K., Moro, T. T., Kilpatrick, S. J., Strassner, H. T., Grobman, W. A., Kimura, R. E., 2012. Divergent views of hope influencing communications between parents and hospital providers. Qualitative Health Research 22, 1232-1246.

Sandelowski, M., Docherty, S., Emden, C., 1997. Qualitative metasynthesis: issues and techniques. Research in Nursing and Health 20, 365-371.

Schneider, J., Kaplan, S. H., Greenfield, S., Li, W., Wilson, I. B., 2004. Better physician-patient relationships are associated with higher reported adherence to antiretroviral therapy in patients with HIV infection. Journal of General Internal Medicine 19, 1096-1103.

Searle, J., 1996. Fearing the worst - why do pregnant women feel 'at risk'? Australian and New Zealand Journal of Obstetrics and Gynaecology 36, 279-286.

Simmons, H. A., Goldberg, L. S., 2011. 'High-risk' pregnancy after perinatal loss: understanding the label. Midwifery 27, 452-457.

Stainton, M. C., 1992. Mismatched caring in high-risk perinatal situations. Clinical Nursing Research 1, 35-49.

Tomeo, C. A., Rich-Edwards, J. W., Michels, K. B., Berkey, C. S., Hunter, D. J., Frazier, A. L., Willett, W. C., Buka, S. L., 1999. Reproducibility and validity of maternal recall of pregnancy-related events. Epidemiology 10, 774-777.

Tykocinski, O. E., 2001. I never had a chance: using hindsight tactics to mitigate disappointments. Personality and Social Psychology Bulletin 27, 376-382.

Tykocinski, O. E., Steinberg, N., 2005. Coping with disappointing outcomes: retroactive pessimism and motivated inhibition of counterfactuals. Journal of Experimental Social Psychology 41, 551-558.

van Dulmen, A. M., van Weert, J. C. M., 2001. Effects of gynaecological education in interpersonal communication skill. British Journal of Obstetrics and Gynaecology 108, 485-491.

VandeVusse, L., 1999. Decision making in analyses of women's birth stories. Birth 26, 43-50.

Waldenstrom, U., 2003. Women's memory of childbirth at two months and one year after the birth. Birth 30, 248-254.

Walsh, D., Downe, S., 2005. Meta-synthesis method for qualitative research: a literature review. Journal of Advanced Nursing 50, 204-211.

White, O., McCorry, N. K., Scott-Heyes, G., Dempster, M., Manderson, J., 2008. Maternal appraisals of risk, coping and prenatal attachment among women hospitalised with pregnancy complications. Journal of Reproductive and Infant Psychology 26, 74-85.

Zandbelt, L. C., Smets, E. M. A., Oort, F. J., Godfreid, M. H., de Haes, H. C. J. M., 2004. Satisfaction with the outpatient encounter: a comparison of patients' and physicians' views. Journal of General Internal Medicine 19, 1088-1095.

Metasynthesis tables

Table 1 Study Characteristics

Study	Aim	Participants				Data Collection	Analysis
		N	Definition of high risk	Stage of pregnancy	Loc		
Corbin 1987	Addresses how a group of chronically ill pregnant women managed the medical risk factors associated with their pregnancies through a process termed protective governing.	20	Women with a chronic illness attending high risk maternity clinics. All conditions relate to women.	Not stated	USA	Interviews and observation	Constant comparative method
Stainton 1992	Gain an understanding of the mother's subjective experience in high-risk perinatal situations.	27	10 from a high-risk inpatient unit, 10 an outpatient high-risk clinic, 7 from NICU. Risk focuses on pre-term labour.	5-35/40	Canada	Interviews and diaries	Hermeneutic method. (Analytic method of searching for meanings embedded in language.)
Patterson 1993	To establish some understanding of what American black women knew about pregnancy and how risk might affect their knowledge and experience of pregnancy.	7	Score on risk screening tool for pre-term labour.	24-36/40	USA	Interviews	Grounded theory. (An analytic approach developed to generate and test theory.)
Heaman et al 2004	Explore factors women consider in determining their perceptions of pregnancy risk, and to compare and contrast the factors considered by women with complicated and uncomplicated pregnancies.	103 complicated 102uncomplicated	Unanticipated complication of pregnancy requiring antepartum hospitalisation for 48 hours or more, and no chronic health condition. Conditions not listed.	>26/40	Canada	Written responses to open ended questions.	Qualitative content analysis.
Jackson et al	To explore women's views on being referred	21	Attendance at the clinic.	14-23/40	UK	Interviews	Constant comparative

2006	to and attending a specialist antenatal hypertension clinic.						method.
Simmons & Goldberg 2011	To explore women's experience of living with a 'high-risk' pregnancy label following a perinatal loss.	7	Risk assessment form score and had had prev misc, sb, nnd, top for anomaly.	13-39/40	Canada	Interviews	Phehomenol ogical thematic analysis.

Table 2 Quality Appraisal Table

Study	**Are the research questions clear?**	**Is the qualitative approach appropriate for the research question?**	**Is the study context clearly described?**	**Is the role of the researcher clearly described?**	**Are the following clearly described?**			**Are the following ap the research questio**	
					Sampli ng	**Data collection**	**Analysis**	**Sampli ng**	**Data collection**
Corbin 1987	1	1	1	0	0	0	0	1	1
Stainton 1992	1	1	1	0	0	1	1	1	1
Patterson 1993	1	1	1	0	1	1	0	1	1
Heaman et al 2004	1	1	1	0	0	1	1	1	1
Jackson et al 2006	1	1	1	0	1	0	1	1	1
Simmons & Goldberg 2011	1	1	1	0	0	1	1	1	1

Table 3 Themes

Studies	Themes				
	Determinants of risk perception	Not seeing it the way others do	Normality versus risk	If the baby is ok, I'm ok	Managing risk
Corbin 1987	Y	Y	Y	Y	Y
Stainton 1992	Y	Y	Y	Y	
Patterson 1993	Y	Y	Y	Y	
Heaman et al 2004	Y		Y	Y	Y
Jackson et al 2006	Y	Y	Y		
Simmons and Goldberg 2011	Y	Y	Y		Y