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### Risk Perception in Women with High Risk Pregnancies

#### Abstract

Risk perception in women with high risk pregnancies affects the decisions they make about antenatal care and so may therefore influence the wellbeing of mother and baby. This article addresses the factors which influence women when making risk assessments and how these assessments may differ from those of healthcare professionals.

Women use multiple sources of information to determine their risk status including advice from professionals, from other trusted sources, and their own intuitive knowledge. They recognise the risks posed by their pregnancies and will take steps to ensure the health of themselves and their babies. However these may not include following all medical recommendations. How they perceive risks and the care they will accept are weighed up in the context of their individual circumstances.

Midwives need to be aware of these factors to ensure the care they give is individually appropriate, respectful and realistic.

#### Introduction

Many women will enjoy healthy and straightforward experiences of pregnancy and birth. However for some women these experiences will be complicated by medical or obstetric conditions which threaten the wellbeing of them and/or their babies. Women whose pregnancies are considered high risk are confronted with emotionally complex situations in which they must process new information and make decisions about their care. They may

respond to these situations with fear, frustration, anger and hope (Leichtentritt et al 2005). Exactly how women feel about their pregnancies will be affected by how they perceive the level of risk and this in turn will affect women's decision making and behaviour (Jordan and Murphy 1999).

Midwives increasingly find themselves challenged by looking after women with high risk pregnancies and need to have the appropriate skills to care for such women. This is in part due to the increased medicalisation of childbirth over the last century which has led to a shift in the pervasive cultural view away from childbirth as a normal event within the life course towards the view of birth as inherently risk and therefore requiring medical supervision (MacKenzie Bryers and van Teijlingen 2010). However, midwives are likely to find themselves caring for increasing numbers of women with conditions associated with morbidity in pregnancy due to lifestyle, e.g. obesity, or advances in medical care for women with conditions where pregnancy may previously not have been possible, e.g. cystic fibrosis. This article considers the perception of risk of women with high risk pregnancies and will be of interest to anyone involved in their care.

Risk perception consists of two elements. The first is a statistical assessment of how likely an event is to occur (Mackenzie Bryers and van Teijlingen 2010). This assessment can be influenced by the way in which the risk is presented, for example whether emphasis is placed on possible positive or negative outcomes, and a person's level of understanding of mathematics (Edwards et al 2002; Keller and Siegrist 2009). Risk perception also has a second psychological component which includes how women feel about the risk. This will be affected by factors including life experience, coping strategies and the context in which the risk occurs (Alaszewski and Horlick-Jones 2003). Pregnant women, especially those with high risk pregnancies, must therefore weigh up many factors which will determine how they perceive the risks they face.

Understanding how pregnant women think and feel about risk is critical because evidence shows pregnant women and healthcare professionals do not perceive risks in the same way. For example Turner et al (2008) found that pregnant women would tolerate greater levels of risk in order to achieve a spontaneous vaginal delivery than midwives and doctors asked to imagine themselves in the same situation. Differences in risk perception can lead to problems in communication and ultimately to a lack of satisfaction with healthcare services (Searle 1996). Dissatisfaction with care may lead to women being less engaged with maternity services and therefore increase the likelihood of poor pregnancy outcomes. The latest CEMACE report highlights the association between maternal deaths and lack of engagement with antenatal care (CEMACE 2011). Healthcare professionals have reported feelings of anxiety, powerlessness and concerns regarding time pressure in consultations with women with high risk pregnancies, emotions which may hamper the communication process (Pozzo 2010). Understanding how women with high risk pregnancies perceive risk should improve communication with them and therefore enhance the care provided.

# How do women perceive risk?

Women with high risk pregnancies are aware that their pregnancies pose a risk to themselves and/or their babies. A metasynthesis of qualitative studies of risk perception in high risk pregnancy showed risk becomes a defining feature of the pregnancy and a focus of women's anxieties (Lee et al in press). However, when asked to rate the degree of risk they perceive in their pregnancies, women classified as high risk do not always rate the risks as extremely high. A systematic review of quantitative studies of risk perception in women with high risk pregnancies identified four studies which asked participants to quantify the degree of risk they perceived during the pregnancy (Lee et al 2012). The studies used different tools to measure risk but in each one, women's mean risk scores fell just below the midpoint of the scale. This suggests women with high risk pregnancies do not perceive the risks as severe.

They are aware of the risks however as the scores were significantly higher than those of women with low risk pregnancies.

Women use information from a variety of sources when assessing their degree of risk. This includes advice from professionals, from other people, and considering their own previous experiences. Socio-economic factors also influence risk perception with higher socio-economic status having some association with increased health risk perception (Lee et al 2008). In pregnancy, lower socio-economic status is associated with greater risk to mother and baby (CEMACE 2011) but women from higher socio-economic groups may display more concern about pregnancy health risks than women from lower socio-economic groups (Papiernik et al 1997). However, women from lower socio-economic groups are still very concerned about the wellbeing of their children and may be sensitive to perceived scrutiny and stigmatisation of their approach to motherhood if it is judged negatively for falling short of middle-class norms (Romagnoli and Wall 2012).

Discussion with healthcare professionals is only one source of information about health in pregnancy and women may not prioritise it over others (Patterson 1993). Reaction to interactions with midwives and obstetricians varies. For some women, advice from healthcare professionals is a source of reassurance and a trusted source of information. When women perceive the care they are receiving as reliable, it is also seen as potentially reducing risks (Heaman et al 2004). The risks remain a concern but the label of a high risk pregnancy is not viewed in a negative light. Rather it can be seen as permitting access to an enhanced degree of care which provides extra reassurance. However, if women suspect information is being withheld, this will lead to a lack of trust in the professional (Stainton 1992). This is the case even if they recognise the professional may be well motivated.

Women with high risk pregnancies also turn to other people for advice. Typically, these would be close family members or friends who have had children. Women regard information obtained in this way as valuable because it is based on personal experience from sources they trust (Patterson 1993).

They also rely on their own experiences and intuitive knowledge of their conditions when assessing risk. A previous poor obstetric history is recognised as a factor which affects subsequent pregnancies and so features in women's assessments of risk, increasing the degree of concern (Simmons and Goldberg 2010). Conversely, experience of previous positive pregnancy outcomes is source of reassurance and may be used to bolster confidence in the current pregnancy, especially when presented with a potentially poor outlook (Corbin 1987). Women whose high risk status is caused by a longstanding medical condition use their understanding of the effects of the conditions when assessing the degree of perceived risk. Frustration may result if they feel this awareness is not acknowledged by healthcare professionals (Corbin 1987).

## Comparison with professionals' risk perception

Little research exists comparing the assessments women with high risk pregnancies make of the degree of risk they face with those of healthcare professionals. The research that has been done shows inconsistent results for the association between the two assessments. A systematic review of risk perception in high risk pregnancy found four studies showing no association between risk ratings of women with high risk pregnancies and professionals' ratings (Lee et al 2012). Only one study (Heaman and Gupton 2009) found a moderate positive correlation between the two sets of scores. A further study (Gray 2006) found no significant difference between risk scores for women and professionals when comparing perceived risks for mother and baby combined and for the baby alone. There was also no

significant difference between scores on perception of risks for the mother between women and doctors. However, nurses' risk scores were found to be significantly higher than women's scores for perceived risk to the mother.

Differences in risk perception can occur between women and professionals in both directions, that is women may rate risks as either higher or lower than healthcare professionals. Women will rate their risks as higher if they believe there is reason for concern about the progress of the pregnancy. This concern may be based on current symptoms or anxieties arising from their obstetric history. If they feel this concern is unacknowledged by professionals, this can lead to frustration, dissatisfaction and potential conflict within the professional/woman relationship (Simmons and Goldberg 2010).

Disagreement may also result if the woman believes that professionals are overstating the risks of the pregnancy. Women may perceive their risks as lower than professionals do for several reasons. They may not know of the effects medical conditions can have on pregnancy. Thus Chuang et al (2010) found non-pregnant women suffering from diabetes, hypertension or obesity were not aware of all of the risks these conditions could pose if they were to become pregnant. Women may also choose to rely on their own interpretation of their symptoms based on intuitive knowledge or previous experience of conditions. Women who therefore feel well may find it difficult to accept a medical diagnosis and therefore an attendant increase in risk. Barlow et al (2008) reported that asymptomatic pregnant women diagnosed with hypertension felt uncomfortable receiving medical care and had difficulty following treatment plans. Finally, beliefs about what constitutes a risk may be incorrect but based on ingrained cultural myths and stereotypes about health and pregnancy (Sutton et al 2011).

Even when women do fully understand the risks involved in a high risk pregnancy, their response to the risks may not be the same as that of the professionals involved in their care. A qualitative study of women with high risk pregnancies reported the women feeling hopeful and focussing on positive news about the pregnancies. They regarded the doctors as taking a contrasting approach and dwelling more on areas of concern (Stainton 1992). The women involved in this study did not feel they were ignorant of the risks they were facing or that they were denying their seriousness. This was however what they believed healthcare professionals' attitudes towards them intimated. These findings are echoed in the work of Roscigno et al (2012) who found women with high risk pregnancies stressed the importance of hope to them and viewed it a source of emotional strength. They did not accept this as evidence of denial of the risks and stated they did want realistic information about the progress of their pregnancies. They also felt that professionals emphasised potential negative outcomes at the expense of offering hope and at times did so in ways which seemed designed to persuade or intimidate them into certain courses of action. This was in contrast to the professionals' understanding of events which was that information was given in a nondirective manner.

#### Women's attitude to care

When women are diagnosed with a condition which increases the risks of their pregnancies, they will be offered a plan of care involving obstetric, midwifery and other services to manage these risks. However, women may not regard this recommended care in the same way as the professionals. Levy (1999) described maintaining equilibrium as a key activity for women with high risk pregnancies. This involves weighing up the needs of the fetus with those of their partners, existing children, employment circumstances and other competing interests. The women in Levy's study would listen to the advice from midwives but not necessarily follow it. Some of the women would assertively state their views and

intentions regarding the extent to which they would follow the recommendations but other women did not feel able to do so. These women were more likely to appear to accept midwives' advice but would then only follow the parts they considered appropriate. All the women modified the advice they were given to suit their individual circumstances.

Women want a healthy outcome for the pregnancies and are committed to the wellbeing of their babies but they also have to consider other elements of their lives when making decisions about treatment (Durham 1999). Other studies of women with high risk pregnancies report similar findings. The women interviewed by Durham (1999) also modified their treatment plans. When they were initially diagnosed with conditions posing a risk to the pregnancies and anxiety was higher, they were more likely to follow all medical advice. However as time passed, and in the absence of any notable deterioration of their or the babies' wellbeing, they began to modify the advice they followed so that it could be more readily accommodated within the context of their lives. Corbin (1987) found that women negotiated control of their pregnancies with their carers. The women were active in monitoring their symptoms and taking the steps they believed necessary protect their babies. They would entrust control to obstetricians if they believed the severity of their condition made this necessary but continued to weigh up the perceived advantages and risks of any suggested treatment. If they believed an aspect of care was not in the best interests of their babies, they would again assume control over decision making.

# **Implications for practice**

Midwives caring for women with high risk pregnancies have an important role to play in ensuring they receive high quality care which should be personalised to take into account individual circumstances. Women want to be kept informed about their care, even when there may be uncertainty about prognosis (Pozzo et al 2010). However not all information

may be welcomed. Levy (1999) found that women sought to avoid information they felt unable to act on or they perceived as irrelevant to their circumstances. Women would also sometimes prefer to delay discussing certain topics if they considered others to be more pressing. Midwives will frequently be involved in discussions with women about the risks they are facing during pregnancy and so need to ensure they work with women and understand their priorities. Communication can therefore be tailored to the woman's needs. If a midwife understands what is important to the woman in her care, she will know better how to present information in a way which is relevant to her. In this way, potentially important information is less likely to be disregarded. It also means that the midwife's time can be used to better advantage by addressing issues which are really considered essential by women rather than making potentially incorrect assumptions and focussing on subjects of less concern to them (Levy 1999).

Midwives need to develop an awareness of their own communication styles and actively work to improve their communication skills to ensure women are able to discuss concerns with them (Risa et al 2011). While midwives are aware of the importance of women-centred care communication, practice does not always reflect this (Kirkham et al 2002). Conversations with women frequently focus on clinical aspects of care to the exclusion of psychological and social issues. Women can feel unable to raise these issues due to lack of opportunity or anxiety about overburdening busy staff (Kirkham et al 2002; Risa et al 2011). Training in communication skills should be part of the on-going development of midwifery skills. The use of open-ended questions in discussions is more likely to elicit information and there should be sensitivity to verbal cues from women seeking reassurance or clarification. If midwives are to communicate effectively with women with high risk pregnancies, they need to ensure the women have the opportunity to raise concerns and that these are explored to the women's satisfaction (Kirkham et al 2002). The ability to

determine the agenda within discussions is connected to perceived power and authority so this must be shared if are to communicate with women in a way which is sensitive and respectful of individual needs and circumstances (Risa et al 2011).

Levy's work highlights the fact that pregnant women want the opportunity to be involved in making decisions about their care and midwives should seek to maximise the degree of control women are able to take in decision making. VandeVusse (1999) found there was a positive association between involvement in care and the emotions women described when recounting their birth stories. Women with high risk pregnancies also want such involvement (Harrison et al 2003). However, not all women will want the same levels of input and involvement and midwives should be sensitive to this. Some women may prefer to hand over control of some aspects of decision making to professionals and may feel vulnerable and pressurised if encouraged to make decisions of which they do not feel certain (Harrison 2003). Midwives should ensure that where women want to be actively involved in making decisions about their care they are supported to do so and their views are respected. When women are less confident, the midwife should act as a support and advocate, ensuring she is informed about, and comfortable with, her plan of care.

Women should not be seen as irresponsible or negligent if they do not follow all aspects of medical advice. Women with high risk pregnancies are highly committed to the wellbeing of their babies and will do what they believe to be the best for them (Durham 1999). Handwerker (1994) and Robinson et al (2011) both note an increasing tendency to blame women for causing, or apparently failing to remedy, risks in pregnancy. Midwives should ensure women are informed about any medical conditions which will affect their pregnancies and work with them to facilitate positive health choices while respecting individual circumstances. Sensitive and honest exploration of which aspects of care a woman is realistically likely to accept may increase overall compliance with care (Durham 1999).

Obstetricians often regard risk in pregnancy in solely medical terms and in isolation from other aspects of women's lives (Lyerly et al 2007). An awareness of how women perceive their risk status can help midwives assist women to identify their priorities and how these can best be achieved within the context of their lives.

#### **Conclusions**

Women with high risk pregnancies may not perceive the risks they face in the same way as healthcare professionals. Midwives need to be sensitive to this when discussing risks with women. Failure to do so can lead to misjudged and misinterpreted communication which risks alienating women. Midwives should explore women's unique circumstances and concerns and respect the choices the choices they make about their care. They should ensure the care they give is personalised to meet each woman's needs and support women's individual preferences for coping with the many issues raised by a high risk pregnancy. Women should be involved in decisions about their care to the degree to which they feel comfortable and midwives should respect and facilitate women's choices regarding involvement in decisions. Further research is needed to establish how women prioritise the different sources of information they receive during pregnancy and how they decide which are trustworthy. It should also address how professionals interact with women who choose not to follow aspects of the advice they have given.

# **Key phrases**

Risk perception affects women's attitude towards antenatal care.

Women may not perceive risks in the same way as healthcare professionals.

Women will act in the way they believe best to protect their babies' wellbeing.

Midwives need to ensure the care they give is respectful and sensitive to individual women's circumstances.

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