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Risk perception of women during high risk pregnancy: a systematic review

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Abstract

Background: Risk perception in women with high risk pregnancies can affect their attitude to medical care and therefore influence the wellbeing of mother and baby. This paper reviews quantitative measures of risk perception in women with high risk pregnancies. ***Method:*** A systematic search of eight electronic databases was conducted. Additional papers were obtained through searching references of identified articles. **Seven** studies were identified that reported quantitative measures of risk perception in relation to high risk pregnancy. ***Results:*** Women with high risk pregnancies perceive themselves and the pregnancies to be at risk. However, mean risk scores consistently fall below the midpoint on risk perception measures suggesting women do not perceive this risk as extreme. Women with high risk pregnancies consistently rated their risk as being greater than that of women with low risk pregnancies. Results were inconsistent for the association between women's risk perception and that of healthcare professionals. Women with higher socio-economic status were more likely to be concerned about risk, although lower socio-economic status is known to increase risk in pregnancy. There was a consistent association between high risk pregnancy and higher levels of anxiety. ***Conclusions:*** This review suggests women at high risk during pregnancy do not perceive this risk to be extreme, and that there is poor agreement between women's and healthcare professionals' perceptions of risk. This is likely to have implications for medical care and pregnancy outcomes.

Key words: Risk perception, High risk pregnancy, Risk assessment, Risk communication.

Introduction

Whilst most women in developed countries enjoy healthy and straightforward experiences of pregnancy and childbirth, a proportion of women experience complicated or high risk pregnancies that pose some threat to their own and/or their babies' wellbeing. Overall, the likelihood of dying as a result of a condition either directly related to, or aggravated by, pregnancy or childbirth is low but still in 2009 there were 90 maternal deaths in the United Kingdom, 49 in Germany and 1000 in the USA (WHO, UNICEF et al. 2010). Women who do not die of such conditions may experience significant morbidity. In the same year 2630 babies were stillborn in the UK and 13 070 in the USA (Cousens, Blencowe et al. 2011). Many of these were born to women who fell into a high risk category. Common conditions which increase risk in pregnancy include diabetes, which is associated with higher rates of miscarriage, congenital malformation and premature birth (NICE 2008); and pre-eclampsia, which can lead to growth restriction in the fetus, and liver failure, disordered blood clotting and intracranial haemorrhage in the woman (RCOG 2006). As well as physical conditions which pose a threat to maternal and fetal health, some societal factors are also associated with increased risk. In the UK and USA women from minority ethnic and/or lower income populations are more likely to die from pregnancy related conditions than White women or those of higher income (Amnesty International 2010; CEMACE 2011).

The perception of risk in general consists of both objective and subjective components and so cannot be considered a neutral entity. The objective assessment of risk involves the use of statistics to predict probabilities of outcomes (MacKenzie Bryers and van Teijlingen 2010). However, risk also includes a psychological component encompassing factors such as the extent to which the individual perceives the risk, the feelings this provokes, and the coping strategies employed to deal with these feelings (Corbin 1987; Heaman, Gupton et al. 2004; Chuang, Velott et al. 2010). Thus, an individual's perception of risk is a subjective

response based not only on statistical information, but also on previous life experiences, coping strategies, the context in which the risk occurs, and the weight attached to information about the risk obtained from a variety of sources (Edwards, Elwyn et al. 2002; Alaszewski and Horlick-Jones 2003). This is equally true of risk perception in pregnancy (White, McCorry et al. 2008; Jordan and Murphy 2009)

Once a pregnant woman has been identified as experiencing a complication which poses a higher degree of risk to her or her fetus, she will be offered an enhanced level of obstetric care in order to optimise their safety (NICE 2010). For this care to be acceptable to women there must be some agreement between them and healthcare professionals about the need for the treatment and the form it should take. One of the factors which therefore influences the medical management and outcome of high risk pregnancies is the perception of risk on the part of the woman and the healthcare professionals involved.

Differences in attitude to risk can potentially result in misjudged and misinterpreted communication between healthcare professionals and pregnant women and subsequent lack of satisfaction with healthcare provision (Searle 1996). The most recent Report on Confidential Enquiries into Maternal Deaths in the United Kingdom (CEMACE 2011) found lack of engagement with antenatal services was associated with increased risk of maternal death. This finding echoed that of the previous Report (Lewis 2007) which recommended that antenatal care should be provided in a way that is "accessible and welcoming", as "overcoming the barriers to care women face... will help improve... outcomes for maternal and newborn health" (p. x). The World Health Organisation links access to antenatal healthcare services to human rights, including the "right to liberty" and the "right to receive and impart information" (WHO 2001) and states services should be "responsive, adequate, appropriate, and gender and culturally sensitive (WHO 2010). A greater understanding of the

risk perception of women with high risk pregnancies may therefore contribute to good clinical care through improved communication.

How risk information is presented also affects an individual's response to it. For example, the use of different graphics and/or numerical data, whether positive or negative outcomes are emphasised, and numeracy levels may all affect perceived risk (Edwards, Elwyn et al. 2002; Keller and Siegrist 2009). There is also debate about whether information should be presented in terms of absolute or relative risk. Absolute risk would be a statement concerning the likelihood of an outcome, e.g. a probability of 1/100. This allows the risk to be considered in its own terms (Jordan and Murphy 2009). Relative risk would be a comparison with another group, e.g. members of one group are three times more likely to experience an outcome than members of another group. This may provide a useful context for the individual who has to make decisions based on the information (Edwards, Elwyn et al. 2002), but may also confuse the issue (Jordan and Murphy 2009).

Other factors in the communication of risk which can affect its perception include the use of indefinite terms such as 'probable' and 'unlikely', and the manipulation of the framing of the information, i.e. emphasising one aspect of a situation over another when they are logically equivalent. For example, in a discussion of a treatment which itself carries a risk, people are more likely to accept the treatment when the emphasis is placed on the chance of survival than when it is placed on the chance of death (Edwards, Elwyn et al. 2002). Even statistical data may be open to interpretation. In a qualitative study of perception of risk in pregnant women and healthcare professionals, it was found that a figure of 20% could be interpreted as both high and low risk by different individuals (Handwerker 1994).

Any discussion of risk is also influenced by the social context in which it occurs. As information about risk can be presented in a way which will affect its perception, some

authors suggest information giving may be used by doctors as a strategy to exert control over women (MacKenzie Bryers and van Teijlingen 2010). The giving of information in a way that affects the outcome of a decision related to it may lead to 'informed compliance' on the part of the patient, rather than the ideal of informed choice (Jordan and Murphy 2009). It has been argued that pregnant women are widely regarded as an especially vulnerable group in need of increased monitoring and intervention (Lupton 1999). This desire to control the behaviour of pregnant women in order to protect them from perceived danger has been shown to extend beyond the medical profession (Sutton, Douglas et al. 2010). In a study of US female undergraduates, Sutton et al used questionnaires to assess levels of sexism, knowledge of pregnancy, and perceived willingness to intervene if a pregnant woman was witnessed doing something perceived as unsafe. They found participants endorsed benevolent sexism (actions that were motivated by feelings of protectiveness towards women rather than hostility) and were willing to intervene in situations perceived as risky to pregnant women. Perceived level of knowledge of pregnancy was not a moderating factor in the relationship between sexism and willingness to intervene.

Lupton (1993) argues that this use of risk perception to exert control over behaviour works by promoting the concept of social cohesion. In other words, which risks are emphasised over others may be seen as a matter of social selection; and women who are considered by wider society as contributing to their own degree of risk are considered to be stepping outside societal norms. Outsiders may be considered worthy of censure, therein maintaining prevailing social norms, and the definition of risk becomes an instrument used to maintain existing power structures. Research suggests this may be the case. For example, Handwerker (1994) found American healthcare professionals stressed issues of responsibility and blame if pregnant women were perceived to be behaving in ways which increased their risk status. Another study asked US college students to rate the extent to which it is

legitimate to feel negatively towards certain groups likely to encounter prejudice. Pregnant women who drink alcohol ranked tenth out of 105 groups as acceptable targets for prejudice, above alcoholics and men who leave their families (Crandall, Eshleman et al. 2002). The concepts of blame and risk have become linked in a contemporary context which is characterised by a level of individualization: individuals may have more freedom to define their roles and behaviours than in previous times, but they are also held more responsible for the consequences of doing to (Lupton 1999). Thus pregnant women face a culture which is highly focussed on pregnancy as a time of risk, and condemnation if they do not behave in ways perceived to reduce risks (Robinson, Pennell et al. 2011), but have little or no control over socio-economic factors which are consistently associated with poor pregnancy outcomes.

Doctors are also subject to a number of societal influences. Childbirth is now generally safe for women in the developed world but continues to be perceived by many medical professionals as a time of risk to wellbeing (Enkin 1994). Technological developments which were designed to improve the safety of childbirth by providing more information about the status of the mother and fetus may also create anxiety because this information demands a medical response (MacKenzie Bryers and van Teijlingen 2010). In turn, this provokes greater intolerance of risk and a belief that there is a professional duty to eliminate any degree of risk (Jordan and Murphy 2009). Doctors' practice, including the discussion of risk, may also be affected by fear of litigation (Enkin 1994; Handwerker 1994). Medical texts discussing risk communication acknowledge the subjective nature of patients' risk perception but may be less likely to consider the subjectivity of healthcare professionals (Paling 2003). This can imply professionals possess more rational judgement than patients when faced with the same factual information.

These multiple factors which affect risk perception mean both objective and subjective appraisals of risk may change over the course of pregnancy. Some women with high risk pregnancies will go on to have straightforward pregnancies and women with low risk pregnancies may develop complications or have unexpected bad outcomes involving maternal and/or neonatal morbidity and mortality (Murphy 1994; MacKenzie Bryers and van Teijlingen 2010). However, Handwerker (1994) notes that risk status is far more likely to be raised during pregnancy than lowered. Other difficulties in assigning a risk status to women include the degree of risk to associate with a certain factor, how to combine multiple factors into a single risk score, and the tendency to dichotomise continuous variables, for example blood pressure measurements (Enkin, Keirse et al. 2000).

Healthcare professionals and pregnant women may have different perceptions of risk. Turner et al (2008) found that when pregnant women were presented with descriptions of vaginal birth they were willing to tolerate a much higher degree of risk to themselves in order to achieve a normal vaginal delivery than doctors were. However this study is complicated by the fact that comparisons were drawn between women in their first pregnancies who had no experience of labour or birth; and either female doctors of whom the majority had given birth, or male doctors who were asked to consider what they would recommend to their female partners. This discrepancy in the tolerance of risk by women and healthcare professionals may have many explanations. For example, one qualitative study of pregnant women's perception of risk found women with high risk pregnancies were more likely than those with low risk pregnancies to differentiate between risk to themselves and risks to the baby, the latter being of greater concern (Heaman, Gupton et al. 2004).

Perception of risk is therefore subjective and extends beyond a straightforward assessment of probability. Knowledge about activities which are believed to present a risk to pregnant women may be based on folklore and tradition rather than medical science, but still

maintain an influence over thinking and behaviour (Snow, Johnson et al. 1978; Sutton, Douglas et al. 2010). In their qualitative study of low income, multi-ethnic urban American women regarding what behaviours were believed to constitute a risk in pregnancy, Snow et al uncovered beliefs such as the denial of maternal food cravings or going out during a lunar eclipse resulting in fetal abnormalities. Where knowledge is accurate, it is not necessarily related with levels of risk taking behaviour (Cook and Bellis 2001). In making decisions about risk, factors such as its relationship to other perceived risks, how much trust is placed in the source of the information, the fit of the information with other perceived risks, and the importance of the decision involved all influence the response (Alaszewski and Horlick-Jones 2003).

Perception of risk, of both women and professionals, is therefore a factor which strongly influences the care high risk women receive during their pregnancy, and hence its outcome. If women and professionals perceive the degree of risk differently it is unlikely they will agree on a management plan. This can lead to women feeling their concerns are unacknowledged and so be less willing to engage with healthcare services, potentially increasing risk to the pregnancy. There is as yet no standardised measure of women's risk perception in high risk pregnancy and comparatively little research exists in the area. Research that is available is inconsistent in definitions of high risk pregnancy and in what questions are addressed, so it is currently difficult to include in the clinical management of women with high risk pregnancies. A review of existing research is therefore needed to provide clarity by summarising key findings of existing studies. The current paper aims to do this and examine methodological issues of existing studies to highlight how these may be addressed in future research. It will draw on psychological and sociological literature to provide a clearer understanding of how women with high risk pregnancies perceive these

risks and so hopefully aid communication with these women. In turn this may improve satisfaction with healthcare provision.

This paper systematically reviews quantitative studies of risk perception in women with high risk pregnancies. The chosen focus is perceived rather than actual risk as actual risk is measured by epidemiological studies and, as has been described, is only one factor in the perception of risk. Risk perception is therefore a logical starting point in a consideration of women's behaviour in the context of high risk pregnancy as it will affect the decisions a woman makes about her pregnancy, her relationship with healthcare professionals and attitude towards treatment. This paper will inform the clinical management of high risk pregnancy and suggest further areas for research in order to continue improving care.

Method

Search strategy

A systematic review was conducted to identify studies of the perception of risk in women experiencing high risk pregnancies. The primary search method was a review of the medical and psychological literature conducted between January and March 2011 using the following computerised databases: Medline, PubMed, PsycINFO, PsycARTICLES, Web of Science, Scopus, Embase and CINAHL. A wide ranging definition of high risk pregnancy encompassing any conditions either predating or developing during pregnancy which have the potential to cause harm to the mother or fetus was used to ensure as many articles as possible would be identified. The use of broad search terms reflected this. 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". Once key authors were identified, searches were also conducted under their names. The search returned 1347 citations. Due to the broad search terms many papers identified were not relevant for inclusion the review when the title and abstract of each paper were inspected. Additional studies were located through inspection of the reference sections of relevant papers. This approach yielded a preliminary database of 83 papers published between 1978 and 2011.

Inclusion and exclusion criteria

These 83 papers were examined to determine eligibility for inclusion in the review. Studies were included if they reported a quantitative measure of perceived risk in women experiencing a high risk pregnancy. Although qualitative studies do exist in the field, it was felt that studies including a quantitative measure had greater potential to transfer to other groups of women with high risk pregnancies and so be of more immediate use in clinical management. Studies were excluded if they included only a qualitative assessment of perceived risk (n=10), no measure of perceived risk (n=58), studies of non-pregnant women (n=3), meta-analyses and review papers (n=0), and studies not published in English (n=3). Studies from developing countries were also excluded (n=2) as the increased health risks of giving birth in these countries means perceived risk of women in these populations is unlikely to be comparable with that of women from developed countries. Authors of studies were contacted if further clarification was required to determine whether studies were suitable for inclusion.

A total of seven studies was therefore included in the review. These included six cross-sectional studies of women with high risk pregnancies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; Gray 2006; White, McCorry et al. 2008; Headley and Harrigan

2009; Heaman and Gupton 2009) and one retrospective study of mothers of twins conducted within the first three days following delivery (Papiernik, Tafforeau et al. 1997).

Quality assessment

The methodological quality of each paper was assessed using a checklist based on that developed by Mirza and Jenkins (2004). The nine dimensions assessed were: 1) clear study aims, 2) adequate or justified sample size, 3) sample representative of population, 4) clear inclusion and exclusion criteria, 5) reliability and validity of measure stated, 6) response and / or dropout rate specified, 7) adequate description of data, 8) appropriate statistical analysis, and 9) discussion of potential for generalisation included. A score of 1 was awarded for each of these points present and so each study was given a total mark for quality out of 9. Quality scores ranged from 5 to 9. Inter-rater reliability was checked for four studies and agreement across dimensions was high (mean agreement across studies was 97%, Kappa=.94). Most studies were of reasonable quality with 6 of the 7 scoring 6 or more. No studies were excluded from the review because of quality scores due to the early stage of the research in this area.

Measurement and data analysis

All studies in the review contained a measure of risk perception, although in three papers, this was not the central issue being investigated. Heaman, Beaton et al (1992) compared the expectations of childbirth women with high and low risk pregnancies; White, McCorry et al (2008) focussed on the effect of risk on prenatal attachment, and Heaman and Gupton (2009) described the development of a risk perception measure. Where studies focussed on other issues, the results regarding perceived risk were extracted for the purpose of this review.

All studies used self-administered questionnaires and in total five different measures of risk perception were used. All measures were developed by study authors. Within the cross-sectional studies, Heaman et al (1992), Gray (2006) and White et al (2008) used their own measures. Gupton et al (2001) developed and used the Perception of Pregnancy Risk Questionnaire. This was subsequently used in two other studies reviewed (Headley and Harrigan 2009; Heaman and Gupton 2009).

Some studies compared women's perceived risk with that of other relevant groups. In samples of women with high risk pregnancies, two studies compared women's perceived risk with a medical assessment of risk (Gray 2006; White, McCorry et al. 2008). A further four studies compared medical risk with perceived risk in samples of women with low risk pregnancies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; Headley and Harrigan 2009; Heaman and Gupton 2009).

Results

The studies included in the review were conducted between 1992 and 2009. The number of participants in the cross-sectional studies totalled 676 women with high risk pregnancies (M=112.7, mdn=102.5, mode=176). The retrospective study had 546 participants. Participants were recruited from antenatal clinics and hospitals.

Table 1

Definition of high risk pregnancy

Different sampling methods meant studies varied in their definition of what constituted a high risk pregnancy. The majority of the cross-sectional studies recruited participants from high risk antenatal clinics or from women who had been hospitalised with pregnancy related conditions. White et al (2008) and Headley and Harrigan (2009) included

in their samples any women receiving care for high risk pregnancies. This wide definition encompasses any condition which could increase the likelihood of an adverse outcome for mother and/or fetus. In contrast, Heaman et al (1992), Gupton et al (2001) and Heaman and Gupton (2009) only included women who had developed medical conditions during pregnancy and therefore excluded those with chronic medical conditions including diabetes mellitus and cardiac disease even though these are known to increase risk in pregnancy. Other studies focused on particular high risk groups; for example, Gray (2006) only considered women with diabetes mellitus, hypertension or pre-term labour. It is not clear whether the diabetic women were suffering from pre-existing diabetes or whether the condition had developed during pregnancy. Papiernik et al (1997) only studied women who had given birth to twins.

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 studies reviewed will be derived from various circumstances and comparisons between studies will not exactly compare like with like. However, whatever 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 to risk.

Assessment of women's perception of risk

Assessment of women's perception of risk varied across studies. Four of the cross-sectional studies reported women's actual scores on risk perception measures. However, they all used different measures. Heaman et al (1992) found that women with high risk pregnancies had a mean risk perception score of 4.2/10. Gupton et al (2001) found a mean risk score of 474.3/1100 using an earlier version of the Pregnancy Perception of Risk Questionnaire (PPRQ). Gray (2006) found women had a mean self-rating of 88.46/200 for

total risk, i.e. risk to mother and baby combined. Heaman and Gupton (2009) used a later version of the PPRQ and found a mean risk rating of 41.4/100. Thus in the studies where an actual score for risk perception was stated, scores were consistently just below the midpoint on the scale.

Table 2

Comparison with medical risk scores

All the cross-sectional studies compared women's perception of risk with that of a more objective, medically defined risk assessment. Methods for assessing medical risk varied across studies. White et al (2008) and Headley and Harrigan (2009) had women's medical histories reviewed by obstetricians to identify risk factors. Gray (2006) developed her own risk measure to be used by health care professionals which was completed by physicians and nurses caring for participants. Heaman et al (1992), Gupton et al (2001) and Heaman and Gupton (2009) all used the existing Biomedical Risk Scoring Form (Coopland et al, 1977) to calculate obstetric risk. Heaman and Gupton (2009) had obstetric nurses question participants in order to complete the measure. Heaman et al (1992) and Gupton et al (2001) do not state who completed the measure.

Results pertaining to the association between women's perceived risk and medical risk are inconsistent. Three studies (Heaman, Beaton et al. 1992; White, McCorry et al. 2008; Headley and Harrigan 2009) found no relation between women's ratings of risk perception and medical ratings of scores. In contrast, two studies have found some association between perceived risk by women and healthcare professionals. Gupton et al (2001) found a positive correlation between women's perceived risk and medical risk scores. This association was evident in their total sample of women with both high and low risk pregnancies. However, when they looked at risk groups separately, the association between

women's perceived risk and medical risk was only significant in the group of women with low risk pregnancies, and *not* in those with high risk pregnancies. Heaman and Gupton (2009) found a moderate positive correlation between the risk perception scores of women with high risk pregnancies and medical risk scores.

Gray (2006) found no significant difference between risk scores for women and healthcare professionals when comparing total risk for the pregnancy (i.e. risk to mother and baby combined), and risk to the baby. There was also no significant difference between scores on perception of risk to the mother between women and physicians. However, nurses' risk scores were found to be significantly higher than women's scores for perceived risk to the mother.

Comparison with risk perception scores of women with low risk pregnancies

Four studies compared the perception of women with high risk pregnancies with that of those with low risk pregnancies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; Headley and Harrigan 2009; Heaman and Gupton 2009). All found that women with high risk pregnancies had significantly increased perception of risk. However, when Gupton et al (2001) looked at specific risks results were not consistent between the groups. Significant differences were found in ratings of risk for premature delivery, risk of the baby needing to go to a neonatal intensive care unit, overall risk to the baby and risk of the mother developing an infection. However, there were no significant differences between the women in their assessments of risk of needing to have a caesarean delivery, overall risk for the pregnancy, risk to the mother, risk of maternal haemorrhage, or risk of the mother or baby dying.

Sociodemographic variables

The majority of studies did not report a significant relationship between sociodemographic variables and perception of risk. Where demographics were reported, the majority of study participants were married, or cohabiting and had completed college education. Headley and Harrigan (2009) was the only study to report a predominantly non-white sample.

Findings for sociodemographic variables between groups of high and low risk women were mixed. Heaman and Gupton (2009) found no significant differences in sociodemographic variables between the groups. However, two studies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001) found that women with high risk pregnancies were more likely to have finished education earlier than those with low risk pregnancies. Gupton et al (2001) also reported that women with high risk pregnancies were more likely to be in lower income groups than women with low risk pregnancies and more likely to be of a racial group other than white.

Papiernik et al (1997) did report a difference in risk perception according to socio-economic status. They found that women who had completed higher levels of education were more likely to have a higher degree of concern for themselves and their children. They also found that women with a higher socio-economic index were more likely to choose to give birth in a setting with more highly qualified medical staff and more sophisticated equipment.

These results suggest that whilst lower socio-economic status may be associated with a higher degree of actual risk in pregnancy, women who have achieved a higher level of education are more likely to be concerned about risk.

Healthcare professionals were not asked about the socioeconomic status of women in their risk assessment measures.

Comparison of risk to baby and risk to mother

Only one study (Gray 2006) separated women's appraisal of risk to themselves from their appraisal of risk to the baby. Risks were compared between women suffering from diabetes, hypertension and preterm labour. No significant difference was found in women's estimates of risk to the baby between the three groups, but women experiencing preterm labour were found to rate risk to themselves as lower risk than those suffering from diabetes or hypertension.

Two studies addressed other aspects of the effects of high risk pregnancy on the maternal/fetal relationship. White et al (2008) found that women's appraisal of their own health and that of their baby were predictors of both the quality and intensity of maternal/fetal attachment. This relationship between risk assessment and attachment was mediated by coping strategies. Heaman et al (1992) found that women with high risk pregnancies had less positive expectations for childbirth than those with low risk pregnancies and engaged in lower levels of activity in preparation for childbirth.

Association of risk appraisal with anxiety

Four cross-sectional studies examined the association of risk appraisal and anxiety. In three studies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; Heaman and Gupton 2009) anxiety was measured using the state component (which refers to how participants feel at that time) of the State-Trait Anxiety Inventory (Spielberger, Gorsuch et al. 1983). The fourth cross-sectional study (White, McCorry et al. 2008) used both state and trait (which refers to how participants feel in general) components of the measure.

The association between higher perception of risk and anxiety was consistent across studies. Gupton et al (2006) and Heaman and Gupton (2009) found a positive correlation

between higher assessment of risk and higher anxiety scores. Heaman et al (1992) found women with high risk pregnancies scored higher on the anxiety measure than those with low risk pregnancies. White et al (2008) found that anxiety mediated the relationship between appraisal of risk and maternal/fetal attachment.

Effect of admission to hospital on perception of risk

Hospitalization status was found to influence risk perception according to two studies but results were mixed. Gray (2006) found women who were currently in hospital as a result of their condition rated the risk to themselves as lower than other women. Women who had never been hospitalized were found to have significantly higher risk scores regarding risk to themselves, but had the lowest risk scores for risk to the baby. Women who had previously been in hospital, but were not so at the time of the study reported the highest risk scores for mother and baby. However, Gupton et al (2001) found that risk scores increased with length of stay in hospital.

Summary

Data from studies in this review show women with high risk pregnancies are likely to recognise their condition presents a degree of risk to the wellbeing of themselves and/or their babies. They are also likely to rate their degree of risk as higher than women with low risk pregnancies. Results are inconsistent for the association between women's perceived risk scores and healthcare professionals' ratings of risk. Socio-economic factors, where reported, suggest that women with high risk pregnancies are more likely to have finished education earlier, be of a low income, and be of a racial group other than white. Women from a higher socio-economic background are more likely to show concern about health risks. There is a consistent positive association between risk perception and anxiety.

Discussion

This is the first systematic attempt to review the literature on perceived risk in women with high risk pregnancies. It highlights the lack of research in the area and raises methodological issues about existing studies. Given the limited data, conclusions should be drawn with some caution but implications for clinical practice are suggested along with recommendations for further research.

There was some consistency in the scores women with high risk pregnancies gave as ratings for their own perception of risk. This suggests that women with high risk conditions are aware of the risks that these present to themselves and their babies. However, the fact that mean risk scores were all below the midpoint of the scales used suggests that even when women's pregnancies are defined as high risk, women do not perceive the level of risk posed as severe. This was found in three studies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; Heaman and Gupton 2009) which defined high risk pregnancy in the same way, and also in one other (Gray 2006) which used a different, more specific definition. The differences in the ways studies defined high risk pregnancy meant participants were suffering from a wide variety of conditions. However, the similarity in risk perception scores suggests that women evaluate threats to the wellbeing of their pregnancies in similar ways. This finding is supported by the fact that when women with high risk pregnancies were compared with those with low risk pregnancies, they consistently rated their perceived risk as being higher.

Differing definitions of high risk pregnancy mirror the lack of international agreement on what constitutes risk in pregnancy. Epidemiological figures are collected for some conditions and the WHO publishes guidelines for managing many pregnancy related conditions. Some individual countries also publish national guidelines, for example NICE

guidelines in the UK. This is not consistent practice across the developed world however. The USA, for example, does not have nationally agreed guidelines for identifying and managing obstetric emergencies. This has been linked to its persistently high maternal death rate compared to many other developed countries (Amnesty International 2010). The lack of international agreement on a definition of high risk pregnancy makes it difficult to estimate overall numbers.

The oldest study in the review was published 19 years ago (Heaman, Beaton et al. 1992) and the most recent two years ago (Heaman and Gupton 2009). Both studies found comparable mean anxiety scores of just below the midpoint of the measure and that women with high risk pregnancies had consistently higher perception of risk than low risk women, and higher anxiety scores. This suggests women's perception of risk in high risk pregnancy has not changed substantially in the period between the papers and so has not been affected by other factors which may have altered during this time, for example increased internet usage and changes in medical practice.

As risk perception will have a direct impact on women's care and their satisfaction with it, it is recommended that it be acknowledged within the provision of antenatal healthcare. This would require healthcare professionals to explore with women their perception of risk and to not make assumptions or judgements regarding women's risk perception. The development of a standardised measure of risk perception for women with high risk pregnancies would aid this. The consistency in the scores for risk perception in the instruments used in the studies reviewed suggests this need not be long as the instruments with more items did not elicit different responses to those with fewer. The use of such a measure would therefore not be difficult to fit into existing healthcare services.

Several of the studies acknowledge that socio-economic factors play a role in determining a woman's risk status in pregnancy (Papiernik, Tafforeau et al. 1997; Gupton, Heaman et al. 2001; Headley and Harrigan 2009) but none included these in the health professionals' risk measures. This approach is consistent with the way risk is presented in medical texts. Enkin et al (2000) differentiate between risk factors, that is elements known to cause risk, and risk markers, elements statistically associated with risk. They argue labelling women as high risk due to factors medicine cannot alleviate and women cannot control, e.g. social class, may simply increase women's anxiety without improving outcomes. However, this approach diverts attention from the need to consider social inequality within rates of both health problems and healthcare provision. Further research could usefully highlight how both healthcare professionals and pregnant women understand their risk status to be associated with socio-economic variables.

Only one study (Papiernik, Tafforeau et al. 1997) found a positive association between socioeconomic status and risk perception. Women from higher socioeconomic groups were more likely to choose to give birth in a more medicalised setting. This may be a manifestation of healthism, a phenomenon characterised by a high level of health awareness and willingness and ability to 'shop around' regarding healthcare provision. Such behaviour is more commonly associated with a university educated, semi-professional population (Greenhalgh and Wessely 2004).

There was a lack of consistency between women's perception of risk and that of healthcare professionals. Three studies (Heaman, Beaton et al. 1992; White, McCorry et al. 2008; Headley and Harrigan 2009) found no association between women's risk scores and those of professionals. One study (Gupton, Heaman et al. 2001) did find an association for the total sample of women with both high and low risk pregnancies and for those whose pregnancies were at low risk, but not for the women with high risk pregnancies. One study

(Heaman and Gupton 2009) did find a moderate positive correlation between risk scores for women and healthcare professionals.

Studies varied in the ways medical risk scores were collected and not all studies state how this was achieved, making comparisons between studies difficult. The methodological approach of most of the studies also makes it difficult to interpret whether there are actual differences in the risk perception of women and healthcare professionals or whether inconsistencies are due to study design. The majority of studies (Heaman, Beaton et al. 1992; Gupton, Heaman et al. 2001; White, McCorry et al. 2008; Headley and Harrigan 2009; Heaman and Gupton 2009) asked women to make some form of judgement about how at risk they felt they or their babies were. Results were contrasted with professionals' risk ratings generally based on simply totalling the number of medical risk factors for each woman. This approach does not take into account that in a medical consultation the professional is also influenced by all the subjective factors which affect risk perception. The studies which present results in this way may give the impression that healthcare professionals are immune to the subjective elements of risk assessment.

Gray (2006) found no significant difference between risk scores for women with high risk pregnancies and healthcare professionals when comparing risk for mother and baby combined, and risk to the baby, and no significant difference between scores on perception of risk to the mother between women and physicians. This study used a different type of instrument to measure the professionals' assessment of risk, one much more closely aligned with that used by the women. The healthcare professionals were asked to give an estimate of the likelihood of "serious health problems (or negative pregnancy outcome)" (Gray 2006 p.222). In other words, they were asked to make a judgment. This would have allowed the more subjective factors inherent in risk assessment to operate, so giving a better estimate of professionals' actual perception of risk and a more true reflection of how they approach the

issue with patients, rather than merely counting the number of risk factors present. Further research into healthcare professionals' perception of risk when caring for women with high risk pregnancies is needed to help clarify how their risk perception affects clinical care.

In the one study that did find an association between the women's scores and medical risk scores (Heaman and Gupton 2009), medical scores were ascertained by having obstetric nurses question the women with high risk pregnancies about factors in their medical history. This is in contrast to the studies which did not find an association between scores (White, McCorry et al. 2008; Headley and Harrigan 2009), in which obstetricians reviewed women's medical histories to determine their risk scores. It may be that if obstetricians had reviewed the histories of the participants in the Heaman and Gupton study, different risk factors would have come to light, or different emphasis been placed on known risk factors, leading to a different outcome. Questioning participants about their own risk factors may not have elicited the same information that an obstetric review would have produced as participants may have had different views concerning what information was relevant.

Gray (2006) found no significant difference between risk scores for women with high risk pregnancies and doctors regarding perception of risk to the mother, but found that nurses' risk scores were significantly higher. This suggests a need for further research into differences in risk perception between healthcare professionals. This is supported by the work of Turner et al (2008) who found differences in attitudes to the risks of vaginal delivery between midwives, obstetricians, urogynaecologists and colorectal surgeons. Women with high risk pregnancies may see a variety of professionals during the course of the pregnancy. If each perceives a different degree of risk, the woman is unlikely to receive a consistent message regarding the severity of her condition to assist in her own assessment of risk. This may increase the likelihood of confusion and dissatisfaction in communication with professionals as described by Searle (1996).

. Gray's was the only study to differentiate risk scores between perceived risks to mother and baby. Further research into how women differentiate these risks will help in an understanding of their perception of risk.

Methodological issues alone may not account for the differences in risk perception ratings between pregnant women and healthcare professionals. Other factors may exist which mediate the relationship between actual and perceived risk, for example anxiety. The results of the studies which considered anxiety consistently found an association between high risk pregnancy and higher levels of anxiety. Further research would be useful to explore this relationship, for example to consider the relationship between trait anxiety and risk perception, or how the discussion of risk with healthcare professionals influences anxiety.

Qualitative studies of risk perception in women with high risk pregnancies also provide evidence that women and health professionals view risk differently. Corbin (1987) found women with high risk pregnancies engage in a process of protective governing consisting of assessing, balancing and controlling risk factors. The women interviewed would not always agree with their doctors on the degree of risk involved in the pregnancy believing it to be at times both under and overestimated. They would negotiate management of the pregnancy with doctors and not comply with plans they did not believe to be appropriate. Another qualitative study found women to be very aware of the risks to their pregnancy and constantly concerned for the wellbeing of their babies. However the women felt doctors regarded them as being in denial of the risks because in consultations the women preferred to focus on possibilities and positive aspects of the pregnancies (Stainton 1992). Differences in risk perception between women and medical professionals may therefore be differences in focus rather than concern. Women are more likely to contextualise the risks within their life circumstances, doctors to view them as isolated medical issues (Lyerly,

Mitchell et al. 2007). Decisions viewed outside their context are more likely to seem irrational to professionals (Lupton 1999).

Differences in risk perception between women and healthcare professionals also cannot be explained in terms of inferior knowledge on the part of women. The women in Stainton's study reported feeling their knowledge of their pregnancies was not valued by professionals. Lupton (1999) contrasts lay, individualized knowledge which is localized and contextualized, with professional knowledge which is universalized and generally held in higher status. Lay people are aware of the power imbalance in these definitions of knowledge and of their subsequent lack of power to challenge professional knowledge. However, Corbin's study shows that if women feel they cannot negotiate an acceptable management plan with their doctors they will take back some control through non-compliance and researching their own care.

This is again linked to the concept of healthism in which lay or alternative knowledge is highly valued and there is a general suspicion of medical and scientific knowledge. Asserting this lay knowledge can be a challenge to the traditional power imbalance in the doctor/patient relationship (Greenhalgh and Wessely 2004). It may appear paradoxical that healthism can potentially incorporate behaviour which both challenges the medical profession and also welcomes more intensive medical care (Papiernik, Tafforeau et al. 1997), but individuals may alternate between these stances according to circumstances (Lupton 1997).

Although women may not be aware of all the risks posed in pregnancy by chronic health conditions (Chuang, Velott et al. 2010), in a study of women attending a fertility clinic no association was found between whether a woman had received counselling from a healthcare professional regarding the risks of the potential pregnancy and their subsequent risk perception (Grobman, Milad et al. 2001). Research can aid in the improvement of

communication with women regarding risks to their wellbeing however many factors will inform women's level of perceived risk. Information from professionals should be accurate and appropriately communicated, but women weigh this information alongside information from other sources and in the wider context of everyday life (Alaszewski and Horlick-Jones 2003). The study by Sutton (2010) which found willingness to intervene when a pregnant woman was observed doing something perceived to present a risk did not have an association with perceived level of knowledge of pregnancy, suggests risk in pregnancy remains an emotive subject of which factual knowledge is only one aspect. Healthcare professionals should therefore remember that women will take many factors into account when assessing their perceived degree of risk and not assume that statistical information about risk or an increased amount of factual information will be the most influential of these.

What influences women in their assessment of perceived risk was not considered by any of the studies and is a valuable area for potential research. It is recommended further research explore the sources from which women receive information about their pregnancies, and how they assess the quality of source and information. It would also be useful to investigate how women prioritise the many physical, psychological and social demands a high risk pregnancy can place on them.

This paper provides the first systematic review of studies of risk perception of women with high risk pregnancies, summarising the findings and so providing some clarity for those working with pregnant women. It shows women with high risk pregnancies do recognise that the increased risks they face but there is potential for difference in the risk perception of women and healthcare professionals. It is limited by the small number of studies in this area but has demonstrated that risk perception is a complex issue which has a direct impact on the care of women with high risk pregnancies and so on the wellbeing of women and infants. Differences in risk perception between women and professionals should be managed with

respectful and sensitive conversation if women are not to feel alienated from, and so less likely to engage with, healthcare services. It is strongly encouraged that future research explores the issues highlighted, for example what information influences women when they make judgements about risk, how professionals assess risk, and the development of a standardised risk perception measure. These issues should be considered in the context of societal factors including how the definition of risk is used to maintain power imbalances and social control, and how the phenomenon of healthism is reshaping some of the interactions between pregnant women and healthcare professionals. It is hoped this research will promote better communication between high risk women and professionals and so strengthen and improve maternity care.

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