

Taking Antenatal Group B Streptococcus Seriously: Women's Experiences of Screening and Perceptions of Risk

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ABSTRACT: Background: Early-onset group B streptococcal disease is a serious cause of neonatal morbidity and mortality. Although screening protocols for group B streptococcus are common, little is known of women's perceptions of this screening and the disease itself. The purpose of this study was to gain an understanding of women's experiences, knowledge, and perceptions about this bacteria and its screening. **Methods:** Nine focus group interviews with 35 women explored their experiences and understanding of group B streptococcus screening. Transcribed interview data were interpreted to identify and articulate the women's experiences. **Results:** Most women had little knowledge or understanding of group B streptococcus, obtaining their information largely from the stories or experiences of friends or family. Women struggled to understand the meaning and implications, both physical and "moral," of the disease for their baby and for themselves, clearly indicating both the subjective and statistical importance of the concept of risk for pregnant women. **Conclusions:** Group B streptococcus continues to be poorly understood by pregnant women who try to understand and weigh up its risks and implications so as to make the best decisions about screening. The women participated in screening ultimately, however, since it was seen to be patently "best for baby," relatively easy for them to undergo, and part of routine antenatal care. (*BIRTH* 30:2 June 2003)

Early-onset group B streptococcal disease is a serious cause of neonatal morbidity and mortality and "an important health problem in much of the world"

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(1, p F82). This paper reports the qualitative element of a multimethod study. The quantitative arm, which will be reported separately, evaluated timing and detection strategies for group B streptococcus screening by comparing the current practice of screening at 31 to 33 weeks with later screening at 35 to 37 weeks. In addition, perianal swabs combined with low vaginal swabs were compared with low vaginal swabs alone to ascertain best predictive value for colonization at delivery.

The purpose of the qualitative arm of the study, described here, was to explore women's experiences and perceptions about group B streptococcus, its screening, and possible treatment options. The rationale for the study was the recognition that pregnant women may experience the process of screening as being more than merely the collection of specimens. If policies and practice are to become more sensitive and responsive to women's needs, a

greater knowledge about how women experience and understand such screening is crucial.

Women's Experiences of Prenatal Screening

Increasing research attention is being paid to women's experiences with respect to screening in general (2–13), but we found no studies that specifically determined women's experiences of group B streptococcus screening. Such reports about antenatal screening are primarily concerned with tests predicting fetal abnormalities such as maternal serum alpha-fetoprotein, ultrasound, or chorion villus sampling (5). Little has been reported of women's views of commonplace, so-called "minor" (10) tests, such as urine or blood testing. In her 1988 review, Reid concluded that: "women remain fairly ignorant about many of the prenatal tests which they undergo throughout pregnancy" (10, p 84). The situation may have not have improved almost a decade later, when Searle's study of women's informed choice reached a similar conclusion (12, p 272).

These deficits in information provision and understanding relate to many aspects of screening (2,8,14,15), such as women being insufficiently well informed to appreciate the significance of particular information or to know that that they may be missing important information. Women also described the need to fight for information with health professionals, who were perceived as being sometimes dismissive of their requests (16). Whether or not increasing women's knowledge lessens anxiety is unclear (2,8,13), but addressing the issue is more complex than by simply offering women "more information." Information, as Gregg has noted, "is not neutral, and neither is it necessarily a tool of empowerment" (4, p 61). Recognizing the importance of the "consumer's voice" in health care is now well appreciated, and has been advocated in prenatal screening (5,10). Attending to the understandings and perceptions of women being screened is an important aspect of the evaluation of any treatment or screening practices. This study seeks to redress the lack of attention paid to women's perceptions and experiences of screening.

Methods

Qualitative research methods are now widely used in general health research and increasingly in screening research (2,4,6,7). This approach enabled us to ascertain and interpret how women articulated and make sense of their experiences related to group B streptococcus and screening. The study was conducted at the Women's & Children's Hospital, Adelaide,

Australia, between January 1998 and December 1999.

Focus group interviews were chosen as a data collection strategy for this study, since they "are a particularly good choice of method when the purpose of the research is to elicit people's understandings, opinions and views, or to explore how these are advanced, elaborated and negotiated in a social context" (17, p 187).

Study Participants

After institutional ethics approval was obtained, women were assured of confidentiality and of their right to withdraw from the study at any time without prejudice. In addition to routinely available patient information sheets, detailed information was given to women on recruitment, which included details of group B streptococcus, its potential effects, screening, treatment, and what would be required of them during the research. Verbal explanation to women before each interview emphasized that they could choose to respond or not respond to any of the questions.

Recruitment took place in all antenatal clinics at the women's 28-week visit. Information about the qualitative and quantitative components of the study was given concurrently, and women could participate in both or either arms of the study. The inclusion criteria of the quantitative arm of this screening study (singleton pregnancy and intention to deliver at Women's & Children's Hospital) were intentionally broad so that women approached would be representative of the patient population at a major teaching hospital. These inclusion criteria applied to both the qualitative and quantitative arms of the study.

Procedure

Nine focus groups ($n = 35$), of 3 to 8 women were held, 7 antenatally (at approximately 36 weeks' gestation) and 2 postnatally; 4 women were interviewed in both an antenatal and postnatal group. Since our focus was on screening experiences, the women's carrier status was initially unknown to the researchers unless volunteered by a participant. Subsequently, however, we invited group B streptococcus-positive women to participate in a specific focus group to explore their particular concerns and experiences about screening and treatment. Two such focus groups were conducted with the same group of women, 1 antenatally and 1 postnatally.

No prescriptive, predetermined interview schedule was applied, since this research approach requires an

interpretive openness to the participants' agendas and issues. However, because focus groups must, by definition, have a focus, generative or trigger questions about screening were devised in initial discussions among the researchers, based on the study question and existing literature. These questions covered areas, such as knowledge, understanding, and perceptions of group B streptococcus screening and disease, the decision to undergo testing, awaiting/receiving results, and deciding whether or not to take antibiotics.

Data Collection and Analysis

The interviews were informal conversations that enabled participants to describe and discuss their experiences and perceptions of screening. Interviews were tape-recorded, transcribed verbatim, and checked to ensure accuracy and completeness of the interview data; they were conducted by authors [PD] and/or [CC]. Each group was held at the hospital, and lasted between 60 and 90 minutes.

The interview transcripts were organized and coded using N-Vivo® qualitative software (26). Data collection and initial analysis occurred concurrently, allowing themes and issues from early data to inform subsequent interviews, thus maintaining a clear focus on the salient study question. The interview data were discussed and analytically refined in detail to identify and articulate important themes, patterns, commonalities and disparities, events, perceptions, and understandings illustrating the women's perceptions and experiences related to screening. When reporting participants' quoted comments, S1, S2, S3, etc., refers to the different focus group participants and the FG number refers to the respective focus group.

Results

The mean age of participants was 29 years (range 21–37 yr). Participants were well educated, 17 with a certificate or diploma qualification and 12 with a bachelor degree or higher. Nineteen women were primigravidas, and the others were para 1 or 2. Participants' antenatal care arrangements comprised 12 (34%) at a birthing center, 9 (26%) in midwifery care, 7 (20%) cared for by an obstetrician or registrar, and 7 (20%) in general practitioner shared care.

Women's Understanding of Group B Streptococcus

A striking feature of the women's accounts was how poorly informed they considered themselves to be about group B streptococcus.

Group B Streptococcus: Never Heard of It

Despite its potential seriousness, most participants had no prior knowledge or awareness of group B streptococcus, and for most women, hearing of it as part of the explanations about this study was their first exposure to the term.

S4: Yeah, I hadn't heard about it at all, until the study. (FG6)

S3: This is my third pregnancy and that's the first time I'd heard of it. (FG6)

S1: The first time I heard about it was when I was asked to take part in the study. I didn't know anything about it before then. (FG2)

Other women recalled reading about it in pregnancy information booklets, but their recollections of the detail of written information were fuzzy:

S5: I think I read about the testing of it when I went through the book. (FG4) [This refers to the hospital's antenatal information book.]

S3: Maybe I should've heard about it, but whether I did or not, you know, because they seem to take so many tests, I don't know. (FG6)

Some women remembered the term from experiences during their previous pregnancies but were unaware of other details about their screening. This seemed to have been "just another test" among many.

Sources of Information: "I Was Talking to This Friend"

The women whose awareness of group B streptococcus was more detailed often included a cautionary note about its potentially serious effects on the baby, usually gained through hearing of "a friend," relative, or someone else whose baby had become seriously ill or had even died as a result of it:

S1: I'm a trained childcare worker, and I worked in the baby room, and one of my parents told me about it. I was pregnant and we were just talking about pregnancies, and she actually lost a child to strep B. So that's how I found out about it. (FG4)

S1: I didn't really think about it much until I was talking to a friend who's had two children and with the first one she had the test done and was found that she was positive... and then she was telling me about someone else she knew who had never heard of it and never had the test done, had a baby and the baby died like 9 hours later.... So it wasn't until I heard that, I thought, wow, you know this is really something important. (FG1)

The story of "the friend of a friend," "this woman," or as Howson notes, "the woman around the corner" operates as a powerful "cultural tale" (7, p 207) that acts to bring the previously abstract, theoretical

aspects of group B streptococcus into the realm of human possibilities, and thus closer to the women's lives in ways that hospital information booklets may not. Medicine and nursing have long used this anecdotal, "most memorable case" approach to help students and new practitioners to learn important lessons (18). Thus it is no surprise to find that this more personal knowledge had a strong influence on some women's awareness of the condition.

Sources of Information: Looking for Linguistic Clues

Most women were unclear about group B streptococcus. In the absence of understandable explanations or close personal experience of it, they struggled to make sense of a term, which, as 2 participants noted, belonged to "the category that I couldn't pronounce" (S2, FG4) and "sounded like one of those diseases from the TV ads" (S1, FG2).

S3: I had no idea about it. It just sounded like a common cold to me. (FG2)

S2: Like a disease. Like it was some, like AIDS you think, something along those lines. That's what I was thinking. (FG4)

The women described how they tried to make sense of the term "group B streptococcus" by searching for familiar linguistic referents:

S3: I always associate it to a cold or something like that, obviously a much severer form, but yeah just, maybe it's because it's Strepsils® or something, I don't know. (FG2) [Strepsils are a popular brand of throat lozenges.]

S4: Meningitis or whatever, it had that kind of ring to it. (FG2)

S4: Sounds like meningococcal. (FG6)

It was difficult for the women to gauge the possible severity and importance of the disease. A "strep throat," for example, is a common ailment that causes only minor temporary discomfort, and so it is not difficult to see how another "strep" infection in another part of the body could be seen as equally innocuous. Conversely, the term *meningococcal* meningitis would alarm most parents, and so perhaps something *streptococcal* would be construed as being just as dangerous.

Group B Streptococcus as a Morally Neutral Bacteria: "It Hasn't Got a Sting in the Tail"

We considered the possibility that the women may have perceived the bacteria as having the moral connotations of a condition for which they may have felt "responsible." It is well accepted that women are increasingly being held personally and individually

responsible for fetal health, what Gregg refers to in the particularly litigious United States context as "policing pregnancy" (4, p 67). These women articulated this well:

S2: I always think in terms of responsibility like what did I do, to get that or what did I, what was my behavior like to ... so that I was effectively bad and had, you know how could I have changed it? And how can I change it? I was, I haven't ever thought about that until I'd been pregnant, in terms of such responsibility and such reflection on my own behavior. (FG4)

S1: You're just so responsible, you know that you're responsible, and even if it turns out to be a situation in which you're not responsible. I can't think of a situation in which I wouldn't retrace my behavior to find out what it was that I did to make it happen like that. (FG4)

S4: And socially...very...I mean everyone sort of reminds you of your responsibilities.... I do, I think if there was something wrong with the baby, there would be that feeling from other people and from yourself that it was something you ... yeah, there was something you did to contribute to it. (FG4)

Although the medical and technological potential for early detection of problems during pregnancy brings many benefits, researchers have cautioned that the increasing scrutiny of women during pregnancy (and even preconception) also carries costs (4,7,19). Foucault scholars, in particular, point to screening and monitoring as being extremely powerful technologies of surveillance. They can be so effective that not only can the health and legal systems then justifiably involve themselves in governing pregnancy, but women may also feel the force of wider public scrutiny of their behavior and decisions. The zenith of surveillance medicine is, of course, where women feel the need to monitor and survey themselves constantly, since "everyone" is there and ready to "remind you of your responsibilities," owed almost entirely to the unborn baby.

We also explored whether or not women possibly perceived group B streptococcus as similar to a sexually transmitted disease. Although staff were careful not to describe it as an "infection," its association with rectal and vaginal bacteria, which were tested for by taking swabs and which could be treated by antibiotics, created the potential for misunderstanding. We appreciate the distinction in group B streptococcus between "having an infection" and having the body "colonized" by normal commensals. We also suspect, however, that such a distinction may not be immediately obvious to many women. One woman highlighted this issue:

S3: But yeah, I mean I probably didn't realize the seriousness of it either. And I wonder how do you get it? Like is it a STD? (FG7)

The initial awareness of group B streptococcus engendered by participating in the study caused concern in some women, there was little evidence in the women's accounts of a "blame and shame" discourse which might have indicated that they saw it as having the "moral" overtones which characterize other genital area infections:

S1: Yeah, I thought the same way about it. I thought, oh well, you know, it's not, it hasn't got a sting in the tail that's OK. It's something that people are not going to shout you down about. (FG4)

S1: (People would) sort of look at you and go, what's that, you know it's not to take three steps away from you. (FG4)

Two attributes of group B streptococcus distanced it from the moral censure connotations that often accompany other conditions mentioned, such as herpes or human immunodeficiency virus. One was its comparatively low public profile, and the other was the perception that it was eminently treatable and thus transient:

S2: I don't think it would be an issue because it's, you know, treatable...it's not going to cause any moral dilemma if you're positive or negative. (FG5)

Another element alluded to by participants was the unpredictability of acquisition. Unlike conditions that can carry moral overtones of blame and shame, the women understood group B streptococcus as haphazard and random, and thus not something they had "brought upon themselves." As this woman explained:

S1: ...because Pap smears are, and things like that are so routine now....Well, I certainly don't feel as if it's some reflection on me that I'm having a Pap smear. Whereas if I went to have a herpes test, that would be quite different. (FG4)

Understanding Seriousness and Risk

Important consideration in any screening program is how those being screened perceive the seriousness of, and risks associated with, the condition for which screening was being done. We therefore asked participants how seriously they viewed the risks associated with group B streptococcus.

A Serious Business?

Seriousness and risk are integral to the understanding of prenatal screening. During pregnancy women try to achieve a balance of a complex set of understandings, responsibilities, and expectations, which can determine *how* pregnancy is perceived, for example, as a time of personal growth and happiness or of risk and danger. Most participants viewed group B streptococcus, at least initially, as fitting within a simple model of "diagnose/medicate/cure," where

screening was merely one of many tests that they rather passively experienced as they progressed through pregnancy. The bacteria was harmless to them but possibly dangerous for the baby, but it was relatively easy to detect and once detected, antibiotics would solve the problem:

S4: Just that it can affect the baby at birth, and that you'd have to have a course of antibiotics to prevent the baby getting meningitis or pneumonia or death. (FG1)

S5: I mean it was just sort of like another test, you'll have this test and, if you find that you are positive to it you'll be given an injection for it and that'll be fine. So it wasn't really that major an issue. (FG1)

Other women, however, were aware that this could be more serious for the baby and had heard or understood that a baby could actually die from early-onset group B streptococcal disease:

S3: If the baby contracted it and got seriously ill from it, then there was a potential that that baby could die. (FG7)

A Risky Business?

The concept of risk is multifaceted, involving the calculable, the predictable, and the perceptual. There are important differences between objective epidemiological risk and what Gifford calls "lived risk" (20, p 220). In this vein, Lupton calls for this concept:

...a move away from viewing risk perception as a rational cognitive process that can and should be influenced by the external efforts of health promotion, to more critical and theoretically informed investigations into the meaning of risk to individuals in contemporary society (21, p 433).

We thus asked participants to comment on how they had heard about and understood the associated risks. The common perception was that this posed a minimal risk:

S2: I thought the risks were fairly low. (FG1)

S4: Rare. Something, well, that happens to a minority rather than a majority. (FG2)

S2: Between 2 and 5 percent or something, is that? (FG2)

Although participants may have understood this condition as a statistically rare if dangerous infection, lived risk proved more problematic as they tried to translate the more detached and objective figures of risk and probability into more meaningful personal terms, showing how "lay assessment and evaluation of risk is a social process, not a scientific, technical one" (20, p 215). One woman articulated this tension clearly:

S1: This is what's important because X amount of people in 100 will be affected so there's a fairly good chance, and so you should have the test. That's how information seems to be generally presented to you here.... But then your feelings come in to it as well...Then that sort of becomes very difficult to weigh up. (FG4).

Appreciation of lived risk did not mean, however, that “facts and figures” were unimportant. Several participants described how they valued being given “the numbers,” since these were another important piece of the jigsaw that was assembled to help them make the best choices:

S3: The ratios, I do think about them, definitely. They mean something to me. (FG5)

S1: I personally would prefer some statistics; it might help me to make my mind up a little bit....knowing the risk or the percentage is a lot better for me because I can assess it a little bit easier. (FG6)

Personalizing Risk

Women described how they would try to make sense of incidence rates and relative risks by personalizing abstract numbers into scenarios that were more real for them. One woman worked with people with disabilities, and her experiences had a major influence on how she viewed the possibility of having a baby with a disability:

S3: I work with young adults with intellectual disabilities from mild to very severe. And so I look at it and go, this could happen to my baby, and I will not know until my baby's born....so for me it's an issue. And it's something that I worry about. (FG5)

Another described translating figures into more personal and meaningful possibilities regardless of whether these strategies were “rational” or not:

S2: Sometimes I do a number count which I know is incredibly stupid ... you go, 1 in 10, I've got 9 friends with healthy kids, my number's up. You know it just doesn't work like that. (FG5)

S2: Yeah, I think when the numbers get to, you can look around a room and count that many people, and say that it would have affected several people in that room that's when you start thinking this is something to really think about. (FG5)

The Baby: “It's Different When You're the One Carrying It.”

Women recollected stories of other people to try to put a human face to the bacteria and its possible effects. More commonly, however, participants centered the discussions of associated risks on the health and well-being of their baby. Thus the welfare of the baby became the touchstone for all decisions and understandings about the condition:

S4: When people normally talk about 1 in, whatever, then it seems I can, rationalize it and think well, realistically the chance isn't very great.... Being pregnant and, then asking me that, I think it's different.... I feel more, like, do

anything, to find out, sort of thing. That's not a rational thing anymore.... It's different when you're the one carrying it. (FG4)

These women remind us that perceptions of risk are influenced by more than statistical ratios. The “what if it is *your* baby?” question looms large for women in relation to screening, especially in the light of the personal responsibility imperative that seemed to make them exclusively responsible for not doing “anything wrong” that might compromise the baby's well-being. This meant always putting the baby's needs before their own, and essentially agreeing to anything that was proposed as being “best for the baby.” As one participant explained:

S6: You'd just do anything for your baby. I mean you just would never put it at risk. (FG6)

Discussion and Conclusions

This study explored women's experiences and perceptions of group B streptococcus and its associated screening at a time when pregnancy and childbirth are becoming subtly and overtly characterized as uncertain and dangerous events. The more obviously litigious aspects of risk and danger are familiar, including debates over increasing professional practice and health insurance costs, “wrongful life” lawsuits, and the increased involvement of the state in regulating reproductive choices and technologies. Less newsworthy are the changes influencing how women may come to understand pregnancy as a state of increasingly embodied risk to be managed and their own pregnant bodies as sites where various competing interests will all stake their respective claims to know and do what is best.

We cannot generalize widely from this comparatively small-scale qualitative study, but we maintain that much can be learned from a rich and detailed account of a particular context and of the experiences of even small numbers of participants. This study suggests some broad commonalities of women's experiences that merit attention. The answer to the question, “What can we possibly learn from a small-scale study?” is surely “as much as we can.”

Echoing the findings of earlier screening studies, we showed that women's understanding of this bacteria and its associated screening continues to be generally poor—largely because it had either never been mentioned or had only been cursorily described. This became a more serious issue for women when their life experiences gave it a human context, for example, when they knew of a friend or colleague whose baby had been affected by the

bacteria. The women's understanding of risk and danger highlighted that risk perception is not primarily a rational, neutral, statistical measurement, but rather a subjective, emotional, and often ambiguous concept where "your feelings come into it." This interpretation is not a deficient appreciation of risk that necessarily requires quantitative and epidemiological work to supplant these feelings with more "precise" indicators; rather, it is part of being humans.

Several forces combined to make the decision by women to undergo group B streptococcus screening seem like no decision at all. Given the prevalent climate where "People—doctors, strangers, family members, judges, society at large—feel free to judge and condemn women, figuratively if not literally, for their maternal behaviors" (4, p 68), it was not surprising that women decided to do "what was best for baby." "The best-for-baby rationale is the trump card that pregnant women must play lest it be played against them. Under this imperative it is not difficult to see how women's prenatal screening choices can seem like no choice at all, or in Morgan's memorable phrase "coerced voluntariness" (22). With other screening tests, such as maternal serum alpha fetoprotein, there may be more vexing discussions concerning who is best placed to pronounce what is "best for baby" (2,23–25), but with group B streptococcus screening this seemed clear-cut. Aspects that helped make screening choices easier for the participants were that early-onset group B streptococcal disease was explained as being a potentially very serious, if not fatal, illness that fortunately was simply screened for, easily detected, and then effectively treated. In addition, when this screening is offered as part of prenatal care, as it is at the study hospital, the nature of the process can change from being an optional screening choice with inherent ethical and social implications to being simply part of "the routine flow of prenatal care" (23, p 984). The participants' descriptions of their screening being much like just another test among many that they accepted as routinely as it was offered is further evidence that women will generally accept without question those procedures and tests that are undertaken as part of a trusted institution's standard prenatal care (23).

Both benefits and problems are inherent in this situation. Incorporating group B streptococcus screening into routine prenatal care minimizes some of the difficulties that women face as they are given the often illusory freedom involved in having "choices" to make about their pregnancy. The appeal of choice loses some of its autonomous cachet when it is one that you *must* make, or where you feel that you

lack the necessary knowledge and information to make the best choice, or when the consequences of this choice will directly affect the well-being and even the life of your unborn baby. Gregg is scathing of women's freedom of choice that amounts to little more than the freedom to be blamed and condemned for making a choice that is "wrong" or "inappropriate" (4, p 69). Bundling this screening into the comforting package of routine prenatal care could potentially obscure some of the important social and ethical issues related to screening, such as women's autonomy and treatment options. Against this, however, must be balanced the possible benefit that "routinizing" such screening to render it commonplace could minimize women's apprehension and diminish any potential stigmatization that they may experience should they be group B streptococcus positive. A clear message from women in this study was that, given the pluses of this screening and its few minuses, the "decision" to undergo screening for group B streptococcus was relatively easy for the women to make.

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