“They told me all mothers have worries”, stillborn mother’s experiences of having a ‘gut instinct’ that something is wrong in pregnancy: Findings from an international case control study

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Title:
“They told me all mothers have worries”, stillborn mother’s experiences of having a ‘gut instinct’ that something is wrong in pregnancy: Findings from an international case control study.

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Introduction

Counselling pregnant women is a process of two-way interpersonal communication, one aspect of which involves the maternity care provider (MCP) informing a mother about signs of possible problems that she may encounter during pregnancy, and in turn she informs the MCP about any symptoms she is currently experiencing. When a woman reports physical symptoms such as itching, headache, or epigastric pain, these may identify an obstetric complication (e.g. preeclampsia or obstetric cholestasis) which can be managed according to recognised clinical guidelines. However, sometimes women report symptoms that can seem more nebulous and therefore may be more difficult for clinicians to interpret and manage. One such instance is when the pregnant woman expresses intuitive feelings about her pregnancy.

Intuition is difficult to define because it encompasses the ability to understand something instinctively, without the need for conscious reasoning (Gore and Sadler-Smith 2011). Intuition is commonly described in terms of the person having a gut instinct, hunch or sixth sense. Mothers can use maternal intuition to protect and advocate for their child often in the face of no ‘evidence’ or even ‘evidence’ to the contrary (O'Leary and Warland 2016) and in some cases this informed insight can even save their child’s life (Davis-Floyd and Fishel Sargent 1997; McPherson 2006; Staton Savage 2006). Indeed, care providers, especially paediatricians, often rely on the mother’s thoughts in order to test how concerned they need to be about a child’s illness, especially if a child is preverbal (Cooke 2012). However, because intuition is linked to feelings, senses and hunches, it has the potential to be easily discounted and devalued in the current biomedical model of illness. In fact, even if the MCP takes maternal intuition seriously it can be challenging to respond to, as there may be nothing objective to measure and no symptom to be recorded or treated.

Although the notion of maternal intuition occurring in pregnancy has received limited attention, in an international cohort study of 1,714 women who had experienced a stillbirth, 65.5% of respondents experienced a "gut instinct" that something was wrong during their pregnancy (Warland et al. 2015). This is in agreement with other studies which found that mothers of stillborn babies can report a “gut instinct” that something is wrong, while still pregnant, well before the death of the baby. For example, 392 of 614 (64%) Swedish mothers indicated in a web-based questionnaire that they had had a premonition that their stillborn baby was unwell, (Erlandsson et al. 2012) and two qualitative reports from this group provide
further insight into this experience (Malm, Lindgren and Rådestad 2011; Trulsson and Rådestad 2004). Together, these findings suggest that women may have intuitive feelings about the wellbeing of their baby, which relate to stillbirth. As the incidence of stillbirth after 28 weeks, in most high income countries ranges between 2-6 per 1000 births (Flenady, Middleton, Smith, et al 2011), this is an important phenomena which merits further exploration. Here, we report the findings of an international case control study in which women were asked about their intuitive feelings about their pregnancy.

SUBJECTS AND METHODS

Methods
The objective of this study was to describe and/or explore ‘gut instinct’ that something was wrong in women who identified that they experienced gut instinct during pregnancy. This case-control study was run alongside an international cohort study previously described (Warland et al. 2015). Women either took part in the cohort or case-control component of the study depending on how recent their stillbirth was, if it was within 30 days women participated in the case-control study. Details of the case-control study, have also been reported previously (Heazell et al 2017). In this study cases were women who had delivered a singleton stillborn baby with no evidence of congenital anomaly at or greater than 28 weeks gestation less than 30 days prior to completing the survey. Controls were either still pregnant (greater than 28 weeks) or had recently delivered a living baby less than 30 days before they completed the survey. All participants had to be 18 years or older and fluent in English. Women with multiple pregnancies, neonatal death, or fetal loss/live birth prior to 28 weeks gestation were excluded. The participant flow diagram (Figure 1) shows the number of cases and controls in the study (n=153 cases, n=480 controls) and those who answered the ‘gut instinct’ question (n=146 cases and n= 234 controls) as well as those who provided comment data (n=84 and n=27) on their experiences.

Survey Design
Data were collected via an international, anonymous, web-based survey which we have previously reported (Warland et al. 2015). The survey consisted of questions related to established and novel risk factors for stillbirth including sleep position and fetal movements. The questionnaire was developed with women who had experienced a stillbirth; a question about intuition was included because this was raised by several parents at the Stillbirth Summit where the study was conceived (Mitchell 2015). The questionnaire applied a mixed-
methods approach to both quantify the frequency of this symptom and then explore the feeling in more depth. The question specifically asked was: “During this pregnancy did you ever have a "gut instinct" that something was not right?” Participants could choose an answer from the following options: Yes/No/Don’t Remember. If participants answered “yes” they were provided with a "free text" comment box response labelled “If yes please describe.” To provide consistency in recall, both the cases and controls were asked this question after the baby’s birth.

Ethical Approval
This study was approved by the Institutional Review Board (IRB) of the University of Michigan (HUM#00063655). Prior to gaining access to the survey, participants were informed about the purpose of the study (to look for trends and risk-factors for stillbirth) as well as contact information for a stillbirth support group (First Candle) if they became distressed whilst completing the survey. Informed consent was gained by the participants reading an online participant information and consent form and clicking an “I agree” button prior to gaining access to the survey.

Participants
Participants were recruited by responding to social media, internet advertising and word of mouth advertising between September 2012 and August 2014.

Analysis
Data were cleaned by two authors (JW and LMO) prior to analysis. The fixed option question “During this pregnancy did you ever have a "gut instinct" that something was not right?” was analysed using $\chi^2$ to determine unadjusted odds ratio (OR) with 95% confidence intervals (CI). The level of statistical significance was set at $p < 0.05$.

Comment data from the intuition question mainly consisted of one or two sentences. These were analysed using ‘summative content analysis’ outlined by Hsieh and Shannon (Hsieh and Shannon 2005). Firstly, the data set was searched for recurrence of certain words or content. Recurring words were then identified and quantified with the purpose of understanding the contextual use of the words. Once these words were identified, interpretation of their meaning in the context they were given occurred. The data were then coded by two independent investigators (JW and JB) who then reached agreement on the common recurring
words which were then grouped into “themes”. As is often the case with this type of data analysis some of the longer comments fell into two or more of these themes.

Results
Overall, 110 (75.3%) of the 146 cases and 28 (12.0%) of 234 live born controls answered “yes” to the question regarding whether they had ever had a “gut instinct” that something was not right. (Figure 2). The unadjusted odds ratio from the logistic regression model was OR 22.5 (95% CI 13.0-38.8 p=0.001).

Of the 110 cases and 28 controls who answered “yes” 84 (76.4%) cases and 27 (99%) controls also gave a text response. The following four main themes emerged:

Themes:
- When the gut instinct occurred
- How the gut instinct made the woman feel
- Dreams and other related phenomena
- Reassured by someone or something

Each of these main themes had several subthemes described in detail here. The percentage given is the percentage within the comment data received i.e. percentage response from the 84 cases and 27 controls.

When the gut instinct occurred.
This theme was illustrated by the participants indicating when in their pregnancy the gut instinct occurred. There were five sub-themes within this main theme:
- Gut instinct in response to change in fetal movement

Thirty-four (40%) of the cases and 7 (26%) controls who made a comment about when the gut instinct occurred indicated that it was triggered by concern regarding a change in fetal movement for example:
  - When my baby wasn't moving as much I just had a sick feeling thinking that something wasn't right (case)
  - I thought that the times when he would be extremely active were unusual but my doctor said he was just a very busy boy (case)
  - He would be very still for days at a time - went to L&D [labour and delivery] for monitoring (control)
A lot of my pregnancy was spent anxious and convinced she was going to die because of hiccups, slowed movements, funny Doppler readings, spotting etc... I was sure she wouldn't make it, she has. (control)

- Gut instinct occurring throughout pregnancy:
  Eighteen (21%) of the cases and 1 control who gave a comment response indicated that the ‘Gut instinct’ had been present for most or all of their pregnancy. The following participant quotes were typical:
  - From the moment I knew I was pregnant... Increased as we neared the end (case)
  - I had a lot of anxiety throughout the entire pregnancy, always thinking there was something wrong with me (case)
  - It is hard to explain - I just had this overwhelming sense that something was not right from early on. My OB [obstetrician] said it was not uncommon to worry (case).
  - Not so much that something was wrong but that something would happen [miscarriage, stillbirth, abnormal baby] (control)

- Gut instinct occurring the day/night before birth:
  20 (23%) of cases and 3 (11%) of the controls indicated in their responses that the Gut instinct occurred the day or night before the baby’s birth:
  - The night before I went into labor, I knew something was wrong, but I thought I was overreacting (case).
  - The last night of pregnancy I mentioned to husband that I "didn't feel right" but couldn't explain the feeling (case)
  - Night before delivery woke and was positive that if he was not born shortly that he would be stillborn (control)
  - Before I went in to the hospital I felt something was wrong (control)

- Gut instinct due to a specific experience
  A small group of both cases 12 (14%) and 10 controls (37%) described their gut instinct in association with something physical occurring such as pain or vaginal bleeding, this was the only theme that was more prevalent in controls than in cases:
  - Had a terrible pain the day before that really scared me but I had been to my doctor that day and he said everything looked ok (case)
The whole last month did not "feel right," too many contractions, bloody show, off and on for three weeks prior to delivery, felt like I was in labor all the time. (case)

After having low PAPP- I knew that something would go wrong, I knew I would not make it to my due date (control)

I thought I was having a miscarriage in the beginning and the doctors found a bleeding in my uterus. (control)

How the Gut instinct made the woman feel
This theme described by 16 (19%) cases and 2 controls (7%) shows how the woman explained the instinct to herself, how she justified how she was feeling, in short, what she put the feeling down to. In the cases this was either due to “first time pregnancy” “hormones” or “natural” worry /anxiety:

Being that this was my first pregnancy and she (Doctor) reassured me that everything was fine, I tried to put it to the back of my head and blamed the "gut instinct" on my hormones (case).

I brushed it off as just a nervous first time mom (case)

I thought every pregnant mother would worry to some extent about anything going wrong (case)

Based on historical pregnancies...I was terrified (control)

Dreams and other related phenomena
This theme describes a group of experiences that included participants narrating episodes of precognition, premonition and dreams (n=12, 14%) cases and one control described these experiences:

I had a funny dream which made no sense, and so I ignored it. In the dream I was in labour in the hospital but I was crying. I thought it was because I was scared of labour. I wish I'd paid attention TO MYSELF! (case)

Told husband I was worried she would die. The following night I dreamed her birth announcement: [name] was born sleeping.(case)

I never prepared the nursery (case)

I was able to sell all of my son's clothes in a garage sale, but could not sell my maternity clothes...since I had a feeling I would need them again...although this was supposed to be my last pregnancy. I could not understand why I was feeling that way, since I
have one son and this was supposed to be our second and it was a girl and I thought I was done with pregnancies (case)

- At 19 weeks I felt something wasn't right. Went for a check up and a scan showed my cervix had shortened and funnelled significantly. An emergency cerclage was fitted that day (Control).

**Reassured by someone or something**

Participants (n=10 cases, 12%) indicated that they were reassured by someone or something regarding their gut instinct. None of the controls mentioned this kind of reassurance.

- *I knew something was wrong but when I went to see the midwife, she found a heartbeat and told me everything was ok and not to worry. Worst mistake of my life. I should have listened to my body to know something was wrong, not her [the midwife] (case).
- *When he was so quiet the last few days I was uneasy about it but my doctor didn't seem concerned (case)
- *When she stopped moving I was worried. But, my husband was very reassuring. He reminded me how my babies usually “settle in” and move less at the end. That put my mind at ease a little (case)
- *Instead of acting on my worries, I tried to suppress them in order to accommodate family who told me to just stop worrying and that everything would be okay (case)

**Discussion:**

Our findings suggest that maternal intuition may be present in pregnancy. A significant proportion of women who go on to experience stillbirth reported having an intuitive feeling that something was wrong from the beginning of pregnancy. When a woman perceived a change in fetal movement this also often made her suspect that something was wrong. Women also reported premonitions and dreams about their baby’s wellbeing and that if they tried to tell someone about these feelings that they were often reassured and their concerns discounted.

Our findings complement and extend other studies describing maternal intuition in women who have experienced a stillbirth. Another web-based questionnaire (Erlandsson et al. 2012) which explored 614 Swedish women’s experiences prior to and following stillbirth. Of the 614 respondents, 392 (64%) reported “a premonition that their unborn baby might be unwell”. Many of the women’s experiences described by Erlandsson et al. were also
comparable. For example, they indicated that their premonition occurred upon noticing changes in fetal activity (including strength, frequency increase and decrease, and pattern changes). Interestingly, participants in this Swedish study also reported experiencing a long-standing perception that something was wrong from the beginning of the pregnancy, which was described as “uncertain from the start.” Many of the participants also described dreams that there was something wrong and often told someone about their concerns and were reassured.

In addition, two qualitative studies have also reported common themes regarding intuition. One study of 12 Norwegian women “almost all” participants had had a premonition that something was wrong with their baby before they contacted the hospital (Trulsson and Rådestad 2004). Many of these reported that a change in their baby’s movements had triggered this concern. Another qualitative study from this group interviewed 26 mothers and similarly reported that 22 of the mothers had a premonition that something had happened to their unborn baby prior to receiving the information that the baby had died (Malm, Lindgren and Rådestad 2011). However, both of these studies were conducted well after the baby’s death and asked their participants to report on their recollection of the time leading up to the diagnosis of their baby’s death, rather than asked about feelings that might have occurred during the entire pregnancy, as occurred in the current study. Nevertheless, our findings also suggest that noticing a change in fetal movements and the mother feeling something is wrong may be somewhat interrelated with cases being more likely to also indicate that they had noticed significantly less movements and/or decreased strength during pregnancy than the control mothers. 46 and 48% versus 16 and 6% respectively).

Schraeder and Fischer (Schraeder and Fischer 1987) suggest that drawing on previous clinical experience is a necessary element of clinical intuition. Similarly, some mothers in our study may have known that their baby was unwell because they had a previous pregnancy and noticed subtle differences between their pregnancies. However, about half of the respondents in this study were nulliparous and they still seemed to have been a gut instinct that there was something wrong as this nulliparous case said: I worried throughout my entire pregnancy. But I seemed to be having an absolutely perfect, healthy pregnancy so I kept telling myself not to worry. So even though I sensed something was a little off, I was very reassured by everyone’s confidence in my pregnancy- I thought it was just normal worries. If I’d really felt like anything was wrong, I would have trusted my instincts- but whatever instincts I might
have had were mild enough to be easily dismissed. This quote illustrates that some women may not have been aware of stillbirth as a potential outcome or that acting on their intuition especially within a biomedical model of maternity care may prove difficult. It therefore behoves the maternity care provider to ask the mother if she feels “everything is okay” to empower her to share her intuitive feelings and thereby to enable the MCP to act to assess fetal wellbeing where it is warranted.

According to the contemporary views about dreams, the majority reflect psychological concerns and preoccupations, and serve other functions including mood regulation (Hartmann 1996) and problem solving (Cartwright 2008). Also modern dream research acknowledges that some category of dreams could also have some prophetic functions (Hastings 1977; Ryback and Sweitzer 1993; Salem 2010). Many of the participants in both this and the Swedish study (Erlandsson et al. 2012) indicated that they had dreams about their poor pregnancy outcome well ahead of the actual event. However, having ‘bad’ dreams’ is quite common during pregnancy with one study reporting that 25% of pregnant women have a ‘terrifying’ dream about the baby (Blake 1993) and others that dream imagery is more frightening during pregnancy (Ablon 1994). It is difficult to know how this may be usefully applied in clinical practice. However, it does point to care providers being alert to the woman when she expresses intuitive feelings, as well as asking her to report concerns and acting on physical signs that can be managed such as appropriate management of maternal perception of changes in fetal movements (Sinha et al. 2007) and assessment and management of reduced fetal growth (Gardosi et al. 2013) and/or conducting a fetal ultrasound (Alfirevic, Stampalija and Gyte 2010).

Many of the participants encountered institutional barriers that they apparently couldn’t overcome, when narrating how they tried to articulate their concerns and seek intervention they commonly used words like “begged” and “pleaded”. For example, I begged to be induced just because I had a feeling. I blame myself for not being more insistent but I also blame my doctor for not taking me seriously. Once again this points to the need for maternity care providers to always listen to a pregnant women’s concerns and requests, addressing them appropriately. To be of use to clinicians, MCPs need to better understand the origins of such intuitive feelings; as a first step research could address whether such feelings have a biochemical basis (changes in pregnancy hormones), physical basis (response to fetal behaviour) or psychological basis (underlying maternal concerns/experiences/anxiety). In the
absence of such evidence, addressing women’s experiences should be on an individual level; if women express strong intuitive concerns that something is wrong with her baby then MCPs should explore this feeling, specifically addressing concerns about fetal activity or wellbeing, which would prompt testing for fetal wellbeing.

MCPs also need to take care to distinguish anxiety from intuition. Many times when the participants expressed concern about their intuitive feelings this was misinterpreted as primary anxiety. Often the participants were told it is “normal to be anxious,” however, anxiety and intuition are distinctly different. Anxiety is a persistent feeling of heightened fear characterised by spending a high percentage of waking hours worrying about something (American Psychiatric Association 2013) whereas maternal intuition in this context could be better described as natural inborn intelligence that guides and supports the pregnant mother to deeply know, without external influence, about her unborn baby’s wellbeing. Maternity care providers should therefore neither minimise nor discount the pregnant woman’s intuitive concerns about fetal wellbeing and should manage signs of anxiety and expression of intuitive concerns differently.

Limitations
These data are not without limitation. The question about gut instinct was asked in retrospect and so it is plausible that some of the participants who had this feeling late in the pregnancy felt something was wrong because of physical symptoms due to their baby dying or being already deceased, that they later interpreted and reported as feelings of intuition/premonition. The group who indicated that their gut instinct was associated with a change in fetal movements may also have been aware, at some level, that their baby was unwell causing them to associate the change in their baby’s behaviour with a gut instinct. However, it should be noted that more than one fifth of women in this case-control study as well as the STARS cohort study (Warland et al. 2015) reported the ‘gut instinct’ occurred from the beginning of pregnancy, well before they could possibly have known or interpreted signs or symptoms of fetal compromise.

Furthermore, our findings may be subject to recall negativity bias (Vaish 2008). This bias causes humans to respond more strongly to negative than to positive or neutral stimuli, such that negative events are remembered more strongly than positive ones. It is therefore possible that the controls may also have had these intuitive feelings and 'forgotten' them prior to completing the survey because of their recent positive birth experience. While this is certainly
possible, it is unlikely to entirely account for the stark difference between the cases and controls recollections. While it is true that both the cases and controls completed this question within 30 days weeks of the baby’s birth/death we consider it unlikely that large numbers of controls would have forgotten this "feeling" so soon after the birth especially as pregnancy and birth is such a memorable event in any woman’s life.

Not all participants provided a response. This is because the question was in the post birth pregnancy outcome section of the survey and 246 of the 480 controls did not return to complete the survey following the birth of their baby. Nevertheless, there was a substantial and statistically significant difference between the “yes” responses of the cases and controls (110/146 vs 29 /234 figure 2) that is difficult to completely attribute to recollection or recall bias. Nonetheless, a prospective study could potentially overcome these limitations by routine collection of information about “Gut instinct” from all women in late pregnancy and again at onset of labour. However, a very large sample size would be required due to the relatively low rate of stillbirth.

Conclusions.
A mother’s perception of fetal wellbeing may well be experienced at both a physical and intuitive level. Maternity research may benefit from a better description and documentation of how the sense of maternal intuition evolves, how it influences maternal behaviours and how others, particularly maternity care providers can best respond when the mother reports these feelings. Also maternity care providers should be open to the possibility that maternal intuition starts in pregnancy and just as it would be unwise to discount the intuitive concerns of a mother for the health of her toddler it may be equally unwise to discount concerns of a pregnant mother about her unborn baby. The findings of this study emphasise the importance of good quality communication between a pregnant mother and maternity care professional, and why continuity of care may be beneficial to pregnancy outcome, as women’s concerns and experiences can be shared within a trusting professional-patient relationship.
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international internet survey of the experiences of 1,714 mothers with a late stillbirth: the 
Figure 1: The participant flow diagram (Figure 1) shows the number of cases and controls in the parent study, those who answered the ‘gut instinct’ question and those who provided comment data.
110 (75.3%) of the 146 stillborn cases (stillbirth less than 3 weeks prior) and only 28 (12.0%) of 234 live born controls (livebirth less than 3 weeks prior) answered yes to this question. OR 22.5 (95% CI 13.0-38.8 p=0.001).

Figure 2: Percentage response to question "During this pregnancy did you ever have a "gut instinct" that something was not right?"