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Communicating Risk in Pregnancy: Supporting Women with Multiple Long Term Health Conditions

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By Sally Darby

The experience of pregnancy and of navigating maternity services can feel daunting and isolating. This is particularly true for women with multiple long term health conditions (MLTC). Many disabled women struggle to find community or support from others who have similar experiences. In 2016 I set up an online community aiming to allow disabled women to support each other through fertility, pregnancy and motherhood. The community is called Mums Like Us and consists of 1500 members on Facebook primarily, but not exclusively, from the UK. I myself have been a frequent and consistent patient over many years since being diagnosed with a severe visual impairment and then Multiple Sclerosis. My interactions with health professionals have generally been very positive but in my experience this is not the case for many women with MLTC.

A particular problem faced by these women is that there is little or no research or clinical guidance on the combination of two or more health conditions with pregnancy, birth and early parenthood. Many women will have to make multiple decisions during their pregnancy journeys, about their care and that of their baby. These decisions will be significantly informed by risk. This means that women may have to carry more of the burden of estimating risks and decision making than they feel equipped for. Drawing on my own experience, plus contributions from Mums Like Us members, I want to examine the purpose and practices of risk communication within this context, considering what types of risks are commonly discussed, how women interpret these communications, and the tools professionals can use to present risks meaningfully and compassionately.

While some women may prefer not to confront the risks unless they arise, it is common for women and their families to want to feel prepared, to know the risks in advance and to feel empowered in shared decision making.[1] When women with MLTC become pregnant, they may already be well versed in the risks and complications that might await them. The journey towards starting a family could have begun with a conversation about risk, be this with a medical professional or a partner. From my own experience I recall discussing risks at length with my husband, specialist nurse team and then my consultants, all before I decided to try and get pregnant. I had many questions about risks to my own health and that of my baby. Effective risk communication can help to ensure women are well-informed and able to make choices that align with their values, expectations, and medical realities.

For women with MLTC, decisions about becoming pregnant or continuing a pregnancy can carry heightened stakes. The aim of effective risk communication is not to sway a woman's decision, but to empower her to make informed choices based on balanced, relevant information. Risk communication is therefore an ethical as well as a clinical process. Best practice risk communication should be tailored to the individual woman and her evolving needs. For women with MLTC, particularly for those facing complex pregnancies, misinterpreting or misunderstanding risk can lead to anxiety or distrust.

Women with MLTC face a wide array of risks both pre-conception and during pregnancy. These risks can include fertility complications, medication that may harm the pregnant woman or the fetus, worsening of existing conditions and the impact of childbirth on overall health. Many women with MLTC may also face a higher likelihood of pregnancy complications like preeclampsia, gestational diabetes, preterm birth, and miscarriage. For the mother, there may be increased risks of flare-ups in pre-existing autoimmune conditions or worsening of mental health.

Medical professionals need to clearly communicate how a woman’s individual health profile might interact with these general risks. For example, during pregnancy I had to decide if the risk was greater for me to continue on medication which held a risk to the fetus, or not, which held risks for my health. This had to be a shared decision between me and my medical professionals where we not only assessed the risks but balanced them against one another.

Risk communication is not received in a vacuum. Each woman’s interpretation will be shaped by her previous experience, emotional state and individual diagnosis. For some, clear communication fosters confidence. Understanding that a 10% risk of a complication still means a 90% chance of no complication can be reassuring. Others may focus on the worst-case outcomes. A woman with health anxiety or past traumatic medical experiences might perceive even low-probability risks as inevitable. Health conditions themselves can influence interpretation. For example, women with depression may experience greater anxiety leading them to focus on risk; those with ADHD might struggle to follow complex numerical explanations, and chronic pain patients may be more focused on potential suffering or loss of control than statistical probabilities. Understanding this interpretive process allows clinicians to tailor their language, clarify misconceptions, and offer emotional support as well as providing much needed information.

Personal experience and anecdotal evidence suggest that risk is often communicated in one of two ways. The first is numerical/ probability based communication that involves presenting statistical data percentages, ratios, or probabilities. For example: “There is a 20% chance of preterm delivery.” The second is contextual/ real world communication framing risk in terms of real-life examples, comparisons, or storytelling. For example: “This risk is slightly higher than what we see in the general population, but many women with your condition go on to have healthy pregnancies.”

Both models have their merits and limitations. The numerical model is clear and evidence based but may not be easily understood by all. The contextual model offers relatability and empathy but can lack precision if not done carefully. Often, the best communication strategies integrate both.

By using verbal explanation, written information or pictorial aids, medical professionals can deliver information about risk in a more patient friendly way. For example, explaining numbers in plain language. Instead of “a 10% risk,” saying “1 in 10 women in your situation may experience this.” Infographics can show levels of risk in a less intimidating and more digestible form and providing take home leaflets or digital resources allows women to revisit the data in their own time and away from the potential stresses of a clinical environment. Regardless of how risk is communicated, it is crucial that it is combined with appropriate emotional support and guidance, either from the medical professional where possible or from external services.

Health professionals can also contextualise the risk, which may offer reassurance to the individual woman. For example, if a person’s risk is twice as high as that of the general population, the risk is perceived as high by the patient, whereas adding that the risk to the general population is only 2% puts it in a more useful perspective. It can also be helpful to contextualise individual risk by comparing her to other women. For example, a nurse telling someone that they have cared for 20 other women who have had successful pregnancies whilst living with their health condition could be of significant reassurance. It can be helpful for health professionals to describe the spectrum of outcomes. Rather than presenting a single risk percentage, discussing the range of possible outcomes and what each might mean in practical terms helps women weigh not just the probability but the severity of potential scenarios.

I posted a question on the MumsLikeUs Facebook group, asking if anyone would be willing to share their thoughts and experiences regarding risk and how it should be communicated. Bethany (not her real name) shared her experiences with me. She described a very contextual and honest approach. She said, “I have weakness in my left leg up to paralysis. I have POTS [Postural Orthostatic Tachycardia Syndrome], FND [Functional Neurological Disorder], and ME [Myalgic Encephalomyelitis - also known as Chronic Fatigue Syndrome]. I was worried being pregnant would affect my ability to walk and that my heart would struggle.” She shared her concerns firstly with her midwife and then with a consultant. “The consultant didn’t know what would happen to me but said from what she had seen, some people made a temporary improvement while pregnant.” Bethany appreciated honesty and transparency as well as the fact that the consultant had made the effort to research her conditions. Despite the consultant being unable to give statistical information, she found this reassuring. During childbirth she was concerned about how pain relief might interact with her health conditions. Again, the doctors were unable to give numerical risks. She continues, “The entire time I was in control. I had choice, but maybe too much. I wanted to be led a bit more… I felt supported but we were clear - it was unknown.”

This testimony raises an interesting question about how health professionals can communicate riskwhen the data to support it is unknown. Without statistics to rely on they have only the contextual model available to them. For women with MLTC this may be a common issue. For example the professional might know the risks for a patient with ME but not who also has FND and POTS. In these situations, women may have to carry more of the burden of the decision making than they would have liked. Shared planning, whereby as comprehensive a risk profile as possible is provided, will support her with this.

Clare (not her real name) had a very different experience. She told me: “for me it was more reassuring when I read about the absolute risks of something vs the relative risks.” Clare found it difficult when “doctors will tell you the relative risk without telling you that the baseline risk is very low and even if it’s ten times more likely it’s still very unlikely.” Clare highlighted that risk described as higher than the average must, therefore, be communicated alongside the data for the general population. She went on to describe feeling that communication sometimes lacked compassion and sensitivity; “[they] tell you that you’re higher risk for things you can’t change or do anything about, which felt quite blaming.” Clare also felt her autonomy over her birth choices was diminished, “I was told I wouldn’t be allowed to use the midwifery led birth centre because I was too high risk.” This neither quantified her risk level nor contextualised it, which, for Clare, was unhelpful. As mentioned earlier, risk communication best practice allows patients to make informed choices but should not be used to dictate those choices to her.

Clare had concerns during her pregnancy about her risk of miscarriage. She was repeatedly told this was 'very unlikely.' At 23 weeks gestation, she was admitted to hospital for an emergency cesarean section, at which point she was given numerical risk communication. As she describes it, "Fortunately he stayed in a bit longer but the rest of the pregnancy was horrendous and every time someone told me a statistical risk I just zoned out because what did it matter how unlikely something was if someone still had to be the unlucky 10, 5, 1, 0.1%?" This experience has left Clare feeling that she can't trust statistics. She, like many others, think risk should be assessed and used together with women to create holistic pregnancy and birth plans.

Both case studies demonstrate the importance of tailoring risk communication to the individual. Effective communication of risk to pregnant women with MLTC must be balanced, neither minimising nor exaggerating potential outcomes. It must be bespoke, considering each woman's health literacy, emotional state, and diagnosis. It is vital that risk is communicated clearly and honestly whilst maintaining compassion and empathy.

To avoid misinterpretation, clinicians should check understanding frequently, provide opportunities for questions, and offer further resources for the woman to look at in her own time. Involving women in decision making doesn't mean burdening them with every possibility, but guiding them through a process of informed, supported choice.

The NHS GPs, consultants, midwives, healthcare assistants and countless others have supported me through the loss of my sight, independence and mobility. They have been there as I lost both my parents and welcomed both my children. The work health professionals do to support us all throughout our lives is invaluable. Compassion and care runs deeply through this work. We all know how stretched crucial health services are. I feel enormously lucky and grateful to have experienced risk communication in the ways I have described in this article.

Author Bio: Sally is a mother of two girls. She is visually impaired and lives with MS. She is the founder of Mums Like Us, a network for disabled mothers and a MuM-PreDiCT parent advisory group member.

Readers may also want to look at: Communicating benefits, risks and uncertainties, a guide from the Patient Information Forum that highlights a range of approaches and tools for unbiased communication of benefits, risks and uncertainties to patients.

[1] Editor's note: 'Shared decision-making' is a term used a lot in healthcare. It is intended to convey the idea that the mother should be involved in discussions about her care and that her preferences should inform those discussions. The term is misleading though. Legally, it is the mother (the patient) alone who makes every decision. This is because her consent is required for any and every aspect of her care from allowing an examination or agreeing to a scan, to accepting the offer of a procedure or a medication, and she is free to decline. She may not realise this or even want this, but she alone is the sole decision-maker. Therefore, in AIMS we use the term 'supported decision-making', and we have this position paper

explaining why we think this distinction is so important.