AIMS For a better birth...

Screening for twins: Why good guidelines matter

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By Stephanie Ernst

Multiple pregnancies come with a lot of additional worries and risks, and I know that a lot of us ask questions about whether the increased screening and the discussion about the risks are essential. Why are we worrying people about something that might not happen and taking away the feeling of control that they have over their pregnancy?

As advocates and activists, we know that there's often little clarity around the reasoning and that things are hidden behind walls of jargon and white coats. That's why it's essential to talk about the relevant guidelines, the quality of the evidence behind them, and where they may need to be updated. Guidelines provide a pathway for better care but can also fall short.

In this article, I'll refer to the Twin and triplet pregnancy NICE guideline [NG137][1] and draw additional information from the ISUOG Practice Guidelines: role of ultrasound in twin pregnancy.[2]

The NICE Guidelines

In 2019, the latest version of the Twin and triplet pregnancy NICE guideline was launched,[1] covering the care that should be offered to pregnant people during pregnancy. This was considered a comprehensive upgrade to previous guideline and utilised the voices of leading experts in twin pregnancy, those involved

in the day-to-day care of twin pregnancies, and lay experts from multiple birth organisations.

Based on new evidence and the surveillance processes, there was a recognised need for these guidelines to be updated. As per the scope for the update:[3]

> *"The surveillance process also identified that the topic of intrapartum care related to multiple pregnancy should be added"*

and

> *"In current practice, a significant proportion of multiple pregnancy losses occur intrapartum, and the risk of adverse perinatal outcomes is greater in multiple than in singleton pregnancies."*

Multiple births are at a higher risk for perinatal mortality and complications (as evidenced by the MBRRACE report of 2021),[4] and the purpose of updating and improving the NICE guideline was to provide better guidance for those working with women with multiple pregnancies and improve outcomes.

This guideline emphasised establishing chorionicity (twin type)[5] early, providing evidence-based information on screening pregnancies appropriately, and referring to expert centres when complications appear.

One notable difference between the NICE and the ISUOG guidelines is the approach to screening and diagnosis. While both emphasise the importance of early identification and monitoring, the ISUOG guidelines provide more comprehensive recommendations for ultrasound assessment. ISUOG guidelines are developed in conjunction with a Clinical Standards Committee,[6] and are subject to rigid peer review, much like a scientific paper. These guidelines are structured differently to NICE Guidelines, with more input from scientific communities, without guidance from the community.

The NICE guidelines, although robust, lack the specificity required for managing twin and triplet pregnancies effectively. An example of this lies within the recommendations for screening for Twin Anaemia Polycythaemia Sequence (TAPS). While there are excellent recommendations in place for screening after laser surgery treating Twin-to-Twin Transfusion Syndrome (TTTS), the guidelines only recommend screening for TAPS when there is a size discordance (difference in size between twins) of 25% or more, cardiac compromise, abnormal umbilical artery or isolated polyhydramnios (polyhydramnios in just one twin).

Although cardiac compromise is present in around 69-72% of TAPS cases,[7] and around 50% of cases present with some size discordance, neither of these are considered primary diagnostic criteria for TAPS. And if we consider the recommendation to screen when isolated polyhydramnios is present, we only have to look at the differences between TAPS and TTTS – *"TAPS is characterised by large inter-twin hemoglobin differences in the absence of amniotic fluid discordances"*.***[8]***

Relying solely on the NICE criteria to screen for this disease may lead to missed cases. It is known that

TAPS presents with no symptoms to the parent,[9] and that routine doppler of the mid-cerebral artery (MCA) is the most accurate way of detecting it, and monitoring disease progression, leaving concern that following NICE recommendations may lead to delayed diagnoses and tertiary referrals for interventions.

Why good screening matters

Quality screening for twin and multiple pregnancies is crucial in ensuring the well-being of both parents and their babies. Recent studies, such as one published in the European Journal of Obstetrics & Gynecology and Reproductive Biology,[10] make it clear that multiple pregnancies come with increased risks, including a higher likelihood of preterm birth and low birth weight. (For more information on the risks within multiple pregnancy, refer to the earlier AIMS article, "Multiple Multiples", by Rebecca Freckleton.)[11] Early and accurate screening helps identify these risks, allowing healthcare providers to tailor their approach and provide the best possible care. Another study, published in the Journal of Clinical Medicine,[12] emphasises the impact of multiple pregnancies on maternal mental health, highlighting the importance of screening not only for physical but also psychological well-being. Quality screening is like a proactive health check for expectant parents carrying more than one baby, helping healthcare professionals anticipate and address potential challenges earlier.

Screening during pregnancy is about potentially improving outcomes. Recent studies[12] emphasise the importance of expanding screening guidelines for twin pregnancies to include conditions like Twin Anaemia Polycythaemia Sequence (TAPS), Twin-to-Twin Transfusion Syndrome (TTTS), and Selective Fetal Growth Restriction (SFGR). These conditions can significantly impact the health of babies in multiple pregnancies. The ISUOG Practice Guidelines provides recommendations for ultrasound screening specific to twin pregnancies. Comprehensive screening for these conditions helps doctors detect and address potential issues early on, potentially saving lives and improving the overall health of babies. So, when it comes to screening during pregnancy, it's not just about routine - it's about being thorough and proactive to ensure multiples receive an appropriate standard of care, which can lead to better outcomes.

Updating Guidelines

The current NICE guideline leaves some gaps in screening for specific conditions in multiple pregnancies and does not provide detailed support for complications in monochorionic twins. These conditions can impact up to 25% of these pregnancies[13] and significantly impact the health of babies. The guideline falls short in giving clear directions to healthcare providers on how to screen for and address these potential issues early, leaving room for missed opportunities to improve outcomes for parents and babies. As we aim for the best care during pregnancy, we must advocate for guidelines that cover all bases, ensuring that every expectant parent receives the support and information they need to make effective decisions about their pregnancies.

NICE guidelines have been criticised for not fully addressing essential aspects of multiple pregnancies. These guidelines, while offering valuable information on general care during pregnancies with more than one baby, may not adequately support the screening for conditions like Twin Anemia Polycythemia

Sequence (TAPS), Twin-to-Twin Transfusion Syndrome (TTTS), and Selective Fetal Growth Restriction (SFGR). We must continue to advocate for screening for these diseases, as they have potentially devastating short and long-term outcomes.

To the future

In conclusion, navigating multiple pregnancies' complexities can be exciting and challenging. The recent updates to the NICE guidelines represent a commendable effort to improve care for expectant parents of twins and triplets. However, our journey toward optimal care doesn't end with guidelines but involves an ongoing commitment to education and advocacy.

As highlighted, guidelines, including those from NICE, might sometimes fall short in addressing all essential aspects of multiple pregnancies. One area that stands out is the non-inclusion of routine TAPS screening, based on technically inaccurate diagnostic criteria as previously discussed in this article. On International TAPS Day, 3rd March 2024, we are drawing attention to the need to update screening guidelines worldwide. This is not only to accommodate the updates in research, but also so that parents and the wider community can be educated about the complications that can happen and make informed decisions about their care during and after pregnancy. Families have the right to all the information available, and to be actively involved in decision making processes. This is more than just a policy, it is now a matter of ethics.[14]

As advocates, it is empowering for us to be educated about the evolving evidence landscape and to actively participate in discussions around the need for updates to screening protocols. We need to recognise the gaps in the guidelines, not as criticisms, but as opportunities for improvement. By staying informed and engaged, we can contribute to the collective effort in building on and updating guidelines, ensuring that they encompass the latest evidence and provide comprehensive support for the unique challenges of twin and triplet pregnancies. It is up to us to proactively advocate for our well-being, fostering a healthcare environment that continually strives for the best possible outcomes for parents and babies in multiple pregnancies.

Author Bio: Stephanie Ernst is a parent of monochorionic twins born at 31 weeks with Twin Anemia Polycythemia Sequence, and founder of the TAPS Support Foundation. As an advocate for changes to screening protocols for monochorionic twins and TAPS awareness, she has been published in several magazines and is a recognised speaker on issues like rare diseases, the involvement of patients in research, and breaking down communication barriers with medical professionals. She has also participated in research as a patient, a parent, and as an author and has spoken at several international congresses on what twin parents need. In her spare time, she cooks, reads, and hangs out with the coolest 10 year old twins ever (and her husband!).

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[1] NICE (2019) Twin and triplet pregnancy - NICE guideline [NG137]www.nice.org.uk/guidance/ng137

[2] ISUOG Practice Guidelines: role of ultrasound in twin pregnancy, Ultrasound Obstet Gynecol 2016; 47: 247–263 https://obgyn.onlinelibrary.wiley.com/doi/10.1002/uog.15821

[3] NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE Guideline scope Twin and triplet pregnancy (update) www.nice.org.uk/guidance/ng137/documents/final-scope

[4] MBRRACE (2021) Perinatal Confidential Enquiry: Stillbirths and Neonatal Deaths in Twin Pregnancies www.npeu.ox.ac.uk/mbrrace-uk/reports/perinatal-mortality-and-morbidity-confidential-enquiries

[5] Editor's note: Dichorionic twins each have their own membranes and placenta, whereas monochorionic twins share a placenta. www.researchgate.net/figure/a-Monochorionic-monoamniotic-twins-MCMA-shown-in-the-top-image-have-1-chorion-and-1_fig1_297592162

[6] Proposal for ISUOG Guidelines www.isuog.org/clinical-resources/isuog-guidelines/proposal-for-isuog-guidelines.html

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