

What do these studies mean for women with AMC?

In short, these studies show that pregnancy is feasible for most women with AMC. While C-section, preterm deliveries and small for gestational age babies are more frequent, many women have uneventful pregnancies and healthy babies.

None of the studies showed evidence that pregnancy worsens joint contractures or functional ability. The risk that a child will also have AMC depends on the presence of a genetic disease. In most women, particularly those with amyoplasia or other non-hereditary forms, the risk of recurrence is low (Hall, 2014). In families with a known genetic variant, a clinical geneticist can provide tailored counseling and discuss testing options.

The findings underline the importance of multidisciplinary care and planning of a pregnancy. Women with AMC benefit from early counseling, ideally before conception, in a setting where obstetric, anaesthetic, and rehabilitation medicine expertise are available. These teams can anticipate mobility issues, anaesthesia challenges, and postpartum needs.

Anaesthetic management deserves particular attention. The questionnaire study showed that epidural placement and surgical positioning can be a challenge in some women with spinal deformities or limited joint mobility. Advance assessment by an experienced anaesthetist is therefore essential.

Finally, the MECA study revealed that the majority of mother of a child with AMC feel movements during pregnancy. The implementation of repeated ultrasound examinations in case of contractures should be improved. Mothers' experiences of reduced fetal movements should lead to follow-up and not be dismissed.

We would like to express our gratitude to all participating patient support groups:



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Summary

Based on the combined findings:

- Women with AMC can have successful pregnancies and deliveries.
- Multidisciplinary treatment enhances support and reduces risks.
- Genetic and pre-pregnancy counseling are strongly recommended.
- Changes in fetal movement patterns should prompt ultrasound follow-up in case of known fetal contractures.
- Implementation of follow-up ultrasound examinations in case of contractures has to be improved.
- Patient support networks remain crucial for shared experience and practical advice.



If you have questions or would like to learn more, please visit the website of your national patient support group for AMC. They can provide information in your own language and connect you with other families who share similar experiences.

You can also contact the investigators of the Amsterdam UMC Expertise Center for Fetal Akinesia Deformation Sequence and Arthrogryposis Multiplex Congenita for more details about the studies: expertisecentrumfadsamc@amsterdamumc.nl

Pregnancy in women with arhrogryposis multiplex congenita (AMC): what recent research tells us.

Introduction

Until recently, healthcare providers and patient support groups for AMC were unable to answer many of the questions women with AMC had about pregnancy, such as whether pregnancy is feasible, and possible outcomes for both mother and baby. This lack of knowledge was mainly because AMC is a rare condition, and the few published studies described only one or two pregnancies at a time.

To fill this knowledge gap and due to a low number of women with AMC per country, three new international studies were carried out in close collaboration between healthcare professionals with knowledge on AMC and representatives from several national patient organizations. The patient support groups participated from the Netherlands (www.spierziekten.nl), Canada/United States (www.amcsupport.org), Spain (www.artrogriposis.org), Germany (<https://arthrogryposis.de/>) and United Kingdom (www.arthrogryposis.co.uk).

The three studies have been published in 2025 in international medical journals and are summarized below concerning results, challenges, and conclusion. These studies aimed to collect and analyze available information on pregnancy outcomes, counseling experiences, and fetal movements in pregnancies affected with AMC. The main findings are summed up here in layman's language for women with AMC and their families, as goal to help to understand what is known, what the challenges can be, and how to use this knowledge to prepare for the future and for visits to a medical health provider.

This summary was created by A. Arduc, MD MSc, and Prof. J.I.P. de Vries, MD PhD, as part of an international effort with patient support groups to make scientific knowledge on pregnancy and AMC accessible to women with AMC, their families, and healthcare providers.

1. Maternal, fetal and neonatal outcomes among pregnant women with AMC: a scoping review.



Authors: A. Arduç, J.I.P. De Vries, M.B. Tan-Sindhunata, F. Stoelinga, R. Jansen & I.H. Linskens.
Journal: Orphanet J Rare Dis. 2025 Mar 17;20(1):129.

Results: In the medical literature, 27 publications were found describing 43 women with AMC their 82 pregnancies. The types of AMC were amyoplasia (18), distal arthrogryposis (20) and other/ unknown (5).

Detailed information about the pregnancies was available for 26 of these women, covering 31 pregnancies, these include:

- Uncomplicated pregnancy and delivery occurred in 16 out of 26 women (62%).
- C-section was performed in 23 out of 31 pregnancies (74%), most of them planned in advance.
- Vaginal birth took place in 8 out of 31 pregnancies (26%).
- Preterm birth (before 37 weeks of pregnancy) happened in 7 out of 31 pregnancies (22%).
- Small for gestational age babies (below the 10th percentile for birthweight) were reported in 6 out of 24 pregnancies (25%).

In 9 out of 82 pregnancies (11%), AMC was already suspected in the fetus before birth based on ultrasound findings. After birth, 35 out of 71 babies (49%) were diagnosed with AMC. From the 72 liveborn babies, two newborns passed away, one caused by AMC and the second by another congenital anomaly.

Challenges: Three women had temporary breathing problems during pregnancy, likely related to an abnormal spine or chest shape.

Conclusion: Although information is still limited, the available studies show that many women with AMC can have uncomplicated outcome of their pregnancies. Caesarean section is more common, and preterm birth and smaller babies occur slightly more often than in the general population.

2. AMC and counseling before and during pregnancy: a questionnaire study.



Authors: A. Arduç, J. Slootbeek, J.I.P. de Vries, M.B. Tan-Sindhunata, F. Stoelinga, B. Sawatzky, I. Filges & I.H. Linskens, for the Arthrogryposis and Pregnancy Study Group.
Journal: Orphanet J Rare Dis 2025, 20, 378.

Results: A questionnaire was completed by 53 women with AMC who were asked about their preferences and experience concerning childwish, pregnancy and parenthood. About two-thirds of them, 34 out of 53 (64%), had been pregnant and together they had 45 children. Mode of delivery:

- Vaginal birth in 15 out of 45 deliveries (33%).
- C-section in 30 out of 45 deliveries (67%), and most of these were planned in advance.

Almost all women with AMC described their pregnancy and childbirth experiences as positive. None of the 45 children born in this study were affected by AMC. Nearly all women (45 out of 47, or 96%) indicated that they would have liked to receive pre-pregnancy counseling, meaning a consultation with healthcare professionals to discuss pregnancy plans, chances, and possible risks. Ideally, they preferred this counseling to be provided by a gynaecologist from the age of 18 years or older.

Of the 53 women, 39 (74%) stated they would had liked to see a genetic specialist to better understand why they have AMC and whether their child could inherit it. They also wanted care from a team of professionals – including gynaecologists, anaesthetists, rehabilitation doctors, genetic specialists, neonatologists, and midwives – who have knowledge on AMC and can guide pregnancy and birth safely together. Many also hoped for more awareness and continuity of care among healthcare providers.

Challenges: A few women experienced some medical challenges during childbirth related to AMC:

- In 4 out of 45 deliveries (9%), there were difficulties placing an epidural for pain relief because of spinal or joint limitations.
- In 3 out of 45 deliveries (7%), additional time and adjustments were required to achieve the appropriate positioning on the operating table.

These situations were manageable and did not lead to serious complications for mother or baby.

Conclusion: Pregnancy is feasible and generally safe for women with AMC when supported by early counseling, careful planning, and teamwork between specialists.

3. Maternal experience of fetal movements from a child with AMC: MECA survey



Authors: A. Arduç, I.H. Linskens, C.U. Dussa, H. van Bosse, S. Lemin, B. Sawatzky, I. Filges, J.I.P. De Vries for the MECA Study Group
Journal: Early Human Development 2025, 207,106308

Results: In the past, many healthcare providers believed that babies with Arthrogryposis Multiplex Congenita (AMC) move very little or not at all during pregnancy. However, mothers from AMC patient support groups shared more varied experiences. Earlier publications on fetuses with contractures advised follow-up ultrasounds to exclude the development of amongst others AMC.

To learn more, researchers carried out the MECA survey, which included 170 mothers of children with AMC. Of these, 118 mothers (69%) had also been pregnant with a child without AMC, making it possible to compare the two situations.

Movements during pregnancies affected by AMC:

- 75% of mothers felt fetal movements.
- 69% felt movements every day.
- 63% said the movements stayed stable throughout pregnancy.
- 42% described the movements as “normal.”

In comparison, movements during pregnancies without AMC:

- 96% of mothers felt movements.
- 85% felt daily movements.
- 80% said movements were stable throughout pregnancy.
- 89% described them as normal.

Conclusion: The MECA study shows that most mothers of babies with AMC feel fetal movements. Ultrasound follow-up should be done in all cases with contractures and repeated if movements decrease. Combining maternal experiences with imaging helps healthcare providers might recognize AMC earlier and provide better guidance and care.