


Prenatal diagnosis (or lack thereof) of arthrogryposis multiplex congenita and its impact on the perinatal experience of parents: A retrospective survey

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Abstract

Objective: To examine parental experiences during pregnancies affected by Arthrogryposis Multiplex Congenita (AMC) by identifying commonalities, risk factors, and areas for improvement in detection rates, care protocols, and patient experience.

Study Design: An online survey was distributed via AMC support groups on Facebook. Topics included demographics, risk factors, parental recall of sonographic findings, delivery characteristics and neonatal findings. Responses were divided into antenatally detected cases (ADCs) and postnatally detected cases (PDCs). Quantitative responses were analyzed with the Fisher exact test. Qualitative data were analyzed with thematic analysis.

Results: The antenatal detection rate of arthrogryposis was 37%. Decreased fetal movement was reported by 53% and early bleeding by 21%. Sonographic findings in ADCs included clubfoot (83%), clenched hand (51%), decreased fetal movement (50%), elbow contracture (51%), and knee contracture (46%). Among ADCs, 29% delivered vaginally and 71% delivered by cesarean versus PDCs (44% vaginal, 56% cesarean). Neonatal intensive care unit admission rate was 63%. Bone fracture occurred in 9%. Detection led to a planned change in delivery mode in 33% and location in 50%. Among ADCs, 17% felt their concerns were not adequately addressed versus 43% of PDCs.

Conclusions: Antenatal detection of arthrogryposis was low. We propose enhanced screening criteria to aid prenatal diagnosis and promote utilization of more robust practice guidelines.

Key points

What is already known about this topic?

- The antenatal detection rate of Arthrogryposis Multiplex Congenita (AMC) by ultrasound is low.

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- Risk factors include extrinsic (uterine/placental) factors and intrinsic (fetal neuromuscular and genetic) factors
- Guidelines for prenatal care following prenatal detection have been proposed but are not yet routinely recommended

What does this study add?

- Our data reproduce previous detection rates and risk factors and identify additional factors
- Evaluation of fetal movement is an underappreciated tool in the detection of AMC
- Antenatal detection impacts the mode, timing, and location of delivery
- Parental experiences have not previously been reported and are important considerations for utilization of published care guidelines

1 | INTRODUCTION

Arthrogryposis, also referred to as Arthrogryposis Multiplex Congenita (AMC), is defined as joint contractures in two or more body areas that are present at birth. Contractures develop as a result of fetal akinesia during critical weeks of limb development and usually involve the extremities but may also include limitation of full range of movement of the jaw, neck, and spine.¹ AMC is not considered a specific diagnosis but rather an umbrella term referring to a condition that may be present in over 400 different diagnoses with a wide range of outcomes. The incidence of AMC is approximately 1 in 3000 live births, which would equal approximately 1220 births annually in the U.S.^{2,3} The most common type, Amyoplasia, has a frequency of one in 10,000.¹ Although considered rare by many, the overall incidence is comparable to other congenital conditions such as Trisomy 18 (1 in 5000 live births), Trisomy 13 (1 in 5000 live births), congenital heart disease (8 in 1000 live births), and spina bifida (1 in 5000 live births).^{4–6} Screening for these conditions and others such as cystic fibrosis, Fragile X Syndrome, and Spinal Muscular Atrophy has become a common part of routine prenatal care by ultrasound, non-invasive prenatal testing and genetic testing for carrier status in parents.

Despite the similar incidence of AMC, there is no standard protocol for prenatal screening for AMC or disorders of fetal movement in general. The American College of Obstetrics and Gynecology (ACOG) and The American Institute of Ultrasound in Medicine (AIUM) recommend an initial routine screening ultrasound in the first trimester to evaluate dating and number of fetuses and an anatomy survey at 18–20 weeks wherein the required documentation is merely the presence of the extremities without mention of shape or movement.^{7,8} Previous studies have demonstrated that isolated movement of the fetal limbs can be seen sonographically as early as 9–10 weeks gestation and *abnormal* fetal motor and postural findings can be detected as early as 11–12 weeks.^{9–11} Pregnant mothers have reported decreased or abnormal fetal movements in up to 67% of affected pregnancies. Despite this, prenatal diagnosticians have failed to detect AMC prior to birth in 47%–75% of cases.^{12,13}

This retrospective observational cohort survey was developed to collect quantitative data regarding pregnancies affected by

arthrogryposis and to qualitatively appreciate parents' experiences during their antenatal, intrapartum, and postpartum care. The results compare antenatally detected cases (ADCs) to postnatally detected cases (PDCs) to search for commonalities and risk factors and to examine the impact of the detection of arthrogryposis (or lack thereof) on the prenatal care experience. This is done with the goals of raising awareness and developing improved protocols and resources.

2 | METHODS

A survey in the English language was created on an online platform ([SurveyMonkey.com](https://www.surveymonkey.com)) and distributed via social media (Facebook). Eight Facebook groups supporting families and people with arthrogryposis were identified via the Facebook search function, including *Arthrogryposis Moms*, *AMC Families*, *AMC Support Inc*, *ARTHROGRYPOSIS*, *The Arthrogryposis Group (UK)*, *AMC*, *AMC (unser kleiner sonnenschein)* and *Take Time for AMC*. Posts to these groups included a brief explanation of the survey, a hyperlink with which to participate, and an encouragement to share the survey with other AMC friends and family who may not be members of the targeted Facebook groups. Reminder posts were made at regular intervals throughout the enrollment period. It was assumed that people may be members of more than one support group and posts included a comment that any individual should respond only once.

The anonymous survey included 57 quantitative and qualitative questions about respondents' experiences during the antepartum, intrapartum, and postpartum stages (Appendix A). If arthrogryposis was not detected until birth, the program used skip logic to automatically move the respondent past questions regarding their detection-specific care during pregnancy to questions regarding only the intrapartum and postnatal phases of the pregnancy. The survey was submitted to our institution's Human Research Review Board and deemed exempt as no personal identifying information was collected.

Biological parents of children with a diagnosis of arthrogryposis were eligible to participate in this survey if they were at least

18 years of age at the time the survey was conducted. Exclusion criteria included age younger than 18 years, not being the biological parent, or cases that did not involve at least two joints or body areas. The method of diagnosis by either medical professional or parental supposition was not specified. The first question provided a description of the survey and obtained consent to participate. Responses were collected over an 8-month period from March 2020 to October 2020. Quantitative responses were analyzed with the Fisher's exact test with the level of marginal significance set at a p value less than 0.05. Qualitative and free-text responses were reviewed by thematic analysis. The design of the survey did not require a response to each question and thus the denominators varied slightly among questions, though never by more than 2%.

3 | RESULTS

3.1 | Respondent characteristics

Of the 379 total respondents, 13 were excluded from not being the parent and two cases were excluded from involving only one joint. An additional 63 started but did not complete all questions, leaving a total of 301 responses for analysis. The demographic characteristics of the respondents are summarized in Table 1. Responses were received from 23 different countries on six continents. The majority of the participants (77%) were 18–34 years old during the subject pregnancy. Nearly 50% of the subject pregnancy children were 5 years old or younger, and the oldest was over 20 years. Respondents identified their race as White or Caucasian (78%), Hispanic/Latino (10%), Asian (3%), Black (2%), or Other (6%). Types of health insurance included a mix of commercial/private (45%), government-funded (32%), military insurance (3%), or none (20%). The most common type of AMC was Amyoplasia (36%) and 26% of respondents stated no specific type of arthrogryposis had been determined.

3.2 | Detection of physical findings of arthrogryposis

Antenatal detection of arthrogryposis occurred in 37% of pregnancies (prior to 18 weeks (9%), 18–23 weeks (23%), and after 24 weeks (5%)) and was **not** detected prior to birth in 63% of affected pregnancies (189 out of 301). Among pregnancies within the last 5 years, the antenatal detection rate was 46%.

Among ADCs, the most common ultrasound finding recalled by respondents was talipes equinovarus, or clubfoot (83%). Joint contractures (either flexion or extension) were noted in the elbows of 51% and knees of 46%. Also noted were little or no fetal movement (53%), clenched hands (51%), and the fetus remaining in the same position throughout pregnancy (41%). Nearly all ADCs had two or more findings on ultrasound (Table 2).

TABLE 1 Respondent characteristics.

Age of mother at delivery	
Younger than 18	3%
18–25 years	31%
26–34 years	46%
35–39 years	16%
40 years or older	4%
Current age of child with AMC	
0–5 years	49%
6–10 years	20%
11–15 years	11%
16–20 years	6%
20 years or older	14%
Type of health insurance	
None	20%
Government funded	32%
Military	3%
Private/commercial	45%
Gestational age at detection of AMC	
12–18 weeks	9%
18–23 weeks	23%
24 weeks or more	5%
After birth	63%
Type of AMC	
Amyoplasia	36%
Distal arthrogryposis	21%
Escobar syndrome	1%
Unknown	26%
Investigation in process	8%
Other	8%
Geographic locations	
North America	74%
Central and South America	<1%
Europe	15%
Middle East and Asia	3%
Africa	1%
Australia	7%

Note: $n = 301$.

Abbreviation: AMC, arthrogryposis multiplex congenita.

Among all pregnancies, the most common neonatal findings at birth were clubfoot (85%), contractures of the wrist (75%), fingers (70%), knees (62%) and elbows (61%), hypotonia (60%) and “stork bite” facial hemangioma (50%). The overall occurrence of a fractured

TABLE 2 Physical findings during ultrasound and at birth.

	At ultrasound ADCs only (n = 112)	At birth All respondents (n = 301)
Small jaw	8%	6%
Neck hyperextension	3%	8%
Scoliosis	2%	10%
Shoulder contracture	0%	29%
Elbows fixed in extension	32%	37%
Elbows fixed in flexion	19%	24%
Wrists fixed in flexion	35%	75%
Clenched hands/finger contracture	51%	70%
Heart defect	2%	6%
Diaphragmatic hernia	0%	3%
Gastroschisis	3%	3%
Hip dislocation	0%	29%
Knees fixed in extension	25%	28%
Knees fixed in flexion	21%	34%
Clubfoot	83%	84%
Rocker bottom feet	10%	0%
Little or no fetal movement	53%	
Fetus always in same position	41%	
Oligohydramnios	18%	
Polyhydramnios	13%	
Low muscle tone		60%
Low birth weight		32%
Broken bone(s)		9%
"Stork bite" facial hemangioma		50%
Seizures		2%
Intracranial hemorrhage		1%
Respiratory problem requiring ventilatory support		19%
Feeding problem requiring feeding tube		35%
Other <1% each (tortacolis, undescended testes, hypospadias, sacral dimple, cleft palate, pectus excavatum, 2-vessel cord)		11%

Abbreviation: ADC, antenatally detected cases.

bone was 9% and did not differ significantly between 6% of all vaginal deliveries versus 11% of cesareans ($p = 0.16$) or between 11% of all ADCs versus 8% of PDCs ($p = 0.54$). The femur was the most commonly fractured bone (16/28) followed by the humerus (9/28), radius (2/28), tibia (2/28) and clavicle (1/28). All neonates had two or more physical findings consistent with arthrogryposis (Table 2).

TABLE 3 Services offered during antenatally detected cases.

Amniocentesis	82%
Referral to maternal fetal medicine	62%
Referral to genetic counseling	65%
Parental bloodwork for genetic testing	55%
Consultation with neonatologist	39%
Referral to orthopedic surgeon	35%
Referral to pediatric neurologist	26%
Fetal MRI	23%
Referral to social services/financial aid	22%
None of the above	4%

Note: $n = 112$.

Antenatal detection of arthrogryposis afforded an opportunity for additional testing and services (Table 3). Amniocentesis was offered to 82% of ADCs. Referrals to maternal fetal medicine (62%) and genetic counseling (65%) were also common. The option for termination of pregnancy was discussed by 84% of ADC respondents.

3.3 | Obstetric and maternal conditions

Maternal health conditions among pregnancies affected by AMC were similar to background rates seen in unaffected pregnancies (Table 4). Bleeding or spotting in the first and/or second trimester was reported by 21% of all respondents, while 17% reported hyperemesis gravidarum and 12% experienced a viral illness or fever. Obstetric conditions included oligohydramnios (18%), polyhydramnios (12%), multiple gestation (4%), and preterm labor (13%). Forty-six percent of respondents were primigravidas. Breech presentation at delivery was 40% and 10% reported an abnormally shaped uterus.

Maternal perception of fetal movement was reported as excessive by 2% of all respondents (2% of ADCs, 2% of PDCs), normal by 32% (21% of ADCs, 37% of PDCs), decreased by 54% (63% of ADCs, 49% of PDCs), and absent by 12% (14% of ADCs, 12% of PDCs), $p = 0.034$.

3.4 | Delivery methods and outcomes

The majority of all deliveries were performed by generalist OB/GYN physicians (61%), with ADCs being more likely than PDCs to be delivered by a high-risk specialist ($p = <0.01$). Overall, 62% of deliveries occurred by cesarean section (46% primary, 16% repeat). Among ADCs, 71% were cesarean versus 56% of PDCs (Table 5). There was an increased likelihood ($p = 0.01$) of a primary cesarean delivery among ADCs compared with PDCs. ADCs reported a change in the **type** (33%), the **timing** (28%) and **location** (51%) of their delivery due to detection of arthrogryposis, being less likely to deliver

TABLE 4 Maternal conditions during pregnancy.

	All respondents	ADCs	PDCs
(n = 275)			
Bleeding or spotting in 1st/2nd trimester	21%	26%	17%
Viral illness or fever in 1st/2nd trimester	12%	12%	12%
Hyperemesis gravidarum	17%	19%	15%
Trauma (fall, car accident, violence) in 1st/2nd trimester	4%	4%	4%
(n = 292)			
Oligohydramnios	18%	22%	16%
Polyhydramnios	12%	18%	9%
Preterm labor	13%	14%	12%
Multiple gestation	4%	2%	6%
Preeclampsia or HELLP syndrome	4%	4%	5%
Placenta previa	3%	3%	3%
Leaking fluid <24 weeks	2%	2%	2%
(n = 293)			
Hypertension	9%	13%	7%
Diabetes	7%	10%	5%
Thyroid disease	5%	5%	5%
Uterine fibroids	3%	6%	2%
Abnormally shaped uterus	10%	9%	10%
Myasthenia gravis	0%	0%	0%
Autoimmune disease	1%	1%	1%
None of the above	60%	58%	61%
Other: Anemia, asthma, obesity, UTI, surgery, endometriosis, celiac, MTHFR, cholecystitis, pancreatitis	18%	10%	23%

Abbreviations: ADCs, antenatally detected cases; MTHFR, methyltetrahydrofolate reductase; PDCs, postnatally detected cases; UTI, urinary tract infection.

beyond 40 weeks ($p = <0.01$) and more likely to deliver in a hospital with a neonatal intensive care unit (NICU) ($p = <0.001$).

Overall, 63% of infants were admitted to the NICU (71% of ADCs, 57% of PDCs). Transfer of care to a higher-level facility occurred in 17% of deliveries (12% of ADCs, 22% of PDCs) within the first 3 days of life. The majority of infants (55%) were discharged home within the first week of life (52% of ADCs, 62% of PDCs), whereas 16% were discharged more than 30 days after birth (22% of ADCs, 13% of PDCs) and 1% died prior to discharge (2% of ADCs, 0% of PDCs) (Table 5). Mechanical ventilation was required by 19% of all neonates (19% of ADCs, 19% of PDCs) and 13% of those born at or beyond 37 weeks (12% of ADCs, 12% of PDCs). Use of a feeding tube

TABLE 5 Characteristics of delivery.

	All respondents	ADCs	PDCs
Type of provider (n = 301)			
General obstetrician	61%	51%	67%
High risk specialist (maternal-fetal medicine)	21%	38%	11%
Certified midwife	13%	7%	16%
Family practitioner	3%	1%	4%
Other	2%	3%	2%
Mode of delivery (n = 301)			
Primary cesarean delivery	46%	55%	40%
Repeat cesarean delivery	16%	16%	16%
Spontaneous vaginal delivery	35%	28%	40%
Vaginal birth after cesarean (VBAC)	2%	<1%	2%
Forceps or vacuum-assisted vaginal delivery	1%	0%	2%
Facility (n = 300)			
Hospital with NICU	79%	96%	69%
Hospital without NICU	17%	4%	25%
Community birth center or midwifery center	2%	0%	3%
Home	2%	0%	3%
Gestational age at delivery (n = 301)			
Less than 24 weeks	1%	2%	0%
24–27 weeks	2%	2%	2%
28–31 weeks	3%	5%	2%
32–36 weeks	20%	22%	18%
37–40 weeks	62%	63%	62%
41–42 weeks	12%	5%	16%
Stillborn	<1%	<1%	0%
Type of nursery (n = 294)			
Neonatal intensive care unit (NICU)	63%	72%	57%
Regular newborn nursery	24%	17%	28%
Birth center or home	13%	11%	15%
Infant length of stay in hospital (n = 289)			
0–3 days	33%	27%	36%
4–7 days	25%	24%	26%
8–14 days	12%	10%	13%
15–30 days	13%	15%	12%
More than 30 days	16%	22%	13%
Infant died prior to discharge	1%	2%	0%

Abbreviations: ADC, antenatally detected cases; PDC, postnatally detected cases.

was required by 35% of all neonates (46% of ADCs, 29% of PDCs) and by 27% of those born at or beyond 37 weeks (40% of ADCs, 20% of PDCs, $p = 0.025$).

3.5 | Provider support and educational resources

The 112 parents who learned of their child's arthrogryposis antenatally (ADCs) described the information they received about arthrogryposis with variable responses. Examples of the wide spectrum of reported adjectives included *accurate* (28%), *compassionate* (27%), *scary* (61%), *confusing* (39%), *depressing* (37%), and *inconsistent* (34%). The utility of the information received was considered *somewhat helpful* by 34% and *not at all helpful* by 31% (Table 6). On a sliding scale of 0–100, ADCs averaged a rating of 39/100 when asked whether their prenatal care improved their understanding of arthrogryposis prior to delivery and an average rating of 38/100 when asked how prepared they felt for the delivery and care of their child with AMC. ADCs rated the knowledge level about arthrogryposis of their various providers with average scores for specialists including orthopedics, genetics, neurology (65/100), therapists including physical/occupational, speech, nutrition (42/100), pediatricians (29/100), and pregnancy providers (19/100). Eighty-four percent of ADCs had discussions with their providers regarding the option for pregnancy termination (abortion) with a mix of favorable and unfavorable impressions of the encounter (Table 6). Presumably, none of the parents in this survey chose to terminate since a requisite for participation was to be the parent of a child born with AMC.

Parents reported using a variety of resources to learn more about arthrogryposis, including social media groups (71%), Internet searches (70%), arthrogryposis support group websites (AMCSupport.org) (61%), websites of hospitals specializing in AMC (49%), specialists such as orthopedics, genetics, neurology (65%), therapists (47%), and pediatricians (18%).

Both ADCs and PDCs were asked whether signs of arthrogryposis that could have led to an earlier detection were observed but not appreciated antenatally. Responses included *perceived decreased fetal movement* (43%), *abnormal limb shape or movement on ultrasound* (40%), *baby always in the same position on ultrasound* (37%), *abnormal fluid level* (17%) and *no unusual findings noted* (18%). Overall, 33% of respondents felt their concerns were not adequately addressed by their providers (17% of ADCs, 43% of PDCs).

3.6 | Qualitative responses regarding parental experience

Respondents were asked a series of free-response questions (Appendix A), giving them a chance to reflect on their overall experiences with their providers during and after their AMC pregnancy. Common themes arose in the observations and recommendations from parents:

TABLE 6 Information from providers to ADCs about arthrogryposis.

	Yes	No
Discussion about termination of pregnancy		
My provider listened to my concerns and answered all my questions	70%	30%
My provider treated me with empathy and compassion	67%	33%
My provider gave me adequate time to make my decision	76%	24%
My provider respected my decision as final	79%	21%
I felt pressured to consider termination/abortion	42%	58%
My provider displayed disagreement with my decision	31%	69%
My provider made me feel guilty about my decision	22%	78%
My provider was condescending	33%	67%
Adjectives used to describe information received		
Accurate	28%	
Inaccurate	17%	
Clear and understandable	19%	
Confusing	39%	
Compassionate	27%	
Biased/pressuring	12%	
Hopeful	18%	
Depressing	37%	
Scary	61%	
Inconsistent among providers	34%	
How helpful was the information received		
Extremely helpful	9%	
Very helpful	12%	
Somewhat helpful	34%	
Not so helpful	15%	
Not at all helpful	31%	

Note: $n = 112$.

Abbreviation: ADC, antenatally detected cases.

- Evaluation of limb shape and movement should be a standard part of a routine ultrasound during pregnancy.
- Providers often dismissed a mother's perception of decreased fetal movement, especially when it was her first pregnancy.
- Providers seemed inadequately knowledgeable about arthrogryposis and gave inaccurate diagnoses and prognoses
- Providers should admit when they do not have answers and be willing to refer to specialists.
- Providers commonly presented "worst case scenarios" while failing to provide a sense of hope or a positive outlook.

- Providers should be more cognizant of parents' emotional health and provide better resources for education, social support, and coordination of care during and after birth.
- Some providers were perceived to impose personal beliefs or to pressure parents during discussions about pregnancy termination.

Appendix B provides representative direct quotes from respondents.

4 | DISCUSSION

This survey sheds light on many obstetric considerations for pregnancies affected by arthrogryposis. The objective data characterize common clinical findings in maternal, fetal, and neonatal evaluations, while the subjective responses describe parents' experiences. Collectively, the data highlight the need for improved awareness of arthrogryposis among providers and improved protocols to aide in its detection and guide obstetric care.

Our survey has some limitations. While previous studies have demonstrated the utility of online surveys including cost-effectiveness, ease of distribution to and recruitment of specific target populations, and immediate collection of responses in an electronic fashion,¹⁴ it is recognized that an exact number of potential participants reached and subsequent response rates are unable to be calculated. Due to the online nature of recruitment, our results were subject to selection bias as participation required access to the Internet, fluency in the English language, and self-identified membership within a group designated for the specific purpose of arthrogryposis support. Parents who chose to terminate their affected pregnancy or those whose child is no longer living are less likely to be active in such groups and would therefore be likely underrepresented, thus skewing our data to include fewer ADCs and fewer severe cases. Survey responses were also subject to recall bias. Many parents recall pregnancies from fewer than 5 years ago, but some were over 20 years in the past, during which time technology and standards of care have changed. The survey relied on respondents to remember the content of medical information given to them by their providers and the accuracy of this information, including the specific type of ultrasound examination performed or content evaluated therein, could not be independently verified.

With its robust number of responses, this survey highlights several obstetric considerations. Previously reported risk factors for AMC, such as uterine overcrowding by structural anomalies and multiple gestation, as well as insults affecting placental perfusion during critical weeks of gestation, such as bleeding or viral infection, were again appreciated in our results.¹

Maternal perception of fetal movement, though often clinically underacknowledged, was a commonality worthy of prompting a more thorough investigation into limb shape and movement when reported. The survey did not delineate the gestational weeks over

which this fetal movement was noted, whether it was consistently or intermittently observed. Overall, ADCs more commonly endorsed decreased or absent fetal movement than PDCs, though this retrospective observation may be subject to hindsight bias as the outcome was known at the time of the survey. It is unclear whether the report of decreased movement prompted a more thorough evaluation of the limbs (thus leading to the diagnosis), or whether the knowledge of the diagnosis heightened a mother's awareness of the decreased movement. Future studies with more delineation of maternal perception of fetal movement and the resulting follow-up studies would provide important clinical insight into this diagnostic tool.

While it may be expected that fetuses with limited movement are more likely than unaffected fetuses to remain in a breech presentation or require a cesarean delivery as seen in our data, it is notable that a cesarean delivery did not appear to be protective against broken bones as might be intuitively expected. It should also be reassuring to providers that even though the structural and functional abnormalities may appear antenatally to be profound, the majority of children were relatively stable after delivery and went home within a week after birth. It was not able to be determined whether more severe conditions correlated with a higher rate of antenatal detection. When the need for mechanical ventilation was used as a surrogate for non-orthopedic severity among full term deliveries, there was no difference between ADCs and PDCs, while the need for a feeding tube reached statistical significance. Other studies have shown that certain signs such as hydrops, nuchal edema, scoliosis, and absent stomach filling may provide early prognostic value with regard to unfavorable outcomes.¹⁵

This study demonstrates a low rate of detection of arthrogryposis in affected pregnancies (37%), which is consistent with previously reported rates of 25%–53%.^{12,13} Even among pregnancies within the past 5 years, with the most current technology and standards of care, the detection rate was only 46%. Protocols to standardize ultrasound assessment of limb shape and fetal movement during the first trimester nuchal translucency scan and the fetal anatomy scan at 18–22 weeks have been proposed.^{13,16,17} Unfortunately, such recommendations have yet to be included in the standards from professional societies such as ACOG and AIUM. It has been shown that 15 min is sufficient time to perform an assessment of fetal movement.¹¹ In our survey, clubfoot deformity was present in 83% and clenched hand in 51%. Breech presentation was 10 times more common than the general population (40% vs. 4%).¹⁸

We propose the following enhancements to routine prenatal ultrasound screenings:

- All first and second trimester exams should include evaluation of fetal movement
- All anatomy surveys should evaluate the shape and movement of each limb
- Further investigation with targeted evaluation of the extremities is warranted with the following findings:
 - Clubfoot deformity or clenched hands

- Persistently decreased or absent fetal movement, whether by maternal perception or sonographic appearance
- Persistence of fetus in the same position over serial exams, especially breech presentation or position of the knees and/or elbows
- Maternal bleeding or viral illness in the first and early second trimesters

ADCs were most commonly diagnosed in the second trimester. In the third trimester, available space within the uterus and amniotic fluid becomes limited, making individual limb shape and movement more difficult to evaluate. Additionally, third trimester growth scans are not routinely performed in otherwise uncomplicated pregnancies. If a case of AMC is detected in the third trimester, attempts should be made to characterize the nature of joint contractures and to evaluate growth and amniotic fluid volume.

Our survey also highlights the need for better awareness, education, and understanding of arthrogryposis among providers of obstetric care. Clinicians with such training could be better equipped to offer more thorough and accurate diagnoses and prognoses to expectant parents as well as to provide the empathy and compassion that parents deserve. Recent publications have proposed detailed algorithms and care pathways for clinicians to follow after AMC has been detected, including suggested referrals, imaging studies, invasive testing for genetic studies, plans for delivery and counseling for future pregnancies.^{19,20} Our survey supports the need for and utility of such guidelines, as ADCs were able to prepare for delivery and early infancy, while PDCs were left with little confidence in their obstetric providers as they hurried to understand their child's condition and seek appropriate care. The emotional stress placed on families should not be taken lightly, as demonstrated by the many unfavorable parental experiences displayed in this survey.

There is a clear need for more educational materials and resources for parents. The vast majority of parents reported utilizing social media and Internet search engines to find information about arthrogryposis. Unfortunately, when one enters the term "arthrogryposis" into any popular search engine, the first results displayed are quite dismal and outdated. There are valuable online resources in the form of support groups on social media, websites, and national registries to which informed providers can point expecting parents. The large response rate to our survey reflects the wide acceptance of the use of Internet and social media platforms to find information and connect socially with people from all over the world with similar circumstances.

5 | CONCLUSION

Although the incidence of arthrogryposis is similar to that of other congenital conditions, the awareness among obstetric providers and protocols for prenatal screening trail significantly behind. Continued efforts to collect quantitative data on these pregnancies could allow

for a broader understanding and generalizable obstetric recommendations. More inclusive screening protocols could potentially lead to improved detection rates, which could in turn afford more expecting parents the opportunity to educate themselves, make accurately informed decisions, and prepare for the delivery and care of their affected child. Improved education among providers of obstetric care could allow for better recognition of arthrogryposis and its impact on the care of the pregnancy and encourage utilization of published recommendations to provide such care in a more empathetic and compassionate manner.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data are available through the corresponding author.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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