Rehabilitation needs of youth with arthrogryposis multiplex congenita: Perspectives from key stakeholders

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Rehabilitation needs of youth with arthrogryposis multiplex congenita: Perspectives from key stakeholders

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ABSTRACT

Background: Arthrogryposis multiplex congenita is a term used to describe congenital contractures in at least two body parts with an overall prevalence of 1 in 3000 live births. It is often caused by lack of fetal movement in utero and presents as contractures of varying severity, which may affect the upper and lower extremities, the spine and jaw. Currently, no practice recommendations exist to inform best clinical practice for arthrogryposis multiplex congenita.

Purpose: To identify the needs surrounding rehabilitation as experienced by youth with arthrogryposis multiplex congenita, caregivers, and clinicians and to propose solutions to develop family- and client-centred rehabilitation recommendations.

Materials and methods: A modified experience-based co-design methodology was used where qualitative interviews were conducted with key stakeholders.

Results: Twenty-seven participants completed the interviews and demographic information was collected where early-active rehabilitation began at birth in most cases and became less frequent through adolescence. Three overarching themes were determined for each stakeholder group.

Conclusions: All participants reported that early-active rehabilitation is beneficial as it helps determine future treatments. Transition times and participation need to be at the center of interventions to ensure that the needs of youth with arthrogryposis multiplex congenita are being met. The development a condition-specific outcome-measure and rehabilitation practice recommendations will assist clinicians in addressing the needs of youth with arthrogryposis multiplex congenita.

IMPLICATIONS FOR REHABILITATION

- Arthrogryposis multiplex congenita presents in at least two different areas of the body as multiple congenital contractures of varying severity which may affect the upper and lower extremities, spine and jaw.
- Youth with arthrogryposis multiplex congenita identified participation as an essential component of their life, however caregivers and clinicians did not emphasize this need.
- Gathering information from different stakeholders is important to ensure varying needs are addressed.
- Rehabilitation was reported to be beneficial from early childhood to late adolescence by youth, caregivers, and clinicians.
- Frequency of rehabilitation diminished over time, emphasizing the need for continued follow-up into adolescence.

Introduction

Arthrogryposis multiplex congenita (AMC) is a term used to describe multiple contractures present at birth in at least two body parts with an overall prevalence of 1 in 3000 live births [1,2]. It is most often caused by lack of fetal movement in utero, can be sporadic or inherited in an autosomal or recessive fashion. Individuals with AMC display variable clinical features, which may include contractures of varying severity to the upper and lower extremities, the spine and the jaw, as well as involvement of the gastro-intestinal, genito-urinary and central nervous systems [3-6]. The contractures are non-progressive in nature but may impact and limit independence in mobility, self-care and activities of daily living [3-6]. For this reason, early intensive rehabilitation is warranted to provide splinting, range of motion exercises, strengthening programs. Surgical interventions are carried out to correct deformities and promote daily function [7-10].

Despite early intervention and the non-progressive nature of the condition, recurrence of joint contracture is common,
particularly in skeletally immature patients [7]. Although early and continued intensive rehabilitation is justified for children with AMC and advocated by many researchers, very few studies have documented the rehabilitation process and services required for children with AMC and their families [11, 12]. Indeed, the Second International Symposium on Arthrogryposis held in St-Petersburg in 2014 indicated an urgent need for guidelines to be developed regarding various therapies [12]. As such, no rehabilitation guidelines or practice recommendations currently exist to inform best clinical practice for this population.

The current literature available on rehabilitation treatment for children with AMC, emphasizes improving range of motion and minimizing joint contractures in order to facilitate mobility and increase autonomy in activities of daily living [13, 14]. Multiple models, including the Canadian Model of Occupational Performance and Engagement (CMOP-E), have shown that health does not solely rely on physical function but rather is influenced by a multitude of factors including psychosocial well-being, participation and the environment [15]. The lack of information regarding interventions to address issues in areas other than physical function in AMC creates a large knowledge gap for clinicians [8, 14, 16–20]. Additionally, as AMC is heterogeneous, with each individual and family experiencing different needs which permeate throughout all spheres of function, care must be holistic and take into account the needs of both youth and their caregivers.

Materials and methods

Aim

The objective of this study was to identify the needs surrounding rehabilitation as experienced by youth with AMC, caregivers, and clinicians (i.e., occupational therapists and physical therapists) and to propose solutions to develop family- and client-centred rehabilitation recommendations.

Study design

A modified experience-based co-design methodology was used. It is an approach to improving healthcare services that uses a “co-design” process, involving key stakeholders to reflect on their experiences and work together to identify priorities, devise and implement changes [21]. In this study, qualitative interviews were conducted in person or by telephone with key stakeholders, consisting of youth with AMC, their caregivers, and clinicians. All interviews were digitally recorded and transcribed for further analysis. The research team developed two interview guides, for youth and caregivers, and clinicians. The CMOP-E was used as the theoretical framework to develop these interview guides, which included items on the physical (e.g., strength, range of motion, endurance), cognitive (e.g., perception, judgement, attention), affective (e.g., self-esteem, motivation, interpersonal relations), environmental (e.g., physical, social, institutional barriers), occupational performance and activity (e.g., self-care, mobility), productivity and participation domains (e.g., employment, education and leisure). Tables 1 and 2 provide the interview guides used with the youth and caregiver, and clinician groups.

Recruitment of participants

Youth between the ages of 14–21, living in Quebec, Canada, with AMC were recruited between April 2016 and June 2017. These included current and former patients of Shriners Hospital for Children – Canada specifically. Youth participants were excluded if they did not speak French and/or English and had severe cognitive and communication difficulties, which would interfere with their ability to participate in an interview. Caregiver participants were approached for inclusion if their child had AMC, was younger than 14 years old and was a current or former patient of Shriners Hospital for Children – Canada living in the province of Quebec. Clinician participants consisted of occupational and physical therapists with at least two years of experience in pediatric rehabilitation and who currently work with children with AMC at Shriners Hospital for Children – Canada in Montreal, Centre de réadaptation de déficience physique le Parcours in Jonquière, and l’Institut de réadaptation en déficience physique de Québec in Quebec City. Only participants who provided signed informed consent were included. Ethics approval was obtained from the Faculty of Medicine Institutional Review Board, McGill University and from the Centre intégré universitaire de santé et de services sociaux du Saguenay–Lac-Saint-Jean. Institutional approval was obtained for each participating center.

Data analysis

Recruitment was stopped upon saturation, which was defined as no new content for two consecutive interviews. Each audio recording was transcribed verbatim by a research assistant. The
first transcript for each of the three stakeholder groups (youth, caregiver and clinician) was coded by two members of the research team (C.E. & N.D-O) applying a coding template analysis using NVivo (version 10), which summarizes themes identified by the researchers as important in the dataset [22]. Every third transcription was coded as a pair with another member of the research team to generate stronger inter-coder reliability. The domains were selected a priori using a deductive approach based on the interview guides for the youth, caregiver and clinician groups. The sub-domains representing the rehabilitation needs as expressed by the three stakeholder groups arose from the transcription content using an inductive approach. Supplementary Tables S1–S3 present the broad domains for each stakeholder group as well as subdomains [see Supplementary Tables]. Following an analysis and synthesis of the comprehensive list of domains and subdomains, the research team derived the final themes and subthemes relating to rehabilitation needs. Trustworthiness was ensured by addressing the four following components: (1) credibility, (2) transferability, (3) dependability, and (4) confirmability [23]. The first component, credibility, is determined by the data collection and analysis, and researcher triangulation. This was achieved by using a data management tool i.e NVivo (version 10) for systematically coding the data in which specific quotes were categorized into themes [24]. Triangulation was achieved by conducting interviews with three groups of stakeholders at three different sites to identify the rehabilitation needs from the perspectives of youth with AMC, their caregivers and clinicians. Some themes and subthemes were mentioned by all three groups, whereas other themes and subthemes were specific to the needs of one stakeholder group. Specific quotes were carefully selected to illustrate the meaning of each theme. In some instances, a forward-backward translation process was used to translate French quotes to English to ensure appropriate meaning was retained. The second component, transferability, refers to the generalizability of inquiry [23,24]. Transferability was accomplished by providing in-depth descriptions of the themes to enable transfer of findings to different areas of care related to AMC. The third component, dependability, is determined when researchers ensure the research process is logical, traceable, and clearly documented [23,24]. The research design and its application, as well as the data collection and analysis were reported in detail ensuring reproducibility of this study [24]. Finally, the fourth component, confirmability, refers to the neutrality and assurance that the findings are exempt of researcher bias [23,25]. This was achieved by using triangulation, detailed methodological description, and involvement of the research team in the methodological (i.e., interview guide development) and analytical steps (i.e., data analysis), thus reducing the effect of investigator bias [23].

Results
A total of 30 participants were approached to participate and 27 participants completed the interviews (see Figure 1 for a flow chart of participants). For the youth group, mean interview length was 21 minutes, for the caregiver group it was 25 minutes, and for the clinician group it was 28 minutes. The demographic information collected for all three stakeholder groups demonstrated that early-active rehabilitation began at birth in most cases and became less frequent through adolescence (i.e consultation basis). Tables 3 and 4 report the demographic information for youth and caregivers, and clinicians, respectively. The main rehabilitation needs that arose from the data are illustrated as themes and are identified per stakeholder group in Figure 2.

Themes per youth group
Three overarching themes were revealed in the youth group: AMC and me, life with AMC and navigating my resources. The first theme, AMC and me, encapsulates all intrinsic factors to the youth and their condition. Sub-themes included description of how AMC affects the youth daily, particularly in the areas of ADLs, pain, and physical function. When prompted, only one youth reported issues with cognition, specifically concentration. Two of the youth reported having affective needs such as anxiety and body image issues.

[…] I get fatigued easily and I have pain in both my feet. […] This year I travelled and I walked a lot during the day and the pain got worse the more I walked. […] Especially when you have blisters. […] The only way to reduce the pain is to stop walking and sit. […] (Male with AMC, 17 years old)

The second theme, life with AMC, included sub-themes revolving around participation, social interactions, and the environment.
Youth described how their abilities to participate in their roles are affected by their environment, such as their homes, school and community, and change during transition periods. They also discussed how they select leisure activities as well as their interactions with other people including family, friends and members of society based on their abilities and interests.

... I can’t really bend my extremities, whether it is upper or lower, obviously, I take more space. For traveling it could be encumbering. I definitely need to take into consideration when I take the plane. For long distances also, I have to calculate, if I decide that I’m going shopping all day, I won’t go by foot. I take my wheelchair [...]. (Male with AMC, 18 years old)

The final theme, navigating my resources, encompasses how the youth view the rehabilitation process and healthcare trajectory including cost associated to services and access to care.

... I am taking a manual driving course [...]. The only thing I would have to say is with respect to the price. [...] It’s $300 more per session to practice on an adapted car. [...] $300 is starting to become expensive to have access to an adapted car. Especially since it should be a right for everyone. We need to drive too. (Male with AMC, 19 years old)

Themes per caregiver group

The coding process of the caregiver transcriptions elucidated three themes: caring for my child with AMC, supporting my child’s personal growth and development, and managing care. In the first theme, caring for my child with AMC, caregivers reported dealing with the many aspects of their child’s needs, including affective, physical and cognitive needs, pain, burden of care, mobility, and adaptations. Caregivers expressed several complex needs to be taken into account when raising a child with AMC.

... No, it’s because he, he often has appointments. It means I can’t work. There is no one who will hire you if you have many, many appointments. Now he is going to get operated and he will restart [rehabilitation] three times a week. (Mother of a 7-year-old boy with AMC)

The second theme, supporting my child’s personal growth and development, included environmental, social interaction, participation, and concerns sub-themes. Through this theme, caregivers conveyed the facilitators and challenges presented by the various establishments, institutions and social situations so that their children with AMC could grow, develop and participate in society.

... The only thing I would have to say is with respect to the price. [...] It’s $300 more per session to practice on an adapted car. [...] $300 is starting to become expensive to have access to an adapted car. Especially since it should be a right for everyone. We need to drive too. (Male with AMC, 19 years old)

Table 3. Demographic information for youth and caregiver group.

<table>
<thead>
<tr>
<th>Stakeholder category</th>
<th>Age of youth AMC (in years)</th>
<th>Gender of youth with AMC</th>
<th>Co-morbidity condition(s) to AMC</th>
</tr>
</thead>
<tbody>
<tr>
<td>YOUTH</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth</td>
<td>19</td>
<td>Male</td>
<td>None</td>
</tr>
<tr>
<td>Youth</td>
<td>14</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Youth</td>
<td>18</td>
<td>Male</td>
<td>Allergies and asthma</td>
</tr>
<tr>
<td>Youth</td>
<td>17</td>
<td>Male</td>
<td>Unilateral Deafness, renal agenesis, bladder issues</td>
</tr>
<tr>
<td>Youth</td>
<td>20</td>
<td>Female</td>
<td>Epilepsy, episodic ataxia</td>
</tr>
<tr>
<td>Youth</td>
<td>16</td>
<td>Male</td>
<td>Scoliosis</td>
</tr>
<tr>
<td>CAREGIVER</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother</td>
<td>6</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Mother</td>
<td>9</td>
<td>Male</td>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
<td>Male</td>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>Father</td>
<td>8</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Father</td>
<td>12</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Mother</td>
<td>6</td>
<td>Male</td>
<td>Hearing Impairment</td>
</tr>
<tr>
<td>Father</td>
<td>2</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Father</td>
<td>11</td>
<td>Female</td>
<td>Fetal Alcohol Syndrome</td>
</tr>
<tr>
<td>Mother</td>
<td>7</td>
<td>Male</td>
<td>Polymicrogyri in biparietal region</td>
</tr>
<tr>
<td>Mother</td>
<td>4</td>
<td>Female</td>
<td>None</td>
</tr>
<tr>
<td>Mother</td>
<td>13</td>
<td>Female</td>
<td>Dysarthria, dyspraxia and ADHD</td>
</tr>
</tbody>
</table>

Table 4. Demographic information for clinician group.

<table>
<thead>
<tr>
<th>Clinician’s profession</th>
<th>Years of practice</th>
<th>Number of AMC patients followed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational therapist</td>
<td>25</td>
<td>~20</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>3</td>
<td>~5</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>5</td>
<td>Between 5–10</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>24</td>
<td>Between 15–20</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>12</td>
<td>4</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>20</td>
<td>2</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>14</td>
<td>~10</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>35</td>
<td>3</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>17</td>
<td>1</td>
</tr>
</tbody>
</table>

She is the third of three kids. She follows her brother, her sister without any problem. For us she is a child like any other without a disability. We don’t consider her as a child who needs more support, we give her what she needs, but not more. We push her to do the things we know she is able to do. She doesn’t realize her condition; it does not affect her confidence. (Father of an 8-year-old girl with AMC)

The final theme, managing care, included satisfaction with care, parent involvement in rehabilitation and communication with service providers. Caregivers expressed how closely they work with clinicians to ensure their child is receiving the best care in order to maximize their function. This also covers their obligation to seek second opinions when necessary.

... I think about the frequency of care. I know last time we had [an appointment with] physio, I asked about getting a document with exercises for my daughter. [...] I thought about it and asked about how frequently these important exercises needed to be done each week. [...] I think she was more active at home just by having this document. (Father of a 10-year-old girl with AMC)

Themes from the clinician group

The clinician transcriptions were coded into three themes: clinician as enabler, clinician as communicator and collaborator, and clinician and institutional factors. In the first theme, clinician as enabler, occupational and physical therapists discussed their current assessment, goal setting and intervention practices despite limited evidence on best practice available. Clinicians enable exchanges with the youth and their caregivers leading to tailored solutions according to their underlying capacities and limitations.

... The only thing I would have to say is with respect to the price. [...] It’s $300 more per session to practice on an adapted car. [...] $300 is starting to become expensive to have access to an adapted car. Especially since it should be a right for everyone. We need to drive too. (Male with AMC, 19 years old)
This youth- and family-centered approach to problem-solving aims to increase function and maximize independence in daily activities.

The main reason to address the physical is to improve the performance. They manage to do most of these things, with either adaptations or nothing. Our goal is to see if we can decrease adaptation and address the wrist to be more typical in their self-care […] With techniques of dressing […] it’s often them teaching us how to do it, and the more we have seen, we get better at knowing how to do, but this is clearly one of our main interventions. (Occupational therapist)

Under the second theme, clinician as communicator and collaborator, the need to consult peers regarding expertise and treatment plans was conveyed. Due to the rarity of AMC, clinical experience is highly dependent on the volume of cases. Therefore, clinicians emphasized the need to share expertise, as well as the benefits of clear and consistent communication ensuring continuity of care among different healthcare institutions. Clinicians expressed a clear need to increase their knowledge regarding accessible community resources including leisure, so that these may be communicated back to address family-centered goals.

I researched with my physio colleague, it was our first client with arthrogryposis, so we researched arthrogryposis, we called specialized centres, it’s what we did and we certainly did not use standardized evaluations, we looked at range of motion, function […] (Occupational therapist)

Additionally, clinicians reported a need for a condition specific outcome measure for this population as it would enable them to objectively evaluate and determine effective treatments for youth with AMC.

I think the most important thing is the evaluation. I am not sure there are standardised evaluations for AMC. Also, the goals of the parents and the patients, and how we can know what is realistic and what is overshooting. Like if the doctor that is referring, we need to be able to communicate with the doctor before and after a surgery […] (Physical therapist)

Finally, the theme clinician influenced by institutional factors, revolved around how occupational and physical therapists perceive their role, as well as the influence of institutional factors affecting the care provided. These factors included the type of setting in which they practice, the referral process and expectations from management.

[…] Since we are a rehabilitation center, we need to get a referral. It could be sent by the parents, as long as important information [referral from physician] is included. Most times they [referrals] come from tertiary centers where specialists usually refer patients to us. […] (Physical therapist)

Discussion

The goal of this study was to identify the needs surrounding rehabilitation as experienced by youth with AMC, their caregivers, and clinicians and propose solutions to develop family- and client-centred rehabilitation recommendations. By conducting semi-structured interviews with all involved stakeholders, physical, social and environmental needs were identified and informed the areas to be addressed in rehabilitation practice recommendations. Rehabilitation for school-aged children and adolescents focused mostly on physical limitations, which did not always correspond to the youth’s specific participation needs, such as leisure and driving. While caregivers expressed that they feel their child with AMC is well socialized and adjusted, the youth expressed concerns regarding their limited participation and environments that present many obstacles, particularly during times of transition, such as going from elementary to high school, and from high school to post-secondary education or employment. In Nouraei et al.’s [26] study on 177 adults with AMC from over 15 countries, participation was also raised as a concern since participants reported being primarily sedentary with minimal levels of involvement in moderate to heavy physical activity. Not surprisingly, the rehabilitation needs raised by the three stakeholder groups were varied. This difference among the self-reports of youth and their caregivers has also been expressed in research studies concerning osteogenesis imperfecta [27], a rare genetic bone disorder also present at birth. Indeed, qualitative interviews conducted with youth with osteogenesis imperfecta, their parents and clinicians [27] yielded themes similar to the ones identified in this study, but with different justifications for each theme.

All involved parties stated that rehabilitation for children with AMC should and usually does begin at a very early age and intensively. As pre-teen years approach, rehabilitation treatment was less intense and was rather offered on a consultation basis. Yet, youth in this study reported having to regularly adapt in order to be independent and participate in developmentally-appropriate activities, such as leisure, driving and interpersonal relations. Of importance, these domains were also raised by adults with AMC as reported in a survey of 295 adults in the UK [28]. In Hartley et al.’s study [28], adults also reported low self-esteem, shyness, body image issues, pain and fatigue, which may lead to difficulties with socializing, intimacy, and feeling they had missed a part of life by not marrying. This signifies the importance of addressing not only the physical needs, but also those in the affective and participation domains. The importance of participation in leisure activities should be supported by clinicians early on as have been previously recorded in the literature with other childhood chronic conditions such as cerebral palsy. Notably, Palisano et al. [29] found that healthcare professionals should help in locating community resources and leisure opportunities and assist families during periods of transition, which was echoed by the youth in this study. These findings indicate that the need for rehabilitation services during adolescence should not be underestimated as youth experience new challenges during the transition years to adulthood.

The major need expressed by clinicians was a lack of interventions and evaluations specific to AMC, as they felt they could not address the real issues without an AMC specific tool and evidence-based treatment recommendations. This similar view was expressed in the study conducted by Hill et al. [27] in which clinicians expressed the need for a condition-specific quality of life measure in order to properly assess youth with osteogenesis imperfecta. The development of a standardized outcome measure specific to children with AMC would allow clinicians to accurately and consistently describe the functional status of children, evaluate patient changes over time, guide surgical and non-surgical (i.e., splinting and stretching) treatment planning, and determine treatment effectiveness. Based on the current needs identified by the three key stakeholder groups, this study suggests that rehabilitation practice recommendations be developed collaboratively with youth with AMC and their caregivers, together with clinicians. Future steps will include a series of focus groups, one with clinicians, one with youth and caregivers and one joint session to validate the priorities and the achieve consensus for practice recommendations. These practice recommendations will ultimately promote consensus-based, coordinated and equal services delivered to children with AMC and their families. As well, a standardized evaluation and treatment process for AMC may support shared communication and best practice among
rehabilitation providers in the education, healthcare, community and private sectors.

Limitations
Clinicians were recruited from different sites across the province, yet for feasibility purposes, youth and caregivers were recruited from one geographical region, which may limit the generalizability of findings. The research team could have further ensured dependability of the study by having an additional individual that was not involved in the research study perform an audit trail.

Conclusion
Intensive early-active rehabilitation was deemed to be beneficial to all stakeholder groups as it helps determine future interventions, including surgical and non-surgical management, and recommendation of adaptive aids. However, as children with AMC grow, their needs begin to diverge from those expressed by their caregivers and focus more on participation and environmental obstacles. Thus, clinicians need to be sensitive to these transition times and include participation goals and interventions to ensure that the needs of youth with AMC are being met. The development of a condition-specific outcome measure and rehabilitation practice recommendations will assist clinicians from various sectors in addressing the needs of families and youth with AMC.

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Disclosure statement
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Data availability
The data that support the findings of this study are available on request from the corresponding author, CE. The data are not publicly available due to privacy restriction (i.e. their containing information that could compromise the privacy of research participants).

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