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Towards Shared Protocols in AMC Physiotherapy: Developing Personalized Models Based on Multidimensional Functional Assessment

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Abstract

Arthrogryposis Multiplex Congenita (AMC) is a rare, non-progressive condition marked by congenital joint contractures and varying degrees of neuromuscular impairment. Its clinical heterogeneity poses significant challenges for physiotherapists in designing effective, consistent rehabilitation pathways. A recent systematic review highlighted the fragmented nature of existing interventions and the urgent need for structured yet adaptable treatment models.

This article proposes a shared and modular physiotherapy protocol for individuals with AMC, grounded in multidimensional functional assessment. The approach integrates key domains such as joint mobility, muscle strength, posture, respiratory function, daily living activities, and psychosocial context. By segmenting rehabilitation into age- and severity-specific modules, the proposed model enables clinicians to tailor interventions while maintaining coherence across care settings.

Techniques including kinesitherapy, hydrotherapy, respiratory training, orthotic support, and occupational therapy are incorporated within flexible modules. Clinical goals are defined through SMART criteria, fostering measurable outcomes and patient-centered progression. A consensus-building process, such as Delphi methodology, is suggested to validate the model among experts.

Expected benefits include enhanced treatment efficacy, reduced clinical variability, improved adherence, and greater caregiver engagement. The model aims to transform AMC rehabilitation from a case-by-case challenge into a replicable and scalable practice. Future research directions include pilot implementation studies, multicentric validations, and the integration of digital monitoring tools.

This article marks a transition from evidence synthesis to operational design, offering a practical framework for standardized, personalized care in AMC physiotherapy.

Introduction

Arthrogryposis Multiplex Congenita (AMC) represents a spectrum of rare, non-progressive syndromes characterized by multiple joint contractures present at birth, often affecting at least two different body areas. The condition stems from fetal akinesia due to diverse etiological factors including genetic mutations, neuromuscular anomalies, and intrauterine environmental disturbances. Despite its stable anatomical course, AMC may lead to profoundly disabling functional consequences across the lifespan.

The global prevalence of AMC is estimated at approximately 1 in every 5,000 live births, though underdiagnosis and variability in classification systems may obscure accurate epidemiological representation. Clinically, patients display a wide array of phenotypes—from isolated distal involvement to complex presentations with scoliosis, joint dislocations, muscle hypoplasia, and respiratory compromise. This heterogeneity demands personalized, multidisciplinary rehabilitation strategies, where physiotherapy plays a pivotal role.

In 2025, a systematic review conducted by the present author [1] consolidated findings from 14 studies involving 212 patients across pediatric and adult age groups. The review confirmed the central role of early, individualized physiotherapy in promoting joint mobility, functional autonomy, and quality of life. However, it also exposed significant gaps in the literature: most interventions lacked standardization, were rarely validated across clinical settings, and often depended heavily on local expertise or caregiver availability. No unified rehabilitative protocol currently exists that can adapt to different age ranges, levels of functional severity, and evolving patient needs.

The present article responds to these gaps by moving from evidence synthesis to operational planning. Its primary objective is to propose a shared, modular, and adaptable physiotherapy model for individuals with AMC, built upon a multidimensional functional assessment framework. This approach aims to reduce clinical variability, empower caregivers, and enable consistent, patient-centered rehabilitation across diverse clinical contexts.

Theoretical and Methodological Framework

The development of a modular and personalized rehabilitation protocol for patients with Arthrogryposis Multiplex Congenita (AMC) requires

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a robust and multidimensional assessment system. This framework is essential to capture the complex interplay of motor, functional, and contextual variables that characterize each individual's clinical trajectory.

1. Multidimensional Functional Assessment

The cornerstone of the proposed model is a comprehensive evaluation across six key domains:

- Joint Mobility: Assessment of passive and active range of motion (ROM) using standardized goniometric tools. ROM limitations vary between distal and proximal segments and are crucial in defining baseline therapeutic needs.
- Muscle Strength: Quantified through manual muscle testing (MMT) and, where feasible, handheld dynamometry. Muscle hypoplasia and imbalances are frequent and must guide progression criteria.
- Postural Control and Balance: Analyzed through static and dynamic balance tests, including pediatric-specific scales like the Pediatric Balance Scale (PBS) or gross motor function evaluations such as GMFM.
- Activities of Daily Living (ADL): Evaluated with tools such as the Pediatric Evaluation of Disability Inventory (PEDI) or the Functional Independence Measure for Children (WeeFIM), allowing the measurement of autonomy and participation.
- Respiratory Function: In cases of thoracic involvement, spirometry and inspiratory muscle testing are crucial to monitor pulmonary risk and guide respiratory physiotherapy.
- Psychosocial and Environmental Context: Family dynamics, home environment, and emotional coping resources are assessed through structured interviews and validated scales (e.g., PedsQL Family Impact Module).

2. Rehabilitation Planning and SMART Goals

This multidimensional profile forms the basis for rehabilitation planning through SMART goals (Specific, Measurable, Achievable, Relevant, Time-bound), allowing each therapeutic path to be both personalized and trackable. The use of SMART criteria encourages realistic expectations and facilitates interdisciplinary coordination.

3. Family-Centered and Contextualized Approach

The model integrates psychosocial and environmental aspects as core variables. Family training and empowerment are embedded in the rehabilitation process from the start, fostering treatment adherence and autonomy in the home setting. Cultural sensitivity, resource availability, and caregiver readiness are considered when selecting and sequencing therapeutic modules.

4. Adaptive Protocol Structuring

Based on the assessment data, patients are stratified by age (infancy, childhood, adolescence, adulthood) and functional severity (mild, moderate, complex), guiding the selection and prioritization of intervention techniques. This stratification supports a dynamic, stage-appropriate approach to care.

Operational Proposal

The proposed rehabilitation model for Arthrogryposis Multiplex Congenita (AMC) is designed as a modular, personalized, and scalable framework, adaptable to the diverse needs and trajectories of patients across different age groups and functional severities. The model is grounded in the principles of multidimensional assessment and patient-centered care.

1. Stratification by Age and Functional Severity

Patients are classified according to two axes:

- **Age Group:**
  - o Neonates and Infants (0–2 years)
  - o Children (3–10 years)
  - o Adolescents (11–18 years)
  - o Adults (19+ years)
- **Functional Severity:**
  - o Mild (isolated distal contractures, good motor prognosis)
  - o Moderate (multi-joint involvement, mo

Table 1 - *provides a structured mapping between functional assessment domains and corresponding therapeutic actions, serving as a clinical guide for tailoring interventions based on multidimensional evaluation.*

Assessment Domain	Therapeutic Action
Joint Mobility	Passive/Active Kinesitherapy, Orthotic Devices
Muscle Strength	Progressive Strengthening Exercises, Resistance Training
Postural Balance	Postural Re-education, Balance Training, Hydrotherapy
Activities of Daily Living (ADL)	Occupational Therapy, Functional Training, Caregiver Education
Respiratory Function	Respiratory Physiotherapy, Thoracic Mobility Exercises
Psychosocial and Environmental Context	Family-centered Training, Environmental Adaptations, Educational Support

derate limitations)
o Complex (global hypotonia, scoliosis, respiratory or feeding issues)

Each stratified group receives access to specific intervention modules, which can be adjusted over time based on re-assessment.

2. Rehabilitation Modules and Techniques

Each module includes a core set of techniques, tailored to the individual's profile:

- Kinesitherapy: Passive and active-assisted mobilization, stretching, and functional range-of-motion exercises, particularly in infants and early childhood.
- Hydrotherapy: Aquatic therapy for proprioception, anti-gravity motor learning, and safe mobilization, especially effective in preschool and school-age children.
- Respiratory Training: Thoracic mobility exercises, breathing techniques, and inspiratory muscle training in cases of scoliosis or reduced vital capacity.
- Orthotic Devices: Custom orthoses for positioning, contracture prevention, and joint function enhancement. Devices are adapted to developmental stages.
- Occupational Therapy: Promotion of fine motor function, self-care skills, and environmental adaptation, particularly during transitions to school and adolescence.
- Family Education: Ongoing caregiver training, home exercise programs, orthosis management, and psychosocial support are integrated into all modules.

3. Illustrative Protocol Example

Case: 6-year-old with moderate AMC (upper and lower limb involvement)

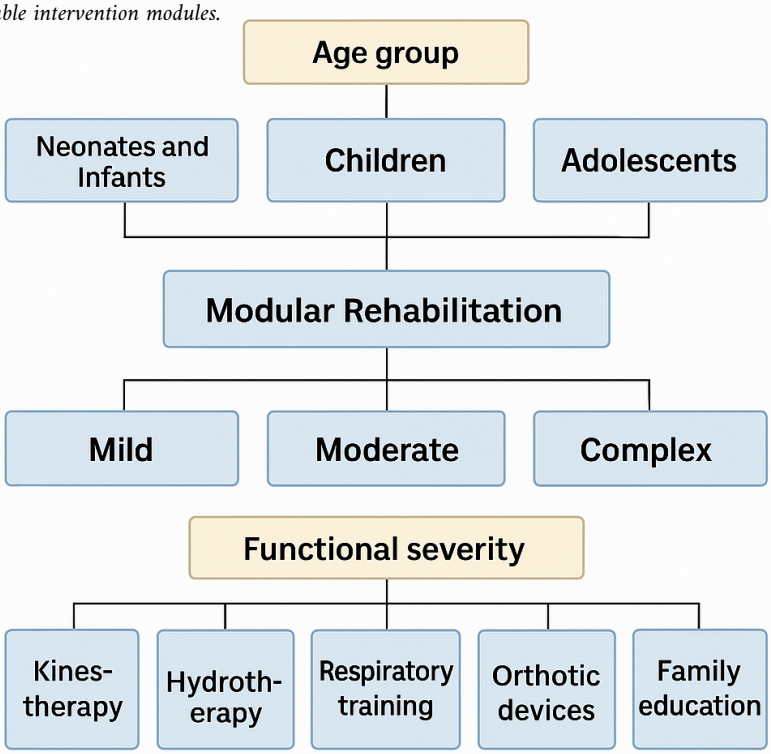
- 3x/week center-based physiotherapy with a focus on ROM and muscle strengthening
- 1x/week hydrotherapy
- Daily home exercises prescribed to family via digital app
- Quarterly respiratory check-up and adaptive orthosis adjustments
- Annual multidimensional reassessment to update therapeutic targets

4. Validation Pathway

To ensure clinical applicability and consensus, the proposed protocol structure will be validated through a Delphi process involving a multidisciplinary panel of physiotherapists, pediatricians, orthopedic surgeons, and patient advocacy representatives. The process will aim to refine and standardize core modules, outcome measures, and progression criteria. As of the time of writing, the Delphi process is in the planning phase, with the preliminary identification of expert participants and consensus domains underway. The objective is to launch the first round of consultation within the next academic quarter.

A detailed visual diagram of the protocol architecture and a mapping table of assessment domains to therapeutic actions have been developed to support implementation (see Figure 1 and Table 2).

Figure 1 - *illustrates the overall structure of the modular rehabilitation protocol, organizing age and severity stratification in relation to the available intervention modules.*



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The following table summarizes the key components of the proposed modular rehabilitation protocol for AMC, offering clinicians a quick reference for implementation.

- Improved respiratory capacity in thoracic-involved cases
- Greater independence in activities of daily living (ADLs)

Table 2 - *Clinical Application Box – A summary of practical elements for implementing the modular physiotherapy protocol in AMC. It includes age/severity-based stratification, core therapeutic modules, recommended treatment frequency, and key assessment instruments*

Component	Operational Specification
Functional Stratification	Age groups: 0–2 y (Infants), 3–10 y (Children), 11–18 y (Adolescents), 19+ y (Adults)
	Severity levels: Mild / Moderate / Complex
Core Therapeutic Modules	- Kinesitherapy (all groups)
	- Hydrotherapy (children, moderate+)
	- Respiratory Training (complex, scoliosis)
	- Orthotic Devices (moderate/complex)
	- Occupational Therapy (all age groups)
	- Family Education (universal, continuous)
Recommended Frequency	- Center-based physiotherapy: 2–4x/week depending on age and severity
	- Hydrotherapy: 1x/week (if available)
	- Home exercise: daily (caregiver-supervised)
	- Reassessment: every 6–12 months
Assessment Tools	- Joint Mobility: Goniometry
	- Muscle Strength: MMT, dynamometry
	- Balance/Posture: PBS, GMFM
	- ADL Function: PEDI, WeeFIM
	- Respiratory Function: Spirometry, Peak Flow
	- Psychosocial Context: PedsQL, caregiver interviews

Expected Benefits

The implementation of a shared, modular, and personalized rehabilitation protocol for Arthrogryposis Multiplex Congenita (AMC) offers multiple clinical and systemic advantages, addressing key limitations identified in the current literature and practice.

1. Improved Clinical Outcomes

By aligning therapeutic strategies with individual functional profiles—assessed through a multidimensional lens—the model enhances the specificity and effectiveness of interventions. Early and consistent application of age-appropriate modules contributes to:

- ncreased joint mobility and reduced progression of contractures
- Enhanced postural stability and motor function

Standardization of intervention logic also allows for better longitudinal tracking of progress and facilitates data aggregation for research purposes.

2. Reduction of Clinical Variability

One of the most significant barriers in AMC rehabilitation is the heterogeneity of physiotherapy approaches across centers and professionals. This model introduces a structured decision-making framework, based on severity and developmental phase, which promotes:

- Consistency in treatment pathways
- Replicability of interventions across clinical settings
- Easier comparison of outcomes between services and regions
- Development of benchmarks and quality indicators

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3. Enhanced Adherence and Family Empowerment

Active involvement of caregivers—through personalized training, digital tools, and collaborative goal setting—fosters a therapeutic alliance that extends beyond clinical sessions. This relational dimension:

- Increases adherence to home exercise programs
- Reduces dropout and disengagement
- Promotes psychological wellbeing and self-efficacy of both patient and family
- Facilitates integration of rehabilitation into daily life contexts

Caregiver empowerment transforms the home into a continuity-of-care environment, amplifying the effects of in-clinic interventions and enabling real-life skill generalization.

4. Systemic Benefits and Cost Efficiency

A modular and standardized framework facilitates training for new professionals, supports interdisciplinary teamwork, and may reduce reliance on trial-and-error approaches. In the long term, it may also:

- Shorten hospitalization or intensive care durations
- Reduce the incidence of secondary complications
- Optimize resource allocation and funding strategies
- Foster networked care models and data sharing

Future Directions

The proposed rehabilitation model for AMC represents a foundational step toward structured, evidence-informed, and patient-centered care. However, its long-term value depends on iterative refinement, clinical validation, and strategic integration into healthcare systems. The following directions are recommended to ensure sustainability and evolution:

1. Pilot Studies and Multicenter Implementation

To test feasibility and effectiveness, pilot studies should be initiated in specialized pediatric rehabilitation centers. These studies should:

- Compare outcomes between modular protocol users and conventional care groups
- Assess caregiver satisfaction, adherence rates, and patient-reported outcomes
- Evaluate usability and adaptability in varied socioeconomic and geographic settings

Successful pilot programs may lead to multicenter clinical trials, promoting broader validation and enabling regional customization within a unified framework.

2. Delphi Consensus and Professional Endorsement

As outlined in the operational proposal, a Delphi consensus process is key to refining the protocol's structure, outcome metrics, and assessment tools. Involving a diverse panel—including physiotherapists, pediatricians, occupational therapists, orthopedic surgeons, and caregivers—will enhance:

- Multidisciplinary ownership
- Cross-professional alignment
- Clinical acceptability and implementation readiness

Formal endorsement by professional societies (e.g., WCPT, national physiotherapy associations) will further consolidate its legitimacy.

3. Integration of Digital Tools and Remote Monitoring

Incorporating digital rehabilitation platforms and mobile applications can support home-based therapy, progress tracking, and real-time feedback. These tools enable:

- Daily monitoring of adherence and exercise quality
- Secure data exchange between families and therapists
- Adaptive adjustments based on recorded outcomes or caregiver input

Tele-rehabilitation modules, already piloted in AMC populations [13], may be embedded as a scalable solution, particularly for underserved or remote areas.

4. Longitudinal Registries and Personalized Metrics

To refine prognostic models and guide adaptive care plans, longitudinal data registries should be developed, capturing:

- Functional progression trajectories
- Response to specific modules
- Social and environmental determinants of rehabilitation outcomes

These data can inform the development of personalized therapeutic metrics, enabling physiotherapists to stratify risks, optimize resource use, and anticipate care needs over time.

Limitations of the Proposed Model

Despite its structured and integrative approach, the proposed modular rehabilitation model for AMC presents several limitations that must be acknowledged:

- Lack of empirical validation: While grounded in a synthesis of current literature and clinical reasoning, the model has not yet been formally tested in controlled or longitudinal studies. Its real-world effectiveness and generalizability remain to be demonstrated.
- Resource-dependent implementation: The model assumes access to multidisciplinary teams, advanced assessment tools, and specialized therapeutic modalities (e.g., hydrotherapy, respiratory training), which may not be uniformly available across all care settings or regions.
- Training and consistency among professionals: Successful adoption requires adequate training and adherence to shared operational standards.

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Without structured onboarding, there is a risk of variability in application and interpretation of modules.

- Family readiness and socioeconomic variability: While caregiver empowerment is central to the model, the time, literacy, and emotional resources required from families may vary significantly, potentially influencing treatment adherence and outcomes.
- Technological infrastructure: The integration of digital tools and remote monitoring presumes the availability of secure platforms, technical literacy, and internet access—conditions that are not universally guaranteed.

These limitations underscore the need for iterative refinement of the model through clinical trials, stakeholder feedback, and contextual adaptation. Future implementation efforts should also incorporate strategies for scaling the protocol in resource-limited settings.

Additionally, systemic and structural barriers may affect the feasibility and scalability of the proposed protocol. These include disparities in insurance coverage for long-term rehabilitation, the absence of nationally standardized clinical guidelines for rare neuromuscular disorders, and inconsistencies in healthcare policy frameworks across regions. Such factors could limit the integration of modular physiotherapy models into routine clinical practice, especially in low-resource or non-specialized settings.

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Author Contributions

Francesca UMMARINO conceived the theoretical framework, conducted the synthesis based on prior systematic review data, and developed the operational proposal. She is solely responsible for the writing, editing, and submission of the manuscript.

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