# Understanding and Adapting Amplified Musculoskeletal Pain Treatment for Youth with Autism Spectrum Disorder

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## Background

- **Amplified Musculoskeletal Pain Syndromes (AMPS)** are a spectrum of chronic musculoskeletal pain presentations characterized by central and/or peripheral sensory pain amplification[1] and associated with intense pain and functional impairment[2] despite the absence of tissue damage. [3]
- Individuals with **Autism Spectrum Disorder (ASD)**[4] have been shown to be disproportionately impacted by chronic pain compared to the general population (e.g., 8.2% of neurotypical children experience chronic pain compared to 20% of children with Autism).[5] [6]
- While there is evidence of the benefit of an interdisciplinary and exposure-based approach to AMPS treatment in general pediatric pain populations (PT/OT/Psychotherapy for conditioning, desensitization, coping and stress management)[7], little has been done to assess the experiences of youth with ASD in these programs.
- Youth with co-occurring AMPS and ASD may have different needs and preferences for effective and appropriate care due to social, communication, and sensory differences.[8] [9]
- Examination of adapted approaches to assessment and treatment already occurring within pediatric pain programs (e.g., Han et al., 2024) may offer insights into the strengths and challenges of the current gold standard approach to AMPS treatment for this population.

## Aims

1. Assess the finding that youth with ASD are disproportionately represented at a higher rate in the pediatric pain population.
2. Gather staff observations of the experiences of youth with ASD within the AMPS program, strengths and challenges in their care, and current approaches being applied to adapt treatment for this group.

Findings will inform quality improvement efforts in the **Golisano Children's Hospital Amplified Musculoskeletal Pain Program (GCHAMPP).**

## Method

- **Archival review** of medical records (2015 – 2023) of 281 patients assessed by GCHAMPP multidisciplinary evaluation team
- **Qualitative Survey** of staff experience

| GCHAMPP Team (N = 5) | Pediatric Rheumatology Team (N = 4) |
|---|---|
| 1 Nurse Practitioner | 1 Nurse Practitioner |
| 1 Occupational Therapist | 1 Fellow Physician |
| 2 Physical Therapists | 2 Attending Physicians |
| 1 Psychologist | |

- **Interpretative phenomenological analysis** of staff responses (IPA; Smith & Osborn, 2015), **inductive coding** (Miles et al., 2014; Rossman & Rallis, 2017)

## Results – Medical Record Review

| Retrospective Chart Review | |
|---|---|
| Total Patients Evaluated and Dx AMPS | **N = 254** |
| % ASD Dx General US Population (Youth) | **2.8 %** |
| % Formal Dx ASD in GCHAMPP | **4%** |
| % Formal, Suspected, or Pursuing Evaluation for ASD Dx in GCHAMPP | **11%** |

*"I offer **more structured choices** for increased autonomy in the sessions, work with the patient/family for solutions to completing the home program - this could be **changing the expectations** for frequency or amount, giving other ways to prompt doing the exercises at home, etc."*

*"I **look to parents for guidance** on best ways to interact with their child since they know them best"*

*"Identify **preferred ways of communication** or what works best for their learning (e.g. use analogies or visuals)"*

*"**More education for us as providers** about how to accommodate this patient population to have success in the program.*

## Results – Staff Survey

| Provider Positives of Work with Patient Population |
|---|
| Creativity (2) |
| Special interests (2) |
| Progress/treatment success (2) |
| Complexity (2) |
| **Provider Challenges of Work with Patient Population** |
| Understanding of diagnosis/treatment/buy-in (3) |
| Adherence/home exercise program (3) |
| Greater functional impairment at intake (2) |
| Individualizing treatment (4) |
| Communication (3) |
| Sensory differences (4) |
| Concrete thinking related to pain cognition and programming (2) |
| **Observed Challenges for Youth/Youth Feedback** |
| Sensory/desensitization (6) |
| Demands/expectations of the treatment (4) |
| Clinic environment (2) |
| Social communication demands (2) |
| **Informal Treatment Adaptations** |
| Autonomy/choice for patient (3) |
| Frequency/intensity/pace of Intervention (6) |
| Communication aids (2) |
| Collaboration with families and other providers (4) |
| **Hopes & Next Steps** |
| Provider education (5) |
| Collaboration with specialists (3) |
| Consistent expectations for treatment and prognosis across stakeholders/contexts (4) |
| Other treatment formats (2) |
| Understanding other factors impeding progress in this population (2) |

*"Kids with comorbid AMPS and ASD can come up with **creative** approaches to connect with their body and be physically active. They can develop deep ways of understanding themselves and use creative **language/analogies to communicate** or have insight."*

*"Once they have a grasp on the understanding of what they have and how the treatment can be beneficial, **it works.**"*

*"Engaging conversations of **patient interest**."*

*"May be more difficult to understand their **experiences of pain** due to differences in both perception and communication."*

*"Patient **buy in** to activities at home outside of the sessions. Tailoring for a **patient centered approach** without altering the integrity of the program itself."*

*"It also **takes time to understand their experience** of the world with ASD and then adjust communication/treatment to fit their experience."*

*"Buying in to challenging aspects of sensory processing and **desensitization**... Sometimes the **environment** of the clinic has been challenging for patients to focus…or transitioning between therapists or areas of the clinic for interventions."*

*"I think youth with ASD would say there is a lot of social communication across the team and that can feel overwhelming for them. They have shared they **feel overwhelmed communicating** with providers to tell them to slow down or that they need a break or something different."*

## Conclusions

- Results supported prior findings of a higher prevalence of youth with ASD in GCHAMPP compared to general population.
- Themes identified by GCHAMPP staff parallel prior study (Han et al., 2024) suggesting common needs for better understanding and supporting this population.
- Multiple respondents noted uncertainty about differences in the experiences of patients with and without ASD, highlighting that many providers may not have an adequate understanding of ASD to consider its impact on patient experiences.
- **Feasible next steps for GCHAMPP quality improvement should include:**
  - In-service training to increased understanding of ASD, adapted assessment/treatment
  - Review of Han et al., 2024 recommendations for treatment adaptation; use to develop policies, procedures, and materials for treatment adaptation
  - Increase recognition of existing Psychologist on AMPS team as a resource for ASD expertise/consultation; foster relationships with other specialists as needed
  - Reinforce importance of collaboration with all stakeholders in the treatment process (patient, family, school, multidisciplinary treatment team, other external providers)
- **Subsequent studies should focus on amplifying voices of patients and caregivers** in this process to gather their direct perspectives of strengths, challenges, and needs of GCHAMPP and related programs.