CPF SYNC

PAIN IN CP
Symposium Summary

September 20, 2016

Hollywood, Florida

This Workshop was supported through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (EA-3535)
1.0 OVERVIEW

1.1 Background

Nearly one million people in the United States have cerebral palsy (CP). Advances in medical and surgical care over the last few decades have resulted in significant gains in the long-term survival of children into adulthood with permanent physical disabilities. This results in many chronic co-morbid conditions (1). The experience of pain is one of the most prevalent, poorly understood, and inadequately treated conditions in the medical world, particularly as it involves disabilities. It is a historically nebulous and subjective concept. Pain is described by the International Association for the Study of Pain as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage [2]. Pain in the population with CP is common. Based on pain prevalence studies from the current literature 54% to 70% of pediatric patients with CP experience pain on a monthly to weekly basis, and when present, it results in significant morbidity and decreased quality of life for patient and caregiver alike [3-5].

Children with CP have been shown to experience more pain than age matched controls. There are various etiologies contributing to pain in patients with CP, including surgical, procedural, GI, orthopedic, neuromuscular and rehabilitative-related pain. This pain has been variously described as "neuropathic, overuse, transition zone, radicular and visceral" and oftentimes manifests as sleep disturbance [1,6]. Additionally, 70% of patients with CP are characterized as high-tone, significant spasticity is thought to contribute to pain which likely results from atypical biomechanical forces, muscle contractures and tendon shortening. [7].

There is a recent literature suggesting that patients with CP receive inadequate pain control due to the poor communication of pain [9,10]. Although a number of tools have been created to aid evaluation of postoperative pain in preverbal pediatric patients or those with cognitive impairments, these are not widely used in the medical community [11]. Moreover, observational nursing pain assessments often rely on stereotypical pain behaviors, which may not be a reliable indicator of pain in this population [12].

Compared to those with a disability acquired in adulthood, people with cerebral palsy have most likely experienced pain and many stages of their life. Thus, they may have less awareness of how they should be appropriately treated or examined by health care professionals. Cognitive impairment and communication difficulties pose an inherent difficulty in assessing pain in this population. McKearnan et al. note that children with cerebral palsy may find it difficult to convey pain experiences due to cognitive limitations, developing or underdeveloped communication skills, relative inexperience with pain, and various socio-environmental influences [6]. This failure in communication has resulted in a systemic lack of recognition of pain and failure to appropriately manage it on the part of providers stemming both from poor communication as well as a poor understanding of pain mechanisms in this population [8].

The greater incidence of cognition, hearing, and vision issues in adults with CP may impede their awareness or education in appropriate screening, treatment, and follow-up. Without proper assessment and thorough follow-up by their health care providers, they are at much higher risk for exacerbated health problems.
1.0 OVERVIEW (CONT)

To address this priority, the CPF SYNC: Pain in CP Symposium was convened at the 2016 American Academy of Cerebral Palsy and Developmental Medicine Annual Conference in partnership with the Cerebral Palsy Foundation and the AACPDM. The AACPDM mission is to provide scientific education for health professionals and promote excellence in research and services for the benefit of people with and at risk for cerebral palsy and other childhood-onset disabilities. It has had a long standing commitment to pushing the field forward and identifying research priorities. With the EACD and Australasian Academies, it has formed the International Alliance of Academies of Childhood Disability (IAACD) with the goal of improving the health and well-being of children, youth and adults with childhood-onset disabilities around the globe.

This report summarizes the highlights of the symposium deliberations, factors that merited special consideration regarding interventions, and recommendations for studies that will help advance this area. In addition to discussing issues related to direct intervention and research strategies, we also emphasized patient and family education and addressed the importance of activity, participation, and family dynamics. We illustrate the need for sequential and systematic research and clinical agendas.
2.0 SYMPOSIUM METHODOLOGY

2.1 Participants

A total of 29 individuals participated in the symposium. The steering committee identified participants from different regions (USA, Canada, UK, France and Australia) representing several target audiences (i.e. practitioners, educators, researchers, representatives of professional bodies, government liaisons/consultants, patients and their families). All participants submitted a biographical sketch and a 3-6 min presentation that focused on the subject of pain in CP and highlighted their own research. The biographical sketches were included in the symposium preceding’s to maximize information sharing and help participants become familiar with one another’s research and expertise, thereby facilitating networking and communication during the symposium.

The planning committee applied for and received funding from PCORI to support the cost of the summit.

2.2 General procedures

The CPF SYNC: Pain in CP symposium was a 1-day conference designed to systematically address the current state of clinical research in the area of pain in CP and to create research networks and goals. The day was broken up into three sessions.

1. The morning session focused on information exchange and identification of knowledge gaps.
2. The second session built on the information presented in the morning by formulating scientific questions and considering research designs.
3. The third session was dedicated to the development of recommendations, action plans, and research priorities.

The morning included a 3 min “Quick Hits” presentations from each attendee and a 60 min stakeholder panel to set the stage for the afternoon discussion groups of the symposium. The goals of this session were to “frame the symposium” and to present the current “state of the science”. A panel of 3 family members and 3 individuals with CP completed the consumer panel who highlighted the realities of living with pain and being on the receiving end of clinical practice and the implications for patients and their families. The quick hit presentations were intended to provide a catalyst for discussions and planning, expand recognition and appreciation of the impact of pain and its complexity, and highlight potential research questions. Presentations by all participants were intended to expose the group to the breadth and themes of research activities in which participants are engaged, exchange information on current and past research efforts, and highlight potential areas for collaborations and strategies for funding.
2.0 SYMPOSIUM METHODOLOGY (CONT)

2.3 Small and Large Group Discussions

The afternoon included two small group discussion sessions of 1 hour each followed by 30 min of large group discussion with all participants. The goals of the first small group discussions were:

1. Propose research themes
2. Choose the top 3, and
3. To promote discussion of preliminary research proposals, action plans, and recommendations.

Experienced researchers were grouped with less experienced investigators based on areas of interest or expertise. There were a total of 4 small-group discussion sessions, each consisting of at least 7 participants. The research themes identified were then dot-voted on over lunch.

The second small group discussions were designed to explode the top 4 research themes as voted by participants and explore a care pathway and knowledge translation activities. Finally, under the guidance of the facilitator, 30 min were allocated to whole group discussion about developing an action plan and recommendations as a starting point for change in clinical practice as well as research agendas.

The facilitators oriented the group to the charge and tasks at hand, maintained the focus and integrity of the Symposium goals, facilitated large-group discussions, helped the group adhere to time guidelines, provided guidance when needed, and summarized discussions. Four members of the planning committee served as small-group facilitators to maintain the integrity of the goals of the small-group discussions relative to the summit goals and to record the small-and large-group discussions for later transcription.

The World Cafe methodology was selected since it is a simple, effective and flexible format for hosting large group dialogue. The basic method is composed of five components.

1. Setting: The environment is modeled after an intimate cafe’ (i.e. small round tables equipped with flip chart paper and colored pens).
2. Welcome and Introduction: An experienced facilitator welcomes participants, introduces the World Café process, describes the context, and puts the participants at ease.
3. Small group rounds: The process begins with the first of a series of short rounds of conversation for the small groups seated around the individual tables.
4. Questions: Each round is prefaced with the question of interest designed for the specific context and desired purpose of the session.
5. Harvest: After the small group discussions, individuals are invited to share insights or other results from their conversations with the group assembled as a whole. The facilitator is then able to qualify and elaborate upon the complexities and nuances of the context, question crafting and purpose.
2.0 SYMPOSIUM METHODOLOGY (CONT)

Figure 1.0 Flow of the day

Collaboration during meals and breaks

- Opening Large Group:
  - Introduction from CPF and AACPDM
  - Stakeholder Panel
  - 3 minute “Quick Hits”

- 4 Small Groups Session Research priorities
  - Each group identify top 3 research ideas

- Dot Voting

- 4 Small Group Sessions
  - Explode your theme
  - Top 4 voted research themes
  - Knowledge Translation
  - Care Pathway

- Final Large Group
  - Entire Group Discussion
  - Final Consensus
  - Action Plan
3.0 PROCEEDINGS

In the sections that follow, we highlight and summarize deliberations from small and large-group discussions, specific aspects that merited critical consideration on the topic of procedural pain, and recommendations for research generated by the summit participants. Examples from the target areas of knowledge translation and care pathways are also included.

3.1 Stakeholder Panel

Stakeholders including people with cerebral palsy as well as parents completed the panel. A wide variety of topics were discussed during the panel including the importance of physical activity and fitness in reducing and managing pain, management of procedural pain, encouraging functional and fun activities, the difficulties and importance around advocacy and starting education early for both families as well as children, the effect of chronic pain on mental health and anxiety and the benefits of having a pain management plan. Quotes from the panel are outlined below.

“I try to take care of myself with diet and exercise. I always try to keep moving and using my muscles. There was a two-year period in my life where I was in a lot of pain from having multiple leg and foot surgeries. I was in almost constant pain and discomfort even doing simple things like getting up. The goal of my operations was to get my legs to stop turning inward and to prevent my feet arches from caving in. It was meant to make walking easier later in life. I’ve been doing PT and training almost all my life. Whenever I don’t do my regular routine I definitely feel it. I exercise and do activities regularly to prevent back and hip pain.”

“My pain varies on a daily basis, depending on how much activity I’ve done or what I’ve been doing, but I have a great pain management plan so I’m able to manage it quite well. My pain management plan has definitely changed and evolved over time, as I’ve gotten older I’m really able to understand and take control of my pain management, so now I’m able to say ok, I’m feeling at a five so I need to take this med instead of Mom or Dad asking me, I ask them. When the pain is getting really, you know, intense, I just try and focus on the pain is only as small, negative aspect of my life, I have so many larger, positive aspects. I’m in school, I have made friends, I have an amazing family and pain is just aches, insignificant, annoying little thing. It doesn’t, it’s not all of me either. I will also add that, not to CP, but disability in general, it’s not all of a person. It’s part of who you are, don’t let it become all of you, because it’s only a small part of you.”

“Well from the very beginning when she would scream during therapy when she was just one-year-old. It was terrifying and sometimes I had to go sit in the other room because I couldn’t stand to see her crying so much. I knew that it was both a combination of fear and pain.”
“Pain has been part of our reality when your daughter has imbalanced muscle tone, high spasticity and you have all those things, you’re battling your body all the time so you know, I don’t have CP, but I try my best to try to imagine what it’s like for her and how can I be of help?”

“At times I have been extremely apprehensive to address my needs. Doctors did not engage in necessary dialogue and discussion with me because they saw me as “my diagnosis” and not the woman I am.”

“Botox appointments are the most difficult of all our son’s appointments, for him and us as parents. We consider the injections a necessary evil because, from a functional perspective they help him. However, they cause a significant amount of pain. We have tried a few different methods of pain management during the injections over the past five years, but they haven’t been very effective. This includes EMLA cream, ice and distraction techniques. No other forms of pain treatment have been offered – I think partly because we are in a secondary treatment center and not a hospital that has access to an anesthesia team. In the past three years, we have started preparing him for the upcoming appointments by talking about how the needles help him. He also gets a small surprise within minutes of the injections being done (typically a small toy car or action figure). The procedure itself is difficult. After the physical exam, we walk into an adjoining treatment room and he immediately starts to whimper or cry. Once on the plinth, it requires 3-4 adults to hold him down while the physiatrist does ultrasound guided injections. All the while, he is screaming for the physician to stop and calling out for me and his dad to help him. It is all we can do to hold the tears back while we’re doing whatever we can to distract him (from blowing on his face, counting down during each injection, and having him ‘breathe’). But, he gets so upset and cries so hard that at more recent appointments he has started gagging when the injections begin. Once he has settled a bit, we just try to get through the injections as quickly as possible. Thankfully he recovers very quickly and within 20-30 seconds after the injections he stops crying and is asking for his surprise. But, we know this process is having an effect on him. Anytime we go near the treatment room where the injections occur, he asks if he is getting ‘leg needles’.”

“Without exception, my group of friends, who had mixed feelings about the medicines available to treat CP, all agreed that a critical factor in pain management is for doctors to encourage and familiarize families with how to do weekly workouts outside of therapy. Many people with disabilities and their families think therapy will last forever. A good habit of going to the gym or working out at home is invaluable for us all, yet often people with disabilities think working out is not something they can do. Families are focused on many other concerns, and figuring out an exercise routine can be difficult. In the face of many other needs, exercise habits may often be deprioritized or outside the traditional area of concern of many doctors following people with CP—but exercise was the single biggest factor my friends mentioned as making a difference for them.”

My husband and I, along with two home-care nurses, and babysitters my husband and I hire and train provide round the clock care for our son. It is no exaggeration to say that late at night, after he has had his meds, and he and his sister are asleep, my husband and I drape ourselves in ice packs or heat packs to soothe our aching backs. Even after multiple requests, we have not been trained on how to lift and move
him, or on strategies of how to most ergo dynamically dress him or lift him on to the toilet. When anyone requires such a sustained and involved level of care, it's almost a fiction to consider that person in isolation. The three of us, and our hired caregivers, are a sort of a unit, albeit a unit of shifting composition over time.

3.2 Clinician and Researcher 3 min Quick hits

See Appendix B. for complete summary of presentations
3.0 PROCEEDINGS (CONT)

Table 1: Themes from the first group discussion

<table>
<thead>
<tr>
<th>Group</th>
<th>Identified Themes</th>
<th>Top 3 ‘Identified’ for Further Prioritization</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>• Early Education of stakeholders (person, family, professional)</td>
<td>1. Early Education of stakeholders (person, family, professional)</td>
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<td></td>
<td>• How much pain (classification and scales)</td>
<td>2. Understanding pain (experience, anxiety, anticipation)</td>
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<td></td>
<td>• Understanding pain (experience, anxiety, anticipation)</td>
<td>3. Pain Classification/ Scales</td>
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<td></td>
<td>• Gain without pain</td>
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<td></td>
<td>• Early Intervention</td>
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<td></td>
<td>• Aging with pain</td>
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<td></td>
<td>• Robotics as prevention</td>
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<td>2</td>
<td>• Definition of pain in CP (acute, persistent, neurological, nociceptive, inflammatory, visceral)</td>
<td>1. Definition on pain in children with CP (type of pain, impact on CP, MRI)</td>
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<td></td>
<td>• Emotional, psychological comfort with pain</td>
<td>2. Individualized identification of pain</td>
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<td></td>
<td>• Measurement (subjective, emotional, quantitative)</td>
<td>3. Treatment (medical vs. non-medical, individualized, family involvement, advocacy)</td>
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<td></td>
<td>• Prevention (neonatal, infancy, childhood)</td>
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<td></td>
<td>• Treatment (medical vs. non-medical, individualized vs. family)</td>
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<td></td>
<td>• Recognition of pain (constant, chronic)</td>
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<td></td>
<td>• Ownership &amp; Roles (Individual, Carer/Advocate, Family, Professional)</td>
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<td></td>
<td>• Understand Brain + Pain in CP (mechanisms)</td>
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<td></td>
<td>• Individualized Perception</td>
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<td></td>
<td>• Functionality</td>
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<td>• Impact of pain (function and participation)</td>
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<td>3</td>
<td>• Biopsychosocial &amp; spiritual approach</td>
<td>1. Prevention of physician/procedure induced pain</td>
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<td></td>
<td>• Guiding principle life course</td>
<td>2. International approach review of policies and understanding (advocacy)</td>
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<td></td>
<td>• Outside of basic science</td>
<td>3. Pathophysiology of pain in CP (brain processing, inflammation, etc.)</td>
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<td></td>
<td>• Pathophysiology of pain in CP (brain processing, inflammation, etc.)</td>
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<td></td>
<td>• Prevention of physician/procedure induced pain</td>
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<td></td>
<td>• Pain→impact on long term outcomes</td>
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<tr>
<td></td>
<td>• Addressing knowledge gaps with tools that are CP specific</td>
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<td></td>
<td>• International approach to review of policies (advocacy)</td>
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<td>4</td>
<td>• Pro-active “pain” planning pre intervention</td>
<td>1. Pain and procedures (inventory of “now”).</td>
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<td></td>
<td>• Control over medication (within guidelines)</td>
<td>2. Prevention (what are the correct metrics and targets?)</td>
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<td></td>
<td>• Pain management and treatment (non-pharmacological)</td>
<td>3. Across the lifespan (brain health and neurodevelopment)</td>
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<td>• Continuity of care (seeing same clinician over time)</td>
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<td></td>
<td>• Transition Planning</td>
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<td></td>
<td>• Emotional Support</td>
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<td></td>
<td>• Control / inclusion understanding why it is important</td>
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<td>• Biofeedback and role of mindfulness</td>
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<td></td>
<td>• Pain and procedures (inventory of “now”)</td>
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<tr>
<td></td>
<td>• Prevention (what are the correct metrics and targets?)</td>
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<td></td>
<td>• Across the lifespan (brain health and neurodevelopment)</td>
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Table 2: Top voted research themes to explode during afternoon session

<table>
<thead>
<tr>
<th>Research themes dot voted by whole group</th>
<th>Number of votes</th>
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<tbody>
<tr>
<td>1. Pain and Health across the lifespan</td>
<td>21</td>
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<tr>
<td>2. Prevention of procedural pain, create inventory of best practices</td>
<td>20</td>
</tr>
<tr>
<td>3. Advocacy by individuals with CP and parents around strategies</td>
<td>19</td>
</tr>
<tr>
<td>4. Treatment medical and non-medical</td>
<td>17</td>
</tr>
<tr>
<td>5. Understanding pathophysiology of pain</td>
<td>15</td>
</tr>
<tr>
<td>6. Robotics and tech as prevention</td>
<td>14</td>
</tr>
<tr>
<td>7. Importance of defining pain in children and young people with CP</td>
<td>7</td>
</tr>
<tr>
<td>8. Pain and prevention (metrics, targets, variety of impacts)</td>
<td>6</td>
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<tr>
<td>9. Early Education of stakeholders (person, family, professional)</td>
<td>3</td>
</tr>
<tr>
<td>10. Development of pain classification scales and the individualized identification of pain</td>
<td>3</td>
</tr>
<tr>
<td>11. Understanding experience of pain (experience, anxiety, anticipation)</td>
<td>2</td>
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<tr>
<td>12. Understanding the approaches to pain internationally- beyond North America</td>
<td>2</td>
</tr>
<tr>
<td>13. Different toolboxes that are CP specific</td>
<td>1</td>
</tr>
</tbody>
</table>

*Number of votes in ()

Final Top 4 research themes to explode

1. Pain and Health across the lifespan
2. Prevention of procedural pain, create inventory of best practices
3. Advocacy by individuals with CP and parents around strategies
4. Treatment medical vs. non-medical

Pre-nominated themes

5. Knowledge Translation
6. Care Pathway
4.0 SUMMARY OF RESEARCH THEMES

4.1 Pain in Health Across the Lifespan
This is an important subject for many reasons. We are only recently asking our patients about the presence of pain and trying to characterize that pain. We are only recently trying to fill the void of knowledge about pain in those who cannot respond for themselves. We are only recently recognizing the missing demographic and clinical information on adult patients with cerebral palsy. We are proposing a platform of research on pain in cerebral palsy across the lifespan. The purpose of this research platform is to define the issues around pain in individuals with cerebral palsy to provide information needed to assess outcomes of interventions for pain, to provide information needed to design new interventions, and to provide the information needed to inform individuals with CP and their providers.

Opportunities/ Next Steps

- Systemic review of the literature. Our patient population would include adolescents through adulthood and older adults and all levels of involvement.
- We propose qualitative interviews to start the project to reveal the narrative particularly in the adults. The information derived from the qualitative study will guide future research.
- The next phase might be a cross sectional look at adolescents and adults from existing registries in the US and Canada. The Weinberg Family Cerebral Palsy Center has a registry of more than 5000 lives that could be utilized. The Minnesota and San Diego groups have adult registries as well.
- Using the results of the cross sectional studies, national data bases from the hospital associations, Medicare and Medicaid could be used for a more population based definition of the problems around pain that we are attempting to define.
- The CP Research Network has developed common data elements that will be collected prospectively and will continue over time. This may be another source of research data. Our group felt strongly that we should include screening for co-morbidities, anxiety and depression. As a part of this project we are recommending using social media to contact and query individuals with cerebral palsy and their caregivers. This project needs to be crafted as a PLATFORM of research, not a single study. The start can be sustained by small grants in the 50K range. The later phases need real funding that will likely need to be federal – either PCORI or NIH.

4.2 Prevention of Procedural Pain, Create Inventory of Best Practices
Individuals with cerebral palsy are subjected to frequent painful procedures. The reaction to this fact has been that the procedure is necessary and the pain was transient. This is a major quality of life issue for individuals with CP. Therefore, prevention of procedural pain needs to be a priority. To achieve this, we need to create an inventory of common procedures which are known to cause pain. We need to determine if these procedures are really necessary – are they efficacious? If procedures are performed, how can we decrease pain and are there alternatives to the painful procedures. There are current solutions such as the ‘Pediatric Pain Listserv’ where questions can be answered. In this area, traditional research is not necessarily the answer. There should be a focus on knowledge translation. Comparative effectiveness studies would also be powerful looking at the best information on Botox administration, perioperative pain, stretching monitoring and preoperative analgesia.
4.0 SUMMARY OF RESEARCH THEMES (CONT)

Opportunities Next Steps

- Pediatric Pain Listserv - If you have a question it will get answered.
- Educational challenge - We don’t need to conduct traditional research, instead we should focus on knowledge translation.
- Comparative Effectiveness Study - Best available information regarding Botox, perioperative pain, stretching, monitoring and preoperative analgesia.

4.3 Advocacy by Individuals with CP and Parents Around Strategies

It is vital that stakeholders including families/parents/individuals are involved from the start in research. The end users of this information need to be involved in the design and implementation of research protocols and to help frame the research question. There are several mechanisms to achieve these goals including a knowledge translation steering group to push forward the importance of advocacy. This could be accomplished in part by educating the stakeholder about pain and engaging the patient as a child. Our methods and techniques of communication need to be engaging (e.g. effective use of social media). Planning for integration of KT needs to acknowledge the lifelong biomedical effect of cerebral palsy and related conditions on children, adolescents, adults and their families.

Opportunities/ Next Steps

- Educational resources for families to encourage early conversations with their children to help explain ‘What is CP? What does it mean to you?’
- Awareness campaign around the use of goal setting and how to be an active participant in decision making (e.g. use of COPM). Help focus their time and give families the opportunity to make decisions.
- Online Resource development for Pain Management in CP.
- 5x90 min workshops using ICF as a framework and the F words (Fun, Family, Fitness, Future, Function, Friends) to shift from a focus on disability and pain to one of wellness.

4.4 Treatment Medical and Non-Medical

The treatment of pain in CP must be predicated on understanding the pathophysiology of pain in CP. We need to develop pain assessment tools that can be used across all functional levels. We need to understand what assessment tools exist and where gaps exist that need attention. There is a need to understand the etiology of pain across the different types of CP. Needed data includes intensity, frequency, duration and function. There is a need to develop animal models that reflect the pain pathways in CP so that we can ascertain pain processing and to evaluate interventions for pain. Our efforts in pain treatment in CP need to be focused on both medical and “non-medical” treatments that will allow the most holistic approach to pain in CP.
Opportunities/ Next Steps

- We need to analyze the work outside of the CP world. First recommendation would be to do a Non-CP literature review. What can we learn about the pathophysiology of pain in relation to CP? Is it the same? Is it different?
- Currently there is no single best instrument for assessing pain. We may consider an international protocol recommendation for a measure or a couple of measures that we have. (e.g. FLACC? PPP? Observation?)
- Recommendation of use of this measure in future studies so they can be compared across studies. We ask in so many different ways, we need to take a systematic approach.

4.5 Knowledge Translation

‘Pain is a constant companion’ – this powerful statement by a parent set the tone for the brainstorming that ensued. The discussion led to recognition that there is a general lack of knowledge about the prevention and management of pain in cerebral palsy. A key focus of the effort in educating stakeholders and providers is to “make pain a priority” and debunking the idea that “pain is normal”. Given the multifactorial and complex nature of pain, multiple strategies will be needed to drive awareness and to change behavior. Parents, caregivers, individuals with CP and families need to be enlisted in this effort as they all have a strong potential to act as knowledge brokers and advocates. Other targets for creating a new environment around pain include the CP experts, providers, schools and community and the broader pain community.

Opportunities/ Next Steps

The group identified that there is good information out there, but a need to prioritize pain as an issue and motivate conversations, as well reducing fragmentation of information and enhancing access. A proactive rather than reactive approach is key. Potential avenues offered include:

- Creating a centralized resource (1 stop shopping for families/orientation to rehab community).
- Developing multi-disciplinary pathways to equip providers to respond.
- Electronic tools/tracking apps to monitor pain experience.
- Using coaching paradigms to incorporate pain conversations in everyday routines.
- Ensuring pain prevalence and prevention are key topics at CP forums (first line of defense).
- Equipping providers to talk about caregiver health as a conversation starter for pain prevention/management among children.
- Educational modalities (workshops, webinars, storytelling, videos, etc) for providers and families.
- Awareness campaign (e.g., ‘Our bodies, ourselves’ movement).

Guiding principles noted included ensuring a family-centered focus, engaging varied stakeholders in generating solutions and an emphasis on mobilization so that young people, families and providers can act.
4.0 SUMMARY OF RESEARCH THEMES (CONT)

4.6 ‘Pain’ Care Pathway

There was enthusiasm for developing and promoting a ‘Pain Care Pathway’ for individuals with cerebral palsy. The group identified that it would be important to determine who the pathway was developed for (e.g. the primary care physician or a clinician specialist). In the United Kingdom a NICE guideline has recently been developed for pain in CP that is organized into three categories: i) cause of pain, ii) assessment, iii) prevention and treatment. The group outlined that it will be important to assess the NICE guideline and build on rather than replicate information provided in the guideline. There was general support around the ADOPT framework (Assessment, Demystification [enhancing understanding of pain for the individual and caregiver], Optimize Health, Promote Physical and Psychological Wellness and Treatment). The group outlined that it was very important to enhance nonpharmacological approaches to the treatment of chronic pain including biofeedback and mindfulness. This was identified as an underutilized and under-resourced area that may require specific strategies to develop/promote.

Further discussion focused on expanding important areas of the ADOPT framework. The group outlined that clinicians need enhanced training to become ‘good’ at diagnosing the cause of pain. There was discussion around the benefits of a ‘continuity of care’ model where the clinician sees the same individual over time - to help train clinicians to become a ‘good diagnostician’. There needed to be more anticipatory guidance provided to individuals with CP and their families about pain. In addition, more focus on empowering caregivers to recognize pain in the individual with CP and advocate for prevention and treatment, should be undertaken. There was much enthusiasm for promoting physical activity and changes in position to help to prevent and manage pain in CP. The group recommended positioning oral medications such as opioids as a second or third line approach with long-term use of these medications minimized as much as possible.

Opportunities/Next steps

- Review the format of the NICE Guidelines and build on them to develop an AACPDM Care Pathway that spans the lifespan.
- Form a steering group to develop the Care Pathway.
- Include psychological expertise on mindfulness, biofeedback on the steering group.
- Include a stakeholder group to help shape the Care Pathway.
- Include knowledge mobilization experts and build in knowledge dissemination strategies throughout the pathway development.
- Seek funding to support the development and dissemination of the Care Pathway.
5.0 FUTURE DIRECTION

We need to take a strategic and systematic approach

Knowledge translation
- Ensuring pain prevalence and prevention are key topics at CP forums (first line of defense)
- Educational modalities (workshops, webinars, storytelling, videos, etc) for providers and families
- Mainstream media Awareness campaign

Research Agenda
- Systematic review of pain in CP (youth and adults)
- Seek funding and complete a qualitative study to guide research
- Seek funding and complete a comparison effectiveness study utilizing current CP databases.

Pain Care Pathway
- Establish a steering group
- Seek funding and build pathway
- Disseminate Pathway with strategies for primary and specialized clinicians and individuals with CP and their families

Dissemination
- Review and audit of current patient and family resources
- Development of patient resources, online tools and Book with McKeith Press
- Development of centralized resource for patients, families, physicians and general practitioners