

S/mptom Surveillance After Hemispheric Surgery
Neuropsych Working Group Meeting
May 31, 2024
1:00 PM PST

Attendees: N. McNamara (initiative co-lead), Monika Jones (patient advocacy lead), Madison Berl, Cindy Salorio, Marylou Smith, Nancy McNamara, Samantha Kliman
Unavailable: Lynn Paul (Neuropsych working group lead), Hanna Ammons

[Full video recording of meeting](#) (unlisted)

Notes

- M. Jones reviewed the purpose and goal of the initiative
 - The problem we want to solve: Parents, caregivers, and clinicians do not have a roadmap to navigate medical symptoms and functional outcomes after hemispheric surgery.
 - The solution: develop recommendations for post-operative symptom surveillance and screening
 - Our goal:
 - Minimize surprises in chronic postoperative care
 - Prepare clinicians and caregivers for what may happen
 - Provide scaffolding for caregivers to manage medical and functional outcomes through adulthood.
- Systematic review has been completed and draft statements prepared
 - [List of all literature with corresponding domains](#)
 - [List of all proposed statements w/ corresponding literature](#)
 - Domain literature folders: [Neuropsych](#), [Speech and Language](#)
 - M. Jones discussed the desire to model the structure of these recommendations after the paper titled "[Recommendations for Screening Pediatric Psoriasis Co-Morbidities for Primary Care Providers](#)." She highlighted that this paper is well-organized, with each section having its own table and summary of recommendations, followed by specific recommendations supported by literature and a concluding paragraph, and highlighted the importance of robust knowledge dissemination to ensure families and clinicians, especially those not at major hospitals, are well-informed.
- The group discussed the following preliminary statements resulting from literature review:
 - Statement P1: Educate all patients about neuropsychiatric comorbidities after hemispheric surgery.
 - Discussion:
 - The group discussed the difference between neuropsychiatry and neuropsychology. Parents often lack awareness of the importance

of neuropsychological assessments. Emphasis on the need for education about neuropsychological comorbidities post-surgery.

- There was significant discussion on category definitions and organization, highlighting the overlap and complexity of these areas.
- Suggestions to create a Venn diagram to illustrate the overlap between these categories in the preamble to this section.
- Discussion re making neuropsych the main category and splitting it into subdomains - behavioral, cognitive, psychosocial, and mental health domains (terms that are familiar and less intimidating to families.) Preamble to this section will define each category.
 - Status: Consensus on amending statement to *Educate all patients about [neuropsychological comorbidities/subdomains] after hemispheric surgery. Further refinement of this statement is needed.*
- P2: Describe what is known about the spectrum of cognitive ability and functioning observed in patients who have undergone hemispheric surgery.
 - Discussion: Discussion on the importance of educating families about potential changes in cognitive domains, as well as whether to include specific behavioral and cognitive challenges that may arise. Mention of the importance of periodic evaluations.
 - Status: Consensus reached to include specific behavioral and cognitive challenges that may arise. Amend statement to read *Educate all patients about what is known about the spectrum of cognitive ability and functioning observed in patients who have undergone hemispheric surgery, including [behavioral challenges, autistic characteristics, attention issues, perseveration ...]* Further refinement of statement needed.
- P3: Describe the benefits and limitations of getting IQ or cognitive testing from a neuropsychologist before hemispheric surgery
 - Discussion: Emphasis on preoperative testing to establish a baseline. This helps set realistic expectations and provides a comparison for postoperative outcomes. Consensus that this is crucial for proper management and understanding of cognitive changes. Strike IQ. Change *describe* to *educate*.
 - Status: Consensus reached to amend to *Educate all patients about the benefits and limitations of cognitive testing from a neuropsychologist before hemispheric surgery.*
- P4: Describe the rationale for conducting a neuropsychological assessment following hemispheric surgery and recommended time-points/ages.
 - Discussion: Extensive discussion re need for post-operative neuropsychological assessment. Group concluded that this statement is better as a broad description/explanation in the preamble.
 - Status: Strike this statement.

- P5: The following new-onset cognitive impairments may be observed following hemispheric surgery.
 - Discussion: Statements should address both new onset and pre-existing cognitive impairments. The group discussed creating a table to outline these assessments clearly. Cognitive impairments should be assessed post-surgery to provide a comprehensive understanding.
 - Status: Consensus to strike this statement as it is addressed better in other statements.
- P6: Patients should anticipate worsening or, alternatively, improvement in pre-existing cognitive impairments following hemispheric surgery.
 - Discussion: Agreement that this statement is necessary but should be carefully worded to avoid false hope. Suggestion to include a disclaimer about the likelihood of continued development but not necessarily catching up to peers. Consideration of adding the term "rarely worsen" to provide clarity. Agreement that this statement is necessary but should be carefully worded to avoid false hope. Suggestion for a disclaimer about the likelihood of continued development but not necessarily catching up to peers. Status: Consensus to rewrite to *Educate all patients that pre-existing cognitive status may improve or remain stable after surgery. Over the long term, improvement is likely. Further refine and reconsider this statement, addressing the need for regular evaluations and screenings for various cognitive and behavioral issues.*
- P7: The following cognitive domains may be impacted by hemispheric surgery:
 - Discussion: Change *describe* to *educate*. General agreement on the necessity of regular assessments. Suggestion to include specific domains such as attention, behavior, mood, and autism spectrum features.
 - Status: Consensus reached to include as amended to *Educate all patients that the following cognitive domains may be impacted by hemispheric surgery. Further discussion needed on domain areas to be addressed and develop corresponding table of domains and symptoms.*
- P8: Post-operative cognitive impairments are likely to improve, worsen, or remain stable over the long term.
 - Discussion: Consideration of adding the term "rarely worsen" to provide clarity. The group agreed on the importance of addressing potential changes in behavior and cognition. The group debated whether to include the term "worsen" due to its potentially alarming nature. Suggestion to separate statements for short-term and long-term outcomes. Emphasis on the need to manage expectations realistically. Recommendation to provide a detailed preamble or table to clarify these areas. Emphasis on the need for regular evaluations and screenings for various cognitive and behavioral issues.
 - Status: Consensus reached to strike this statement as it is addressed in P6.

- P9: The following patient-specific variables appear to predict cognitive or neuropsychiatric outcomes (e.g., etiology, age at surgery, duration of disease, hemisphere, etc.).
 - Discussion: Preoperative and postoperative seizure burden may affect cognitive outcomes. Agreement on the need to include this statement, highlighting the impact of seizure burden on cognitive outcomes. Other postoperative medical complications that may impact cognition, such as hydrocephalus. The group discussed using terms like "consequences" and "comorbidities" to better capture these aspects in the preamble/statement descriptions. Discussion on the variability of outcomes based on different etiologies. Existing data points to the impact of age at surgery on language outcomes. Unique challenges faced by children with specific conditions like hemimegalencephaly.
 - Status: Consensus reached to amend this statement to read *Educate patients that certain variables, such as etiology, age at surgery, pre-operative and post-operative seizure burden, and post-operative medical complications, may impact neuropsychological outcomes.* Further description in preamble required.
- P10: Cognitive and neuropsychiatric impairments pose the following functional impacts following hemispheric surgery:
 - Discussion: N/A
 - Status: Tabled for next meeting.
- P11: Patients should anticipate new onset mood disorders or behavioral disturbances following hemispheric surgery.
 - Discussion: N/A
 - Status: Tabled for next meeting.
- P12: Patients should anticipate worsening or, alternatively, improvement in pre-existing mood disorders or behavioral disturbances following hemispheric surgery.
 - Discussion: N/A
 - Status: Tabled for next meeting.
- P13: List any additional cognitive or behavioral domains that should be addressed.
 - Discussion: N/A
 - Status: Tabled for next meeting.

Action Items:

- Participants to review the revised statements and provide feedback.
- Consider contents of the preamble and table to clarify cognitive, behavioral, and psychosocial domains.
- Agreement to reconvene on June 14, 2024, at 1 pm PST to review last few statements as well as speech/language statements.

- The goal is to present a draft of these statements at the plenary session on August 1st, acknowledging that the neuropsych group may need additional time to finalize statements due to the complexity of the topics discussed.

TRANSCRIPT (unedited)

Monika Jones: And Dr. Beryl just joined us.

Madison Berl (she/her/hers): Hi! Patty!

Monika Jones: You know about everyone except for maybe—oh, you know Dr. McNamara, right? You know Nancy.

Monika Jones: And then Samantha Kleman just introduced herself. She's a speech pathologist who works with Dr. McNamara at CSM. She does a lot of the pre- and post-epilepsy surgery evaluations.

Madison Berl (she/her/hers): Awesome.

Monika Jones: Patty can't join us. Why don't we get started?

Monika Jones: I have a brief presentation for all of you before we dive into the proposed statements.

Monika Jones: So this is the first meeting of the neuropsych working group for our initiative titled Symptom Surveillance After Hemisphere Surgery.

Monika Jones: It's an initiative from the Pediatric Epilepsy Surgery Alliance to develop recommendations for symptom surveillance and screening after hemisphere procedures, such as hemispherectomy and functional hemispherectomy.

Monika Jones: The problem we want to solve is that parents, caregivers, and clinicians generally don't have a roadmap to navigate all the medical and functional outcomes after surgery. We want to put all of these various things into one unifying document. After we publish that document, we aim to have a robust knowledge dissemination plan so that our families learn about all of these symptoms and the clinicians working with them, especially those not at big hospitals that perform a lot of these surgeries.

Monika Jones: I just wanted to briefly show you the presentation we gave at the American Epilepsy Society, where we presented some data from our patient registry. This data shows the neuropsychological outcomes that the kids have.

Monika Jones: This is a topic of major importance: social well-being and psychological health. Many patients have anxiety and, anecdotally, depression. Autism spectrum disorder is reported at 20%, but I would say that's probably much higher. Keep in mind, many of the patients who have filled out this registry are still in the one to two-year age range, so they may not have been

formally diagnosed. There are many challenges that these patients face, which you can see listed here.

Monika Jones: So that's really it. None of this should be new to any of you—the children, many of them, have neuropsychological challenges preoperatively. A lot of those things don't go away, or they change, or they may worsen after surgery. Another major topic to tackle is pre- and post-operative language acquisition.

Monika Jones: What we want to do is develop some preliminary recommendations for postoperative symptom surveillance and screening in these domains. Our goal is to minimize surprises for our families and chronic postoperative care, prepare clinicians and caregivers for what may happen, and provide scaffolding for caregivers to understand how to navigate medical and functional outcomes through adulthood.

Monika Jones: We have a series of proposed statements prepared. We already did the heavy lifting for you—our research coordinator, who works with Dr. Taylor Able at UPMC, Pittsburgh, did a fantastic job of pulling together all the relevant literature for us. She and I went through everything and started developing these statements around what may happen or what does happen postoperatively. We'd like you to consider these statements in the context of quality of life, burden of care, access to care, coordination, and the transition into adulthood.

Monika Jones: For example, the auditory group met last week, and one of the biggest challenges for that group is that audiologists qualified to assess central hearing disorders are really few and far between. How does a child living in a rural area of the country, for example, access someone with that level of experience? It's something for you all to consider as well.

Monika Jones: Before we dive into your statements, we really like this paper, and I'm sure you all have similar papers that you're familiar with, but this one around screening recommendations for pediatric psoriasis co-morbidities is really clean. It has a table of statements and recommendations, and each statement has a paragraph of literature that supports that statement. I found this paper to be clean, easy to navigate, and effective. We're hoping to mirror this paper in our final document.

Monika Jones: Does anyone have any questions so far?

Monika Jones: No? Okay. So, we have statements in the domains of speech and language, and then we're calling them psychiatric. I guess they could be neuropsychological or behavioral, or however you want to term them in the end.

Monika Jones: The first statement is sort of easy but also complicated: educate all patients about neuropsychiatric comorbidities after hemispherectomy. Speaking from my personal experience, I didn't know what a neuropsychologist was until my son was about nine or ten years old. I'm fairly well-educated and deep in this world, and I frankly just had no idea what this

whole area was in terms of what to investigate. I knew what a neuropsychologist was, but I didn't know how important it was for my son to have an assessment.

Monika Jones: In social media groups, there's a family every week asking, "What is a neuropsychologist? Does my child need this assessment? How can it help?" We always have surprises and comments from families saying, "Before surgery, my child was like this, and now, after surgery, they're seizure-free, but their behaviors are through the roof." I know you all see that.

Monika Jones: I'd like to open it up to discussion around these statements. Which ones do you feel should be in this document? Go ahead, Cindy.

Cindy Salorio: I just want to clarify. At Kennedy Krieger, for example, we have neuropsychologists and neuropsychiatrists. Those are two separate professions. So, I'm wondering if, rather than psychiatric, which mixes neuropsychiatry and neuropsychology, we want to do it more behavior versus cognitive. I don't know if that makes sense in the structure you already have, but I think it's confusing. That first statement is confusing to me just because we do have both specialties here. I know most places probably don't.

Monika Jones: I agree. I think you're right. Yup.

Marylou Smith: Yeah, I agree. I wonder if the term psychiatric might be a bit frightening or off-putting. Not to ignore it, but just to have it as a big, bold header. Might think about how to present that in a different way.

Monika Jones: How do you all present it in the clinical context?

Marylou Smith: Behavioral or psychological.

Madison Berl (she/her/hers): Yeah, psychosocial.

Cindy Salorio: Mental health versus cognitive.

Marylou Smith: Mental health and behavior could be the category together.

Marylou Smith: It's not to say we don't want parents, families, or individuals to seek out psychiatric care when they need to, but as you say, if this is going to an audience who may not be that familiar, we don't want to scare them off.

Monika Jones: Yeah, they're already scared as it is, candidly. Okay, so educate all parents about...changing the category to one of these various suggestions: behavioral, psychosocial, mental health, and behavior. So, that would be the first comment.

Monika Jones: And then, go ahead.

Marylou Smith: You could have a little preamble that defines what you mean by these categories. These recommendations pertain to this, this, and this. A bit of a preamble to the recommendations might be helpful.

Monika Jones: Okay.

Madison Berl (she/her/hers): I think the confusion is that there is overlap. These are Venn diagrams. Do you have another heading for language? Because Samantha and our work overlap, but she definitely dives in. I think there's that education there, and we do look at behavior in relation to cognition. The confusion over terms is warranted. Maybe just a Venn diagram of these things, showing their overlap and specialization.

Madison Berl (she/her/hers): You could educate about the providers, if possible.

Monika Jones: Well, at AES or CMS, there was a whole workshop on behavior, and I kept saying, "Hold on, sometimes the behaviors are seizures, or pre-seizures. If my son's non-verbal and doesn't have his communication app, his behaviors escalate. That's related to being non-verbal versus having a psychiatric disorder."

Monika Jones: So, we should consider the preamble and the Venn diagram, and how we present this.

Monika Jones: Okay, for the first statement, should that be rewritten to...

Marylou Smith: Do you want to separate the terms, mental health, psychosocial, cognitive, or keep them all in the same category?

Monika Jones: I think we should separate them out. Yeah.

Monika Jones: Let's assume we change this to behavioral comorbidities. We should decide on the three main sections: behavior, mental health, psychosocial.

Cindy Salorio: Where are you putting cognitive? Or is that mixed up together?

Monika Jones: It's all mixed up together. This is the most complicated in terms of what you all cover. Vision is easier.

Cindy Salorio: Even simple things like changes in attention after hemisphere surgery and ADHD. The attention piece is cognitive, but the diagnosis is thought more to be mental health, psychiatric, or behavioral. It's hard to tease apart.

Samantha Kliman: From a parent perspective, do you think labeling something like cognitive-behavioral comorbidities would capture everything?

Madison Berl (she/her/hers): If you're trying to organize by providers, you could do neuropsychological comorbidities, speech-language, and psychiatric. Underneath it, you could have education about neuropsychological comorbidities, mostly cognitive aspects, and speech-language. Psychiatric is more behavior and emotional. Mental health and behavior could be the

category together.

Cindy Salorio: You could call it all neuropsychological if you wanted to. The items you have cover cognitive, mood, and behavior. If the rest is discipline-specific, it makes sense to split out neuropsychological from behavior, mood, and psychiatric.

Madison Berl (she/her/hers): I don't know that every epilepsy surgery center does a pre-post neuropsychiatric evaluation. It's more common to do neuropsych than psychiatric, and we refer.

Cindy Salorio: We look at behavior and mood as part of neuropsychological. Our center doesn't do a behavioral or psychiatric assessment pre-surgery.

Monika Jones: Maybe it's easiest to keep it as neuropsych and then split it into sub-domains, making neuropsych the main category.

Madison Berl (she/her/hers): That works. I'd argue the same for speech and language. Samantha, maybe you're doing more of those evaluations, but that's rare.

Samantha Kliman: We touch on some things, but most of the cognitive, executive functioning, and attention come from neuropsych.

Madison Berl (she/her/hers): We integrate and then refer as needed, where we reach the limits of our competence. Rehab, when speech, language, and vision are needed due to surgery, is more on the post-side.

Monika Jones: I think I'd rather have it in two places than one because ideally, those topics would be brought up in different ways in both visits.

Monika Jones: Are there statements we see here that are a given, an easy "yes"?

Monika Jones: P8 seems reasonable, but the word "likely" bothers me. I prefer "may."

Monika Jones: P8 changed to "may," but otherwise, we agree?

Monika Jones: Yay, we got one.

Madison Berl (she/her/hers): If these are meant to be pre and post, I'd put the pre first. It may feel more logical as you read the statements.

Monika Jones: We can reorganize them. These are not in the order they'd be presented; they were our brainstorming.

Monika Jones: So, would it be "educate all patients about the spectrum of cognitive ability and function observed"? P3 changes to "educate all patients about the benefits and limitations of getting formal IQ or cognitive testing before surgery."

Marylou Smith: Yes.

Monika Jones: Most of them will be "educate." Understand? Educate is fine.

Marylou Smith: These are directed towards healthcare givers, what the healthcare giver should be doing?

Monika Jones: Yes.

Marylou Smith: For P5, how would you word it? Inform patients that the following cognitive domains may be impacted?

Monika Jones: We want to avoid broad brush statements that imply everything will be fine post-surgery. We need to inform that there will be challenges cognitively. Should we say "inform" or "educate"?

Madison Berl (she/her/hers): You could have a blanket statement at the beginning: educate all patients about the following neurosurgical comorbidities that these cognitive domains may be impacted by surgery.

Marylou Smith: Could we say that pre-existing cognitive impairments may remain stable, improve, or worsen after surgery? Nancy, are you comfortable with that?

Nancy McNamara (she/her/hers): Yes, that's better worded.

Monika Jones: Patients should anticipate no change, improvement, or worsening after surgery. Let's chew on this one a little bit.

Monika Jones: P6 will be yellow. Yellow means we're thinking about it.

Monika Jones: Is there anything we don't want in here?

Monika Jones: For P7, if we're going to list everything, is it useful?

Madison Berl (she/her/hers): Isn't it similar to P2 about the range of functioning?

Monika Jones: There should be a statement for families of infants who've had surgery. They're surprised by autistic characteristics and behavioral challenges. Should we include that?

Cindy Salorio: Would it make sense to integrate that into P3, stating the need for evaluations at specific time points to look at behavior, mood, cognition, features of autism, etc.?

Monika Jones: Maybe we should address the main categories here.

Nancy McNamara (she/her/hers): Everyone should have pre-testing for these things. Postoperatively, have neuropsych testing with specific categories. In addition, if not part of it, specific testing for ADHD, autism, etc.

Marylou Smith: Or at least screening.

Cindy Salorio: Like the table of signs and symptoms for spasticity, we could do a table for screening for post-surgical behavior, cognitive, etc.

Monika Jones: That makes sense for P7. We should think about the main categories we'd address here.

Nancy McNamara (she/her/hers): We will end up with pre-testing and post-testing at specific intervals. Screening for ADHD, autism, and other domains this group comes up with.

Marylou Smith: For P7, do you need to list everything?

Madison Berl (she/her/hers): Maybe it should be a blanket statement that the following domains should be assessed post-surgery.

Monika Jones: P4 seems universally agreed upon.

Monika Jones: P4 can go in the preamble.

Monika Jones: We've done a good job here. We've accomplished a lot today.

Monika Jones: I can't get the neurosurgeons to agree on a date. The fact we all have a date is good. I'm a little frustrated.

Monika Jones: Let's stop. I think we've done a good job. If everyone could take the time to review these, we'll revisit. Is the last Friday of June good for our next meeting?

Madison Berl (she/her/hers): I can't make that.

Monika Jones: I can't either. The 21st?

Madison Berl (she/her/hers): I'm out the 19th through the 30th.

Monika Jones: Is the 14th too soon?

Marylou Smith: 14th is okay with me.

Monika Jones: Everyone else can do the 14th?

Cindy Salorio: I could do this time on the 14th. I have a post-hemisphere evaluation during the day.

Monika Jones: Madison, can you do the 14th at this time?

Madison Berl (she/her/hers): I can.

Monika Jones: Let's do that. I'll send out an invitation. Thank you, everyone, for coming. I know this is a big ask, but I feel we can knock it out.

Monika Jones: Great, have a great weekend.