NEUROPSYCHOLOGY AND THE PSYCHOLOGICAL ASPECTS OF SPINA BIFIDA

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ABOUT ME

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  • Owner of private neuropsychology practice, Dallas Neuropsychology, PLLC, with offices in Greenville and Rockwall, TX
  • Privileges to see patients at Hunt Regional Medical Center in Greenville and component of treatment for acute in-patient rehab
  • Neuropsychologist at Outpatient Brain Injury Program in Dallas
WHAT IS NEUROPSYCHOLOGY AND NEUROPSYCHOLOGICAL TESTING?

- Neuropsychology is the study of the structure and function of the brain as they relate to specific psychological processes, cognition, and behaviors.

- Neuropsychological evaluations assess cognitive processes associated with learning, memory, language, visual-spatial, attention, executive functioning, and motor skills while also taking into consideration the affects of psychological, social, and biological functioning.

- Neuropsychological evaluations incorporate a diagnostic interview, self-report assessments, review of medical records, and standardized neuropsychological testing to determine appropriate diagnoses and treatment recommendations. Understanding a patient’s cognitive strengths and weaknesses in functioning helps aid in self-understanding and in establishing appropriate treatment/accommodation/rehabilitation.
WHY IS NEUROPSYCHOLOGICAL TESTING NECESSARY FOR PERSONS WITH SPINA BIFIDA?

• All individuals need to understand that if Spina Bifida is associated with myelomeningocele, it is not simply an orthopedic disorder (“physical disability”). The brain malformations and hydrocephalus (with or without shunting) affect learning.

• Neuropsychological evaluations can help to provide a more comprehensive understanding of strengths and weaknesses, as well as the significant discrepancies often present in their profiles. These findings can be related to neuroimaging findings for a more careful determination of the basis for any difficulties experience by the child.

• It is important to advocate for eligibility for special education services or academic 504 accommodations that emphasize the need for ongoing care and attention to changes in brain development. Re-evaluation may be required every two years.
RESEARCH INDICATES…

- Though individuals with SB who do not have hydrocephalus have less neurocognitive deficits, cognitive changes as well as psychological symptoms of depression and anxiety are commonly present in individuals with SB.

- Individuals with SB usually demonstrate difficulty with attention, processing speed, working memory, information retrieval, impulsivity, difficulty staying on task, abstract reasoning, visual-spatial organization, mental flexibility, and difficulty with social cues.

- Brain areas: Frontal lobe and cerebellum
• Children and adults with Spina Bifida (and other disabilities) are at an increased risk of experiencing symptoms of anxiety and depression (CDC).
  • A Rhode Island study showed that 29.8% of people with severe disabilities suffered from frequent depression, compared to 14.6% of people with moderate disabilities and 4.2% of people with no disabilities. Thus, compared with the no disabilities group, people with severe disabilities were 7 times more likely to report frequent depression (defined as 15+ days a month).
In addition to the cognitive and learning problems associated with the underlying neurological disorder, adolescents with spina bifida are vulnerable to feelings of depression secondary to reduced quantity and quality of social interactions. Structured opportunities for social interaction through school, church, and afterschool opportunities may be needed to decrease a potentially higher risk for depression. (Essner & Holmbeck, 2010)

Special considerations (per SBA): “The 1st step in identifying a depressive disorder is to rule out physical causes of behavior or mood change. In people who have Spina Bifida and shunted hydrocephalus, this is especially important because many signs and symptoms of depression may actually be caused by medical conditions (shunt malfunction, infections, or medications) rather than depression. In those situations, the symptoms disappear when the underlying medical condition is treated or corrected.”
SYMPTOMS OF DEPRESSION

• Difficulty concentrating and remembering details
• Fatigue and decreased energy
• Feelings of guilt, helplessness, and worthlessness
• Insomnia or excessive sleeping; irritability/restlessness
• Loss of interest in activities or hobbies that were once pleasurable
• Overeating or appetite loss
• Persistent sadness, anxiousness, or feelings of “emptiness”
• Thoughts of suicide, suicide attempt
SYMPTOMS OF ANXIETY

- Excessive, uncontrollable worrying
- Panic attacks with physiological symptoms
- Sleep disturbance
- Digestive issues
- Irritability and/or social withdrawal
- Paranoia
- Obsessive thoughts and behaviors
- Cognitive shut-down
FACTORS RELATED TO MENTAL HEALTH / SOCIAL ECOLOGICAL THEORY
There is a stigma attached to people with disabilities, perpetuating the idea that they are less valuable members of society than people without disabilities. Children begin to prescribe to this stigma during late elementary school, giving rise to the rejection and isolation that inhibits the development of social competence (Salmon, 2013).
INTERPERSONAL – PEER RELATIONS/SOCIAL SUPPORT

- Kids begin their academic careers with comparable social and academic competency as their peers. By the end of elementary school, however, children with physical disabilities have experienced some type of rejection or bullying that inhibits their social competency. Peers without disabilities are less likely to view those with disabilities as potential friends. These children become excluded and are unable to develop the social skills that their peers do.

- Schools: 80% of children with SB are taught in mainstream classrooms.

- People with physical and cognitive disabilities tend to have fewer friends and less social acceptance from peers; less “positive peer experiences” (Essner & Holmbeck, 2010).

- Reduced opportunity to participate in social activities (physical play and social communication).

- Children who do not learn how to build and maintain friendships turn into adults who lack interpersonal skills (Essner & Holmbeck, 2010).

- Sexuality/reproductive ability: The key to helping lower anxiety in this area is just to make sexual education important as it relates to disability.)
INDIVIDUAL - COGNITIVE DISTORTIONS AND DEFICITS

• Negative early life experiences like loss or rejection influence your core belief, which is the prism through which you interpret the world. (Beck, 1967)
  • Schemas
    • Ex: Negative Core Belief of “I’m no Good”
      • A minor negative event occurs, which activates our belief and reinforces idea that the world is dangerous or terrible
      • Produces automatic negative thought (ex: “I always fail”)
      • Anxiety

• Cognitive Deficits
  • Abstract reasoning, attention, shifting, comprehension, fluency, comprehension, social cognition, impulsivity all affect expressive and receptive communication
PHYSICAL COMPONENTS OF ILLNESS AFFECTS MENTAL HEALTH AND COGNITION

- Incontinence (developing independence and acceptance) and preventing infection
- Chronic pain correlated with anxiety, depression, and cognitive change
- Frequent surgery (this is very much anxiety-provoking because there is such a loss of control and the decision about it comes from parents; try to talk about the surgery several weeks beforehand and give choices where you can such as having a toy with them or what color the cast is)
PREVENTION STRATEGIES

- Early and continuous neuropsychological testing
- Appropriate nutrition and exercise
- Involvement in the SB community
- Relationships and Social Support
  - Family, neighbors, friends, community/religious affiliations
- Positive Self-Talk and Attitude
  - Parent’s attitudes directly relate to children’s attitudes
  - Build self-awareness
PREVENTION STRATEGIES (CONT.)

- Increasing independent living skills
  - Self-care: bladder and bowel management, transferring, transportation, skin care, appointment setting, medication, self-advocacy
  - Catheter Training
    - request a FREE copy of the Medikidz Explain Clean Intermittent Catheterization comic book at marketinglofric-us@wellspect.com.

http://www.wellspect.us/For-users/Bladder-management/Your-child-and-catheterization
INTERVENTION STRATEGIES – MENTAL HEALTH

• Relaxation Techniques
• Puzzles
• Pets and animals
• Art/coloring
• Journaling
• Nature
• Medication: Treat symptom or cause? Most effective when combined with therapy

Overview of relaxation techniques:

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<th>Body techniques:</th>
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<tr>
<td>- Progressive relaxation</td>
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<tr>
<td>- Breathing exercises</td>
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<tr>
<td>- Physical exercise</td>
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<tr>
<td>- Yoga</td>
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<td>- T’ai Chi</td>
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<td>- Qigong</td>
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<tr>
<td>- Biofeedback</td>
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<td>- Massage and self-massage</td>
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<th>Mind techniques:</th>
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<td>- Meditation (mindfulness)</td>
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<td>- Guided imagery</td>
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<td>- Self-hypnosis</td>
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<td>- Cognitive behavioural techniques</td>
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<tr>
<td>- Music</td>
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<tr>
<td>- Problem-solving techniques</td>
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<tr>
<td>- Humour</td>
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<tr>
<td>- Music</td>
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<th>Spirit techniques:</th>
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<td>- Gratitude and self-compassion</td>
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<td>- Connecting with others through socialising or a shared interest</td>
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<td>- Prayer, meditation, chanting and singing</td>
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<td>- Volunteering, showing kindness to others and being generous</td>
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<td>- Reflecting on your own inner thoughts &amp; feelings and writing them in a journal</td>
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Consultation can also be used to gather information about Omega 3 for attention. Recent research high/therapeutic doses improve mood, attention, and impulsive symptoms in people diagnosed with attention and/or mood disorders. Recent research uses dosages in the range of 2.5 g with a 2:1 relationship of EPA to DHA; however, body weight must be taken into account.

Speech therapy to address expressive language weaknesses.
  - Recommendation of Courtney Willis, ST; Speech Wings Therapy, 6370 Lyndon B. Johnson Freeway, Dallas, Texas; 214-864-3013; speechwingstherapy.com

Occupational therapy is recommended to address his fine motor deficits.

Internet websites that provide cognitive exercises for the brain. There are several websites now available including: www.lumosity.com, www.mybraintrainer.com/, and www.positscience.com/

Specific accommodations for school such as extended time for testing, access to a quiet area for testing, academic tutoring/support and pre-teaching of concepts, guidance around task completion/organization, and support around fine motor tasks.
- Presenting information in a visual and verbal format with repetition of information presented.
- Giving cues and/or choices when he appears to have difficulties with free recall (multiple choice cues will aid the ability to recall previously learned information)
- Disruption in motivations and sensitivity to rewards is due to malfunction in neuronal circuit pathways that are specifically responsible for reward and motivation and will cause a disruption in “interest” causing difficulty doing the thing that you know you should do due to wavering interest—also referred to as amotivation. Therefore, external structure is required to assist with internal motivation. One strategy to address this is to make the task much more engaging. Another way is to use small rewards to help motivate him to get started. For example, “I will get to eat one of my favorite snacks during my 5 minute break after I work on _____ for 30 minutes.”
- Learning and memory (mnemonic) strategies such as applying meaning or past knowledge to new information, and continuing to categorize information semantically or chunking it into other meaningful contexts and using retrieval cues, such as acronyms, when learning new information. Discovering strategies that help create meaningful associations between pieces of information will improve the consistency of learning and recall. Visual information should be paired with verbal information. Still, cues in the form of multiple choices will greatly aid his retrieval of information he has learned.
Additional interventions may include:

- Maintain good eating and sleeping habits. Eat frequent, small, nutritious meals with a little protein at each meal. Go to bed and wake-up at the same time each day.
- Provide external structure. Use lists, color-coding, reminders, notes, rituals, and files. Keep a notepad with him for when he wants to remember something. Make a weekly time to organize his work area and plan for the week.
- Break down large tasks into smaller ones. Attach deadlines to the small parts and then the large tasks get done. A large task will seem overwhelming to him. Smaller components of the larger task are more manageable.
- Use the FRAT system to organize paper flow. Try to touch each paper only once. File it, Route it to the correct person, Action it, or Throw it away.
- When reading or completing tasks, build in breaks. For example, read for 10 minutes, then stretch or do something relaxing for 2 minutes, e.g. watching sports. Read with a pen in hand for notes, and to write down extraneous thoughts.
- Create a space where he can be free of distracting people and sounds. Use ear plugs if necessary and place a do not disturb sign on the door.
- Prioritize. He will fight the desire to procrastinate. Make lists of what needs to be done. Sort the list by importance (A=immediate, B=can wait, C=not essential). Do items on the A-list first.
- Continuously remind him of his successes and strengths.
Use of compensatory strategies such as a daily organizer/memory notebook to aid in daily recall and organization; cell phone apps that help with organization, scheduling, and reminders; handheld tape recorder to make quick verbal notes; dry erase board for reminders; and/or pill organizer for medication management.

To assist with time management and task completion, consider a watch or a phone with several programmable alarms. The alarms can be set for reminders of tasks and appointments as well as set to control the amount of time spent on a task. For example, some models also ring (or vibrate for discretion) every three minutes (for up to four hours), reinforced by a text message, up to 36 characters long, that appear on the face. These watches can be ordered at amazon.com or via a Google search or the iPhone has the Reminder App.

The child needs to be taught how to process information conceptually rather than relying on explicit or literal interpretations. He will need to continue with direct instruction in reading comprehension strategies—this area may be challenging given his literal interpretations. Direct instruction/tutoring for reading comprehension that should involve the following:

- Story structure from which he learns to ask and answer who, what, where, when, and why questions about the plot and, in some cases, maps out the time line, characters, and events in stories.
- Summarization in which he attempts to identify and write the main or most important ideas that integrate or unite the other ideas or meanings of the text into a coherent whole.
INTERVENTION STRATEGIES – MENTAL HEALTH

• Lack of programs focused on individual mental health needs of people with physical disabilities

• Tips for parents of children with anxiety disorders and/or depression:
  • pay attention to their feeling/listen,
  • normalize (many kids experience this),
  • remain calm when your child becomes anxious,
  • educate them on anxiety and depression by learning about them yourself,
  • recognize and praise small accomplishments, don’t punish mistakes or lack of progress,
  • be flexible (don’t force them),
  • modify expectations during stressful periods,
  • plan for transitions (like allow for extra time in the morning if getting to school is difficult).
- Peer support/group counseling- see if your local SBA chapter has support meetings- nothing is more effective than talking with someone else who truly understands.

- Cognitive Behavioral Therapy (CBT)
  - teaches people to evaluate their thinking about common difficulties, helping them to change their thought patterns and the way they react to certain situations. Helpful in improving core beliefs and reducing cognitive distortions.
RESOURCES

- SpinaBifidaAssociation.org

- Spina Bifida/Hydrocephalus books and information for children: http://www.sbhao.on.ca/programs-services/youth/kids-resources

- National Alliance on Mental Illness Information Helpline – Trained volunteers can provide information, referrals, and support for those suffering from anxiety disorders/depression in the U.S. Call 1 (800) 950-NAMI (6264), Monday through Friday, 10 am-6 pm, Eastern time. (NAMI) http://www.nami.org/Find-Support/NAMI-HelpLine


- Anxiety info/self-help website for parents, children, teens, and adults: https://www.anxietybc.com
QUESTIONS OR COMMENTS?

Thank You!

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Resources

American Association on Health and Disability, 2008.


Center for Disease Control, 2013.


Spina Bifida Association website