

ACC AND HEALTH ISSUES

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The information presented in this talk is based on:

- A survey conducted by the ACC Network (Schilmoeller & Schilmoeller, 2002) of individuals with ACC, collected from 732 participants
- Information from current literature (Currently, there is no body of research which looks specifically at medical/health issues in individuals with callosal conditions)
- Anecdotal reports from parents collected over the last 15 years by the ACC Network

Although individuals with callosal disorders may seem remarkably “unique,” this may be due to differences in *additional* neurological, medical, or behavior diagnoses as well as familial and personal characteristics

Despite these differences, the ACC Network survey and family reports indicate there may be some patterns in health-related issues which warrant special attention

Much more research must be done- this is very preliminary information

Considering individuals with callosal disorders:

“ACC only”- Individuals who primarily have a callosal disorder without other neurological or congenital conditions. Many of these individuals are considered very healthy (physically).

“ACC with other medical or health related diagnoses” - Individuals with additional neurological and/or congenital diagnoses *in addition* to ACC

Health-related issues may be:

- Syndromes, neurological disorders, genetic diagnoses, other congenital disorders
These may or may not be related to the “cause” of the callosal disorder
- “Unrelated” to the callosal condition (for example: asthma)
- “Typical” health-related problems (issues like early feeding difficulties, injuries, bowel and bladder control) While these may be common health concerns/issues for any individual, there are patterns emerging which indicate there may be special concerns for individuals with ACC and other callosal disorders.

Some health-related concerns for individuals with callosal disorders

Neurological issues

- Seizures 55.6% reported no seizures
40.0% reported to have had at least one seizure
29.1% reported to have been diagnosed with a seizure disorder
- Headaches- some parents report frequent or problematic headaches

Sensory issues

- Vision 62% report current or previous vision difficulties
26.6% report they wear glasses (farsighted, nearsighted)
19.6% report they have problems with depth perception
Strabismus (23%), nystagmus (16%) also reported

Some anecdotal reports of early diagnosis of blindness that was later retracted

Implications:

1. Early detection and treatment of visual/motor problems
2. May look like clumsiness/lack of coordination

- Hearing 23% report current or previous hearing difficulties
Some anecdotal reports of initial diagnosis of deafness that was later retracted

- Touch 40% report more sensitivity to touch than typical
55.7% report the individual has less pain perception than typical

Implications:

1. Pain is our primary warning system to detect injury and illness in the body
2. Without the normal experience of pain, individuals may be more likely to continue "painful" activities
3. Accidents and injuries may go undetected
4. Illnesses may not be discovered until later stages (ear infections, for example)
5. May be less likely to recognize dangerously cold weather conditions
6. Undiscovered injuries may be "discovered" by health professionals

Feeding/eating issues

The development of proper feeding and swallowing is influenced by many factors including normal oral, pharyngeal, and esophageal structures, proper nervous system integration, proper tone and coordination of more than 20 muscles, and the ability to process tactile sensations and provide the necessary feedback

- Early feeding/sucking /swallowing/chewing issues
55.4% report inadequate sucking at birth
16.2% report had/have a gastric feeding tube
28.9 report difficulties with swallowing occasionally or often
50.2% report chewing difficulties now or in the past
- Gastro esophageal reflux disease
17.3% report they experienced reflux in the past
25% report they experience reflux occasionally or often

Implications:

1. Social-emotional component to feeding
2. Adequate nutritional intake
3. Early feeding difficulties can lead to "learned" food avoidance behaviors
4. Importance of obtaining early assistance from feeding specialists

Bladder and bowel control

- Many individuals with callosal disorders have delayed/difficult bladder and bowel training (more than 60% report occasional or frequent difficulties with bladder control after three years old)
- Over 50% report experiencing difficulties with constipation occasionally or frequently
 - Implications:
 1. Late potty training is difficult for all!
 2. Are they physically capable? (lots of mechanisms must be working and coordinated)
 3. Are there other unknown issues at work here?
 4. Social stigma

Sleep issues

- 56.3% report they do not have a regular pattern of sleep
- 51.4% report occasional or very frequent night time waking
- 42.1% report occasional or very frequent difficulties getting to sleep

Other sleep difficulties were also reported but less frequently- bedwetting, night terrors, and other unusual nighttime behaviors

Motor issues

- Delays in gross motor abilities such as sitting alone, crawling and walking
- Delays in fine motor abilities such as holding a crayon, manipulating toys
- Coordination difficulties

Health-related issues of interest which also need additional research

- Cardiovascular- some individuals with ACC also have congenital heart anomalies
- Endocrine disorders (hormones, chemical imbalances, growth disorders?)
- Others?

We cannot say these issues are “caused” by the callosal disorder, only that they should be considered as you raise your child and interact with health professionals. Much more research is necessary!

Healthcare professionals you may come in contact with:

Feeding specialist- *a professional, usually a speech-language pathologist, trained in disorders of feeding and swallowing*

Geneticist- *a physician who specializes in patterns of inheritance*

Neurologist- *a physician who specializes in diagnosing and treating diseases of the nervous system*

Neuropsychologist- *a psychologist who specializes in the relationships between the brain and behavior*

Nurse- *a healthcare professional formally educated and trained to care for individuals with actual or potential health problems*

Obstetrician- *a physician who specializes in the care of women during pregnancy, labor, and delivery*

Pediatric nurse- *a nurse who specializes in the care of infants and children*

Pediatric Nurse Practitioner- *an advanced practice nurse with specialized education and training in diagnosing and treating infants and children*

Pediatrician- *a physician who specializes in the care of infants and children*

Radiologist- *a medical doctor who specializes in the use of imaging techniques such as x-rays, ultrasounds, CT scans, and MRIs*

What can parents do to advocate for their child in the health care arena?

1. Remember, you are ultimately responsible for your child's well-being, making you the most important member of the healthcare team.
2. Recognize and seek the best quality care for your child- this includes care providers who are willing to listen to you and your child, explains things clearly in common language, answers your questions, includes you in decision making, and shows respect and courtesy.
3. Try to communicate clearly and concisely with your health care providers. Time is often strained for healthcare professionals.
4. Remember- in today's healthcare system, quantity and quality of care is often prescribed by paying agencies- an uncomfortable position for both you and your healthcare professionals.

Try these techniques to get the most out of your health care visits:

1. Inquire about scheduling longer appointments for your child- the usual appointment times are probably not enough time for your child. You might also consider trying to schedule appointments earlier in the day (when possible) when it is usually less hectic in the pediatrician's office.
2. Discuss any special needs your child may have with your healthcare providers to see if special arrangements can be made.
3. Consider whether a smaller physician practice may better meet the needs of your family, if possible. This way the healthcare providers and staff may get to know your child and his/her special needs better and your child may be more comfortable.
4. Write down all important information prior to the visit. Be a keen observer- sometimes even subtle changes in behavior are important. In the rush of the moment it is easy to forget important information or questions you may have.
5. Write down any questions you may have prior to the visit- you have a right to know and understand your child's medical needs and issues, treatments and procedures.
6. Provide the important facts to the health care provider at the visit, but also have available your own records of past visits, medical procedures and reports, lab results, etc. (A three ring binder with divided sections is a great organizer.)
7. Take notes (during or soon after the visit) to keep track of important information.
8. Develop a healthcare plan with your provider and follow up on the plan.

(Adapted from Allshouse, C., 2001 and Volkmar, F., 2004)