

Collaborating with Physicians: Perspective from Psychiatry

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Objectives

- 1. To recognize problems and important strengths in the patient-physician relationship
- 2. Understand the importance of collaborative team models and empowering parents for treating autism
- 3. appreciate special situations in autism where communication is important

Failed therapy

- <http://www.youtube.com/watch?v=B94AziI04lk>

Survey of parents of children with ASD and pediatricians Williams

- **Parents of children with ASD want:**
 - Written information on ASD
 - Information on community resources and treatment options
 - Better treatment of associated conditions
 - Sleep, GI, feeding,
 - Aggression
 - Depression, anxiety

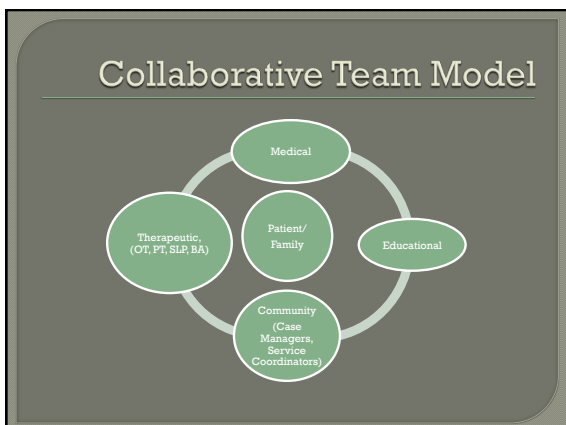
Survey of parents of children with ASD and pediatricians Williams

Pediatricians report:

- 41% of pediatricians reported no CME sessions on autism
- Would like more support treating anxiety, depression, aggression, and sensory issues
 - 25% of children had seen behavioral pediatrician
 - 44% had received psychiatric consultation

Survey of parents of children with ASD and pediatricians Williams

- **Opportunities for Growth:**
 - Improved education of pediatricians about autism
 - Improved use of local and national resources for autism
 - Improved coordination of care with behavioral pediatricians/child psychiatrists
 - Team collaboration



- ### Collaborative Team Models
- Autism and the paternalistic authoritarian model
 - Source of information
 - Source of evaluation
 - Source of treatment
 - Autism as a neurodevelopmental condition
 - Core deficits are chronic and require management
 - Goals of treatment: minimize deficits, maximize function
 - Broad-based interventions
 - Myers SM, Johnson CP. Management of children with autism spectrum disorders. *Pediatrics*. Nov 2007;120(5):1182-1182.

- ### Strengths of collaboration
- Ourantes 2009; Lubetsky et al, 1995
- Pinpoints strengths and weaknesses
 - Multiple sources of information
 - Guides intervention
 - Improved outcome measures
 - Improved retention and compliance
 - Empowers parents
 - Shared decision making
 - Parents as co-therapists.
-

- ### Family-centered/interdisciplinary team approach
- Kennedy-Kreiger Institute family-centered consultation model
 - Determine parent-professional relationship and goals
 - Generate strategies to meet the goals
 - Decide who will provide the services
- ky MJ, et al. *Mental retardation*. Aug 1995;33(4):251-256.
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- ### The team at work
- Autism Speaks 100 day kit
- Team communication
 - Email
 - Notebook/journals
 - Track data
 - Team meetings
 - Identify goals
 - Assign work
 - Monitor progress
-

The parent advocate


- 7 principles for advocating for your child with autism
 - 1. take responsibility – be a leader
 - 2. learn – be an expert
 - 3. think critically – be discerning
 - 4. speak with authority – be proactive
 - 5. document – be prepared
 - 6. collaborate – be a team builder
 - 7. educate – be a voice for your child



• *Everyday Advocate: Standing Up for Your Child with Autism, Martin, A.*

Parent learning


- Office websites
 - Description of office and services provided
 - Research opportunities
 - Forms
- Internet
 - Prepared questions and information
- Patient decision aids
 - Help fit between patients and chosen therapies
 - Mayo Clinic
 - *Teusch C. Patient-doctor communication. The Medical clinics of North America. Sep 2003;87(8):1115-1145.*



Internet-education programs


- Studied in newly diagnosed breast cancer patients
 - Intervention group had higher knowledge level overall but were less satisfied with information from hospital
 - More ownership
 - Less reliant on information from health professionals

• *Ryhanen AM, et al. Patient Educ Couns. Mar 15 2012.*



Document-be prepared

- Gather information and questions
- Document and journal concerns
 - Behavioral counts
 - Excel graphs
 - Symptom trackers – ipad apps
- The binder approach
 - Electronic binder



Family support

- Key role
- Higher rates of depression and stress in parents and siblings of children with ASD
- Education/Training
- Access to resources
 - Parent and sibling support
 - State programs
 - Regional and national support groups


• *Myers SM, Johnson CP. Management of children with autism spectrum disorders. Pediatrics. Nov 2007;120(5):1162-1182.*



Factors in patient-physician relationship

- Attire rated by outpatients in a VA clinic
 - Patients prefer professional attire
 - Increased trust
 - Increased compliance
 - Increased confidence in knowledge and competence
 - Increased ratings of compassion

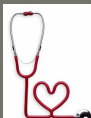
• *Rehman SU, et al. The American journal of medicine. Nov 2005;118(11):1279-1286.*



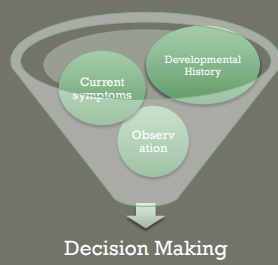
Factors in patient-physician relationship

- Positive ratings for relational communication from audio recorded visits
 - Patients asking unprompted questions
 - Accumulated knowledge
 - Patient-physician interaction outside the exam room
 - Patient education level

Shay LA, et al. Patient Educ Couns. May 1 2012.




Good data in



Problems for clinical judgement



- Series by Redelmeier et al in CMAJ from Feb. 2001 until June 2002.
- Clinical judgement = reasoning under uncertainty when caring for patients
 - Scientific education
 - Personal experience
 - Patient history

THE GREY AREA



Cognitive psychology


- How do people make decisions?
- Mistakes are not random
 - Complex situations
 - Errors can be predicted

Redelmeier DA, et al., CMAJ/ Feb 6 2001;164(3):358-360.

Cognitive factors in medical errors


- Intellectual
 - Overconfidence, (driving)
 - Finite capabilities of human brain
- Lack of checking for errors
 - Attachment to opinions, (grandparent)
 - Unquestioning self-approval
- Environmental
 - Continuation of previous errors



Solutions for medical errors

Redelmeier DA, et al., CMAJ/ Feb 6 2001;164(3):358-360.


- Intellectual
 - Prompt feedback and focused attention
 - Balance clinical judgment and scientific training
- Check for errors
 - Humility
 - Peer review
- Environment
 - Automated systems, supervision



Problems with obtaining a medical history of present illness

Redelmeier DA, et al., *CMAJ*, Mar 6 2001;164(5):647-651


- **Problems with comprehension**
 - **Ambiguous language**
 - Wording of questions affects memory and response, (video of car crash)
 - Questions of timing
 - **Misunderstandings, (ratings of happiness and satisfaction with life)**
 - Patients and families need to ask questions



Problems with obtaining a history of present illness

Redelmeier DA, et al., *CMAJ*, Mar 6 2001;164(5):647-651


- **Problems with recall**
 - **Failure of memory, (your grades in elementary school)**
 - Symptom diary, track data, provide written instructions
 - Automatic shortcuts, (white foods)
- **Problems with Expression**
 - **Distractions**
 - Clean vs. dirty rooms
 - Temporary mood states



Problems with obtaining a history of present illness

Redelmeier DA, et al., *CMAJ*, Mar 6 2001;164(5):647-651

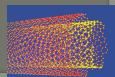
- **Problems with evaluation**
 - **Inconsistent expectations**
 - Subjective report of symptoms vs. objective measurement
 - Downward comparisons
 - **Faulty personal beliefs**
 - Placebo/electric shocks



Problems with the past medical history

Redelmeier DA, et al., *CMAJ*, Mar 20 2001;164(6):809-813


- **Problems with memory**
 - **Telescoping, (underestimate how long)**
 - Data tracking, use holidays, events as markers
 - **Sequencing of questions**
 - **False memories**
 - Suggested or distorted, (29% accepted false memory)
 - Collateral information
 - **Memories can be inhibited by cues, (30 word list)**




Problems with the past medical history

Redelmeier DA, et al., *CMAJ*, Mar 20 2001;164(6):809-813

- **Problems with evaluations of success of past treatment**
 - **Halo effects**
 - Extraneous factors (likeability)
 - **Persistence of beliefs**
 - Coincidences and chance, (car wash)
 - Check for contrary data
- **Problems with expression**
 - **Positive self-presentation**
 - Written surveys, pre-emptive compassion



What did you say?



- **Study of 755 patients aged 55 to 74 years viewing video scenario of physician visits**
 - 50% recall of verbal instructions at 15 minutes
 - Information presented as a list had worst recall
 - Greatest recall for information involving time of follow-up
 - **Solution – counseling training, written materials**
 - McCarthy DM, et al., *Medical care*. Apr 2012;50(4):277-282.

Narrative medicine

- Stories
 - Tell of ourselves, connect, influence
 - Telling of the story, reception, response
 - Narrative grows
 - Charon R. *Academic medicine : journal of the Association of American Medical Colleges*. Mar 2012;87(3):342-347.



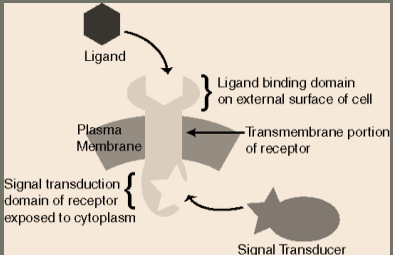
Narrative medicine

- Clinical care = narrative
 - Illness is told the story of signs and symptoms
 - Family and team repeat the story
 - Story grows and determines cares
 - Writing/telling the story is a creative
 - Becomes reality
 - Reveals relationship and empathy
 - Connect to humanity, suffering, death



Charon R. *Academic medicine : journal of the Association of American Medical Colleges*. Mar 2012;87(3):342-347.

Narrative Medicine



The diagram illustrates a cell receptor. A hexagonal ligand is shown binding to the external surface of the cell. The receptor is embedded in the plasma membrane, with its transmembrane portion crossing the membrane. The signal transduction domain of the receptor is exposed to the cytoplasm and is connected to a signal transducer.

Narrative medicine


- Stories penetrate our self and alter the experience of the world
- Study of literature may enhance the doctor's skills
- Narrative skills
 - Attention/reception
 - transformation
 - Affiliation/empathy/cosmic



Charon R. Mar 2012;87(3):342-347.

Narrative medicine

- Improved perspective
- Team cohesion
- Self-awareness
- Reversal of burnout
- Not a checklist

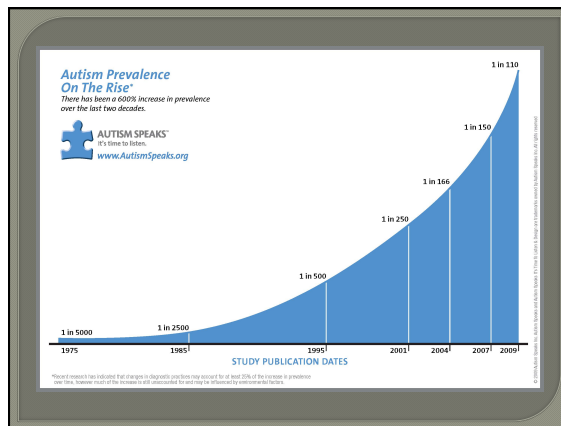



Narrative Psychiatry

- <http://www.youtube.com/watch?v=qM-gZintWDc>
- <http://www.youtube.com/watch?v=qM-gZintWDc&t=2m50s>

special areas of concern

- Collaboration in clinical areas
 - Diagnosis
 - Aggression
 - depression

Definitions

- **Sensitivity**
 - Measures a test's ability to find those patients with a disease
 - If a person has a condition, how often will the test find it
 - Finds true positives
- **Specificity**
 - Measures a test's ability to identify those patients without a disease
 - If a person is healthy, how often will the test find it
 - Finds true negatives

• wikipedia.org

Sensitivity and Specificity of DSM-5 criteria

McPartland et al. JAACAP. 2012;51(4):368-383.

- 933 patients evaluated from DSM-IV field trial exposed to DSM-5 criteria
 - Overall 60% of cases with ASD met revised DSM-5 criteria
 - Overall specificity was 94.9%

Diagnosis	Sensitivity
Autism	0.76
Asperger's disorder	0.25
PDD-NOS	0.28
IQ < 70	0.70
IQ > 70	0.46

Proposed DSM-5 criteria for Autism Spectrum Disorder, (revised Jan 20 2011)

- Must meet criteria A, B, C, and D:
- **A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:**
 - 1. Deficits in social-emotional reciprocity
 - 2. Deficits in nonverbal communicative behaviors used for social interaction
 - 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers)

• www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

Proposed DSM-5 criteria for Autism Spectrum Disorder, (revised Jan 20 2011)

- **B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:**
 - 1. Stereotyped or repetitive speech, motor movements, or use of objects
 - 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus
 - 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment

• www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

Proposed DSM-5 criteria for Autism Spectrum Disorder revised

- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms together limit and impair everyday functioning.



• www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

Collaborative diagnosis

- Collaboration provides advantage in measuring current symptoms
 - Multiple viewpoints of social communication and RRB
 - Multiple areas of dysfunction
 - Severity levels
- Collaboration provides reliable past history
 - Onset criteria
 - Developmental concerns

Pharmacotherapy

- Core Symptoms vs. Target Symptoms
 - Target symptoms must be identified
 - Establish a hierarchy of target symptoms which may be consolidated
 - Target symptoms include aggression, SIB, hyperactivity, and repetitive behaviors
 - Role in the overall treatment plan
 - Best results if medications are combined with intense behavioral plans
- Frazier TW et al, J Child Adol Psychopharm, 2010

Pharmacotherapy

- Risk/Benefit Ratio
 - Monitor for side effects
- Assess Change
 - Efficacy based on report from parents, teachers, staff
 - Rating scales
- Up to 45% of children with autism are treated with medications

• Aman MG, et al. *J Autism Dev Disord.* Oct 2003;33(5):527-534.

Common causes of aggression in autistic children

- Impaired understanding of actions and consequences
 - Impaired communication
 - Impaired coping skills
 - Peer conflict
 - Psychosocial dysfunction
 - Undiagnosed medical conditions – pain, constipation, seizures
 - Psychiatric comorbidity
- Nazeer, A, *Ped Clin N Am* 58 (2011)

Team approach to aggression

- Functional behavioral analysis
 - Antecedents, behavior, consequences
 - What function does aggression serve
 - Guides responses
- Rule out medical causes
- Track data – frequency, intensity, number of events, duration of events

• Robb AS. *psychiatric annals.* 2010;40(4):231-236.

Team approach to aggression

- Implement and evaluate behavioral and environmental treatment
 - Behavioral
 - Education
 - Family support
- Monitor effects – outcome measures

Collaborative approach to depression

- Diagnosis of depression in ASD is difficult
 - Lack of self-report
- Presentation may be atypical
 - Changes in behaviors/moods
 - Changes in sleep/appetite/energy
 - Changes in core autistic symptoms
 - Changes in skills, self-care
- Multiple informants/settings helps
 - Magnuson KM. J Dev Behav Pediatr. Apr 15 2011.

Summary

- 1. Collaboration plays an important part in evaluation and treatment in patients with autism and empowers families
- 2. Understanding specific factors in the patient-physician relationship can improve collaboration
- 3. collaboration improves diagnosis, treatment of aggression, and recognition of depression.

Thank you!

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Break Time!



Medical Homes for Children with Autism Spectrum Disorders

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University of Louisville

Overview

- Medical home concept
- Principles of the medical home
- Need for medical home for children with autism
- Medical home in Kentucky
- Promoting successful implementation of the medical home

Medical Home

- Proposed in 1992 and confirmed in 2002 by AAP as model of care for Children with Special Health Care Needs (CSHCN)
- Should be comprehensive, coordinated, culturally effective, family centered, continuous, accessible
- Especially important for children with ASD and their families

Principles of the Medical Home

- Patient and family are center of care team
- Other team members include medical professionals in medical office and clinical/ nonclinical professionals in community
- Care team is responsible for coordinating health care across settings and services over time
- Care team facilitates services from other providers (mental health, etc.)

Principles of Medical Home

- The medical home considers the patient's life situation in making health care decisions
- Information is communicated in an understandable fashion
- Patients, families and clinicians are partners in making treatment decisions
- The care team provides evidence based information on all treatment options

Principles of Medical Home

- The care team works to develop goals for care for the patient
- The medical home fosters an environment of trust and respect and ensures confidentiality
- The care team encourages feedback from and collaborates with patients and caregivers about ways to improve quality of care



AAP Medical Home Video



Autism

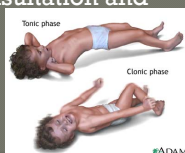
- Core features are severe social communication deficits and restricted interests and activities
- Secondary to the pervasive nature of these deficits, impacts on multiple areas of function: family, school, community
- Treatment concerns: social, adaptive, developmental/academic, behavioral, medical

Autism: Medical Needs

- Routine care (anticipatory guidance, immunizations, monitoring growth and development, addressing behavioral concerns, addressing safety issues, etc.)
- Addressing medical concerns commonly associated with autism: seizures, gastrointestinal problems, sleep problems, feeding issues, concerns about immunizations

Seizures

- Approximately one third of children with autism have seizures; up to one half of children have abnormal EEG's
- Two peaks of new onset seizures, one in infancy and the other in adolescence
- Requires neurology consultation and appropriate treatment



Gastrointestinal concerns

- Many complaints about constipation and diarrhea, stomach pain
- Needs to be investigated
- May require gastroenterology consult
- Can impact appetite, behavior if not addressed



Sleep problems

- Many children with ASD have disrupted Circadian rhythms
- Difficulty falling asleep, maintaining sleep, waking early
- Behavioral strategies first line
- Trial of melatonin may also be considered
- Sleep medicine evaluation may also be needed



Feeding difficulties

- Many children with ASD have very limited food repertoires
- Behavioral strategies which approach new foods in a systematic fashion with positive reinforcers often effective
- Feeding team consultation may be helpful



Immunizations

- Initial concern raised about measles component of MMR vaccine in 1998 study out of Great Britain
- Study later discredited; numerous subsequent studies have demonstrated no connection between MMR and autism
- Thimerosal also raised as possible risk factor
- Preservative no longer in immunizations; research does not support link



Alternative Biomedical Treatments

- Wide variety of complementary biomedical treatments
- Include casein-gluten free diet, vitamins and supplements, chelation therapy, hyperbaric oxygen, etc.
- Minimal research to support or refute efficacy
- Guidance regarding available research, benefit versus harm, expense, potential fit with other interventions, etc.

Autism: Developmental Needs

- Early identification of developmental concerns suggestive of autism
- AAP recommends autism specific screen at 18 and 24 months of age
- Referral for appropriate intervention services (First Steps, public school system)
- Referral for diagnostic clarification

Autism: Developmental Needs

- Promoting awareness of educational rights of special needs child
- Helping families advocate for appropriate educational services
- Identification of agencies which help support families in meeting educational goals
- Support for needed therapy services
- Continuity of educational services

Autism: Emotional/Behavioral Concerns

- Behavioral concerns are quite frequent and include marked irritability, aggression, self injurious behaviors, attention and impulse control difficulties
- Children and adolescents with ASD may also have anxiety and depression



Anxiety/Depression

- Combination of therapy and medication
- Cognitive behavior therapy first line but often not appropriate for children with ASD due to language deficits
- Family interventions often needed
- Consider use of medication; SSRI's can be effective but may cause agitation, mania
- Discuss benefits, side effects, target behaviors and monitor

Attention and impulse control difficulties

- Approach is 3-pronged: educational accommodations, behavioral interventions and medication
- Educational accommodations: preferential seating, modification of length and content of assignments, individualized instruction, help with organizational skills



Attention and Impulse Control Difficulties

- Behavioral interventions: helping parents develop appropriate strategies for challenging behaviors; use of structure and consistent expectations and responses to behaviors; maximize use of positive reinforcers
- Medication: stimulants first choice for ADHD, but may not be appropriate for children with ASD; may need nonstimulant or combination approach

Irritability, mood lability, aggression, self injurious behavior

- Behavioral interventions key: promote self regulation, reduce frustrations surrounding communication, use of visual scheduled to help with transitions, etc.
- Medication: two FDA approved medications for severe irritability associated with autism; often dramatic improvement
- Must monitor side effects, such as weight gain, blood glucose, cholesterol, dystonia, etc.



Autism: Social/Adaptive Needs

- Opportunities for social interaction
- Specific social skills training
- Achieving functional communication system
- Promoting independence at home and in community
- Providing vocational or higher education training and supports
- Community supports to allow maximum self realization
- Transitioning from school to adult services

Medical Home Team

- Physician and office staff
- Patient and family
- Medical subspecialists
- Therapists (OT, speech and language therapists, etc.)
- Teachers
- Behavioral interventionists, psychologists
- Community supports

Barriers to Medical Home for Autism

- Complexity of autism
- Time needed to coordinate services
- Difficulty addressing treatment options, particularly alternative biomedical treatments
- Poorly accessible services
- Lack of training in autism

Medical Home in Kentucky

- Survey of 114 parents of children with ASD and 25 pediatricians in Kentucky
- Most parents reported routine health care as very good to excellent
- Over 40% reported concerns about the physician's ability to discuss treatment options for ASD and make recommendations regarding community resources

Medical Home in Kentucky

- Of those parents who reported sleep, feeding, or GI problems, less than 30% were mostly or completely satisfied with their PCP's ability to address these concerns
- Of those parents who reported aggression or anxiety/depression as problems for their children, only 18% and 20% respectively reported high degrees of satisfaction with treatment

Medical Home in Kentucky

- Most physicians (68%) rated their ability to provide routine preventive care for children with ASD as good or excellent
- Approximately 50% of physicians reported routinely administering an autism specific screening test at the 18 and 24 month well child checks as recommended by the AAP
- Most physicians (58%) were comfortable in addressing concerns about immunizations but few (26%) were comfortable discussing alternative treatments for ASD or (37%) community resources for ASD

Medical Home in Kentucky

- While a majority of physicians reported reasonable comfort in dealing with sleep problems ((67%) and GI problems (55%), less than one third felt comfortable dealing with aggressive behaviors and only 44% and 47% felt comfortable dealing with anxiety and sensory issues respectively
- Nearly half of physicians reported never attending a CME on autism

Ways to promote the medical home

- Physician outreach regarding autism resources, both nationally and regionally
- Physician education regarding autism (early identification, treatment options, etc.)
- Innovative systems changes in primary care offices (co-location model)
- Partnerships with families to find solutions
- Establishing relationships with educators, therapists

Promoting the Medical Home

- Develop and identify community resources with whom to partner
- Consider multidisciplinary clinics specifically to serve children with autism
- Provide an infrastructure that facilitates coordination of services (EMR)
- Advocate for adequate reimbursement of coordination services
- Provide readily available handouts regarding resources in autism

National Autism Resources

- American Academy of Pediatrics (Autism Toolkit)
- Center for Disease Control
- Autism Speaks
- First Signs
- Autism Society of America

Regional Autism Resources

- University of Louisville Autism Center
- Kentucky Autism Training Center (Family Guide, county school experts)
- STAR (direct services including ST, OT, behavior interventions, social skills, biomedical consultation)
- Bingham Clinic (medication management)

Regional Resources

- Home of the Innocents
- Autism support groups (Families for Effective Autism Treatment, Autism Society of Kentuckiana, etc.)
- First Steps
- Public school systems

Conclusions

- The medical home is the model of care for children
- This is particularly true for autism due to the complexity of needs that must be met
- The medical home involves a partnership between physician, patient and families
- The medical home provides not only coordination of medical services, but also community resources which support families

Conclusions

- Implementation of the medical home in Kentucky will require education for physicians and families
- Increased state autism resources will also be needed
- Communication and collaboration between all those providing services is key



Providers & Pediatricians – What You Need to Know

Pediatricians

Medical Terminology
Roles

Where does it begin?



Someone notices a difference....

Medical Terminology

- ◉ **DME** – Durable Medical Equipment
- ◉ **CCN** - Complex Communication Need
- ◉ **CSHCN** – Children with Special Health Care Needs

Children with special health care needs (CSHCN)

According to the Maternal and Child Health Bureau and adopted by the American Academy of Pediatrics (AAP), CSHCN have or are at “increased risk for a chronic physical, developmental, behavioral, or emotional conditions and require health and related services beyond” what is normal (Ziring, P. R., Brazdziunas, D., Cooley, W. C., Kastner, T. A., Kummer, M. E., Gonzalez de Pijem, L., et al., 1999).

CSHCN

These children represent 13% of the total pediatric population but 70% of all pediatric health care expenditures (Ziring, et al., 1999).

Pediatric Medical Residency

- Residency as 'the period of training in a specific medical specialty' " (American Medical Association, 2008, [Data File] para, 8)
- Residency is also synonymous for any student in a graduate medical education program.

Current Study

Problem

- Significant and growing body of CSHCN with communication disorders and a need for AAC
- Previous evidence (Sneed, et al., 2004) found limitations preparation and leadership of pediatricians for the prescription of specialty therapies and durable medical equipment for CSHCN.
- The need of residents for proper training in identifying communication disorders and the need for AAC.

Purpose

- Current information about the state of pediatric resident education at U of L
- Residents' abilities to identify and provide ongoing care for children with communication disorders and AAC within the framework of the ACGME competencies.
- 3 major areas of concern:
 1. Medical educational
 2. Medical knowledge
 3. Professional practice.

This study investigated differences in perceived ACGME competency regarding communication disorders and AAC across the three levels of pediatric residency at the University of Louisville.

Research Questions

- To what extent are there differences in perceived pediatric resident **educational** training experiences for communication disorders and AAC across pediatric levels?
- To what extent are there differences in perceived pediatric resident **knowledge** of communication disorders and AAC across pediatric levels?
- To what extent are there differences in perceived pediatric resident competency for **professional practice** regarding the care of children with communication disorders and AAC across pediatric levels?
- What effects do **demographic variables** have on residents' perceived competency?
- What **perspectives** do pediatric residents hold regarding communication disorders and AAC as part of their training?

Methodology

Research Questions 1 – 3

One-factor multivariate analysis of variance.

- *Independent variable* - education level of resident (three levels, from 1 to 3 years).
- *Dependent variables* - average scores on the three constructs from questionnaire.

Methodology Continued

Research Question 4

Independent *t* tests and correlation coefficients

- *Independent variables* - five demographic variables
 - Gender
 - Specialization
 - Rotation completion
 - Educational methods
 - Educational time
- *Dependent variable* - perceived competency (the average scores on the three constructs obtained from the questionnaire)

Methodology Continued

Research Question 5

Qualitative data - open-ended questions

- What are your thoughts about the survey regarding communication disorders and AAC?
- How do you perceive your current role regarding communication disorders and AAC?, and
- How do you perceive your future role regarding communication disorders and AAC?

RESULTS

Results

Research Questions 1 – 3

Main Effect

MANOVA was a significant difference among the means of the dependent variables

Wilks' Lambda = .67, $F(6, 76) = 2.789$, $p = .017$
 $< .05$. η^2 was .18

Results Continued

Main Subject Effects for Education, Knowledge and Professional Practice

Dependent Variables	Sum of Squares	df	Mean Square	F	p
E	8.58	2	4.30	6.43	.00*
K	1.90	2	.952	3.34	.046*
P	.84	2	.417	1.13	.33

Note. E = Education; K = Knowledge; P = Professional Practice

* $p < .05$

Results Continued

Post hoc

DV	PLs	MD	SE	p
E	PL2 X PL 3	-1.07	.32	.01*
	PL3 X PL1	-.73*	.29	.048*
K	PL2 X PL 3	-.54	.21	.04*

DISCUSSION

Research Question 1

Differences in perceived educational training experiences for communication disorders and AAC across pediatric levels

- Main effects, individual dependent variables and paired comparisons (1 x 3; 2 x 3).
- Average means for residents for construct questions
- Overall trend - majority of residents do not believe they are receiving educational experiences regarding communication disorders and especially AAC.

Research Question 2

Difference in perceived pediatric resident knowledge of communication disorders and AAC across pediatric levels

- Main effects, individual dependent variables and paired comparisons (2 x 3).
- Average means for residents for construct questions
 - Confidence for recognition of abnormal communication/ speech development; impact regarding educational success
 - Care Coordination

Research Question 3

Difference in perceived pediatric resident competency for professional practice regarding the care of children with communication disorders and AAC across pediatric levels

- Not any significant differences
- Trend toward neutral - overall mean of 3.07

Research Question 4

Effect of demographic variables on resident's perceived competency

- Gender
- Specialization
- Rotation completion
- Educational methods
- Educational time

Research Question 4

Gender

Positive outcome that there were no differences between genders regarding their perceptions of their competency.

- More females responded than males
- Trend today for an increase in women within the field of pediatrics (Goodman, 2005)

Research Question 4

Specialization

No significant difference

- Additional education does not change perceptions of competency
- American Academy of Pediatrics expects all pediatricians to have knowledge of communication disorders and AAC (Desch, et al., 2008)
- Changes within the core training may be needed

Research Question 4

Rotation Completion

Difference was found between the means for completion versus non-completion of rotations for adolescent medicine, pediatric intensive care unit and Weisskopf Child Evaluation Center (WCEC)

- Third year differences
- 60.5% no discussion of communication disorders
- 74.4% no discussion of AAC

Research Question 4

Rotations Continued

Several questions are raised by completion versus noncompletion of different rotations

- What factors within the significant rotations contribute to differences in perceived competency?
- Timing – when topics need to be taught?
- Education content – what needs to be taught?
- Would changing any of these factors change the statistical outcomes in the future?
- How much time is enough time?
- What types of educational methods are being applied within this time frame, and what is most effective?

Research Question 4

Educational Methods

Didactics - difference in perceived competency for Medical Education and Professional Practice

- Methods and content within each rotation were not analyzed
- Needs further analysis

Research Question 4

Educational Time

Summed and correlated with the average levels of self-reported competence across three constructs

No significant relationship between communication disorders and perceived competency across constructs

AAC – moderate positive relationship between time and Professional Practice

Research Question 5

Focus Group

Lack of educational emphasis or training

- Corresponds with the quantitative data (trend towards a lack in educational experiences)
- In-patient versus out-patient setting
- Residents do not “get a lot of exposure”
- Non-completion of Weisskopf Child Evaluation Center rotation

Confident regarding their current and future roles

- Referrals

Research Comparison

Lack of confidence in prescribing therapies or devices; little knowledge base of residents regarding CSHCN (Sneed et al., 2004)

- Improved perceptions/ confidence

Significant need for training (Sneed, et al., 2000)

- Current education
- Instructional time

Diagnoses and not much else (Sneed et al., 2004)

- Referrals but lack of confidence in care coordination

Implications

Care Coordination

Lack of perceived competence

- Find resources
- Difficulty with team dynamics, medical systems management, the care coordination process, and education (American Academy of Pediatrics Advisory Committee, 2002; American Academy of Pediatrics, 2002; Antonelli, & Antonelli, 2004; Antonelli, Stille, & Antonelli, 2008).

Education system change

Implications

Care Coordination Continued

Compounds barriers

- Lack of reimbursement, complex eligibility criteria, communication breakdown, language, economic and socio-cultural barriers, a lack team collaboration, and a lack of single point of entry into the medical system

Result

- Incomplete, and episodic, expensive, fragmented care of children (Antonelli, & Antonelli, 2004; Antonelli, et al., 2008; McPherson et al., 2004).

Implications

AAC Guidelines

Ensure access to appropriate augmentative and alternate communication services due to the complexity of the process for acquiring and using a communication device (Desch, et al., 2008)

Roles - writing letters of medical necessity, assisting with the implementation of the plan, finding and advocating for funding, device procurement, device training, and monitoring device use and therapy programs

Implications

Standards for Hospitals and Skilled Nursing Facilities

Provided patients with an alternative means of communication, AAC, when they are not able to be understood or understand the communication of the medical professional

- Communication breakdown between patients and professionals
- Safety issues/ sentinel events/ reduced quality of care (Pressman, & Blackstone, 2010, p. 8)
- Inpatient versus outpatient

Implications

ACGME Competencies

Areas of weakness –

- Medical Knowledge
- Patient Care
- Medical Education

Systematic quality control

Implications

Current Education Practices

University's objective of current educational and continuing professional quality

- Room for improvement
- Professional practice – unclear
- Medical Knowledge/ Medical Education

Limitations

Sample Size

Return rate

- Confounding factors:
 - Timeline
 - Other scheduled event
 - Minimal responses

Generalization

Current population at the University of Louisville but with caution

Future Research

- Will these results hold true for other graduate medical institutions?
- What impact additional educational opportunities may have on resident competency?
- Identification of the form and method of resident training.
 - *Follow up study currently underway!*

Future Research

- If current pediatric residents demonstrate specific strengths and weaknesses, do practicing pediatricians respond in a similar fashion?
- How competent is the medical support staff, such as nurses, in their identification of needs, especially within a hospital setting?
- What are the consumers (user's and parent's) experience with pediatricians regarding CD and AAC?

**WHAT DOES THIS
MEAN??**

How do we address this?

- Educate yourself
- Educate your family/ client
- Educate/ communicate with your pediatrician
- Advocate
- Get involved!

Educate yourself

Local opportunities -

- **University of Louisville** CD and EDSP courses
- **Local group** (Louisville AAC Professionals @ <https://sites.google.com/site/louisvilleaacproviders/>)
- **State Assistive Technology Programs**
 - KATS Network

Educate yourself

- **ASHA** Division 12 information
- **ASHA** publications regarding AAC
 - AAC in the Schools: From Consideration to Implementation
 - AAC Interventions to Maximize Language Development for Young Children
 - An Overview of the Health-Based Funding Programs That Cover Speech-Generating Devices (SGDs)
 - Functional AAC Approaches for Severe Aphasia: An Introduction
 - Intervention Strategies for Severe Disabilities
 - Maximizing the Literacy Skills of Individuals Who Use AAC
 - Supporting Transitions to the Adult World for Individuals Who Use AAC
 - Vocabulary Instruction for Children and Adolescents With Language Disorders

Educate yourself

Read

- Beukelman, D. R., & Mirenda, P. (2005). *Augmentative and Alternative Communication: Supporting Children and Adults with Complex Communication Needs*. (3rd ed.) Baltimore: Paul H. Brookes Publishing Co.
- Downing, J.E (2001). *Teaching Communication Skills to Students with Severe Disabilities*. (2nd ed.) Baltimore: Paul H. Brookes Publishing Co.
- Wetherby, A. M., Warren, S.F., & Riechle, J. (1998). *Transitions in prelinguistic communication*. (vol 7). Baltimore: Paul H. Brookes Publishing Co.
- McCormick, L., Loeb, D.F., & Schiefelbusch, R.L. (2003). *Supporting children with communication difficulties in inclusive settings: School-based language intervention*. (2nd ed.). Boston: Allyn & Bacon.

Educate yourself

Websites

- AAC institute – self study courses (12 CEUS)
- YAACK - Augmentative and Alternative Communication (AAC) Connecting Young Kids (YAACK)
- ISAAC – International Society for Augmentative and Alternative Communication
- AAC Centers - <http://aac.unl.edu/>
- Closing the Gap
- Vendors
- **List is not inclusive!**

Educate the family/ client

- Listen
- Respect their needs
- TEAM
- Share information
- Train
- Families/ AAC users and other stakeholders are undervalued.

Communication/ education with pediatricians

- Consistent communication and progress updates
- Establishing expertise/ be a ready resource
- Don't use jargon
- Call/ leave message
- Send a brief note
- **Don't** be afraid to challenge the pediatrician's opinion (in a very nice way)
- Listen
- Have family bring up concerns

Advocacy = Tenacity



*Never Give In,
Never,
Never,
Never*

Winston
Churchill

Advocacy

There are five basic steps that you should follow if you are trying to persuade someone to do something.

1. Show them the benefits of your idea.
2. Be prepared for contradictions and objections.
3. Be willing to be agreeable... even if you don't agree!
4. Admit mistakes or miscalculations.
5. Ask him/ her to consider your recommendations and agree to continue the discussion at a later time.

Fighting the Good Fight: How to Advocate for Your Students Without Losing Your Job - Rick Lenoir (2006)



Thanks !

Questions?