Today, increasing numbers of medically complex children require an increasing degree of complex care. At the same time, parents are becoming better informed and looking for ways to ensure their child receives the comprehensive care they need. With changing health coverage and reimbursement issues and the movement toward the medical home model, there is a need for physicians to develop a systems-based approach to co-management and transitions to improve efficiency and quality of care for patients with genetic conditions. This information was presented during the webinar, “Co-management and Transitions for Patients with Genetic Conditions,” held February 2014. The webinar, which featured Kerry Baldwin Jedele, MD, FAAP, FACMG, was part of the Integrating Genetics into your Practice webinar series hosted by the Genetics in Primary Care Institute (GPCI).

What is Co-Management?
Co-management refers to shared, delegated care of a patient’s medical condition among providers with either similar or disparate clinical expertise and/or professional credentials.

As with any care, a co-management approach should fit the values specified in the American Academy of Pediatrics’ medical home model

- Accessible
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally effective
- Family-Centered

In order for a co-management approach to be successful, there must be

- **Motivation** among healthcare providers and family to pursue team approach to care
- Good **communication**
- **Agreement** on how to divide care
- Means to **negotiate** concerns
- Mutual **respect**
- **Reliability**
- **Ownership** of problems
When to Consider Co-Management

While a co-management approach can be used in almost any care situation, including between two primary care providers (PCPs) who work in the same office and see the same patients, co-management should be considered for

- Complex or multisystem medical issues
- Conditions requiring providers with specific technical skills
- Conditions which require specialty teams, such as metabolic diseases
- Rare conditions
- Patients and families with many questions about diagnosis and care
- Any case where patient, family, PCP, or specialist feels co-management would benefit care

Involving Genetics in Co-Management

While geneticists’ time can be quite limited, their expertise in patient care, ability to discuss and address rare or complex issues, and access to resources make them a valuable member to a co-management team.

Benefits include

- Expertise in areas such as diagnosis, inheritance pattern and recurrence risk, mechanism of disease, evolution of clinical manifestations with age, and syndrome management
- Access to patient information, support resources, and additional genetics expertise
- Ability to share current information with families about issues such as testing and biobanking
- Experience and comfort with rare conditions, end-of-life issues, and post-mortem investigations

Is Co-Management the Right Fit?

Co-management offers many benefits, but also can add complexity to patient management if it’s not the right fit. A few determinants include

- Geography
- Clinic systems and insurance limitations
- Specialist availability/desired involvement
- Frequency of need for specialty visits
- Patient/family buy-in to team approach
- Family barriers (ie finances, time, etc)

Additional considerations

- Many patients with genetic conditions are cared for by multiple other pediatric specialists, each of whom should have defined patient care responsibilities
- All members of the co-management team must be clearly identified for family and providers
- It is best to establish a relationship with specialty providers prior to referral
- Multidisciplinary clinic care may often be preferable due to better coordination of care, proximity, communication, like-mindedness, and more

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Tools for Co-Management

**Electronic Medical Record**
- Share access to medical records
- Reference documentation/results from other visits when talking to patients and each other
- Scan in parental permission

**Nurse Care Coordinators**
- Provide single point of access and promotes involvement from appropriate non-medical professionals such as social workers
- Assist family by coordinating visits, preparing them for visits, accompanying them on visits, reinforcing medical advice and medication and more
- Assist team by tracking participants, gathering and disseminating records, documenting and communicating care and changes, assisting with orders
- Available in both in- and out-patient settings
- Likely to be cost-effective (proven in adult settings)

**Multidisciplinary Clinics**
Greater coordination of care due to close proximity, existing relationships, ease of communication, shared systems, like-minded mission, and more

**Syndrome-Specific Health Management Guidelines**
- Allow you to assess quality of care and act as a foundation for interactions with the genetics provider
- List of guidelines available at GPCI Web site: www.geneticsinprimarycare.org

**Written Agreements**
- Written agreements to establish co-management and specialty care responsibilities
- Document templates available at www.pediatricmedhome.org

**Direct Communication Between Providers**
- Get release of information forms filled out ASAP
- Ensure medical records are sent in timely fashion
- Designate a care coordination specialist for each complex patient
- Ask the family for feedback on the process
- Contact specialist with questions
- Maintain and expect professional and cordial interactions
- Establish methods for addressing disagreements
- Do not criticize other providers in front of patients and families
- Improve quality by tracking referrals
- Give the specialists constructive feedback

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Handling Transitions

Patients experience a number of transitions throughout their life, whether typical transitions like prenatal to birth, or from “normal” to “something’s wrong.” A critical transition is the transition from a pediatric to an adult medical home. The goal for a successful transition is for the young adult, parent/guardian, and professionals to work together to help the patient realize his/her potential, satisfy his/her own needs, develop capacities needed to interact successfully with biological, physical, and social environments, and become a responsible medical consumer.

The following are keys to managing this transition:

- Decide on your age (or other) cut-offs
- Ask genetics specialists about their scope of practice
- Ask genetics what management or follow-up is needed in adulthood
- Identify options for appropriate adult providers-genetics and others
- Look into adult care coordination
- Let your patients and families know well in advance about transitions
- Develop a written plan for transitions in partnership with the patient and family
- Discuss quality-of-life and end-of-life issues openly, as indicated
- Document and track transition process

Tools & Resources

From planning tools to clinical decision algorithms to resource binders, there are a number of resources available to help develop and execute a transition management program including:

- www.medicalhomeinfo.org
- www.genesinlife.org
- www.uwppc.org
- www.waisman.wisc.edu/cshcn/cdrom.php
- www.region4genetics.org/Education/Families.html
- www.gottransition.org/6-core-elements

"Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home” is a clinical report authored by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians and provides detailed guidance on how to plan and execute better health care transitions for all patients. Visit www.aap.org/transitions to access this report.

Conclusions

- Keep the patient and family at the center of care
- Cultivate good relationships with your genetics colleagues
- Communication is a two-way street
- Use available tools and standard processes to ensure consistent co-management and transitions

About the Presenters

Dr Jedele is the director of clinical genetics at Gundersen Health Systems. She is presently the Medical Director of the Pediatric and Adult Down Syndrome Clinics, the Learning and Developmental Diagnostic Center, and the Pediatric and Adult Neurodevelopmental Clinics. She is the director of outpatient care for medically complex and special needs children, and is a founding member of the Perinatal and Pediatric Palliative Care Working Groups. She is on the Advisory Board for Genetics for the State of Wisconsin and the Newborn Hearing Subcommittee of the State Newborn Screening Program. She is also a Clinical Adjunct Associate Professor at the University of Wisconsin- Madison.

About GPCI

The GPCI was established to increase primary care providers’ knowledge and skills in the provision of genetic-based services. The GPCI is a cooperative agreement between the US Department of Health and Human Services, the Health Resources & Services Administration, the Maternal & Child Health Bureau and the American Academy of Pediatrics.

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