

Enhancing the Medical Home via Integrative Solutions: Experts with Experience

Panel:

Stacy Abrams, MA (MD), Jodee Crace, MA (IN), Mallorie Evans, MA, FAAA (CA)

Wyatte Hall, PhD (NY), Mark Ramirez, LSW (NM)

Moderators:

Julie Rems-Smario, MA, MS (CA), Julia L. Hecht, MD, FAAP (NM)

Overview

- Moderator and Panel Introductions
- Audience Background
- Medical Culture
- Cultural Challenges
- Case Presentation
- Wrap up

Introductions:
Moderators
Panel
Audience

Cultural Challenge: Medical Culture

Culture:

The behaviors and beliefs characteristic of a particular group

List some features of medical culture.

Medical Culture

Physicians typically view medicine as above culture because the “truth” of medical decisions is based on science

“Medical knowledge is understood to be not merely 'cultural' knowledge but real knowledge. In this perspective, it may be reasonable to describe medicine as perceiving itself to be a 'culture of no culture.' “

Taylor JS. Confronting “culture” in medicine’s “culture of no culture.”
Acad Med 2003; 78:555–559.

Medical Culture

“The professional culture of medicine can be viewed as the language, thought processes, styles of communication, customs, and beliefs that often characterize the profession of medicine.”

Boutin-Foster C, Foster JC, Konopasek L. Physician know thyself: The professional culture of medicine as a framework for teaching cultural competence. *Acad Med*, 2008; 83:106–111.

Virtues vs Culture

- Formal teaching extols the virtues of medical professionalism: Honesty, empathy, altruism, honor and respect.
- Enculturation via a “hidden curriculum” and role modeling: distancing via case presentation, doctor talk, white coat, **rigid conceptions of health**, explanatory model of communication.
- Does the “Culture” support expression of the “Virtues”?

Medical Reality

For better or for worse, Western medicine is one-sided.

Doctors endure medical school and residency in order to acquire knowledge that their patients do not have.

Until the culture of medicine changes, it would be asking a lot of them to consider, much less adopt, the notion that. . .

“our view of reality is only a view, not reality itself.”

Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures.*

Dialogue with Deaf Experts

- Challenge our **rigid concepts** of health and wellness
- Suspend our **distancing** - us and them
- Allow ourselves to step outside the “**medical reality**”.
- Be **honest** about our limitation of knowledge and experience
- **Honor** the wealth of experiences of Deaf individuals - including their trauma
- **Respect** their perspective as legitimate, valid, and true

Cultural Challenge: Technology

What are the important technologies used by Deaf children and Deaf adults in their daily lives?

Cultural Challenge: Speech

- Why does medical culture focus on acquisition of spoken language for Deaf children?
- Does acquisition of speech = acquisition of language?
- What is the relationship between speech and independence, success, happiness, for Deaf people?

Cultural Challenge: Identity

- What does a child need to develop a sense of wholeness and belonging?
- How does a Deaf child develop a healthy identity in a family of all Hearing people?
- What are the unique challenges of Deaf children with a lot of hearing (sometimes known as Hard of Hearing)?

BREAK

Case 1:

Background and Identification

Healthy girl born without complications. Referred at newborn screen. Passed the 2nd screen. At 2 1/2 years, parents noticed that she didn't respond to her name, or follow commands, and the younger sibling had more words.

Audiogram showed moderate to severe hearing loss, bilaterally.

Case 1: Early Intervention

Early intervention consisted of hearing aids, private speech and developmental therapy and a deaf mentor, all in place within a few months from identification. There were 3 visits with the deaf mentor who began to develop a rapport with the family.

Mom learned about 50 signs and did communicate via gesture.

Case 1: Technology

There are 2 other siblings who are hearing. The family spoke all the time and the child would mouth words without vocalizing. At age 3 she received bilateral CI's.

Mom went back to work to afford private auditory training services for her daughter. She cancelled the deaf mentor services.

Mom stated "We are all hearing and she is already 3."

Her stated goals regarding intervention and language are for her child to develop speech so she can talk and be independent.

Pediatrician as “Expert”

- Vetting through schooling
- Rigorous education
- Rigorous training
- Generalized authority - white coat syndrome
- Conferred status
- **Do we have exposure to deaf children and adults??
Are we educated about deaf children and language acquisition? How did we become “experts”?**
- **How can we become truly competent?**

Other Experts:

- OAE Screener in Hospital
- Audiologists
- ENT
- SLP
- Geneticist and other physician specialists

Summary: Deaf Children

- Whose perspective defines reality? What do we, as physicians, think and say? Is it fact or culture? Does it represent the collective experiences of Deaf individuals or is it “medical reality”?
- Who informs the parents of the impact of the hearing status on a child’s life? Who explains the impact of interventions? Who makes recommendations?
- Who determines the desired outcome? What are the goals for deaf children? Whose goals are they and why? Society? Parents? What do they cost the child?

Additional References

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