Disclosures and Conflicts of Interest

This presenter has no disclosures, nor conflicts of interest and makes this presentation in his role as Chief Policy Officer of the American Academy of Pediatric Dentistry.

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What We Hope to Accomplish Today

- Open the lives of families with children with special health care needs
- Provide some strategies I have found useful in establishing a therapeutic relationship with these special families
- Provide suggestions on saying yes or no to treatment

My Assumptions About You

- All levels of clinical expertise and experience
- Variable experience with parents of special needs children (maybe mainly craniofacial families)
- Experience with case presentation in general
- Variable desires to enter this area of patient care
- An open mind as to the benefits of engaging these challenging and rewarding patients

What Families Go Through

- Initial shock and combinations of total despair, depression, fear, deep guilt, anger
- There is a period of mourning
- Parents accept the reality of their family member’s condition
- Parents become immersed in care of child or elder
- Families may need respite
- Families face making family member’s life more public
- Caretakers adapt to changing role
- Parents face adolescence and transition to adulthood
- Family members at some point relinquish care

Stages of Grief and You

In presenting options, these are some expectations:

- Denial - don’t try to convince; better to offer second opinion
- Anger - Let it abate before you close
- Bargaining - Be careful in negotiation - the buck stops with you
- Depression - Family might need assurances; find the silver lining
- Acceptance - Get buy in on their co-therapist role
CASE EXAMPLE

From Chip-on-the-Shoulder to Arms-Around-the-Shoulder

Bonnie’s son, David, had an intellectual difference, visual impairment and a distaste for health professionals. She had battled the medical and educational establishment. He had severe enamed disclase on two widely spaced maxillary permanent incisors. She wanted him fixed and no lectures. Success in treatment was a combination of recognition of David’s strengths (nice kid), her devotion to his care, and engagement of Bonnie in behavior guidance BEFORE it was kind. Small increments of care allowed David to adapt and me to form a friendship with Bonnie.

Evidence Based Practice:
The American Dental Association

- Interdisciplinary approach
- Best available evidence
- Involves complex decision making
- Patient care is individualized
- Integrated with practitioner expertise
- It is not rules of thumb, folklore and tradition
- Goal is to eliminate unscientific and risky practices and “the way it’s always been done” or “it works in my hands”

http://ebd.ada.org/VideoTutorials.aspx

Begin with Today’s Treatment Paradigm

A Venn Diagram More Like This

Evidence on Parents of CSHCN

- Highly motivated, ready to care for appliances, motivation often exceeds parents of other kids
- Parents expect better appearance and better social acceptance but report satisfaction with less than expected
- Orthognathic patients have reasonable expectations
- Almoohi OM et al. Patient’s perceptions of orthognathic treatment, well-being and psychological or psychiatric status; a systematic review. Acta Odont Scand 2010;68(5): 249

On the Web....

- Many orthodontic practices offer care for children with special needs
- Wealth of vague “TLC” statements
- Clear aligners and scanners offered to replace impressions and fixed appliances (not much data I could find)
- I couldn’t find many of parental positive attestations
- Also couldn’t find parental criticisms
Patient-Centered Care Versus EBD?

- Care that considers patients' cultural traditions, personal preferences and values, and family situations
- Makes the patient an integral part of the care team who collaborates in making clinical decisions
- Puts responsibility for important aspects of self-care and monitoring in patients' hands — along with tools and support needed to carry out that responsibility
- Ensures that transitions between providers are respectful, coordinated, and efficient
- When care is patient centered, unneeded and unwanted services can be reduced

Who May Be Caregivers in the Mix?

- Parents of newly diagnosed children
- Foster care parents
- Advocacy groups and parent groups
- ADA bureaucrats
- Family friends, family members who 'know', other professionals invested in care
- Paid employees of health facilities overseeing incapacitated or own-guardian patients

You? A Philosophy of Care for All

- Is normalcy a category or a continuum?
- Function results from a matrix not a threshold
- Severity has no linear relationship to care
- Labels mean little, harm much
- Be prepared for the worst so you can offer the best
- Care is a cycle or continuum, not an event
- Able-ism for people with special needs

Intellectually Impaired Patient Wants to Communicate with You

- Leveling
- Remove distractions
- Use declarative sentences
- Use open-ended questions
- Provide corrective feedback
- Rephrase questions if needed

(From: Harper ET Al: A Strategy to Train Health Care Professionals...)

What You Can Count On, So Use It!

- Parents have had to make hard decisions already, some heart-wrenching
- Parents expect a built-in error rate in professionals' decisions
- They are probably tired and can use some help in this decision
- They are used to celebrating little successes
- They read stuff, use the internet, and have a network

Difficult Choices for All

- Parent/Carer MapSMARTs of Patient-Parent Distinctions with Caregiver's experience of children's care and development
-Transition to Patient/Parent during cloning over...
**CASE EXAMPLE**

**A Decision Hard On All of Us**

Sophie, a beautiful child who started seeing me when her posterior teeth began to erupt and she began chewing her lips. Extracting primary teeth was not pleasant, but needed. When we had to decide whether to extract her permanent incisors, it was gut-wrenching. Her mother found strength in Sophie's joy and beauty and made the hard call.

**What You Can Count On, 2!**

- Try to be clear
- Establish trust
- Be very clear on home care
- Check your superiority at the door
- Know about the ADA, condition
- Ask about employment and a typical 24-hour day, and other therapies
- Ask the patient

**CASE EXAMPLE**

**No Good Deed Goes Unpunished**

Dr. M agrees to see Michael, a teen with ASD. His usual practice is to take time with special patients, so he schedules him at a time that interferes with Michael's other therapy. Mom and Dr. M fail to reach a compromise on time so Mom contacts the state's ADA office and an ADA attorney fines Dr. M.

**Caregivers Want to Talk to You**

- Put yourself in their shoes
- Focus on helping the patient
- Be open to trying their suggestions
- Finish in a positive way and with a plan
- Thank them for sharing their feelings

**Talking with Families**

- Schedule the meeting ahead of time
- Tell families what the topic of the meeting will be
- Find a comfortable and private meeting place
- Think about what you are going to say
- Thank the family for coming
- Make sure they know that the conversation is private

**Talking with Families of SHCN**

- Encourage families to talk about their concerns
- Be patient
- Listen carefully when they talk—clues to feelings
- Let them finish before you talk
- Keep an open mind
- Give them feedback
Don't Be a Dummy!

- Dissatisfied patients will issue complaint or sue even if the treatment is SOC!
- If parents/patients like and trust you, they are less likely to sue you
- Three tools: orient parents, use laughter and humor, seek opinions and encourage parents to talk

These are lessons learned from decades of studying medical malpractice.

Some Not-So-Good Examples

- Second cousin Ernie is an orthodontist in a distant state and says it can be done
- Child has a limited lifespan
- The treatment may be worse than the condition
- Broken appliances and stressful visits become a part of your life
- Parents are happy with result but you aren’t
- Lack of transition, retreatment, and endless “likes” make friends forever
- Can we try ___ (fixed, clear aligner, other)?

So, It Doesn’t Go So Well... LEAP

- L: Listen to the family’s concerns
- E: Empathize with them — validate their opinion
- A: Apologize that “this” happened
- P: Provide an alternative

* Apologizing is not an admission of responsibility but simply a statement of your feeling bad about the occurrence

Is This Your Happy Place?

- If you meet or exceed the expectations of the family, you will have their lifelong admiration
- You will also have a lifelong relationship that carries into other professional areas — they will ask your opinion
- You will also be “liked” on social media and have many new friends 😊
- You will have a great sense of satisfaction and the admiration of your colleagues

CASE EXAMPLE

An Unexpected Happy Place

In 1982, I took two brothers, from rural Kansas, ages 7 and 8, with Fragile X syndrome, to the operating room and did sealants and restorations. In 2008, I received a call from their mother to thank me because at their most recent adult examination, the sealants were still there!

In Summary on Parent Expectations

- Not exhaustive, high quality literature on any aspect of care, particularly outcomes
- Clearly, challenges in caring for special needs patients accompanied by intensive parental expectations
- Not for the faint of heart; like general dentists caring for special needs kids, it is a calling
- Rewards are there, as is a seeming lack of patient shortages and challenges
THANK YOU VERY MUCH!