TELL ME ABOUT IT!
TALKING TO YOUNG PATIENTS
ABOUT THEIR DIAGNOSIS AND
TREATMENT

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Disclosures
■ I, Rocio V. Garcia, have no relationships with commercial companies to disclose.

Learning Objectives
At the end of this presentation the participant will be able to:
1. Understand the importance of communicating with young patients about their diagnosis and treatment
2. Recognize barriers to communicating with young patients during clinical encounters
3. Identify specific strategies to implement when communicating with young patients in future encounters

Introduction
■ Research suggests that children have limited involvement in pediatric consultations (Cahill and Papageorgiou, 2007)
  - Ranges between 3% and 14%
  - Provide information about illness
  - Cooperate with exam
■ Involvement is less likely during planning and decision making part of the visit (towards end of consultation)
  - Parent and physician discussions

Introduction
■ Study explored contribution of children in pediatric outpatient encounters (Dulmen, 1998)
  - Instrumental (giving information, asking questions) vs
  - Affective communication (comfort, reassurance)
Results:
■ Child participation was limited to 4% (parent 36%, pediatrician 60%)
■ In 36% of the encounters, no child verbal participation
■ In 9% of encounters, pediatrician did not engage in verbal communication with child

Introduction
■ Child contributions primarily social talk, laughter, provision of information
■ Pediatrician communication behaviors and child communication behaviors increased with child’s age
■ Girls were less active participants than boys (paraphrases, asking for understanding, providing psychosocial information)
■ No relationship between child’s contribution and duration of encounter (avg 15 min)
■ Pediatricians asked more questions (26%) compared to the amount of information directed at the child (13%)
Why is Communication Important?

- Important to increase participation of young patients in medical encounters and identify any barriers to communication
- Physician-patient communication is associated with better treatment adherence
- Amount of physician-child communication has been positively associated with increased compliance and better understanding of medical condition
- Children are more likely to participate in encounters if encouraged by the parents and provider

Why is Communication Important?

- Lack of information in new or ambiguous situations can lead to increased anxiety and stress
  - Perception of threat
- Helping young patients understand their medical condition and treatment expectations may assist with coping, adherence, and overall adjustment
- Involving children in decisions about treatment may:
  - Improve alliance and cooperation with treatment
  - Improve clinician-parent-child communication
  - Increase realistic expectations of treatment
  - Provide opportunities for development

Importance of Communication

- One study examined patient-centered communication (PCC) among parents and adolescents (10 to 14 yrs) with type 1 diabetes
- PCC – Partnership building, empathy, interpersonal sensitivity, mutual exchange of information
- Results:
  - PCC was associated with increased sense of disease control and belief in the effectiveness of the treatment regimen for adolescents
  - PCC also associated with higher self-efficacy for diabetes and better treatment adherence among adolescents

Importance of Communication

- Adolescent reports of PCC at baseline predicted positive change in adolescent’s perceived self-competence and self-efficacy for management of diabetes at 6 months
- Adolescent perceived competence (reported by both the parent and adolescent) was an important mediator of disease management
  - Implications for involving adolescents in medical care and supporting their autonomy in disease management

WHAT IS GETTING IN THE WAY OF COMMUNICATION?

Barriers to Communication: Children and Adolescents

- Emotional state
  - Anxious, frustrated, irritated, etc.
- Physical state
  - Pain, attention span
- Perceived provider status and own inferiority
- Style of coping with information
  - Preference for how much they want to know
Barriers to Communication: Children and Adolescents
- Time – Brevity of appointments, feeling rushed
- Familiarity – adolescents disclosed more to providers they had known the longest
- Presence of trainees (medical students) and parents in the room inhibited disclosure of information by adolescents
  - Perceived threat to privacy
- Communication skills - Not knowing how to ask questions
- Child’s age – younger were more inhibited
- Gender - Girls reported a male provider as more inhibiting; boys had no preference in provider gender
- Fear of negative consequences by asking questions
  - Disclosure of worsening symptoms, poor adherence

Barriers to Communication: Parents
- Preference regarding child’s level of involvement
- Interruptions
- Leading conversations – answering for child
- Fear, protection of child
- Underestimate child’s ability to understand and participate in their care
- Lack of parental understanding
- Unsure how to communicate with child
- Emotional distress
- Distraction

Barriers to Communication: Provider
- Perceived lack of time
- Training and experience – provider’s comfort level and communication skills
  - Three-way consultations are more complicated
- Language
  - Medical jargon
- Addressing parents directly
  - Excluding children from discussions
- Taking a condition-centered vs patient-centered approach
  - Symptom focused questions
  - Overlooking psychosocial impact of medical condition

Other Factors Influencing Communication: Culture
- Language barriers
- Beliefs about the role of adults and children in specific situations
- Health beliefs
  - How to interact with medical providers
  - Acceptable behaviors
- Family structure and roles

Involving Children in Treatment Decisions
- Appropriate level of involvement in decision-making
  - Provides opportunity to learn responsibility safely
  - Enhances self-control, self-efficacy, self-respect
- Limiting child’s involvement in decision-making may undermine their use of own resources and motivation for self-help
- Fine balance between too much and too little involvement
  - Anxiety may result if decisions are too complex or if children are excluded from decisions all-together

Involving Children in Treatment Decisions
- Developmental factors
  - Cognitive
  - Social
- Cognitive development influences capacity to understand and reason
  - By mid-adolescence, can engage in abstract reasoning, consider consequences, and request information
Involving Children in Treatment Decisions

- Social
  - Relational style with authority figures (conformity)
  - Sense of personal control, autonomy
  - Period of identity development, particularly in adolescence, can affect decisions
    - Physical appearance
    - Peer acceptance
- Clinical factors
  - Discussed earlier – physical and emotional state

Involving Children in Treatment Decisions

- Situational factors
  - Complexity of decision
  - Time constraints
  - Difference of opinion between providers, parents, and/or children
- Protect children from serving as tie-breakers when parties disagree
- Respect the child/adolescent’s right to self-determination and family integrity

WHAT TO DO…

Improving Communication

- Most children need some information about medical visits/procedures
  - Who do they prefer deliver this information?
- Particularly important to provide developmentally appropriate information about their condition
  - Name of diagnosis, alternative names
  - What it means, what it does NOT mean
- Purpose and projected course of treatment
  - Medication side effects, benefits, risks
- Risks and benefits of alternatives, including no treatment
- Encourage parents to let the child answer for themselves

Improving Communication

- Ask the patient about their goals or expectations for the clinic visit (or hospitalization)
- Summarize and provide clarification if needed
- Share your plan for the visit/hospitalization
  - “I want to check how your lungs are working”
  - “You will need to sleep here tonight, but you will go home tomorrow”
- Explain the purpose of tests, what patient can expect
  - Increases familiarity and predictability

Improving Communication

- Watch your language!
  - Avoid medical terminology, it can create fear, confusion, intimidation
  - Age and developmentally appropriate
  - Minimally threatening
  - Paraphrase
  - Brief statements, save details for parents
- Assess the child’s understanding
  - “Do you know why you are here today?”
  - Have them repeat information
  - No questions? Do not assume they understand!
- Offer information about common questions, concerns, and feelings other children have expressed in similar situations
Improving Communication

- Provide structured choices when possible
  - Right vs left, sit up vs lay down
- Ask the patient for help
  - “Your job is to sit still”, “…take this medicine every day”
- Non-verbal influences
  - Eye contact; sitting at the child’s eye-level
  - Gentle touch
  - Interpersonal space
- Be mindful about the number of trainees in the room
  - Explain why, if possible

Desai and Pandya, 2013

Summary

- A collaborative relationship with young patients can lead to a sense of empowerment about disease management and improve treatment adherence
- It is important to identify barriers to communication at the child, parent, and provider level
- Strategies discussed today aim at addressing some of the identified barriers

QUESTIONS