Improving Adherence

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- Average **medication compliance** is **50%** in the **pediatric** population

Compliance:

- The extent a person's behaviour coincides with medical advice
- Some believe "compliance" implies more of a one-way process *(clinician dictates the treatment & patient must comply).*

Adherence:

- The extent a person's behavior corresponds with agreed recommendations from a health care provider
- **Adherence** emphasizes the patient's/caregiver's role as a **partner** in the treatment and decision-making process
- Many prefer the term **adherence**

- Compliance/adherence depends on the patient's & physician's committing to the same objectives.

- **Communication is a central element in adherence**

  - One-on-one relationship between one doctor & one patient.
  - Physicians' informativeness
  - Collaboration & cooperation with the patient & family
  - Familiarity of the physician & the office staff with the patient, family, & treatment program

Availability & continuity of care promote compliance:

- Telephone availability 24 hours a day, 7 days a week
- Off-hours availability
- Consistent response to questions or problems

- **Parent's beliefs in the:**
  - Seriousness of their child's conditions
  - Severity of the complications their child suffer if they fail to adhere

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- Can increase adherence

- **Effective communication causes perception of:**

1. Interest
2. Caring
3. Warmth
4. Responsiveness
5. Empathy
6. Respect
7. Honesty

- **Relationships have a dramatic effect on:**

  - Recall of instructions
  - Satisfaction

- **Its effect is more than written instructions or the amount of time spent!**

Parents' most criticisms of health care practice is:

- Relationships with practitioners

Communication for procedures:

Find a private setting

Use language the family can understand

Use visual aids *(drawings, models, and radiographs)*

Pace the information

Providing it in a logical sequence

Be prepared to repeat information and answer questions

Recognize emotional distress

Consider child's developmental stage

- **Discuss:**

1. Indications
2. Risks & benefits
3. All alternatives *(including not doing the procedure at all)*
4. Associated risks & benefits
5. Who will be carrying out the requisite actions (parent or child)
6. How recommended drug therapy regimens will fit with their lifestyle.

- **Discuss:**

Clarify information

Clarify plans

Personalize the information

(rather than giving it as a rote speech, e.g., use the child's name)

Ask to repeat what they understood

Avoid last-minute surprises

- **Often large discrepancies between:**

- What health care staff feel they have told

- What patients actually recall.

- Carefully check the understanding of parents/children about what is expected of them

- **Education** is helpful, although they forget much of them soon
- Most information retained is presented during the **first third** of the session
- Parents **forget 50%** of the information presented during a **15-minute** meeting

➢ **Short, repeated educational sessions are the best!**

- **Audiotapes:**

- Allow parents to listen to the information repeatedly
- Dissemination of information to others

- Parents consult others for their children:

  - *Extended family members*
  - *Other practitioners*
  - *Other parents*
  - *Religious leaders*
  - *Tribal elders*

- **Parents of chronically ill children need:**

- More & clearer information about:
- Child's condition
- Treatment
- Opportunity for advance care planning

- Shared with them as soon as it is known

- **Parents want advice about:**

- Child's behavior
- Child's development
- Genetic implications
- Long-term care plan

- **In surgical conditions, parents want to know:**

- Duration of surgery
- Amount of hair to be removed
- Location and length of the incision and bandages
- Location and purpose of intravenous lines and other assorted tubes
- Child's appearance after the procedure

Parents need:

- Their views & concerns be factored into the care plan
- Be treated like **partners** in their child's care
- Affirmation of their efforts

- **Social support**
- **Support for child care**
- **Support for professional services**

- Regular meetings of the family and physician to discuss the "big picture."

- They want a **"medical home"**

- Patients have to be inoculated for "**failure**" & "**relapse**"
- So that when this inevitably occurs, they do not panic or engage in self denigration.
- **Relapse training** helps patient/family members anticipate & plan for high risk situations

- **Nonthreatening** & **nonjudgmental** manner in determining the extent & reasons for non-adherence is more helpful.

- **Strategies to engage children:**

Speak **with** the child *(not at or to him)*

Speak in private setting

Determine whom the child would like to be present

Begin with a nonthreatening topic

Use drawings, games, or other creative communication tools

- **Strategies to engage children:**

Listen actively

Pay attention to body language and tone of voice

Elicit fears and concerns by reference to self or a third party

Ask the child about 3 wishes

Strategies to improve adherence in children:

- Simplified drug regimens

  (e.g., once-daily dosing)

- Pleasant-tasting medicines

  (e.g., sweeteners, chocolate flavoring, ...)

- Liquid or other nonpill formulations

- Rewards for remembering.

  (e.g., stickers, small toys,..)

Reminders:

- Incorporate dosing into daily routines
- Take medication at the same time each day
  (e.g., after brushing teeth, before a meal)
- Keep a tally sheet, mark a calendar, or use a pillbox
- Use visual reminders
  (e.g., notes on the medicine cabinet or refrigerator)
- Ask a friend/family member to remind you.
- Set an alarm on your clock or watch.
- Use a paging system with a beeper.

- **Strategies to improve adherence in children:**

Health education & disease management games.

Ethical considerations

- It is a moral & ethical obligation to discuss health & illness with the child
- Children will be active participants in their care
- Principle of self-determination applies to children & adults

- Involving children in communication about their health
- In decisions regarding their health care
- Shows respect for their capacities
- Enhance their skill in making health decisions

- Child health decision making is a **family-centered** decision making

- When the child is addressed in information gathering & treatment plan, parents & children are more satisfied

- Adherence to the treatment is enhanced

- Parents want to be involved regarding how their children are informed

- **Important to understand:**

1. Parent-child relationship
2. Family's cultural and values
3. Developmental needs of the child
4. Child's desire to participate in his or her own care plan

- Parents' perspectives on the child is **imperative.**
- Adherence improves when the child is treated as a **partner**.

❑ **Pediatric health care quality improve if child is:**

- Recognized as having his own cognitive & emotional needs
- Taken seriously
- Considered to be intelligent
- Considered to be capable
- Considered to be cooperative

- **Parents & practitioners should decide together:**

1. Whether the child will be present at the informational consultations
2. Whether parents would prefer to tell the child themselves
3. Whether parents would prefer to have another person tell the child
4. Whether the informing interview will occur with or without the parents presence

- **Effective child participation:**

Parents think that not informing the child is best!!

To withhold "harmful" information from the child!!

- Children understand more than has been assumed

- Children 3 years of age can be aware of their diagnosis & prognosis without ever having been told by an adult.

- Avoidance of disclosure & denial of information led the child to feel abandoned & unloved

- The child's response is often to **"protect"** the "unaware" adults

- This situation is called **"mutual pretense"** & hurts both parties

Children need:

- To have usable information
- To be given choices
  (including their desired level of involvement)
- To be asked their opinion
- *Even when their decision will not be determinative!*

- Understanding provides sense of control
- Which in turn mitigates fear
- Reduce the harms associated with illness
- If the child is asking about the condition, he knows something is wrong
- & is checking to see whom to trust
- Children who do not ask, should be given the opportunity to receive information
- If they refuse it, information should never be forced on them.

- Parents are also harmed in nondisclosure to their children
- Counsel parents about the benefits of disclosure

- **When patient & family disagree, these factors should be considered :**

  - Cultural values
  - Family values
  - Family roles
  - Family structure

  - Because they govern the relationship

- It is better to ask family members about the etiquette for communicating with them

  "*How should I give your family, medical information about "Mary"?"*

  "*With whom do I share information?"*

  "*Who makes decisions?*"

  "*Are there topics that should not be directly discussed in your family?*"

- Offering to wait until the relevant persons arrive is respectful

Cultural considerations:

- Have to be understood and attended to
- May interfere with medical care
- Practitioner is responsible to be aware of it
- Practitioner is responsible to accommodate the needs of such families

- **Members of subcultures have special needs if:**

- Passive with authority figures
- Are fearful in medical situations
- Make decisions that favor the group over the individual
- Have low educational levels

- **These needs include:**

- Repeated invitations to ask questions
- Use of long silences during discussions
- Accommodation of large groups for information dissemination
- Extra time to consult with others when decisions are to be made
- Written summaries or tapes to facilitate understanding & sharing information with others

Causes of Dissatisfaction

- Feeling of not being treated with respect
- Fears unrecognized or unaddressed
- Unhappy about the amount of information provided

  (even with detailed explanations!)

Barriers of effective communication:

- Time constraints
- Unpleasant waiting
- Pressure of a crowded waiting room
- Distractions by restless children

Improved communication skills:

- Shorten visit duration
- Improve patient response
- Decrease needed follow-up care

Barriers of adherence:

- Health literacy
- Cultural factors
- Lack of appreciation of the treatment's benefits
- Concern over drug adverse effects
- Form of administration

- **Barriers of adherence:**

- Disorganized home environment
- Families with many children
- Parental anxiety or depression
- Long duration of treatment

- **Barriers of adherence:**

- Economic factors
- Complexity of medication schedule
- Forgetfulness
- Drug administration to infants or young children

- **Barriers of adherence:**

- Palatability
- Medication taste
- Dosing at school or day care
- Interference with school performance
- Restriction of activity
- Peer group modeling

Developmental issues which affect adherence:

- Separation/individuation
- Low abilities in risk assessment
- Conscious risk-taking
- Peer pressures
- Regimens contradictory to the family:

  (e.g., the child with CF eats high fat, high calorie foods while other family members attempt to lose weight)

- **Adolescents' roles in decisional authority:**

They must receive to be given authority for decisions:

- Thorough & understanable information
- Developmentally appropriate information

- To enable understanding of the condition
- What to expect with various tests & treatments
- Alternative care plans
- Outcomes of each option

- Only then they can participate as partners in their health care
- Ability to comprehend and decide is fluid & variable within & between individuals
- Assent given by an informed child/adolescent should be given progressively greater weight
- Adolescent depression can threaten adherence

- **Child development changes:**

- Beliefs
- Attitudes
- Social interactions
- Autonomy
- Dependency
- Needs

- Paternalism toward adolescents' decisions undermines respect for the adults they will become
- & the emotional investment they have in their current values
- Overriding the adolescent's decision should be undertaken with trepidation
- Using the same criteria as are used to override an adult's choice.

Adolescents and Forgoing "Life-Prolonging" Treatments

- Adolescents are able to appreciate the hoped-for benefits
- Decisions to forgo life-prolonging treatments made by adolescents have been upheld in courts of law

Legal & Ethical Issues:

Emancipated minors are persons younger than 18 years who:

- Live independent of their parents
- Have taken on the responsibilities of an adult
- Are financially independent
- Are in parenthood
- Are in military service
- Are emancipated by court

Use of Translators:

- Translators require to be trained
- Use of untrained translators is inappropriate.

  (e.g., bilingual children or other family members, nonprofessional hospital employees,..)

- Well-trained translators are aware of cultural norms
  - *"I may ask you to say some things you think are not culturally acceptable"*
  - *"Please let me know and guide me to approach these topics appropriately"*

- **The 5As model in chronic illness management:**

1) **Assess**: Beliefs, behaviors, & knowledge

2) **Advise**: Information about health risks and benefits of change

3) **Agree**: Collaborative goals based on patient interests & confidence

4) **Assist**: Support for chronic illness model

5) **Arrange**: Specific plan for followup visits