

5th Joint Meeting on Adolescence Medicine

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**Approaching the treatment of adolescents
affected by chronic disease:
easy to say, but....**

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From the WHO discussion paper

- ...“The management of any chronic condition during adolescence, a time of rapid growth and physiological changes accompanied by important individuation and socialization processes, constitutes a major challenge for the individual, his/her family and the health-care team” ...

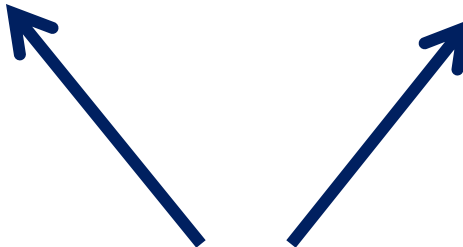
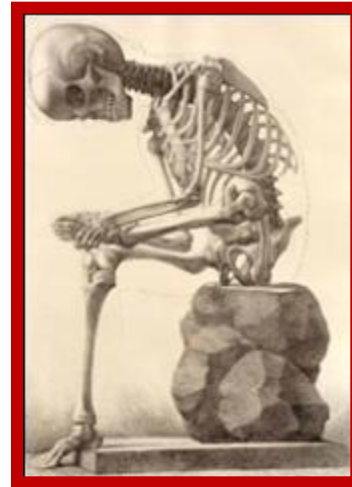
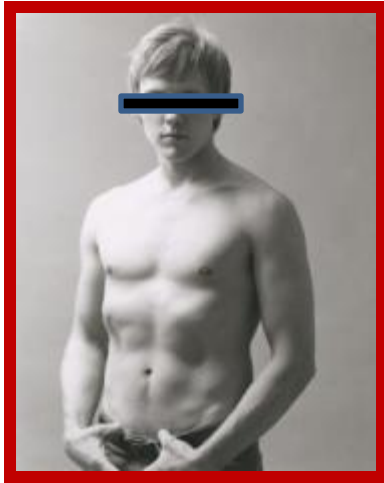
**I wish there was a good recipe for
dealing with adolescents with chronic
conditions...**



Michael

“Hi, my name is Michael, I am 16 and I have Crohn’s disease. Dr. Kerem asked me to tell her how I felt about being an adolescent with a chronic illness. It was a tough task, because so many things were not going my way, especially as I was hospitalized during the summer vacation...”

- “...Do you have any idea how hard it is to be the shortest kid in class? To be skinny while most my friends work out in the gym? “



Michael

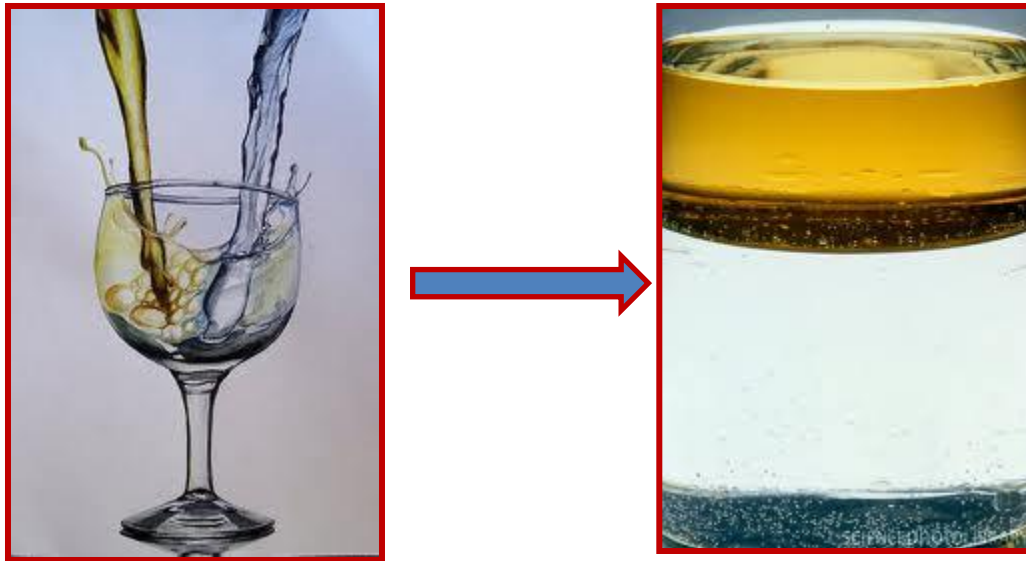
- “... You say it doesn't matter whether I have a female or a male doctor, but I have news for you – it matters a lot. I can speak more freely with a female doctor, but I truly don't feel comfortable when I get a rectal exam from one...”
- “...I hate when I am on steroids – my face gets round, I get pimples and I become very moody...”



Michael

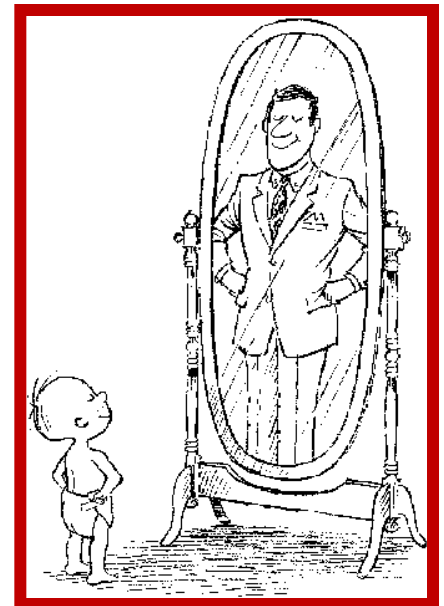
- ...”I could not join my class’ fieldtrip last year because I had a flare up, and I spent at least 12 times a day in the toilet while my friends were having fun” ...
- ...”Have you tried to ask a girl out (of course a girl younger than you, because you look like you are 14 max) while you are “gassy” and need to go to the toilet every 15 minutes? It’s a nightmare, so I simply don’t date”....

Adolescents and Chronic Conditions – Can they peacefully co-exist?



Adolescence – Time of Rapid Changes

- Physical growth, pubertal changes
(and accepting the new body image)
- Identity formation
- Cognitive development
(concrete to abstract thinking)
- Shift in primary attachments, independence
- Sexual identity, orientation

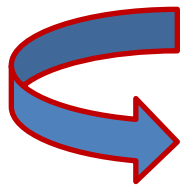


Chronic illness in adolescents

- 6-8 % of all adolescents suffer from a chronic condition, that results in limitation of daily activities or disability
- The most common causes:
 - airway disease (mostly asthma)
 - musculoskeletal disorders (i.e. CP, scoliosis)
 - heart disease (congenital, acquired)
 - mental conditions (mostly depression)
 - hearing and visual impairments

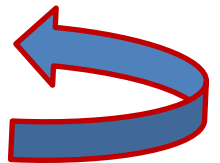
Adolescence ↔ Chronic condition

- The developmental processes involved in adolescence have a **complex and bi-directional interaction** with chronic illness:



Disease effects adolescent development

Adolescent development effects the disease




Examples:

- Chronic condition can delay growth and puberty
(CF, IBD, celiac, Thalassemia)
- Puberty (increased level of hormones) may impact the chronic illness
(DM - difficult glucose control due to increased GH, CHD)



Physical growth and puberty:

- Higher rate of body dissatisfaction
- Difficulties with body image are increased if
 - Visible illnesses
 - stomas, use of devices
- Unhealthy weight control measures,  ED



Identity formation:

- May have been “seen as their disease”
by others and by themselves




Education:

- Missing school at crucial times (and often more days than their treatment requires)
- May prioritize education over treatment during the key educational stages in later adolescence
- Condition or treatment may cause learning difficulties

Identity formation – cont.

- Teachers may not believe complaints
- Teachers may have low expectations
- **School can be an excellent source of support!**

Recreation:

- Important for social interaction, self esteem
- Physical activity important (asthma)
- Vicious cycle (i.e. morbid obesity)
- Some conditions  energy requirements
- May need special equipment to protect joints, other areas

Cognitive Development

- Not linear, everyone regresses under stress
- Concrete to abstract thinking during adolescence

In younger ages: any difference =totally different

Take things literally

In older ages: Concerns about future, death

Ability to plan ahead (for clinic appointments)

Preventing oneself from skipping medication

- Disease process/ treatment can effect cognition

(i.e. neurodegenerative dis, radiation, hypoglycemia)



Independence, Autonomy

- Autonomy = Defining characteristic of adulthood in Western culture
- Overprotection by family (and physicians)



- Physical autonomy often “repeatedly invaded”
- Learned dependence
- Caregiver fatigue, guilt, anger
- Sibling issues

Independence, Autonomy – cont.

- Peer interactions:
 - Accessibility
 - Fear of unknown
 - Missed school = missed social opportunities
 - Appearance (i.e. young looking, cushingoid)
- Some illnesses (as cancer) may increase peer acceptability
- Peer interaction in waiting rooms (relationships, confidence)
- **Peers can be huge source of support!**

Sexuality

- Potential physical and psychological barriers
- Reproductive capacity often not discussed
- Decreased privacy, Societal assumptions
- Body image problems may act to increase risk taking in sexual behaviour
- Special contraceptive needs
- Visible conditions were not found to effect the rate of teen sexual activity



Chronic Illness in Teens

Many adolescents manage their disease and treatment well




For others, reduced adherence to medical regimens can be seen as “developmentally appropriate”:

- as another risk taking behavior (“exploratory behavior”)
- Immature ability to imagine future consequences
- A concept of themselves as “bullet-proof”
- Poor physician manners...



More long term complications can be seen

Substance Use and Abuse

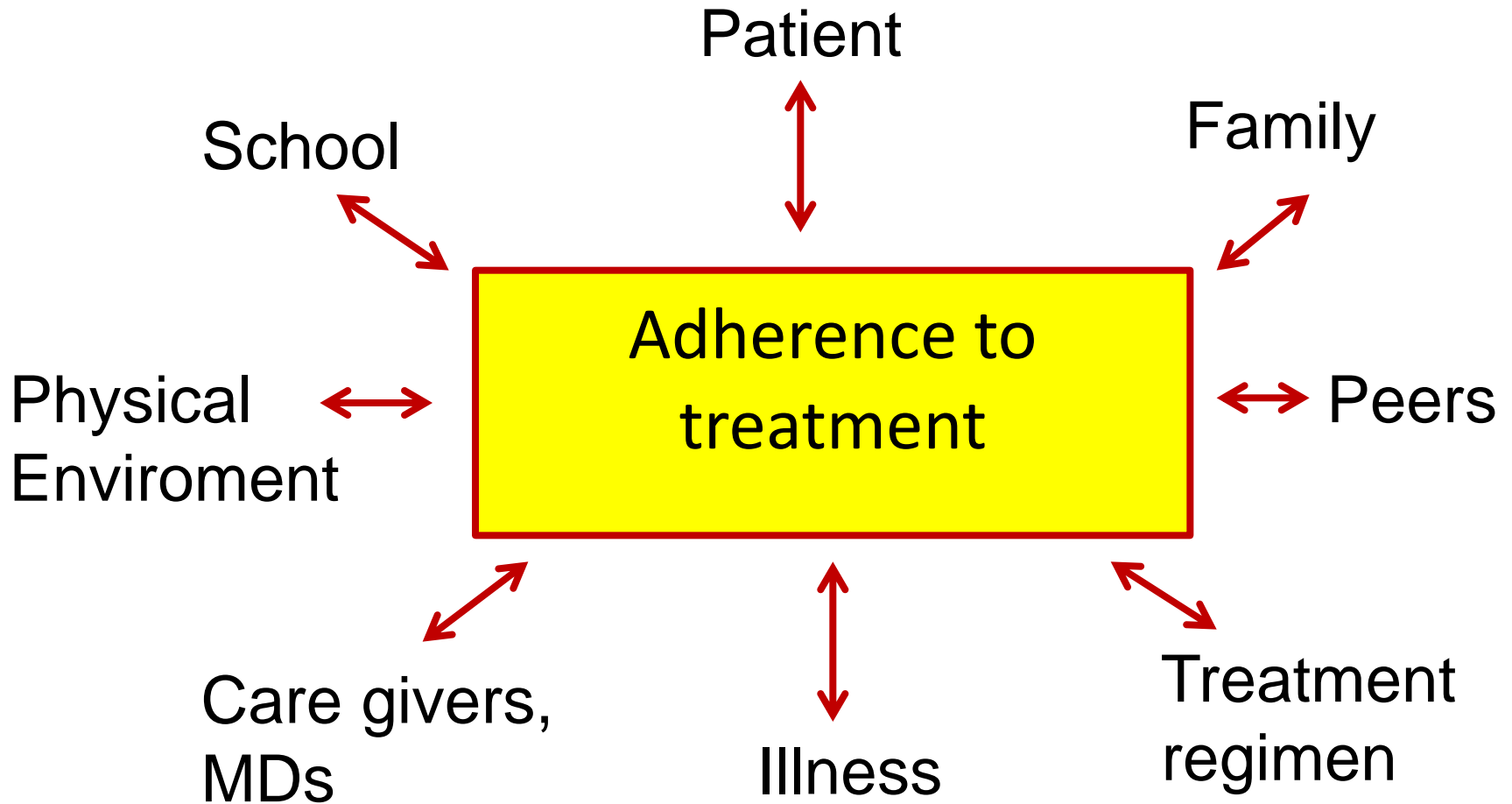
- Chronic illness  **Increased risk** for substance use/ abuse
- Interaction concerns (i.e. cigarettes and asthma, alcohol and antidepressants)
- May stop medications
- Substance use may  or  symptoms (i.e. alcohol and migraine)
- Self medication
- To be a “normal adolescent”

Mental Health

- Mixed literature
- Higher prevalence for at least 1 psychiatric problem (not in DM)
- Increase prevalence of low mood but not depression
- Mood may be “appropriately” sad or angry
- Some syndromes linked to mental illness
- May lack opportunities to learn how to self-soothing techniques

Adherence to Treatment





Improving adherence to treatment

Factors related to the patient

- Personality traits:
 - Resiliency
 - self esteem
 - personal organization
- Involvement in disease process
- opportunity to make choices from an early stage
- Psychological support when needed
- Adaptation of therapy to adolescent's life style
- **Ask the adolescent to make proposals for improving the treatment**

Ways to improve adherence – cont.

Factors related to family/ environment:

- Adapt patient's physical surrounding
- Lack of primary psychopathology (mostly anxiety and depression) in patient's family (mostly in mothers)
- "Connectedness"
- Setting limits is important--too much or too little can inhibit identity formation

Ways to improve adherence – cont.

Illness:

- Visibility
- Magnitude of interference with every day activity – try not to “give up” recreational activity
- Impact on future, prognosis
- A planned and gradual transition to the adult medical world



Ways to improve adherence – cont.

Treatment regimen:

- Continuity – try to have a single “case manager”
- Assess adherence on a regular basis
- Complexity
- Duration
- Need for lifestyle change
- Pharmaceutical



Potential to maximize adherence if:

**Management strategies are
decided together with the patient
in light of his/ her personal goals**

Selected references

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All adolescents



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(& colleauges.)



**You, who
managed to stay
awake...**

Adolescents and Chronic Conditions – Can they peacefully co-exist?



ALEXANDROS AIDONIDIS
PHOTOGRAPHY