Risky behaviour in Adolescents affected by Chronic Disease

Joint Meeting on Adolescent Medicine

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ADOLESCENCE

- The preparatory period for an independent and mature social existence.
- The adolescent with chronic disease must often make a bid for independence in a situation of maximum dependency on family, doctors/nurses and a strict and exacting treatment regime.

Risky behavours

QUESTIONS FROM A NON-EXPERT

Q1: Why is risky behaviour an issue?

Q1.1Is the adolescent with chronic disease more likely to engage in risky behaviour ?

- Because of the need to achieve ‘normality’ and acceptance by peers?
- As a ‘compensation’ for perceived weakness?

Q1. Why is risky behaviour an issue?

Q1.2 Are adolescents with chronic disease less likely to engage in risky behaviour?

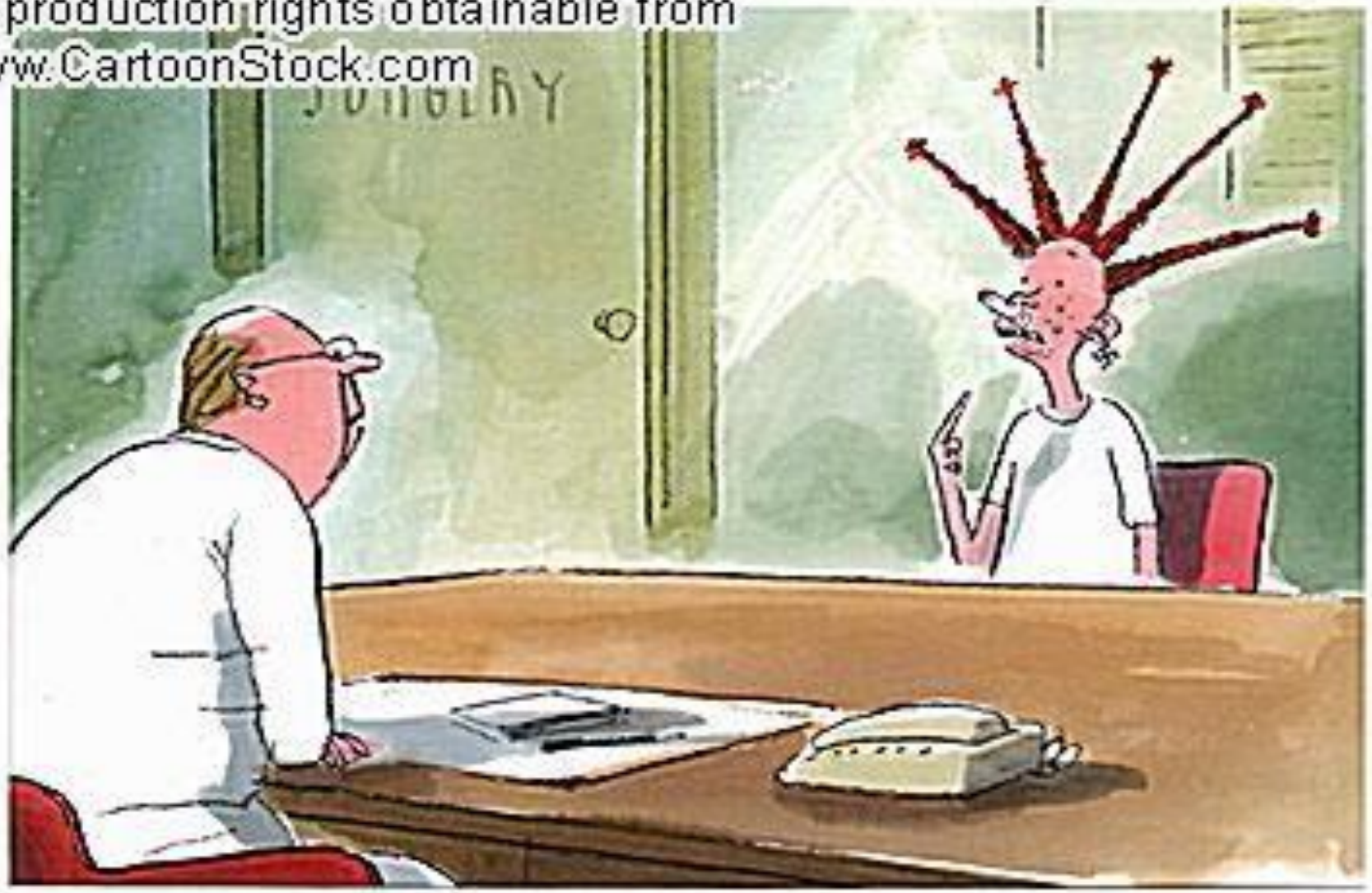
- Because of the ill health and ‘weakness’ limiting daily activities?

Literature agrees:

- Chronically suffering adolescents are just as likely to engage in risky behaviour as healthy adolescents (if not a little more)
- See: Alderman (1995),Suris (1996), Britto (1998), Blum (2001), Suris (2005), Tyc (2006), Sawyer (2007), Scaramuzza (2010)

Q1.3 Why are Adolescents worrying ?

- Bid for autonomy may lead to risky behaviour
- Engage in behaviour parents may perceive as dangerous
- Possible treatment refusal
- Risky behaviour may affect the control and outcomes of their disease



"It's me acne Doc, it's gettin' so's i'm feelin' too ashamed to go out"

Q2. What are risky behaviours?

Most researchers look at:

- Potential dependency: alcohol, smoking, marijuana and other substances
- Sex (!): mainly unsafe sex, more than one partner (?), pregnancy

Others have looked at:

Bullying, weapon carrying, theft, seat belt use

Q2. What are risky behaviours?

2.1 Is risky behaviour dependent on environment, social setting and culture?

- For example is inner city behaviour more likely to be risky?
- Smokers in a smoking environment (Tercyak 2003)
- Intact vs broken families

Q2. What are risky behaviours?

- 2.2 Do we need a sociological approach in research by professionals? (look at the work of Ken Atkins, Waqar Khan and Dyson: they have researched more factors including ethnicity, religion and more)
- Chronic disease care should be multidiciplinary, what about research?

Q2. What are risky behaviours?

Q2.3 Is non-adherence to treatment another risky behaviour?

- Are non-adherent adolescents more likely to engage in other risky behaviours?
- Is there a profile of the naughty adolescent with chronic disease?
- Around 10% of chronic disease patients have psychological problems. Is this the group to look at more closely?

Q3. Which chronic diseases?

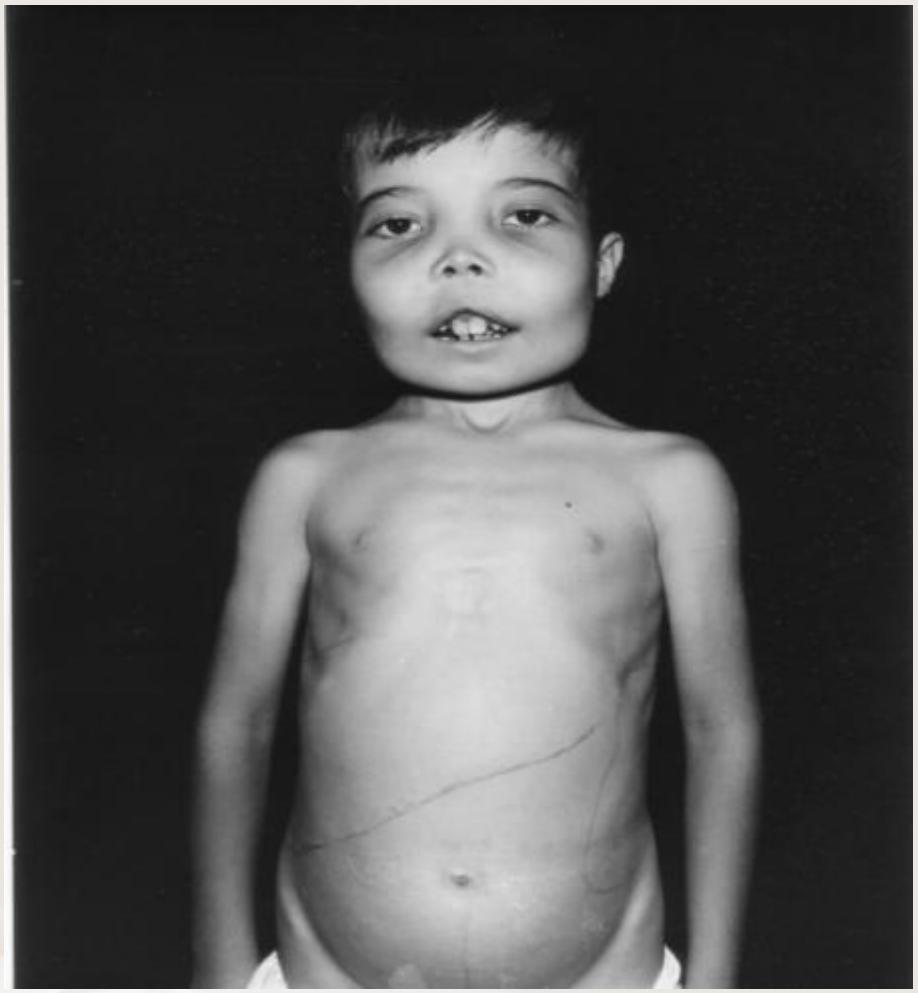
- Usually samples studied include: diabetes, asthma, Cystic fibrosis, cancer, sickle cell disease (see Suris & Parera)
- My experience is thalassaemia, SCD, Congenital immune deficiency, FMF,CP
- “There is considerable commonality in the psychosocial ramifications of chronic illness that research would benefit from a non-categorical approach” (Wallander & Varni 1998)

Q3. What Chronic Diseases?

Q3.1 Is the non-categorical approach justified? Some chronic patients have:

- Altered appearence & poor growth
- Chronic and acute pain
- Delayed puberty

β-Thalassaemia is such a disease



- Lifelong adherence to a demanding and expensive needed to achieve survival and a good quality of life.
- This adolescent needs to feel normal!
- Will he try risky behaviour? Certainly!

Stress Factors Affecting Patients

- Altered appearance, poor growth.
- Delayed puberty.
- Sense of being different from peers.
- Uncertain future (health/death, work etc.).
- Possible guilt feelings for being a burden.
- Engulfement.

Patients must also cope with:

- The disease, its complications and chronicity.
- Demanding treatment, especially chelation.
- Family : supportive but may increase stress.
- Caregivers (doctors/nurses) - overprotective, or figures of authority, unresponsive.
- Society: peer relationships, stigmatisation, education, career, marriage

Psychological disorders described in Patients.

- Low self esteem, poor self image (Logothetis J et al Pediatrics 1971, 48: 740-3).
- Emotional and conduct disorders (Sherman M et al Ann NY Acad Sci 1985, 445:327-336).
- Attention deficit disorders.
- Impulsive, uncontrolled temper.
- Dysphoric moods.
- Dependency.
- Fears, anxiety (Woo R et al Ann NY Acad Sci 1985 445: 316-23

Stress factors affecting the family
(Tsiandis J, Ann NY Acad Sci, 1990,612: 451-61)

- Guilt.
- Anxiety over patient's treatment and future.
- Low income/poor education/social isolation
- Engulfement.
- Ethnicity, immigrants.
- Poor quality of services, unsympathetic professionals.

Q3+ What is correct parenting?

- Children with chronic disease are vulnerable, with special needs: may disrupt optimal parenting
- Evolution from parental control to monitoring to independence expected
- Are parents always to blame foe risky behaviour? Need for research
  Elliot, Templin et al 2008

"Really, Kevin! You'll ruin your teeth!"

Q4. Does chronic disease affect development?

Conclusions of a study by Seiffge-Krenke 1998 in diabetics:

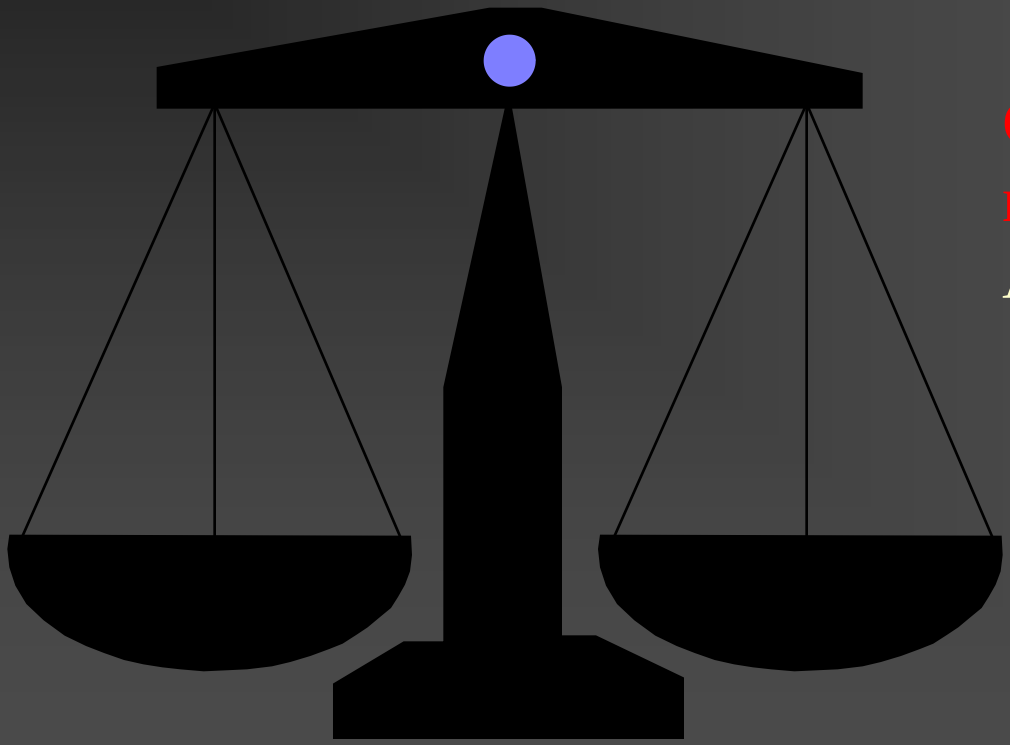
- Both healthy and diabetic adolescents share the same goals
- No indication of developmental breakdown in chronic illness
- Chronically ill adolescents perceive themselves as competent as their peers

Q4. Does chronic disease affect development?

- “Thalassaemic adolescents scored better than healthy peers in tests of social adjustment” – Zani, di Palma, C.Vullo 1995.
- “Children and adolescents with chronic disorders do not differ as much as assumed from healthy controls”

The Psychosocial Balance

Stress factors - Psychological Disturbance.



Coping mechanisms - Adaptation

Patient coping: aims

- Positive adaptation and good quality of life.
- Autonomy, to grow from passive acceptance to self care.
- Participation in decision taking.
- Sense of normality

Patient: coping strategies (Milousheva J et al, Acta Pediatr Jpn,1996, 38)

- Avoidance/denial: passive coping, maladaptive - social withdrawal.
- Distraction: forget the illness, reduce impact
- Resignation - passive acceptance.
- Seeking social support.
- Problem solving, decision taking: playing an active role.

Patient: coping strategies (Spirito A et al J Pediatr Psychol, 1988, 13: 555)

- Aggressive behaviour, blaming.
- Spiritual support - role of religious belief.

35% of adolescents with SCD pray once or more /day, seeking God's love and care (Cotton S et al J Ped Hematol Oncol 2009. Univ of Cincinnati)

- Professional support - doctors, nurses, psychologists - the multidisciplinary team.

Adaptation/Coping with Chronic Disease.

- “Adolescents are more flexible in changing their ways of coping, adults remain relatively stable. Interventions should target children and adolescents, before maladaptive coping becomes entrenched.” Gil 1997, Schmit et al 2003

Services for Chronic Health Condition.

- " Services must be expanded to include more than management of the chronic condition….they should maximize children's functional abilities, sense of well-being, quality of life and their development into healthy and productive adults". Policy Statement, American Academy of Pediatrcs.

Service Provision

Q5. ARE WE DOING WHAT WE CAN TO HELP?

Doctor's Avoidance

Wissow et al 2005

- Consciously or unconsciously contribute to patient hesitation to express personal matters, fears etc.
- Doctors troubled by emotions.
- Feel they lack the skills, and the time.
- Distance themselves from matters not in their specialty.
- Overwhelmed by a barrage of problems

Talking with Patients.

- Improves coping and quality of life.
- Helps to attain independence.
- Communication enhanced to address patient's lifestyle, culture, environment.
- Need to enhance clinician's skills.
- Environment without interruptions, private.
- Chronically sick adolescents expect emotional support from their health care providers – those who listen, pay attention to their opinions and respond to them.
  Kyngas 2003.

One Adolescent patient said

- " It is the individual who is the one who proves himself, recognition does not come from others"

"Integration results in giving meaning to our life through our complex relationships with "others", and leading to a sense of achievement and self-realization".

Quote from an "expert patient" May 2009

Educational Needs of the Chronically Sick Adolescent.

- Education in regular classes.
- Regular classes + supplementary services.
- Special education.
  “Children with disabling conditions and chronic diseases are entitled to appropriate modification within their educational program to accommodate their special needs.” Rehabilitation Act USA 1973.

Summary/conclusions.

- Comprehensive care for the adolescent with chronic disorder must not be limited to somatic interventions. Psychosocial support must be integrated into the service.
- Meet the needs of the individual patient.
- Include clinical psychology and social services in the multidisciplinary team.
- Provide information to the adolescent and counseling.
- Encourage self-management.
- Listen attentively.

Conclusions

- Developing services for adolescents requires knowledge and understanding of their problems, medical & psychological
- In planning services we must ensure staff training. A training course for doctors & nurses dealing with the chronically sick adolescent is essential.
- COMMUNICATION

Thank you for bearing with me

Catanzaro

Città tra due Mari