EuTEACH

European Training in Effective Adolescent Care and Health

Chronic Conditions

So far we have covered...

Objectives

1. Recognize the interrelated impacts of chronic conditions and adolescent bio-psychosocial development.
2. Demonstrate proficiency in developing and implementing interventions directed at adolescents affected by a chronic condition, along with the parents and the professional network.

Epidemiology

Survival estimates to age 20 years for certain chronic conditions

Condition	Survival
Diabetes mellitus	95%
Hemophilia	90%
End-stage renal disease	90%
Acute lymphocytic leukemia	71%
Congenital heart disease	71%
Cystic fibrosis	60%
Spina bifida	50%

(Taken from R.W. Blum)

Chronic illness: the definition issue

WHO definition

Chronic conditions are
health problems that
require ongoing management
over a period of years or decades

Chronic conditions: Prevalence

France (1994):	8.3% (girls) 9.0% (boys)
Switzerland (2002)	9.5% (girls) 10.4% (boys)
Canada (1994):	11.0% (girls) 7.0% (boys)
Catalonia (2001):	11.2% (girls) 7.7% (boys)

Influencing factors

- **Duration**
- **Physical or mental**
- **Visible or not**
- **Limiting or not**
- **Congenital or acquired**
- **Episodic or persistent**
- **Life-threatening or not**

Non-categorical approach

Stein & Jessop, Public Health reports, 1982

"Conceptually it is difficult to imagine that each of the thousands of chronic conditions has distinct effects on children and families or fundamentally different implications for health services or policy."

Perrin et al., *Pediatrics, 1993*

Pubertal development

Due to the condition or the treatment, pubertal timing may be different than peers.

Age at menarche

Cystic Fibrosis	**14.5 years**
Sickle cell Disease	**14.5 / 15.4 years**
Childhood malignancies	**12.2 years**
Chronic renal disease	**15.9 years**
Diabetes	**12.8 / 13.0 years**

Positive body image: girls

	Chronic C.	Control
BC, Canada (1994)	36%	50%
MN, USA (1994)	48%	60%
Barcelona (1994)	49%	61%

An abnormal body image may lead to:

- **Lower of self-esteem**
- **Segregation from peers**
- **Lower participation at school and other activities**
- **Higher anxiety over their sexual functioning and sexual relationships**
- **Depression and/or anger**

Adolescents with chronic conditions report less satisfaction with their body and higher rates of risk weight loss practices than their peers.

Neumark-Szrainer et al., 1995
(*Arch Ped Adolesc Med*)

Independence

For adolescents with chronic conditions, transition towards independence can have the additional burden of excessive dependence on the family, and overprotection can affect their development.

Possible barriers to becoming independent

- **Limitations due to the condition or the treatment**
- **Severity of the condition**
- **Financial and psychological support from the family**
- **The adolescent’s motivation**

Factors influencing self-esteem in adolescents with spina bifida

(Wolman & Basco, 1994)

- ↑ Age-appropriate treatment by parents
- ↑ Parental permissiveness in social participation

- ↓ Having problems at school (teasing, rejection)
- ↓ Feeling that they were considered disabled by others

Parents may not be sure of what is *normal*

for their adolescent and what degree of autonomy to give him.

(Patterson & Blum, Arch Ped Adol Med, 1996)

When both the parents and the adolescent are able to redefine autonomy as the ability to be responsible of your own behavior, to take your own decisions, and to develop adult relationships characterized by mutuality, transition is smoother.

(Patterson & Blum, Arch Ped Adol Med, 1996)

Family

Parents play an essential role in the development of CC adolescents, but fathers and mothers do not take care of their child’s condition the same way.

Divorce rates are not higher among parents of CC adolescents.

Although marital distress may be more frequent.

However, they could stay together «for the sake of children».

(Sabbeth & Leventhal, Pediatrics, 1984; Cappelli et al, J Dev Hevah Pediatr 1994; Taanila et al, Dev Med Child Neurol 1996; Setlzer et al, Am J Mental Retard 2001;)

If parents and siblings see the adolescent as worthwhile and give him/her appropriate responsibilities, the adolescent's self-image is usually good.

(Batshaw et al., 1992)

The relationship with the siblings is good if:

- **They are informed.**
- **They have a good social network.**
- **Parents do not forget that <u>all</u> their children need them.**

(Barrera et al, Child Care Health Dev, 2004)

School

CC adolescents miss more school days than their healthy peers.

Missing school implies:

- **Less contact with peers**
- **More isolation**
- **Lower academic achievement**

(Bloch, 1988)

CC youth miss three times more school days than their peers

(*Newacheck et al, Pediatrics, 1998*)

But many of them miss more school days than what could be attributed to the severity of their condition or to their treatment needs

(*Charlton et al, Arch Dis Child, 1991*)

However, they also skip class more often

(*Hogan et al, Disabil Rehabil, 2000*)

Although it is not clear that their academic performance is lower, it is less frequent that:

- **They finish their schooling**
- **They follow university studies**
- **They are well oriented academically and professionally, and, on the long term, economically**

(Stevens et al, J Adolesc Health,1996; Leblanc et al, Ped Clin N Am, 2003)

Friends

- **Most CC adolescents report having a *best friend* who is often younger** ***(Blum et al, Pediatrics, 1991)***
- **The probability to participate in their peers' activities is limited by the severity of the condition and the treatment needs** ***(Schmidt et al, Child Care Health Dev, 2003)***

Friends (2)

- **CC adolescents indicate receiving more pressure from their peers** ***(Hogan et al, Disabil Rehabil, 2000)***
- **Risk-taking behaviors may be a way to make friends and catch attention** ***(Strax, Pediatric Annals, 1991)***

Risky behaviors

Research indicates that CC adolescents have similar or even higher rates of:

- **Smoking**
- **Alcohol misuse**
- **Use of cannabis and other illegal drugs**
- **Unprotected sexual intercourse**
- **Being sedentary**
- **Risk weight-loss practices**

than healthy adolescents

CC Swiss youth aged 16-20 y.

	CC	Controls
Regular smoker	41.5%	35.2%
Alcohol misuse	33.1%	29.4%
Cannabis use	39.9%	33.1%
Other illegal drugs	13.1%	7.9%
No condom	52.9%	45.7%
No exercise	**48.4%**	**38.9%**
Been on a diet	20.9%	15.2%

SMASH-02

raisons de santé

SANTÉ ET STYLES DE VIE DES ADOLESCENTS ÂGÉS DE 16 À 20 ANS EN SUISSE (2002)

WHY?

During adolescence,

the main objective is to be

NORMAL

Healthy adolescents
do not need to prove
that they are normal.

Chronically ill adolescents DO.

Wanting to be *normal*

often means trying to emulate risky behaviors as part of their normal process of maturation.

There is evidence indicating that there are more similarities than differences between CC youth and their healthy peers and that CC adolescents have the same guidance needs…

…but problems not related with the condition are rarely discussed by specialists or by primary care providers.

Adolescents with CF or SCD reported that their regular providers infrequently addressed health-promoting or risky behaviors at an encounter occurring in the last year.

(Britto et al., Arch Ped Adolesc Med, 1999)

Percentage reporting physician counseling in past year

	C. Fibrosis	Sickle Cell D.
Weight/Dieting	65%	32%
Sexual issues	30%	43%
Depression/Suicicide	20%	22%
Tobacco use	21%	30%
Alcohol use	20%	30%
Safety	20%	26%
Illegal drug use	18%	30%
Drinking & driving	16%	30%
Weapons/fighting	6%	15%

Britto et al., 2000

Discussion of reproductive options of males with CF by health care providers

(*Sawyer et al., 2001*)

- **Don't talk about reproductive options 12%**
- **Talk about reproductive options if asked 19%**
- **Talk about reproductive options (any age) 69%**
  - **Talk with adolescents 19%**
  - **Talk with young adults 22%**
  - **Talk at premarriage counseling 25%**
  - **No specific time 3%**

Reasons why health care providers do not give consideration to the sexual issues of chronically ill adolescents:

(Anderson & Wolf, 1986)

A) sex is viewed as an area not vital to recovery and the maintenance of good health.

B) not comfortable and/or not competent confronting sexual issues.

C) they frequently assum that the causes of sexual dysfunctioning are disease-based.

Having a chronic condition

does not mean

that they are not adolescents

and that they will not behave as such

Health care

CC youth have more contact with the health system, and providers have a very important role to play.

The provider's role

- **Be person-centered and <u>not</u> disease centered**
- **Go beyond purely medical issues and discuss issues such as personal development, familial and social support, substance use and reproductive & sexual health**
- **Help the adolescent and his family do the <u>transition</u> as smoothly as possible**

Features of the encounter
(Beresford & Sloper, 2003)

- Familiarity
- Duration
- Privacy

Doctor-centered factors
(Beresford & Sloper, 2003)

- **Behavior towards the adolescent**
- **Condition-centered vs. Person-centered approach to care**
- **Communication skills**

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Themes for health professionals to address when working with young people:

- treat me like a person
- try to understand
- don't treat me differently
- give me some encouragement
- don't force me
- give me options
- have a sense of humour
- know what you are doing

Woodgate R. Adolescents' perspectives of chronic illness: "it's hard". J Pediatr Nurs 1998;13:210-23.

Adherence / Compliance

Strategies to improve compliance/adherence

FACTORS RELATED TO THE ADOLESCENT

- **Provide information meeting the adolescent's maturational stage**
- **Take into account underlying psychological factors**
- **Tailor the treatment to the patient's individuation process and stage / adapt the therapy to the adolescent's lifestyles**
- **Communicate information in a straightforward way, trust the adolescent**
- **Tailor the doses of the medication to the patient's physiological status (puberty/growth)**
- **Ask for proposals from the patient**

Strategies to improve compliance/adherence (2)

FACTORS RELATED TO THE TEENAGER'S ENVIRONMENT

- **If needed, suggest the support of siblings, peers**

FACTORS RELATED TO THE SETTING & COMMUNICATION

- **Keep the same professionals in charge of the same patients over time**
- **Assess adherence regularly and in a non-threatening manner, check for side-effects**
- **Simplify the therapeutic regimen as much as possible, negotiate**

Transition

Aspects of the patient's condition and situation which may be discussed on the long term

1. Interference of the disease with pubertal processes
2. Degree of invalidity
3. Visibility of the disease (including side effects affecting self image)
4. Evolution (continuous, or sporadic)
5. Prognosis
6. Associated mental health problems
7. Everyday constraints (physical disability, complex treatment)
8. Beliefs and expectations
9. Defence mechanisms: denial, expectations, etc

Ingredients of a good transition program

1. Discuss the matter during childhood and as the young person grows up
2. Acknowledge issues facing both the patient and his/her parents
3. Identify colleagues who have an interest in young adults
4. Select a health worker (family practitioner, nurse, etc) who may supervise the transfer
5. Organise common meetings with the new team
6. Secure some follow-up phone calls
7. Identify individuals, (adults, peers) who can give support