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Chronic Conditions

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So far we have covered...

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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.

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Epidemiology

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Statement # 1

Nowadays, around 90% of adolescents suffering from a chronic illness reach age 20

TRUE

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Survival estimates to age 20 years for certain chronic conditions

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)

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Statement # 2

Around 30% of adolescents suffer from a chronic condition (chronic illness and/or disability)

It depends on the definition!

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Chronic illness: the definition issue

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WHO definition

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

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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)

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Statement # 20

Whether the condition is visible or not has an impact on the adolescent: those with non-visible conditions do better

FALSE

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Influencing factors

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

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Non-categorical approach

Stein & Jessop, Public Health reports, 1982

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"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*

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Pubertal development

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Statement # 3

Adolescents suffering from chronic conditions start their puberty later than their healthy peers

It depends on the condition

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

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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**

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Statement # 4

Overall, adolescents suffering from a chronic condition have a worse body image than their healthy peers

TRUE

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Positive body image: girls

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

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An abnormal body image may lead to:

- **Lower 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**

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Statement # 5

Adolescents suffering from chronic conditions report higher rates of risky weight-loss practices than their peers

TRUE

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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*)

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Independence

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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.

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Statement # 6

For the adolescent suffering from a chronic condition, his/her motivation is a barrier towards independence

TRUE

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Possible barriers to be independent

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

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Statement # 13

Adolescents suffering from a chronic condition tend to be overprotected

TRUE

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Children of families that exhibited more positive emotional support and communication had:

- **↑ self-care participation**
- **↓ impact of diabetes**
- **↓ worries about diabetes**
- **↑ life satisfaction**
- **↓ school absences**
- **↓ interruptions in social relationships**
- **↓ overprotection by parents**

Faulkner & Chang, J of Pediatric Nursing, 2007

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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)

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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)

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Family

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Statement # 21

Fathers and mothers of adolescents suffering from a chronic condition take care of their child the same way, it all depends on who has more time

FALSE

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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.

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Paternal involvement

- Paternal involvement is associated with better maternal, marital and family outcomes.
- Greater paternal involvement in the medical regimen might enhance marital communication and satisfaction with the partner.

Gavin & Wysocki, J of Pediatric Psychology, 2006

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Children whose parents were distressed were more likely to be distressed themselves

Robinson et al., J of Pediatric Psychology, 2007

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- **↑ self-care participation**
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Faulkner & Chang, J of Pediatric Nursing, 2007

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Impact of parenting style among youths with cerebral palsy

- It was a most important factor affecting the psychosocial aspects of quality of life.
- Its impact was far greater than other factors, including severity of the illness, IQ or SES.
- Autonomy allowing and accepting styles were reflected in improved mental health, higher self-esteem, better behavior, and less social and emotional limitations.

Aran et al., J of Pediatrics, 2007

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Statement # 7

Divorce rates among parents of adolescents suffering from chronic conditions are higher than among other couples

FALSE

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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

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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)

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Statement # 22

The siblings of adolescents suffering from a chronic condition are not affected by their brother/sister condition

TRUE, BUT…

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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)

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School

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Statement # 12

Adolescents suffering from a chronic condition are more likely to miss school

TRUE, BUT…

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CC adolescents

miss more school days

than their healthy peers.

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Missing school implies:

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

(Bloch, 1988)

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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*)

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Statement # 9

Adolescents suffering from a chronic condition have worse academic results than their healthy peers

NOT SO CLEAR

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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)

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Statement # 10

Adolescents suffering from a chronic condition report receiving more pressure from their peers

TRUE

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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)*

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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)*

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Friends (3)

- Diabetic adolescents were equally likely to have a best friend and boyfriend/girlfriend than their peers, but healthy adolescents were more likely to have an other-gender friend.
- Negative relations with friends were inversely related to psychological health and predicted a decline in psychological health over time. Negative relations also predicted poor metabolic control and a deterioration of metabolic control over time.

Helgeson et al., J of Adolescent Health, 2007

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Risky behaviors

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Statement # 11

Adolescents suffering from a chronic condition (such as asthma, for example) are less likely to smoke than their healthy peers

FALSE

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Statement # 8

Adolescents suffering from a chronic condition are less likely to misuse alcohol than their healthy peers

FALSE

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Statement # 14

Adolescents suffering from a chronic condition are less likely to use illegal drugs (such as cannabis, for example) than their healthy peers

FALSE

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Statement # 16

Adolescents suffering from a chronic condition are less likely to have unprotected intercourse than their healthy peers

FALSE

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Statement # 17

Adolescents suffering from a chronic condition are less likely to practice sport than their healthy peers

TRUE, BUT…

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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**
- **Sedentarity**
- **Risk weight-loss practices**

than healthy adolescents

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Risky behaviors among CC youth in Switzerland

	Control	CC
Regular smoker	37.1 %	43.4 %
Alcohol misuse	30.5 %	31.7 %
Cannabis use	33.9 %	40.0 %
Illegal drugs	7.1 %	10.1 %
Sexual intercourse< 15y	7.8 %	10.0 %
Eating disorder	5.0 %	7.2 %
Violent acts	15.9 %	20.3 %
Antisocial acts	28.3 %	35.7 %

Suris et al., Pediatrics, 2008

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Co-occurring Risk Behaviors among CC youth in Switzerland

	Control	CC
0 risk behavior	31.8 %	25.1 %
1 risk behavior	22.3 %	21.3 %
2 risk behaviors	17.5 %	16.3 %
3 risk behaviors	13.4 %	15.4 %
4 risk behaviors or more	15.1%	21.8 %

Suris et al., Pediatrics, 2008

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Weight control behaviors among diabetics

	Girls (N=66)	Boys (N=69)
Fasted	7.4 %	1.4 %
Ate very little	23.5 %	5.6 %
Skipped meals	27.9 %	7.0 %
Increased smoking	5.9 %	4.2 %
Diet pills	2.9 %	1.4 %
Vomited	2.9 %	- -
Skipped insulin	10.3 %	1.4 %
Used less insulin	7.4 %	1.4 %
Laxatives	3.0%	- -

Neumark-Sztainer et al., Diabetes Care, 2002

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Physical activity among diabetics

	Diabetics (N=138)	Controls (N=269)
Inactive	24.6 %	7.8 %
Moderately active	50.7 %	55.4 %
Active	24.6 %	36.8 %
Sports participation	47.1%	63.2 %

Valerio et al., Nutrition, Metabolism & Cardiovascular Diseases, 2007

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Sport practice among CC adolescents ages 16-20 years

	Females		Males	
	Control	CC	Control	CC
No sport	35.6%	29.7 %	31.3 %	19.2 %
Once a week	26.0 %	29.3 %	19.0 %	20.0 %
2-3 times/wk	28.8 %	30.9 %	35.0 %	40.8 %
Daily or almost	9.7 %	10.1 %	14.8 %	20.1 %

Pittet et al., Arch Pediatr Adolesc Med, 2009

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WHY?

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During adolescence,

the main objective is to be

NORMAL

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

Chronically ill adolescents DO.

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Wanting to be *normal*

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

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Statement # 15

Adolescents suffering from a chronic condition receive more guidance/prevention from health professionals than their healthy peers because they see them more often

FALSE

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Statement # 23

Health providers dealing with adolescents suffering from a chronic condition openly discuss any issue their patients have

FALSE

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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…

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

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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)

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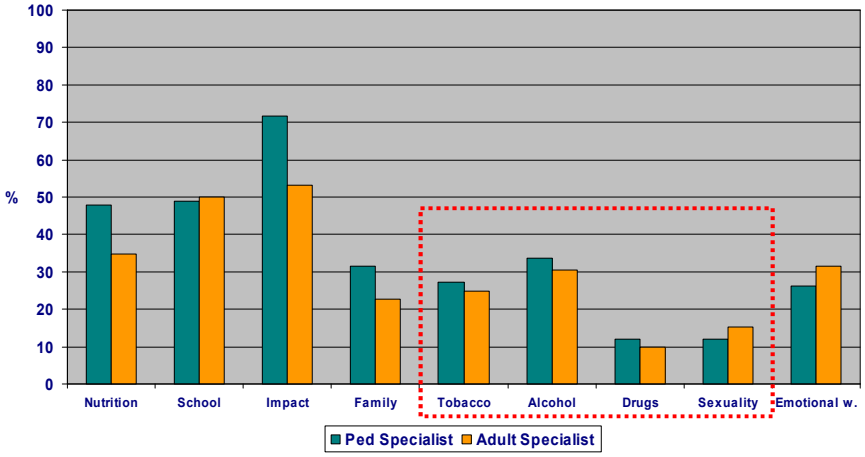
Percentage reporting physician counseling in past year

	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

Issues discussed. Chronically ill adolescents, Switzerland 2007



Suris & Rutishauser, preliminary results

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%**

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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 disfunctioning are disease-based.

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Statement # 24

Due to their condition, adolescents suffering from a chronic condition should be treated differently than their healthy peers

FALSE!!

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Having a chronic condition
does not mean
that they are not adolescents
and that they will not behave as such

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Health care

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

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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**

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Features of the encounter
(Beresford & Sloper, 2003)

- **Familiarity**
- **Duration**
- **Privacy**

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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.

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Adherence

(remember that few human beings are able to achieve one hundred percent therapeutic compliance)

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Compliance or adherence?

- Compliance: extent to which patients are obedient and follow the instructions, proscriptions and prescriptions of health-care professionals
- Adherence: active, voluntary, collaborative involvement of the patient in a mutually acceptable course of behavior to produce a desired preventive or therapeutic result

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Statement # 18

Adolescents suffering from certain diseases (such as HIV) are very compliant/adherent with the prescribed medication

FALSE

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Forms of non-adherence

- Receiving a prescription but not filling it
- Taking an incorrect dose
- Taking medication at the wrong times
- Increasing or decreasing the frequency of doses
- Stopping the treatment too soon
- Delaying in seeking healthcare
- Non-participation in clinic visits
- Failure to follow doctor's instructions
- "Drug holidays"
- "White-coat compliance"

(Jin et al., Therapeutics and Clinical Risk Management 2008)

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Adherence rates

	Diabetes	Asthma	HIV	Global
Adherence :				
Complete	19%	42%	27%	23%
Satisfactory	75%	42%	60%	60%
Poor	6%	16%	13%	17%

Kyngas, J Pediatr Nurs, 2000
Kyngas, Seizure, 2000
Kyngas et al., J Adolesc Health 2000

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Predictors of good adherence

- Support from physician (attitude)
- Support from parents (attitude)
- Motivation
- Not a threat to their social wellbeing
- Threat to their physical/mental wellbeing
- Strong sense of normality
- Experience of results
- Energy and willpower to take care of themselves
- Good communication

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Predictors of adherence failure

- Non adherence to the plan
- Side effects
- Stressful life
- Multiple, conflicting priorities
- Difficulty in forming new routines
- Concerns about the effectiveness of medication/treatment

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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**

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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**

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Transition

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Transfer or Transition?

- **Transfer**: sudden, arbitrary event where the patient is transferred from paediatric to adult services with referral information only.
- **Transition**: purposeful, planned movement of a young person from child-centred to adult-orientated health care systems, whose main goal is to optimize health and to facilitate each young person's attaining his or her maximum potential. It includes the transition from childhood to adulthood, from school to employment, from dependence to independence.

Sawyer et al., J of Paediatrics & Child Health, 1997
McGill M, Hormone Research, 2002
Rosen et al., J Adolescent Health, 2003

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Statement # 19

Adolescents suffering from a chronic condition have a smooth transition from paediatric to adult care <u>when both clinics are in the same hospital</u>

FALSE

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Failure to acknowledge and plan for transition to adult health care may result in patients being “lost in transition”

Kennedy et al., Internal Med J, 2007

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Only 47% of patients with congenital heart disease has transferred successfully to adult care.

More than one quarter (27%) of adult patients with congenital heart disease reported having had no cardiac appointments since age 18 years.

Reid et al., Pediatrics, 2004

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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