

## **Module B5: The adolescent with a chronic condition**

### Entry Scenario

*The entry scenario addresses a variety of issues and problems associated with the module topic. It may be used at the beginning of the course to stimulate the students to identify their own needs and interests. The results may be utilized by the individual to assess own learning process, or be integrated with class objectives.*

A 14 year-old boy who was diagnosed at age 8 with diabetes is brought to consultation by his parents. Both parents, especially the mother, are worried because the boy has been acting out for the past six months, and not following his treatment regime. Two weeks ago, he was admitted to the emergency room for keto-acidosis, the second such event in the six months period. The responsible endocrinologist has announced that the boy must either adhere to the prescribed therapy or search for another doctor.

### General Goals for Learners

***By completing the module the participant will be able to:***

- I. Demonstrate an understanding of the adolescent's experiencing of chronic condition
- II. Recognize the interrelated impacts of chronic conditions and adolescent bio-psychosocial development
- III. Understand quality of life and ethical issues affecting a patient with a chronic disease
- IV. Demonstrate proficiency in developing and implementing a management plan with an adolescent affected by a chronic condition, with the parents, and with the professional network. Communicate effectively with all persons involved.

**Goal I. Demonstrate an understanding of the adolescent experience of chronic condition**

	<b>Training Objectives</b> Key topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>K N O W L E D G E</b>	<p><b>A. Identify the 5 most prevalent chronic conditions in one's clinical work and compare this information with national data</b></p> <p><b>B. Know the definitions used by WHO for chronic diseases</b></p> <p><b>C. Consider alternative approaches to defining the concept of chronic condition</b></p> <p><b>D. Identify characteristics of chronic conditions and describe how they have an impact on the adolescent's life</b></p> <ul style="list-style-type: none"> <li>- Prognosis &amp; course</li> <li>- Intensity of care</li> <li>- Visibility</li> <li>- Acceptability &amp; cultural value</li> <li>- Functional impairment</li> </ul>	<p>Reading</p> <p>Class discussion</p> <p>Interactive lecture Small groups discussion followed by plenary</p>	<p>If participants do not have access to national or local data, have them list the most prevalent chronic conditions for the adolescents they see in their professions.</p> <p>Discuss the non-categorical approach as described by Perrin and Stein &amp; Jessop.</p> <p>Groups reflect on what might be the similar needs of a 15 year-old diabetic girl, a 15 year-old boy with mild hemiparesis, and a 13 year-old girl with a cystic fibrosis. Determine the impact on the adolescent of therapeutic regimens, of the functional limitations, of the visibility of the condition, of the predictability of the disease course and its prognosis.</p>

	<b>Training Objectives</b> Key topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<b>S K I L S</b>	<b>E. Elicit the feelings and experiences of an adolescent with a chronic condition</b>	Patient volunteer or role play	Using the example adolescents in the case studies above, explore the meaning given to the condition by the adolescent and by his/her environment, as a basis for delivering patient-centred care. Utilize “trigger questions” in annex 1.

**Goal II.**

**Recognize the interrelated impacts of chronic conditions and adolescent bio-psychosocial development**

<p><b>Training Objectives</b> Topics to be covered</p>	<p><b>Educational Methodology</b></p>	<p><b>Activities, Issues, and Questions</b></p>
<p><b>A. Identify the impact of chronic conditions and its treatment on the fulfilment of the bio-psychosocial and development tasks including</b></p> <ul style="list-style-type: none"> <li>- Biological: growth &amp; puberty</li> <li>- Psychological: identity formation, and development of sexuality, body image, and abstract thinking</li> <li>- Social: autonomy development, family &amp; peer relationships, educational achievements</li> </ul>	<p>Readings</p> <p>Mini lecture followed by small group work</p> <p>Role play I (f time permits)</p>	<p>For objectives A and B: groups use the worksheet in annex 2 to formulate the developmental grid for each of the following examples. Discuss, or role play, the trigger questions in annex 1.</p> <p><u>Example 1:</u> Compare a girl with spina bifida experiencing precocious puberty at age 9, and a girl with CF with delayed puberty at age 15. Consider the different developmental tasks of adolescence and describe how the condition might affect these developmental trajectories.</p> <p><u>Example 2:</u> Compare three boys seen in a diabetes clinic for a yearly check-up. One is in early adolescence, one is in middle adolescence, and one is in late adolescence. Work through issues of adherence, the role of the parent in treatment, and autonomy (see annex 2).</p> <p><u>Example 3:</u> A 15-year-old boy, Tanner G2 P3, diagnosed with diabetes at age 4 is admitted to an emergency room with keto-acidosis; his mother complains that he binges on sugar every time he participates in social events.</p>

<p><b>Training Objectives</b> Topics to be covered</p>	<p><b>Educational Methodology</b></p>	<p><b>Activities, Issues, and Questions</b></p>
<p><b>B. Identify the impact of developmental changes on the course and management of chronic illness, including:</b></p> <ul style="list-style-type: none"> <li>- Treatment regimen &amp; adherence</li> <li>- Non-compliance, and its determinants</li> <li>- Changing role of parents</li> <li>-Transition to appropriate autonomy in treatment and adult health care</li> </ul>	<p>Group (or small groups) discussion</p>	<p>Develop more examples that illustrate the interrelated impacts of chronic conditions and adolescent development. Describe situations that interfere with usual life (family, school, professional, etc.) Describe factors that can influence (both positively and negatively) treatment adherence or compliance.</p>



**Goal III. Understand quality of life (QOL) and ethical issues affecting a patient with a chronic disease**

	<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
	<p><b>A. Consider aspects of outcome other than disease prognosis</b></p> <p>- Quality of life such as client satisfaction, vocational/ educational possibilities, financial, and emotional independence</p> <p>Handicap/impairment/disability as a social construct</p>	<p>Mini lecture and Class discussion</p>	<p>Present summary of literature if participants have not read reference articles. Trainer presents examples from own materials that exemplify the experiences of an adolescent with a chronic disease.</p> <p>Class discuss how to assess QOL, what are the “ingredients” of QOL, and what is the health provider’s role in improving QOL for an adolescent with a chronic condition.</p> <p>Discuss the consequences of the disabling process itself and the lack of opportunity associated with being disabled.</p> <p>Use trigger questions in annex 1 to elicit information about the adolescent’s quality of life and future.</p> <p>Discuss how health professionals are socialized around illness management and how this might affect their work with patients, parents and teams.</p> <p>Discuss the influence of culture on how chronic conditions are perceived.</p>



<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<p><b>B. Identify outcomes important to patient, family, and the health professional</b></p> <p><b>C. Incorporate ethical considerations into the decision-making process</b></p> <ul style="list-style-type: none"> <li>- Consent and confidentiality</li> <li>- Genetic screening</li> <li>- End of life decisions</li> </ul>	<p>Patient volunteer, role play, or patient encounter at local hospital or clinic</p>	<p>Elucidate the adolescent's perception of his physical health, psychological state, level of independence, social relationships and personal beliefs in relation to his goals, expectations, values, standards, and concerns. What issues should be included in discussion with the family? Whose perceptions of outcomes are most important? How can the quality of life be measured?</p>



**Goal IV. Demonstrate proficiency in developing and implementing a management plan with an adolescent affected by a chronic condition, with the parents, and with the professional network. Communicate effectively with all persons involved.**

Training Objectives Topics to be covered	Educational Methodology	Activities, Issues, and Questions
<p><b>A. Develop and negotiate a management plan with the adolescent and his/her parents</b>            - Needs and priorities assessment, including the perspective and concerns of all parties            - Prerequisites of optimal medical care            - Traditional, complementary and alternative care (CAM) options            - Information and assistance, including community, school, and self-help</p> <p><b>B. Tailor guidance and primary care to the particular circumstances of chronic conditions</b>            - Standard health promotion            - Disease-specific anticipatory guidance, including issues of sexuality</p>	<p>Group work and role play</p> <p>Case study role play            Medical consultation/patient encounter at local facility</p>	<p>Negotiate a plan for a 17 year-old male with cystic fibrosis who is a smoker and does not want to do his physiotherapy because it takes too long and he prefers being with his friends.            Determine the adolescent's understanding of his situation, his needs, wants and capabilities, using a developmental perspective. Determine parents' perspective and concerns. Reach agreement in balancing medical care with the above perspectives and possibilities.</p> <p><u>Case 1:</u> An 18 year-old girl with epilepsy wants contraception, but is afraid of the side effects of most of the contraceptive methods, about which she has heard from friends, on television, and on the internet.  <u>Case 2:</u> A 13 year-old boy with asthma who is leaving for a scout camp does not want to take all his medication with him. The mother accompanied him to the clinic, and appears upset about letting her child go to the camp.  <u>Case 3:</u> A 16 year-old boy with severe asthma reports improvement in his condition when he inhales cannabis. He also admits to smoking half a pack of cigarettes par day.</p> <p>Role-play an intake interview for the above cases. What agenda should the health provider have? Refer to trigger questions in annex 1.</p>





<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<p><b>C. Manage complex situations requiring the intervention of many professionals</b></p> <ul style="list-style-type: none"> <li>- Elements of team leadership</li> <li>- Identification of case requirements</li> </ul> <p><b>D. Effectively communicate with the adolescent patient and parents during perceived or actual life threatening situations, and when communicating bad news.</b></p>	<p>Role play group discussion</p> <p>Role play</p>	<p><u>Case 1:</u> A 15 year-old CF patient with decreasing lung function and the onset of diabetes is about to be expelled from school because of excessive absenteeism. Create a role-play, which includes the professional's first encounter with the teenager and parent, a discussion with the school principal who is uncooperative, and a meeting with different medical specialists to negotiate and implement a treatment plan.</p> <p><u>Case 2:</u> 16 year-old girl with well-controlled epilepsy under treatment with valproic acid and carbamazepine, is 8 weeks pregnant. Organize a case conference with all the specialists that should be involved. Decide who should be the case manager, which options can be offered, and who should talk to the girl.</p> <p>How would one communicate a new diagnosis of diabetes mellitus to a 12 year-old boy, or tell a 17 year-old girl with cystic fibrosis that tests indicate declining lung function? How would one tell a 15 year-old with Down syndrome that he has leukaemia?</p>



<b>Training Objectives</b> Topics to be covered	<b>Educational Methodology</b>	<b>Activities, Issues, and Questions</b>
<p><b>E. Identify the essential elements of a planned, coordinated transition from child-centred care to adult health care setting</b></p> <ul style="list-style-type: none"> <li>- Key people involved in transition</li> <li>- Transfer of contents</li> <li>- Facilitating factors and barriers</li> </ul>	<p>Readings</p> <p>Local patient encounter, medical consultation case study</p>	<p>Articles from Blum, Viner, Bowes</p> <p><u>Case study:</u> An 18 year old boy with cystic fibrosis has been transferred to adult care but has not attended the clinics for 6 months. He continues to visit the emergency ward for antibiotics and inhalants.</p>
<p><b>F. Identify personal attitudes that may interfere with a health provider’s decision-making regarding a patient with a chronic condition</b></p>		<p>Discuss the feelings and reactions a health provider might experience during the process of transitioning a patient, using negative as well as positive examples of patient-doctor relationships. Consider one’s own attitudes regarding the competency of physicians who provide care to adults.</p>



## References

**Blum R, Britto M, Sawyer SM, Siegel DM. Transitions to adult health care for adolescents and young adults with chronic conditions. Position paper of the Society for Adolescent Medicine. J Adolesc Health 2003; 33:309-11.**

[http://www.adolescenthealth.org/SAHM\\_Main/media/Advocacy/Positions/2003-Transition\\_from\\_Child-Centered\\_to\\_Adult\\_Health-Care\\_Systems\\_for\\_Adolescents\\_with\\_Chronic\\_Conditions.pdf](http://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/2003-Transition_from_Child-Centered_to_Adult_Health-Care_Systems_for_Adolescents_with_Chronic_Conditions.pdf)

**American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home**

<http://pediatrics.aappublications.org/content/128/1/182.full.pdf+html>

**Canadian Paediatric Society (CPS): Care of Adolescents with Chronic Illness**

<http://www.cps.ca/en/documents/position/transition-youth-special-needs>

**The Adolescent with a Chronic Condition**

[http://www.who.int/child\\_adolescent\\_health/documents/9789241595704/en/index.html](http://www.who.int/child_adolescent_health/documents/9789241595704/en/index.html)

**Chronic Illness in Adolescents**

[http://www.mja.com.au/public/issues/179\\_05\\_010903/saw10713\\_fm.html](http://www.mja.com.au/public/issues/179_05_010903/saw10713_fm.html)

**BMJ Series: The Adolescent with a Chronic Condition**

[http://adc.bmj.com/content/89/10/938.Web\\_pages](http://adc.bmj.com/content/89/10/938.Web_pages)

**ABC of adolescence. Yeo M, Sawyer S. Chronic Illness and disability. BMJ330: 721-723 (2005)**

[http://web.squ.edu.om/med-Lib/med/net/E-TALC9/html/clients/bma/bmj/2005/26\\_3/721.pdf](http://web.squ.edu.om/med-Lib/med/net/E-TALC9/html/clients/bma/bmj/2005/26_3/721.pdf)

**Liv Fegran et al. Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: A qualitative metasynthesis**

<http://download.journals.elsevierhealth.com/pdfs/journals/0020-7489/PIIS0020748913000382.pdf>



**Tasks for teachers:**

- Identify national data on chronic conditions in adolescence
- Identify adolescent stories (books, diaries, videos, personal testimony) of chronic illness in national context
- Identify examples community resources for adolescents with a chronic condition

**Annex 1: Trigger questions**

The following trigger questions are given as examples of how to appropriately elicit important information from the adolescent.

**Goal I, Objective E:**

Can you explain your condition in your own words?

Do you know other people who have the same condition?

Who knows that you suffer from this illness?

What do other people think of you having this illness (peers, teachers, neighbours etc.)?

Why do you think that you have this condition?

What does this illness hinder you from doing (be very specific!) now, and later in your life?

How much time does the management of the disease take you and your parents? (Consider everyday tasks, routine medical care and unforeseen examinations. Possibly use a diary approach).

**Goal II, Objective A:** (Note: questions from HEEADSSS also apply, and will give an interesting profile of psychosocial development.)

How do you like your body? What would you like to be different?

Have your menses started already?

Who does what in your treatment (diary approach)? What is your role, what is the one of your parents?

How do you approach your prescriptions and care routines?

Do you know why you should do certain care routines?

How does the health care schedule fit into your daily life?

Estimate which percentage of the prescribed treatment you did in the last 2 weeks?



**Goal III, Objective A**

What do you enjoy in life?

Tell me about your friends. How many friends do you have? What is the age and gender of your friends?

What do you do with your friends outside of school?

What can you do on your own? What would you like to do on your own?

Tell me about your future plans. Can you be specific about how you plan to achieve them?

What would help you to make your life more enjoyable?

**Goal IV, Objective B**

Tell me why you need treatment?

What information have you found on your disease in books, the Internet, on the TV, and from experts?

Question to parents: what are you afraid of happening if you give the responsibility of the care to your adolescent?

## Annex 2

A developmental grid for the assessment of adolescent with chronic conditions

<b>Development</b>	<b>Early Adolescence</b>	<b>Mid Adolescence</b>	<b>Late Adolescence</b>
<b>Biological</b>	<b>pubertal development</b>	<b>increase in pilosity breaking</b>	<b>increase in muscle &amp; bone mass, modific. of body shape</b>
<b>Cognitive &amp; Emotional</b>	<b>concrete thinking focus on body changes need for intimacy</b>	<b>abstract thinking lack of control sexual experiences Conflicts with parents</b>	<b>abstract thinking perspectives on one's future consolidation of sexual orientation</b>
<b>Social</b>	<b>separating from the parents staying with friends of same sex</b>	<b>peer activities going out fist sexual experiences</b>	<b>Acceptance of parents' support Intimate relationships Capacity for compromise</b>