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Checklist for follow-up of adolescents with chronic illness.

A monitoring tool and a help to prepare transition from pediatric to adult care

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Abstract

Adolescence can be a particularly challenging period for individuals with a chronic illness. To help the specialized teams, an expert panel drafted a checklist of topics to be addressed throughout adolescence that are often not covered in subspecialty clinic visits such as peers, coping, adherence, understanding of illness, sexuality... as they apply to youth with special health care needs. Every member of the specialized team can discuss one of the themes according to their place with the adolescent, whether they are a doctor, educator, nurse, dietician, etc.... The coherence of the team enables a comprehensive approach and will facilitate the transition to adult medical care.

Key words: chronic illness, adolescent, transition, health-care, biopsychosocial interview

Introduction

Adolescence is the age of change: change for the young person, both physical and psychological, change for the family, which needs to redefine itself, and change for the doctor, who needs to learn to work in triangulation with the parents and the young person, or even with several others, because peers form an entity in themselves that needs to be taken into account. Much has been written about chronic illness in adolescence, and the interactions between the independence, risky behaviors and projection into the future of adolescence, and the regression, dependency and the inability to project oneself in chronic illness. [1,2]. Chronic illness has implications in all areas of a teenager's life: family, social life, school, development, sexuality...[3]. How can one remain "normal" with a chronic illness? How can an adolescent compare him/herself to his/her peers when he/she has life restrictions, or even a disability? The recognition of the teenager as distinct from his or her chronic illness probably facilitates the important transition process between pediatric care and adult medical care [4].

The medical team following a teenager with a chronic illness therefore needs not only to manage the evolution of the chronic illness, its treatment, and its complications, it also needs to cope with the physical and psychological impact on the teenager. [3,5,6]. The literature on this subject recommends evaluating a number of factors such as growth, pubertal development, social adaptation, the experience of illness, the evolution of the chronic illness, compliance, the young person's knowledge about his or her condition and its treatments....[7-9]. The list is long and consultations do not always enable the scheduled topics to be addressed. Adolescents often have their own questions.

In addition, all scientific societies recommend working on the transition from pediatric departments to adult care. For this purpose, scales have been created and validated to determine

whether the young person is ready to move on [7,10,11]. The process of preparing the adolescent for this transition should begin as early as possible, even as soon as the diagnosis is made according to some. While many articles focus on what a young person needs to know before moving from pediatric departments to adult care, there is very little description of the preparatory steps in the literature. When should we start talking to them, and about what?

Regarding the interview guides, we did not find any that included both general questions and questions specifically related to chronic disease and transition. As transition is also a very important period for disabled adolescents we performed a specific search on that subject but few studies describe the stages of the transition [12].

As a result of these observations, a group of pediatricians, specialized in adolescent medicine has drafted a checklist of topics to be addressed throughout adolescence for a patient with a chronic illness (Table 1). These “Guidelines for Clinical Practices” were written according to the HAS (Haute Autorité de Santé, French National Authority for Health) recommendations :

Method

First a review of the literature was made on the specific needs and characteristics of adolescents followed for chronic illness and the subject of transition. Literature search strategies was developed using medical subject headings (MeSH) and text words. Reviews were completed by CS using the terms: “adolescent”, “chronic illness” “chronic disease”, “Chronic condition », “HEADS”, “Transition to adult care”, “skills”. In order to ensure that all relevant material was identified, we also scanned the reference lists of included articles identified through the search.

Based on the articles found and their experience, the working group drafted a first version of the recommendations in the form of a checklist serving as an interview guide. The working group was composed of CF, PJ, SR, RT, MM, CS.

Finally the checklist was validated by a evaluating group (HL, HS, ASL, MD, ACG) made up also of pediatricians and general practioners specialized in adolescent medicine.

This checklist enables the doctor or nurse to track what has already been discussed and what remains to be raised, to ensure that the important issues to be discussed with any adolescent with a chronic illness have been addressed and that the preparation for transition to adult structures is underway. In this article, we propose this checklist and an explanatory sheet to help the team complete it. The teenage interview is not reviewed, nor are the ways of approaching the various subjects, as they have already been covered in many books or articles. [13,14], but the different items in the HEADSS instrument are detailed in the annex. We stress the importance of the content and the timing in preparing the adolescent for his/her adult life with his/her illness. The number of hospital consultations per year varies according to the patient and the pathology. We considered that they should be seen at least twice a year, but that there were some areas to be raised only once a year (e.g. pubertal stage, living conditions at home) and others twice a year (e.g. screen time and sleep). Patients are also seen, depending on their needs, by the general practitioner, the education nurse or other professional involved in their care. The frequency of visits depends on the teenager and his needs but also on the medical teams. The distribution of tasks depends on the composition of the teams. The boxes were designed accordingly: the un-shaded boxes represent the subjects to be addressed, the shaded boxes those that can be carried over. This is of course very schematic but is intended as a guide so that nothing is forgotten.

The aim is for the items to be addressed by any of the members of the team following the adolescent. Everyone can discuss one of the themes according to their place with the adolescent,

whether they are a doctor, educator, nurse, dietician, etc.... The coherence of the team enables a comprehensive approach and will facilitate the transition to adult medical care.

Explanatory note

The first section of 13 items is part of the usual interview with an adolescent for any reason (see HEADSS) but with a focus on living with chronic illness. The next section of 10 items specifically concerns chronic illness, the last lines concern specific clinical examinations.

A few clarifications:

HEADSS items:

Family life: living conditions at home, relationship with parents, siblings, parental separation, recomposed family

Schooling, professional activity: level, skills, projects, limitations due to illness, prohibited occupations

Activities, sport: fun, general leisure-time activities, restrictions on activities. Sport: energy-intensive activities, whether supervised or not, excessive sport, restrictions on sports

Screen time: Outside school usage, and type of screen activity (games, videos, social networks...)

Diet/ED: Assessment, regardless of the pathology, of the adequacy of the diet, screening for an eating disorder.

Sleep: Bedtime and waking hours during the week and at weekends. Insomnia, nightmares, ruminations.

Friends: Evaluation of socialization in general.

Sexuality, affective life: Including the ability to love and to be loved, sexual orientation, gender dysphoria. Risk of infertility. Risk of transmission to children. Problems that can appear during sexual intercourse because of the illness (hypoglycemia for diabetics, loss of stools for MICI....)

Gynecology, contraception, pregnancy: menstruation (regularity, abundance, dysmenorrhea), adapting contraception, particularities of pregnancy with a medical condition etc ...

Harassment, intimidation, cyberbullying, violence: frequent among chronically ill children, harassment is rarely discussed in follow-up consultations. It should be considered when there is a radical change in behaviour or in the management of the illness.

Substance use, risk-taking: including the effect of substances on the illness.

Mood: including suicidal ideation, self-mutilation

Chronic illness items

Peers: ask about the way he (she) talks about his (her) illness, whether or not peers know about his (her) illness. Visibility of the disease. Feelings of difference.

Transition: to be discussed at the beginning of secondary school and then to be prepared according to the protocols of each team. [10].

Parents and illness: relationships with them, especially concerning the illness, sharing of tasks in the daily management of the illness, conflicts.

Clinical examination

Immunization checklist: to be administered once in early adolescence to make sure they have not forgotten a vaccine (they are usually up to date by age 13).

Puberty: pubertal stage until the end of puberty. Scrotal content, phimosis at 12 years if not examined before. Gynecomastia, acne, hirsutism.

Conclusion

Adequate management of chronic illness in adolescence requires the development of the young person as a whole to be monitored. It takes a lot of time, and consultations do not always afford this time. Our aim is to help the teams to organize follow-up without omitting important themes. This grid makes it possible to orient adolescents as early as possible according to what is screened: therapeutic education workshops, psychological consultation, family interviews, intensification of social support, support the adolescents on the transition etc ... Additional studies will be conducted to determine whether the use of this checklist enables improvement of the comprehensive care of adolescents with chronic conditions.

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Annex 1: Detailed items of the HEADSS instrument: psychosocial interview for

Adolescents as first described by Goldering and Rosen [14].

H: Home

E: Education and employment

E: Eating

A: Activities

D: Drugs

S: Sexuality

S: Suicide and depression

S: Safety

List of tables

Table 1: Checklist for follow-up of adolescents with chronic illness

Checklist for follow up of adolescent with chronic illness												
	12 years old		13 years old		14 years old		15 years old		16 years old		17 years old	
	0	6 months	0	6 months	0	6 months	0	6 months	0	6 months	0	6 months
Teenager seen alone												
HEADSS items												
Living conditions at home (bedroom, people present, conflicts...)												
Schooling, professional activity												
Activities, sport												
Screen time												
Diet / Eating disorder												
Sleep												
Friends												
Sexuality, affective life												
Gynecology, contraception, pregnancy												
Harassment, violence												
Self-image												
Substance use, risk-taking												
Mood												
Body image												
Chronic illness												
Reiteration of the diagnosis			once before 15 years									
Re-explanation of treatments and their side effects												
Talking about the expected course of the disease							to be renewed if necessary					
Compliance												
Peers: knowing how to talk about the illness												
Parents and illness												
Transition												
Complete "good to go" with the adolescent									1 year before transition			
Consider sessions for therapeutic education												
Specific Social Rights												
Clinical Examination												
Vaccinations												
Growth Curve Analysis/BMI												
Pubertal stage up to stage 5												
Dental condition, hearing, eyesight												
Scoliosis (up to Tanner stage 5)												