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Chronic illness, life style and emotional health in adolescence: results of a cross-sectional survey on the health of 15-20-year-olds in Switzerland

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Abstract The objective was to evaluate the prevalence of chronic conditions (CC) in adolescents in Switzerland; to describe their behaviour (leisure, sexuality, risk taking behaviour) and to compare them to those in adolescents who do not have CC in order to evaluate the impact of those conditions on their well-being. The data were obtained from the Swiss Multicentre Adolescent Survey on Health, targeting a sample of 9268 in-school adolescents aged 15 to 20 years, who answered a self-administered questionnaire. Some 11.4% of girls and 9.6% of boys declared themselves carriers of a CC. Of girls suffering from a CC, 25% (versus 13% of non carriers; $P=0.007$) and 38% of boys (versus 25%; $P=0.002$) proclaimed not to wear a seatbelt whilst driving. Of CC girls, 6.3% (versus 2.7%; $P=0.000$) reported within the last 12 months to have driven whilst drunk. Of the girls, 43% (versus 36%; $P=0.004$) and 47% (versus 39%; $P=0.001$) were cigarette smokers. Over 32% of boys (versus 27%; $P=0.02$) reported having ever used cannabis and 17% of girls (versus 13%; $P=0.013$) and 43% of boys (versus 36%; $P=0.002$) admitted drinking alcohol. The burden of their illness had important psychological consequences: 7.7% of girls (versus 3.4%; $P=0.000$) and 4.9% of boys (versus 2.0%; $P=0.000$) had attempted suicide during the previous 12 months. **Conclusion:** Experimental behaviours are not rarer in adolescents with a chronic condition and might be explained by a need to test their limits both in terms of consumption and behaviour. Prevention and specific attention from the health caring team is necessary.

Keywords Adolescence · Chronic condition · Risk-taking behaviour

Abbreviations CC chronic conditions · CI confidence interval

Introduction

The management of chronic conditions (CCs) represents an important part of paediatric practice in Western countries and takes a particular form in adolescence [18, 36]. The health needs of adolescents with a chronic illness or a handicap are indeed linked to the illness they suffer from, to adolescence in general, and to psychosocial problems generated by the interaction between the illness, the adolescent and his immediate environment [41].

The international literature concerning CCs in adolescence highlights the importance of these pathologies to the practitioners, who rarely see these adolescents [11, 18, 21, 28, 43]. However, the prevalence of CCs in adolescence is not well known and varies considerably from one survey to another: most surveys suggest that around 10% of children and adolescents may be affected by a CC [2, 37]. Considerable variations in the definition of CCs and in the survey methods prevent international comparisons [6, 22, 32, 39, 44].

Several authors have suggested that recent progress made in prenatal and paediatric care has helped to improve survival of patients and therefore is responsible for a higher prevalence of CCs in adolescence [2, 3, 37]. This prevalence is important, as CCs have a high economic and social impact due to invalidity, or need for health care facilities which are sometimes highly specialised. This problem has become a priority on a public health level and needs to be carefully evaluated, particularly in Switzerland where few studies have been published.

Despite the highly specialised care available in Western countries, the facilities have not always been adapted to the adolescent's needs, considering that the

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CC affects the young patient in his global process of development. Adolescents affected by chronic illnesses or handicaps have to deal with the same problems and needs as all other adolescents, in puberty and sexuality development, in school and leisure time, in their relationship with peers, in life styles and risk taking, and in somatic health [41]. The results of some studies have shown that despite the feeling of overprotection and the urge to comply with treatment induced by the illness, adolescents affected by a chronic illness or handicap do not take fewer risks than others. They are as sexually active and are not less exposed than others to the risk of pregnancy or sexually transmitted diseases [2, 4, 7, 30, 42]. Drug and alcohol use or risk taking whilst driving, for example, are as frequent or even more frequent than in others [9, 42]. These young people, because of chronic illnesses or handicaps, might feel the need to assert their conformity by testing the norms [3] and by adopting so called "risk-taking behaviours" [1].

A great number of CCs have consequences on the assessment these adolescents make of their well-being [20, 41]. The difficulties they experience may increase the occurrence of problems such as tiredness, difficulties in socialising, harassment (from others), depression, or suicidal ideations [27, 38, 45].

This article presents the results of a Swiss survey. The objectives were to describe these adolescents, to compare them to adolescents who are not affected by CCs: in their behaviour and lifestyle, and in their well-being (expressed malaise, violence, suicide, need for help).

Subjects and methods

Design of the survey and sample

The data were obtained as part of the Swiss Multicentre Adolescent Survey on Health [19], a detailed description of which is given elsewhere [17]. This national survey was conducted in Switzerland during 1992 and 1993, targeting a representative sample of about 9268 in-school adolescents aged 15 to 20 years. The participants were selected through a one step cluster sampling procedure, stratified by educational background, grade and region. The research protocol was submitted to the Ethics Commission of the Medical Faculty at Lausanne University. A self-administered questionnaire was presented by professionals external to the school in order to ensure optimal confidentiality. It included 80 questions targeting health perception and behaviour, health care utilisation, lifestyles and well-being. The assessment of various health behaviours was limited to the preceding year in order to minimise recall biases.

Definition of the variables (design of the questionnaire)

The participants were asked to answer two questions specifically related to chronic illnesses: (1) "Do you have a physical handicap, that is to say a lesion which affects your body's integrity and limits its functioning in any way?" and (2) "Do you have a chronic illness, that is to say an illness which lasts a long time (at least 6 months) and which may need regular care (e.g. diabetes, scoliosis, etc...)"

For the purpose of the subsequent analysis, positive answers to both questions were grouped, thus joining the different chronic

illnesses and handicaps under a same concept of "Chronic Condition" proposed by Pless and Pinkerton [26] and supported and developed by Ruth Stein [31, 33, 34]. This non-categorised approach allowed us to display the illnesses' consequences, the common needs, and to favour a bio-psycho-social approach, rather than to concentrate on a diagnosis with or without impact on the adolescent's life [34].

Analyses

Using an SPSS-Windows version 10.0 data file, we performed univariate and multivariate analyses to compare the characteristics of the two groups, adolescents with CCs and adolescents without CCs. The χ^2 test with a P value <0.05 was used for detecting differences between the two groups.

Results

Socio-demographic characteristics

The sample was representative of an in-school population of the same age in Switzerland in relation to the different socio-demographic variables [17]. Table 1 shows that adolescents affected by a CC were no different from other adolescents in relation to the socio-demographic variables studied. The matrimonial status alone displayed a higher percentage of divorced parents among boys affected by a CC, although the difference was statistically not significant.

Prevalence

The prevalence of a physical handicap was 4.8% (0.95 confidence interval (CI): 4.2–5.6) among girls and 4.7% (0.95 CI: 4.1–5.3) among boys. The prevalence of a chronic illness was 7.4% (0.95 CI: 6.6–8.2) among girls and 5.8% (0.95 CI: 5.2–6.4) among boys. The prevalence of a CC as defined earlier was slightly higher among girls (11.4%; 0.95 CI: 10.4–12.4) than boys (9.6%; 0.95 CI: 8.8–10.4).

Well-being and need for help

Adolescents suffering from a CC declared themselves as less often in a good mood or well and as more often depressed or desperate (Table 2). Fewer young people with a CC declared themselves satisfied with their personal life (but 75% of them were often satisfied) and they reported making friends less easily than their peers (Table 2). They described themselves as being more worried by their relationship with their friends or parents, and also by the idea of seeing their parents divorced. Moreover, they considered their future less positively than their peers and were less confident of finding a job (Table 2). Fig. 1 shows clearly that more adolescents with a CC, either girls or boys, expressed a need for help, in all the fields explored.

Table 1 Socio-demographic characteristics among adolescents with and without chronic condition in the sample, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition			With chronic condition		Without chronic condition			
	<i>N</i>	%	<i>N</i>	%	<i>P</i>	<i>N</i>	%	<i>N</i>	%	<i>P</i>	
Age											
15–17 years	253	56.6	1874	53.9	0.278	252	50.8	2327	49.9	0.702	4706
18–20 years	194	43.4	1604	46.1		244	49.2	2336	50.1		4378
Formation											
Apprenticeship	222	49.8	1903	54.6	0.56	340	68.4	3369	71.8	0.106	5834
School	224	50.2	1585	45.4		157	31.6	1320	28.2		3286
Nationality											
Swiss, double national	374	84.4	2899	83.7	0.683	402	81.2	3891	83.4	0.226	7566
Foreigner	69	15.6	566	16.3		93	18.8	777	16.6		1505
Zone of residence											
Countryside	237	53.1	1947	56.1	0.234	261	52.6	2638	56.8	0.077	5083
City	209	46.9	1523	43.9		235	47.4	2009	43.2		3976
Matrimonial status of parents											
Together	346	78.5	2828	81.5	0.121	391	79.3	3837	82.4	0.090	7402
Separated, divorced	95	21.5	641	18.5		102	20.7	820	17.6		1658
Father's education											
Compulsory school	74	16.9	671	20.0	0.122	90	19.1	808	17.9	0.532	1643
University, professional schools	365	83.1	2688	80.0		381	80.9	3695	82.1		7129
Father's occupation											
Partial or full time job	403	94.2	3132	93.6	0.657	437	92.8	4207	93.6	0.345	8179
Unemployment, illness, retirement	25	5.8	214	6.4		34	7.2	274	6.1		574

Sexuality

Differences were found only in boys. More boys with a CC reported that they had had a complete sexual relationship. They reported the use of a condom during their latest sexual intercourse more often (Table 3).

Experimental behaviours

Adolescents affected by a CC reported having more experimental behaviours than their peers in relation to seatbelt wearing, or tobacco and alcohol consumption (Table 4). Girls affected by a CC reported to have driven more often under the influence of alcohol, whereas boys affected by a CC reported using cannabis more often than others, during their life as well as during the 30 days preceding the survey. The different variables of experimental behaviours correlated to CCs were included in a logistic regression separately for girls and for boys, confirming that these variables were independently linked to the CC (data not presented).

Violence and suicide

Adolescent girls affected by a CC reported that they were more often victims of sexual aggression (sexual aggression was described as follows: “sexual aggression is when someone in your family, or someone else,

touches you in a place you did not want to be touched, or does something to you sexually which they shouldn't have done”) and physical violence and more often feared being beaten by their parents (Table 5). Boys as well as girls expressed anger through physical violence more often than their peers.

During the 12 months preceding the survey, adolescents affected by a CC reported suicidal tendencies more frequently and attempting suicide more often. They described the same restraint in talking about it to their friends and family as did their peers and more than 50% of them did not disclose it (Table 6).

Discussion

These analyses, as well as the results of other studies [12, 27, 45], do not show a relationship between CCs and socio-demographic characteristics. The prevalence of CCs in Swiss adolescents is 11.4% among girls and 9.6% among boys. These results are comparable to those found in the international literature, although there are limits to such a comparison as mentioned previously [37, 39, 44]. The prevalence is based on the adolescents' perception of their condition by way of a self-administered questionnaire, thus introducing a declaration bias [45].

The method allowed us to question a representative sample of Swiss adolescents aged 15–20 years attending school or in an apprenticeship (represents circa 80% of

Table 2 Well-being among adolescents with and without chronic condition, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition			With chronic condition		Without chronic condition			
	<i>N</i>	%	<i>N</i>	%	<i>P</i>	<i>N</i>	%	<i>N</i>	%	<i>P</i>	
Psychological feeling during the last 12months?											
I feel quite well											
Often	339	77.8	2945	87.0	0.000	402	85.0	4131	91.5	0.000	7817
Rarely	97	22.2	439	13.0		71	15.0	386	8.5		993
I feel depressed											
Often	166	38.1	1058	31.1	0.003	100	21.2	697	15.4	0.001	2021
Rarely	270	61.9	2346	68.9		372	78.8	3829	84.6		6817
During the last 12 months, did you think:											
I am happy with my personal life											
Often	336	76.0	2876	83.5	0.000	379	78.5	4033	87.8	0.000	7624
Rarely	106	24.0	570	16.5		104	21.5	563	12.2		1343
I am making a lot of friends											
Often	292	66.4	2486	72.7	0.005	347	72.3	3456	76.0	0.069	6581
Rarely	148	33.6	933	27.3		133	27.7	1089	24.0		2303
Do you worry about the following concerns at this moment?											
My friends' behaviour toward me											
A lot	128	28.8	596	17.2	0.000	101	20.6	591	12.7	0.000	1416
Not at all, little	317	71.2	2878	82.8		390	79.4	4075	87.3		7660
My parents potential divorce											
A lot	88	22.5	408	13.3	0.000	65	14.7	463	11.1	0.026	1024
Not at all, little	303	77.5	2658	86.7		377	85.3	3692	88.9		7030
What do you think about your future?											
I am sure to find a job											
Agree	272	62.1	2436	71.5	0.000	336	69.6	3428	75.0	0.010	6472
Do not agree	166	37.9	969	28.5		147	30.4	1145	25.0		2427

the 15-20-year-olds). The participation rate of the survey and the response rate to the questions were high, but our survey did not include the dropouts and those young people working without any training, thus introducing a selection bias. The adolescents with CCs who were unable to follow a normal school, such as those mentally handicapped and severely physically as well as sensory handicapped, were not included. Studies conducted in France and in Switzerland have suggested that it may be more difficult to follow a traditional training pathway when affected by a severe condition [7, 8]. The Swiss survey reported a higher prevalence of CCs among dropouts: 21% (versus 11%) among girls ($P < 0.005$), and 15% (versus 8%) among boys ($P < 0.005$) [8]. The prevalence results are thus underestimated if the general population is considered.

Three main results emerge from this investigation: the magnitude of risk-taking behaviour among the adolescents affected by a CC; the extent of expressed needs, either directly (need for help) or indirectly (problems in social life and mental health); and the great number of victims of violence among the young people affected by a CC.

The high frequency of risk-taking behaviour by adolescents affected by CCs may seem surprising. Some conditions, such as diabetes for example, have been described as having a protective effect on health related behaviour [9, 10, 13]. But most studies have observed a higher frequency of behaviours such as alcohol

consumption, driving under the influence of alcohol (among girls), cannabis and tobacco consumption, among adolescents affected by a CC [5, 6, 29, 38, 42]. This active sensation seeking is a part of the personality development and independence inherent to adolescence and may include non-adherence to treatment and lack of compliance with medication. In a more pathological context, associations have been made between sensation-seeking or challenges made to death and depressed moods, anxiety disorders, conflicts with parents, or difficulties in coping with various life events [15].

These assumptions support the use of the concept "experimental behaviours" rather than the use of "risk-taking behaviours", the latter term reflecting the underlying negative aspect of an adult judgement on adolescents [16, 42]. There are also positive aspects to risk-taking: it can express a wish of independence and freedom, a search to test one's limits and to obtain a better knowledge of oneself. This view is particularly important for adolescents affected by a CC, as they have to develop specific adaptative strategies [23, 24].

Sexuality is an important sign of autonomy and maturity acquired during adolescence. Stevens et al. [35] cites a number of studies in which adolescents affected by a CC seemed to have a lower rate of sexual activity than others. They suggested that it is due to a delay in gaining overall social maturity as demonstrated by other studies [14] and to a reserve of their parents to discuss sexuality or puberty with them [35]. On the contrary, it

Fig. 1 Need for help expressed in various issues among adolescents with and without CC by gender

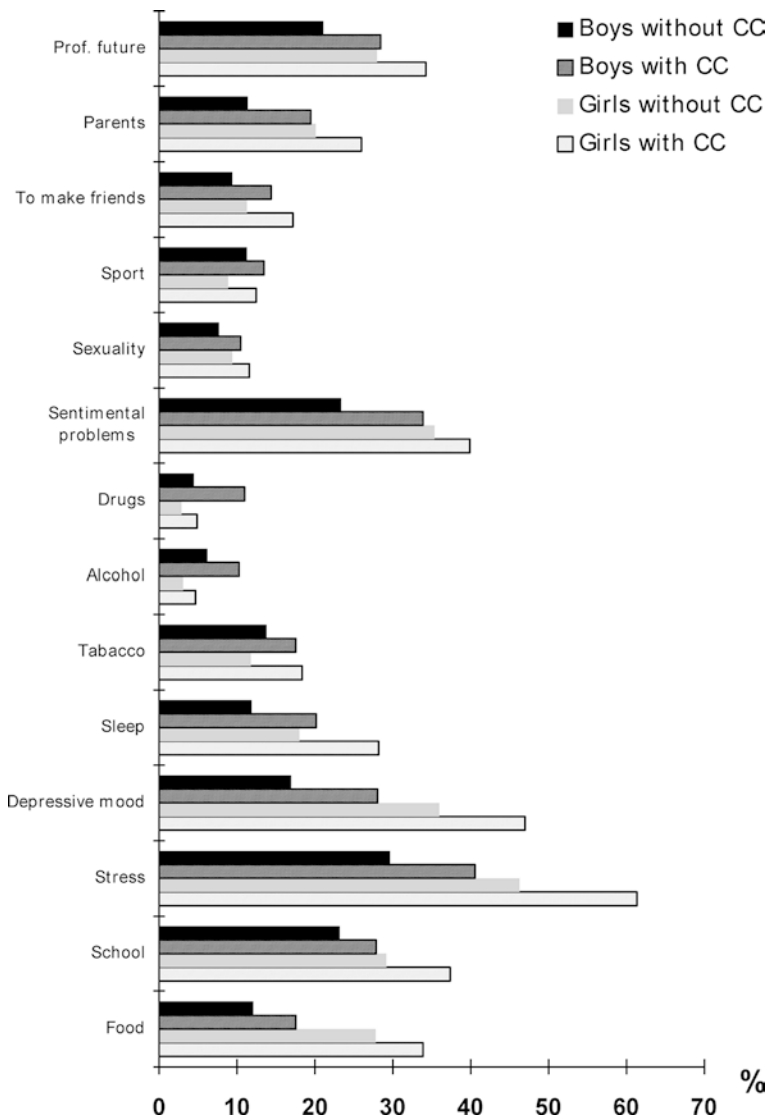


Table 3 Sexual behaviour among adolescents with and without chronic condition, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition			With chronic condition		Without chronic condition			
	<i>N</i>	%	<i>N</i>	%	<i>P</i>	<i>N</i>	%	<i>N</i>	%	<i>P</i>	
Has a boy/girl friend?											
Yes	219	49.5	1593	46.1	0.172	173	34.9	1606	34.6	0.868	3591
No	223	50.5	1862	53.9		322	65.1	3039	65.4		5446
Ever had sexual intercourse?											
Yes	215	49.2	1525	45.2	0.112	261	54.0	1986	44.1	0.000	3987
No	222	50.8	1851	54.8		222	46.0	2518	55.9		4813
Contraception use at first intercourse?											
Yes	165	78.2	1197	80.3	0.479	196	76.0	1529	79.4	0.200	3087
No	46	21.8	294	19.7		62	24.0	396	20.6		798
Condom use at last sexual intercourse											
Yes	85	40.3	598	39.9	0.919	173	68.7	1188	61.4	0.026	2044
No	126	59.7	900	60.1		79	31.3	746	38.6		1851

Table 4 Experimental behaviour among adolescents with and without chronic condition, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition		<i>P</i>	With chronic condition		Without chronic condition		<i>P</i>	
	<i>N</i>	%	<i>N</i>	%		<i>N</i>	%	<i>N</i>	%		
Wearing seatbelt when you drive											
Never, sometimes	17	25.4	77	13.1	0.007	50	37.9	336	25.6	0.002	480
Always	50	74.6	511	86.9		82	62.1	976	74.4		1619
Driving when drinking during the last 12 months											
Never, 1–2 times	405	93.8	3283	97.3	0.000	394	81.6	3843	84.1	0.153	7925
Often	27	6.3	90	2.7		89	18.4	727	15.9		933
Tobacco use											
Yes (regular. or not)	190	42.6	1239	35.6	0.004	232	47.2	1825	39.1	0.001	3486
No (never, stopped)	256	57.4	2240	64.4		260	52.8	2838	60.9		5594
Alcohol use											
A lot	77	17.3	452	13.0	0.013	215	43.5	1695	36.3	0.002	2439
No, few	369	82.7	3027	87.0		279	56.5	2973	63.7		6648
Marijuana use											
3 times or more	79	17.8	550	15.8	0.281	162	32.7	1291	27.7	0.020	2082
No, 1–2 times	365	82.2	2931	84.2		334	67.3	3366	72.3		6996
Marijuana during the last 30 days											
Yes	13	3.5	62	2.1	0.096	32	7.7	168	4.1	0.001	275
No	358	96.5	2847	97.9		385	92.3	3892	95.9		7482

Table 5 Violence among adolescents with and without chronic condition, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition		<i>P</i>	With chronic condition		Without chronic condition		<i>P</i>	
	<i>N</i>	%	<i>N</i>	%		<i>N</i>	%	<i>N</i>	%		
Victim of sexual aggression											
Yes	104	23.7	610	17.9	0.003	23	4.9	174	3.9	0.281	911
No	334	76.3	2796	82.1		449	95.1	4338	96.1		7917
Victim of physical violence during the last 12 months											
Sometimes, often	13	2.9	39	1.1	0.002	17	3.5	104	2.3	0.087	173
No, once	430	97.1	3407	98.9		468	96.5	4497	97.7		8802
Worry about being physically abused by parents											
Yes	38	8.6	205	6.0	0.032	17	3.5	123	2.7	0.291	383
No	402	91.4	3212	94.0		467	96.5	4457	97.3		8538
Worry about being physically abused at school											
Yes	21	4.7	113	3.3	0.111	13	2.7	82	1.8	0.163	229
No	423	95.3	3345	96.7		474	97.3	4544	98.2		8786
When you're angry, do you:											
Hit/break something											
Often	25	5.8	104	3.1	0.003	67	14.1	396	8.8	0.000	592
Never, sometimes	403	94.2	3261	96.9		408	85.9	4123	91.2		8195

has been observed in the present survey that boys affected by a CC had a higher rate of sexual activity and seemed to protect themselves more often than others. Other studies have noted the same tendencies and also a higher prevalence of pregnancies and sexually transmitted diseases among this group, suggesting that in spite of frequent contact with health care professionals, their knowledge and skills about contraception and sexuality are deficient [2, 4, 7, 30, 42].

Experimental behaviours are also influenced by the adolescent's environment but no model has so far been established to report the complexity of this issue [42]. An American survey [5] has underlined the importance of protective factors (familial connectedness, religious values, school network, parental presence) to prevent negative outcomes of experimental behaviours. Other studies have suggested that the higher anxiety levels and the negative body image linked to the chronic illness are

Table 6 Suicidal tendency and behaviour among adolescents with and without chronic condition, by gender

Variables	Girls					Boys					Total <i>N</i>
	With chronic condition		Without chronic condition			With chronic condition		Without chronic condition			
	<i>N</i>	%	<i>N</i>	%	<i>P</i>	<i>N</i>	%	<i>N</i>	%	<i>P</i>	
During the last 12 months:											
Had times when wanted to kill themselves											
Yes	132	29.7	723	20.8	0.000	109	22.0	590	12.6	0.000	1554
No	313	70.3	2748	79.2		386	78.0	4077	87.4		7524
Would have killed themselves if given a chance											
Yes	39	8.8	173	5.0	0.001	32	6.5	180	3.9	0.005	424
No	402	91.2	3289	95.0		459	93.5	4466	96.1		8616
Attempted suicide											
Yes	34	7.7	119	3.4	0.000	24	4.9	94	2.0	0.000	271
No	410	92.3	3354	96.6		469	95.1	4572	98.0		8805
If "yes": disclosed attempt to relatives or friends											
Yes	14	42.4	46	43.4	0.922	8	40.0	38	44.2	0.734	106
No	19	57.6	60	56.6		12	60.0	48	55.8		139

responsible for bad perceived well-being, for lower perceived popularity and for lower self-esteem [38, 45]. These perceptions being more highly correlated to intra-familial cohesion than to the CC per se, the authors have proposed that a poor supportive network (family, peer group and friends) plays a role in the adolescent's perception of well-being and in health-compromising behaviour [45]. Moreover, it was observed in a Canadian study that although these adolescents have friends, they have few out-of-school activities and cannot, therefore, entirely share their generation's culture, preventing them from feeling integrated in a group or accepted by their peers [35].

This negative feeling of self-worth could also be related to the high prevalence of violence or of sexual victimisation among the adolescents affected by a CC, as suggested in other studies [40]. Despite the medical follow-up and frequent contacts with health care professionals, the adolescents affected by a CC do not disclose these concerns to their friends or family (more than 50% of them did not discuss it at all) more frequently than other adolescents, and they do not seek mental health services more often [40]. This need for help, which appeared clearly in the Swiss survey in relation to various fields, illustrates the lack of self-confidence these adolescents experience and the lack of support given to them by the people they are in contact with on a regular basis, such as their family, their peers, or the health care professionals.

Conclusion and recommendations

CCs do not prevent experimental behaviours during adolescence; on the contrary they seem to drive these young people to test their own limits, in terms of consumption (alcohol, drugs) as well as in terms of behaviours

(sexuality, violence). Moreover, this study shows the high prevalence of depressive moods and suicidal tendency among the adolescents with a CC. Therefore, health promotion and preventive strategies have to be reinforced towards adolescents affected by a CC.

Several preventive strategies could be established: (1) by encouraging intra-familial communication, which is a protective element against risk-taking [25, 45]; (2) by ensuring a global management of the adolescent and her/his CC, by attention to their distress, concerns and questions through an appropriate counselling; (3) by giving her/him the possibility to discuss difficult subjects, and by clinical assessment of the difficulties related to suicide or sexuality and (4) by the screening of the experimental behaviours, and a motivational interview to explain the processes and to show the factors and the dangers, especially the negative outcomes directly linked to their illness, and by counselling and guidance [42]. These strategies can be carried out by the general or specialised practitioners who are in charge of the medical follow-up. They should also associate the skills of a physician trained in adolescent medicine in order to develop a bio-psycho-social approach and prepare these adolescents for adulthood by means of a "transitional care" approach.

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