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Contextual factors related to chronic condition in portuguese adolescents: highlights from the HBSC/WHO study

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Abstract

Adolescence's changes may become more pronounced when living with a chronic condition (CC). This study aims to examined the differences in satisfaction with family life, perception of school competence and "pressure with homework" of Portuguese adolescents' 1) living with CC; 2) how living with CC affects school participation; taking into account age, gender and family socioeconomic status (SES).

Five thousand fifty Portuguese adolescents (mean age 14 ± 1.85) of the Health Behaviour in School-aged Children (HBSC/WHO) were included. Results showed increased vulnerability in adolescents living with CC, presenting a lower satisfaction with family life and poor school outcomes. Younger boys, having a higher SES and not having CC are significantly associated with satisfaction with family life. Older girls, having a lower SES and living with CC were associated with more stress related to school work.

Future interventions should include these features combined with 'listening' to adolescents and their needs, allowing their participation in the promotion of personal health.

Keywords: Adolescents, Chronic condition, Satisfaction with family life, School perception, Socioeconomic status

Background

Research that compares adolescents with and without a chronic condition (CC), or different diseases, has been contradictory (Combs-Orme et al. 2002). Some studies suggest an increased risk in chronic population (Barlow and Ellard 2006), while others suggest the possibility of a successful adaptation (Barros et al. 2008). Responses are not homogeneous and depend on various specific individual and contextual factors, on the type of disease/condition and on emerging limitations (Lee et al. 2013). In spite of medical advances, children and adolescents living with a CC still face numerous challenges and can be at higher risk for a healthy psychological development (Verhoof et al. 2012), psychological well-being (Santos et al. 2015) and more adjustment problems (Oeseburg et al. 2010a).

The effects of a CC extend to the entire family system (Quittner et al. 2011), which can be a major adaptation facilitator or, on the contrary, a barrier to adjustment (Braconnier and Marcelli 2000). Parents and parental styles are important in the adaptation process to diseases (Santos et al. 2013a). However, in those situations, parents seem to be more restrictive, overprotective and authoritarian; still, most families have a good overall functioning and adaptation (Pinquart 2013). Good communication (Hartos and Power 1997), a secure attachment relationship, a democratic parenting style and a good social support network are suggested as important protective familiar factors, both in children and adolescents (Moreno 2004).

In addition, adolescents living with a CC can also experience numerous school difficulties (Harris et al. 2013) and academic setbacks (Bethell et al. 2012) including truancy (Boonen and Petry 2012), poor academic performance, poor self-perception of academic competence, impaired ability to cope with the demands of a classroom (Logan and Simons 2010), gaps in knowledge/low cognitive development, decreased readiness to learn (Layte and McCrory 2012) and isolation from peer

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group (Mazur and Małkowska-Szkutnik 2010). Young people's perceived school performance and feeling pressured by schoolwork can influence a wide range of non-academic outcomes such as health, health behaviour and well-being (Currie et al. 2012). Missing school, grade retention and school problems are potentially impeding school success variables, placing those adolescents at higher risk for poor educational, vocational and social outcomes in adulthood (Maslow et al. 2011).

However, the individual's perception of disease and adaptation to a CC is a dynamic and changeable process, moderated by gender, age, corresponding socio-cognitive developmental level (Holden et al. 1997), real perception, exposure to cultural/familiar beliefs and construction of concepts of health/illness (Taylor et al. 2008). Generally, in Europe, school pressure increases with age and is higher in older girls and younger boys. Perceived good academic achievement tend to decrease with age, and girls are more likely to enjoy school and report higher school performance (Currie et al. 2012). In addition, cross-cultural data suggests an association between better health and financial satisfaction (Oishi et al. 1999; Olén et al. 2012). Thus, high SES adolescents have better classmate support, communication with mother/father and a higher perceived academic achievement (Currie et al. 2012). On the opposite, students living with a CC from lower socio economic status (SES) families tend to miss school classes more frequently (Meng et al. 2012) and are at higher risk of perceiving school work and demands as "heavy" (Mazur and Małkowska-Szkutnik 2010).

In Portugal, the studies Health Behaviour School-Aged Children (HBSC/WHO) (Matos and Equipa Aventura Social 2000) and Kidscreen (Gaspar and Matos 2008) have shown similar tendencies, suggesting higher vulnerability population with chronic conditions. These studies also point out the importance of a good communication with parents and peers for adolescents' health (Matos et al. 2006; Tomé et al. 2012) and that school satisfaction is related with higher scores of academic achievement (Simões et al. 2010). In addition, difficulties in communication are associated with violent behaviors in school and also with both physical and psychological symptoms; while a better parental communication is associated with feeling happier (Matos and Equipa Aventura Social 2000). Further details on Portuguese data concerning chronic diseases and in adolescents, related to individual factors, risk behaviours and psychological well-being have been already published (Santos et al. 2013b; Santos et al. 2014; Santos et al. 2015). It seems, therefore, relevant to study the impact of: 1) living with a chronic condition; and 2) living with a chronic condition that affects school participation, and its association with satisfaction with family life (Cantril 1965), "Feeling pressure with homework" and "Perception of school competence". The demographic factors studied within these variables are age, gender and family SES by a proxy (FAS: Family Affluence Scale) (Boyce et al. 2006).

Method

Participants

The present study refers to the Portuguese HBSC 2010 study (Matos et al. 2012a, b), consisting of 5050 Portuguese adolescents attending the 6^{th}, 8^{th} and 10^{th} grades, randomly selected from 256 classes and 125 national public schools. From the total group of adolescents were included all ($N = 4647$) that answered the question corresponding to having or not having a long term disease or health problem that has been diagnosed by a doctor (missing values excluded). These group has a mean age of 14 years ($SD = 1.85$, it is composed by 52.3 % girls and 47.7 % boys and the majority of the participating children and adolescents have Portuguese nationality (94.4 %).

Research design and questionnaire

A self-administered questionnaire from the Portuguese study of the Health Behaviour in School-aged Children (HBSC) was used. This study has been carried on every 4 years since 1996 (Matos and Equipa Aventura Social 2000).

HBSC is a school-based, self-report questionnaire developed cooperatively between international researchers according to protocol, and used in collaboration with the World Health Organization to assess children and adolescents' mental and physical health (Currie et al. 2001; Currie et al. 2009; Roberts et al. 2009).

The aim of the study is to understand health behaviours and well-being among adolescents, within their social context (Roberts et al. 2007). Especially designed to be appropriate for adolescents aged 11–15, this survey consists of items measuring background factors (e.g., socioeconomic status, family structure), individual and social resources (e.g., body image, school environment), health behaviours (e.g., smoking, dieting, sexual behaviour, violence), and health outcomes (e.g., life satisfaction, psychological well-being, and self-reported health). For the purpose of the present work a set of variables was selected, described in Table 1).

Measures

For the purpose of this study, the group of students living with a CC was composed by those who gave an affirmative answer to the question: "Do you have any long term disease or health problem that has been diagnosed by a doctor?" In a second step, participants were inquired on

Table 1 Variables included in the study

Study variables	Range
Gender	1 = Boy; 2 = Girl
Age	Min = 11 years old; Max = 16 years old
Having or not having a long term disease or health problem that has been diagnosed by a doctor (Having/not having a chronic condition – CC);	1 = No; 2 = Yes
Feeling that the disease affects or not participation and regular attendance in school;	1 = No; 2 = Yes
Satisfaction with family life (Cantril, 1965)	0 = Very bad relationship; 1;2;3;4;5;6;7;8;9;10 = Very good relationship
Family Affluence Scale –FAS (Boyce et al., 2006): composed by 4 items, and used to assess familiar socioeconomic status (SES):	
"Does your family have a car, van or other mean of transport?"	1 = No; 2 = Yes, one; 3 = Yes, two or more
"How many computers do you have at home?"	1 = None; 2 = One; 3 = Two; 4 = More than two
Spending holidays with family in the last 12 months	1 = None; 2 = One; 3 = Two; 4 = More than two
"Do you have a bedroom only for yourself?"	1 = No; 2 = Yes
"Feeling pressure with homework"	1 = None; 2 = A few; 3 = Some; 4 = A lot
"Perception of school competence"	1 = Very good; 2 = Good; 3 = Average; 4 = Below average

the extent to which having chronic disease affects school participation. Other variables included in this study are described in Table 1.

Procedure

Data was collected in 139 schools, randomly selected from the official national list of public schools, stratified by region. In each school, according to the international protocol, the class was the analysis's unity and classes were randomly selected in order to meet the required number of students for each grade (Currie et al. 2001). The HBSC study followed all the research rules defined by the Portuguese Ministry of Education and Regional Offices of Education, and was approved by the scientific committee, national ethics committee and national data protection. All participating schools collected informed parental consent.

Questionnaires were sent to schools and, according to the protocol, teachers administered the questionnaires in the classroom with voluntary's student participation. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members. The response rate was of 92 % for schools.

Data analysis

Data was analysed using the Statistical Package for Social Sciences (SPSS), version 19.0 for Windows. After a descriptive analysis, ANOVA was used to compare life satisfaction and Familly affluence in the different CC conditions, Qui-square tests were used to analyse the distribution of gender, age groups, school competence and pressure with schoolwork in the different CC conditions and finally Multiple Linear Regressions were used to determine the relationship and the strength of the associations between the variables.

Results

The majority of the children and adolescents do not have a CC (81 %; $N = 3763$), and the group who has (19 %; $N = 884$) mainly reports chronic diseases (88.2 %), followed by sensorial (5.2 %), motor (4.4 %) and cognitive/psychological (2.2 %) conditions. Teens that indicate to have a chronic health condition mostly report that the disease does not affect their participation and regular attendance in school (85.7 %; $N = 1180$).

Qui-Square tests were used to better understand specific differences or associations between the study variables and 1) having or not a CC, and 2) if that CC affects or not participation and regular attendance in school.

"Having or not a chronic condition" (Table 2) was not significantly associated with gender or "Perception of school competence". Data showed a significantly different distribution according to "Feeling pressure with school homework" [χ^2 (3, $N = 4582$) = 17.48, $p \leq 0.001$]. Adolescents living with a CC present more frequently (15.5 %) "Feel like that a lot" compared with adolescents without chronic condition (11.5 %).

"Having a chronic condition (CC) and feeling that it affects or not the participation and regular attendance in school" (Table 2) were not significantly associated with gender nor with "Feeling pressure with homework". However, a significant association was found regarding "Perception of school competence" [χ^2 (3, $N = 1366$) = 10.96, $p \leq 0.05$]. Adolescents with a chronic condition who feel that the

Table 2 Bivariate analysis (X^2) of study independent variables and 1) having or not a chronic condition (CC), and 2) CC affecting or not participation/regular attendance in school

		Adolescents						
Background		Without CC		With CC		Total	χ^2	Df
		N	%	*N*	%			
Gender	Boy	1797	47.8	395	44.7	2192	2.709	1
	Girl	1966	52.2	489	55.3	2455	($p = 0.100$)	
"Perception of school competence"	Very good	325	8.7	81	9.2	406	0.346	
	Good	1415	37.9	331	37.6	1746	($p = 0.951$)	3
	Average	1781	47.7	416	47.3	2197		
	Bellow average	210	5.6	52	5.9	262		
"Feeling pressure with homework"	None	802	21.6	148	17	950	17.478***	3
	A few	1092	29.4	244	28	1336	($p = 0.001$)	
	Some	1390	37.4	343	39.4	1733		
	A lot	428	11.5	135	15.5	563		
		CC Does not Affect School		CC Affects School		Total	χ^2	Df
		N	%	*N*	%			
Gender	Boy	566	48.0	99	50.3	665	0.354	1
	Girl	614	52.0	98	49.7	712	($p = 0.552$)	
Perception of school competence	Very good	103	8.8	19	9.7	122	10.964*	3
	Good	426	36.4	61	31.3	487	($p = 0.012$)	
	Average	567	48.4	90	46.2	657		
	Bellow average	75	6.4	25	12.8	100		
"Feeling pressure with homework"	None	223	19.2	34	17.5	257	6.068	3
	A few	342	29.5	51	26.3	393	($p = 0.108$)	
	Some	429	37	68	35.1	497		
	A lot	166	14.3	41	21.1	207		

Indicates significant differences for the following levels: ***$p \leq .001$; *$p \leq .05$

disease affects school participation, more frequently (12.8 %) "Feel like being a student below average" than adolescents who felt that the disease does not affect school participation (6.4 %).

ANOVA was used to analyze the differences between adolescents' satisfaction with family life (Table 3) data showed statistical differences between adolescents having or not a CC, and between adolescents feeling that CC affects or not participation in school. The group who does not have a CC has in average higher satisfaction with family life ($F(1.4541; 15.47, p \leq .001)$ ($M = 8.52$, $SD = 1.88$), and the same in the group who has a CC but does not feel it affects participation in school ($F(1.1335; 19.29, p \leq .001)$ ($M = 8.41$, $SD = 1.94$).

Adolescents' family affluence (FAS) showed no significant difference regarding having or not a CC. Nevertheless, the group who has a CC but feels that the disease does not affect participation in school, has a higher FAS ($F(1.1331; 5.27, p \leq .05)$ ($M = 5.86$, $SD = 1.86$).

A set of multiple linear regression models was carried out to estimate the relationship between: 1) adolescents' satisfaction with family life, 2) adolescent's "Feeling pressure with school homework", and 3) adolescent's "Perception of school competence", using as predictors gender, age, socioeconomic status (Family Affluence Scale -FAS) and the chronic disease "status": having or not a CC (Table 4), or, feeling that CC affects or not participation and regular attendance in school (Table 5).

Chronic condition (Table 4)

An adjusted model was achieved for satisfaction with family life [$F(4) = 50.611$, $p \leq .05$], and the variance explained by the final model was of 4.3 %. Table 4 shows that although all the four independent variables in the equation are significantly associated to satisfaction with family life, there is a low impact of gender, FAS and having a CC. The higher association is with age (older adolescents feeling worst about family life), and, although with a much lower impact, being a girl and having a CC makes adolescents feel worst about family life. Also in a lower impact, the adolescents who have higher FAS feel more satisfied with family life.

Table 3 Adolescents' satisfaction with family life and FAS comparing 1) having or not CC, and 2) feeling that CC affects or not school participation (ANOVA)

	Adolescents						
Satisfaction with family life	With CC		Without CC				
	M	*SD*	*M*	*SD*	*F*	*Df*	*P*
	8.23	2.06	8.52	1.88	15.466***	1	.000
	CC Affects School		CC does not Affect School				
	M	*SD*	*M*	*SD*	*F*	*Df*	*P*
	7.71	2.47	8.41	1.94	19.293***	1	.000
FAS	With CC		Without CC				
	M	*SD*	*M*	*SD*	*F*	*Df*	*P*
	5.91	1.84	5.88	1.83	0.291	1	.590
	CC Affects School		CC does not Affect School				
	M	*SD*	*M*	*SD*	*F*	*Df*	*P*
	5.53	1.84	5.86	1.86	5.277*	1	.022

Indicates significant differences for the following levels: ***$p \leq .001$; *$p \leq .05$

An adjusted model was achieved for "Feeling pressure with school homework" [$F(4) = 133.776$, $p \leq .05$], and the variance explained by the final model was of 10.6 %. As for this variable, there is a significant but low impact of FAS and having a CC. The higher association is with age (older adolescents feeling more pressure), and with gender (girls reporting more pressure). Although with a much lower impact, not having a CC and reporting a higher FAS makes adolescents feel more "pressure with school homework".

Finally, an adjusted model was achieved for the "Perception of school competence" [$F(4) = 76.944$, $p \leq .05$] and the variance explained by the final model was of 6.4 %. For this variable there is no significant impact of gender, and there is a significant but low impact of having a CC. The higher association is with age (older adolescents reporting lower school competence), and with FAS (more affluent adolescents reporting more competence) and, although with a much lower impact, having a CC makes adolescents have a higher perception of school competence.

Chronic condition affecting participation and regular attendance in school (Table 5)

Table 5 repeat the same models but instead of the variable having/not having a CC, it considers whenever "CC affects/not affects school participation".

Table 4 Predicting 1) Adolescents' satisfaction with family life and 2) "Feeling pressure with school homework" and "perception of school competence, using as predictors gender, age, FAS and having or not a CC (multiple linear regression model)"

	Included Variables	*B*	Std. Error	*β*	*t*	R^2
Satisfaction with family life [a]	Gender ♂ - ♀	−.169	.057	−.044	−2.982**	.043
	Age	−.185	.015	−.178	−12.097***	
	FAS	.077	.016	.073	4.975***	
	Having or not a CC	−.278	.072	−.057	−3.865***	
"Feeling pressure with school homework" [b]	Gender ♂ - ♀	.288	.027	.152	10.721***	.106
	Age	.145	.007	.283	19.954***	
	FAS	.024	.007	.046	3.254***	
	Having or not a CC	−129	.034	.053	3.778**	
"Perception of school competence" [c]	Gender ♂ - ♀	.035	.022	.023	1.600	.064
	Age	−.086	.006	−.210	−14.493***	
	FAS	.053	.006	.128	8.792***	
	Having or not a CC	.072	.028	.037	2.564***	

B and Std. Error: unstandardized coefficients; β: standardized coefficients
***$p \leq .001$; **$p \leq .01$
[a] $F = 50.611$
[b] $F = 133.776$
[c] $F = 76.944$

Table 5 Predicting 1) adolescents' satisfaction with family life and 2) "feeling pressure with school homework" and "perception of school competence, using as predictors gender, age, FAS and feeling that CC affects or not school participation (multiple linear regression model)"

	Included Variables	*B*	Std. Error	*β*	*t*	R^2
Satisfaction with family life [a]	Gender ♂ - ♀	−.166	.111	−.040	−1.491	.046
	Age	−.179	.030	−.161	−5.919***	
	Socioeconomic Status (FAS)	.068	.030	.062	2.276*	
	Feeling CC affects/not affects school	−.662	.160	−.113	−4.139***	
"Feeling pressure with school homework" [b]	Gender ♂ - ♀	0.269	0.050	0.139	5.363***	0.120
	Age	0.166	0.014	0.317	12.142***	
	Socioeconomic Status (FAS)	0.017	0.014	0.033	1.255	
	Feeling CC affects or not school	0.090	0.072	0.033	1.254	
"Perception of school competence" [c]	Gender ♂ - ♀	−0.064	0.040	−0.042	−1.585	.053
	Age	0.069	0.011	0.167	6.195***	
	Socioeconomic Status (FAS)	−0.60	0.011	−0.147	−5.563***	
	Feeling CC affects or not school	0.037	0.058	0.017	0.631	

B and Std. Error: unstandardized coefficients; β: standardized coefficients
***$p \leq .001$; *$p \leq .05$
[a] $F = 16.497$
[b] $F = 45,462$
[c] $F = 19,620$

An adjusted model was achieved for satisfaction with family life [$F(4) = 16.497$, $p \leq .05$], and the variance explained by the final model was of 4.6 %. Considering satisfaction with family life, there is no significant impact of gender and a low impact of FAS. The higher association is with age (older adolescents feeling worst with family life) and having a CC that affects school participation makes adolescents feel worst with family life, with a much higher impact than merely considering having or not a CC. With a much lower impact, having a higher FAS makes adolescents feel more satisfaction with family life.

An adjusted model was also achieved for "Feeling pressure with school homework" [$F(4) = 45.462$, $p \leq .05$], and the variance explained by the final model was of 12 %. As for this variable, there is no significant impact of FAS and of having a CC that affects school participation. The higher association is with age (older adolescents feeling more pressure), and with gender (girls reporting more pressure).

Finally an adjusted model was achieved for "Perception of school competence" [$F(4) = 19.620$, $p \leq .05$], and the variance explained by the final model was of 5.3 %. For this variable there is no significant impact of gender nor of having a CC that affects school participation. The higher association is with age (older adolescents reporting higher school competence), and with FAS (more affluent adolescents reporting less competence).

Interestingly age seems the worst "risk factor" for (in) satisfaction with family life, pressure with school work and (low) perception of school competence. Focusing on CC, having a CC has a significant but really low impact upon those situations. Interestingly as well is that when considering only having a CC that affects school participation, the impact upon school pressure and perception of school competence decreases, and the impact upon family life increases.

Discussion

A brief overview of main results shows that adolescents living with a CC present higher levels of "pressure with homework" and feel that their school competence is below average. On the other hand, adolescents living without a CC perceive their satisfaction with family life as more satisfying. This data supports the hypothesis evidenced in the literature, proposing that adolescents living with a CC may have increased risk and vulnerability (Barlow and Ellard 2006; Gaspar and Matos 2008; Matos and Equipa Aventura Social 2000; Oeseburg et al. 2010a, b; Santos et al. 2013a, b; Santos et al. 2014; Verhoof et al. 2012), mainly in satisfaction with family life (Michaud et al. 2007; Quittner et al. 2011) and school success (Bethell et al. 2012; Layte and McCrory 2012).

This study also supports previous research that suggests changes can be influenced by gender, age and SES (Currie et al. 2012; Holden et al. 1997; Oishi et al. 1999; Olén et al. 2012; Taylor et al. 2008).

Parents have an important role in the adaptation process to a CC and, concerning school outcomes, parental encouragement can be considered to have a specific positive effect on adolescent health, beyond the effect of school environment and family communication addressed individually (Matos et al. 2006). Thus, family

is necessarily an intervention target when pediatric disabling conditions occur in order to help parents deal with children/adolescents' CC and associated changes in the family environment (Russo et al. 2012). Parental interventions should provide key aspects focused on educational, therapeutic and organizational dimensions.

This study has some limitations namely findings were entirely based on adolescents' self-reports (a widely-used procedure in a national survey design) and the results are cross-sectional (and not ideally longitudinal). Notwithstanding these limitations, this is one of the first investigations concerning the impact of living and attending school in adolescents with CC, using a wide national representative study (HBSC Portuguese study).

Conclusions

Adolescents frequently feel that their lives are ruled by the medical system and so it is increasingly important to include their perspectives in healthcare, highlighting their specific needs, knowledge, competences and rights (Matos et al. 2013; Michaud et al. 2004; Ottova et al. 2013). It is also important to consider their suggestions to parents, such as learning better parenting styles, having greater confidence in their children, and gradually transferring to them the responsibility for medical treatment (Bregnballe et al. 2011).

Therefore, a multifaceted approach and prevention of CCs in schools is highlighted and may reduce the costs of special education services, help adolescents to better control the disease and improve a healthy development into adulthood (Logan and Simons 2010). In addition, when designing and implementing school-based intervention programs, it seems important to promote school assets as important features on school satisfaction and academic achievement for all students and, in particular, for those more vulnerable to achieve success (Simões et al. 2010). Building competences in adolescents with a CC, strengthening connectedness and a better communication within the family, school, peer group and health care professionals will enhance resilience and increase the opportunities to improve health outcomes in this population, creating opportunities to support their school and future professional career (Matos et al. 2012a, b; Oeseburg et al. 2010b).

Competing interests

None of the authors reported any financial interests or potential conflicts of interest.

Authors' contributions

TS and MGM conceived the study, participated in its design and coordination, draft and authored the manuscript; CS and MCM participated in the study design, interpretation of the data, and helped to draft manuscript revisions. All authors read and approved the final manuscript.

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