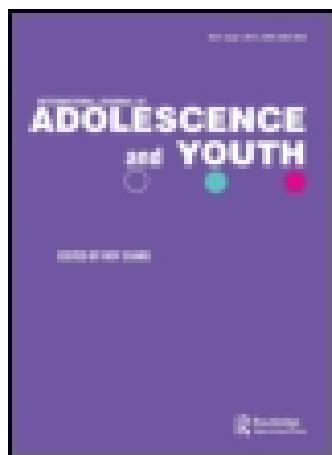


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Psychological well-being and chronic condition in Portuguese adolescents

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Psychological well-being and chronic condition in Portuguese adolescents

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Objective: To examine the differences in the psychological well-being of Portuguese adolescents’ (1) living with a chronic condition (CC) and (2) living with a CC and feeling it affects/not affects school participation. *Methods:* There were 5050 Portuguese adolescents as participants of the Health Behaviour in School-aged Children/WHO. *Results:* Adolescents without CC often feel rarely or never ‘sad/depressed’, ‘irritated/bad humour’, ‘nervous’, ‘fearful’ or ‘so sad that it seems I can’t take it’, compared with their healthy peers. Young people living with CC and feeling that it does not affect participation in school, often feel rarely or never ‘sad/depressed’, ‘fearful’ or ‘so sad that it seems I can’t take it’, comparing with the ones with CC and feeling it affects school. All of these symptoms were higher in adolescents living with a CC. *Conclusions:* Adolescents living with a CC and feeling that it affects participation in school can be at a higher risk for a healthy psychological well-being. Future early interventions based on a ‘health assets’ approach should be implemented.

Keywords: adolescent health; chronic condition; health promotion; health prevention; psychological well-being

Introduction

Chronic condition (CC) refers to any extended/irreversible illness, being asthma, congenital heart disease, epilepsy and diabetes, the most prevalent in adolescence (Barros, 2009). Living and managing any CC and its limitation during adolescence, where profound bio-psycho-social changes occurs, constitute a major challenge for young people, his/her family and healthcare professionals (Michaud, Suris, & Viner, 2007; Simões, Matos, Ferreira, & Tomé, 2010; Suris, Michaud, & Viner, 2004).

Actually, the prevalence of childhood CCs is arising, bringing up significant problems (Delaney & Smith, 2012), whereas infant mortality rates rapidly decline. Advances in medicine made possible to prolong and enhance the lives of children and adolescents with CCs.

However, their general development is still affected (Suris et al., 2004) and youth face numerous challenges, namely more difficulties achieving cognitive skills, family/school/peers relationships, health-related behaviours, health perception (Serrabulho, Matos, & Raposo, 2012a); more limitations in everyday life participation (Law et al., 2006), reaching developmental milestones, adhering to daily treatments and transitioning to adult care.

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Moreover, the effects of a CC extend beyond the individual to the entire family system (Quittner, Romero, Kimberg, Blackwell, & Cruz, 2011) and scholar context, namely through frequent absences, decline of academic performance, poor self-perceptions of academic competence and difficulties to cope with classroom demands (Logan, Simons, Stein, & Chastain, 2008). Therefore, adolescents living with a CC can be at higher risk for an healthy emotional and behavioural psychological development (Bernstein, Soren, Stockwell, Rosenthal, & Gallagher, 2011; Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2012) and can experience more adjustment difficulties (Geist, 2003; Oeseburg, Jansen, Groothoff, Dijkstra, & Reijneveld, 2010), as well as internalising symptoms, such as depression (Miyazaki, Amaral, & Grecca, 2006; Vanhalst et al., 2013), anxiety and social withdrawal, and externalising others related to behaviours (Lavigne & Faier-Routman, 1992).

Thus, this group is doubly disadvantaged and may be more vulnerable to adverse health outcomes (Saunders, 2011; Scaramuzza et al., 2010). In Portugal, the studies Health Behaviour School-Aged Children (HBSC) (Matos & Equipa Aventura Social, 2000, 2002, 2006) and Kidscreen (Gaspar & Matos, 2008) have been also pointing out higher vulnerability in this population. Living with a CC while growing up may also contribute for worse health-related quality of life and symptoms of anxiety and depression in young adults (Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2013), placing them at higher risk for poor vocational/educational and social outcomes (Maslow, Haydon, McRee, Ford, & Halpern, 2011).

Nevertheless, the adaptation to a CC and the individual's perception concerning the disease is a dynamic and changeable process, and it can be moderated by child's age, gender, corresponding socio-cognitive developmental level (Holden, Chmielewski, Nelson, & Kager, 1997), real perception, exposure to cultural/familiar beliefs (Barros, 2003) and construction of concepts of health and illness (Taylor, Gibson, & Franck, 2008). Meanings concerning the disease start to consolidate in scholar ages and having an older age at the disease's onset or longer disease duration are higher risks for adjustment difficulties (Panamonta, Prathipanawatr, & Panamonta, 2012). Boys seem to be significantly more likely than girls to display behavioural and adjustment problems (Gortmaker, Walker, Weitzman, & Sobol, 1990), and girls show higher levels of anxiety (Matos, Tomé, Borges, Manso, Simões, & Ferreira, 2012), depression (La Greca, Swales, Klemp, Madigan, & Skyler, 1995), emotional distress (sadness, expressing depressive symptomatology) and suicide ideation (Suris, Parera, & Puig, 1996). In general population, it can be seen that older pupils, girls, students with low socio-economic status, or frequent health complaints reported decreased mental health (Erhart et al., 2009) and health-related quality of life (Gaspar, Matos, Ribeiro, Leal, & Ferreira, 2009). Also in Portugal, the studies HBSC (Matos & Equipa Aventura Social, 2000, 2002, 2006) and Kidscreen (Gaspar & Matos, 2008) have shown these same tendencies reported in the literature.

Despite the above data summarised, research comparing adolescents living with and without CC, or comparing adolescents across different conditions, is still inconclusive, contradictory and not clear confirming a direct relationship between the CC and degrees of suffering (Combs-Orme, Heflinger, & Simpkins, 2002). Certain studies indicate the possibility of successful adaptation (Barros, Matos, & Batista-Foguet, 2008), whereas others suggest increased risk in chronic population (Barlow & Ellard, 2006). There are several heterogeneous responses, depending on various specific individual and contextual factors, plus on the type of condition and emerging limitations, being worst in the presence of both (Barros, 2009). Thus, cumulative risks may have a strong impact and be a threat to

adolescent well-being, specifically for psychological symptoms (Simões, Matos, Lebre, & Antunes, 2014). In addition, having a greater number of health problems (three/more, compared with two), as well as the type of CC, is concurrently associated with poorer quality of life (Lee et al., 2013). Both in Western and Asian populations, there is evidence of such results (Lee et al., 2013; Sawyer et al., 2002).

Consequently, in this paper, it is important to explore the links between adolescents' psychological well-being and (1) living with a CC; and (2) living with a CC and feeling it affects/does not affect school participation. Based on the literature, it is expected that adolescents with CCs report higher vulnerability in psychological well-being.

Methods

Participants

The participants include young people from the HBSC 2010 study-Portuguese Survey [58] (www.hbsc.org/) and consisted of 5050 Portuguese adolescents (52.3% girls), randomly selected from 139 national public schools, having a mean age of 14 years old ($SD = 1.85$) and attending the 6th, 8th and 10th grades. The majority of the children and adolescents have Portuguese nationality (94.4%).

Research design and questionnaire

A school-based self-administered questionnaire from the Portuguese sample of the HBSC was used. Portugal was included for the first time in this study in 1996, and in 1998, it was already a full partner. Since then, the study has been realised every 4 years (Matos & Equipa Aventura Social, 2000, 2002, 2006).

The HBSC questionnaire is developed cooperatively between international researchers according to the protocol and used in collaboration with World Health Organization; it intends to assess children and adolescents' mental and physical health (Currie, Samdal, Boyce, & Smith, 2001). It is essentially a descriptive and cross-sectional correlation in nature, aiming to understand health behaviours and well-being among adolescents, within their social context (Roberts et al., 2007). Particularly designed to be appropriate for adolescents, ageing 11–15 years, this survey consists of items measuring background factors (e.g. socio-economic 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 were selected and are described in Table 1 (see Measures).

Procedure

The sample data were collected in 139 schools, randomly selected from the official national list of public schools and stratified by region. The class was the analysis's unity in each school, and classes were randomly selected in order to meet the required number of students for each grade, according to the international research protocol (Currie et al., 2001). The HBSC study follows the principles outlined in the Declaration of Helsinki and all the rules for research by the Portuguese Ministry of Education and Regional Offices of Education, and it was approved by the scientific committee, national ethics committee and

Table 1. Variables included in the study.

Study variables	Range
Gender	1 = Boy; 2 = Girl
Age (years old)	Min = 11; Max = 16
School grade	1 = 6th grade; 2 = 8th grade; 3 = 10th grade
Nationality	1 = Portuguese; 2 = Angolan, Capeverdian, Guinean, Mozambican, S. Tomense; 3 = Brazilian; 4 = Ucrainian, Romanian, Moldavian, Russian; 5 = Other
Having/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/does not affect participation and regular attendance in school;	1 = No; 2 = Yes
Psychological well-being had a physical and psychological symptoms evaluated through the question:	1 = About every day; 2 = More than once a week; 3 = About every week; 4 = About every month; 5 = Rarely or never
‘In the last 6 months, with what frequency did you feel’ (King et al., 1996):	
– feeling sad/depressed	
– feeling irritated/bad humour	
– feeling nervous	
– fearful	
‘Feeling so sad that it seems that I can’t take it’ (Matos, Gonçalves, Gaspar & Equipa Projecto Aventura Social, 2005).	1 = Never or rarely never happens; 2 = It happens sometimes; 3 = I’m like that almost always

national data protection. All participating schools made available informed parental consent, required by the committee of parents from each school.

According to the protocol, questionnaires were sent to schools and teachers conducted their administration in the classroom, with a voluntary student participation. Confidentiality was ensured with anonymous response to the questionnaire and restricted access to HBSC research team members, regarding the work on computing and data analysis. The response rate was of 90% regarding schools. No pupil’s refusal was identified.

Measures

For the purpose of this study, the group of students with CC was defined by an affirmative answer to the question: ‘Do you have any long-term disease or health problem that has been diagnosed by a doctor?’ Then, in a second step, it was enquired the extent to which having a CC affects or does not affect school participation. The outcome measure was psychological well-being, and four indicators of adolescents’ psychological well-being were examined using the data from the HBSC/WHO symptom checklist scale (King, Wold, Tudor-Smith, & Harel, 1996). Adolescents were asked how often they had experienced those feelings in the past 6 months (about every day, more than once a week, about every week, about every month or rarely or never). Variables included in the study are described in [Table 1](#).

Statistical analyses

Questionnaire' data were scanned, translated and interpreted by the programme Eyes & Hands-Forms, version 5. Data were entered for statistical analysis, into the database of the Statistical Package for Social Sciences, version 19.0 for Windows. After descriptive analysis, bivariate analysis and chi-square tests were used to determine the differences between respondents' psychological well-being and: 'having/not having a CC or health problem diagnosed by a doctor', and if 'CC affects/not affects participation and regular attendance in school'.

Results

Concerning CC, the majority of the children and adolescents do not have a CC (81%; $N = 3763$), and the group who has a CC (19%; $N = 884$) reports mainly chronic diseases (88.2%), followed by sensorial (5.2%), motor (4.4%) and cognitive/psychological (2.2%) conditions. Young people that indicate to have a chronic health condition mostly report that the condition does not affect their regular participation in school (85.7%; $N = 1180$). Chi-square tests were used to better understand specific differences between the study variables and (1) having/not having a CC, and (2) living with a CC and feeling it affects/does not affect school participation.

Chronic condition (Table 2)

'Having/not having a chronic condition' and gender, school grade or nationality were not statistically significant.

The results for 'having/not having a chronic condition' and 'feeling sad/depressed' [$\chi^2(4, N = 4607) = 22.51, p \leq 0.001$], 'feeling irritated/bad humour' [$\chi^2(4, N = 4613) = 17.57, p \leq 0.001$], 'feeling nervous' [$\chi^2(4, N = 4616) = 18.20, p \leq 0.001$], 'feeling fearful' [$\chi^2(4, N = 4608) = 33.29, p \leq 0.001$] and 'feeling so sad that it seems that it can't take it' [$\chi^2(4, N = 4554) = 24.39, p \leq 0.001$] were statistically significant.

The group of adolescents without a CC often feels rarely or never 'sad/depressed' (63.3%), 'irritated/bad humour' (54.3%), 'nervous' (47.1%), 'fearful' (77.2%) or 'so sad that it seems I can't take it' (52%), comparing with their healthy peers.

Thus, all of these symptoms were higher in adolescents living with a CC and reported in a greater frequency concerning the past 6 months (about every day, more than once a day and about every week).

CC affecting participation and regular attendance in school (Table 3)

'Feeling that CC affects/not affects participation and regular attendance in school' and gender, school grade, nationality, 'feeling irritated/bad humour' and 'feeling nervous' were not statistically significant.

The results for 'CC affecting/not affecting school' and 'feeling sad/depressed' [$\chi^2(4, N = 1359) = 11.10, p \leq 0.05$], 'feeling fearful' [$\chi^2(4, N = 1362) = 30.89, p \leq 0.001$] and 'feeling so sad that it seems that it can't take it' [$\chi^2(2, N = 1349) = 18.73, p \leq 0.001$] were statistically significant.

The group of adolescents living with a CC and feeling that CC doesn't affect participation in school is often feel rarely or never 'sad/depressed' (60.1%), 'fearful' (74.3%) or 'so sad that it seems I can't take it' (49.2%), compared with the ones living with a CC and feeling that it affects school's participation.

Table 2. Bivariate analysis (χ^2) of study variables and having/not having a CC.

Background	Adolescents				Total	χ^2	Df
	Without CC		With CC				
	N	%	N	%			
Gender							
Boy	1797	47.8	395	44.7	2192	2.709	1
Girl	1966	52.2	489	55.3	2455		
School Grade							
6th	1128	30.0	241	27.3	1369	3.673	2
8th	1200	31.9	278	31.4	1478		
10th	1435	38.1	365	41.3	1800		
Nacionality							
Portuguese	3528	94.3	834	95.1	4362	8.397	4
Ang./Capv./Gui./Moz./S.T.	51	1.4	11	1.3	62		
Brazilian	44	1.2	16	1.8	60		
Ucr./Rom./Mold./Russ.	37	1.0	2	0.2	39		
Other	81	2.2	14	1.6	95		
Symtoms: Feeling sad/depressed							
About every day	173	4.6	54	6.2	227	22.511***	4
More than once a week	300	8.0	86	9.9	386		
About every week	257	6.9	84	9.6	341		
About every month	639	17.1	166	19.0	805		
Rarely or Never	2366	63.3	482	55.3	2848		
Symtoms: Feeling irritated/bad humour							
About every day	127	3.4	43	4.9	170	17.571***	4
More than once a week	354	9.5	102	11.7	456		
About every week	371	9.9	87	10.0	458		
About every month	855	22.9	228	26.1	1083		
Rarely or Never	2032	54.3	414	47.4	2446		
Symtoms: Feeling nervous							
About every day	223	6.0	67	7.6	290	18.196***	4
More than once a week	397	10.6	125	14.3	522		
About every week	437	11.7	101	11.5	538		
About every month	922	24.7	227	25.9	1149		
Rarely or Never	1760	47.1	357	40.7	2117		
Symtoms: Fearful							
About every day	103	2.8	41	4.7	144	33.294***	4
More than once a week	148	4.0	65	7.4	213		
About every week	136	3.6	39	4.5	175		
About every month	463	12.4	115	13.2	578		
Rarely or Never	2885	77.2	613	70.2	3498		
'Feeling so sad that it seems I can't take it...'							
Never or almost never happens	1915	52.0	374	43.0	2289	24.388***	2
It happens to me sometimes	1641	44.5	450	51.8	2091		
I feel like that almost always	129	3.5	45	5.2	174		

*** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$.

Thus, all of these symptoms were higher in adolescents living with a CC and feeling that it affects participation in school, and reported in a greater frequency concerning the past 6 months (about every day, more than once a day and about every week).

Table 3. Bivariate analysis (χ^2) of study variables and CC affecting/not affecting participation and regular attendance in school.

Background	Adolescents				Total	χ^2	Df
	CC Not Affects School		CC Affecting School				
	N	%	N	%			
Gender							
Boy	566	48.0	99	50.3	665	0.354	1
Girl	614	52.0	98	49.7	712		
School Grade							
6 th	392	33.2	58	29.4	450	1.101	2
8 th	371	31.4	65	33.0	436		
10 th	417	35.3	74	37.6	491		
Nacionality							
Portuguese	1089	93.1	182	93.3	1271	2.537	4
Ang./Capv./Gui./Moz./S.T.	25	2.1	2	1.0	27		
Brazilian	21	1.8	6	3.1	27		
Ucr./Rom./Mold./Russ.	7	0.6	1	0.5	8		
Other	28	2.4	4	2.1	32		
Symtoms: Feeling sad/depressed							
About every day	70	6.0	21	11.1	91	11.104*	4
More than once a week	92	7.9	22	11.6	114		
About every week	101	8.6	15	7.9	116		
About every month	203	17.4	34	17.9	237		
Rarely or Never	703	60.1	98	51.6	801		
Symtoms: Fearful							
About every day	48	4.1	15	7.8	63	30.894***	4
More than once a week	65	5.6	27	14.0	92		
About every week	42	3.6	13	6.7	55		
About every month	146	12.5	21	10.9	167		
Rarely or Never	868	74.3	117	60.6	985		
'Feeling so sad that it seems I can't take it...'							
Never or almost never happens	569	49.2	66	34.4	635	18.725***	2
It happens to me sometimes	540	46.7	109	56.8	649		
I feel like that almost always	48	4.1	17	8.9	65		

*** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$.

Discussion

In this study, we sought to establish the links between Portuguese adolescents' psychological well-being and (1) living with a CC; (2) living with a CC and feeling it affects/not affects school participation.

A brief overview of main results shows that the majority of adolescents living with a CC mainly report that CC does not affect participation and regular participation in school, in contrast to what is suggested in the literature (Logan et al., 2008; Maslow et al., 2011).

Adolescents living with a CC feel more frequently 'sad/depressed', 'irritated/bad humour', 'nervous', 'fearful' and 'so sad that it seems that it can't take it', all reported in a greater frequency concerning the past 6 months, comparing with young people without a CC.

Also the adolescents living with a CC and feeling that CC affects their participation in school present similar results, often feeling more 'sad/depressed', 'fearful' and 'so sad that it seems that it can't take it' comparing with the young people that don't feel that CC affects school's participation.

Therefore, youth living with a CC seems to be at higher risk for psychological well-being. These data support the suggested hypothesis in this study and reported in the literature, indicating that adolescents living with a CC can have increased vulnerability for an emotional and psychological healthy development (Bernstein et al., 2011; Verhoof et al., 2012), presenting more internalised symptoms, such as depression (Miyazaki et al., 2006; Vanhalst et al., 2013) and anxiety (Lavigne & Faier-Routman, 1992), and this can continue as a risk factor for later in adulthood (Verhoof et al., 2013).

Moreover, when adolescents have a CC and feel that it affects school's participation, data continue to show similar results, namely the higher vulnerability for internalised symptoms, such as depression. The higher psychological vulnerability described above is also consistent with previous research reported in Portuguese studies (Gaspar & Matos, 2008; Matos & Equipa Aventura Social, 2000, 2002, 2006; Simões et al., 2014). In addition, prior studies conducted in the specific area of CC in Portuguese adolescents reinforced that (1) being a girl, being older, having lower socio-economic status, living with a CC and feeling that it affects school participation, are predictors for feeling more frequently unwell (Santos, de Matos, Simões, Fonseca, & Machado, 2013); and (2) adolescents with CC have more internalising behaviours when compared with healthy peers and adolescents reporting that CC affects school participation have more risky behaviours, whereas those who are not affected present more healthy behaviours (Santos, Ferreira, Simões, de Matos, & Machado, 2014).

In terms of public health and health psychology, these issues need to be monitored in children and adolescents with and without CC, and with diverse individual, social and cultural differences (Gaspar, Ribeiro, Matos, Leal, & Ferreira, 2012). To have better understanding concerning important vulnerable predictors is crucial, as well as measures to promote health, wellness and disease prevention, resulting in information, that hopefully can help to plan more preventive or suitable effective intervention programmes (Barros, 2009; Michaud et al., 2007).

Interventions should be implemented as early as possible and focused on individual and contextual aspects, where distressed areas are identified, as well as risk and protection factors for each child or adolescent. Literature has already given some relevant information to include in interventions, such as helping adolescents to better accept the limitations imposed by chronic disease and readjusting life goals (Casier et al., 2011). In Portugal, HBSC and Kidscreen studies have highlighted the need to strengthen the main support structures surrounding adolescents, such as family, schools and peer groups. It also recommended that health and education systems should be alert for the global aspects of youth's mental health. Further, WHO concluded that primary prevention is crucial regarding mental health, pointing out that interventions must consider that most of the health inequalities are based on broad key determinants that co-interact. Thus, WHO recommends an approach based on 'health assets', which in relation to young people includes not only exploring individual skills such as resilience, but also community level attributes such as supportive social networks, strong intergenerational relationships and so on (Morrow & Mayall, 2007).

Taking into account all the above described, these suggestions become even more important for young people with CCs, compared with their healthy peers, need the same guidance and prevention as any other adolescent (Michaud et al., 2007), in order to provide effective support during the transition into adulthood (Serrabulho et al., 2012b). A special attention should also be directed to the adolescents with a CC and feeling that it affects school participation, in order to prevent the impact of cumulative risk factors (Simões et al., 2014).

But rather than interventions mainly implemented by adults, it is also increasingly fundamental to 'give voice' to children and young people with CC. First, because they are

described as competent interpreters of their ‘world’ (Sartain, Clarke, & Heyman, 2000), and second, because interventions should and must respect adolescents’ specific wishes, desires, needs, knowledge, competences and rights (Michaud, Suris, & Viner, 2004).

This study has a number of limitations as described below that should be considered when interpreting the results. The used variables were developed post hoc from an existing survey; consequently, some variables only had a small number of items (the only items available in HBSC questionnaire). Findings were entirely based on adolescents’ self-reports (even if this is a widely used procedure in a national survey design), and biases in perception and reporting cannot be ruled out. Finally, the results are cross-sectional (and not longitudinal), and, therefore, due to the nature of the design, the ideal longitudinal data were not possible. Thus, it is more difficult to draw conclusions about the direction of causality between the variables of interest.

Notwithstanding these limitations, this is one of the first investigations concerning the impact of living with a CC in adolescents in a nationally wide Portuguese representative sample HBSC (Portuguese Survey). So, it is expected that this study can give important suggestions to families, schools and health professionals, while planning interventions for adolescents with CCs that must take into account the promotion of a healthy psychological well-being.

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Disclosure statement

No potential conflict of interest was reported by the authors.

Declaration of interest

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