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Chronic health conditions measured in general health questionnaires for adolescents in Europe

Condiciones de salud crónicas medidas con cuestionarios de salud general para adolescentes en Europa

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ABSTRACT

The present study intends to assess how chronic health conditions are being evaluated in general health questionnaires aimed at adolescents. A review of questionnaires that contain questions about different domains of the adolescents' lives and about chronic disease and/or disability was performed. Different terminologies regarding the domain of chronic conditions (e.g. long-term illness, disability, medical condition, illnesses/disorders, chronic disease, health problems) and different questions formulations and evaluation measures are used. Some questionnaires include questions about the specific areas affected by the chronic health condition and limitations. This work allowed an overview of the main categories present in the questions about chronic disease/disability that are currently being included in these instruments. It highlights the importance of considering the adolescents with chronic conditions in the general health questionnaires, as this allows for increasing knowledge about their needs and difficulties. Data collection on adolescents with chronic conditions' social participation is very important and should be reinforced through improved questions.

KEYWORDS

Review; Health questionnaires; Surveys; Chronic conditions; Adolescents.

RESUMEN

El presente estudio pretende evaluar cómo las condiciones crónicas de salud están siendo evaluadas en cuestionarios de salud general dirigidos a adolescentes. Se realizó una revisión de cuestionarios que contienen preguntas sobre diferentes dominios de la vida de los adolescentes y sobre enfermedades crónicas y/o discapacidad. Diferentes terminologías relacionadas con el dominio de las condiciones crónicas (e.g. enfermedad prolongada, discapacidad, condición médica, enfermedades/trastornos, enfermedades crónicas, problemas de salud) y diferentes formulaciones de preguntas y medidas de evaluación son usados. Algunos cuestionarios incluyen preguntas sobre las áreas específicas afectadas por la condición de salud crónica y las limitaciones. Este trabajo permitió una visión general de las principales categorías presentes en las preguntas sobre enfermedad crónica/discapacidad que actualmente están siendo incluidas en estos instrumentos. También destaca la importancia de considerar los adolescentes con condiciones crónicas en los cuestionarios generales de salud, ya que esto permite aumentar el conocimiento sobre sus necesidades y dificultades. La recopilación de datos sobre la participación social de los adolescentes con condiciones crónicas es muy importante y debe reforzarse a través de preguntas mejoradas.

PALABRAS CLAVE

Revisión; Cuestionarios de salud; Investigaciones; Condiciones crónicas; Adolescentes.

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Introduction

Chronic or non-communicable diseases (NCD) are long-term health conditions that are not transmissible from person to person and that generally progress slowly and require care and management throughout the life cycle (World Health Organization [WHO], 2018a, 2020). NCD result from a combination of genetic, physiological, environmental and behavioral factors (WHO, 2018b) and present different characteristics and needs depending on the type of health condition (Muntaner et al., 2014).

Living with a chronic disease tends to have a considerable impact on all aspects of an individual's life and in many cases translates into a regular need for treatment and medical monitoring (Forestier et al., 2019). Therefore, chronic diseases can produce an overload, both in terms of the disease itself as well as its management and associated treatments (Sav et al., 2015) and affect the psychosocial well-being and quality of life of the individuals (Barlow & Ellard, 2006; Santos et al., 2018; Shaw & McCabe, 2008).

Chronic diseases constitute a risk factor that can affect the positive and adjusted development of those youth (Kim & Yoo, 2010). The literature reports an increased risk for this population regarding problems related to mental health (Barlow & Ellard, 2006; Barros et al., 2008; Santos et al., 2016). There is also evidence of several challenges experienced by children and adolescents with chronic diseases (Kim & Yoo, 2010).

In addition to the chronic diseases per se, learning difficulties (Haverine et al., 2014) or

physical disabilities (Stewart et al., 2011) can also have a negative impact on the adolescents' functioning and psychological well-being. They can also be challenging at a personal, familiar and educational level and contribute to the emergence of mental health problems (Haverine et al., 2014; Stewart et al., 2011).

Adolescence is a phase marked by several changes that individuals face in a variety of ways. It is at this stage of development that some health problems are identified, the relationships with peers become more important and the young people become involved in new experiences that can lead to the involvement in risk behaviours (e.g. substance use and sexual behaviour) (Clements-Nolle & Rivera, 2013). There are cases where a good adaptation to these challenges can be observed and others where the opposite happens (Pooley & Cohen, 2010). This need for adaptation is universal, whatever the adolescents' health condition (Ferguson & Walker, 2014).

The prevalence of chronic disease among children and adolescents has been increasing over time and its implications represent challenges for their lives as well as the lives of their families (Van der Lee et al., 2007) and for the society in general. Therefore, it is important to have studies capable of evaluating the social outcomes of the health condition of children and young people with chronic disease and/or disability (McDougall & Miller, 2003).

Scientific investigations often rely on cross-sectional surveys administered in the school context to collect data on children and adolescents (Kristjansson et al., 2013) as this type of instrument provides evidence on knowledge,

practices and attitudes (Story & Tait, 2019). These surveys are a valuable source of information in the first-person regarding the experience of living with a chronic condition (Lollar et al., 2012; Mazur et al., 2013). On the one hand, the existence of data on the prevalence of chronic diseases in children and adolescents is a crucial factor to enhance their social participation (Van der Lee et al., 2007). On the other hand, a diversity in the operationalization to measure the prevalence of these health conditions can be observed, since the definition of the concept of chronic health condition in childhood is not unequivocally defined (Van der Lee et al., 2007).

The present study intends to review the main available general health questionnaires aimed at adolescents and assess their questions about chronic disease and/or disability and related areas of life (e.g. health, behaviours of health, school, leisure). The importance of having data on adolescents with chronic conditions is emphasized, in order to allow an increase in knowledge regarding their difficulties and needs and inform the interventional responses.

Method

A review of surveys aimed at adolescents and containing questions about chronic disease and/or disability and questions about other domains of their life (e.g. health, health behaviours, school, leisure) was performed. This search was carried out between February and May 2020 and the studies were identified based on searches in PubMed and EBSCO (Psychology and Behavioural Sciences Collection) databases

with publication date between 2010 and 2020 and without language restrictions. The search terms included the following keywords: chronic disease; chronic illness; chronic health conditions; disability; impairment; health survey; health, adolescent(s); youth; and school-based health survey, present in the title or abstract. Some references from articles related to the topic were also consulted and were analyzed within the scope of the search results.

Inclusion criteria

For the purpose of this review, only surveys containing questions about chronic disease and/or disability and about different areas of the adolescents' lives (e.g. health, school, family, leisure) were included. This review has adolescents as target population, aged between 10 and 24 years, as defined by Sawyer et al. (2018). Thus, surveys directed at the adult and older population or only directed at a specific health condition were excluded. In addition, this research focused only on European countries.

The research of the studies was limited to the last 10 years (from 2010 to 2020), in order to have a more up-to-date view of the type of questions that are being included in general health questionnaires aimed at adolescents. Some of the surveys included in this review were collected prior to 2010 but they were analyzed in articles after 2010.

The results include studies that were developed only once and others that continue to be carried out with a defined periodicity (e.g. annually, every 4 years).

Results

We find that in European countries and between 2010 and 2019 there were 16 surveys collecting data on the adolescents' health and behaviour with questions about chronic disease and/or disability. Table 1 gives an overview of these surveys.

Of the 16 surveys presented in Table 1, we could access the questions used to assess chronic disease/disability from 15 of them (Table 2). In the case of the surveys that did not have the questions available online, the authors were contacted to ask if they can share the specific questions on this subject.

Most of the protocols use between one and five questions about chronic disease and/or disability, except for six studies that use more questions: The Young-Hunt Study (Holmen et al., 2014), SMASH-02 (Narring et al., 2004), The Danish National Youth Study 2014 (Pisinger et al., 2017), Young Persons' Behaviour & Attitudes Survey (YPBAS) (Northern Ireland Statistics and Research Agency, 2016), Health Behaviour in School-aged Children – HBSC (Child Functioning Module) (Inchley et al., 2020; Matos et al., 2018; Roberts et al., 2009) and KIGGS (parents' questionnaire) (Hölling et al., 2012; Kamtsiuris, et al., 2007; Kurth et al., 2008; Mauz et al., 2019; Robert Koch Institute, 2017). Different terminologies are used regarding the concept of chronic condition/disability (e.g. learning disability, long-term illness, disability, medical condition, illnesses/disorders, diseases, long-standing illness, chronic disease, health problems).

Three of the questionnaires (The Young-HUNT Study, SMASH-02 and The Public Health

Survey for Children and Young People in Skåne) include separate questions about having or not a chronic disease and a disability (i.e. one question for each condition) and eleven include both conditions in the same question (e.g. do you have any long-term illness, disability, medical condition?). The Liv & Halsa Ung study (Andréasson et al., 2018; Brunnberg et al., 2009; Lindén-Boström & Persson, 2007, 2015) uses these two modalities, depending on the region and year in which the survey was carried out. In the Västmanland region the questions are only about disability. The School Health Promotion Study (SHP) (Finnish Institute for Health and Welfare, 2020) include the questions about chronic conditions for the 4th and 5th graders in the guardians' questionnaires.

All questionnaires include a question about whether the adolescents have a chronic disease/disability using different question formulations. Five of them ask whether this health condition was diagnosed by a doctor (the WAY study (HSCIC & Ipsos MORI, 2015), The Young-Hunt Study (Holmen et al., 2014), SILNE (Smoking Inequalities – Learning from Natural Experiments) (Lorant et al., 2015), HBSC (Inchley et al., 2020; Matos et al., 2018; Roberts et al., 2009) and the School Health Promotion Study (SHP) (Finnish Institute for Health and Welfare, 2020).

Three surveys include a brief definition of the concept under study (e.g. learning disability, long-standing illness or disability): the What About Youth Study (WAY) (HSCIC & Ipsos MORI, 2015), the YPBAS questionnaire (Northern Ireland Statistics and Research Agency, 2016) and RELACHS (Stansfeld et al., 2003). One of them

Table 1

Overview of the main general health questionnaires in European countries that include questions about chronic disease/disability

Survey name	Scope	Date	Countries involved	Age	References
What About Youth Study (WAY)	WAY is a study about youth's health and wellbeing. Some of the topic included are smoking, emotional and mental wellbeing, diet, physical activity, drugs, alcohol and bullying.	2014	England	Adolescents (15 years old)	HSCIC & Ipsos MORI, 2015.
Liv & Halsa Ung / Life & Health - Young People	Cross-sectional survey of young people's lives. It contains questions about living conditions, lifestyle and health.	Every 3 years. The study start date depends on the region.	Sweden (Region Uppsala, Landstinget Sörmland, Västmanland and Örebro län)	Students in the 7th and 9th years of elementary school and 2nd year of high school (13-18 years old)	Andréasson et al., 2018; Brunnberg et al., 2009; Lindén-Boström & Persson, 2007, 2015.
RELACHS – Research with East London Adolescent Community Health Survey	Longitudinal school-based study. The questionnaire included measures of health-related behaviours, risk and protective factors, mental and physical health, community satisfaction, life aspirations and socio-demographic factors.	2001-2005	England	School-aged children: Phase 1: 11-12 years (7th grade); Phase 2: 13-14 years (9th grade); Phase 3: 15-16 years (2nd year of high school)	Damarasingh et al., 2018; Stansfeld et al., 2003.
The Nord-Trøndelag Health Study (HUNT) / The Young-HUNT Study	Health survey with the main topics being asthma and allergies, mental health and quality of life, eating disorders and psychosomatic disorders with special emphasis on headaches, tobacco, alcohol habits, physical activity, health, stages of puberty and literacy problems.	4 waves of data gathering: 1995-1997; 1999-2000; 2006-2008; 2017-2019.	Norway	Participants aged 13-19 years old	Egan et al., 2014; Holmen et al., 2014; Mykkestad et al., 2012
SMASH-02 - Santé et styles de vie des adolescents âgés de 16 à 20 ans en Suisse (2002)	Adolescent's health, health needs and behaviours and their lifestyles.	2002	Switzerland	Adolescents aged 16-20 years old in public schools	Narring et al., 2004; Pitter et al., 2010.

Survey name	Scope	Date	Countries involved	Age	References
SILNE (Smoking Inequalities - Learning from Natural Experiments) Survey	SILNE intends to explore the association between adolescent's social ties at school, their socio-economic background, and their smoking behaviour.	2013	Namur (Belgium), Tampere (Finland), Hannover (Germany), Latina (Italy), Amersfoort (The Netherlands), and Coimbra and Coimbra (Portugal).	Students 14-16 years old	Lorant et al., 2015; Perelman et al., 2017.
Youth Health Monitor	Youth Health Monitor is a school-based cross-sectional questionnaire that provides information about the lifestyle and well-being of high school students. It includes questions about health, psychosocial well-being, use of social media, games, bullying, sports, smoking and drinking. The survey is carried out by the National Institute for Public Health and Environment and Municipal and Regional Health Service (GGD). A sample was taken in each one of the 25 GGD's. Every GGD can add additional questions to the basic questionnaire.	First Youth Health Monitor was held in 2015 and the second in 2019 (every four years).	Netherlands	High school students	Kuiper et al., 2018; RIVM, 2020.
The Danish National Youth Study	The Danish National Youth Study 2019 questionnaire contained questions concerning physical and mental health, health behaviour, health and well-being. It includes questions about sociodemographic factors, alcohol, smoking, cannabis and drug use, diet and meals, sleep, physical activity, sexual behaviour, physical health, body image, mental health, social relations, family life and school life.	2014 and 2019	Denmark	High school students	Pisinger et al., 2017, 2021.

Survey name	Scope	Date	Countries involved	Age	References
Young persons' behaviour & attitudes survey (YPBAS)	YPBAS is a survey that includes questions about important domains of the youth lives: smoking, drinking, physical activity, sexual health, and emotional well-being.	Six rounds: 2000, 2003, 2007, 2010, 2013 and 2016.	United Kingdom	11-16 years old	Foster et al., 2017; Northern Ireland Statistics and Research Agency, 2016.
Health Behaviour in School-aged Children (HBSC)	The Health Behaviour in School-aged Children (HBSC) study provides information about the health, well-being, social environment and health behaviour.	Every 4 years since 1982.	50 countries and regions across Europe and North America. Only a subset of countries includes chronic conditions questions that are not mandatory.	11, 13 and 15 years old	Inchley et al., 2020; Matos et al., 2018; Roberts et al., 2009.
My World Survey 2 – Second Level (MWS-2-SL)	My World Survey 2 is a study about the young people's mental health and wellbeing.	My World Survey 1: published in 2012; My World Survey 2: October 2018-May 2019.	Ireland	12-25 years old - Adolescent sample (12-19 years old); - Young adult sample (18-25 years old); - Seldom Heard sample (Mean age 18/19 years old)	Dooley & Fitzgerald, 2012; Dooley et al., 2019.

Survey name	Scope	Date	Countries involved	Age	References
The School Health Promotion (SHP) Study	SHP study is a school-based survey that explores the health, health behaviours and school experiences of adolescents. The study includes areas as: Well-being, inclusion and leisure; Health and functional capacity; Life-styles; Family and living conditions, among others.	The last one was developed in 2019 (every 2 years).	Finland	4th and 5th grade students in primary education and their guardians (since 2017); 8th and 9th grade students in basic education (since 1996); High school 1st and 2nd year students (since 1996); 1st and 2nd year students in vocational schools (since 2008).	Finnish Institute for Health and Welfare, 2020; Kaltiala-Heino et al., 2016; Ng et al., 2019; Räsänen et al., 2015.
The public health survey for Children and Young people in Skåne (2012)	Health survey that include questions about school, family, health, recreational habits, eating habits, alcohol and tobacco.	2012	Sweden	School pupils in grades 6, 9 and high school year 2 in all the 33 municipalities in Skåne.	Fridh et al., 2017; Grahn et al., 2012
School Health and Wellbeing (SHEU) Survey	This study collects data about the health and the wellbeing of children and young people.	Started in 2007 and is developed annually.	Essex - England	8-17 years old	SHEU, 2019.
The German Health Survey for Children and Adolescents (KIGGS)	KIGGS has a cross-sectional and cohort component. The study collects data on health, health behaviours, risk and protective factors, health services and living conditions. The study is conducted by Robert Koch Institute. The study includes questionnaires for the children/ adolescents and for their parents.	Baseline study: 2003-2006; Wave 1: 2009-2012; Wave 2: 2014-2017.	Germany	Children and adolescents 0-17 years old	Hölling et al., 2012; Kamtsiuris, et al., 2007; Kurth et al., 2008; Mauz et al., 2019; Robert Koch Institute, 2017.

Survey name	Scope	Date	Countries involved	Age	References
Saving and Empowering Young Lives in Europe (SEYLE)	SEYLE is a randomized controlled trial (RCT) that aimed to promote adolescents' mental health and to prevent/decrease suicidal thoughts and behaviours. Data are collected by means of surveys, among other methods.	2009-2011	Austria, Estonia, France, Germany, Hungary, Ireland, Italy, Romania, Slovenia and Spain, with Sweden (scientific coordinating center)	Adolescents aged between 14-17 years old (Mean age 15 years old)	McMahon et al., 2016, 2017; Wasserman et al., 2010, 2015.

(YPBAS) has a question about the provision of support in the management of the existing health condition.

Nine of the surveys included in this review specify the areas that may be affected by the existing chronic disease or disability, such as vision, hearing, mobility, learning and concentration, memory or other options, in which adolescents can write the area(s) that are affected (WAY, Liv & Halså Ung, RELACHS, The Young-HUNT Study, SMASH-02, The Danish National Youth Study 2014, HBSC, SHP and The public health survey for children and young people in Skåne). Nine surveys have questions on the limitations that these health conditions cause in the adolescents' daily life (WAY, Liv & Halså Ung (Region Landstinget Sörmland), RELACHS, The Young-HUNT Study, SMASH-02, The Danish National Youth Study 2014, YPBAS, HBSC and SHP). A question about the impact of the existing health condition specifically at the school level is included in four of the surveys (WAY, Live & Halså Ung, The Danish National Youth Study and HBSC).

The SMASH-02 questionnaire (Narring et al., 2004) includes a specific question about whether the adolescent have a disability and another one about whether the adolescent have a chronic disease, considering the limitations and special care that may exist, in yes or no questions. The question on disability has the option of answering whether it resulted from a disease, an accident or a birth problem. Four questionnaires include a question on whether the chronic condition requires taking medication (WAY, The Young-HUNT study, HBSC and KIGGS).

Finally, it should be noted that KIGGS (Hölling et al., 2012; Kamtsiuris et al., 2007; Kurth et al., 2008; Mauz et al., 2019; Robert Koch Institute, 2017) and SEYLE (McMahon et al., 2017; Wasserman et al., 2010, 2015) correspond to larger scale studies that use other measures for assessing the adolescents' health (each one in its specific aspect) in addition to questionnaires. We were only able to access the questions in the questionnaires filled in by the parents regarding the KIGGS survey. Table 2 presents an overview of the main categories present in the questions about chronic disease/disability found in the questionnaires.

Discussion

The present work intended to review the main general health questionnaires aimed at adolescents and carried out in Europe. Only questionnaires containing questions about different domains of the adolescents' lives (e.g. health, health behaviours, school, leisure) and which include questions about chronic disease and/or disability were considered.

There are specific questionnaires on chronic disease and/or disability that allow obtaining data on certain health conditions. However, given the scope of this review, these questionnaires are more limiting as they only provide information about these conditions, diseases or limitations. Alternatively, the objective of this review was more inclusive, as it intended to explore how data collection instruments directed to the general population (i.e. with and without chronic conditions) allow the integration of data on young people with health conditions in order to observe the results ob-

Table 2
Overview of the main categories present in the questions about chronic disease/disability found in the questionnaires

Survey name	Number of questions about chronic disease/disability	Categories present in the questions about chronic disease/disability						Medical support and information were provided to help manage the existing health condition.
		Have a chronic disease/disability (Yes/No)	Diagnosed by a Doctor	Requires medication	Limits the activities	Affects school participation	Requires special care (e.g. special diet, help from others)	
What About Youth Study (WAY)	5	X	X	X	X	X	--	--
Live & Hals Ung / Life & Health - Young People Region Örebro län	1 (2020) – only about disability	X						
Live & Hals Ung / Life & Health - Young People Region Örebro län	3 (2017)	X	--	--	--	X	--	--
Live & Hals Ung / Life & Health - Young People Region Landstinget Sörmland	2017/2020 2 (7 th grade students) 4 (9 th grade and 2nd year high school)	X	--	--	X	X	--	--
Live & Hals Ung / Life & Health - Young People Region Västmanland	2 (2020)	X	--	--	--	X	--	--

Survey name	Number of questions about chronic disease/disability	Categories present in the questions about chronic disease/disability						
		Have a chronic disease/disability (Yes/No)	Diagnosed by a Doctor	Requires medication	Limits the activities	Affects school participation	Requires special care (e.g. special diet, help from others)	Medical support and information were provided to help manage the existing health condition.
Live & Hals								
Ung / Life &								
Health - Young People	1 (2017)	X	--	--	--	--	--	--
Region Uppsala								
RELACHS - Research with								
East London Adolescent Community Health Survey)	3	X	--	--	X	--	--	--
The Nord-Trøndelag Health Study (HUNT) / The Young-HUNT Study	22	X	X	X	X	--	--	--

Categories present in the questions about chronic disease/disability									
Survey name	Number of questions about chronic disease/disability	Have a chronic disease/disability (Yes/No)	Diagnosed by a Doctor	Requires medication	Limits the activities	Affects school participation	Requires special care (e.g. special diet, help from others)	Medical support and information were provided to help manage the existing health condition.	
SMASH-02 - Santé et styles de vie des adolescents âgés de 16 à 20 ans en Suisse (2002)	10	X	--	--	X	--	X	--	
SILNE (Smoking Inequalities - Learning from Natural Experiments) Survey	1	X	X	--	--	--	--	--	
Youth Health Monitor	1	X	--	--	--	--	--	--	
The Danish National Youth Study 2014	8	X	--	--	X	X	--	--	
The Danish National Youth Study 2019	2	X	--	--	--	X	--	--	

Survey name	Number of questions about chronic disease/disability	Categories present in the questions about chronic disease/disability						
		Have a chronic disease/disability (Yes/No)	Diagnosed by a Doctor	Requires medication	Limits the activities	Affects school participation	Requires special care (e.g. special diet, help from others)	Medical support and information were provided to help manage the existing health condition.
Young persons' behaviour & attitudes survey (YPBAS) 2016 survey	14 (version A and B)	X	--	--	X	--	--	X
Health Behaviour in School-aged Children (HBSC)	3 (Chronic conditions short questionnaire)	--	X	X	--	X	--	--
My World Survey 2 – Second Level (MWS-2-SL)	11 (Child Functioning Module)	X	--	--	X	--	--	--
My World Survey 2 – Second Level (MWS-2-SL)	1	X	--	--	--	--	--	--
The School Health Promotion Study (SHPS)	3 (parents' questionnaire)	--	X	--	X	--	--	--
Health Promotion Study (SHPS)	2 (students' questionnaire)	--	--	--	--	--	--	--

Survey name	Number of questions about chronic disease/disability	Categories present in the questions about chronic disease/disability						
		Have a chronic disease/disability (Yes/No)	Diagnosed by a Doctor	Requires medication	Limits the activities	Affects school participation	Requires special care (e.g. special diet, help from others)	Medical support and information were provided to help manage the existing health condition.
The public health survey for Children and Young people in Skåne (2012)	2	X	--	--	--	--	--	--
School Health and Wellbeing (SHEU) Survey	1	X	--	--	--	--	--	--
The German Health Survey for Children and Adolescents (KIGGS)	49 (parents' questionnaire about diseases)	--	X	X	--	--	--	--

tained by these adolescents in other areas of their lives (e.g. health, school, friends, leisure, substance use).

The research carried out show that researchers can consider adolescents with chronic disease and/or disability through specific questions about their health condition, further allowing them to include this population in their analysis. The different studies included in this review have questions that focus on chronic disease and disability, but use different terminologies and response options, resulting in different ways of assessing the concept and the associated impacts or limitations. It is noteworthy that not all questionnaires had an English version available, so it was necessary to carry out a translation, which is an important fact to take into consideration in the analysis of these results.

Although some questions are formulated using similar logic, there are differences when we compare the way in which all these surveys measure chronic disease and disability. This result is in line with the evidence in the literature that points to the existence of several methods and definitions related to the concepts of chronic disease and disability (Michaud et al., 2007).

The standardization of a set of specific questions about chronic disease would be a possibility that would allow a comparison of results between the different studies and countries. This will contribute to a global vision of how young people with chronic conditions find themselves in different areas of their life and that are usually present in health questionnaires aimed at adolescents (e.g. health,

school, family, leisure). This logic of standardizing the questions used is already verified in relation to disability through the Washington Group Set of Questions on Disability, commonly used in censuses (Altman et al., 2016).

As already mentioned, the use of similar questions allows a greater level of comparison between different studies (HSCIC & Ipsos MORI, 2015). The WAY study, for instance, bases some of its questions on other questionnaires aimed at adolescents (e.g. HBSC) and whose questions already have evidence of their suitability among the students with chronic conditions.

Adolescence is characterized by several changes and there is a tendency towards the involvement in new experiences and an expansion of the social relationships (Clements-Nolle & Rivera, 2013; Pooley & Cohen, 2010). Thus, it is relevant to explore the several dimensions and domains of the life of adolescents with chronic disease and/or disability and the prevalence of behavioral or emotional difficulties (e.g. drug or alcohol abuse, violence, bullying, mental health problems) (Gubelmann et al., 2018; Pacoricona, Ehlinger et al., 2016; Pacoricona, Santos, et al., 2016; Pittet et al., 2010; Surís et al., 2011). For instance, children and adolescents with chronic disease or disability are at a higher risk of being victims of bullying, compared to peers without these health conditions. In recent years, it has been possible to verify a greater integration of the students with chronic conditions in the school context, which reinforces the need to monitor their well-being and quality of life and the impact that the negative attitudes and behaviours can have on them (Sentenac et al., 2011, 2012, 2013).

Youth with chronic conditions tend to need a greater social and emotional support to maximize their potential for relationship with peers and their integration into the school context, depending on the characteristics and symptoms presented. Therefore, it is relevant to use surveys as a source of information and as a means of assessing the psychosocial effects of living with a chronic disease (Mazur et al., 2013).

Another relevant aspect is the social participation of the adolescents with chronic conditions. There is evidence that these students tend to face more barriers (e.g. physical, social, institutional) in terms of the environments in which they are inserted (e.g. school) (Anaby et al., 2013). They also tend to experience more difficulties in establishing relationships with peers and are more likely to experience bullying (Pinquart, 2017; Pittet et al., 2010; Sentenac et al., 2011) which can trigger situations of isolation (Koster et al., 2010). In this sense, it could be interesting to focus more on this dimension in the context of general health questionnaires, since the data collection on the social participation of adolescents with chronic conditions could contribute to a better understanding and planning of future interventions.

This study has associated limitations, namely the translations of the questionnaires into English that might affect the results due to linguistic and cultural variations. Even though a thorough research has been done, some questionnaires may not be included in the search results from the databases due to linguistic barriers (e.g. unavailable translations).

Conclusion

This work allowed an analysis of the European panorama regarding the assessment of chronic disease and disability in general health questionnaires aimed at adolescents. It also allowed to explore the type of questions that are currently being included in these instruments.

The inclusion of adolescents with chronic disease and disability in general health questionnaires allows the exploration of data regarding youths in different contexts of their life, which helps in the design of programs and measures adjusted to their needs. The characteristics and particularities of the different health conditions and the associated risk factors reinforce the need for planning interventions to help these adolescents to face the challenges present in different contexts of their daily life and to promote skills to manage their daily symptoms, limitations and difficulties.

The implications of chronic disease for the life of adolescents are well reported in the literature (Sav et al., 2015). Therefore, it is important to have data available to help outline public policies and appropriate measures for this population (Van der Lee et al., 2007) at the school context and at a physical and mental health level, among other domains.

The perception of illness depends on psychological, social and cultural factors and is influenced by variables such as age. Thus, when constructing the items of a questionnaire, it is necessary to take into account the fact that the questions must be perceptible to the child or adolescent and also aligned with the general definition of the construct under evaluation (i.e. chronic disease or disability) (Mazur, 2013).

In addition, it is necessary to consider the limitations associated, for example with disability, which can pose barriers to participation in self-administered questionnaires. Thus, it is important to emphasize the need to consider the barriers that may arise, as they are factors that may limit the data collection from these adolescents or even make it impossible (Hassain, 2015). In this sense, making adaptations to the general questionnaire to better adjust it to possible limitations of the adolescents can be an important option to cover a larger number of participants.

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