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Brief report: The KIDSCREEN follow-up study on Health-related Quality of Life (HRQoL) in Spanish children and adolescents. Pilot test and representativeness☆

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A B S T R A C T

The Spanish KIDSCREEN follow-up study reassessed the Spanish baseline sample ($n = 840$) of the European KIDSCREEN study 3 years later (2006). The aims of this paper were to describe the KIDSCREEN follow-up study and the pilot test, and to analyze participation rates and representativeness. Instruments included the KIDSCREEN-52 HRQoL measure and a set of scales including the possible explanatory variables. Focus groups and individual interviews were carried out in a pilot test. Participants were compared with non-participants at baseline, and also with Eurostat census data. Twenty-two out of 24 subjects were interviewed in the pilot test. Fifteen items needed to be modified after the pilot test. Participation rate reached 54% ($n = 454$). Participants (mean age = 12.71 years old) were on average 6 months younger than non-participants ($p = 0.03$), and from more educated families. KIDSCREEN follow-up instrumentation seems adequate for collecting factors with potential influence on HRQoL. Follow-up respondents' representativeness seems to be acceptable.

Introduction

To date, few longitudinal studies have analyzed changes in Health-related Quality of Life (HRQoL) in children and adolescents. Most studies assessed HRQoL in children with specific chronic conditions (van Empelen, Jennekens-Schinkel, van Rijen, Helders, & van Nieuwenhuizen, 2005; Sawyer et al., 2004; Vargus-Adams, 2006). Few studies included general population samples in a short follow-up period (Meuleners & Lee, 2003) or were specifically focused on the association of lifestyle factors and changes in self-perceived health (Chen, Sekine, Hamanishi, Yamagami, & Kagamimori, 2005), or pubertal changes and psychological well-being (Benjet & Hernandez-Guzman, 2002). Measurement of changes in HRQOL in population-based samples is needed for obtaining a gold-standard against which changes in different populations or pre-post intervention studies can be compared.

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The KIDSCREEN European project designed a cross-cultural, generic, self-administrated HRQoL measure for young population (8 to 18 years) in 13 European countries (Ravens-Sieberer et al., 2008). The Spanish KIDSCREEN follow-up study was designed to analyze changes in HRQoL and it association with physical, psychological and social predictors during 3-years of follow-up. The aim of this paper is to describe the KIDSCREEN follow-up study, to report on the pilot testing of the instruments, and to analyze participation rates and representativeness.

Methods

The KIDSCREEN follow-up study reassessed in 2006 a representative Spanish sample of children and adolescents that were 8–18 years old at the baseline assessment in 2003, and their parents.

Instruments

KIDSCREEN follow-up instrumentation included questionnaires addressed to children/adolescents and to their parents. The KIDSCREEN-52 is a self-reported, generic measure of HRQoL for use in children and adolescents (Ravens-Sieberer et al., 2008). It includes 10 dimensions: Physical Well-being (5 items); Psychological Well-being (6); Moods & Emotions (7); Self-Perception (5); Autonomy (5); Parent Relation & Home Life (6); Social Support & Peers (6); School Environment (6); Social Acceptance (bullying) (3), and; Financial Resources (3). The Spanish version of the KIDSCREEN-52 has shown acceptable levels of reliability and validity (Tebe et al., 2008) and was administered at both baseline and follow-up. A KIDSCREEN index score can be calculated with 10 out of the 52 items of the research version.

In the questionnaires administered to children and adolescents, and their parents we also collected information on factors known to have a potential influence on changes in HRQoL, such as pubertal development, gender-specific body changes, sexual intercourse, and pregnancy and sexual transmitted diseases. The physical activity and leisure activity scales were adapted from the Health Behaviour School-aged Children (HBSC) (Currie et al., 2004). A brief assessment of dietary patterns was also included (Agència de Salut Pública de Barcelona, 2004). Variables on healthcare services use as reported by children/adolescent and their parents included the number of visits, and type of services used. A risk behaviour scale was added regarding tobacco smoking, drugs and alcohol, patterns of consumption, attitudes, frequency and starting age. The Coddington Life Events Scales (CLES) is a children/adolescent life events checklist which contains 53 items measuring negative and positive life events which have happened during the last three years. The Composite International Diagnostic Interview-Short Form (CIDI-SF), was used to assess parent's mental health.

Pilot test

A pilot test was carried out to assess the feasibility of administration and understandability of the new measurements included in the Spanish KIDSCREEN follow-up survey. A convenience sample of 24 participants (aged between 11 and 21 year-olds) was selected from those registered in a primary care centre (PCC) in Lloret de Mar, Spain (range of ages was defined based on those expected in the KIDSCREEN follow-up assessment). Children/adolescents and their mothers were asked to fill in the self-administered KIDSCREEN follow-up instrumentation at home. Focus groups with children and adolescents and individual interviews with mothers were carried out within 2 weeks after delivery of questionnaires. Interviews focused on questions collecting retrospective information, questions about changes that had occurred in the past three years, and the new added scales. Content analysis of the recorded interviews was carried out.

Data collection

The Spanish KIDSCREEN baseline sample was recruited between May and November 2003 as part of the European KIDSCREEN fieldwork (The KIDSCREEN Group Europe, 2006). A representative address sampling of children/adolescents 8–18 years old and their parents was conducted via computer-assisted telephone interviews. Questionnaires were sent by post to families who agreed to participate, and children/adolescents and parents were requested to fill them up separately. The questionnaires were completed in the respondent's home and sent back to the Spanish coordinating centre in a prepaid envelope.

Between May and November 2006, follow-up questionnaires were posted by mail to all children/adolescents and their parents to all participants at the baseline sample who answered affirmatively to the question: Are you willing to participate in a follow-up study? ($n = 840$ of 926). The fieldwork followed the same methodology applied at baseline (Berra et al., 2007). Postal reminders were sent to those who had not returned their questionnaires and the remaining non-respondents were contacted by phone.

Response rate and respondents' characteristics

At the end of the follow-up fieldwork participants and non-participants were compared by gender, age, parental level of education, socio-economic status and baseline KIDSCREEN-10 index scores, mental health, reporting chronic conditions, limitation of activities and healthcare coverage. A chi square test, *t*-test or the Mann–Whitney test was used in these

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comparisons depending on the nature of the variable. A binomial test was used to compare the achieved sample with Eurostat data (European Commission, 2000) in terms of age and gender. A chi-squared goodness of fit test was used to analyze whether the sample differed significantly from the reference population in terms of level of education, according to the International Standard Classification of Education (ISCED) (Eurostat yearbook '96, 1996).

Results

Pilot test and questionnaire development

Twenty-two out of 24 subjects participated in the pilot test (12 mothers and 10 children/adolescents, 3 boys and 7 girls, age range = 11 – 21 years old); three of them had a chronic condition. Two children/adolescents could not be interviewed.

Average reported time to complete the questionnaires was 40 minutes, although younger children reported more than one hour to do it. Fifteen items in 4 of the modules needed modification after the pilot test. For example, the Spanish translation of items regarding "solving problems with parents" and "become an adult member of a church" in the Life Events Scale were adapted to address participants' concerns and suggestions as expressed during the interviews. Modules that needed some modifications or rewording are shown in Table 1. Retrospective questions about nutritional and physical activities patterns were, in general, easily understood by subjects. Older adolescents found questions of the KIDSCREEN-52 to be acceptable for them in terms of the content and relevance of the questionnaire.

Table 1 shows the KIDSCREEN follow-up instrumentation that resulted from the pilot test phase. The Children/adolescent questionnaire includes 328 items grouped in 24 modules and the parent's questionnaire has 255 items in 17 modules.

Response rate and sample characteristics

The response rate at follow up was 54% ($n = 454$). Non-participants were older at baseline (2003) than participants (13.1 y; SD = 2.91 vs 12.7 y; SD = 2.89; $p = 0.03$); there were no differences by gender (Table 2). Families in the lowest category of education were less likely to participate in the follow-up compared to those with a higher level of education ($p = 0.03$). No statistically significant differences were found on the KIDSCREEN index, chronic conditions, mental health status or limitation of activities (p = NS). Nevertheless, participants scored slightly better than non-participants on almost all of these variables.

Similarly, participants at follow-up were slightly younger and had a higher family level of education than the corresponding group based on Eurostat data ($p < 0.001$) (Table 2).

Discussion

The study analyses feasibility and understandability of the instrumentation, and participation rates and representativeness of the KIDSCREEN follow-up study on HRQoL in children and adolescents.

Table 1
KIDSCREEN follow-up instrumentation: modules and items.

Modules and items	Children/adolescent version	Parent version
	Number of items	
HRQoL, KIDSCREEN (R)	52	52
Children/adolescents general health (R)	29 (M)	37
Children/adolescents satisfaction with health (R)	15	–
Risk behaviour (N)	14	–
Physical activity (N)	3	–
Nutritional patterns (N)	24	–
Children/adolescents mental Health (R)	35	36
Leisure activities (N)	7	–
Sexual health and pubertal development (N)	12	–
Parent child relationship (R)	–	5
Socio-economic status (R)	4	12
Life events (N)	55 (M)	–
Social Support (R)	3	–
Children/adolescents use of healthcare services (N)	48	29
School and job achievement (N)	18	–
Parent health and mental health (N)	–	42 (M)
Parent healthcare utilization (N)	–	30
General and socio-demographic information (R)	5	8 (M)
Final module (R)	4	4
TOTAL	328	255

R: repeated from the baseline instrument.
N: new added scales/items.
M: needed modification in some items after the pilot test.

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Table 2
KIDSCREEN follow-up, comparison of participants with non-participants, and with Eurostat data.

Sample characteristics	Participants	Non-participants	p-Value	Eurostat data for Spain	p-Value
Gender					
Male	48.0 %	52.5 %	NS	48.5 %	NS
Female	52.0 %	47.5 %		51.5 %	
Mean age in 2003 (SD)	12.7 (2.9)	13.1 (2.9)	0.03	13.2 (1.1)	<0.001
Parental level of education					
Low	38.9 %	46.4 %	0.03	63.9 %	<0.001
Medium	26.2 %	19.7 %		18.1 %	
High	33.7 %	31.1 %		18 %	
Socio-economic status (FAS)					
Low	18.2 %	21.8 %			
Medium	49.3 %	48.4 %			
High	30.2 %	28.2 %			
Type of healthcare coverage					
Public	74.4 %	73.8 %	NS		
Double (public and private)	20.9 %	21.8 %			
KIDSCREEN Index (SD)	53.3 (11.14)	51.8 (10.74)	NS		
Mental health status (SDQ)					
Unlikely	80.2 %	76.4 %	NS		
Possible	14.1 %	13.7 %			
Probable	3.9 %	7.8 %			
Chronic conditions					
None	66.1 %	63.2 %	NS		
One or more chronic conditions	32.6 %	35.5 %			
Limitation of activities (number of missed school days)					
0 days	35.1 %	37.6 %	NS		
1 or more days	64.5 %	61.1 %			

SD: standard deviation.
Missing values: parental Level of education, $n = 16$; socio-economic status, $n = 16$; healthcare coverage, $n = 38$; mental health status, $n = 16$; chronic conditions, $n = 12$; limitation of Activities, $n = 7$.

Qualitative analysis of the pilot test found no major problems in retrospective questions regarding three years of follow-up. A small number of items were rewritten to improve the instrument's feasibility. In general, the pilot test showed that if the questionnaire addresses salient aspects for children and adolescents and their mothers and uses and adequate recall period, no major bias should be expected. On the other hand, administering the KIDSCREEN-52 measure seems to be feasible in the population aged 19–21 years old, although future studies are needed to determine its validity and reliability in this specific population subgroup.

The response rate obtained for the KIDSCREEN follow-up was similar to that of comparable studies. Recent studies in children and adolescents 11–21 years old using postal questionnaires showed that the range of responses varies from 30% to 89% (Hawley, Ward, Magnay, & Long, 2004; Hestbaek, Leboeuf-Yde, Kyvik, & Manniche, 2006; Honkalampi et al., 2005; Louwman, van Lenthe, Coebergh, & Mackenbach, 2004; Polinder et al., 2005). (Hille, Elbertse, Gravenhorst, Brand, & Verloove-Vanhorick, 2005) report that adolescents of 19 years were less willing to participate in a mail posted questionnaire than younger children (14 years old). The present study found that participants were slightly younger than non-participants and, contrary to the Hille et al. study, no differences were found in response rates by gender. Participants in the present study tended to have a higher level of education. This fact is common in this type of studies (Hille et al., 2005; Williams, Wake, Hesketh, Maher, & Waters, 2005). Therefore, interpretation of the results on factors related to family's socio-economic status should take into account this issue.

The follow-up sample achieved proportions by age and gender which were similar to the reference population. Nevertheless, results should be treated with caution given that participants seemed to be relatively healthier than non-participants. The status of non-participants and participants may have changed over the 3 year follow-up period, though the absence of data for non-participants did not allow us to analyze these differences. Finally, another factor with potential influence on response rate was the length of the questionnaires, although no major problems were reported during the pilot test.

Conclusions

In summary, KIDSCREEN follow-up instrumentation seems to adequately collect information on factors with potential influence on HRQoL and to capture changes in habits and major life events in healthy adolescents, as well as in a 3 year retrospective assessment. Follow-up respondent's representativeness sample seems to be acceptable and it is expected that no major biases (selection or information bias) would have an effect on the future longitudinal results.

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