

Health-related quality of life in children with and without chronic conditions. A multicenter study

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ABSTRACT

Introduction. Chronic conditions (CCs) in the early stages of life may have an impact on various dimensions of health-related quality of life (HRQoL) in children.

Objective. To compare HRQoL in children with confirmed CCs, reported CCs, and without CC. **Population and Method.** Cross-sectional study conducted in 2012 in the context of a larger research study carried out at schools in Córdoba and Bahía Blanca, and at Hospital Italiano of Buenos Aires and Hospital Prof. Dr. Juan P. Garrahan at Buenos Aires. The presence of a chronic condition was established by medical diagnosis at the hospital or as reported by schoolchildren's caregivers. Eight-to-twelve year-old children completed the KIDSCREEN-52 questionnaire on HRQoL, a pubertal development scale, and a family financial resources scale. The association between CCs and HRQoL adjusted by sex, age, pubertal development, maternal education level, and socioeconomic level was estimated.

Results. Six hundred and seventy children/caregiver dyads participated; 13.3% (n=89) had confirmed CCs, 14.5% (n=97) were schoolchildren with reported CCs, and the rest corresponded to healthy schoolchildren. Their average age was 10.2 years old (standard deviation=1.01); 54.8% were girls. Having a confirmed CC was associated with a higher frequency of low physical well-being (odds ratio [OR]: 2.61; 95% confidence interval [95% CI]: 1.43-4.76), while the presence of a reported CC was associated with a low score in psychological well-being (OR: 1.96; 95% CI: 1.06-3.63), self-perception (OR: 2.22; 95% CI: 1.28-3.87), and parent relations (OR: 2.04; 95% CI: 1.21-3.44).

Conclusions. Children with confirmed CCs showed a higher frequency of physical discomfort, and those with reported CCs showed discomfort in psychosocial areas compared to children without CCs.

Key words: health-related quality of life, children, schoolchildren, chronic conditions.

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INTRODUCTION

Chronic conditions (CCs) may have an impact on the ability to perform daily activities, cognitive development, emotions, self-

perception, interpersonal relationships and relation with the environment.¹

Health-related quality of life (HRQoL) allows to assess the impact of disease on daily life both at a subjective and at an overall level, and therefore provides multidimensional information on performance status and well-being, with a good correlation with pathophysiological indicators,² regardless of the specific clinical manifestations of each disease, also including the individual's perspective. In addition, so-called generic instruments allow to compare healthy and sick groups, or groups with different diseases,³ and consider children with different health problems but who share the same experience.

Information obtained based on the perceptions of a child with CC is supplementary to traditional measures and its inclusion in decision-taking is increasingly relevant.⁴

Previous studies have demonstrated that some perceived health dimensions are altered by the presence of a CC, while others do not suffer any impact, and this varies depending on the different diseases. The hypothesis of this study is that children with CCs will have a higher rate of lower scores in HRQoL than healthy children. The objective of this study was to compare HRQoL in children with confirmed CCs, reported CCs, and without CC.

POPULATION AND METHODS

Cross-sectional study conducted in 2012 at eight schools in the city of Córdoba and five schools in the city of Bahía Blanca, and at Hospital

Italiano de Buenos Aires and Hospital Nacional de Pediatría "Dr. Prof. Juan P. Garrahan", at Buenos Aires, Argentina. In both hospitals, 8 to 12 year-old children attending the outpatient clinic for the management of asthma, juvenile idiopathic arthritis, type 1 diabetes mellitus, and inflammatory bowel disease diagnosed at least 6 months before study initiation were included; and all 4th to 6th grade schoolchildren from schools selected by convenience were invited to participate until reaching the desired sample size. Informed consent signature by the child's caregiver (mother, father or legal guardian), and the child's assent were inclusion criteria to be met. In addition, education authorities approved the study.

This study is the baseline phase of a longitudinal investigation with a sample made up of 472 healthy children and 95 children in each subgroup (confirmed CC and reported CC) conducted to analyze repeated group measures and to find 2-point differences in the mean HRQoL score by accepting an alpha risk of 0.05 and a beta risk of 0.2 in a two-tailed test. This sample size is sufficient to analyze the difference in means and associations using multivariate logistic regression models.

HRQoL was measured using the Argentine version^{7,8} of the KIDSCREEN-52 questionnaire.^{9,10} This is a generic instrument that reports ten HRQoL dimensions: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance, and financial resources. The KIDSCREEN-52 was adapted⁷ and subjected to reliability and validity studies⁸ in relation to the Argentine population. It provides a standard mean score of 50 and a standard deviation of 10 points; the score is then categorized as high or low, and a cut-off value of ± 0.5 standard deviation of the reference mean is established.⁹

The presence of CC was confirmed based on medical records; the same diagnoses were included in both hospitals taking into account hospital departments' willingness to collaborate. At schools, caregivers were asked whether the child had had a chronic condition in the past 12 months, which had been diagnosed by a physician and for which treatment had been administered in the past year using a list of prevalent diseases: chronic allergy, asthma, bronchitis, diabetes,

urinary tract infection, febrile seizures, epilepsy, malignancies, behavioral disorders and mental disorders. An open question was also included and reviewed in order to rule out acute conditions or symptoms. Children with the same conditions included in the hospital samples (for example, asthma) were not excluded. Based on this outcome measure, groups were divided into confirmed CC (children from hospitals), reported CC (schoolchildren) and without reported CC (schoolchildren) so as to compare HRQoL in children with reported and confirmed conditions, while healthy children comprised the reference group for both CC groups. Groups of children with CC differ when considering the source of information (confirmed medical diagnosis versus caregiver's report), prevalence and variety of diagnoses (defined as per inclusion criteria versus any reported diagnosis), and the extent of covered healthcare needs (under specific treatment versus various possibilities).

The Pubertal Development Scale (PBS)¹¹ questionnaire was used as an indicator of pubertal development (PD) based on physical changes in sexual characteristics, which grants a score between 5 and 25. A higher score indicates a higher degree of development.

Family socioeconomic level (SEL) was measured by means of the Family Affluence Scale (FAS)¹² using four questions on household material resources (number of cars and computers owned by the family, whether the child has his/her own room, and family vacations in the past year); the FAS score was categorized as low (score: 0-3), middle (score: 4-5), and high (score: 6-7).

Maternal education level (MEL) refers to the highest completed education level. MEL was categorized as per the International Standard Classification of Education (ISCED) as low (up to complete primary education), middle (complete secondary education), and high (complete tertiary or university education).

The questionnaire aimed at children asked on HRQoL, PD and SEL, while the one aimed at caregivers asked about relationship with the child, MEL and presence of CC in the child. At schools, children completed the questionnaire in the classroom using a self-administration approach guided by trained staff, while caregivers completed questionnaires at home. At hospitals, both questionnaires were administered during an interview at the waiting room. Questionnaires included other questions regarding employment

characteristics and parent-reported HRQoL, but they were excluded from this study.

Absolute frequencies and percentages were calculated for data analysis. Mean scores for HRQoL dimensions were compared based on presence of CC; Bonferroni's correction for multiple comparisons was applied. The effect size was calculated to establish the size of such differences; values ranging from 0.20 to 0.50 were considered small effects, from 0.51 to 0.80, moderate effects, and >0.80, large effects. Finally, the association between the presence of CC and HRQoL adjusted by sex, age, PD, MEL, and SEL was estimated using a multivariate logistic regression analysis. A value of $p < 0.05$ was considered significant.

This study was conducted in the setting of a research study named "Longitudinal, multicenter study on health changes occurring between 8 and 12 years old from children's perspective". The protocol was approved by the Research Protocol Ethics Committee of Hospital Italiano de Buenos Aires, the Bioethics Institutional Board of Hospital Municipal de Agudos Dr. L. Lucero (city of Bahía Blanca), the Institutional

Ethics Committee on Child and Adult Health of Hospitalary District, province of Córdoba, and the Associate Department of Teaching and Research of Hospital de Pediatría Prof. Dr. Juan P. Garrahan at Buenos Aires.

RESULTS

The sample was made up of 670 children/caregiver dyads; of these, 13.3% (n= 89) had a confirmed CC, 14.5% (n= 97) had a reported CC, and 72.4% were schoolchildren without CCs. In most cases, mothers completed the questionnaire (86.1%). Children were between 8 and 13 years old; their mean age was 10.2 years old, with a standard deviation of 1.01 year old. Girls accounted for 54.8% of participants. Mean degree of pubertal development was 9.08 among boys, and 9.34 among girls. A high economic status was observed in 65.9% of patients from Hospital Italiano, in 50.2% of schoolchildren from Bahía Blanca, in 40.9% of schoolchildren from Córdoba, and in 33% of patients from Hospital Garrahan ($p= 0.004$) (Table 1). Less than half of caregivers had completed secondary or tertiary education.

The hospital sample was made up of 89

TABLE 1. Sample description by facility of origin

	Schools in Córdoba		Schools in Bahía Blanca		Hospital Italiano-CABA		Hospital Garrahan-CABA		Total	p*
	n= 339	(%)	n= 242	(%)	n= 41	(%)	n= 48	(%)	n= 670 (%)	
Age										
Mean score	10.2		10.2		9.9		9.9	10.2	0.031	
[SD]	[1.1]		[0.9]		[1.3]		[2.3]		[1.1]	
Sex										
Male	163	(48.1)	102	(42.1)	18	(43.9)	20	(41.7)	303 (45.2)	0.509
Female	176	(51.9)	140	(57.9)	23	(56.1)	28	(58.3)	367 (54.8)	
Degree of pubertal development										
Mean score	9.2		9.5		7.2		8.4		9.2	0.009
[SD]	[3.3]		[3.1]		[3.4]		[2.9]		[3.2]	
Chronic condition										
Confirmed	0		0		41	(100)	48	(100)	89 (13.3)	
Reported	59	(17.4)	38	(15.7)	0		0		97 (14.4)	
Without CC	280	(82.6)	204	(84.3)	0		0		484 (72.4)	
Economic status										
Low	56	(18.2)	33	(13.8)	1	(2.4)	13	(27.1)	103 (16.2)	0.004
Middle	126	(40.9)	86	(36)	13	(31.7)	19	(39.6)	244 (38.4)	
High	126	(40.9)	120	(50.2)	27	(65.9)	16	(33.3)	289 (45.4)	
Maternal education level										
Low	225	(67)	108	(44.6)	0		32	(68.1)	365 (54.8)	0.001
Middle	82	(24.4)	86	(35.5)	12	(29.3)	9	(19.1)	189 (28.4)	
High	29	(8.6)	48	(19.8)	29	(70.7)	6	(12.8)	112 (16.8)	

SD: standard deviation. CABA: Autonomous City of Buenos Aires.

* P value of chi square test and t-test for the comparison of group proportions and mean values, respectively.

children, mostly from the asthma (39.3%) and diabetes (29.2%) groups. Among schoolchildren, 97 caregivers referred that children had one or more CCs; the most common CCs were chronic allergy (28.7%) and pulmonary disease (31.3%) (Table 2).

Children from hospitals had a worse physical well-being, but better moods and emotions, self-perception, school environment, and social acceptance than children without CCs ($p < 0.05$). Likewise, schoolchildren who stated having a CC showed a worse score in physical well-being, and also a worse psychological well-being, self-perception and autonomy when compared to their healthy peers ($p < 0.05$). The size of such differences was small, but statistically significant (Table 3).

As per the multivariate analysis, children with confirmed CCs had a higher frequency of low physical well-being (odds ratio [OR]: 2.61; 95% confidence interval [95% CI]: 1.43-4.76) when compared to healthy children, while the presence of reported CCs was associated with a higher frequency of low scores in psychological well-being (OR: 1.96; 95% CI: 1.06-3.63), self-perception (OR: 2.22; 95% CI: 1.28-3.87), and parent relations and home life (OR: 2.04; 95% CI: 1.21-3.44), when compared to schoolchildren without CCs (Table 4).

TABLE 2. Frequency of chronic conditions among schoolchildren and hospital samples

Hospitals. Confirmed conditions: n= 89	%	(n)
Asthma	39.3	(35)
Diabetes	29.2	(26)
Arthritis	19.1	(17)
Inflammatory bowel disease	12.4	(11)
Schools. Reported conditions: n= 150*	%	(n)
Chronic allergy	28.7	(43)
Recurrent bronchitis	17.3	(26)
Asthma	14	(21)
Urinary tract infection	10	(15)
Behavioral disorders	8.7	(13)
Mental disorders	4	(6)
Epilepsy	3.3	(5)
Gastrointestinal disorders	2.7	(4)
Endocrine disorders	2	(3)
Febrile seizures	1.3	(2)
Diabetes	0.7	(1)
Other chronic conditions	7.3	(11)

* Among schoolchildren, 97 caregivers reported that children had one or more chronic conditions.

DISCUSSION

This study shows the differences in HRQoL among healthy children and those with CCs. Physical well-being and psychosocial dimensions of health were altered among children with long-term conditions.

Children with CCs had a worse physical well-being than healthy children, as observed in other studies;^{10,13} differences are more pronounced among children from hospitals. In a study considering physical CCs, all groups had a worse physical well-being and social functioning than healthy children, except for patients with diabetes, and a lower psychological health; the latter had the best scores.⁵

In addition, it is known that psychological well-being and self-perception are compromised among children with CCs. However, in a study that found differences in physical functioning between most groups of patients and healthy subjects in terms of social and psychological functioning, only some showed differences from the healthy group.^{14,15} In our study, schoolchildren with reported CCs showed a worse psychological well-being, self-perception, and parent relations and home life compared to healthy children. However, children from hospitals showed better moods and emotions, self-perception, school environment, and social acceptance than healthy children. Such differences are an interesting finding, since different CCs may have an impact on different HRQoL dimensions due to specific factors related to their condition and the care received.

Some special sample characteristics that may influence differences observed, such as sex and age, MEL and SEL, were adjusted for the multivariate analysis. However, there are probably other differences, for example, access to health services and treatments, that were not assessed in this study. In addition, children with CCs from hospitals may have scores that are higher than expected¹⁶ in relation to psychosocial dimensions as a result of their resilient attitude towards difficulties, since HRQoL is related with the meaning people attribute to life. In addition, a feeling of personal development associated with the experience, together with a qualitative and quantitative correlation, has been described among survivors of cancer and transplants.¹⁷ Such adaptability has also been suggested by some authors in relation to situations of inequality.¹⁸

In relation to this study's limitations, it is worth noting that the validity of classification by CC varies when it is reported or when it is diagnosed by a physician. However, reported CCs are recognized indicators of perceived needs in health service studies conducted using population surveys. Another limitation, which is inherent to the study's cross-sectional design, is that it is not possible to make causality assumptions between the presence of a CC and a low HRQoL. Recording variability over time in relation to the stage of the disease and the implications in social environment and family support¹⁹ children receive would probably allow to make a more profound analysis.

CONCLUSIONS

Children with confirmed CCs showed a higher frequency of physical discomfort, and those with reported CCs as reported by their caregivers showed discomfort in psychosocial areas compared to children without CCs. ■

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TABLE 3. Mean scores for health-related quality of life dimensions as per the presence of chronic conditions

HRQoL dimensions	Chronic condition	n	M (SD)	95% CI	ES (with CC vs. without CC)
Physical well-being	Confirmed	88	50.4 (9.5)	48.4-52.4	-0.28*
	Reported	95	50.3 (10.3)	48.2-52.4	-0.28*
	Without CC	456	53.4 (11.1)	52.4-54.4	
Psychological well-being	Confirmed	89	56.8 (9.0)	54.9-58.7	0.05
	Reported	96	52.7 (10.3)	50.6-54.8	-0.38*
	Without CC	480	56.3 (9.2)	55.5-57.2	
Moods and emotions	Confirmed	84	51.8 (10.1)	49.6-53.9	0.46*
	Reported	93	45.2 (10.5)	43.1-47.4	-0.17
	Without CC	459	47.0 (10.6)	46.1-48.0	
Self-perception	Confirmed	88	57.7 (10.3)	55.5-59.9	0.31*
	Reported	96	50.9 (10.5)	48.8-53.0	-0.33*
	Without CC	474	54.4 (10.7)	53.4-55.3	
Autonomy	Confirmed	89	53.1 (10.9)	50.8-55.4	0.04
	Reported	97	48.9 (10.0)	46.9-50.9	-0.38*
	Without CC	478	52.7 (9.9)	51.8-53.6	
Parent relations and family life	Confirmed	87	54.3 (9.4)	52.3-56.3	0.19
	Reported	94	49.8 (10.7)	47.6-52.0	-0.26
	Without CC	471	52.4 (9.8)	51.5-53.3	
Peers and social support	Confirmed	85	56.8 (12.2)	54.2-59.5	0.23
	Reported	96	52.4 (12.0)	50.0-54.8	-0.14
	Without CC	466	54.1 (11.7)	53.0-55.2	
School environment	Confirmed	86	60.5 (10.5)	58.2-62.7	0.38*
	Reported	91	55.7 (11.9)	53.2-58.2	-0.02
	Without CC	465	56.0 (12.2)	54.9-57.1	
Social acceptance	Confirmed	89	48.8 (12.4)	46.2-51.4	0.28*
	Reported	94	42.8 (12.4)	40.3-45.4	-0.20
	Without CC	473	45.3 (12.3)	44.1-46.4	
Financial resources	Confirmed	87	49.4 (9.1)	47.4-51.3	0.25
	Reported	96	44.6 (9.2)	42.8-46.5	-0.27
	Without CC	470	47.1 (9.4)	46.2-47.9	

M: mean; SD: standard deviation; CI: confidence interval; ES: effect size; HRQoL: health-related quality of life.

* Significant differences, Bonferroni's test $p < 0.05$.

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TABLE 4. Odds ratio and 95% confidence intervals for low scores in health-related quality of life dimensions as per the presence of chronic conditions

HRQoL dimensions	Chronic condition			OR*	95% CI	
		n	%		LL	UL
Low score in physical well-being	Confirmed	25	41.0	2.61†	1.43	4.76
	Reported	23	29.9	1.35	0.77	2.36
	Without CC	82	23.8	1		
Low score in psychological well-being	Confirmed	8	12.9	1.05	0.46	2.43
	Reported	19	24.4	1.96†	1.06	3.63
	Without CC	50	14.0	1		
Low score in moods and emotions	Confirmed	22	38.6	0.66	0.36	1.20
	Reported	46	61.3	1.34	0.80	2.26
	Without CC	185	53.5	1		
Low score in self-perception	Confirmed	6	9.8	0.48	0.19	1.21
	Reported	29	36.7	2.22†	1.28	3.87
	Without CC	69	19.4	1		
Low score in autonomy	Confirmed	22	35.5	1.73	0.95	3.15
	Reported	30	38.0	1.62	0.97	2.73
	Without CC	96	26.9	1		
Low score in parent relations	Confirmed	21	35.0	1.61	0.88	2.97
	Reported	32	42.1	2.04†	1.21	3.44
	Without CC	97	25.9	1		
Low score in peers and social support	Confirmed	13	22.4	1.17	0.58	2.36
	Reported	24	30.4	1.71	0.98	2.97
	Without CC	70	20.0	1		
Low score in school environment	Confirmed	10	16.9	0.84	0.39	1.79
	Reported	16	21.6	0.98	0.52	1.84
	Without CC	78	22.4	1		
Low score in social acceptance	Confirmed	21	33.9	0.58	0.32	1.04
	Reported	46	60.5	1.48	0.88	2.48
	Without CC	180	50.6	1		
Low score in financial resources	Confirmed	24	39.3	0.88	0.94	1.56
	Reported	42	53.8	1.61	0.97	2.67
	Without CC	150	42.7	1		

*OR: multivariate logistic regression analysis, adjusted by age, sex, pubertal development, maternal education level, and family economic status.

LL: lower limit. UL: upper limit.

HRQoL: health-related quality of life.

† p < 0.05.

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