



The Adaptation and Psychometric Properties of the Kid-KINDL^R for Hospitalized Children in Chile

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ABSTRACT

Purpose: The impact of hospitalization on a child's well-being leads one to consider the health-related quality of life (HRQoL) measure as a fundamental aspect of pediatric care. The aims of the study were to adapt the Spanish version of the Kid-KINDL[®] to hospitalized children in Chile, to obtain a reduced version of the instrument and to analyze the psychometric properties of the reduced version.

Design and Methods: An expert committee and interviews were carried out for the cross-cultural adaptation process. An exploratory factor analysis was conducted to examine the validity of the construct and to select the items for the reduced version. Cronbach's alpha was used to estimate the internal consistency of the adapted version of the Kid-KINDL[®] and the reliability of each component. Convergent validity was based on correlations with a pain scale.

Results: This adapted and shorter instrument, similar to the original version, comprises five components that include the principal dimensions of HRQoL. Evaluating the School dimension in hospitalized children was considered inappropriate in Chilean public hospitals. The study replicates the relationship found between a child with high pain and low reported HRQoL.

Conclusions: The hospitalization process impacted the children's perceptions of their HRQoL. The reduced version of the Kid-KINDL[®] was found to be a valid instrument for assessing children's HRQoL in hospital units.

Practice Implications: Finding effective ways to measure HRQoL and ultimately mitigate barriers and foster resilience are important clinical and research priorities in the pursuit of HRQoL for hospitalized children and their families.

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Introduction

In recent decades, there have been advances that have sought to guarantee rights for hospitalized children, with significant progress and the subsequent creation of legal provisions regarding the care offered in hospitals (Campbell et al., 2008; Chappuis et al., 2011; Ullán & Bolver, 2006). In this framework, quality of life (QoL) has been noted as a possible indicator of health services and quality of care (Bullinger, 1997; Buyan et al., 2010; Gold & Muennig, 2002; Ravens-Sieberer et al., 2006). The World Health Organization (WHO) defines QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1995, p.1403). Health-related quality of life (HRQoL) is the way health is empirically estimated to affect QoL (Karimi & Brazier, 2016) and has emerged as an important outcome, with increasing currency in the

pediatric and rehabilitation literature (Nicholas et al., 2010). HRQoL in childhood includes the functional capacity and psychosocial interactions of the child with his or her family (Shumaker & Naughton, 1995; Teixeira, Novais, Pinto, & Cheik, 2012). Shumaker and Naughton (1995) note that the most frequently included dimensions used to assess HRQoL are as follows: functional status, psychological functioning, social functioning, and symptomatology associated with the health problem and its treatment (e.g., pain and treatment side effects).

Hospitalization is a complex process that involves vulnerable situations and the suspension of daily activities together with adverse clinical conditions, which can negatively affect the well-being of the child (Alves & Mitre, 2012; Anthony et al., 2017; Coyne, 2006; Filippazzi, 2002; Rae & Sullivan, 2005; Schwekbe & Gryski, 2003; Ullán & Bolver, 2006; Ullán & Bolver, 2008). Several studies have shown that sickness leads to significant emotional stress and may have negative effects on the HRQoL of these children (Hegarty, Macdonald, Watter, & Wilson, 2009; Jowsey, 2016; Jowsey, Yen, & W, 2012).

González-Gil, Jenaro, Gómez-Vela, and Flores (2008) found that hospitalized children had a poor quality of life, demonstrating that the

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physical, organizational and human elements of the hospital determined their perception. In the same way, Coniglio, Giammanco, Mertoli, Ferito, and Pignato (2009) found the need to improve communication skills between patients and healthcare teams and to promote opportunities for sharing different activities in a common environment in order to improve QoL during hospitalization. Significant differences determined by gender (girls having worse QoL than boys) and age (younger children having better QoL) have been found in other validation studies of HRQoL instruments (Aymerich et al., 2005; Rajmil et al., 2004; Urzúa, Cortés, Vega, Prieto, & Tapia, 2009; Urzúa & Mercado, 2008).

On the other hand, several investigations have focused on identifying factors that are related to low HRQoL in sick children. A low number of hospitalization days is an indicator related to better HRQoL (Alonso et al., 2013; Rae & Sullivan, 2005). Pain is one of the main conditions that could affect HRQoL (Badia et al., 2012; Badia et al., 2014; Kim et al., 2014; Ramstad, Jahnsen, Skjeldal, & Diseth, 2012). Children with chronic pain reported significantly lower HRQoL compared to children with other chronic illnesses (Gold et al., 2009). The fear of suffering from pain in the hospital because of medical procedures is a very common and highly frightening experience for hospitalized children (Ullán & Belver, 2008). Evaluating HRQoL is a way to have a comprehensive biopsychosocial understanding of pain and its functional impairment.

The impact of hospitalization on a child's well-being leads one to consider the HRQoL measure as a fundamental aspect of pediatric care. According to Rajmil et al. (2012), to select an HRQoL instrument, we should consider if the questionnaire satisfies the purpose of the research, if the dimensions are relevant to the context of the study and if the questionnaire is available for the target age group. It is also necessary to evaluate the sensitivity to change of the instrument and to promote the inclusion of the HRQoL assessment in children as an outcome measure to evaluate different interventions. The KINDL^R (Ravens-Sieberer & Bullinger, 1998) is one of the generic HRQoL instruments that measures physical (Physical Well-Being), psychological (Emotional Well-Being and Self-Esteem) and social (Family, Friends and School) contents, and it has been adapted and validated in Latin American countries (Rajmil et al., 2012). Studies conducted in Europe (González-Gil, 2002; González-Gil et al., 2008; Lopes, 2012) have shown the relevance of the KINDL^R instrument for measuring HRQoL in hospitalized children.

Based on the results of these studies and the fact that the KINDL^R versions contain a subscale of "disease", which should be completed in the case of prolonged illness or hospitalization, we have chosen to use this instrument for the present study.

Study Purpose

The objectives of this study are as follows: (1) to adapt the Spanish version of the Kid-KINDL^R in hospitalized children in Chile who were cared for by the public health network of the Metropolitan Region of Santiago, Chile; (2) to obtain a reduced version of the instrument; and (3) to analyze the psychometric properties of the reduced version.

Methods

Design

We have data from a cross-sectional survey of a convenience sample of the children in 3 hospitals in the public health network of the Metropolitan Region of Santiago in Chile.

Instruments

Kid-KINDL^R

We used the Spanish version of the Kid-KINDL^R (Rajmil et al., 2004), according to the author's recommendation. Three versions of the questionnaire are available as self-report measures for different age groups:

Kiddy, for children aged 4 to 6; Kid, for children aged 7–13; and Kiddo, for adolescents aged 14–17. The Kid-KINDL^R contains 24 items and is divided into six dimensions that are commonly evaluated in HRQoL (Physical Well-Being, Emotional Well-Being, Self-Esteem, Family, Friendships, and School). Each item of each dimension has a score ranging from 1 to 5 on a Likert scale, and the scores are then transformed into a 0–100 scale, on which a higher score indicates better HRQoL. The Spanish version validated by Rajmil et al. (2004) presented similar reliability and validity compared to the original German version (Ravens-Sieberer & Bullinger, 1998). The internal consistency was acceptable for most domains (alpha range 0.40–0.88) (Rajmil et al., 2004).

Adaptation

We conducted the process of cross-cultural adaptation based on guidelines for self-report measures (Beaton, Bombardier, Guillemin, & Ferraz, 2000; Guillemin, Bombardier, & Beaton, 1993). Because we would use it in another country with the same language, we did not need a translation, but a cultural adaptation was required.

An expert committee was invited to participate, formed by 7 Chilean professionals, with clinical and investigative experience in pediatrics to ensure the understanding of the Kid-KINDL^R statements in the health context. Doctors, nurses, educators and psychologists reviewed the 24 items of the questionnaire with respect to its semantic and idiomatic equivalence, experimental and conceptual equivalence, sensitivity, and feasibility, as well as if the item was written in a positive or negative manner. Descriptive analysis of their responses showed that the items had been evaluated with a 60% agreement among judges in all dimensions. Minor changes to the original questionnaire were proposed: (a) items were written in present tense; (b) in the Physical Well-Being dimension, a more colloquial word in the Chilean culture was used to assign "stomach pain"; and (c) in the Family dimension, the word "home" was replaced with "family", so that the children could answer about their relationship with family without considering that they were not at home during hospitalization.

In addition, 11 interviews had been carried out and recorded with children that met the inclusion criteria before the elaboration of the final adapted version of the instrument.

The School dimension caused problems of comprehension. The subjects found it confusing and could not understand if the answers about their academic performance referred to the moments before or during hospitalization, especially because they were not attending school in the hospital. Considering this confusion and the negative reliability found on this scale in the preliminary analysis of the items (Table 3), we opted to eliminate this dimension for the adapted version for hospitalized children. (See Fig. 1.)

Wong-Baker FACES® Pain Rating Scale

The Wong-Baker FACES® scale is a Likert scale consisting of facial expressions that demonstrate variations in the amplitude of pain (Wong & Baker, 1988). It is adequately supported by psychometric data, and in addition to the fact that it is widely used with the hospitalized pediatric population, it is found to be the children's favorite measure (Tomlinson, Baeyer, Stinson, & Sung, 2010).

Sample Population and Sampling

One hundred twenty-two hospitalized children were obtained from three hospitals in the public health network of the Metropolitan Region of Santiago in Chile. The inclusion criteria were boys and girls between 7 and 13 years old, hospitalized for a minimum of 48 h. Patients hospitalized for abuse and intra- or extra-family violence, those in intensive care units, those in palliative care, and those who presented cognitive impairment or any language condition that would prevent them from independently answering the questions were excluded from the study. Different units in each hospital were considered (pediatric, surgery and oncology) in an attempt to make the hospitalization context more relevant than the diagnosis category.

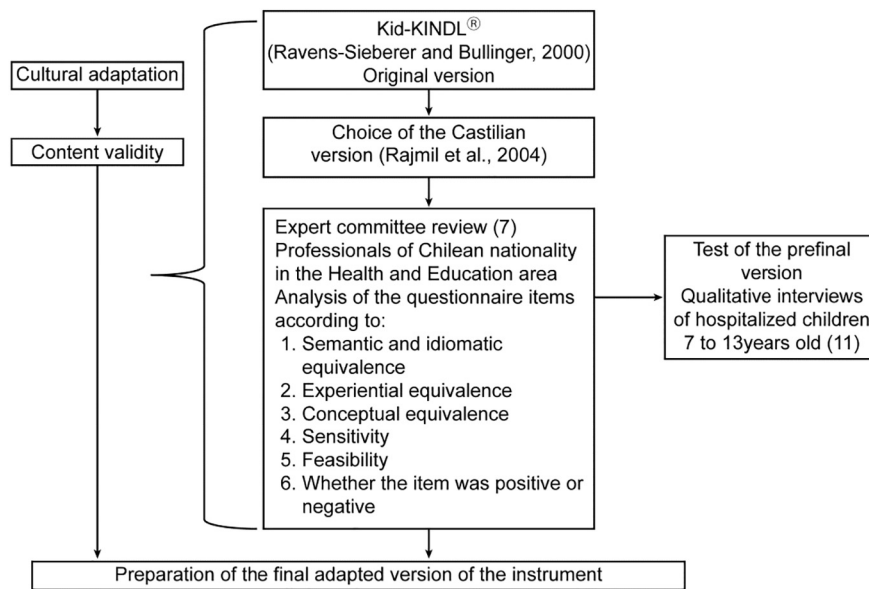


Fig. 1. Flowchart of the cultural adaptation phase based on the recommendations of the guideline for the cross-cultural adaptation of self-report measures. (Beaton et al., 2000; Guillemin et al., 1993)

Power Calculation

A minimum of 100 participants would be needed to conduct an exploratory factor analysis (EFA) of the 20 items of the instrument Kid-KINDL^R (once the items corresponding to the School dimension were removed), based on the suggestions by Gorsuch (1983) of a 5-to-1 ratio (five individuals per scale item) for conducting EFA. Our sample size ($n = 122$) provided sufficient power to conduct psychometric testing of the Kid-KINDL^R.

Procedure

Information about the diagnosis and the date of admission to the hospital was collected from the clinical record with the support of the nurse in charge of the unit. The data collection was carried out for 5 months, between September 2014 and January 2015, and every child who fulfilled the inclusion criteria was invited to participate. Patients were initially instructed to complete the pain scale. The Kid-KINDL^R was provided to children through an interview after permission was granted by the parents, with the decision of the child always being respected first. All questionnaires were completed without any missing responses. The demographic data were collected using a specific questionnaire provided to the family by the investigator and two research assistants. Clinical data (including diagnosis, days of hospitalization and previous experience with hospitalization) were collected from the clinical record with the support of the nurse in charge of the unit.

This study was reviewed and approved by the committees of the university (Universidad Central de Chile) and by the Health Services Committee (Comité Ético Científico del Servicio de Salud Metropolitano Sur Oriente) in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent and assent were obtained from all parents and children included in the study.

Data Analysis

The data were analyzed using SPSS version 20.0 (IBM Corp, 2011), and a 0.05 level of significance was selected to test the statistical hypothesis.

Validity

To examine the validity of the construct, an exploratory factor analysis (EFA) of the principal components with varimax rotation was performed. Varimax rotation was chosen because no correlations were expected

between the factors. The option to establish five components took into account the original version and factors with eigenvalues above 1.00 (Kaiser's criterion). Pattern coefficients above 0.40 were considered salient to be of practical significance and were used to retain items (Stevens, 2002). Before conducting the EFA, Bartlett's test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy were calculated to assess whether the factorial analysis was adequate. Bartlett's test of sphericity ($p < 0.05$) and the KMO value, which can range from 0 to 1 with a minimum standard of 0.6, indicated the appropriateness of using factor analysis on the data (Kaiser, 1974).

To study the convergent validity, Pearson correlations were calculated between the dimensions of the adapted and reduced versions of the Kid-KINDL^R and the Wong-Baker FACES[®] scale.

Reliability

Cronbach's alpha was used to estimate the internal consistency of the adapted version of the Kid-KINDL^R and the reliability of each component. A value for Cronbach's alpha between 0.70 and 0.95 is considered acceptable as a measure of reliability (Tavakol & Dennik, 2011).

Results

Participants

A total of 122 patients (51.6% of whom were girls) met the inclusion criteria of the study. The participants had a mean age of 10.26 years ($SD = 1.92$). Half of the participants had an acute disease (51.6%), 32.8% of whom had a digestive system disease, mainly acute appendicitis, the most frequent emergency surgical illness in children in the target population (Kohan, Zavala, Zavala, Vera, & Schonhaut, 2012). Approximately half of the participants were in the surgery unit (47.5%), and the other 47.5% were in the pediatric unit. Only 5% of the patients were in the oncology unit, where many did not meet the inclusion criteria or had no clinical conditions to answer the questions. The mean number of days of hospitalization was 5.73 days ($SD = 9.49$), with a minimum of 2 days and a maximum of 94 days, and 55.7% of the sample had never been hospitalized before. We found low pain levels ($M = 2.06$, $DT = 2.29$), with a maximum score of 10 points and a minimum of 0. No pain was related by 41% of the patients, 47.5% had mild pain and only 11.5% related moderate or severe pain (Table 1).

Table 1
Demographic characteristics and health data of the studied population (n = 122).

	Male n (%)	Female n (%)	Total n (%)
Age	59 (48.4)	63 (51.6)	122 (100)
7–10 years	33 (55.9)	29 (46)	62 (50.8)
11–13 years	26 (44.1)	34 (54)	60 (49.2)
Type of disease			
Acute	35 (59.2)	28 (44.4)	63 (51.6)
Chronic	24 (40.8)	35 (55.6)	59 (48.4)
Diagnostic category (based on ICD-10)			
Diseases of the digestive system	24 (40.7)	16 (25.4)	40 (32.8)
Injury, poisoning, and certain other consequences of external causes	7 (11.8)	7 (11.1)	14 (11.5)
Neoplasms	3 (5.1)	7 (11.1)	10 (8.2)
Diseases of the respiratory system	5 (8.4)	5 (7.9)	10 (8.2)
Musculoskeletal system and connective tissue	4 (6.8)	6 (9.5)	10 (8.2)
Endocrine, nutritional, and metabolic diseases	6 (10.2)	3 (4.8)	9 (7.4)
Other	10 (17)	19 (30.2)	29 (23.8)
Hospital unit			
Surgery Unit	28 (47.5)	30 (47.6)	58 (47.5)
Pediatric Unit	30 (50.8)	28 (44.4)	58 (47.5)
Oncology Unit	1 (1.7)	5 (8)	6 (4.9)
Hospitals			
Hospital 1	21 (35.6)	28 (44.4)	49 (40.2)
Hospital 2	21 (35.6)	28 (44.4)	49 (40.2)
Hospital 3	17 (28.8)	7 (11.2)	24 (19.7)
Days of hospitalization			
2–3 days	35 (59.3)	34 (54)	69 (56.6)
≤1 week	10 (16.9)	19 (30.1)	29 (23.8)
>1 week	14 (23.8)	10 (15.9)	24 (19.7)
Previous hospitalization			
Yes	31 (52.6)	23 (36.5)	54 (44.3)
No	28 (47.4)	40 (63.5)	68 (55.7)
School			
Public	27 (45.8)	27 (42.8)	54 (44.3)
Private	25 (42.3)	27 (42.8)	52 (42.6)
Other	7 (11.9)	9 (14.4)	16 (13.1)

Construct Validity: Exploratory Factor Analysis

The KMO value of 0.60 and Bartlett's test of sphericity ($\chi^2(190) = 529.74, p < 0.001$) suggested the appropriateness of using factor analysis on the data. The five factors had eigenvalues > 1 with loadings >0.40. The percentage of total variance explained by the five principal components was 50.33%.

According to the results of the factor analysis, item 20, "I felt different from other children", was not included in any subscale, since

the saturation was below 0.40 in any component and was therefore eliminated. On the other hand, item 4, "I have had much strength and energy" and item 8, "I was scared", presented good saturation but was different in one component compared to the original component. Item 4 was included in the original version in the component "Physical Well-Being" and was saturated in the component "Self-Esteem"; item 8 was included in the component "Emotional Well-Being" and was saturated in "Physical Well-Being". Items 4 and 8 were eliminated (Table 2).

Table 2
Factor loadings and factor structure for Kid-KINDL^R items in the Chilean sample.

Items	Component I self-esteem	Component II family	Component III physical well-being	Component IV friends	Component V emotional well-being
9. I was proud of myself	0.77	0.07	−0.00	0.12	−0.06
11. I felt pleased with myself	0.70	0.31	0.02	−0.15	0.08
12. I had lots of good ideas	0.61	−0.20	−0.04	0.23	0.09
10. I felt on top of the world	0.58	0.39	−0.07	−0.11	−0.04
4. I have had much strength and energy	0.53	−0.01	0.27	0.05	0.27
13. I got on well with my parents	0.14	0.74	−0.18	0.09	−0.13
14. I felt fine with my family	−0.09	0.72	−0.07	0.03	−0.10
15. We quarreled with my family	0.06	0.68	0.04	0.01	0.09
16. My parents stopped me from doing certain things	0.11	0.50	0.23	−0.17	0.30
20. I felt different from other children	−0.05	0.27	0.10	0.03	0.20
1. I felt sick	0.25	−0.01	0.72	0.06	−0.04
2. I had a headache or stomach pain	0.03	−0.14	0.68	0.07	−0.07
3. I have been very tired	−0.16	0.03	0.65	−0.15	0.10
8. I was scared	−0.03	0.32	0.53	0.12	0.18
18. Other kids liked me	0.12	0.02	0.06	0.84	−0.07
19. I got along well with my friends	0.22	0.10	−0.02	0.67	0.09
17. I played with friends	−0.23	−0.07	0.03	0.57	0.17
5. I had fun and laughed a lot	0.25	0.01	−0.06	0.22	0.76
6. I was bored	0.07	−0.06	−0.02	0.03	0.75
7. I felt alone	−0.14	0.31	0.16	−0.05	0.41
Explained variance	15.96	10.37	9.59	7.63	6.78

Note: The loadings in bold correspond to factor loadings >0.40.

Table 3
Internal consistency (Cronbach's α) and descriptive statistics in the Spanish version of the Kid-KINDL® and the complete and reduced versions of the pilot test Kid-KINDL® for hospitalized children in Chile ($n = 122$).

Subscale	Spanish version (24 items) Cronbach's α (no. of items)	Complete Chilean version (24 items) Cronbach's α (no. of items)	Adapted Chilean version (17 items) Cronbach's α (no. of items)	Reduced Chilean version (10 items) Cronbach's α (no. of items)
Component I self-esteem	0.88 (4 items)	0.67 (4 items)	0.67 (4 items)	0.61 (2 items)
Component II family	0.76 (4 items)	0.63 (4 items)	0.63 (4 items)	0.69 (2 items)
Component III physical well-being	0.50 (4 items)	0.54 (4 items)	0.55 (3 items)	0.55 (2 items)
Component IV friends	0.68 (4 items)	0.42 (4 items)	0.55 (3 items)	0.57 (2 items)
Component V emotional well-being	0.70 (4 items)	0.49 (4 items)	0.51 (3 items)	0.60 (2 items)
School dimension	0.40 (4 items)	−0.35 (4 items)	X	X
Total	0.87 (24 items)	0.59 (24 items)	0.61 (17 items)	0.52 (10 items)

The adapted scale would consist of 17 items, including the “Self-Esteem” and “Family” components, with 4 items corresponding to the items of the original instrument. The remaining dimensions would include three items each.

For the reduced and adapted version, two items corresponding to each dimension were included, which presented the highest factor loadings in each component:

Component I (Self-Esteem): “I was proud of myself” and “I felt pleased with myself”;

Component II (Family): “I got on well with my parents” and “I felt fine with my family”;

Component III (Physical Well-Being): “I felt sick” and “I had a headache or stomach pain”;

Component IV (Friends): “Other kids liked me” and “I got along well with my friends”;

Component V (Emotional Well-Being): “I had fun and laughed a lot” and “I was bored”.

Reliability: Internal Consistency

Component I, “Self-Esteem”, showed low internal consistency, with alphas of 0.67 and 0.61 in the adapted and reduced versions, respectively. The correlations of the items with the total subscale ranged between 0.29 and 0.53.

Component II, “Family”, showed low internal consistency in the adapted and reduced versions ($\alpha = 0.63$ and $\alpha = 0.69$, respectively). The correlations of the items with the total subscale ranged between 0.38 and 0.50.

Component III, “Physical Well-Being”, showed poor internal consistency, with an alpha of 0.55 in the adapted and reduced versions. The correlations of the items with the total subscale ranged between 0.29 and 0.41.

Component IV, “Friends”, showed poor internal consistency in the adapted and reduced versions ($\alpha = 0.55$ and $\alpha = 0.57$, respectively). The correlations of the items with the total subscale ranged between 0.28 and 0.42.

Table 4
Correlations between component Kid-KINDL® scales (adapted and reduced) and the Wong-Baker FACES® scale.

Scale	Component I self-esteem	Component II family	Component III physical well-being	Component IV friends	Component V emotional well-being	Total
Adapted Chilean version	−0.14	−0.07	−0.34***	−0.15	−0.13	−0.33***
Reduced Chilean version	−0.12	0.09	−0.36***	−0.13	−0.15	−0.29**

** $p < 0.01$.

*** $p < 0.001$.

Component V, “Emotional Well-Being”, showed poor internal consistency in the adapted and reduced versions ($\alpha = 0.51$ and $\alpha = 0.60$, respectively). The correlations of the items with the total subscale ranged between 0.19 and 0.41.

In the Chilean version, the Cronbach's alpha coefficient for the total scale was 0.61 in the adapted version and 0.52 in the reduced version. Table 3 shows the results.

Convergent Validity

The results showed negative correlations between the total scores of the adapted Chilean version [$r(122) = -0.33, p < 0.001$] and the reduced Chilean version [$r(122) = -0.29, p < 0.01$] and the scores of the Wong-Baker FACES scale. All components were negatively correlated with scores on the pain scale, with the exception of Component II (Family) in the reduced version. However, the only statistically significant correlations were found in Component III (Physical Well-Being) in the adapted [$r(122) = -0.34, p < 0.001$] and reduced versions [$r(122) = -0.36, p < 0.001$]. These results indicate that higher levels of physical well-being are associated with lower levels of pain. Table 4 shows the results.

Discussion

The goal of this study was to adapt the Spanish version of the Kid-KINDL® for hospitalized children, to obtain a reduced version of the instrument and to evaluate the psychometric properties of the reduced version of this instrument. The availability of instruments that can be applied within a short period of time is very useful, as long as such instruments have adequate psychometric properties. As a result, we could obtain similar information provided by lengthier instruments, thus reducing adverse effects (e.g., fatigue, lack of motivation) derived from a long administration (Balluerka & Gorostiaga, 2012). A validated instrument gives us empirical support for the evaluation of HRQoL in hospitalized children.

This adapted and shorter instrument, similar to the original version, comprises five components that include the principal dimensions of

HRQoL, namely, Self-Esteem, Family, Physical Well-Being, Friends, and Emotional Well-Being. However, some items were placed in components other than the original and were excluded. The item “I have had much strength and energy” was included in the Self-Esteem component, and the item “I was scared” was included in the component Physical Well-Being. Item 20, “I felt different from other children”, was also eliminated because of its poor saturation in any subscale. All items in the School dimension were removed. They were related to a typical daily school routine: classes, homework and grades (e.g., item 21, “Doing my schoolwork was easy”; item 22, “I enjoyed my lessons”; and item 24, “I was afraid of bad marks or grades”). Item 23, “I was worried about my future”, caused misunderstandings because of the clinical conditions of the hospitalized children, which indeed threatened their future. A low number of patients endorsed formally following their studies during hospitalization (<1%), and the negative reliability values showed that evaluating the School dimension in hospitalized children is inappropriate. Although they point in this direction, the initiatives of the hospital schools in Chile still do not reach the majority of hospitalized patients. The School scale has been considered in other studies of HRQoL in hospitalized children because the patients attended educational services inside the hospital (Geyer, Lyons, Amazeen, Alishio, & Cooks, 2011).

Negative correlations were obtained between all components of the HRQoL scales and the Wong-Baker Faces® scale in both the adapted and reduced versions, except for the Family dimension on the reduced scale. Correlations are only significant for the total HRQoL scale and the Physical Well-Being component. The adapted and reduced scale replicated the relationship found between a child with high pain and low reported HRQoL (Kim et al., 2014) in most of the dimensions. The extreme dedication of families at the time of the sudden or chronic illness of their children seems to maintain the stability of this dimension, even during painful conditions (Ray, 2002). Significantly, pain directly affects only general HRQoL and the Physical Well-Being dimension, which could be explained by the presence of disease in the case of hospitalized children. This relationship can also be verified in other studies, mainly in patients with chronic conditions (Badia et al., 2012; Kim et al., 2014; Ramstad et al., 2012).

With respect to internal consistency, the results of the original Spanish scale were not good in the Physical Well-Being, Friends and School components, and the complete Chilean version presented lower alpha coefficients in all dimensions, except for Physical Well-Being. Better results have been achieved in the Chilean adapted and reduced versions, except for Self-Esteem in the reduced version (Table 3). Together with the Physical Well-Being subscale, the School dimension has always presented lower alpha coefficient values than other subscales in other validations of the KINDL^R (Fernández-López, Fidalgo, Cieza, & Ravens-Sieberer, 2004; Rajmil et al., 2004; Wee, Lee, Ravens-Sieberer, Erhart, & Li, 2005).

The internal consistency of the scale was considered low or poor for all components in the hospitalized children population. This finding may be explained by a combination of the following reasons. First, there is a wide range of factors that directly affect the experience of hospitalization. Studies have reported that the time since diagnosis, the coping strategies of each child, the severity of illness, the parents' emotional state, previous experiences with hospitalization, and the level of cognitive and emotional development of the child directly influence the way he or she faces the hospital (Rae & Sullivan, 2005; Rapoport & Weingarten, 2014; Wright, 1995). Second, young patients also experience challenges, such as difficulties with medication compliance, self-management of care routines, physical activity restrictions, and undesirable medical procedures (Nicholas et al., 2010), all of which could influence their answers to the questionnaire depending on the moment they were interviewed. In addition, the answers to the questions on the Friends dimension were answered by many of the children based on the relationships they had with their peers outside the hospital.

Although the objective of the authors of the KINDL^R has been to design an instrument that is short, methodologically appropriate, and flexible and that can be used for healthy and sick children (generic

approach) (Ravens-Sieberer & Bullinger, 2000), specific experiences of the hospitalization process have impacted both the children's perceptions of their HRQoL and the form in which these patients understood the questions of the instrument. In addition, the sample is very heterogeneous, with very different experiences with respect to the hospitalization, the severity of the disease and the intervention.

Limitations

We recognized several limitations of the study. First, the sample is unlikely to be representative of the general pediatric population in this age group in the Metropolitan Region of Santiago.

Second, the relatively low internal consistency observed was worrisome. However, a low value of alpha could be due to a low number of questions, poor interrelatedness between items or heterogeneous constructs (Tavakol & Dennik, 2011), and similar values were found in other validation studies of the KINDL^R that included sick children, especially for the Physical Well-Being, Friends and School dimensions (Rajmil et al., 2004; Urzúa & Mercado, 2008; Wee et al., 2005). In addition, the values for Cronbach's alpha in dimensions with few reagents is usually low. The minimum value of 0.5 for Cronbach's alpha was achieved on all five scales, and the low reliability reported may also be related to the heterogeneity of the sample. For instance, some of the patients may have experienced recent episodes of acute medical conditions (such as upper respiratory tract infections, gastroenteritis, headaches and injuries) that impair HRQoL. Hence, we were inclined to believe that the heterogeneity of the sample accounts for the poorer reliability observed among hospitalized children.

Third, we have chosen to perform convenience sampling, which may limit the generalizability of the findings of this study to the general population. However, generalizability to the general population was not our primary objective.

This version of the instrument will need further construct validity in future studies and seeking more homogeneous disease samples is recommended (Barthel et al., 2016).

Conclusions

Based on the importance of knowing the needs of pediatric patients to respond adequately to their demands, measuring HRQoL in a hospital setting could contribute objectively to the planning of health services and the promotion of changes in public policies to improve assistance to children. The importance of having validated questionnaires available for children during their stay in the hospital and to consider their opinions and achieve quality of care was reinforced by other studies (Björk, Nordström, & Hallström, 2006; Chappuis et al., 2011; Forsner, Jansson, & Sørli, 2005). The results are encouraging, mainly considering the focus on the perception of children during hospitalization rather than taking into account only the reports of proxies or healthcare professionals. Children are a feasible source for the self-assessment of their HRQoL, and the hospital team and structure should meet children's needs and improve their quality of life (Haiat et al., 2003; Lindeke et al., 2006; Pelander et al., 2007).

Although the reduced version of the Kid-KINDL^R shows promise as a valid measure for assessing children's HRQoL in hospital units; further validation is needed before use in practice to evaluate the efficacy of therapeutic interventions, whether pharmacological or not. Despite we tried to make the hospitalization context the most determinant factor for the results, it seems that medical conditions have a very relevant role for the application of a general instrument in measuring HRQoL in different pediatric units and diseases.

Accordingly, finding effective ways to measure HRQoL and ultimately mitigate barriers and foster resilience are important clinical

and research priorities in the pursuit of HRQoL for hospitalized children and their families.

Conflict of Interest

None to declare.

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References

- Alonso, E. M., Martz, K., Wang, D., Yi, M. S., Neighbors, K., Varni, J. W., et al. (2013). Factors predicting health-related quality of life in pediatric liver transplant recipients in the functional outcomes group. *Pediatric Transplantation*, *17*(7), 605–611. <https://doi.org/10.1111/ptr.12126>.
- Alves, C. A., & Mitre, R. M. A. (2012). *Infantile hospitalisation and chronic disease*. In O. Ozdemir (Ed.), *Complementary Pediatrics* (pp. 235–252) InTech.
- Anthony, S., Selkirk, E., Sung, L., Klaassen, R., Dix, D., & Klassen, A. (2017). Quality of life of pediatric oncology patients: Do patient-reported outcome instruments measure what matters to patients? *Quality of Life Research*, *26*(2), 273–281. <https://doi.org/10.1007/s11136-016-1393-4>.
- Aymerich, M., Berra, S., Guillaumon, I., Herdman, M., Alonso, J., Sieberer, U. R., et al. (2005). Desarrollo de la versión en español del KIDSCREEN, un cuestionario de calidad de vida para la población infantil y adolescente. *Gaceta Sanitaria*, *19*(2), 93–102.
- Badia, M., Riquelme, I., Orgaz, B., Acevedo, R., Longo, E., & Montoya, P. (2014). Pain, motor function and health-related quality of life in children with cerebral palsy as reported by their physiotherapists. *BMC Pediatrics*, *14*, 192. <https://doi.org/10.1186/1471-2431-14-192>.
- Badia, M., Verdugo, M.Á., Orgaz, B., Longo, E., Montoya, P., & Riquelme, I. (2012). *Dolor, función motora gruesa y calidad de vida de los niños y adolescentes con parálisis cerebral*. Salamanca: Inico.
- Balluerka, N., & Gorostiaga, A. (2012). Elaboración de Versiones Reducidas de Instrumentos de Medida: Una Perspectiva Práctica. *Psychosocial Intervention*, *21*(1), 103–110. <https://doi.org/10.5093/in2012v21n1a7>.
- Barthel, D., Fischer, K. I., Nolte, S., Otto, C., Meyrose, A. -K., Reisinger, S., et al. (2016). Implementation of the Kids-CAT in clinical settings: A newly developed computer-adaptive test to facilitate the assessment of patient-reported outcomes of children and adolescents in clinical practice in Germany. *Quality of Life Research*, *25*(3), 585–594. <https://doi.org/10.1007/s11136-015-1219-9>.
- Beaton, D. E., Bombardier, C., Guillemin, F., & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine*, *25*(24), 3186–3191.
- Björk, M., Nordström, B., & Hallström, I. (2006). Needs of young children with cancer during their initial hospitalization: An observational study. *Journal of Pediatric Oncology Nursing*, *23*(4).
- Bullinger, M. (1997). The challenge of cross-cultural quality of life assessment. *Psychology & Health*, *12*(6), 815–825.
- Buyan, N., Turkmen, M., Bilge, I., Baskin, E., Haberal, M., Bilginer, Y., et al. (2010). Quality of life in children with chronic kidney disease (with child and parent assessments). *Pediatric Nephrology*, *25*, 1487–1496. <https://doi.org/10.1007/s00467-010-1486-1>.
- Campbell, H., Duke, T., Weber, M., English, M., Carai, S., Tamburlini, G., et al. (2008). Global initiatives for improving hospital care for children: State of the art and future prospects. [review]. *Pediatrics*, *121*(4), e984–992.
- Chappuis, L. M., Vannay-Bouchiche, C., uckiger, M. F., Monnier, M. e., Cathieni, F., Terra, R., et al. (2011). Children's experience Regarding the quality of their hospital stay: The development of an assessment questionnaire for children. *Journal of Nursing Care Quality*, *26*(1), 78–87.
- Coniglio, M. A., Giammanco, G., Mertoli, P., Ferito, L., & Pignato, S. (2009). Quality of life of hospitalized children: A survey. *Igiene e Sanità Pubblica*, *65*(1), 41–52.
- Coyne, I. (2006). Children's experiences of hospitalization. *Journal of Child Health Care*, *10*(4), 326–336. <https://doi.org/10.1177/1367493506067884>.
- Fernández-López, J. A., Fidalgo, M. F., Cieza, A., & Ravens-Sieberer, U. (2004). Medición de la calidad de vida en niños y adolescentes: comprobación preliminar de la validez y fiabilidad de la versión española del cuestionario KINDL. *Atención Primaria*, *33*(8), 434–442.
- Filippazzi, G. (2002). [Techniques to inform and prepare children to various medical and surgical procedures by using play]. [English abstract]. *Professioni Infermieristiche*, *55*(2), 119–124.
- Forsner, M., Jansson, L., & Sørli, V. (2005). The experience of being ill as narrated by hospitalized children aged 7–10 years with short-term illness. *Journal of Child Health Care*, *9*(2), 153–165.
- Geyer, R., Lyons, A., Amazeen, L., Alishio, L., & Cooks, L. (2011). Feasibility study: The effect of therapeutic yoga on quality of life in children hospitalized with cancer. *Pediatric Physical Therapy*, *23*(4), 375–379.
- Gold, M. R., & Muennig, P. (2002). Measure-dependent variation in burden of disease estimates: Implications for policy. *Medical Care*, *40*(3), 260–266.
- Gold, J. I., Yetwin, A. K., Mahrer, N. E., Carson, M. C., Griffin, A. T., Palmer, S. N., et al. (2009). Pediatric chronic pain and health-related quality of life. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, *24*(2), 141–150. <https://doi.org/10.1016/j.pedn.2008.07.003>.
- González-Gil, F. (2002). *Perceived quality of life of hospitalized children from Castilla and León*. Doctoral dissertation Universidad de Salamanca, Salamanca.
- González-Gil, F., Jenaro, F., Gómez-Vela, C., & Flores, N. (2008). Perceived quality of life and health of hospitalized children. *Child Indicators Research*, *1*(2).
- Gorsuch, R. L. (1983). *Factor analysis*. Hillsdale, NJ: Erlbaum Associates.
- Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, *46*(12), 1417–1432.
- Haiat, H., Bar-Mor, G., Shochat, M., Haiat, H., Bar-Mor, G., & Shochat, M. (2003). The world of the child: A world of play even in the hospital. *Journal of Pediatric Nursing*, *18*(3), 209–214.
- Hegarty, M., Macdonald, J., Watter, P., & Wilson, C. (2009). Quality of life in young people with cystic fibrosis: Effects of hospitalization, age and gender, and differences in parent/child perceptions. *Child: Care, Health and Development*, *35*(4), 462–468 doi: CCH900 [pii] <https://doi.org/10.1111/j.1365-2214.2008.00900.x>.
- IBM Corp (2011). *IBM SPSS statistics for windows (version 20.0)*. Armonk, NY: IBM Corp.
- Jowsey, T. (2016). Time and chronic illness: A narrative review. *Quality of Life Research*, *25*(5), 1093–1102. <https://doi.org/10.1007/s11136-015-1169-2>.
- Jowsey, T., Yen, L., & W. P. M. (2012). Time spent on health related activities associated with chronic illness: A scoping literature review. *BMC Public Health*, *12*(1), 1044. <https://doi.org/10.1186/1471-2458-12-1044>.
- Kaiser, H. F. (1974). An index of factorial simplicity. *Psychometrika*, *39*, 31–36.
- Karimi, M., & Brazier, J. (2016). Health, health-related quality of life, and quality of life: What is the difference? *Pharmacoeconomics*, *34*(7), 645–649.
- Kim, J., Chung, H., Amtmann, D., Salem, R., Park, R., & Askew, R. L. (2014). Symptoms and quality of life indicators among children with chronic medical conditions. *Disability and Health Journal*, *7*, 96–104.
- Kohan, R., Zavala, B. A., Zavala, P. B., Vera, O. F., & Schonhaut, B. L. (2012). Apendicitis aguda en el niño. *Revista Chilena de Pediatría*, *83*, 474–481.
- Lindeke, L., Nakai, M., Johnson, L., Lindeke, L., Nakai, M., & Johnson, L. (2006). Capturing children's voices for quality improvement. [research support, non-U.S. gov't]. *MCN, American Journal of Maternal Child Nursing*, *31*(5), 290–295 (quiz 296–297).
- Lopes, M. G. (2012). *Estudo da Saúde e da Qualidade de Vida Percebida pela Criança Hospitalizada*. Doctoral dissertation Salamanca: Universidad de Salamanca.
- Nicholas, D. B., Otley, A. R., Taylor, R., Dhawan, A., Gilmour, S., & Ng, V. L. (2010). Experiences and barriers to health-related quality of life following liver transplantation: A qualitative analysis of the perspectives of pediatric patients and their parents. *Health and Quality of Life Outcomes*, *8*(1), 150. <https://doi.org/10.1186/1477-7525-8-150>.
- Pelander, T., Lehtonen, K., Leino-Kilpi, H., Pelander, T., Lehtonen, K., & Leino-Kilpi, H. (2007). Children in the hospital: Elements of quality in drawings. *Journal of Pediatric Nursing*, *22*(4), 333–341.
- Rae, W. A., & Sullivan, J. (2005). A review of play interventions for hospitalized children. In L. A. E. Reddy, T. M. E. Files-Hall, & C. E. E. Schaefer (Eds.), *Empirically based play interventions for children* (pp. 123–142). Washington: American Psychological Association.
- Rajmil, L., Roizen, M., Psy, A. U., Hidalgo-Rasmussen, C., Fernandez, G., & Dapuerto, J. J. (2012). Health-related quality of life measurement in children and adolescents in Ibero-American countries, 2000 to 2010. *Value in Health*, *15*(2). <https://doi.org/10.1016/j.jval.2011.11.028>.
- Rajmil, L., Serra-Sutton, V., Fernandez-Lopez, A., Berra, S., Aymerich, M., & Cieza, A. (2004). The Spanish version of the German health-related quality of life questionnaire for children and adolescents: The KINDL. *Anales de Pediatría (Barcelona, Spain)*, *60*(6), 514–521. [https://doi.org/10.1016/s1695-4033\(04\)78320-4](https://doi.org/10.1016/s1695-4033(04)78320-4).
- Ramstad, K., Jahnsen, R., Skjeldal, O. H., & Diseth, T. H. (2012). Mental health, health related quality of life and recurrent musculoskeletal pain in children with cerebral palsy 8–18 years old. *Disability and Rehabilitation*, *34*(19), 1589–1595.
- Rapoport, A., & Weingarten, K. (2014). Improving quality of life in hospitalized children. *Pediatric Clinics of North America*, *61*(4), 749–760. <https://doi.org/10.1016/j.pcl.2014.04.010>.
- Ravens-Sieberer, U., & Bullinger, M. (1998). Assessing health-related quality of life in chronically ill children with the German KINDL: First psychometric and content analytical results. *Quality of Life Research*, *7*, 399–407. <https://doi.org/10.1023/a:1008853819715>.
- Ravens-Sieberer, U., & Bullinger, M. (2000). Manual of KINDL questionnaire for measuring health-related quality of life in children and adolescents. Revised version manual 2000 Retrieved 11 November, 2013, from <http://www.kindl.org>.
- Ravens-Sieberer, U., Erhart, M., Wille, N., Wetzel, R., Nickel, J., & Bullinger, M. (2006). Generic health-related quality-of-life assessment in children and adolescents: Methodological considerations. *Pharmacoeconomics*, *24*. <https://doi.org/10.2165/00019053-200624120-00005>.
- Ray, L. D. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing*, *17*(6), 424–438. <https://doi.org/10.1053/jpdn.2002.127172>.
- Schwewke, S., & Gryski, C. (2003). Gravity and levity—pain and play: The child and the clown in the pediatric health care setting. *Humor in children's lives: A guidebook for practitioners* (pp. 49–68). Westport, CT: Praeger Publishers/Greenwood Publishing Group.

- Shumaker, S. A., & Naughton, M. J. (1995). The international assessment of health-related quality of life: A theoretical perspective. In S. A. Shumaker, & R. Berzon (Eds.), *Quality of life: Theory translation measurement and analysis* (pp. 3–10). Oxford, England: Rapid Communication of Oxford.
- Stevens, J. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Mahwah, NJ: Lawrence Erlbaum Associates.
- Tavakol, M., & Dennik, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, 2, 53–55.
- Teixeira, I. P., Novais, I. D. P., Pinto, R. D. M. C., & Cheik, N. C. (2012). Adaptação cultural e validação do Questionário KINDL no Brasil para adolescentes entre 12 y 16 años. *Revista Brasileira de Epidemiologia*, 15(4), 845–857.
- The WHOQOL Group (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine*, 41(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-K](https://doi.org/10.1016/0277-9536(95)00112-K).
- Tomlinson, D., Baeyer, C. L. v., Stinson, J. N., & Sung, L. (2010). A systematic review of faces scales for the self-report of pain intensity in children. *Pediatrics*, 126(5).
- Ullán, A. M., & Belver, M. H. (2006). *La creatividad a través del juego*. Salamanca: Amarú Ediciones.
- Ullán, A. M., & Belver, M. H. (2008). *Cuando los pacientes son niños: Humanización y calidad en la hospitalización pediátrica*. Madrid: Editorial Eneida.
- Urzúa, A., Cortés, E., Vega, S., Prieto, L., & Tapia, K. (2009). Propiedades Psicométricas del Cuestionario de Auto Reporte de la Calidad de Vida KIDSCREEN-27 en Adolescentes Chilenos. *Terapia Psicológica*, 27, 83–92.
- Urzúa, A., & Mercado, G. (2008). La Evaluación de la Calidad de Vida de los Adolescentes a través del Kiddo-Kindl. *Terapia Psicológica*, 26(1), 133–141.
- Wee, H., Lee, W., Ravens-Sieberer, U., Erhart, M., & Li, S. (2005). Validation of the English version of the KINDL generic children's health-related quality of life instrument for an Asian population—results from a pilot test. *Quality of Life Research*, 14, 1193–1200.
- Wong, D. L., & Baker, C. M. (1988). Pain in children: Comparison of assessment scales. *Pediatric Nursing*, 14(1), 9–17.
- Wright, M. C. (1995). Behavioural effects of hospitalization in children. *Journal of Paediatrics and Child Health*, 31(3), 165–167.