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Does the Small Fit them All? -The Utility of Disabkids-10 Index for the Assessment of Pediatric Health-related Quality of Life across Age Groups, Genders and Informants

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Abstract

29

30 **Introduction.** The objective of this study was twofold: first, to conduct a confirmatory factor analysis
31 (CFA) of the Portuguese versions of Disabkids-10; and second, to examine potential differences in factor
32 structures between age groups, genders and informants.

33 **Method.** The sample included 293 school-aged children and adolescents with chronic health conditions
34 and 197 parents. Both family members (whenever possible) completed the self- and proxy-report versions
35 of Disabkids-10.

36 **Results.** The factorial model of Disabkids-10 had good fit for self-reported data and minimally acceptable
37 fit for proxy-reported data. The multi-group analyses confirmed the model invariance across age groups
38 (children vs. adolescents), genders (boys vs. girls) and informants (children vs. parents).

39 **Discussion.** The generic developmental applicability of these questionnaires makes them recommended
40 for healthcare routine assessments on pediatric intervention needs and outcomes.

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Introduction

49 During the last couple of decades, in a context of elevated prevalences and improved survival
50 rates for a number of chronic health conditions, health-related quality of life (HRQL) assessment has
51 become increasingly important in pediatric health care research and practice (Clarke and Eiser, 2004).
52 This redefinition of health outcomes was motivated by a need of complementing simple biological or
53 physiological endpoints (e.g., growth, mortality), with more meaningful outcomes of child and adolescent
54 care and development (Christakis et al., 2001). Alongside the fact that many clinicians tend to regard
55 pediatric HRQL measurement as too costly or impractical (Varni et al., 2005), there has been a growing
56 demand for assessing HRQL more economically (Muehlan, 2010). On the other hand, despite the
57 acknowledgement of differences between age groups, genders and informants in HRQL assessments
58 (Bullinger et al., 2006; Wallander et al., 2001), measures focusing on common HRQL markers and
59 allowing completion by both patients and proxies (usually parents) are certainly valuable in facilitating
60 data collection and analysis. Therefore, a crucial research question that needs to be addressed is whether
61 brief generic instruments are cost-effective methodologies in providing reliable HRQL measurements for
62 pediatric patients of both genders and different age groups, as well as across informants.

63 HRQL is “a multidimensional concept that includes the broad areas of functional status,
64 psychological and social well-being, health perceptions, and disease- and treatment-related symptoms”
65 (Aaronson et al., 1991: 840). The concept of HRQL incorporates a medical and healthcare perspective
66 and is thus a component of the more general notion of quality of life, which integrates a wider range of
67 aspects such as political freedom and financial issues (Koot, 2001; The European Disabkids Group,
68 2006). Clinical rationales for assessing HRQL include the identification of dysfunction secondary to
69 illness or treatment, the delineation of patient subpopulations at risk for poor psychosocial outcomes, the

70 evaluation of the quality of medical care, the improvement of clinical decision making, and the estimation
71 of healthcare needs of a given population (Spieth and Harris, 1996). In fact, HRQL assessments can
72 predict costs of care for pediatric populations and assist the management of care by enhancing clinical
73 evaluations and identifying suitable candidates for case management (Seid et al., 2005). In this context of
74 routine monitoring and screening, brief measures that summarize scores into a single value (or index)
75 may be especially useful for examining global changes in HRQL, while reducing response burden and
76 saving administration costs (Ravens-Sieberer et al., 2010).

77 In pediatric healthcare settings, developmental issues are pervasive challenges for HRQL
78 assessment: not only there are reciprocal effects of chronic illness/disability and child/adolescent
79 development (Suris et al., 2004), but also development affects the selection of targeted dimensions, item
80 content, instrument format and the use of proxy information (Koot and Wallander, 2001). Therefore, a
81 developmental approach to HRQL assessment calls for the integration of age-related specificities and the
82 consideration of parents' and their children's reports as complementary to each other (Bruil and Detmar,
83 2005; Carona et al., 2012). Despite the overall applicability of three broad domains of HRQL (i.e.,
84 physical, psychological and social) to children and adolescents, there may be substantial variation in their
85 content between age groups and genders (Bullinger et al., 2006; Rajmil et al., 2004). Compared to
86 children, adolescents seem to report fewer positive emotions, be more mindful of others' opinions, have
87 more varied social activities and consider more the distant than the immediate future. Gender differences
88 in HRQL meaning, in contrast, tend to be fewer and to mostly occur at the item level of specific activities
89 (e.g., boys are more likely to describe sports and computers activities, and girls other activities such as
90 dancing, shopping and chatting on the phone) (Wee et al., 2006). Nevertheless, many HRQL studies
91 cover a wide age range with no stratification of results (Gerharz et al., 2003), even if such aggregation
92 across age groups and genders may obscure important differences. On the topic of multiple informants in
93 pediatric HRQL assessment, it has been commented that both parents' and their children's HRQL reports

94 are valid, although they cannot effectively supplant each other (Theunissen et al., 1998). If on the one
95 hand, proxy reports that are usually provided by parents, may be the only way to evaluate HRQL in some
96 patients, due to their young age, severity of illness/disability or cognitive impairment (White-Koning et
97 al., 2007), on the other hand, children and adolescents' self-reports are essential to incorporate a child's
98 perspective within healthcare care settings and thus promote a truly child-centred care (Söderbäck et al.,
99 2011; Varni et al., 2005). For these reasons, it is necessary to ensure that self and proxy-report versions of
100 a given HRQL instrument accurately assess the same construct across different informants.

101 The Disabkids questionnaires represent a sound methodology to assess pediatric HRQL in a
102 developmentally appropriate way and include self and proxy-report forms for a chronic generic module
103 (long and short versions), seven condition-specific modules (e.g., diabetes, epilepsy, dermatitis), and a
104 measure of Smileys for younger children. The short version of the chronic generic module, known as
105 Disabkids-12 or Disabkids-10+2, was developed to assess pediatric HRQL in a more economic way and it
106 was based on the conceptual model of three higher-order domains (Mental, Social, Physical) and six
107 facets (Independence, Emotion, Inclusion, Exclusion, Limitation, Treatment) that underlay the longer
108 version of the generic module, known as Disabkids-37 (Muehlan, 2010; The European Disabkids Group,
109 2006). Although the short version of the instrument initially included two items per each one of the
110 aforementioned facets, later studies indicated a preferred use of an index score based on 10 items, thus
111 excluding the "applicable" items derived from the "Treatment" facet, and allowing the completion of
112 questionnaires by the generality of pediatrics patients, whether they were undergoing medical treatment
113 or not. The measurement model was then examined for this one-factor solution via confirmatory factor
114 analysis (CFA), and results indicated good and acceptable model fits for the self and proxy versions of
115 Disabkids-10, respectively (Muehlan, 2010). Nevertheless, the invariance of such one-dimensional
116 measurement model across age groups, genders and informants remained to be ascertained.

117 The question of whether a pediatric HRQL measure indeed measures that target construct in a
118 given population is intrinsically related to the notion of construct validity. Construct validity is at the
119 heart of psychometric assessment and may be defined as “the extent to which an instrument can provide a
120 good representation of a construct” (Wallander, 2001: 25). A widely used method to investigate construct
121 validity is CFA, in which, contrary to exploratory factor analysis, factor structures are hypothesized a
122 priori and then empirically verified rather than extracted from the data (Lei and Wu, 2007). CFA
123 increases the statistical precision on the investigation of construct validity by reducing measurement error
124 and assisting the comparison of factors structures between two or more groups (Atkinson et al., 2011).
125 Using this statistical procedure, the aim of the present study was twofold: first, to conduct a CFA of the
126 Portuguese versions of Disabkids-10 in a mixed pediatric sample; and second, to ascertain the invariance
127 of Disabkids-10 measurement model across age groups (children vs. adolescents), genders (boys vs.
128 girls), and informants (parents vs. children).

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Method

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Participants and Procedures

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The sample was composed of 293 pediatric patients, between 8 and 18 years-old, with three
different clinical diagnoses, and 197 parents/family caregivers. The sample comprised cases of diabetes,
epilepsy and cerebral palsy, because these three chronic health conditions were already included in the
original studies of Disabkids questionnaires (Muehlan, 2010; The European Disabkids Group, 2006). The
selection of these conditions was also thought to provide an interesting and varied sample of pediatric
patients, as suggested by the following evidence: firstly, type 1 diabetes is one of the most common
chronic diseases in children, for which an increasing prevalence has been reported (Passa, 2002);

141 secondly, epilepsy is among the most prevalent neurological conditions in the developing years (Ronen et
142 al., 2003); and lastly, cerebral palsy is the most common physical disability in childhood (Stanley et al.,
143 2000) and has been described as an interesting prototype of childhood disability (Raina et al., 2004). The
144 participants' socio-demographic and clinical characteristics are presented in Table 1.

145 Using the non-probabilistic convenience sampling method, participants were selected between
146 March 2009 and September 2012 in the outpatient services of four Portuguese public hospitals and 10
147 Portuguese Cerebral Palsy Associations (tertiary healthcare institutions), after the study had been
148 approved by the institutions' Ethic Committees and Direction Boards. For inclusion in the sample,
149 pediatric patients had to meet the following inclusion criteria: (1) age between 8 and 18 years-old; (2)
150 diagnosis of type 1 diabetes, epilepsy or cerebral palsy, established by a physician according to the
151 International Classification of Diseases (ICD-10); (3) ability to understand and answer the questionnaires
152 (for pediatric patients with cerebral palsy, data from previous formal assessment of their intelligence
153 quotient [IQ] was collected and a value of 70 was set as the threshold); and (4) be accompanied by one of
154 the parents or other family caregiver.

155 Informed consents were obtained from all parents and adolescents older than 13, and informal
156 assents were obtained from children. The questionnaires were completed by pediatric patients and
157 parents/family caregivers in a room provided for research purposes in the institution they attended, under
158 the supervision of a trained research assistant. Since patients with diabetes were participating in a
159 concurrent research project that did not include parents' reports on their children's HRQL, proxy-reports
160 were then not obtained for this clinical group.

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162 *[Table_1_about_here]*

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164 **Measures**

165 The DISABKIDS Chronic Generic Measure – Short Version assesses the HRQL of pediatric
166 patients with chronic health conditions aged between 8 and 18 years-old (The DISABKIDS Group
167 Europe, 2006). This short version comprises 10 items measuring the mental, social and physical impact of
168 the health condition (e.g., “Does your condition get you down?”/ “Does your child’s condition get him/
169 her down?”), and two items addressing the impact of treatment (e.g., “Does taking medication bother
170 you?”/ “Does taking medication bothers your child?”). Following previous recommendations on the
171 factorial examination of the measure (Muehlan, 2010), and since the present study was aimed at testing an
172 instrument that would apply to all pediatric patients, whether they were medicated or not, the two items
173 assessing the impact of treatments were excluded from this study. The questionnaire reports to the “past
174 four weeks” and is to be answered within a 5-point Likert scale ranging from 1 (*never*) to 5 (*always*), with
175 higher scores indicating better HRQL.

176 Socio-demographic and clinical data were obtained from parents’ questionnaires.

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178 **Data analysis**

179 Statistical analyses were performed with the Statistical Package for the Social Sciences (SPSS, v.
180 20; Chicago, IL, USA) and with the Analysis of Moments Structures (AMOS, v. 20). Missing data, that
181 were random and lower than 5%, were handled by individual mean score substitution, except for socio-
182 demographic and clinical variables.

183 To examine the factorial structure of Disabkids-10, first-order confirmatory factor analyses
184 (CFA) were performed for both patient- and proxy-reported versions. The assessment of model’s fit was
185 then based on (a) the significance and strength of factors loadings, and (b) the degree to which the overall
186 model fitted the observed data, as suggested by a variety of indices (Weston and Gore, 2006).

187 Specifically, the overall models’ fit was assessed by examining the maximum-likelihood χ^2 and the main
188 approximate goodness-of-fit indexes, namely the comparative fit index (CFI) and the root mean square

189 error of approximation (RMSEA). A model was considered to have a good fit when CFI \geq .95 and
190 RMSEA \leq .06; and was considered to have an acceptable fit when CFI \geq .90 and RMSEA \leq .10 (Browne
191 and Cudeck, 1993; Hu and Bentler, 1999). Complementarily, a χ^2 /df ratio of 5 or less was assumed as
192 indicative of acceptable model fit (Ullman, 1996). In addition, construct reliability was assessed by using
193 the Cronbach's alpha value and the composite reliability (CR) value, calculated from the squared sum of
194 standardized factor loading divided by the squared sum of standardized factor loading plus the sum of the
195 error variance terms. Good construct reliability was established if CR was higher than .70 (Hair et al.,
196 2010).

197 The factorial invariance of the models across age groups, genders and informants was tested in
198 two steps, starting with the examination of the baseline model for each group separately, followed by
199 multi-group analyses comparing the unconstrained model with a model in which factor loadings were
200 fixed equal across groups (Byrne, 2010). The model invariance was established when the chi-square
201 difference ($\Delta\chi^2$) was non-significant, and the difference in CFI values (Δ CFI) was lower than .01 (Cheung
202 and Rensvold, 2002).

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Results

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207 CFA for the Self-report Version of Disabkids-10

208 In order to examine the one-dimensional structure of the Disabkids-10, an initial model was
209 tested, in which the 10 items were hypothesized to load on a single factor representing HRQL. According
210 to the reference values for the main fit indexes, this model presented a marginally acceptable fit to the
211 patient-reported data, with $\chi^2(35) = 139.50$, $p < .01$; χ^2 /df = 3.99; CFI = .86 and RMSEA = .10. Based on
212 modification indices and on item content, the initial model was modified, by allowing the measurement

213 error terms for the items that belonged to the same facet in the long version of the questionnaire to
214 correlate. This modified model, which is depicted in Figure 1, had a significantly better fit than the initial
215 model, $\Delta\chi^2(5) = 76.00, p < .01$, improving the model fit indexes, $\chi^2(30) = 63.50, p < .01$; $\chi^2/df = 2.12$; CFI
216 = .96 and RMSEA = .06. All of the items showed factorial validity, with statistically significant factor
217 loadings ($p < .001$) and, except for items 3 and 10, standardized regression weights above the threshold of
218 .50. The examination of Cronbach's alpha and composite reliability values ($\alpha = .83$; CR = .82) confirmed
219 that the 10 patient-reported items consistently represent the latent construct of HRQL.

220 *[Figure_1_about_here]*

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222 **CFA for the Proxy-report Version of Disabkids-10**

223 Because we aimed to test a strictly equivalent model for both versions of the instrument, the
224 factorial model that was modified to better fit the patient-reported data was also tested for the proxy-
225 reported version. The modified model (Figure 2) had a minimally acceptable fit to the proxy-reported
226 data, with $\chi^2(35) = 101.60, p < .01$; $\chi^2/df = 3.39$; CFI = .93 and RMSEA = .11, even though all of the
227 items showed factorial validity with factor loadings above .50 and statistically significant. The proxy-
228 reported questionnaire also presented good construct reliability, with Cronbach's alpha = .90 and CR =
229 .90

230 *[Figure_2_about_here]*

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232 **Multi-group Analyses for Age Groups, Genders and Informants**

233 To ascertain whether the Disabkids-10 Index was a valid measure to assess HRQL across
234 different groups, the final factorial model was comparatively tested across age groups and genders. For
235 the patient-reported data (Table 2), results showed that the model had acceptable fit for both age groups
236 and genders, and multi-group analyses confirmed the invariance of factor loadings across groups.

237 *[Table_2_about_here]*

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239 For the proxy-report version (Table 3), the model presented poor fit for both gender groups and
240 for children and acceptable fit for adolescents; the multi-group analyses showed no significant differences
241 on factor loading between children and adolescents and between boys and girls, thus confirming the
242 factorial validity across age groups and genders.

243 *[Table_3_about_here]*

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245 Finally, we tested for model invariance across informants (parents vs. children). The multi-group
246 analyses confirmed the measurement invariance, $\Delta\chi^2(9) = 13.94, p = .12; \Delta CFI = .004$, i.e., that the factor
247 loadings did not differ between patient- and proxy-reported data.

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250 **Discussion**

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252 This was the first study to investigate the invariance of a one-dimensional factor structure for
253 Disabkids-10 questionnaires across age groups, genders and informants. The observed results add critical
254 evidence for the overall applicability of Disabkids brief generic module to assess HRQL in pediatric
255 patients with chronic health conditions, regardless of their age group and gender, or even of the selected
256 informant for report.

257 In our first cluster of results, the proposed factorial model of Disabkids-10 displayed good and
258 minimally acceptable fits for self and proxy-reported data, respectively. These results were remarkably
259 similar with those originally reported in the European study of the instrument (Muehlan, 2010). A
260 possible explanation for that discrepancy in model fits relies on the fact that Disabkids items were

261 formulated as a result of focus groups that primarily attended to children and adolescents' perceptions
262 (The European Disabkids Group, 2006). Consequently, the poorer goodness-of-fit indices observed for
263 the proxy-report version do not discard its applicability in pediatric assessments, but instead imply the
264 recommendations that children's subjective self-reports should be considered whenever possible and
265 parents/caregivers should be selectively used as proxies (White-Koning et al., 2007; World Health
266 Organization, 1993).

267 In a second moment, our results further demonstrated the invariance of the one-dimensional
268 measurement model for school-aged children and adolescents of both genders. In terms of construct
269 validity assessment, this is to say that the items of Disabkids-10 reliably depict a general HRQL factor for
270 pediatric patients of a wide age range, who are expectably facing different developmental contexts and
271 dealing with distinct age-related tasks and challenges. Actually, even if major HRQL domains are
272 developmentally universal, substantial variation may exist between age groups and genders at the level of
273 instrument items (Rajmil et al., 2004; Wee et al., 2006). For this reason, despite the fact that Disabkids-10
274 items were extracted from the longer version of the instrument, for which semantic validation had
275 previously established the developmental adequacy (Carona et al., 2011; The European Disabkids Group,
276 2006), factor analyses at the item level were crucial for determining the instrument's construct validity in
277 a developmentally appropriate way. Additionally, the invariance of Disabkids-10 measurement model
278 was also ascertained across self and proxy-reported data, thus highlighting the instrument's construct
279 validity across informants. This result is particularly important because there are certain pediatric patients
280 (e.g., patients severely injured and/or undergoing complex treatments, younger children, patients with
281 cognitive impairment), whose HRQL assessments will mostly rely on their parents' (or other proxies)
282 reports.

283 Taken altogether, these results represent a vital contribution for the refinement of a
284 developmental approach to HRQL assessment, which acknowledges age and gender specificities and

285 commonalities, as well as the consideration of a dyadic parent-child perspective (Carona et al., 2012).
286 Therefore, distinctive strengths of the present study include: the utilization of CFA as a sophisticated
287 statistical procedure to examine construct validity; the consideration of children and adolescents as
288 independent age groups; and the simultaneous examination of self and proxy-report forms of a single
289 pediatric HRQL measure. Nevertheless, three important limitations should be also acknowledged: first,
290 although standing as a common psychometric procedure (cf. Muehlan, 2010), this validation study was
291 based on data from the longer version of the instrument, thus requiring its future replication in an
292 independent sample; second, proxy-reports were not obtained for all the clinical groups included in the
293 study; third, the psychometric property of responsiveness to treatment over time, which is of paramount
294 importance for pediatric settings (Varni et al., 2005), was not investigated; and last, although adequate for
295 the intended purpose, this study's sample comprised three distinct conditions, which even so did not
296 comprehensively depict the most common pediatric populations. For this reason, future psychometric
297 analyses of Disabkids-10 should be performed with data obtained from larger clinical samples, with a
298 wider variety of chronic health conditions, in order to reliably assess the instrument's applicability to
299 different clinical diagnoses.

300 This study substantiated the utility of Disabkids-10 questionnaires to assess pediatric HRQL in a
301 more economic way. In fact, these instruments comply with all the guidelines suggested by Clarke and
302 Eiser (2004) to evaluate the quality of HRQL measures for pediatric practice or clinical trials, namely: the
303 instrument's reliability, validity and developmental appropriateness for the target group; the instrument's
304 brevity (i.e. containing less than 30 items); and the inclusion of self and proxy-report forms. The
305 utilization of Disabkids-10 for routine assessment may be a practical way of incorporating HRQL
306 measurement in clinical practice, which may ultimately assist the identification of hidden morbidities,
307 facilitate patient-clinicians communication and clinical decision-making, and improve patient's outcomes
308 and satisfaction (Varni et al., 2005). Nevertheless, an index measure such as Disabkids-10 is inadequate

309 to obtain more detailed profile assessments, and its use should be complemented whenever possible with
310 supplemental assessments that account for the most age-specific aspects (e.g., adolescent dating). Finally,
311 future prospects for research on Disabkids-10 include the examination of the instrument's responsiveness
312 to medical or psychosocial treatments, as well as its performance as a screener in pediatric healthcare
313 practice.

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447 **Table 1.** *Socio-demographic and clinical characteristics of the sample.*

		Pediatric patients (<i>n</i> = 293)	Parents/caregivers (<i>n</i> = 197)
Socio-demographic characteristics			
Age, <i>M</i> (<i>SD</i>)		12.46 (2.96)	41.39 (6.56)
Age group, <i>n</i> (%)	Children 8-12	144 (49.1%)	
	Adolescents 13-18	148 (50.5%)	
	<i>Missing</i>	1 (0.3%)	
Gender, <i>n</i> (%)	Male	146 (49.8%)	22 (11.2%)
	Female	145 (49.5%)	174 (88.3%)
	<i>Missing</i>	2 (0.7%)	1 (0.5%)
SES ^a , <i>n</i> (%)	Low		113 (57.4%)
	Medium		52 (26.4%)
	High		16 (8.1%)
	<i>Missing</i>		16 (8.1%)
Clinical characteristics			
Diagnosis, <i>n</i> (%)	Diabetes	96 (32.8%)	
	Epilepsy	104 (35.5%)	
	Cerebral palsy	93 (31.7%)	
Using medication, <i>n</i> (%)		211 (72%)	

448 ^a Socioeconomic status was determined using a classification system for the Portuguese context based on
449 the parents' jobs and educational levels (Simões, 1994).

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451 **Table 2.** Factorial model comparison across age groups and genders for the self-report version of
 452 *DISABKIDS-10*.

	Model's goodness of fit				Multi-group analyses			
	$\chi^2(30)$	<i>p</i>	CFI	RMSEA	$\Delta\chi^2$	Δdf	<i>p</i>	ΔCFI
Age groups								
Children 8-12	50.31	.012	.94	.07	3.12	9	.96	.008
Adolescents 13-18	59.11	.001	.94	.08				
Gender								
Male	51.54	.009	.93	.07	6.26	9	.71	.004
Female	66.12	<.001	.93	.09				

453

454 **Table 3.** Factorial model comparison across age groups and genders for the proxy-report version of
 455 *DISABKIDS-10*.

	Model's goodness of fit				Multi-group analyses			
	$\chi^2(30)$	<i>p</i>	CFI	RMSEA	$\Delta\chi^2$	Δdf	<i>p</i>	ΔCFI
Age groups								
Children 8-12	80.77	<.001	.90	.13	12.94	9	.17	.004
Adolescents 13-18	43.78	.05	.97	.07				
Gender								
Male	71.74	<.001	.93	.12	10.56	9	.31	.002
Female	65.40	<.001	.91	.11				

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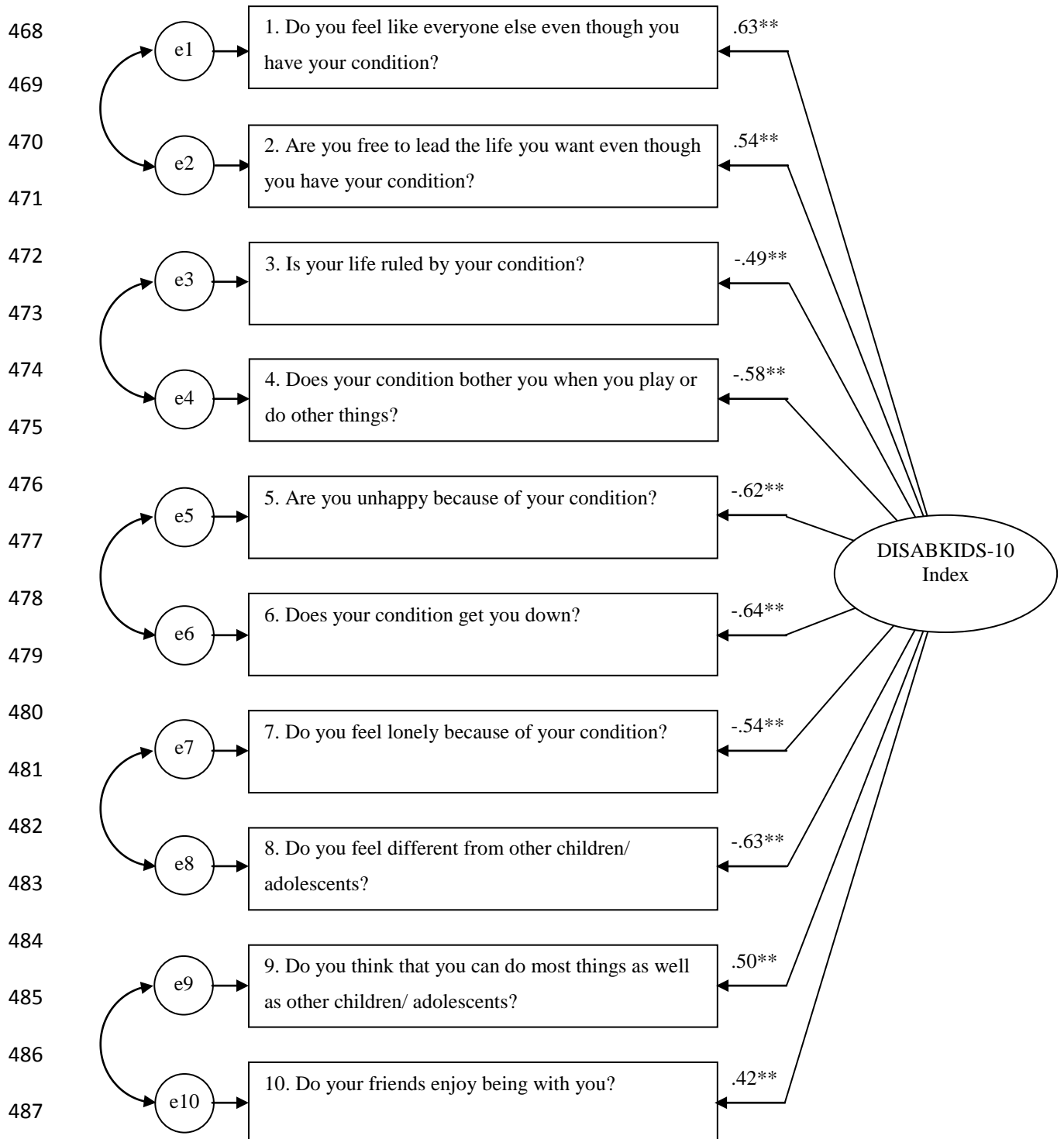
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488 *Figure 1.* Standardized regression weights of factor loadings for the patient-reported version of the
489 DISABKIDS-10.

490 Note. e - error.

491 * $p < .05$; ** $p < .01$, two-tailed.

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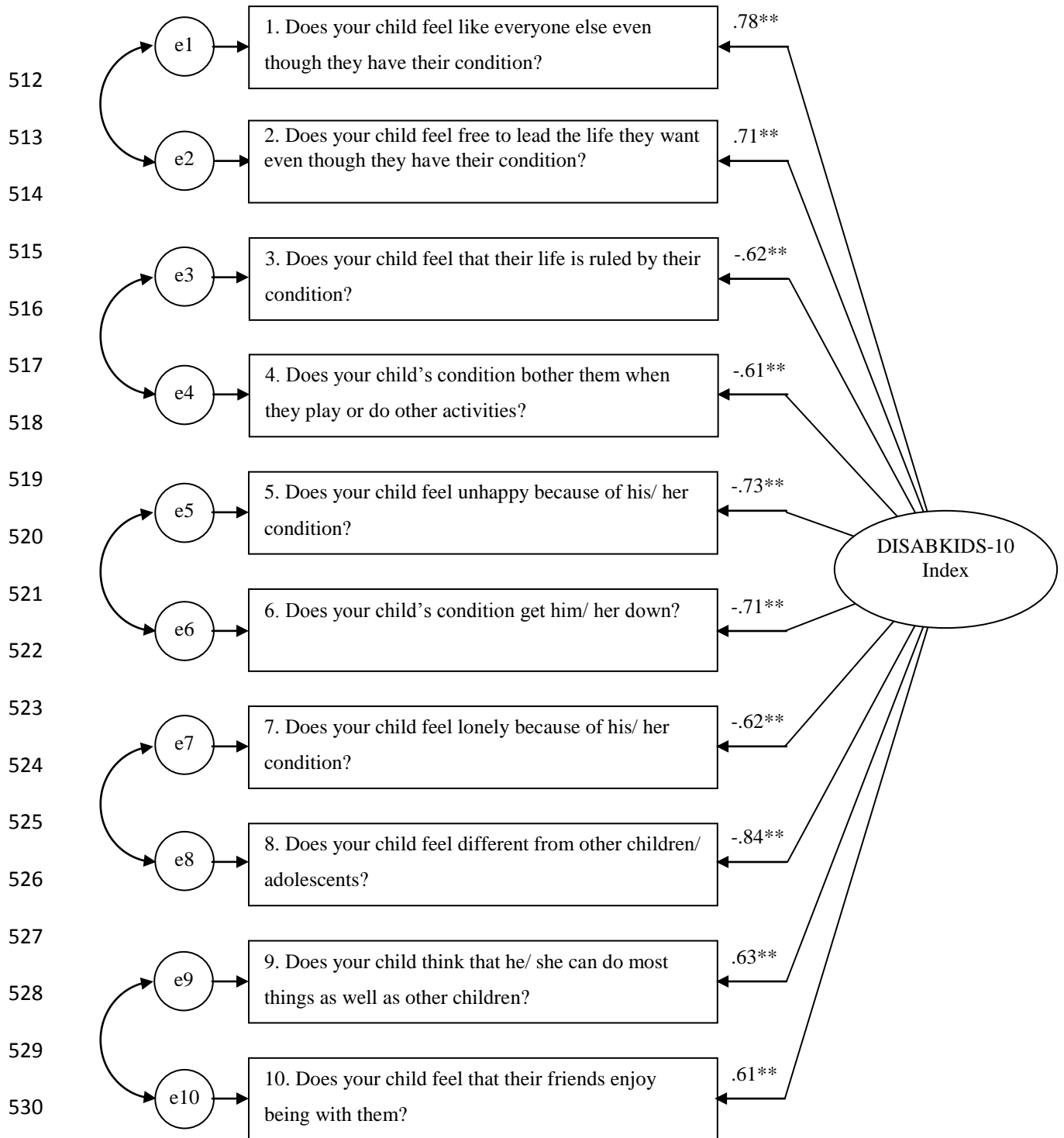
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531 *Figure 2.* Standardized regression weights of factor loadings for the proxy-reported version of the
532 DISABKIDS-10.
533 Note. e - error.
534 * $p < .05$; ** $p < .01$, two-tailed.