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Permalink

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Journal

Acta haematologica, 140(1)

ISSN

0001-5792

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Publication Date

2018

DOI

10.1159/000490408

Peer reviewed

Psychometric Properties of a Modified KINDL-R Questionnaire for Adolescents and Adults, and Construction of a Brief Version, the KINDL-A(dult) B(rief) Questionnaire, KINDL-AB

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Keywords

Quality of life · Hereditary bleeding disorder · Transition · KINDL-R questionnaire

Abstract

Background/Aims: The generic quality of life KINDL-R questionnaire is validated for use in children/adolescents ≤16 years. The aim of this cross-sectional investigation was to modify the KINDL-R questionnaire for use in adults and to validate its psychometric properties. **Methods:** Five items of the KINDL-R questionnaire were adapted and the newly developed KINDL-A(dult) questionnaire administered to 255 patients with hereditary and acquired bleeding disorders (mean age 53 years). Its internal consistency and convergent and divergent construct validity were investigated and confirmatory factor analysis was used to evaluate the latent factor structure. **Results:** The KINDL-A questionnaire showed satisfactory reliability, varying construct validity, but inconclusive factor structure. The KINDL-AB(rief) was developed

by removing half of the items and combining 2 sub-axes. This led to factor loadings between 0.62 and 0.91 and increased overall fit (Goodness of fit >0.8 and Root Mean Square Error of Approximation, RMSEA, <0.08). Results were validated in 966 healthy blood donors (mean age 38 years). In this group, the KINDL-AB questionnaire showed factor loadings between 0.43 and 0.77, Goodness of fit >0.95 and RMSEA <0.05. **Conclusions:** The new KINDL-AB suggests sufficient to good psychometric properties in adult patients with hereditary and acquired bleeding disorders.

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Introduction

In children and adolescents with hereditary bleeding disorders, life expectancy increased due to advances in diagnosis and treatment [1]. There is evidence that these quantitative gains in life-years in children and adolescents are accompanied by corresponding gains in health-related

quality of life (hrQoL) [2, 3]. In adults with hereditary bleeding disorders, especially in severe cases, hrQoL was found to be impaired compared to healthy counterparts [4–6], although this was not the case in all investigations [7]. In order to study the longitudinal consequences of aging on hrQoL, research involving patients with hereditary bleeding disorders would profit from extending the use of a questionnaire first amended during childhood and adolescence and later applied to the same patients during adulthood. One hrQoL questionnaire for use in childhood and adolescence (≤ 16 years) is the KINDL-R questionnaire (www.kindl.org) with population-level [8–10] and clinical-level applications [11, 12]. In patients with hereditary bleeding disorders, studies on hrQoL using the KINDL-R questionnaire exist [3, 13, 14]. As this questionnaire is not validated for adolescents and adults, longitudinal assessment of hrQoL in patients ≥ 17 years of age would require to switch over from the KINDL-R questionnaire to an established hrQoL questionnaires once the adolescent patients have reached their 16th year. Therefore, the aim of the present investigation was to adapt slightly and, if necessary, modify the KINDL-R questionnaire to allow its continuing use through childhood and adolescence into adulthood. A second study group with healthy adult blood donors permitted validation of the new instrument in an independent sample [15].

Material and Methods

Ethics

The present cross-sectional study was approved by the medical ethics committee of the University of Münster, Germany (2008-161-f-S). All study participants provided their written informed consent.

Inclusion Criteria

Adult patients with hereditary and acquired bleeding disorders (HABD) from the outpatient clinic of the Coagulation Center (Study group 1, enrolled between February 2014 and February 2016), and healthy blood donors from the Department of Transfusion Medicine (Study group 2, enrolled between January 2014 and November 2015) at the University Hospital Schleswig Holstein were enrolled into this study.

Exclusion Criteria

Patients aged less than 18 years, non-German speaking patients/donors, patients/donors unable to understand and answer the questionnaires or those who could not provide written informed consent were excluded from this study.

Study Population

Study group 1 encompassed 275 patients with HABD, of these $n = 75$ with hemophilia, von Willebrand disease and further factor deficiencies on regular factor replacement therapy; $n = 20$ with ad-

ditional strokes and $n = 180$ patients with thrombosis on anticoagulant therapy. Patients were aged 18 till 88 years and 255 (92.7%) answered the KINDL-A(dult) questionnaire (see below). Study group 2 encompassed $n = 1,011$ healthy blood donors aged 18–70 years, of whom 976 (96.5%) completed the KINDL-A questionnaire.

KINDL-A(dult) Questionnaire

Two items in the family-related well-being subscale and 3 items in the school-related well-being subscale of the original KINDL-R questionnaire were modified to be more age-appropriate (online suppl. Table 1; for all online suppl. material, see www.karger.com/doi/10.1159/000490408). In family-related well-being, questions now focus on relationship with a partner, for example, “I got on well with my partner” instead of “I got on well with my parents.” The 3 items in the school-related well-being subscale (now “education/work-related well-being”) were adapted slightly, for example, “doing the schoolwork/the professional training/the job was easy” instead of “doing the schoolwork was easy” (item 21). The KINDL-R algorithm for computing the total score (overall well-being) and the 6 sub-scores were used. Scores range from 0 to 100, with higher values indicating better hrQoL. Validation of the newly developed instrument included measures of reliability (Cronbach’s alpha for internal consistency). Divergent construct validity was assessed using Spearman’s correlation coefficients with age and socio-economic pattern. Convergent construct validity was evaluated using Spearman’s correlation coefficients with the short form-36 (SF-36) questionnaire [16] and the total score of the EuroQol five dimensions questionnaire (EQ-5D) [17]. Both questionnaires were administered to a randomly selected subgroup of both study populations. In study population 1, $n = 160$ participants received the KINDL-A questionnaire together with the SF-36 and the EQ-5D. Of these, 156 SF-36 questionnaires and 153 EQ-5D questionnaires had no missing items and were thus eligible for analysis. In study population 2, $n = 156$ participants answered the SF-36 and the EQ-5D questionnaire together with the KINDL-A questionnaire. The 6-dimensional structure of the KINDL-A questionnaire was validated by confirmatory factor analysis (CFA) using the *latent variable analysis (lavaan)* package in R [18]. As with the KINDL-R questionnaire, overall 6 latent variables were defined with 4 items loading on each latent variable. Parameter estimates for each item (“factor loadings”) are reported to be standardized for both latent and observed variables (“completely standardized solution”). The model fit was evaluated using the chi-square value, the Goodness of fit index (GFI), the adjusted GFI (AGFI), the Bentler Comparative Fit Index (CFI), and the residuals-based Root Mean Square Error of Approximation (RMSEA). The CFI (values > 0.93 are required as a measure of a good fit) [19] is regarded as being robust to larger sample sizes [20] as in the case of healthy blood donors ($n > 700$). According to MacCallum [21], RMSEA values below 0.01, 0.05, and 0.08 indicate excellent, good, and mediocre fit respectively.

Construction of the New Scale

Results of the CFA in patients were used to construct the new scale. The primary intention to use the highest threshold of the conservative end with factor loadings ≥ 0.70 [22] was not feasible since for example, emotional/friend-related/education/work-related well-being in patients did not show any factor loadings above this cut-off (Table 3). The practical approach was to weaken this strict criterion. In friend-related/education/work-related well-be-

Table 1. Quality of life in patients with hereditary and acquired bleeding disorder, $n = 275$ and in blood donors, $n = 1,011$

Parameter	Patients		Healthy blood donors	
	n	QoL [#] , mean (SD)	n	QoL [#] , mean (SD)
KINDL-A				
Overall well-being	242	67.7 (13.6)	966	76.0 (9.5)
Physical well-being	254	54.9 (23.3)	966	78.6 (12.6)
Emotional well-being	252	76.1 (17.0)	974	81.5 (12.5)
Self-esteem	255	58.3 (18.9)	976	66.8 (14.7)
Family-related well-being	222	85.6 (13.8)	813	85.8 (14.4)
Friend-related well-being	253	63.2 (16.3)	976	70.7 (14.3)
Education/work-related well-being	162	73.3 (17.8)	913	74.8 (17.3)
SF-36				
Physical functioning	75	77.8 (20.6)	156	94.5 (9.1)
Physical role functioning	73	69.6 (27.7)	155	88.8 (16.9)
Emotional role functioning	71	79.8 (22.7)	156	88.0 (17.9)
Bodily pain	74	65.3 (27.0)	151	82.9 (21.9)
Mental health	73	73.4 (18.1)	153	77.8 (15.4)
Social role functioning	74	79.1 (23.8)	155	86.6 (20.6)
General health perceptions	75	64.2 (19.7)	155	78.4 (16.7)
Vitality	74	58.0 (18.7)	153	64.6 (15.9)
EQ-5D				
Total score	180	77.7 (24.6)	153	91.1 (10.7)

[#] Mean (SD); KINDL-A, adult version of the revised KINDL questionnaire; SF-36, short form-36 health survey; EQ-5D, EuroQol 5 dimensions questionnaire.

ing, the 2 items with the highest factor-loadings were chosen. Self-esteem and emotional well-being (altogether only 3 items with factor loadings >0.6 ; and item number 10 being the only item with a high loading on self-esteem, Table 5) were collapsed into one single sub-axis “psychological well-being.” Thus, the resulting questionnaire had 12 items and 5 sub-axes and its internal consistency (reliability) as well as its factor loadings were evaluated. Results were validated in the group of healthy blood donors.

Descriptive Statistics

The central tendencies of patients’ basic characteristics, when values were normally distributed, were displayed as mean $\pm$ standard deviation. The central tendency of body mass index, a variable with skewed values, was described in terms of median values (range). Count data were displayed as absolute and relative frequencies. All statistical analyses were performed using SPSS software (Version 23.0, SPSS Inc., Chicago, IL, USA) or using R (The R Foundation for Statistical Computing, version 3.4.0).

Results

The mean age of the patients with hereditary and acquired bleeding disorders was 52.6 (standard deviation, SD: 17.5) years and 60.7% were women. Around two-

thirds ($n = 166$, 62.4%) were married and living with their partners, 24.1% ($n = 64$) were single and 13.1% ($n = 36$) were living separated, divorced or widowed. Just 18.7% ($n = 50$) lived in a 1-person household, 49.4% ($n = 132$) in a 2-persons household and 31.8% ($n = 85$) in a >2 -persons household. The mean age of the 1,011 blood donors was 37.5 (SD: 14.2) years and 47.0% ($n = 475$) were women. Most were single (55.3%, $n = 534$), 35.9% ($n = 346$) were married and living with their partner and 8.8% ($n = 85$) were separated, divorced, or widowed. Overall, 22.1% ($n = 215$) lived in a 1-person household, 40.7% ($n = 395$) in a 2-person household and 37.2% ($n = 361$) in a >2 -person household. The crude values of the 3 hrQoL questionnaires (KINDL-A, SF-36, and EQ-5D) for patients and for blood donors are displayed in Table 1. Using the KINDL-A questionnaire, the overall well-being was approximately 8 points higher in blood donors compared to patients (76.0 vs. 67.7 points), while physical well-being was nearly 24 points higher in blood donors compared with patients (78.6 vs. 54.9 points). Total differences in psychological dimensions were less pronounced (81.5 vs. 76.1 points in emotional well-being and 66.8 vs. 58.3 points in self-

Table 2. Scale characteristics and divergent construct validity for patient and blood donor samples, $n = 275$ and $n = 1,011$

KINDL-A subscale	Study group	n	Internal consistency Cronbach's alpha	Divergent construct validity [#]			
				age	gender, male	having no partner	living in a 1-person household
Overall well-being	Patients	125	0.86	0.09	0.10	-0.15*	-0.13*
	Blood donors	716	0.81	0.18**	-0.04	-0.17*	-0.12**
Physical well-being	Patients	247	0.83	0.04	0.15*	0.02	-0.02
	Blood donors	958	0.57	0.10**	0.07*	-0.05	0.00
Emotional well-being	Patients	251	0.71	0.14*	0.00	-0.24**	-0.22**
	Blood donors	971	0.59	0.23**	-0.08*	-0.26**	-0.17**
Self-esteem	Patients	249	0.78	0.05	0.08	-0.60	0.01
	Blood donors	968	0.70	0.10**	0.08**	-0.04	-0.04
Family-related well-being	Patients	220	0.70	0.09	0.07	-0.15*	-0.12
	Blood donors	809	0.69	0.08*	-0.15**	-0.08*	-0.09*
Friend-related well-being	Patients	243	0.60	0.07	-0.04	-0.01	-0.06
	Blood donors	953	0.46	-0.19**	-0.16**	0.16**	0.03
Education/work-related well-being	Patients	156	0.58	0.20	0.10	-0.10	-0.03
	Blood donors	903	0.64	0.34**	-0.02	-0.27**	-0.07*

KINDL-A, adult version of the revised KINDL questionnaire; * $p < 0.05$; ** $p < 0.001$; # Spearman's correlation coefficients; according to Evans JD [12] correlations ranging from 0.00 to 0.19 are "very weak," from 0.20 to 0.39 are "weak," from 0.40 to 0.59 are "moderate," from 0.60 to 0.79 are "strong" and from 0.80 to 1.0 are "very strong."

Table 3. KINDL-A: Convergent construct validity in patients, Spearman's correlation coefficient, $n = 75$ and $n = 161$

KINDL-A overall well-being sub-scales	SF-36 subscales ($n = 75$)								EQ-5D ($n = 161$) total score
	physical functioning	physical role functioning	emotional role functioning	bodily pain	mental health	social role functioning	general health perceptions	vitality	
Overall well-being	0.54**	0.50**	0.42**	0.52*	0.70**	0.62**	0.54**	0.73**	0.43**
Physical well-being	0.64**	0.63*	0.47**	0.68**	0.57**	0.62**	0.57**	0.69**	0.58**
Emotional well-being	0.20	0.22	0.31**	0.30*	0.70**	0.40**	0.42**	0.61**	0.38**
Self-esteem	0.37**	0.30*	0.32**	0.36**	0.49**	0.36**	0.38**	0.50**	0.31**
Family-related well-being	0.02	0.06	0.29*	-0.01	0.59**	0.27*	0.19	0.31	0.12
Friend-related well-being	0.35**	0.30*	0.27*	0.30*	0.35**	0.37**	0.29*	0.27*	0.22*
Education/work-related well-being	0.38**	0.40**	0.30**	0.37*	0.40**	0.38*	0.27	0.34*	0.28**

KINDL-A, adult version of the revised KINDL questionnaire; SF-36, short form-36 health survey; EQ-5D, EuroQol five dimensions questionnaire; * $p < 0.05$; ** $p < 0.001$; according to Evans JD [12] correlations ranging from 0.00 to 0.19 are "very weak," from 0.20 to 0.39 are "weak," from 0.40 to 0.59 are "moderate," from 0.60 to 0.79 are "strong" and from 0.80 to 1.0 are "very strong."

esteem, blood donors compared with patients). Family-related well-being and education/work-related well-being showed differences of around 1 point between the 2 study groups. Subscores of the SF-36 showed a comparable pattern with larger total differences in physical subscores (e.g., in physical functioning, physical role functioning, bodily pain) compared with psychological

subscores (e.g., in emotional role functioning, mental health, vitality). The total score of the EQ-5D differed markedly between patients (77.7 points) and blood donors (91.1 points). Table 2 shows Cronbach's alpha as a measure of internal consistency for the total scale and its subscales in both study populations. Internal consistency was good (alpha > 0.80) for the total scale in both

Table 4. Factor loading matrix standardized for both latent and observed variables of the KINDL-A questionnaire and the brief version, the KINDL-AB questionnaire, administered to patients

Sub-axis	Items		Standardized factor loadings	
	no.	topic	KINDL-A	KINDL-AB
Physical well-being	1	Felt ill	0.79	0.76
	2	Felt pain	0.65	
	3	Felt tired	0.74	0.75
	4	Power and endurance	0.69	0.69
Emotional well-being [§]	5	Lots of fun	0.65	0.66
	6	Felt bored	0.43	
	7	Felt alone	0.61	
	8	Anxious and uncertain	0.64	0.62
Self-esteem [§]	9	Proud of myself	0.42	
	10	Felt comfortable	0.88	0.78
	11	Liked oneself	0.59	
	12	Had many good ideas	0.45	
Family-related well-being	13	Good relations	0.69	0.67
	14	Comfortable at home	0.87	0.91
	15	Dispute at home	0.49	
	16	Felt restricted	0.31	
Friend-related well-being	17	Activities with friends	0.46	
	18	Felt well received	0.54	0.62
	19	Got along well	0.51	0.71
	20	Felt different from others	0.39	
Education/work-related well-being	21	Mastered duties well	0.56	0.70
	22	Felt interested	0.57	0.65
	23	Concerns about future	0.55	
	24	Worries about criticism	0.40	
Goodness of fit indices	Chi square test (DF = 44)		$p < 0.001$	$p < 0.001$
	SRMR		0.100	0.056
	RMSEA		0.086 [#] (0.074–0.097)	0.068 [#] (0.035–0.098)
	GFI		0.76	0.92
	AGFI		0.70	0.86
	Bentler CF)		0.75	0.94

Results were derived from a confirmatory factor analysis, $n = 124$. KINDL-A, adult version of the revised KINDL questionnaire; KINDL-AB, brief Version of the KINDL-A questionnaire; [§] both axes were combined to one subaxis “psychological well-being” in the KINDL-AB questionnaire; [#] according to MacCallum [21] values below 0.01, 0.05, and 0.08 indicate excellent, good, and mediocre fit, respectively.

SRMR, standardized root mean square residual; RMSEA, root mean square error of approximation; GFI, goodness of fit index; AGFI, adjusted GFI; CFI, comparative fit index.

study populations and showed in 5 out of 6 subscales better values for patients compared to healthy blood donors (with the exception for education/work-related well-being, which showed better Cronbach’s alpha in blood donors compared with patients). Taking a cut-off of 0.7 for an acceptable internal consistency [23], 5 subscales in blood donors and 2 subscales in patients did not meet this threshold. Divergent construct validity

was determined by analyzing the correlations of the KINDL-A scales with socio-demographic characteristics: The 4 columns to the right in Table 2 show that overall well-being and its sub-domains correlated only very weakly to weakly with age, gender, having no partner, and living in a 1-person household. For study group 1, convergent construct validity is shown in Table 3, with the following classifications for the overall correla-

Table 5. Factor loading matrix standardized for both latent and observed variables of the newly constructed KINDL-A questionnaire and its brief version, the KINDL-AB questionnaire, administered to healthy blood donors

Sub-axis	Item	Standardized factor loadings	
		KINDL-A	KINDL-AB
Physical well-being	Felt ill	0.48	0.43
	Felt pain	0.37	
	Felt tired	0.65	0.60
	Power and endurance	0.47	0.53
Emotional well-being	Lots of fun	0.41	0.48
	Felt bored	0.49	
	Felt alone	0.67	
	Anxious and uncertain	0.57	0.48
Self-esteem	Proud of myself	0.54	
	Felt comfortable	0.78	0.65
	Liked oneself	0.62	
	Had many good ideas	0.47	
Family-related well-being	Good relations	0.65	0.60
	Comfortable at home	0.67	0.76
	Dispute at home	0.54	
	Felt restricted	0.44	
Friend-related well-being	Activities with friends	0.48	
	Felt well received	0.72	0.60
	Got along well	0.57	0.65
	Felt different from others	0.13	
Education/work-related well-being	Mastered duties well	0.62	0.77
	Felt interested	0.54	0.68
	Concerns about future	0.59	
	Worries about criticism	0.51	
Goodness of fit indices	Chi square test (DF = 707)	$p < 0.001$	0.001
	SRMR	0.070	0.030
	RMSEA	0.066 [#] (0.02–0.071)	0.034 [#] (0.022–0.046)
	GFI	0.89	0.98
	AGFI	0.86	0.97
	CFI	0.78	0.97

Results were derived from a confirmatory factor analysis, $n = 708$. [§] Both axes were combined to one sub-axis “psychological well-being” in the KINDL-AB questionnaire; [#] According to MacCallum [21] values below 0.01, 0.05, and 0.08 indicate excellent, good, and mediocre fit, respectively.

KINDL-A, adult version of the revised KINDL questionnaire; KINDL-AB, brief version of the KINDL-A questionnaire; SRMR, standardized root mean square residual; RMSEA, root mean square error of approximation; GFI, goodness of fit index; AGFI, adjusted GFI; CFI, comparative fit index.

tions: (0.00–0.19 “very weak”; 0.20–0.39 “weak”; 0.40–0.59 “moderate”; 0.60–0.79 “strong”; 0.80–1.0 “very strong,” according to [24]) were moderate to strong between KINDL-A questionnaire, both SF-36 sub-dimensions and the EQ-5D, especially regarding overall well-being and physical well-being. Correlations of the psychological and social dimensions of the KINDL-A

questionnaire with the psychological and social dimensions of the SF-36 and the overall score of the EQ-5D were predominantly weak to moderate. Exceptions were emotional well-being of the KINDL-A questionnaire and Mental Health of the SF-36 (Spearman: 0.70, $p < 0.001$) and emotional well-being of the KINDL-A questionnaire and Vitality of the SF-36 (Spearman: 0.61, $p <$

0.001), which both showed strong correlations. None of the correlations could be classified as very strong (i.e., $0.80 < \text{Spearman} < 1.0$). In blood donors (online suppl. Table 2), no single strong correlation ($0.60 < \text{Spearman} < 0.79$) existed. Only a few values exceeded values of 0.4 and none showed values greater than 0.5. The correlation between physical well-being of the KINDL-A questionnaire and physical functioning of the SF-36 was only weak as was the correlation between emotional well-being of the KINDL-A questionnaire, and emotional role functioning of the SF-36 (both correlations with Spearman: 0.22, $p < 0.001$). The correlation with the Mental Health subscale of the SF-36 was somewhat stronger (Spearman: 0.38, $p < 0.001$).

Results of the CFA are displayed in Tables 4 (patients) and 5 (blood donors). Only 4 items in patients and 2 items in blood donors showed item loading above 0.7 (a very conservative threshold according to Matsunaga [22]) but still 8 out of 24 items in patients and 9 out of 24 items in blood donors did not meet the criterion of 0.5, which is sometimes defined as the cut-off for sufficiently large factor loadings [22]. RMSEA as a measure of model fit indicated mediocre fit (i.e. values between 0.05 and 0.08) in healthy blood donors only. In patients, RMSEA was not adequate (RMSEA = 0.086). Other measures, such as the GFI or the CFI showed higher values in blood donors compared with patients, all of them exceeding 0.7. However, values higher than 0.8 are sought. After deleting items with low factor loadings, the new questionnaire with 12 items overall (items 1, 3–5, 8, 10, 13, 14, 18, 19, 21, and 22 of the KINDL-A questionnaire, respectively) and 5 subscales showed factor loadings between 0.62 and 0.91 (Table 4). The RMSEA indicated mediocre fit (0.068) and the GFI, the AGFI, and CFI yielded acceptably high values of 0.92, 0.86 and 0.94 respectively. Validation of the KINDL-AR questionnaire in healthy blood donors showed factor loadings between 0.43 and 0.77 (Table 5). The RMSEA as well as GFI (0.034), AGFI and CFI indicated good fit (0.98, 0.97, and 0.97, respectively). Likewise, internal consistency of the new questionnaire remained satisfactory: in patients, internal consistency of the overall scale was 0.81 and for the subscales – (physical/psychological/family-related/friend-related/education/work-related well-being – was 0.77, 0.72, 0.75, 0.61, and 0.62 respectively. For healthy blood donors, the internal consistency of the overall scale was 0.74 and was 0.52, 0.54, 0.64, 0.58, and 0.65 for the 5 subscales respectively. Online supplementary Tables 3 and 4 depict the correlations between the sub-axes of the KINDL-A questionnaire

and the KINDL-AB questionnaire. In patients (online suppl. Table 3), high correlations (between 0.5 and 0.7) occurred between physical well-being and emotional/psychological well-being and self-esteem in both the KINDL-A questionnaire and the KINDL-AB questionnaire respectively. The other sub-axes showed more variable values, although the newly developed questionnaire showed relatively invariant correlations between 0.2 and 0.4 for all sub-axes except physical and emotional well-being. In healthy blood donors (online suppl. Table 4), correlations were generally lower and showed no clear pattern between the KINDL-A questionnaire and the KINDL-AB questionnaire. Notably, the values of the psychological well-being subscale of the KINDL-AB questionnaire fell in between the emotional well-being and self-esteem subscales of the KINDL-A questionnaire (online suppl. Table 5).

Discussion

In a study population of adult patients with hereditary bleeding disorders, the 24-item version of a slightly modified version of the KINDL-R questionnaire showed acceptable reliability, inconclusive divergent construct validity as well as inconclusive convergent construct validity with established QoL questionnaires in adults. Furthermore, the factor loadings did not convincingly reproduce the underlying theoretical structure. Removing half of the items and collapsing 2 subscales increased factor loadings and goodness of fit indices. Cross-validation of the new KINDL-AB questionnaire in a study population of healthy blood donors generally showed weaker factor loadings but increased goodness-of-fit indices.

The idea of minimally adjusting the KINDL-R questionnaire – a QoL instrument designed for children and adolescents up to 16 years – emerged from the desire to follow children and adolescents through transition into adulthood with comparable QoL scales. As demonstrated here, convergent validity of both the KINDL-A questionnaire and the KINDL-AB questionnaire in relation to the SF-36 and the EQ-5D was low. Thus, these hrQoL questionnaires measure different constructs and may not be appropriate for use in longitudinal studies, when starting with the KINDL-R questionnaire in infancy/adolescence and then switching to one of the established QoL questionnaires for adults. Results of comparisons between such different QoL scales over repeated assessments would not be meaningful. This is a com-

elling argument for the construction of new age-appropriate scales conceptually comparable to the KINDL-R scales. However, the full-sized KINDL-A questionnaire showed unsatisfactory psychometric properties. More specifically, 2 psychological subscales (emotional well-being and self-esteem) showed unacceptably low factor loadings, suggesting that the underlying structure was a poor fit for the adult data. While item 10 showed excellent loading on self-esteem, the other 3 items did not. In contrast, emotional well-being showed 3 items with relatively good loadings, while 1 item showed a weak loading. Furthermore, those items with negative formulations in family-related well-being (items 15 and 16), in friend-related well-being (item 20), and in education/work-related well-being (items 23 and 24) had insufficiently large loadings on the intended sub-axes. Combining these subscales into one single “psychological subscale” and removing items throughout the whole scale increased factor loadings and improved goodness-of-fit indices for the whole scale. In both study populations, the CFI exceeded 0.9, a cut-off indicating good fit to the data [25]. The internal consistency remained high for the overall questionnaire and its subscales.

The correlation structure of the sub-axes in both the KINDL-A questionnaire and the KINDL-AB questionnaire suggests a stronger correlation of physical well-being with emotional well-being, self-esteem, and psychological well-being (for the KINDL-AB questionnaire, respectively) than with the 3 social dimensions of hrQoL. Their relatively weak correlation (correlation coefficients between 0.21 and 0.36 for the KINDL-AB questionnaire in patients) underscores the necessity to capture these dimensions separately. In healthy blood donors, the correlation between physical well-being and emotional/psychological well-being was weaker, but physical well-being was also less correlated with the social dimensions of hrQoL. Collapsing emotional well-being and self-esteem into one single psychological dimension in healthy blood donors may be a less convincing solution in patients, where these subscales were relatively strongly correlated (correlation coefficient = 0.57, compared to 0.40 in blood donors).

Strengths and weaknesses of the current study: The challenge of assessing hrQoL repeatedly throughout the adolescence to adult transition has not yet been resolved satisfactorily. The solution of slightly modifying items taken from the KINDL-R questionnaire and reducing the overall number of sub-axes and items allows researchers to proceed with hrQoL measurements in ex-

isting adult cohorts conceptually comparable to the hrQoL measures obtained previously from the same individuals as children/adolescents previously assessed with the KINDL-R questionnaire. Research can thereby assess health-related QoL of longitudinal cohort members as they transition from adolescence into adulthood. The newly developed adult version of the questionnaire was validated in a population of healthy adult blood donors but could still benefit from cross-validation in independent samples of patients. Such cross-validation is needed to confirm that the factor loadings of the suggested new factor structure define a statistical model that fits the observed data well. So far, in both study populations studied here, the fit indices were promising and the factor loadings in the study population of patients were especially convincing. Of note, in both study groups, the scale values of the newly developed KINDL-AB questionnaire followed the pattern of the KINDL-A questionnaire (online suppl. Table 5).

The reduced number of items facilitates application of this new scale but necessarily results in less information being collected. Given the recognized importance of addressing the QoL of young people with chronic disease throughout their transition into adulthood, more developmental research using this new scale in other study populations is warranted.

Disclosure Statement

The authors declare that they have no conflicts of interest.

Funding Source

This study was financed by unrestricted grants from Biotest AG, Langen, Germany, to Ulrike Nowak-Göttl. William McCarthy was supported by PCORI grant CER-1306011 during the writing of this paper.

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