ORIGINAL ARTICLE

The Parent Health Literacy Questionnaire (HLQ-Parent). Adaptation and validity testing with parents of children with epilepsy

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Abstract

Aims: The aim of this study was to adapt the Health Literacy Questionnaire (HLQ) in English and Norwegian for use with parents. *Methods:* The research group evaluated all HLQ items and, where relevant, modified them to refocus the attribution of care to that of a child by a parent. Five cognitive interviews with parents were undertaken to gain a detailed depiction of the meanings and processes they used to respond to the HLQ items. Assessment of the psychometric properties of the revised HLQ was undertaken using data from a cross-sectional survey of 254 parents of children with epilepsy. Analysis included internal consistency (Cronbach's alpha) and confirmatory factor analysis (CFA). *Results:* Some 22 out of 44 items and the names of three domains were modified (e.g. attribution changed from 'me' to 'my child'). Cognitive interviews indicated that parents interpreted the HLQ-Parent items in the way intended. All but three factor loadings were high to acceptable. All nine HLQ scales showed satisfactory to good internal consistency (Cronbach's alpha 0.70 to 0.87). When fitting one-factor CFA models, correlated residuals were required for four scales to generate an acceptable fit. One scale, '8. Ability to find good health information', required inclusion of two correlated residuals to generate an acceptable CFA model fit, indicating that further work on this scale is warranted. ***Conclusions:*** **The results from both the adaptation process and the CFA analysis supported the relevance, understanding and theoretical structure of the instrument in a parental context.**

Keywords: *Parental health literacy, Health Literacy Questionnaire (HLQ), confirmatory factor analysis, adaptation, cognitive interviews, epilepsy*

Background

Epilepsy in childhood is a chronic disease characterised by unprovoked seizures that can have a significant impact on a person's emotional, cognitive and social development and functioning [1]. Hence, many children with epilepsy are at increased risk of unsuccessful school experiences [2]. In childhood epilepsy, parents are expected to participate in their child's healthcare. This may involve administering complicated treatment regimens (e.g. diet, medication), addressing their health needs, and navigating the different parts of the healthcare system [3]. Parents' health literacy – that is, their ability to access, understand, remember, critically assess, and use health information and services to achieve successful collaborations with healthcare providers – is crucial to their child's health [4]. Health literacy is a contextual and dynamic phenomenon, since factors such as stress and the complexity of treatments and services can affect health literacy. This is a salient point in complex medical conditions such as childhood epilepsy, as chronic stress is known to frequently affect the parents [5].

In a recent scoping review [6] on pathways linking parental health literacy with health behaviours directed at the child, researchers found that the most prominent pathway was a direct association. Variables considered to be mediators were self-efficacy, attitudes, beliefs and education. However, the review found an apparent lack of theoretical models to illuminate these pathways. An article on the relationship between parental health literacy and the health outcomes of children with medical complexity [5] underscores this knowledge gap and the need for novel research to examine the relationships between communication, healthcare delivery and the accessibility of the healthcare system for which parental health literacy is likely to be essential.

There is growing evidence that health literacy challenges in parents are associated with several poor health outcomes in children, including medical errors [7]. However, less is known about the relationship between parental health literacy and the health outcomes of children with medical complexity, for instance childhood epilepsy [6]. A study by Paschal et al. [3] showed that higher health literacy was associated with fewer missed medication doses and seizure frequency. Health literacy was estimated through parents' confidence in filling out forms, understanding health information, and whether they needed help with reading [3]. In another study investigating the same topic [8], a 17-item public health literacy knowledge scale was used, and the caregivers' health literacy knowledge was found to be associated with adherence to antiepileptic drugs. A third study [9] aimed to evaluate the content, quality, useability and efficacy of a web-based epilepsy education programme developed for youth with epilepsy and their parents. The results showed the positive effects of ehealth literacy, among other outcomes. In this study, ehealth literacy was measured by eHEALS [10].

Although several instruments have been developed to measure health literacy, there are important distinctions to consider when measuring health literacy related to caregiver roles compared with parents' own health literacy. Children with medical complexity, such as epilepsy, are especially dependent on their parents' skills and ability to conduct tasks related to understanding and critically assessing health information, to navigate the healthcare system, and to achieve successful collaboration with healthcare providers [6]. To achieve a broader and more in-depth knowledge about these tasks and skills, parental health literacy needs to be evaluated by comprehensive instruments that incorporate the full multidimensional nature of health literacy [11].

Few instruments provide specific information on the full range of health literacy elements for public health planning and clinical practice. To the best of our knowledge, parental versions of such instruments are sparse and cover a limited range of dimensions [11-14]. The Health Literacy Questionnaire (HLQ) is a generic, comprehensive instrument that measures health literacy. Originally developed using a validity-driven approach [15-18] in Australia by Osborne et al. [16], it has since been applied and tested in many countries and languages. The HLQ was designed to detect a wide range of health literacy strengths and needs, and to be used for a variety of purposes, such as describing the health literacy needs of populations in national health surveys, informing fit-for-purpose health literacy actions and interventions, and measuring outcomes of public health and clinical interventions designed to improve health literacy [16,18]. For these reasons, the HLQ was identified as a potentially useful tool to illuminate parental health literacy in childhood epilepsy and other parental contexts.

Aims

The aim of this study was to adapt the HLQ in English and Norwegian for use with parents of children with epilepsy in Norway. Qualitative (i.e. cognitive interviews) and quantitative (i.e. psychometric) analyses were undertaken to contribute evidence on the content of the parent version of the HLQ (i.e. HLQ-Parent) the response processes of the parents completing it, and its structure.

Methods

Design and sample

To adapt the HLQ [16] to a parental context, the research group discussed and came to a consensus about the changes needed in close collaboration with the HLQ development team in Australia. Five cognitive interviews with parents were performed to gain a detailed depiction of the meanings and processes used to respond to the HLQ statements. The psychometric properties of the HLQ-Parent were assessed with data from a cross-sectional survey of 254 parents of children with epilepsy obtained from two contexts:

1) parents of children with complex epilepsy admitted to a hospital in tertiary healthcare, and 2) parents of children with epilepsy that answered an identical survey on the National Epilepsy Association website from June to December 2020. In addition, data were collected on selected socio-demographic (sex, age, education and civil

Table I. Sample characteristics (*n* = 254).

	N (%)
Age groups (*N* = 249)	
18–30	26 (10.4)
31–35	57 (22.9)
36–40	62 (24.9)
41–45	63 (25.3)
>46	41 (16.5)
Gender (*N* = 254)	
Male	53 (20.9)
Female	201(79.1)
Education level (*N* = 254)	
0 = ≤13 years of education	88 (34.6)
1 = >13 years of education	166 (65.4)
Work status (*N* = 254)	
Not working	62 (24.4)
Living alone (*N* = 254)	
Yes	38 (15)
Country of birth (*N* = 245)	
Norwegian	231 (90.9)
Duration of epilepsy (*N* = 249)	
Less than 1 year	27 (10.8)
1–3 years	105 (42.2)
More than 3 years	117 (47)
Comorbidity (*N* = 254)	133 (53)

status) and clinical variables (duration of the child`s epilepsy, number of hospitalisations, comorbidity and self-assessed health status). The research was approved by the Norwegian Centre for Research Data (#187824) and the department for the security of sensitive information in the study site hospital (#20/07884). The study was conducted in accordance with the Declaration of Helsinki.

The adaptation processes

The HLQ had previously been translated and tested in the Norwegian context and used with many different populations in Norway [19,20]. The HLQ comprises 44 items representing nine independent health literacy domains. Each domain comprises four to six items. Items are scored from 1 to 4 in the first five scales (Strongly Disagree, Disagree, Agree, Strongly Agree), and from 1 to 5 in the remainder (Cannot Do or Always Difficult, Usually Difficult, Sometimes Difficult, Usually Easy, Always Easy) [18]. The domain scores are calculated as the average of the item scores, higher scores indicating better health literacy. For further information on the domains, content and keywords of the generic HLQ see Table I [19].

The process of adapting the HLQ to parents was as follows. Authors MKT, MHL, RJ and AKW (representing various backgrounds related to the healthcare of children with medically complex conditions and health literacy measurements) reviewed the HLQ and assessed what changes were necessary to orient the form towards children's health for both the Norwegian and English versions of the HLQ. After reaching consensus in the group, the changes suggested were submitted to the developers of the HLQ (author RHO) and the Translation Integrity Protocol[17] was used to evaluate and coordinate comments, corrections and to facilitate consensus. Five cognitive interviews with parents were conducted. The parents were recruited from the Norwegian National Centre for Epilepsy. Each parent completed the HLQ-Parent version and was subsequently independently interviewed. The interviewer (MBT) assessed whether the parents understood the HLQ-Parent in the way that was intended (referenced against the item intent detailed in the management grid of the Translation Integrity Protocol). Furthermore, each parent's response process was assessed, that is, the underlying process that led to their particular understanding of each question and answer. Qualitative questions included, 'what was your first reflection of the item, and what made you answer the way you did?'. After the cognitive interviews, the research group discussed the parents' comments and their consensus into the management grid. Two blinded translators – one authorised translator and one native English speaker fluent in the Norwegian language – independently back-translated the HLQ-Parent into English. The items of this version were ultimately approved by the questionnaire developers.

Data analysis – confirmatory factor analysis

Analyses were carried out using Stata v16 (StataCorp, College Station, TX). Descriptive analyses were undertaken and Cronbach's alpha was calculated to investigate each scale's internal consistency with Pearson's *r* being used to estimate interscale correlations. As the structure of the original HLQ is established [16], the factor structure was specified a priori. Confirmatory factor analysis (CFA) was therefore employed to investigate the structure of each scale. Overall, the amount of missing data per HLQ item was low with an average of 0.78% of respondents having missing values on one of the nine HLQ scales. Maximum likelihood was applied for model estimation. Model evaluation was based on chi-square tests for model fit and additional model fit indices, including the root mean square error of approximation (RMSEA), comparative fit index (CFI), the Tucker–Lewis index (TLI) and the standardised root mean square residual (SRMR). For model fit to be interpreted as acceptable, an RMSEA of <0.05 was considered a close fit, while an RMSEA and an SRMR of up to 0.08 were considered acceptable. Comparing the fit of a

target model to that of an independent or null model, the CFI has a cut-off for good fit of ≥0.90. A TLI of 0.95 indicates the model of interest improves the fit by 95% relative to the null model; the cut-off for good fit was therefore set at TLI ≥0.95 in the current study. Furthermore, the presence of correlated residuals among one-factor models was considered. Correlated residuals <0.2 were considered acceptable when fitting the models [21,22]. Potential model adjustments were based on modification indices, as provided in the Stata output using the 'estat gof, stats (all)' command. To obtain information on potential problematic items, nine 1-factor models were fitted to the data. To test whether modifications, in terms of correlated within factor residuals, led to significant model improvement, modification indices were obtained using the 'estat mindices' command in Stata.

Results

Sample characteristics (cognitive interviews)

Five cognitive interviews (three fathers, two mothers) were conducted with parents who broadly represented those of children with epilepsy (high/low education, residence, language, culture, age, gender).

Cross-sectional survey sample characteristics

The characteristics of the sample who provided data for the psychometric analysis are shown in Table I. The sample consisted of 79% women, 73% of whom were between 31 and 45 years of age. Over 90% were Norwegian born. Sixty-five per cent of the parents had completed higher education in addition to primary and secondary school, and 76% were working either full- or part-time. Forty-seven per cent reported their child's disease duration to be more than 3 years. The proportion of children with one or more comorbidities was 53%.

Revisions made to the Health Literacy Questionnaire to generate a parent version

Twenty-two of the 44 items and the names of three of the original domains were changed as a result of the adaptation process. The changes made were to items and domains containing wording related to 'my health/situation' and renamed as 'my child's health/ situation'. The revised domain names were 1. Feel that healthcare providers understand and support my child's situation, 2. Having sufficient information to manage my child's health, and 3. Actively managing my child's health.

The cognitive interviews

The parents were observed to interpret the HLQ-Parent as intended when their interpretations of the items were matched against the item intent. In addition, they understood that the questions were directed towards their child's health and healthcare support, not their own health. However, the cognitive interviews revealed some specific information on the content of the questionnaire. The parents understood the questions about health information regarding their child to be general health information, but also specific information about the child's diagnosis that was necessary to adequately care for their child's epilepsy. General information covered nutrition, being physically active, and getting enough sleep. Information about the child's diagnosis included, for example, receiving adequate information to follow the recommended treatment. Specific information from the parents is shown in Table II.

Based on the cognitive interviews, only minor grammatical adjustments were made to the questionnaire.

Confirmatory factor analysis

Nine 1-factor models were fitted to the data (see Table III). The factor loadings from the nine 1-factor models, with no correlated residuals, are shown in Table IV.

All but three factor loadings were high to acceptable (i.e. >0.5; see column headed 'Standardised factor loading' in Table IV); the three items that had a somewhat low loading were 1Q16 (i.e. Part 1, Question 16) (0.428) in Scale 5 (Appraisal of health information); 2Q14 (0.451) in Scale 8 (Ability to find good health information); and 1Q20 (0.360) again in Scale 5 (Appraisal of health information'). When fitting the one-factor models, correlated residuals were sequentially added, which improved each model fit significantly.

Table III shows the results of the CFAs for the nine HLQ-Parent scales. While model fit without modifications was acceptable for five scales, 1. Feel that healthcare providers understand and support my child's situation 2. Having sufficient information to manage my child's health, 3. Actively managing my child's health, 5. Appraisal of health information, and 7. Navigating the healthcare system, one or more correlated residuals were observed in the remaining four scales (Domains 4, 6, 8 and 9). The correlated residuals were 0.237 for one adjustment in Domain 4: Social support for health; and 0.307 for the one adjustment in Domain 6: Ability to actively engage with healthcare providers. In Domain 8: Ability to find good health

Table II. Cognitive interviews with parents on the content of the Health Literacy Questionnaire parent version (HLQ-Parent).

Domains	Comments from parents in the cognitive interviews
1. Feel that healthcare providers understand and support my child's situation	The parents interpreted the questions to be ascertaining the extent/level of support experienced in relation to their child's health from the child's multidisciplinary providers. As the level of support from health providers varied according to the context and time, they explained that they had 'summed up' their overall feelings of support when they answered the questions.
2. Having sufficient information to manage my child's health	Two parents seemed borderline offended by the questions about actively managing their child's health, wondering how someone could even ask that question: 'When you decide to have a child, of course, you actively care for its health!'. Further, all the parents described that they had interpreted the questions to be about how they managed their child's epilepsy, including all the additional challenges (social, psychological, physical) that were associated with the disease.
5. Appraisal of health information	Questions about the appraisal of health information received comments like, 'We trust the information we get from the neurologist responsible for our child's treatment, nurse-specialists in epilepsy, and other providers with special knowledge of epilepsy'. The fathers reported they did not search for health information elsewhere, especially not on the Internet (Facebook groups, Google, etc.), as they did not trust this to be a qualified source of information. Some of the mothers reported checking the Internet for health information, but that they then verified the sources, or discussed them with the neurologist if they felt it was necessary.
7. Navigating the healthcare system	Three parents commented that they were too exhausted from taking care of their child to be bothered to check whether their child was entitled to social benefits: 'You have to figure out everything on your own, no one tells you anything regarding social benefits'. Regarding how to navigate finding the right health services, most parents relied on their child's neurologist. However, several were not happy about the information they had initially received, especially in relation to the comprehensive assessment of additional difficulties that are common in childhood epilepsy.
8. Ability to find good health information	Some parents actively searched for information, then checked its content by asking professionals they trusted to be competent/knowledgeable about epilepsy. Others simply trusted their child's neurologist to 'know all there is to know'.
9. Understand health information well enough to know what to do	The questions to gauge whether they had understood the information well enough to know what to do were understood as intended. However, most parents answered, 'If I have questions, I simply ask the neurologist'.

Table III. Confirmatory factor analysis and internal consistency (Cronbach's alpha) of the HLQ-Parent (one-factor models).

Model	χ^2	p	RMSEA	CFI	TLI	SRMR	Correlated error
1. Feel that healthcare providers understand and support my child's situation*							
Original	3.69	0.158	0.058	0.995	0.985	0.017	
Cronbach's alpha: 0.81							
2. Having sufficient information to manage my child's health*							
Original	2.46	0.292	0.030	0.999	0.997	0.012	
Cronbach's alpha: 0.87							
3. Actively managing my child's health							
Original	5.76	0.33	0.024	0.997	0.994	0.025	
Cronbach's alpha: 0.75							
4. Social support for health							
Original	18.74	0.002	0.104	0.969	0.937	0.042	
1Q3 with 1Q5	6.92	0.140	0.054	0.993	0.983	0.025	0.237
Cronbach's alpha: 0.81							
5. Appraisal of health information*							
Original	5.715	0.335	0.024	0.997	0.993	0.030	
Cronbach's alpha: 0.70							
6. Ability to actively engage with healthcare providers							
Original	24.49	0.000	0.124	0.955	0.910	0.041	
2Q15 with 2Q20	6.94	0.139	0.054	0.993	0.993	0.022	0.307
Cronbach's alpha: 0.83							
7. Navigating the healthcare system*							
Original	8.84	0.452	0.000	1.000	1.000	0.022	
Cronbach's alpha: 0.85							
8. Ability to find good health information*							
Original	29.53	0.000	0.140	0.936	0.872	0.049	
2Q3 with 2Q10	5.35	0.148	0.056	0.994	0.980	0.023	0.283
2Q6 with 2Q14							−0.433
Cronbach's alpha: 0.79							
9. Understand health information well enough to know what to do*							
Original	47.46	0.000	0.184	0.853	0.706	0.074	
2Q9 with 2Q21	5.17	0.270	0.034	0.996	0.990	0.023	0.426
Cronbach's alpha: 0.75							

Note: 1Q3: Part 1, Question 3, and so on. RMSEA, root mean square error of approximation; TLI, Tucker–Lewis index; CFI, comparative fit index; SRMR, standardized root mean squared residual.

*Scales incorporating items adapted for parents.

information, there were two adjustments (0.283, −0.433) and one adjustment in Domain 9: Understand health information well enough to know what to do, with a correlated residual (0.426). After the respective model adjustments, the one-factor models were acceptable. All nine HLQ scales showed satisfactory to good internal consistency, with Cronbach's alpha ranging from 0.70 to 0.87 (see Table III).

The interscale correlations of the HLQ-Parent are shown in Table V. The highest correlations were between Domains 8: Finding good health information, and 9: Understanding health information ($r = 0.72$), and between Domains 6: Ability to engage actively with healthcare providers and 7: Navigating the healthcare system ($r = 0.71$), which were modest and indicated, overall, that the scales tended to broadly measure the different constructs as intended and therefore had reasonable discriminant validity.

Discussion

In this paper, we have reported the adaptation process and psychometric properties of the HLQ-Parent in the context of childhood epilepsy. The results from both the adaptation process and the CFA analysis, with some adjustments, supported the relevance, understanding and coherence of nine aspects of parental health literacy derived from the well-tested and widely applied HLQ.

The adaptation process made use of thorough methods and was performed in close collaboration with the developers of the HLQ [16]. The adaptation team easily reached consensus on the wording and structure of the parental version and the participating parents were observed to interpret the HLQ-Parent the way it was intended. The parents quickly understood that the questions were directed towards their child's health and healthcare support, not their own health.

A few other instruments measure aspects of parental health literacy, such as the PHLAT (Parental Health Literacy Activity Test) [12], the CPHLQ (Chinese Parental Health Literacy Questionnaire) [13], and the PPSI (the Parenting Plus Skills Index) [14]. The PHLAT measures functional health literacy (i.e. restricted to health-related reading and numeracy ability), the CPHLQ is limited to parents

Table IV. Confirmatory factor analysis of the HLQ-Parent, nine 1-factor models, standardised factor loadings and standard errors.

HLQ scale/item number	Standarised factor loading	Standard error	HLQ scale/item number	Standarised factor loading	Standard error
1. Feel that healthcare providers understand and support my child's situation			6. Ability to actively engage with healthcare providers		
1Q2	0.701	0.040	2Q2	0.679	0.042
1Q8	0.790	0.034	2Q4	0.756	0.037
1Q17	0.608	0.046	2Q7	0.724	0.038
1Q22	0.810	0.033	2Q15	0.660	0.044
			2Q20	0.692	0.042
2. Having sufficient information to manage my child's health			7. Navigating the healthcare system		
1Q1	0.656	0.040	2Q1	0.709	0.038
1Q10	0.841	0.025	2Q8	0.613	0.045
1Q14	0.840	0.025	2Q11	0.737	0.035
1Q23	0.835	0.026	2Q13	0.733	0.036
			2Q16	0.652	0.042
			2Q19	0.765	0.033
3. Actively managing my child's health			8. Ability to find good health information		
1Q6	0.570	0.054	2Q3	0.669	0.044
1Q9	0.731	0.045	2Q6	0.812	0.034
1Q13	0.602	0.052	2Q10	0.633	0.046
1Q18	0.593	0.052	2Q14	0.451	0.058
1Q21	0.595	0.052	2Q18	0.742	0.038
4. Social support for health			9. Understand health information well enough to know what to do		
1Q3h	0.640	0.043	2Q5	0.616	0.052
1Q5	0.635	0.044	2Q9	0.512	0.063
1Q11	0.864	0.027	2Q12	0.748	0.048
1Q15	0.529	0.050	2Q17	0.594	0.052
1Q19	0.775	0.033	2Q21	0.581	0.060
5. Appraisal of health information					
1Q4	0.585	0.054			
1Q7	0.705	0.048			
1Q12	0.743	0.046			
1Q16	0.428	0.062			
1Q20	0.360	0.065			

of children between 0 and 3 years of age, and the PPSI is a performance-based comprehension test. Consequently, a more comprehensive and generic measure of parental health literacy, suitable for a diversity of health literacy settings, was needed. Rather than developing a parental health literacy measure *de novo*, which involves extensive, highly specialised developmental work over several years, we adapted an existing widely used and well-tested measure as a starting point. This is both time- and cost-effective. Another positive element related to the adaptation of the HLQ to a parental context is the possibility of using the widely applied Ophelia (OPtimising HEalth LIteracy and Access) community co-design process to develop comprehensive health literacy-informed interventions in a paediatric setting to improve healthcare access, equity and outcomes for families with a child with medical complexity [23].

A previous validation study of the HLQ showed that the Norwegian language version replicated the original factor structure of the English version, indicating that the questionnaire has cogent, independent scales with good reliability [19]. For the HLQ-Parent, this conclusion was further supported in the context of

parental health literacy. The one-model approach resulted in acceptable values for RMSEA, SRMR, CFI and TLI for five of the scales without any adjustment, and needed just one adjustment in three scales and two adjustments in one scale. The factor loadings were acceptable for all but three items. Cronbach's alpha showed acceptable internal consistency across all scales, and interdomain correlations indicated that the scales had acceptable discriminant validity.

Strong parental health literacy is likely to improve child health outcomes through effective parental health behaviours such as optimal healthcare use, engaging in a healthy lifestyle and/or increased adherence to treatment [24,25]. The HLQ-Parent, with its multidimensional structure, capturing both strengths and challenges related to a wide range of domains, has the potential to contribute to uncovering pathways between parental health literacy and child health outcomes. Factors related to parents, health personnel and the health services, in addition to factors such as physical and emotional support, can affect children's health outcomes. The HLQ-Parent measures several of these factors, including social support for health, ability to actively engage with

Table V. Interscale correlations (Pearson's *r*): HLQ-Parent.

Domains	1	2	3	4	5	6	7	8
1. Feel that healthcare providers understand and support my child's situation								
2. Having sufficient information to manage my child's health	0.49							
3. Actively managing health	0.23	0.19						
4. Social support for health	0.37	0.27	0.13					
5. Appraisal of health information	0.27	0.25	0.36	0.26				
6. Ability to actively engage with healthcare providers	0.59	0.53	0.10	0.30	0.22			
7. Navigating the healthcare system	0.49	0.58	0.11	0.35	0.28	0.71		
8. Ability to find good health information	0.31	0.48	0.13	0.19	0.36	0.58	0.67	
9. Understand health information well enough to know what to do	0.28	0.37	0.22	0.09	0.34	0.48	0.55	0.72

healthcare providers, and navigating the healthcare system.

This research has some noteworthy strengths and limitations. As noted, we started with a widely used and well-tested multidimensional questionnaire and were therefore able to relatively quickly adjust it to provide rich information on parents' health literacy. However, a potential weakness of the study was the population the HLQ-Parent was tested in. Because parents of children with epilepsy will have specific health-system experiences, they are unlikely to be representative of parents in the general community, however, the sample was large and the demographics were diverse. Consequently, we recommend further testing of the HLQ-Parent in diverse populations before making generalisations about the applicability of the questionnaire to the wider community. While the results of these initial psychometric tests were promising, further qualitative and quantitative work might improve the Norwegian language framing of certain items to reduce the number and size of correlated errors. Validity testing of patient-reported outcomes is an ongoing endeavour and a range of tests needs to be applied in each distinct target population [17,18]. Future analysis should examine the psychometric structure in more depth, including whether items cross load and whether the domains are sensitive to change.

Conclusions

The cognitive interviews and the range of psychometric tests applied to the HLQ-Parent have provided preliminary evidence that it is likely to be a useful health literacy tool in a parental setting. Although the instrument was developed in the context of childhood epilepsy, it is generic in nature and therefore likely to be useful in other parental health literacy applications.

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References

[1] Kerr M, Linehan C, Brandt C, et al. Behavioral disorder in people with an intellectual disability and epilepsy: a report of the Intellectual Disability Task Force of the Neuropsychiatric Commission of ILAE. *Epilepsia Open*. 2016;1:102–111.

[2] Wo SW, Ong LC, Low WY, et al. The impact of epilepsy on academic achievement in children with normal intelligence and without major comorbidities: a systematic review. *Epilepsy Res* 2017;136:35–45.

[3] Paschal AM, Mitchell QP, Wilroy JD, et al. Parent health literacy and adherence-related outcomes in children with epilepsy. *Epilepsy Behav* 2016;56:73–82.

[4] Nutbeam D, Levin-Zamir D and Rowlands G. Health literacy in context. *Int J Environ Res Public Health* 2018;15:2657.

[5] Lawrence PR, Feinberg I and Spratling R. The relationship of parental health literacy to health outcomes of children with medical complexity. *J Pediatr Nurs* 2021;60:65–70.

[6] Pawellek M, Kopf FM, Egger N, et al. Pathways linking parental health literacy with health behaviours directed at the child: a scoping review. *Health Promot Int* 2022;37(2):daab154.

[7] Lick AF, Farkas JS, Rosenberg RE, et al. Accuracy of parent perception of comprehension of discharge instructions: role of plan complexity and health literacy. *Acad Pediatr* 2020;20:516–23.

[8] Korkmaz MF, Erdem-Uzun M, Korkmaz M, et al. Adherence to antiepileptic drugs and the health literacy of caregivers in childhood epilepsy. *P R Health Sci J* 2020;39:45–50.

[9] Tutar Güven Ş, İşler Dalgiç A and Duman Ö. Evaluation of the efficiency of the web-based epilepsy education program (WEEP) for youth with epilepsy and parents: a randomized controlled trial. *Epilepsy Behav* 2020;111:107142.

[10] Norman CD and Skinner HA. eHEALS: the eHealth Literacy Scale. *J Med Internet Res* 2006;8:e27.

[11] Tian CY, Xu RH, Mo PK, et al. Generic health literacy measurements for adults: a scoping review. *Int J Environ Res Public Health* 2020;17:7768.

[12] Kumar D, Sanders L, Perrin EM, et al. Parental understanding of infant health information: health literacy, numeracy, and the Parental Health Literacy Activities Test (PHLAT). *Acad Pediatr* 2010;10:309–16.

[13] Zhang Y, Li M, Jiang H, et al. Development and validation of a Chinese parental health literacy questionnaire for caregivers of children 0 to 3 years old. *BMC Pediatr* 2019;19:293.

[14] Ayre J, Costa DSJ, McCaffery KJ, et al. Validation of an Australian parenting health literacy skills instrument: the Parenting Plus Skills Index. *Patient Educ Couns* 2020;103:1245–51.

[15] Jordan JE, Osborne RH and Buchbinder R. Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. *J Clin Epidemiol* 2011;64:366–79.

[16] Osborne RH, Batterham RW, Elsworth GR, et al. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health* 2013;13:658.

[17] Hawkins M, Elsworth GR and Osborne RH. Application of validity theory and methodology to patient-reported outcome measures (PROMs): building an argument for validity. *Qual Life Res* 2018;27:1695–710.

[18] Hawkins M, Elsworth GR, Nolte S, et al. Validity arguments for patient-reported outcomes: justifying the intended interpretation and use of data. *J Patient Rep Outcomes* 2021;5:64.

[19] Wahl AK, Hermansen Å, Osborne R, et al. A validation study of the Norwegian version of the Health Literacy Questionnaire (HLQ): a robust nine-dimension factor model. *Scand J Public Health*, 2021;49:471–8.

[20] Larsen MH, Strumse Y, Borge CR, et al. Health literacy: a new piece of the puzzle in psoriasis care? A cross-sectional study. *Br J Dermatol* 2019;180:1506–16.

[21] Browne M and Cudeck R. Alternative ways of assessing model fit. In: Bollen K and Long J (eds) *Testing structural equation models*. London: Sage, 1993, pp.136–62.

[22] Hu L and Bentler P. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Modeling* 1999;6:1–55.

[23] Batterham RW, Buchbinder R, Beauchamp A, et al. The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. *BMC Public Health* 2014;14:694.

[24] Paasche-Orlow MK and Wolf MS. The causal pathways linking health literacy to health outcomes. *Am J Health Behav* 2007;31:S19–26.

[25] von Wagner C, Steptoe A, Wolf MS, et al. Health literacy and health actions: a review and a framework from health psychology. *Health Educ Behav* 2009;36:860–77.