



## Parents of children with epilepsy: Characteristics associated with high and low levels of health literacy



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### ABSTRACT

Parents of children with epilepsy play a key role in the management of their child's condition. Their level of health literacy (HL), which refers to their ability to seek, understand, assess, remember, and utilize health information, is essential for handling the child optimally. The aim of this study was to investigate characteristics associated with high and low levels of different dimensions of HL in parents. HL was assessed with the multidimensional Health Literacy Questionnaire (parents' version) and the electronic Health Literacy Scale, using data from a cohort of 254 parents of children <12 years. Bivariate correlation and multiple hierarchical linear regression (STATA version 16 SE) were used to investigate variables associated with HL. Self-efficacy (St.  $\beta = 0.14-0.34$ ) was the only variable that predicted higher scores on every HL scale. Being older than 35 years (St.  $\beta = 0.18-0.21$ ), level of education (St.  $\beta = 0.16-0.27$ ), and the child having a coordinator of services (St.  $\beta = 0.16-0.28$ ) were associated with higher scores, while sick leave due to the child's epilepsy (St.  $\beta = -0.13$  to  $-0.16$ ), child comorbidities (St.  $\beta = -0.15$  to  $-0.19$ ), and higher levels of mental distress (St.  $\beta = -0.13$  to  $-0.19$ ) were associated with lower scores in several of the different HL dimensions. A total of 44.8% of the parents scored over the cutoff ( $\geq 1.85$ ) predicting a mental disorder on the Hopkins symptom checklist. This is the first study to investigate multidimensional parental HL in a childhood epilepsy context. Our results highlight the need to investigate multiple variables, especially mental distress, to determine characteristics that may predict low parental HL. Further qualitative studies are needed to explore the underlying reasons for the parents' HL scores and to develop interventions tailored to meet different HL needs.

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## 1. Introduction

Childhood epilepsy is associated with comorbidities, such as developmental delay, cerebral palsy, autism spectrum disorder, or attention deficit hyperactive disorder [1–4]. A nationwide Norwegian registry study revealed that almost 80% of children with

**Abbreviations:** HL, Health literacy; HLQ-p, Health Literacy Questionnaire – parent version; CEPABL-project, The “Childhood Epilepsy and PArEntal Health Literacy”-project; OPHELIA, The OPTimizing Health LItErAcY approach; eHEALS, The electronic HEALTH Literacy Scale; GSE, The General perceived Self-Efficacy scale; HSCL-10, The Hopkins Symptoms Checklist – 10; NEA, The Norwegian Epilepsy Association.

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epilepsy had one or more comorbidities of a physical, cognitive, psychiatric, or behavioral nature [1]. When such comorbidities are combined with uncontrolled and unpredictable seizures, the disorder is a significant burden, not only for the child but also for the whole family [5–7]. Such complex conditions often require long-term multidisciplinary treatment and follow-up [5].

Parents play a crucial role in managing their children's condition by participating in the decision-making regarding treatment and acting as a team partner along with the multidisciplinary healthcare providers [6,7]. In addition, parents must cope with stress due to unpredictable seizures, administer drug treatments (both seizure-preventing and seizure-stopping drugs), try to adapt to a seizure-preventing lifestyle, and manage the strain placed on healthy siblings [4,6,7]. Dealing with such a difficult situation requires knowledge, skills, and emotional resources on the part of the parents [7].

Health literacy (HL) is a person's ability to access, understand, appraise, remember, and apply information about health [8]. Con-

ceptually, HL has been recognized as an important and modifiable social determinant of health, and differences in HL levels may lead to inequity in access to healthcare providers and health outcomes [9,10]. Low parental HL has been associated with reduced child health outcomes in the form of increased hospitalization [11–13] and poor adherence to treatment for the child [14,15]. However, studies on HL in pediatric settings, including the childhood epilepsy context, are limited [15–18]. We hypothesize that parents' level of HL may strongly influence their capacity to cope with their child's medical condition, leading to suboptimal treatment for the child [15]. Hence, we believe there is a need to explore further possible associations between parental HL and children's health outcomes. The current common understanding is that HL is a multidimensional concept comprising a range of cognitive, affective, social, and personal skills and attributes [19]. However, most studies on parental HL have used functional measurement tools, such as the Rapid Estimate of Adult Literacy in Medicine (REALM) or the Test Of Functional Health Literacy in Adults (TOFHLA) [20]. Functional health literacy measurements assess a person's basic reading and writing skills, which are important to be able to understand health information [21]. However, to care for a child with epilepsy, the parents must communicate with healthcare providers, navigate the healthcare system, and critically assess and make use of medical information in a way that benefits their child. This requires multifunctional HL skills, such as understanding the physiology of illness, the ability to communicate symptoms to healthcare providers, and knowledge about how the health system is organized. In addition, parents need the ability to interpret electronic and non-electronic health information and apply this information in changing circumstances [21,22]. Hence, compared to a unidimensional HL measure, a multidimensional HL measure has the potential to provide a more nuanced picture of the different dimensions of HL skills needed to manage the child's condition optimally [22]. Different parental characteristics and clinical characteristics of the child's condition may have a variable impact on the different dimensions of parental levels of HL, and the parents' need for tailored health education and support may vary accordingly. For instance, parents' level of education may have an impact on their ability to access, understand, appraise, remember, and apply information about health. In addition, clinical characteristics of the child's condition may have an impact on the parents' need for HL.

The object of this study was to investigate characteristics (socio-demographic variables, clinical variables of the child, parental self-reported self-efficacy, and level of perceived mental distress) associated with high and low levels of health literacy in parents of children with epilepsy.

## 2. Material and methods

This is the first study that reports on the Childhood Epilepsy and Parental Health Literacy (CEPAHL) study, which aims to develop an HL intervention to optimize parental HL to support equity in access to healthcare for children with epilepsy. The CEPAHL project is inspired by the theoretical framework OPTimising HHealth LiterAcY (Ophelia), which defines a structured process that enables clinicians, service users, and community groups to co-produce meaningful and effective HL interventions within clinical, personal, and community settings [23].

### 2.1. Data sources

#### 2.1.1. Study population

This cross-sectional study was undertaken from June to December 2020 and included participants from two cohorts of parents.

**Cohort A** included parents of children hospitalized at the National Center for Epilepsy, a tertiary referral hospital for patients from all over Norway with difficult-to-treat epilepsy.

Due to a limited number of inpatients during the study period because of the COVID-19 pandemic, we employed online data collection and posted the questionnaire used for Cohort A on the National Epilepsy Association's (NEA) website. Thus, **Cohort B** consisted of parents of children with epilepsy who answered this anonymous online questionnaire and included a broader range of parents of children with epilepsy, not only parents of children with severe epilepsy. Except for minor changes necessary to ensure parental anonymity (e.g., only fixed-answer alternatives without spaces for comments or remarks), the questionnaires used by the two cohorts were identical.

#### 2.1.2. Inclusion and exclusion criteria

The parents had to be at least 18 years old and have a child under the age of 12 years diagnosed with epilepsy to be included. For Cohort A, parents were excluded if their child was hospitalized for less than three days, as this was considered the minimum time-frame for the parents to receive and process the information necessary to attend the study. In addition, parents were excluded if they had apparent cognitive or mental health problems (assessed by the pediatrician treating their child at the hospital). The nurses handed out written information about the study, including informed consent, on the first day of the child's stay at the hospital. The first author (MKT) provided additional oral information to parents wishing to participate. The parents could answer the questionnaire manually or digitally through a link sent from the unit for safe data collection services at the University of Oslo to an e-mail address of their own choice. The participants in Cohort B had to have access to NEA's websites to gain information about the study.

## 2.2. Measures

### 2.2.1. Sociodemographic and clinical variables

The questionnaire included questions about the parents' age, gender, civil status, educational level, employment status, and clinical data of the child, including the duration of epilepsy, type of seizures and epilepsy, seizure frequency, comorbidities, and whether the child had a coordinator of health services.

In Norway, children with long-term complex healthcare needs are entitled by law to have an individual care coordinator: "Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes." [24]. The coordinator is the person responsible for the interaction between parents and the multidisciplinary healthcare providers involved in the child's follow-up.

### 2.2.2. The Health Literacy Questionnaire parent version

We used the generic Health Literacy Questionnaire (HLQ), translated into Norwegian. HLQ has shown strong construct validity and reliability in different settings and populations [25,26]. HL related to parenthood and caring for a chronically ill child may be influenced by many factors, including the parents' own health situation. Therefore, the generic HLQ was adapted to a parental context (HLQ-p). The HLQ-p consists of 44 items comprising nine separate scales, each describing a different aspect of HL. In the first part of the questionnaire, the respondent rates their level of agreement to 23 questions. In the second part (21 questions), the respondent is asked to rate their capability to perform tasks related to their child's disease [27]. The HLQ-p provides nine scores based on an average of the items within each scale. There is no cutoff, but a high score indicates a high level of health literacy [27].

For a more detailed description of the HL dimension, each of the nine different scales are measuring, we kindly recommend the

**Table 1**  
The independent variables in the regression model.

Step 1: parent demographics	Cohort A/B, age, gender, education level, on a sick leave in the last 3 months as a consequence of the child's epilepsy.
Step 2: severity of child's condition, contact with the health service	Plus, seizure frequency, comorbidities (child), having a coordinator of health services
Step 3: self-efficacy	Plus, General Self- Efficacy scale (GSE)
Step 4: mental health status (parent)	Plus, Hopkins Symptoms check list (HSCL-10)

reader to study [Table 1](#) in the article by the HLQ developers; Osborne et al. [27].

The questionnaire developer supervised the process of translating and adapting the HLQ-p, following the Swindon translation and management grid [28]. The Norwegian version was then tested using cognitive interviews with parents to assess whether they understood the questionnaire according to the intention. The Norwegian version of the HLQ-p was assessed on the target population, with all scales showing satisfactory internal consistency.

### 2.2.3. The e-Health Literacy Scale

The e-Health Literacy Scale (eHEALS) is a questionnaire comprising eight questions developed to measure a person's perception of their ability and knowledge in using electronic information to solve problems related to health [29]. Each item in the eHEALS consists of a five-point Likert scale with response options ranging from 1) "strongly disagree" to 5) "strongly agree." There is no cutoff, but a high score indicates a high level of eHealth literacy [29]. The eHEALS has shown strong construct validity and reliability in different settings and populations [30–32].

### 2.2.4. The General Perceived Self-Efficacy Scale

The General Perceived Self-Efficacy Scale (GSE) was designed to assess self-beliefs regarding one's ability to cope with difficulties in life. Self-efficacy has been proven to have an impact on achievements in health-related functioning, such as adaption to treatment [33,34]. The GSE consists of ten items ranging from 1) "not at all confident" to 4) "extremely confident." A high score indicates high self-efficacy. The GSE has demonstrated strong validity and reliability in previous studies on patients with various conditions [33,34].

### 2.2.5. The Hopkins Symptom Checklist-10

The Hopkins Symptom Checklist-10 (HSCL-10) is a short version (ten questions) of the more comprehensive HSCL-25, and it has proven to be a useful tool for assessing mental health [35,36]. Each item is answered on a four-point scale ranging from 1) "not at all bothered" to 4) "extremely bothered." The item scores are added and divided by the number of items, with a higher mean score indicating a higher level of experienced distress. A cutoff of 1.85 or higher is considered to be a valid predictor of depression, as assessed independently by a clinical interview [37]. The HSCL-10 has demonstrated strong construct validity and reliability in previous studies [35,36].

## 2.3. Statistical analyses

Statistical analyses were performed using STATA software version SE 16. Missing items in the HLQ-p were imputed using the expectation maximization algorithm according to the HLQ user manual [37]. There were few missing items; at most 1.2% or less in the HLQ-p, GSE, eHEALS, and HSCL-10. Therefore, the missing items in the mentioned scales were considered missing at random and considered not significant to the validity of the outcome [38]. Descriptive analyses of the characteristics of the whole sample

included the means, standard deviations (SDs), or medians and ranges ([Table 2](#)). Demographic data, clinical information of the children, and the parents' GSE and HSCL-10 scores in Cohorts A and B are shown in [supplementary files 1 and 2](#).

Cohen's statistical analyses of effect size (ES) were used to measure the significance of the different mean HLQ-p domains and the eHEALS scores between Cohort A and Cohort B. The ESs were small, a maximum of 0.3 SD from each other (Cohen's *d* 0.1–0.3) [39]. Therefore, Cohorts A and B were merged and are described as one sample in this paper. To further increase the validity of the analyses, the regression models with the merged sample were checked for possible variance between the two cohorts by including a dummy variable in the model ([Table 4](#)).

The associations between the nine HLQ-p domains, the eHEALS, and the independent variables were explored individually using bivariate correlation analysis (Pearsons' *r*) followed by a hierarchical linear multiple regression analysis (enter method) ([Table 1](#)). The independent variables/covariates entered in the ten regression models (nine HLQ-p domains and eHEALS) are listed in [Table 3](#) (demographics, clinical variable (child), GSE, and HSCL-10). To be included in the regression models, the independent variables/covariates in the regression models ([Table 4](#)) had to be significantly associated with at least one of the dependent variables in the fourth and final step of the hierarchical regression analysis ([Table 4](#)). To facilitate a comparison of the different covariates' strength of association with each HLQ-p domain and eHEALS, the associations are presented by standardized  $\beta$  coefficient (St.  $\beta$ ). Adjusted  $R^2$  explains the variations of the different associations.

## 2.4. Ethical considerations

The research project 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

**Table 2**  
Descriptive data for the parent sample and clinical variables for the child.

Parents' demographics (n = 254)	N (%), Mean (SD) Median (Range)
Age groups, years (n = 249)	
18–30	26 (10.4%)
31–35	57 (22.9%)
36–40	62 (24.9%)
40–45	63 (25.3%)
>46	41 (16.5%)
Gender, female (n = 254)	201 (79.1%)
Education level (n = 254)	
Not faculty/college education*	88 (34.6%)
Work status (n = 254)	
Not working**	62 (24.4%)
On sick leave as a consequence of the child's epilepsy (n = 248)	110 (44.4%)
Short-term: ≤ two weeks	77 (31%)
Long-term: From two weeks – three months	33 (13.3%)
Living alone (N = 254)	38 (15%)
Country of birth (n = 245)	
Norwegian born	231 (90.9%)
Clinical variables (child)	
Newly diagnosed with epilepsy < 1 year ago (n = 241)	27 (11.2%)
Seizures at weekly basis (n = 246)	120 (48.8%)
Administering acute medicine at least once per 6 months (n = 243)	61 (25.1%)
1 or more comorbidities (n = 244)	128 (52.5%) Range:0–8
Coordinator (n = 246)	96 (39%)
Hospitalized one or more times the last year (n = 246)	154 (62.6%)

\* Primary-, secondary-, and high school.

\*\* Disabled/retired/student/unemployed.

° On sick leave as a consequence of the child's epilepsy, duration from ≤2 weeks to >2 weeks – 3 month, the last 3 months.

study was conducted in accordance with the Declaration of Helsinki. All participants were given oral and written information and signed an informed consent before participating.

### 3. Results

#### 3.1. Descriptive data

##### 3.1.1. Sociodemographic and clinical information

A total of 254 parents participated in the study. The majority of the participants (66.7%) were older than 35 years, female (79.1%), co-habitant (85%), Norwegian born (90.9%), and had faculty or college (higher) education (65.4%). Most of the participants (75.6%) were working full-time or part-time. Of the working participants, 44.3% had been on a sick leave (range ≤ two weeks – three months) as a consequence of the child's epilepsy the last three months. The majority of the children (89.2%) had experienced epilepsy for more than one year and had been hospitalized at least once the last year (62.6%). A detailed description of the sociodemographic information of the parents and clinical data of the children is shown in Table 2.

##### 3.1.2. Health literacy scales

In the HLQ-p, we found the highest mean score in domain three, that is, actively managing my child's health (mean score 3.37 (SD ± 0.4), maximum score 4). The lowest HLQ-p score was obtained in domain seven, that is, navigating the healthcare system (mean score 3.15 (SD ± 0.6), maximum score 5) (Table 3). The parents also had high mean score in eHEALS (mean score 3.79 (SD ± 0.6), maximum score 5), indicating their ability to use

electronic health resources when managing their child's health (Table 3).

##### 3.1.3. Self-efficacy and mental health

The mean GSE score was 3.15 (SD ± 0.4, maximum score 4), with no significant gender differences. The mean score of experienced mental distress (HSCL-10) was 1.89 (SD ± 0.6), maximum score 4) (Table 3). Regarding perceived mental health, 44.8% had a mean score of 1.85 or higher, which is the recommended cutoff point for a valid predictor of depression [35]. There were no significant gender differences in the HSCL-10 scores; in between group differences, or in the number of parents who had a mean score over the cutoff for prediction of a mental disorder.

#### 3.2. Characteristics associated with high and low levels of health literacy

The results from the bivariate correlation analysis and the last step in the regression analysis are presented in Table 4. The fourth and final step in the regression models explained between 10% and 22% of the variance in the HL domains (Table 4). This is a summary of the characteristics associated with high or low HL scores.

Being older than 35 years was significantly associated with high scores concerning sufficient health information (domain two) (St. β = 0.21), ability to engage with healthcare providers (domain six) (St. β = 0.21), and ability to navigate the healthcare system (domain seven) (St. β = 0.18). Regarding gender, being female was only significantly associated with high scores on the ability to actively manage the child's health (domain three, St. β = 0.18). Higher education was significantly associated with high scores in domains concerning finding and understanding health information (domain

Table 3

Descriptive statistics of Health literacy Questionnaire parent (HLQ), The e-Health Literacy Scale (eHEALS), The General Perceived Self-Efficacy Scale (GSE), The Hopkins Symptom Checklist-10 (HSCL-10).

	n (%)	Mean (SD) Median (range)	Min-max	Cronbach α
<b>Health literacy scores (HLQ-p)</b>				
<b>1. Feel that healthcare providers understand and support my child's situation</b>	254 (100)	2.96 (0.6)	1-4	<b>0.81</b>
Response categories 1-4: strongly disagree, disagree, agree, and strongly agree (higher score = higher HL)				
<b>2. Having sufficient information to manage my child's health</b>	254 (100)	2.72 (0.6)	1-4	<b>0.87</b>
Response categories 1-4: strongly disagree, disagree, agree, and strongly agree (higher score = higher HL)				
<b>3. Actively managing my child's health</b>	254 (100)	3.37 (0.4)	1-4	<b>0.75</b>
Response categories 1-4: strongly disagree, disagree, agree, and strongly agree (higher score = higher HL)				
<b>4. Experience social support for my child's health</b>	254 (100)	2.59 (0.6)	1-4	<b>0.81</b>
Response categories 1-4: strongly disagree, disagree, agree, and strongly agree (higher score = higher HL)				
<b>5. Appraisal of health information</b>	254 (100)	2.94 (0.5)	1-4	<b>0.7</b>
Response categories 1-4: strongly disagree, disagree, agree, and strongly agree (higher score = higher HL)				
<b>6. Ability to actively engage with healthcare providers</b>	254 (100)	3.52 (0.6)	1-5	<b>0.83</b>
Response categories 1-5: cannot do, very difficult, quite difficult, quite easy, and very easy (higher score = higher HL)				
<b>7. Navigating the healthcare system</b>	254 (100)	3.15 (0.6)	1-5	<b>0.85</b>
Response categories 1-5: cannot do, very difficult, quite difficult, quite easy, and very easy (higher score = higher HL)				
<b>8. Ability to find good health information</b>	254 (100)	3.48 (0.6)	1-5	<b>0.79</b>
Response categories 1-5: cannot do, very difficult, quite difficult, quite easy, and very easy (higher score = higher HL)				
<b>9. Understand health information well enough to know what to do</b>	254 (100)	3.82 (0.5)	1-5	<b>0.75</b>
Response categories 1-5: cannot do, very difficult, quite difficult, quite easy, and very easy (higher score = higher HL)				
<b>eHEALS</b>				
<b>Ability and knowledge in using electronic information to solve health problems</b>	252 (99)	3.79 (0.6)	1-5	<b>0.91</b>
Response categories 1-5: strongly disagree, disagree, neutral, agree, strongly agree (higher score = higher eHL)				
<b>GSE</b>				
<b>Self-efficacy</b>	253 (99)	3.15 (0.4)	1-4	<b>0.89</b>
Response category: not at all true, hardly true, moderately true, extremely true (higher score = higher self-efficacy)				
<b>HSCL-10</b>				
<b>Experienced mental distress</b>	252 (99)	1.89 (0.6)	1-4	<b>0.89</b>
Response categories 1-5: not bothered, a little bothered, quite bothered, extremely bothered (higher score = higher experienced emotional distress)				



**Table 4**

Bivariate correlation (first column) and the final step of multiple regression for HLQ-parent, with the parent's socio-demographic data and clinical data of child, and psychological well-being.

Dependent variables → independent variables	1. Feeling understood and supported by healthcare providers (bivariate corr.)		2. Having sufficient information to manage my child's health (bivariate corr.)		3. Actively managing my child's health (bivariate corr.)		4. Social support for health (bivariate corr.)		5. Appraisal of health information (bivariate corr.)	
	r	St. β	r	St. β	R	St. β	r	St. β	r	St. β
SSE vs NEA (SSE = 0, NEA = 1)	-0.11	-0.07	-0.15*	-0.04	-0.05	-0.04	-0.14*	-0.11	0.13*	<b>0.16*</b>
Parents' demographics:										
Age (= <35 yrs = 0, >35 = 1 yrs)	0.12	0.11	0.26***	<b>0.21***</b>	-0.12	-0.09	0.09	0.04	-0.01	-0.01
Gender (Men = 0, Women = 1)	0.07	0.10	0.05	0.10	0.18***	<b>0.18**</b>	0.03	0.05	0.11	0.08
Education (Low = 0, High = 1)	0.06	0.02	0.15*	0.07	-0.06	-0.05	0.08	0.02	0.06	0.06
Sick leave (No = 0, Yes = 1)	0.03	-0.01	-0.13*	<b>-0.13*</b>	0.03	0.03	-0.03	0.01	0.02	-0.02
Clinical data (child):										
Seizures at weekly basis (No = 0, Yes = 1)	0.25***	<b>0.15*</b>	0.20***	<b>0.19***</b>	0.11	-0.00	0.05	0.08	0.17**	0.12
Comorbidities (No = 0, Yes = 1)	0.15*	-0.04	0.11	-0.03	0.02	-0.09	-0.17**	<b>-0.19**</b>	-0.04	-0.11
Community coordinator (No = 0, Yes = 1)	0.33***	<b>0.28***</b>	0.20***	<b>0.16*</b>	0.20***	<b>0.23***</b>	-0.06	0.07	0.12	0.14
Parents perceived self-efficacy, mental health										
Self-efficacy (GSE) (higher score = better self-efficacy)	0.20***	<b>0.15*</b>	0.30***	<b>0.18**</b>	0.27***	<b>0.28***</b>	0.25***	<b>0.14*</b>	0.25***	<b>0.26***</b>
Perception of mental health (HSCL-10) lower score = better self-assessed mental health.	0.07	0.04	-0.16**	<b>-0.13*</b>	0.09	0.10	-0.26***	<b>-0.19**</b>	0.07	0.10
R <sup>2</sup>	0.19		0.25		0.17		0.14		0.14	
Adjusted R <sup>2</sup>	0.15		0.22		0.13		0.10		0.11	
Dependent variables → Independent variables	6. Ability to actively engage with healthcare providers (bivariate corr.)		7. Navigate the healthcare system (bivariate corr.)		8. Ability to find good healthcare information (bivariate corr.)		9. Understanding health info. well enough to know what to do (bivariate corr.)		10. eHEALS: Using technology to process health information (bivariate corr.)	
	r	St. β	r	St. β	r	St. β	r	St. β	r	St. β
SSE vs NEA (SSE = 0, NEA = 1)	-0.17**	-0.07	-0.10	0.01	-0.11	-0.03	-0.07	0.01	0.04	0.06
Parents' demographics:										
Age (= <35 yrs = 0, >35 = 1 yrs)	0.22***	<b>0.21***</b>	0.23***	<b>0.18**</b>	0.16**	0.09	0.14*	0.12	0.09	0.02
Gender (Men = 0, Women = 1)	-0.01	0.02	0.02	0.03	0.05	0.06	0.12	0.09	0.08	0.07
Education (Low = 0, High = 1)	0.07	-0.01	0.16**	0.09	0.20**	<b>0.16**</b>	0.22***	<b>0.16**</b>	0.27***	<b>0.27***</b>
Sick leave (No = 0, Yes = 1)	-0.15*	<b>-0.14**</b>	-0.16**	<b>-0.16**</b>	-0.15*	-0.12	-0.12	-0.08	0.04	0.02
Clinical data (child):										
Seizures at weekly basis (No = 0, Yes = 1)	0.10	0.09	0.11	0.10	0.03	0.03	0.05	0.03	0.07	0.04
Comorbidities (No = 0, Yes = 1)	-0.04	<b>-0.16*</b>	0.02	-0.07	-0.02	-0.05	-0.00	-0.02	-0.09	<b>-0.15*</b>
Community coordinator (No = 0, Yes = 1)	0.11	<b>0.17*</b>	0.11	0.13	0.02	0.05	0.04	0.03	0.07	0.13
Parents perceived self-efficacy, mental health										
Self-efficacy (GSE) (higher score = better self-efficacy)	0.28***	<b>0.19**</b>	0.32***	<b>0.21***</b>	0.32***	<b>0.23***</b>	0.39***	<b>0.34***</b>	0.25***	<b>0.21**</b>
Perception of mental health (HSCL-10) (lower score = better self-assessed mental health.)	-0.18***	-0.09	-0.19***	-0.10	-0.21***	-0.09	-0.13*	0.03	-0.03	0.05
R <sup>2</sup>	0.18		0.2		0.16		0.2		0.16	
Adjusted R <sup>2</sup>	0.15		0.16		0.13		0.17		0.12	

° On sick leave as a consequence of the child's epilepsy, duration from ≤2 weeks to >2 weeks - 3 months, in the last 3 months.

\* Significant on a 0.05 level.  
 \*\* Significant on a 0.01 level.  
 \*\*\* Significant on a 0.001 level.

eight, St. β = 0.16, and domain nine, St. β = 0.16) in addition to the ability to use electronic information to solve health problems (eHEALS, St. β = 0.27).

Being on a sick leave was significantly associated with low scores in domains concerning sufficient information (domain two, St. β = -0.13), ability to engage with healthcare providers (do-

main six,  $St. \beta = -0.14$ ), and navigating the healthcare system (domain seven,  $St. \beta = -0.16$ ). Having seizures at least weekly (child) was significantly associated with higher scores on feeling understood and supported by healthcare providers (domain one,  $St. \beta = 0.15$ ) and having sufficient information (domain two,  $St. \beta = 0.19$ ). The occurrence of at least one comorbidity was significantly associated with lower scores on experiencing social support for the child's health (domain four,  $St. \beta = -0.19$ ), low ability to engage with healthcare providers (domain six,  $St. \beta = -0.16$ ), and a low eHEALS score ( $St. \beta = -0.15$ ).

Having a child health coordinator was significantly associated with high scores on having sufficient information and actively managing the child's health (domain one and three,  $St. \beta = 0.16$  and  $St. \beta = 0.23$ , respectively), in addition to the perception of being supported by and actively engaging with healthcare providers (domain one and six) ( $St. \beta = 0.28$  and  $St. \beta = 0.17$ , respectively).

High self-reported GSE was the only variable that was significantly associated with high scores in all nine HLQ-p domains ( $St. \beta = 0.14-0.34$ ) and eHEALS ( $St. \beta = 0.21$ ). High self-reported levels of mental distress (HSCL-10) were significantly associated with low scores in domain two, having sufficient information to manage my child's health ( $St. \beta = -0.13$ ), and domain four, social support for my child's health ( $St. \beta = -0.19$ ).

#### 4. Discussion

To the best of our knowledge, this is the first study to investigate parental HL as a multidimensional concept, comprising functional, interactive, and critical skills in the context of parents of children with epilepsy [21]. Our study provides an important step toward understanding the characteristics associated with high and low levels of HL in a cohort of parents of children with epilepsy. Our main findings are that higher levels of general perceived self-efficacy was the only variable that predicted higher scores on every health literacy scale, while being older than 35 years, high level of education, and having a coordinator of services for the child were the characteristics that were most frequently significantly associated with high scores in several HL domains. The variables most frequently significantly associated with lower scores in several HL domains were sick leave due to the child's epilepsy within the last three months, comorbidities (child), and high levels of mental distress.

Being able to actively engage with healthcare providers and navigate the healthcare system requires knowledge and experience. High HL due to more experience interacting with the healthcare services may be a plausible explanation for why parents older than 35 years in this study had higher HL scores than the younger ones. This is supported by results from a recent study, which showed that HL improved with increasing age [40].

As expected, those with high levels of education were better at finding and understanding health information, including electronic information, than those with low levels of education. This is in line with the results of previous studies [10,21,26]. The relatively high number of parents who had been on sick leave in the last three months due to their child's epilepsy compared to the average Norwegian population (44%, vs 6.23%, respectively) may be seen as a marker of a significant care burden [41–43]. However, low levels of HL may reduce the parents' ability to combine work with caring for a sick child, thus increasing personal and socio-economic costs.

To our surprise, we found that the occurrence of comorbidities in the child was associated with low scores on engaging with healthcare providers. As the presence of comorbidities increases medical complexity, we had expected that these parents would have worked closely and actively with the multidisciplinary providers [42]. One possible explanation is that these parents are too

exhausted from coping with the everyday challenges of caring for the child to engage with healthcare providers. The presence of a child healthcare coordinator was a strong driver of high scores in several HLQ-p domains. One previous study showed that, among other tasks, childcare coordinators helped the parents navigate the healthcare system, provided them with health education, and acted as a bridge builder between the families and multidisciplinary providers involved in the child's treatment [44]. These are all activities that may increase parents' HL, offering support to our findings.

In contrast to other studies measuring self-reported HL in persons looking after *their own health* [13,26,45], we found that the parents reported an overall high ability to manage *their child's health*. This result may indicate that the parents were highly motivated and capable of trying to provide the best available health service to their child, which is an important starting point to receive health information and guidance.

In this study, a higher level of self-efficacy was significantly associated with higher scores across all of the HLQ-p domains and eHEALS. Parental self-efficacy, or parents' confidence in their ability to successfully care for their child, has been linked to higher parental responsiveness and sensitivity toward their child and lower parental perception of distress [46]. A study by Wood et al. [47] found a statistically significant relationship between parents'/guardians' HL levels and their self-efficacy expectations in managing their child's asthma, supporting our findings.

Parents' ability to successfully care for their children has been linked to low parental perception of mental distress [46]. Bandura's self-efficacy theory suggests that parental depression may have a negative impact on the way parents perceive their self-efficacy [48]. In our study, 45% of the parents had a mean HSCL-10 score higher than the score predicting depression or anxiety [35]. This is in line with previous studies showing an association between the parent-reported burden of care for children and high levels of experienced parental mental distress [6,7,49]. The children in this study had frequent seizures (49% at least weekly) and a rather high comorbidity profile (52% at least one comorbidity), which indicates a considerable care burden for the included parents.

Also in line with our results, childhood epilepsy, especially in combination with comorbidities, has been reported to have a negative impact on parents' experience of social support [42].

Parents are expected to become active participants in managing their child's care in partnership with providers, and it is important for healthcare providers to acknowledge that this may require a high level of multidimensional HL skills from the parents [6,7].

Increased knowledge of characteristics that may predict lower parental levels of HL could help healthcare providers to identify parents that may need extended attention and support to ensure that health education meets their individual needs.

Our results need to be interpreted with caution, as 140 out of 254 parents were recruited from the epilepsy center during the COVID-19 pandemic. During this period, the number of hospitalized children was reduced, and those with the most severe epilepsies were prioritized. Thus, the majority of our study population (Cohort A) is biased toward parents of children with very difficult-to-treat epilepsies. One must assume that managing these children requires higher HL skills than managing children with epilepsies that are more easily controlled. Nevertheless, parents in Cohort B, recruited through NEA's websites, and who most likely have children with more common epilepsies, did not vary substantially in HLQ-p and eHEALS scores compared to those in Cohort A. Therefore, we believe that our results may be representative of parents of children with epilepsy with similar sociodemographic and clinical (child) characteristics. We were not able to recruit parents of foreign origin who did not speak Norwegian or English. In

addition, the parents in our study had a higher level of education than the average Norwegian population (65% vs 35.3%, respectively) [50]. Thus, parents with low HL may have been underrepresented. Finally, the cross-sectional design does not enable causal explanations. The HLQ-p and eHEALS are subjective measures of HL, and the participants may have over- or underestimated their HL skills.

## 5. Conclusion

This is the first study to investigate multidimensional parental HL in a childhood epilepsy context. Our results highlight the need to investigate multiple characteristics, especially the level of parental self-efficacy and mental distress, as it may have an impact on parents' HL levels and could influence their capacity to cope with their child's medical condition. Further qualitative studies are needed to explore the underlying reasons for parents' HL scores, enabling healthcare providers to develop tailored interventions to meet parents' HL needs.

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## Declaration of interest

The authors claim that there are no conflicts of interests or competing interests in this project.

## Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this paper is consistent with those guidelines.

The work described in this paper follows the STROBE guidelines and checklist for observational studies: <http://strobe-statement.org>.

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## Registered

The study is registered in Open Science Framework (OSF): [www.osf.io/772r4d/](http://www.osf.io/772r4d/).

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2022.108658>.

## References

- [1] Aaberg KM, Bakken IJ, Lossius MI, Lund Soraas C, Håberg SE, Stoltenberg C, Surén P, Chin R. Comorbidity and childhood epilepsy: A nationwide registry study. *Pediatrics* 2016;138: e20160921–e20160921.
- [2] Lin JJMD, Mula MMD, Hermansen BPP. Uncovering the neurobehavioural comorbidities of epilepsy over the lifespan. *Lancet* 2012;380:1180–92.
- [3] Reilly C, Atkinson P, Das KB, Chin RFMC, Aylett SE, Burch V, et al. Neurobehavioral comorbidities in children with active epilepsy: A population-based study. *Pediatrics* 2014;133:e1586–93.
- [4] Hunter MB, Yoong M, Sumpter RE, Verity K, Shetty J, McLellan A, et al. Neurobehavioral problems in children with early-onset epilepsy: A population-based study. *Epilepsy Behav* 2019;93:87–93.
- [5] Jennum P, Gyldenborg J, Kjellberg J. The social and economic consequences of epilepsy: A controlled national study. *Epilepsia* 2011;52:949–56.
- [6] Jones C, Reilly C. Parental anxiety in childhood epilepsy: A systematic review. *Epilepsia* 2016;57:529–37.
- [7] Puka K, Tavares TP, Anderson KK, Ferro MA, Speechley KN. A systematic review of quality of life in parents of children with epilepsy. *Epilepsy Behav* 2018;82:38–45.
- [8] The World Health Organization. Health literacy. 2021.
- [9] Batterham RW, Hawkins M, Collins P, Buchbinder R, Osborne RH. Health literacy: applying current concepts to improve health services and reduce health inequalities. *Public Health* 2016;132:3–12.
- [10] Sorensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *Eur J Public Health* 2015;25:1053–8.
- [11] Morrison AK, Glick A, Yin HS. Health literacy: implications for child health. *Pediatr Rev* 2019;40:263–77.
- [12] DeWalt DA, Hink A. Health literacy and child health outcomes: A systematic review of the literature. *Pediatrics* 2009;124:S265–74.
- [13] Jessup RL, Osborne RH, Beauchamp A, Bourne A, Buchbinder R. Health literacy of recently hospitalised patients: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Health Serv Res* 2017;17:52.
- [14] Yeh J-Z, Wei C-j, Weng S-f, Tsai C-y, Shih J-h, Shih C-l, Chiu C-h. Disease-specific health literacy, disease knowledge, and adherence behavior among patients with type 2 diabetes in Taiwan. *BMC Public Health* 2018;18:1062–115.
- [15] Paschal AM, Mitchell QP, Wilroy JD, Hawley SR, Mitchell JB. Parent health literacy and adherence-related outcomes in children with epilepsy. *Epilepsy Behav* 2016;56:73–82.
- [16] Neter E, Brainin E. Association between health literacy, ehealth literacy, and health outcomes among patients with long-term conditions: A systematic review. *Eur Psychol* 2019;24:68–81.
- [17] Korkmaz MF, Erdem-Uzun M, Korkmaz M, Ekici A. Adherence to antiepileptic drugs and the health literacy of caregivers in childhood epilepsy. *P R Health Sci J* 2020;39:45–50.
- [18] Guven ST, Dalgic AI, Duman O. 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: 107142–107142.
- [19] Kickbusch I, Pelikan J, Apfel F, Tsouros A. Health Literacy. WHO Regional Office for Europe. 2013.
- [20] Morrison AK, Myrvik MP, Brousseau DC, Hoffmann RG, Stanley RM. The relationship between parent health literacy and pediatric emergency department utilization: A systematic review. *Acad Pediatr* 2013;13:421–9.
- [21] Nutbeam D. The evolving concept of health literacy. *Soc Sci Med* 2008;67:2072–8.
- [22] Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012;12:80.
- [23] Batterham RW, Buchbinder R, Beauchamp A, Dodson S, Elsworth GR, Osborne RH. 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;14:1–10.
- [24] Antonelli RC, McAllister JW, Popp J. Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. *Commonwealth Fund Pub* 2009:1277.
- [25] Wahl AK, Hermansen Å, Osborne RH, Larsen MH. A validation study of the Norwegian version of the Health Literacy Questionnaire: A robust nine-dimension factor model. *Scand J Public Health* 2020: 1403494820926428.
- [26] Larsen MH, Strumse YSS, Borge CR, Osborne RH, Andersen MH, Wahl AK. Health literacy - a new piece of the puzzle in psoriasis care? - Results from a cross-sectional study. *Br J Dermatol* 2019;180:1506–16.
- [27] Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health* 2013;13: 658–658.
- [28] Hawkins M, Elsworth GR, 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.
- [29] Norman CD, Skinner HA. eHEALS: The eHealth literacy scale. *J Med Internet Res* 2006;8:e27.
- [30] Brørs G, Wentzel-Larsen T, Dalen H, Hansen TB, Norman CD, Wahl A, et al. Psychometric properties of the Norwegian version of the Electronic Health Literacy Scale (eHEALS) among patients after percutaneous coronary intervention: cross-sectional validation study. *J Med Internet Res* 2020;22: e17312.
- [31] Dale JG, Lüthi A, Skaraas BF, Rundereim T, Dale B. Testing measurement properties of the Norwegian version of electronic health literacy scale (eHEALS) in a group of day surgery patients. *J Multidisc Healthc* 2020;13:241.
- [32] Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth literacy scale (eHEALS). *Patient Educ Couns* 2017;100:320–6.

- [33] Luszczyńska A, Gutiérrez-Doña B, Schwarzer R. General self-efficacy in various domains of human functioning: Evidence from five countries. *Int J Psychol* 2005;40:80–9.
- [34] Gramstad A, Iversen E, Engelsen BA. The impact of affectivity dispositions, self-efficacy and locus of control on psychosocial adjustment in patients with epilepsy. *Epilepsy Res* 2001;46:53–61.
- [35] Strand BH, Dalgard OS, Tambs K, Rognerud M. Measuring the mental health status of the Norwegian population: A comparison of the instruments SCL-25, SCL-10, SCL-5 and MHI-5 (SF-36). *Nord J Psychiatry* 2009;57:113–8.
- [36] Schmalbach B, Zenger M, Tibubos AN, Kliem S, Petrowski K, Brähler E. Psychometric properties of two brief versions of the Hopkins Symptom Checklist: HSCL-5 and HSCL-10. *Assessment* 2021;28:617–31.
- [37] Beauchamp A, Dodson S, Batterham RW, Asproloupou D, Osborne R. Ophelia Manual - How to apply the Ophelia health literacy process for improving health outcomes. In: Swinburne University of Technology, Australian Government, the Australian Research Council, 2019. p. 80.
- [38] Newman DA. Missing data: five practical guidelines. *Organizational Research Methods* 2014;17: 372–411.
- [39] Cohen J. *Statistical power analysis for the behavioral sciences*. Academic Press; 2013.
- [40] Sántha Á. The sociodemographic determinants of health literacy in the ethnic Hungarian mothers of young children in Eastern Europe. *Int J Environ Res Public Health* 2021;18:5517.
- [41] Lawrence PR, Feinberg I, Spratling R. The relationship of parental health literacy to health outcomes of children with medical complexity. *J Pediatr Nurs* 2021;60:65–70.
- [42] Nevin SM, Wakefield CE, Schilstra CE, McGill BC, Bye A, Palmer EE. The information needs of parents of children with early-onset epilepsy: A systematic review. *Epilepsy Behav* 2020;112: 107382–107382.
- [43] Statistics Norway. Sickness absence. In: <https://www.ssb.no/arbeid-og-lonn/arbeidsmiljo-sykefravaer-og-arbeidskonflikter/statistikk/sykefravaer>; 2020 [Accessed 03.Des.2021].
- [44] Hafeez B, Miller S, Patel AD, Grinspan ZM. Care coordination at a pediatric accountable care organization (ACO): A qualitative analysis. *Epilepsy Behav* 2017;73:148–55.
- [45] Dahl KG, Andersen MH, Urstad KH, Falk RS, Engebretsen E, Wahl AK. Identifying core variables associated with health literacy in kidney transplant recipients. *Prog Transplant* 2020;30:38–47.
- [46] Jones TL, Prinz RJ. Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clin Psychol Rev* 2005;25:341–63.
- [47] Wood MR, Price JH, Dake JA, Telljohann SK, Khuder SA. African American parents'/guardians' health literacy and self-efficacy and their child's level of asthma control. *J Pediatr Nurs* 2010;25:418–27.
- [48] Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 1977;84:191.
- [49] Reilly C, Atkinson P, Memon A, Jones C, Dabydeen L, Das KB, et al. Symptoms of depression, anxiety, and stress in parents of young children with epilepsy: a case controlled population-based study. *Epilepsy Behav* 2018;80:177–83.
- [50] Statistics Norway. Educational attainment of the population. In: <https://www.ssb.no/utdanning/utdanningsniva/statistikk/befolkningens-utdanningsniva>; 2020 [Accessed 29. Nov. 2021].