



Developing and maintaining health literacy: A continuous emotional, cognitive, and social process for parents of children with epilepsy—A qualitative study



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ABSTRACT

Childhood epilepsy is often complicated by neurobehavioral comorbidities, and parents are expected to actively engage in managing the condition. Insufficient parental health literacy (HL) has been associated with reduced health outcomes for children with epilepsy. Little is known about the parents' experiences of information seeking, social support, navigating the healthcare system, and interactions with healthcare professionals and how these skills may contribute to the development of sufficient HL.

This study explored parents' experiences of their caregiver responsibility and the development of their HL in relation to caring for their child with epilepsy. Ten parents of children under 12 years of age with epilepsy were purposely sampled and interviewed individually, using semi-structured interviews. The interviews were analyzed using qualitative content analysis, in line with Graneheim & Lundman.

The analyses resulted in three themes, each comprising two sub-themes. The themes were: (1) *Alone with the responsibility*, (2) *The combat for information and support*, and (3) *Developing vigilance and distrust in system competence*. Lack of flexibility in healthcare services, insufficient multidisciplinary collaboration, and unclear treatment provider responsibility made the parents feel alone in the caregiver's responsibility. Poor local provider competence related to childhood epilepsy was a barrier to developing sufficient HL. A trusting relationship with professionals and timely access to competent health services were facilitators for developing HL. Higher HL made the parents more critical for the healthcare services, which triggered vigilance and reduced their trust in the professionals' information.

For the parents, developing and maintaining HL was a continuous emotional, cognitive, and social process. Health information and care support need to be adjusted to the severity of the child's condition, the resources are available, and the parent's HL. The results of this study may contribute to the development of future interventions for strengthening parental HL in the childhood epilepsy context.

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1. Introduction

There are numerous definitions of health literacy (HL) [1–3]. However, most of them refer to a person's ability to access, understand, and use health information in a way that maintains and promotes good health for themselves and those around them [4]. Further, HL can be categorized as a person's functional literacy, interaction, and critical appraisal skills [5]. A person's HL is a mod-

ifiable asset that develops over time through interaction with healthcare professionals and services [5]. Lower levels of HL in parents of children with chronic diseases are associated with poor child health outcomes, including more medical errors, lower adherence to treatment, and increased hospitalization rates [6–10].

Health literacy is a societal determinant of health outcomes, and having lower HL is a risk factor in the effectiveness of clinical care [5]. Being sensitive to each parent's HL and facilitating its development are therefore crucial tasks for healthcare professionals.

Epilepsy is one of the most common childhood neurological disorders, with an incidence of 4–7 per 1000 children, with higher rates in developing countries [11,12]. The disorder is often complicated by comorbidities, such as attention deficit hyperactivity dis-

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order and cerebral palsy [13,14], in addition to academic and psychosocial difficulties, which may be a result of central nervous dysfunction, seizures, or the side effects of antiseizure medication [15]. Children with the most severe forms of epilepsy may experience a medical emergency known as status epilepticus (SE), which are seizures that do not stop despite the use of acute medicine and may lead to mortality and morbidity [16]. Parents are expected to actively manage their caregiver responsibility, adhere to treatment, and participate in shared decision-making regarding their child's comprehensive follow-up [17,18]. This requires emotional resources, knowledge, and skills on the part of parents [18]. Children with medical complexities, such as epilepsy, depending on their parent's ability to manage their complex symptoms and to collaborate with multiple healthcare providers involved in the treatment [19]. Due to the nature and treatment of their condition, these children are especially vulnerable to medical errors [19]. A parent's need for HL skills depends strongly on the severity and complexity of the child's condition. Hence, individual characteristics impact their need for information and support, their understanding, and their motivation [5]. In addition, available resources, such as access to healthcare services, social benefits, healthcare provider support, and social support from friends and family, impact parents' level of HL [2].

Although the development of patient (or parent) HL largely depends on interactions with healthcare professionals and access to healthcare services [5], the focus is often on the improvement of the individual's abilities [20,21]. In addition, broader factors, such as the organization of healthcare services and cultural influences, can facilitate but also be potential barriers to increasing parents' HL [22]. There are few studies on parents' experiences of information seeking and how interactions with healthcare professionals and ways of organizing healthcare services may contribute to the process through which parents develop sufficient HL to manage their child's epilepsy [19,23].

Consequently, this study aimed to explore parents' experiences of their caregiver responsibility and their development of HL in relation to caring for their child with epilepsy.

2. Material and methods

2.1. Study design

The study utilized individual semi-structured, which allowed the parents to introduce their issues related to the topic, providing nuanced insights into their experiences [24].

2.2. Study setting, recruitment, and participants

The study was part of a larger research project with the overall objectives of investigating parental HL in the childhood epilepsy context and co-developing and testing the feasibility of an intervention tailored to address parents' HL needs [25]. The study site was a hospital with national treatment responsibility for persons with pharmacoresistant epilepsy, hereafter referred to as the National Hospital. Therefore, the participating parents were recruited nationwide.

The parents in this study had participated in the project's first sub-study, hereafter named sub-study one [25]. Sub-study one was a cross-sectional study, and the included parents answered a survey on their subjective reported level of HL, with measures based on the Health Literacy Questionnaire – parents' version (HLQ-p) [26,27]. The parents also reported their individual sociodemographic characteristics and answered clinical questions about their children's condition in sub-study one [25].

The parents had all signed an informed consent indicating their willingness to be interviewed (the current study). Following the inclusion criterion in sub-study one, from which the parents in this study were recruited, they were 18 years or older and had a child younger than 12 years, who had been diagnosed with epilepsy and hospitalized in the National hospital at the time of inclusion in sub-study one. In addition, none of the parents had apparent cognitive or mental health problems (assessed by the pediatrician treating their child at the National hospital) at the time of their inclusion in sub-study one. For further details, we refer the reader to the published article [25].

In this study, we wanted to obtain a deeper and more nuanced understanding of the parents' individual experiences related to their caregiver experiences and the process of developing sufficient HL in relation to their child's epilepsy.

Based on the parents' subjective reported answers in sub-study one [25], we were able to include parents purposively [28], representing a continuum from lower to higher scores. To further increase the information power of the sample (sample specificity), we ensured the parents represented various demographic and societal characteristics in addition to different clinical variables for the children [28]. A detailed description of the participants' characteristics is presented in Table 1.

2.3. Interview guide and semi-structured interviews

The research group developed an interview guide based on a multidimensional understanding of HL [5,22,29–31], expressed in the nine different HL domains in the Health Literacy Questionnaire – Parent Version (HLQ-p) used in the cross-sectional study referred to in section 2.2 [27]. To explore the parents' experiences, each question in the interview guide was directed toward one of the nine HL domains in the HLQ-p [27] (see supplementary file 1). For example, to explore the parent's experiences concerning HLQ-domain 7 (the parent's ability to navigate the healthcare system), the interview guide contained the following questions:

- When you are worried about your child's health/well-being, how do you go about seeking professional help?
- How do you know who/where to contact?

Before the interviews, the interview guide was pilot tested by interviewing one colleague with a chronically ill child and one colleague with healthy children to ensure its suitability [32]. The first author conducted all the interviews by telephone, each with only one parent present. The parents were contacted within two months after they had participated in the cross-sectional study. The interviews provided rich information, lasted from 35 to 90 minutes, and were audiotaped.

2.4. Data analysis

Content analysis, following an inductive approach as described by Graneheim and Lundman [33] and Lindgren et al. [34], was used to interpret the patterns of the parents' experiences across the interviews. An inductive approach involves a search for patterns by looking for similarities and differences in the data, described as categories and themes, with low levels of abstraction (manifest meaning) or higher levels of abstraction (latent meaning) [35]. The purpose of the analysis was to analyze the interviews beyond the parents' specific descriptions, searching for underlying (latent) meanings that captured the essence of the parents' experiences related to the study objective [35]. NVivo qualitative data analysis software (version 12, 2018) was used for data management.

To increase the credibility of the analysis, the research group (comprising the authors of this article) read through the interviews

Table 1
Participants' characteristics and children's clinical variables.

Participants' characteristics (N = 10)	Number of respondents
Age:	
30–34	1
35–39	2
40–44	4
45–49	3
Gender:	
Female	7
Education level:	
Vocational	3
Faculty/College	4
University	3
On sick leave as a consequence of the child's epilepsy (n = 9)	4
Cohabitant	8
Norwegian born	9
Children's clinical characteristics (N = 10)	n
Child's current age	
≤ 3 years	1
3.1 – 6 years	1
6.1 – 9 years	5
9.1 – 12 years	3
Age of onset of epilepsy (range 0 – 8 years)	
From birth	3
Within the first year of life	2
Between 3 – 4 years old	2
Between 5 – 6 years old	2
8 years	1
Duration of epilepsy	
-Newly diagnosed with epilepsy < 1 year ago	1
-Between 1–3.99 years ago	3
- > 4 years ago,	6
Epilepsy diagnosis	
Generalized epilepsy	2
Focal epilepsy	4
Generalized and focal epilepsy	2
Subclinical epileptic activity(only)	
Epilepsy syndrome:	
– Lennox-Gastaut syndrome	1
– Tuberous sclerosis syndrome	1
Seizures on a weekly basis	5
Administering acute medicine at least once per six months	4
The child has one or more comorbidities	5
Type of diagnosis:	
– Attention deficit hyperactivity disorder (ADHD)	2
– Cerebral palsy (CP)	2
– Autism	1
– Intellectual disability	3
The child has a coordinator of health services	4
The child has been hospitalized at least once in the last year	6

individually. After discussions with the research group, the first author developed a coding frame for a preliminary organization of the codes in categories, which constituted the manifest content of the parent's experiences [33]. Interpreting the interviews further, the first author suggested themes, each with sub-themes, that seemed to capture the latent meanings of parents' experiences across the interviews [33]. The other authors commented and helped in reviewing the suggested themes and sub-themes for a final result [33,34]. An example of the interpretation process from manifest to latent meaning is shown in Table 2.

2.5. 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 study was conducted in accordance with the Declaration of Hel-

sinki. Data were stored on the university's server for sensitive data [36]. All participants were given oral and written information and signed an informed consent form before participating. They were informed orally and in written form that they could withdraw from the study at any time, without providing a reason. They also had the opportunity to read and correct the interviews before they were analyzed. Talking about their child's severe condition could trigger emotional reactions, and the parents were encouraged to contact the interviewer if they needed support and guidance to establish contact with local sources of support.

3. Results

The analyses from manifest to latent meaning resulted in the identification of three overarching themes: (1) *alone with the responsibility*; (2) *the combat for information and support*, and (3) *developing vigilance and distrust in system competence*. Table 3 presents an overview of the themes and sub-themes.

3.1. Alone with the responsibility

At the onset of the child's epilepsy, most of the parents described a feeling of being left alone with the everyday medical responsibility, fearing that they would not be competent enough to manage the child's condition. Despite the complex nature of their child's condition and the need for integrative follow-up, they experienced fragmentation in the organization of the healthcare services. Some claimed that none of the professionals involved in treatment seemed to be willing to take overall responsibility for the child's health. This theme has two sub-themes: (1) *the need for flexible health provider support* and (2) *unclear provider overall treatment responsibility*.

3.1.1. The need for flexible health provider support

The parents described the discrepancy between not having access to tailored support from competent healthcare professionals outside working hours despite being given the responsibility of handling potentially harmful seizures on a 24-hour basis as one of the main barriers keeping them from developing sufficient HL. Five of the parents had experienced medical crises without having access to sufficient healthcare advice from professionals familiar with their child's condition. Having the 24-hour caregiver responsibility for their child, without having timely access to competent providers in times of medical crisis, was described as a continuous emotional burden, especially for the parents of children with the most severe types of epilepsy.

"It has been extremely difficult to get in touch with the child's neurologist other than in consultations. The epilepsy nurse only works daytime, but our child often has accumulations of seizures, or falls in a seizure and gets injured in the evenings or at nighttime. In the beginning, we ended up in the emergency department and had to repeat his medical history time and time again."

3.1.2. Unclear provider treatment responsibility

The parents indicated that their child's multiple disorders influenced each other, sometimes aggravating the symptoms. Despite this, seven of the parents experienced the exchange of information and collaboration between multiple healthcare professionals as scarce and insufficient. In addition, with several experts in different healthcare fields involved in the treatment, it seemed to be unclear which of the professionals should have the overall treatment responsibility.

"The local habilitation services have follow-up responsibility, but they only seemed to be concerned about his cerebral palsy... Then

Table 2
Examples of meaning units, condensed meaning units, sub-themes, and themes.

Meaning unit	Condensed meaning unit (manifest meaning)	Condensed meaning unit of latent meaning	Sub-themes	Themes
<i>"It has been extremely difficult to get in touch with the child's neurologist other than in consultations. The epilepsy nurse only works daytime, but our child often has accumulations of seizures, or falls in a seizure and gets injured in the evenings or at nighttime. In the beginning, we ended up in the emergency department and had to repeat his medical history time and time again."</i>	The parents do not have access to medical advice from competent professionals when the child's seizures occur outside of working hours. The parents feel responsible for assessing the child's medical condition without guidance from professionals who know their child. They end up in the emergency department.	The organization of healthcare services is not flexibly adjusted to the parent's need for support in times of crisis. The parents experience a discrepancy between their need for information and the support to ensure the child's safety and the support offered by the healthcare system. They are given too much responsibility for assessing the child's situation.	The need for flexible health provider support	Alone with the responsibility
<i>"The local Habilitation services have follow-up responsibility, but they only seemed to be concerned about his cerebral palsy... then there is the neurologist... and then we have controls at the National hospital every year, we put all our trust in the National hospital... then there is the general practitioner, he only makes sure that the blood samples are taken [...] the collaboration between the providers could have been better, no one seems to take the overall responsibility."</i>	Each professional is occupied with and solely treats the diagnosis related to their specialist field. The parents experience that no one takes overall, comprehensive responsibility for the child's health.	The organization of healthcare services in specialist fields causes difficulties for professionals to take overall responsibility for complex conditions that require integrated multidisciplinary treatment. Parents experience that they are the only ones able to communicate the child's comprehensive needs between healthcare professionals due to a lack of clarity regarding provider responsibilities.	Unclear provider treatment responsibility	

Table 3
Themes and sub-themes.

Themes	Sub-themes
Alone with the responsibility	The need for flexible health provider support Unclear provider treatment responsibility
The combat for information and support	Struggling to access tailored information Building local provider relationships for support
Developing vigilance and distrust in system competence	Compensating for insufficient interdisciplinary info exchange Reluctance of trusting childcare to others

there is the neurologist... and then we have controls at the National hospital every year, we put all our trust in the National hospital. Then there is the general practitioner, he only makes sure that the blood samples are taken [...] the collaboration between the providers could have been better, no one seems to take the overall treatment responsibility."

As a result, some parents experienced and were alarmed by the fact, that many of the medical decisions made by the professionals were solely based on their observations of the child as parents. With little or no direct communication between the various professionals involved in managing the child's complex condition, the parents felt responsible for describing and transferring information between the professionals. The parents described a fear of not being able to adequately explain the child's complex symptoms, leading to treatment misunderstandings. Keeping updated on the child's complex medical situation and feeling responsible for describing the child's symptoms and transferring information between professionals were continuous emotional, social, and intellectual processes. The parents whose children had been assigned a coordinator of health services or those who had long-standing contact with a professional (e.g., child neurologist or epi-

lepsy specialist nurse (ESN)), described feeling profound relief when professionals helped them to get an overview of their child's medical situation, comprehensive treatment, and health services.

3.2. The combat for information and support

The experience of not having access to sufficient information, accompanied by uncertainty about whether their child received adequate follow-up, appeared to be of great concern and was frequently brought up by the parents. An important prerequisite for the development of HL throughout the course of the child's illness seemed to be to access information adjusted to the child's illness profile. This theme consists of two subthemes: (1) *struggling to access tailored information* and (2) *building local provider relationship for support*.

3.2.1. Struggling to access tailored information

To explore what HL represented for the parents and the basis on which they answered the questions, the parents were asked how they understood the words HL and parental HL. Across the interviews, the parents' responses were similar to the following:

"It is the competence I would expect healthcare professionals to have, or be able to provide, to ensure our child optimal treatment."

When asked to describe how they understood the word parental HL, most of the parents hesitated, having to reflect on it. Some immediately responded that parental HL would be a competence they learned over time from experiences of managing their child's condition.

The parents' expectations of HL as a competence that healthcare professionals should have or be able to provide did not seem to have been met for nine of the parents. They described how they would receive mostly general information about epilepsy at the time of diagnosis. The information would not be adjusted to their child's condition, and therefore it seemed less useful for them in handling the child's condition optimally.

"When he got the diagnosis, the local healthcare personnel focused mainly on large convulsion seizures and acute medicine. My son

has subtle focal seizures and sub-clinical epileptic activity that gives him behavioral difficulties. We only learned about the potentially challenges caused by sub-clinical epileptic activity at the National hospital. If we had received this information earlier, we would have handled our son's behavior in a better way."

Three of the parents did not receive information about the health and social benefits that they were entitled to receive. As a result, some stopped working and only learned after several years that their workplace was legally required to adapt to the working conditions, enabling them to care for their child.

3.2.2. Building local provider relationship for support

The parents indicated that the trajectory of their child's condition was unpredictable and changed over time. The need for care support and information changed accordingly, but the local follow-up was experienced as coincidental, depending on the parents' initiative. In particular, the parents of the children with the most severe epilepsies stated that the caregiver responsibility forced them to handle living with sustained uncertainty. This included not only uncertainty about when the next seizure would occur and how to interpret the symptoms but also regarding the child's illness trajectory and if the local healthcare professionals would provide them with sufficient information and give the child access to necessary multidisciplinary assessments. Most of the experienced parents had built a long-lasting relationship with a local provider that understood their child's condition. They trusted this professional's ability to facilitate tailored healthcare services when new challenges emerged along their child's illness trajectory.

"You know, there are no definitive answers. We have had excellent help from the child's coordinator. She has really taken the responsibility; contacted professionals and arranged provider meetings. We didn't know that our son would need a physiotherapist nor an occupational therapist, nor how to reach them...?"

3.3. Developing vigilance and distrust in system competence

Regarding the last theme, six of the parents described situations in which healthcare professionals were not able to interpret the child's symptoms correctly. According to the parents, this sometimes resulted in incorrect handling of potentially harmful medical situations. Over the years, the parents seemed to develop a protective vigilance, a non-trusting attitude that involved always questioning whether the health professionals were competent and in control of the child's current situation. This theme has two subthemes: (1) *compensating for insufficient interdisciplinary information exchange* and (2) *reluctance to trust childcare to others*.

3.3.1. Compensating for insufficient interdisciplinary info exchange

All the parents reported that information about their child's health was occasionally exchanged incorrectly or insufficiently between the many providers involved in the child's treatment. Some of the parents had received conflicting information from healthcare professionals working in different sections of the same hospital. These experiences left them anxious and uncertain if medical decisions would be made based on incorrect information, potentially harming their child. Developing higher levels of HL regarding their child's condition over time from their experiences with caregiving along with different treatment regimes, made the parent more critical towards the quality of healthcare services. They said that they had to be vigilant, ensuring that information was correctly exchanged, to be certain that the doctors made decisions about treatment based on updated information.

"We have experienced a lot of medical records where it seems like they did not really listen to what we were saying. Instead, the doctor copied and pasted the text from the outdated medical record from last year. It's frustrating and makes us uncertain if they really are in control of the situation. We have to control them and cannot relax for a second!"

The experience of constant distrust concerning whether the information was exchanged correctly between the child's providers and having to make sure the providers made decisions based on updated information was described as a constant, cognitive, and emotional challenge.

3.3.2. Reluctance to trust childcare to others

In particular, the parents of the children with the most severe forms of epilepsy experienced a certain reluctance to trust the care of their child to others. They seemed anxious, expressing doubt that even healthcare personnel would be capable of safeguarding their child in the event of an emergency.

"My child was on respirator... I thought: 'I cannot be a mother now, then I would have a complete breakdown. I must learn all there is to know quickly, so I can help her,' cause I do not dear to trust the healthcare personnel to have sufficient competence, despite their good intentions."

Receiving social support from friends and family was described as crucial for managing the child's condition. Parents who had family members they could trust to take responsibility for the child expressed profound relief at being able to "unwind," take time off or discuss care challenges with supportive relatives. Some were disappointed in their relatives, as they were unwilling to babysit the child despite being offered courses on how to handle seizures.

Some were disappointed in their relatives, as they were unwilling to babysit the child despite being offered courses on how to handle seizures. Seven of the children had additional behavioral challenges caused by the underlying or additional neurobehavioral disorders (e.g., autism, ADHD), seizures, subclinical epileptiform activity, and/or side effects of the antiseizure medication, which the parents found socially challenging. The parents described a lack of understanding of their child's behavioral challenges on the part of friends, family members, and school personnel and feared it would lead to blaming and poor handling of the child. Although the situation was described as socially challenging, some parents seemed reluctant to trust even their family members to care for their child, indicating they thought it would be "too much to ask" and fearing that it would cause their friends and family to withdraw from contact, leaving them even more isolated.

4. Discussion

This study explored parents' experiences of caregiver responsibility and the development of HL in relation to caring for their child with epilepsy. The parents gained considerable knowledge through their caregiving experiences. Their experiences also supported their development of and ability to maintain sufficient HL to feel confident with the caregiver's responsibility, which was described as a continuous emotional, cognitive, and social process. Poor local professional knowledge about epilepsy was a barrier, whereas timely access to competent healthcare services and a trusting relationship with a professional facilitated the development of HL. Higher HL made the parents more critical of the quality of healthcare services, triggered vigilance and reduced their trust in the information provided by professionals.

The onset of their child's epilepsy was a particularly vulnerable period for the parents in terms of feeling left alone with the caregiver's responsibility. To experience one's child becoming chronically

cally ill with seizures that may occur at any time is a devastating and fearful experience, which requires considerable strength for parents to process [37]. The lack of access to knowledgeable professionals to ask for advice to ensure they address symptoms correctly represents a considerable source of stress for parents of children with epilepsy [38].

The parents described being offered similar healthcare support, regardless of the severity of their child's epilepsy. In particular, the parents of the most severely ill children experienced an unacceptable discrepancy between their need for information and support to ensure the child's safety, and the actual support offered [39]. Considering the rare, but potentially life-threatening consequences of a child experiencing SE [16], the parents' distress is highly understandable. When contacting the 24-hour open emergency center in times of crisis, the personnel rarely had sufficient competence to assess and treat epilepsy, and they lacked access to the child's medical records to give adequate medical advice. Lower parental HL is associated with more frequent child emergency hospitalizations [40]. However, the parents in this study suggested that some of the emergency hospitalizations could have been avoided if they would have had access to medical advice from knowledgeable professionals in times of crisis. The need for flexibility in service delivery and individual pathways of care for children with complex medical conditions has been documented [41], but current initiatives to meet these needs are insufficient, according to the parents in this study.

Writing a structured plan for follow-up in collaboration with the parents is associated with reduced hospital readmission [42] and a reduced feeling on the part of parents that they are being left alone with the caregiver's responsibility. In addition, parents need comprehensive information presented at a pace and in a format specific to their situation and level of HL to get a sense of control over the situation [38,43]. Ensuring that the information is patient-centered and delivered in an understandable format requires the professionals to have good communication skills [38]. In addition, it requires sensitivity to factors that may impact parents' capacity to process information [44], such as having an emotional reaction to their child becoming chronically ill [6,45]. Hence, it is crucial for healthcare professionals to have increased awareness of the impact of the parent's HL on their need for information and support, and to adjust information and support accordingly.

The children's treatment involved multidisciplinary providers across different levels of health and social services. However, the parents experienced being the only ones able to communicate the child's comprehensive needs due to a lack of routines for structured collaboration between the professionals. Recent research suggests that insufficient information flows across healthcare service boundaries lead to unclear overall treatment responsibility, and there is a need for an integrated care approach to improve the multidisciplinary sharing of expertise [41]. This includes defining clear responsibilities for all professionals involved across the healthcare spectrum as well as the parents to ensure the quality of care [41]. This could help prevent parents from becoming exhausted from taking on more responsibility than they should be expected to [39,41,46].

When beginning to feel safe handling their child's seizures, the parents described a need for information about a variety of issues, such as behavioral and academic aspects of their child's illness. However, one barrier to developing sufficient HL seemed to be the generally poor competence of local healthcare services related to childhood epilepsy. The parents often had to persuade the local professionals to refer their child to multidisciplinary experts, which resulted in an unnecessarily prolonged diagnostic journey. The individual, complex, and unpredictable trajectory of childhood epilepsy is well documented [14,37,38]. However, our findings are

not unique, as parents have previously reported a lack of professional healthcare knowledge about epilepsy, leading to delayed neurobehavioral assessments [37,38,47].

Unfortunately, these experiences seemed to reduce the parents' trust in the local health services significantly. A lack of trust in health professionals' competence has been reported to be a barrier to the development of HL by patients [48]. Trust is a fundamental prerequisite for parents to be willing to provide sensitive information about their child's health, and to follow treatment recommendations [49]. A strategy for managing life with the sustained uncertainty of an unpredictable disorder trajectory and developing sufficient HL was building a trusting relationship with a professional. Other studies have shown that by building a partnership with a professional they trust and expect to act on their child's behalf in the unpredictable future, parents gain a sense of control over the situation [41,49]. None of the parents in this study were offered regular consultations with a specialist epilepsy nurse (ESN), who could facilitate access to multi-agency services, even though that is part of the National Clinical Treatment Recommendations (NICE) [50].

In addition, reliance on one dedicated professional to empower parents to navigate the fragmented healthcare services and advocate for their child's needs is vulnerable to changes in personnel at the service level [41]. Hence, establishing a central repository of information and prioritizing resources to establish routines for multidisciplinary communication would represent a less vulnerable and more integrative approach to healthcare [41,46]. Further, the continuity of professionals facilitates long-term knowledge of the child's unique illness trajectory, and thus taking the time to build such relationships should be prioritized in clinical practice.

Higher levels of HL made the parents more critical of the services being offered. Critical appraisal of health information and services demands a certain level of HL related to childhood epilepsy, and it is acknowledged that HL is an important asset [5]. Low parental HL is associated with medical errors [9,10]. In this study, the parents described having to prevent healthcare professionals from making medical errors due to inadequate health information exchange. To the best of our knowledge, this developed level of parental expertise has not been described in previous studies.

Reduced trust in the healthcare services triggered vigilance. The parents constantly checked up on medical information and professionals' knowledge to ensure that their child received optimal care and to prevent treatment misunderstandings. Research suggests that vigilance is the way in which some parents respond to living with the persistent uncertainty of the illness trajectory [51]. However, avoiding medical errors and ensuring patient safety are the responsibilities of the healthcare services, not the parents. Excessive, vigilant parenting has been associated with parental exhaustion and reduced mental well-being [52], which may have a negative impact on the parent's HL capacity [48].

Unfortunately, for some parents, reduced trust in others' ability to care for their child also included their own family members. Family cohesion and support have been strongly associated with increased parental psychological well-being and the quality of the parent-child relation [18]. Social support is also an important resource that contributes to a person's level of HL [2,31]. This lack of trust in others' ability to care for the child is understandable but may be detrimental to parents' health and well-being and thus should be investigated and addressed by healthcare professionals.

4.1. Study strengths and limitations

Our results need to be interpreted with caution, as the parents were recruited from a tertiary epilepsy center. Hence, most of the interviewed parents had children with pharmacoresistant epilepsy, presumably a complex condition that may require higher HL skills

than managing children with more easily treated types of epilepsy. A strength of the study is that the National hospital receives patients from all over the country. Therefore, the parents had a rich sociodemographic variety, living in different parts of the country, both rural and urban.

The sample was relatively small in size, considering parents' individual experiences of the caregiver responsibility and development of HL with such heterogeneous socio-demographic variables and children with various epilepsy profiles [53]. Hence, there is a need for further studies on the experiences of the caregiver responsibility and the process of developing sufficient HL in relation to their child's epilepsy for parents of children with less severe epilepsies as well.

The research method was chosen to obtain deep insights into the parents' variable experiences through rich descriptions of their experiences, not to produce generalizable findings. Nevertheless, the insights provided by the parents in this study may be transferable to the experiences of parents of children with other complex childhood conditions.

According to Malterud et al. [28], the quality of data in qualitative research, called "information power," depends on the extent to which it is capable of answering the research questions and should be determined based on the study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy [28]. Following the reasoning of Malterud [28], the more relevant information a sample holds for a study, the lower the number of participants needed. In this study, we were able to purposefully sample parents with various characteristics, enabling rich, subjective descriptions of different ways the parents may experience the caregiver responsibility and process of developing sufficient HL in relation to caring for their child with epilepsy [28].

The first author is an experienced interviewer with extended clinical epilepsy experience, which contributed to the quality of the interviews [28]. This experience enabled her to pose follow-up questions on topics related to the study aim that may have gone unnoticed by an interviewer without in-depth knowledge of the area of interest [28]. However, close proximity to the work field may pose a risk of interpreting the parents' experiences a certain way, that is, reproducing one's preconceptions [24]. It is essential to remain open to the parents' experiences and avoid preconceptions [24]. The interview guide was used flexibly, adjusting the order of the questions based on the themes the parents brought up and posing follow-up questions to pursue the experiences and themes they introduced [24].

The methodical rigor of the analysis and the authors' contributions to the clinical and research perspectives are strengths of this study [24].

Except for one parent, only ethnic Norwegian parents were included. The experiences of the caregiver responsibility and the process of developing sufficient HL may be different for parents of other ethnic backgrounds due to different understandings of the illness, parental responsibility, linguistic challenges, and other cultures' ways of organizing healthcare services. There is a need for further studies exploring the experiences of parents with different ethnic backgrounds.

The interviews were performed in the middle of the COVID-19 pandemic and had to be conducted by telephone to prevent the spread of the infection. Telephone interviews reduce visual feedback, which is considered an important part of the interaction process, compared to face-to-face interviews [54]. Hence, the interviewer may lose crucial contextual information and thus the possibility to pursue an important issue [54]. However, reduced feedback may also make the interviewer and the interviewee more attentive to the questions and responses of the semi-structured interview, thus resulting in more focused responses [54]. Further, telephone interviews may provide a sense of anonymity and moti-

vate the interviewee to speak more freely about the experiences they consider important [54].

4.2. Implications for practice

Healthcare professionals need to have increased awareness of the impact of the level of HL on parents' need for information and support. Due to the frequent occurrence of neurobehavioral comorbidities in childhood epilepsy [14], neurobehavioral screening close to diagnosis should be considered for all children.

Adequate HL is essential for parents to manage their child's condition [44]. All children with epilepsy and their parents should have access to an ESN providing them with tailored information and facilitating access to multi-agency services. The parents of children with a severe epilepsy diagnosis and a high risk of repeated SE should be offered timely access to competent healthcare providers and services.

The parents of children with epilepsy have an increased risk of experiencing mental distress compared to parents of healthy children [55]. Reduced psychological well-being may temporarily reduce the parents' HL capacity [48], so parents' psychological well-being should be considered and addressed by healthcare providers.

In addition, there is a need for better routines in training health professionals in communication skills to ensure that the parents' individual HL needs are assessed and met [56]. Further, there seems to be a need for an increased focus on health professionals' interactive skills and approaches for building trusting relationships to support parents' development and maintenance of HL. Finally, there is a need to prioritize resources for establishing routines for multidisciplinary communication, supporting an integrative approach to complex epilepsy healthcare.

5. Conclusion

The parents experienced developing and maintaining HL as a continuous emotional, cognitive, and social process. Health information and care support need to be adjusted to the severity of the child's condition, the resources available, and the parents' HL. The results of this study may contribute by providing useful information for the development of future interventions aimed at strengthening parental HL in the childhood epilepsy context. There is a need for further studies on parents' experiences of the process of developing sufficient HL in relation to their child's epilepsy in general, particularly for parents of different ethnic backgrounds.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Merete Kristin Tschamper reports financial support was provided by The DAM foundation. This project has received financial support from Stiftelsen DAM, a non-profit foundation, and the Norwegian Epilepsy Association, a non-profit association.

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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 Consolidated criteria for reporting qualitative studies (COREQ) [53].

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Appendix A. Supplementary material

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2023.109222>.

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