



## Review

## Social functioning of children after epilepsy surgery: A literature review

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## ABSTRACT

This literature review on social functioning of children after epilepsy surgery is based on 24 papers addressing two categories of social functioning: social cognition ( $n = 4$ ) and general social functioning ( $n = 20$ ). Overall, studies that compared with healthy peers revealed children who had undergone epilepsy surgery to have more problems in both social cognition and general social functioning. Half of the studies found some improvement in social functioning in the first year(s) after epilepsy surgery, but this pertained to general social functioning, not to social cognition. The persistence of the problems in social cognition after surgery may be related to the critical period of brain maturation, lacking improvement of impairments in related cognitive domains or to a defective underlying brain condition – rather than to the epilepsy. Problems in general social functioning may be explained by the adjustments the children and their families had to make because of the child's drug-resistant epilepsy and difficulties to adjust to the new situation after surgery. The neurological and behavioral explanations are likely to be interrelated in light of the multifaceted and complex nature of social functioning. Epilepsy surgery does not appear to solve the problems in social functioning associated with having had drug-resistant epilepsy. As social functioning is an important aspect of healthy development, it should be assessed comprehensively in order to obtain a knowledge base that allows 1) proper treatment of children with epilepsy (CwE) and 2) counseling patients and families prior to and after epilepsy surgery.

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## 1. Introduction

Epilepsy is the most common chronic neurological disorder in children. It is strongly associated with neuropsychological problems [1] and has a great impact on the child's social functioning [2–5]. Epilepsy surgery is recognized as the most effective way to treat focal lesional epilepsy, when antiepileptic drugs (AEDs) fail to control seizures [5]. Successful epilepsy surgery is largely defined in terms of seizure freedom. Having seizures, using AEDs, and the stigma of being a person with epilepsy negatively influence social functioning [2,6], as could do the radical change that epilepsy surgery can bring to the lives of these children and their families. Therefore, it is important to consider children's social functioning before and after epilepsy surgery.

Social cognition is an umbrella term for the cognitive and emotional–mental processes required to interpret the behavior and internal

states of others and to respond in an appropriate manner [7]. Cognitive tests are used to assess this functionality. Human social cognition – usually studied in terms of theory of mind (ToM) – is the ability to make inferences about other people's minds [8]. This capacity to attribute mental states – like thoughts, emotions, and intentions – to others is considered essential for interpreting and predicting other people's behavior [9]. An important component of ToM is the capacity to derive from another person's facial expression how she or he is feeling. More generally, in order to understand another person's behavior and mental state, one must be able to recognize subtle nonverbal signals, such as the emotion displayed in the facial expression of other persons [10,11]. General social functioning can also be described as daily social functioning and includes the quality of one's social life, participating in social activities, social competence, and establishing and maintaining social relations. General social functioning is mostly assessed with questionnaires and interviews with both the child and important others.

Social cognition and general social functioning are mutually dependent, and children with epilepsy (CwE) are at risk for impairments in both [12]. Deficits in social cognition may have an impact on general social functioning, like engaging in social interactions in a manner consistent with age-appropriate expectations [3], and vice versa; a lack in social activities may hamper the development of social cognition.

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We aimed to provide an overview of the existing literature on social functioning in children whose epilepsy had been treated surgically. We included studies from both paradigms, focusing on social cognition and general social functioning.

## 2. Methods

The PubMed database was searched (last search at March 24th 2019) for relevant research articles, using the search terms: [epilepsy surgery] AND [(child\*) OR (pediatric)] AND [(social) OR (social cognition) OR (emotion recogn\*) OR (theory of mind)].

Inclusion criteria for the review of papers examining social functioning of children after (and preferably also before) epilepsy surgery were the following: (1) reporting on social functioning in children (0–18 years; in studies also including adults, the data on children had to be separately reported or retrievable), (2) a sample size of at least 10 children, (3) at least one assessment after epilepsy surgery, (4) results should pertain to at least one measured dimension (scale) of a test/questionnaire

addressing social functioning, social behavior perceived by relevant others, or social cognition, (5) original research, written in English, and (6) published between 2003 and 2019. Initial selection of studies, based on title and abstract, was done by CM and OB independently. Final selection of studies based on full texts and extraction of data were also done by CM and OB. The reference lists of the included articles were searched to identify further studies that met the inclusion criteria.

## 3. Results

The search resulted in 263 hits, of which 20 met the inclusion criteria. Three papers were added as a result of screening the references of these 20 papers. One not yet published (but accepted) article of our own group was included, resulting in 24 papers. Four papers reported on social cognition assessed by specific social–cognitive tasks (Table 1), and 20 papers reported on general social functioning assessed by questionnaires, observational screening, or interviews (Table 2).

**Table 1**  
Social cognition after epilepsy surgery in children.

Study	Sample	Design	Age at surgery (years): mean (range)	Postsurgery follow-up range (years)	Seizure outcome: Seizure-free (SF) or Engel class I–IV	Domain(s) measured	Measures	Outcome
Braams et al., <sup>a</sup> 2019 [13] accepted for publication.	Surgical patients (N = 15), healthy peers (N = 30)	Longitudinal: before surgery, and at least 2 of 3 follow-up assessments after surgery	7.1 (4–11)	0.5–2	SF: 13 (87%) after 2 years	Theory of mind (ToM)	ToM Storybooks	No change in ToM after surgery. Higher VIQ, later onset of epilepsy and temporal origin were associated with better ToM. Children in whom the amygdala was resected performed worse on ToM. Seizure freedom was not related to ToM.
Braams et al., <sup>a</sup> 2015 [11]	Cross-sectional: surgical patients (N = 41), healthy peers (N = 82). Longitudinal: surgical patients (N = 11); healthy peers (N = 22)	Cross-sectional: postsurgery; longitudinal: before surgery, and 3 follow-up assessments after surgery	Cross-sectional group: N/A, age at 2-year follow-up assessment: 13.5 (4.2–20) Longitudinal subset: 11.9 (6.5–17.2)	0.5–2	N/A	Facial emotion recognition	Facial Expression of Emotion: Stimuli and Tests (FEEST)	Surgically treated children were poorer at recognizing emotions than controls. Younger children (≤12 y) had a decline after surgery but had recovered to presurgical level after 2 years. Adolescents had a continued increase in performance after surgery. Neither seizure freedom nor any other epilepsy variable was related to facial emotion recognition.
Golouboff et al., 2008 [14]	CwE (N = 37; of whom 21 treated surgically), healthy peers (N = 37)	Cross-sectional: CwE (considered as one group, regardless of whether they were surgically treated or not) vs. controls	N/A; age at assessment: 13.2 (8–16)	N/A	N/A	Facial emotion recognition	Facial emotion recognition test for children (Test de Reconnaissance des Expressions Faciales pour Enfants (TREFE))	Children with epilepsy performed worse than controls, there was no difference between CwE with and without surgical treatment. Early-onset and temporal localization were related to more impaired recognition of facial expressions of emotion.
Pinabiaux et al., 2013 [15]	Surgical patients (N = 25); healthy peers (N = 50)	Cross-sectional: postsurgery only	9.7 (4.1–18.1)	1–7.25	I: 25 (100%)	Memory for facial emotion recognition	Facial emotion recognition test for children (TREFE)	Healthy peers showed enhanced memory for happy and fearful faces; surgical group (temporal lobe epilepsy) showed enhanced memory for fearful faces only. There was an impact of early seizure onset on the identification of fearful faces.

Abbreviations: CwE = children with epilepsy; N = number; VIQ = verbal intelligence quotient.

<sup>a</sup> Studies have partially overlapping samples.

**Table 2**  
General social functioning after epilepsy surgery in children.

Reference	Sample	Design	Age at surgery (years): mean (range)	Postsurgery follow-up range (years)	Seizure outcome: Seizure-free (SF) or Engel Class I–IV	Domain(s) measured	Measures	Outcome
Andresen et al., 2014 [16]	Surgical patients (N = 100)	Longitudinal: before surgery and 1 follow-up assessment after surgery	10.8 (N/A)	Range N/A; mean = 0.7 (sd = 1.1)	I: 84 (84%) II: 5 (5%) III: 4 (4%) IV: 7 (7%)	Psychosocial functioning, social anxiety	CBCL parent report; Revised Children's Manifest Anxiety Scale (RCMAS) self-report	No difference between pre- and postsurgical parent-reported social problems. Children with left frontal (not those with temporal) lobe epilepsy had higher levels of presurgical social anxiety, which reduced significantly after surgery. Before epilepsy surgery, CwE considered themselves more (socially) inadequate, perseverant, and recalcitrant than healthy peers. Social inadequacy decreased after surgery. There was no relation between seizure freedom and personality traits. Sporadic relations were found with gender, lobe of surgery, and the use of levetiracetam.
Braams et al., 2017 [17] <sup>b</sup>	Surgical patients (N = 23); healthy peers (N = 39)	Cross-sectional: CwE vs. healthy peers; Longitudinal: before surgery, and 3 follow-up assessments after surgery	12.8 (N/A)	0.5–2 years	SF: 17 (74%) after 2 years	Personality	Dutch Personality Questionnaire self-report	Higher QoL scores in domain 'social activity' after surgery compared with baseline. Patients who were seizure-free had significantly more increase in social QoL than those with recurrent seizures. After surgery, scores on psychosocial functioning had changed positively in 10 children, not changed in 6 children, and changed negatively in 8 children. Of all 7 seizure-free children, none changed negatively. No significant change after 1 year in social competence for both groups. No significant difference between both groups. (But significant between-group change favorable for the surgical group.)
Conway et al., 2018 [12]	Surgical patients (N = 111)	Longitudinal: before surgery and one follow-up assessment after surgery	12 (N/A)	1	SF: 79 (71%)	Social domain QoL	QoLCE parent-report	Between-group difference over time was significant: surgical group had a reduction in social problems over time whereas they increased in the nonsurgical group. Seizure freedom and lower number of AEDs were predictors of improved social function.
Danielsson et al., 2009 [18]	Surgical patients (N = 24)	Longitudinal; before surgery and 1 follow-up assessment after surgery	12.6 (4.2–19.4)	2	I: 7 (29%) II: 7 (29%) III: 5 (21%) IV: 5 (21%)	Psychosocial functioning	Children's Global Assessment Scale (CGAS); examiner report	Groupwise (infants and toddlers together): median preoperative SIQ = 59 and median 2 years postoperative SIQ = 72. Preoperative SIQ was higher in the infant compared with the toddler group (64 vs. 56). Postoperative, in seizure- and AED-free children, SIQ was higher in infants compared with toddlers (86 vs. 63). Overall difficulties
Dwivedi et al., 2017 [19]	Surgical patients (N = 57), nonsurgical CwE (N = 59)	Longitudinal: before surgery and 1 year follow-up assessment after surgery	Surgical group: 9 (0.8–17); nonsurgical group: 10 (2–17)	1	Surgical group SF: 44 (77%); Nonsurgical group SF: 4 (7%)	Social competence	Vineland Social Maturity Scale parent report	
Elliot et al., 2008 [20]	Surgical patients (N = 20); nonsurgical CwE (N = 12)	Longitudinal: before surgery (or baseline), and 2 follow-up assessments after surgery/baseline	14.2 (8.5–18.3)	1–2	SF: 10 (50%) after 2 years	Psychosocial functioning	CBCL parent report	
Gröppel et al., 2018 [21]	Surgical patients (N = 20)	Nonstatistical Longitudinal: before surgery, and 2 follow-up assessments after surgery	1.3 (0.3–2.7)	0.3–2	IA: 13 (65%) I: 1 (5%) III: 1 (5%) IV: 5 (25%)	Social Interaction Quotient (SIQ)	Denver Scales	
Hannan et al.,	Surgical patients	Longitudinal:	10.8 (5–17)	0.4–8.5	IA & II: 10 (77%)	Emotions,	Strengths and	

Table 2 (continued)

Reference	Sample	Design	Age at surgery (years): mean (range)	Postsurgery follow-up range (years)	Seizure outcome: Seizure-free (SF) or Engel Class I–IV	Domain(s) measured	Measures	Outcome
2009 [22]	(N = 13)	before surgery and at least 2 follow-up assessments after surgery			IV: 3 (23%)	behavior, and psychosocial impairment	difficulties questionnaire (SDQ) parent report	gradually decreased over 3 follow-ups. Authors suggest, but did not analyze, that improvement was related to seizure freedom.
Hum et al., 2010 [23]	Surgical patients (N = 27)	Qualitative: postsurgery only	N/A. Age at interview: 16.5 (11.3–21.2)	1.5–3.4	IA: 13 (48%) I: 2 (7%) II: 3 (11%) III: 4 (15%) IV: 5 (19%)	Self-perception of social functioning	Semistructured, open-ended interview on physical, psychological, social, and cognitive/academic experiences	Many of the seizure-free participants reported more independence, increased confidence, and improvement in their social experiences. Nevertheless, most participants, irrespective of seizure status, continued to report problems with peer relations and isolation (verbatim).
Korneluk et al., 2003 [24]	Surgical patients (N = 13)	Cross-sectional: postsurgery	11 (4–17)	1.6–2	I: 10 (77%) II: 2 (15%) III: 1 (8%)	Psychosocial functioning	CBCL parent report and teacher report form (TRF)	Parents reported higher scores on social problems compared with the normative sample, but teachers did not. No difference was found between children with (n = 9) and without (n = 4) removal of the amygdala.
Law et al., 2015 [25]	Surgical patients (N = 147), nonsurgical CwE (N = 40)	Longitudinal: before surgery (or baseline) 1 follow-up assessment 1 year after surgery/baseline	12.2 (3.1–18.3)	0.5–4.1	Surgical group SF: 95 (65%). Nonsurgical group SF: 8 (20%)	Psychosocial functioning	CBCL parent report	No difference in social problems between baseline and follow-up for both groups. Data from baseline and follow-up pooled showed more social problems in the nonsurgical group relative to the surgical group. Seizure freedom was not related to social problems, but early onset of epilepsy and number of used AEDs were. Low VIQ and PIQ were related to poorer social functioning.
Mikati et al., <sup>a</sup> 2008 [26]	Surgical patients (N = 17), nonsurgical CwE (N = 12)	Cross-sectional: postsurgery	11.2 (4–16)	Range N/A; mean = 2.4 (sd = 0.25)	I: 14 (82%) II: 2 (12%) III: 1 (6%)	Social domain QoL	QoLCE parent report	No difference in social QoL between the surgical and nonsurgical group.
Mikati et al., <sup>a</sup> 2010 [27]	Surgical patients (N = 19), nonsurgical CwE (N = 19), healthy peers (N = 19)	Cross-sectional: postsurgery	7.7 (2–14)	Range N/A; mean = 3.8 (sd = 2.3)	I: 15 (79%) II: 1 (5%) III: 2 (11%) IV: 1 (5%)	Social domain QoL	QoLCE parent report	No difference in social QoL between the three groups when analyzed together. Analyzed per two groups (three combinations possible) showed a difference only between the nonsurgical group and healthy peers.
Puka and Smith, 2015 [28]	Surgical patients (N = 71), nonsurgical CwE (N = 38)	Cross-sectional: postsurgery	13.2 (4.3–18.9)	4–11	Surgical group SF: 40 (56%) in last year. Nonsurgical group SF: 16 (42%).	Social functioning	QoL in Epilepsy for Adolescents self-report; QoLCE parent report	No significant difference in social QoL between the surgical and nonsurgical group. Seizure-free patients had better social QoL, irrespective of having had surgery. Antiepileptic drug use was negatively associated with social functioning.
Pulsifer et al., 2004 [29]	Hemispherectomy patients only (N = 71)	Longitudinal: before surgery (in 53 patients) and 1 follow-up assessment after	7.2	Range N/A; mean = 5.4	I: 46 (65%) II: 16 (23%) III: 6 (9%) IV: 3 (4%)	Socialization development/adaptation	Developmental Profile (DP II) parent report	There was no difference in socialization developmental quotient (DQ) between before and after

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**Table 2** (continued)

Reference	Sample	Design	Age at surgery (years): mean (range)	Postsurgery follow-up range (years)	Seizure outcome: Seizure-free (SF) or Engel Class I–IV	Domain(s) measured	Measures	Outcome
		surgery						hemispherectomy for all three etiology groups. At follow-up, socialization DQ was significantly lower for children with dysplasia, compared with Rasmussen's encephalitis and vascular etiology. There was no significant difference in social QoL between pre- and postoperative scores; seizure-free patients showed significant improvements in social interactions and activities.
Sabaz et al., 2006 [30]	Surgical patients (N = 35)	Longitudinal: before surgery and 1 follow-up assessment after surgery	11.9	1–1.5	SF: 20 (57%)	Social domain QoL	QoLCE parent report	No difference between surgical and nonsurgical patients: no change after surgery in both groups. Seizure status did not predict psychosocial scores or change. Improvement in social subscale was largest in those with more social problems before surgery. Seizure outcome and temporal vs. extratemporal localization were not significantly associated with change of psychosocial outcome variables. Self-concept improved more in older children compared with young children.
Smith et al., 2004 [31]	Surgical patients (N = 30); nonsurgical CwE (N = 21)	Longitudinal: before surgery (or baseline) 1 follow-up assessment after surgery/baseline	13.3 (6–18)	1	I: 17 (57%) II: 5 (17%) III: 2 (7%) IV: 6 (20%)	Psychosocial functioning	CBCL parent report; Piers–Harris (PH) Children's Self-Concept Scale self-report	Improvement in social subscale was largest in those with more social problems before surgery. Seizure outcome and temporal vs. extratemporal localization were not significantly associated with change of psychosocial outcome variables. Self-concept improved more in older children compared with young children.
Thomas et al., 2010 [32]	Surgical patients (N = 16)	Longitudinal: before surgery and up to 3 annual follow-up assessments after surgery	6.6 (0.7–13.3)	1–3	I: 15 (94%) II: 1 (6%)	Social competence; social age	VSMS parent report; Gesell's Developmental Schedule/Binet–Kamat Scale of Intelligence child assessed by psychologist	Vineland Social Maturity Scale score and personal social skills significantly improved 3 years after surgery. Later seizure onset and shorter duration of seizures prior to surgery were related to more social age gain at follow-up.
Titus et al., 2013 [33]	Surgical patients (N = 28)	Longitudinal: before surgery, and 1 follow-up assessment after surgery	12.7 (8–16)	0.5–1.2	I: 15 (54%) II: 6 (21%) III: 4 (14%) IV: 3 (11%)	Social domain QoL	QoLCE parent report	Significant increase of social activities subscale – however, due to an increase in engagement in social activities rather than social interaction. Improvement of seizure status was related to improvement in socialization.
van Empelen et al., 2005 [34]	Surgical patients (N = 21)	Longitudinal: before surgery, and at least 2 follow-up assessments after surgery	11.2 (6.2–16.8)	0.5–2	I: 15 (71%) II: 4 (19%) III: 2 (10%)	Health-related QoL and self-perceived competence	HAY (How Are You) questionnaire, child and parent version; Harter Self-Perception Profile for Children/Adolescents	Improvement of social activity after surgery reported by children and parents. Increase in self-perceived social competence and self-worth after surgery.

Abbreviations: N = number; CBCL = Child Behavioral Checklist; QoL: Quality of life; QoLCE = Quality of life in childhood epilepsy questionnaire; CwE = children with epilepsy; AED = antiepileptic drug; VIQ = verbal intelligence quotient; PIQ = performance intelligence quotient; VSMS = Vineland Social Maturity Scale; sd = standard deviation.

<sup>a</sup> Studies have partially overlapping samples.

<sup>b</sup> Sample partially overlaps with [11,13].

### 3.1. Social cognition

Four papers reported on social cognition (before and) after epilepsy surgery in children (Table 1). Two papers had overlapping samples [11,13].

#### 3.1.1. Comparing pre- with postsurgical data

Of the two papers in which pre- with postsurgical data were compared, one reported no change in social cognition [13], and the other described a gradual improvement in social cognition in children older than 12 years. The improvement was, however, not different from the increase seen in healthy peers [11].

#### 3.1.2. Comparing surgical patients with control groups

One study included nonsurgical CwE and found no difference between the surgically treated children and nonsurgical CwE in facial emotion recognition [14]. All four papers compared patients with healthy peers and reported poorer social cognition in patients than in controls [11,13–15].

#### 3.1.3. Relation with seizure freedom

In neither of the two papers (with partially overlapping samples) that included seizure freedom in the analyses, a relation between seizure freedom and social cognition was found [11,13].

#### 3.1.4. Other variables related to social cognition

All four papers described the outcome of analyzing relations between social cognition and demographic and/or illness variables (other than seizure status). One paper reported no relation with epilepsy variables but a temporary decline in children aged  $\leq 12$  years that was not present in older children [11]. Later epilepsy onset was found to be associated with better social cognition in three papers [13–15]. Two papers reported children with a temporal origin of epilepsy to have better social cognition than children with extratemporal [13] or frontocentral [14] epilepsy. One paper reported children in whom the amygdala was resected to have worse ToM than children in whom the amygdala was not included in the resection [13].

### 3.2. General social functioning

Twenty papers reported on general social functioning after epilepsy surgery in children (Table 2). Two had partially overlapping samples [26,27]. Among these 20 papers, 13 provided data that enabled us to compare with norm data; the overall outcome was that general social functioning was impaired in children who have had epilepsy surgery [16–22,24,25,29,31,32,34].

#### 3.2.1. Comparing pre- with postsurgical data

In 15 papers, pre- and postsurgical data were compared. Eight papers reported positive changes in social functioning after surgery [12,16,17,21,22,32–34]. Based on observations or child reports, these positive changes included reduced social anxiety [16] and social inadequacy [17], increased social competence and social activities [34], and improved social skills [32] and social interaction [21]. Parents reported decreased emotional and behavioral difficulties [22], increased social activity [12,33,34], and increased social maturity [32]. The remaining papers reported no change after surgery with respect to psychosocial functioning [18], social competence [19], socialization [29], social problems [20,25,31], and social quality of life (QoL) [30].

#### 3.2.2. Comparing surgical patients with control groups

Seven papers reported on the comparison of general social functioning between surgical patients and nonsurgical CwE. In four papers, no difference between the two groups emerged: three papers (two had overlapping samples) reported no difference in social QoL between postsurgical children and nonsurgical CwE [26–28], and one found no

difference in change of social problems between the two groups [31]. One study found more social problems in the nonsurgical group compared with the surgical group, when pre- and postoperative data were pooled [25]. In two studies, changes over time in social competence and social behavior differed between the groups, in favor of the surgically treated group [19,20].

Two studies included a control group of healthy peers. Before epilepsy surgery, CwE rated themselves as both overall and socially more inadequate (feeling tense, anxious, sad, and concerned), perseverant, and recalcitrant than did their healthy peers [17]. The other paper reported no difference in social QoL between healthy peers and patients four years after surgery [27].

#### 3.2.3. Relation with seizure freedom

Eleven studies evaluated the relation between general social functioning and whether or not achieving seizure freedom after surgery. Two studies qualitatively described a positive relation. In one study, authors stated that none of the seven seizure-free children's psychosocial functioning had changed negatively (compared with a negative change being observed in 6 of the 17 children with recurrent seizures) [18]. In the other study, many of the seizure-free participants reported greater independence, increased confidence, and improvement in their social experiences than before [23].

Four studies reported a statistically significant relation between seizure freedom and more increase in social QoL [12], better social QoL [28], and improvement of social functioning after surgery [20,30] compared with those who had not achieved seizure freedom. In one study, improvement of seizure status was related to improvement of socialization [33].

In four studies, no relationship was found between seizure freedom and social domains of personality [17], social problems [25], social QoL [27], or changes in social behavior and self-concept [31].

#### 3.2.4. Other variables related to general social functioning

Ten studies analyzed relations between social functioning and demographic and/or illness variables other than seizure status. Earlier age at onset was related to poorer social functioning in two studies [25,32], as was longer duration of epilepsy [32]. One qualitative study reported better postoperative social interaction in children operated upon during infancy ( $< 1$  year) compared with toddlers (between 1 and 3 years of age), but only in children who were seizure- and AED-free [21]. Three studies found a negative effect of higher numbers of AEDs used [20,25,28] and one of levetiracetam use specifically [17]. Of the four studies that analyzed the relation between surgical area and social functioning, two found an effect. In one study, children with left frontal (but not those with right-sided frontal or left or right temporal) epilepsy had higher level of presurgical social anxiety, which reduced significantly after surgery [16]. In the other study, social inadequacy was less in children with temporal compared with extratemporal epilepsy and surgery [17]. In the remaining two papers, the analyses yielded no significant relations with area (temporal vs. extratemporal) [31] or with removal of the amygdala or not [24]. In the study on children before and after hemispherotomy, socialization developmental quotient was significantly lower in children with cortical dysplasia, compared with children with Rasmussen's encephalitis and with vascular etiologies [29]. One study found lower verbal intelligence quotient (VIQ) and performance intelligence quotient (PIQ) to be related to poorer social functioning [25]. Self-concept improved more in older children than in young children [31], and when comparing boys with girls, boys rated themselves as more recalcitrant [17].

#### 3.2.5. Relation with length of follow-up

Length of follow-up differed between the papers from four months up to 11 years. Most studies ( $n = 15$ ) had follow-up intervals of between 1 and 3 years after surgery. Five studies had follow-up intervals of more than three years [22,25,27–29]. Two of these, with follow-up

ranges between 0.5 and 4.1 years [24] and between 4 and 11 years [28], analyzed the relation between follow-up interval and change in social functioning. Neither found a relation between length of follow-up and change in social functioning. Scrutinizing the other 18 papers, we found no indication that the results varied with length of follow-up. Five papers suggested in their discussion sections that longer follow-up could possibly have revealed more positive change [16,17,19,20,23], and two papers stated that one year [32] or even only 6 months [34] should be enough to disclose positive change.

#### 4. Discussion

In this literature review of social functioning in children (before and after epilepsy surgery, focus was on two different paradigms: social cognition, as a cognitive function, and general social functioning, as an aspect of daily functioning. The literature was scarce, and no study evaluated social cognition and general social functioning simultaneously.

No evident improvements of social cognition were reported after surgery whereas some postsurgical improvement in general social functioning was reported in approximately half the studies.

Comparing surgical patients with nonsurgical CwE, the majority of studies found no difference in either social cognition or general social functioning. Only one study reported more social problems in the nonsurgical group than in the surgical group. In two studies, the change over time differed between groups in favor of the surgical group, because of an increase of problems in social competence and social behavior in nonsurgical CwE and a decrease of problems in the surgical group. In all but one study, surgical patients had poorer scores on social functioning than their healthy peers. Seizure freedom and lower numbers of AEDs used were, in some studies, related to better general social functioning, but not to social cognition. Later onset and temporal origin of epilepsy were associated with better social cognition and general social functioning in a few studies.

##### 4.1. Social cognition

The only two papers on longitudinal studies of social cognition (with overlapping samples of participants) both described no relevant change after epilepsy surgery [11,13]. The first paper reported on ToM and the other on recognizing facial emotions. In this second paper, however, an influence of age was suggested: the older children (13–17 years) gradually improved after surgery, similar to controls. The younger children ( $\leq 12$  years) displayed a temporary dip in facial emotion recognition six months after surgery [11].

As stressed previously, the causes of affected social cognition in children with drug-resistant epilepsy are complex, multifactorial, and interdependent [35,36].

##### 4.1.1. Disrupted cognitive development during critical periods of maturation

If the development of a cognitive function is hampered by abnormal neural activity during a critical period of brain maturation, it is unlikely that this cognitive function will ever develop fully later in life. An association has been demonstrated between an earlier onset of epilepsy and more severe social cognitive impairments [37]. Three studies on social cognition confirmed that relation [13–15]. In the remaining study, the influence of epilepsy onset was not analyzed, but a relation was found between social cognition and epilepsy duration before surgery [11]. Abnormal brain activity during critical periods of development can disrupt the neural circuits responsible for cognitive functions implicated in social development [38]. Outside these periods, further development of this function is limited, if not impossible [39], also, when epilepsy surgery is successful, and seizure activity has stopped.

##### 4.1.2. Persistent impairments in related cognitive domains

The lack of improvement in social cognition may be caused by persistent impairments in cognitive domains that are related to ToM

abilities [40–42]. Children with epilepsy, particularly drug-resistant epilepsy, are not only impaired in social cognition but also in a wide range of other cognitive functions such as attention, memory, intelligence, language, and communication [43,44]. These cognitive functions have been found to improve at most slightly after epilepsy surgery [45,46]. None of the four studies on social cognition in this review, however, correlated social cognition to other cognitive functions. Only broad measures such as intelligence quotient (IQ) or VIQ, if any, were included to control for general cognitive functioning. The issue whether poor social cognition is part of an overall impairment of cognitive functioning, or rather a specific vulnerability in children before and after epilepsy surgery, remains to be evaluated.

##### 4.1.3. Complex relationship between seizures and cognition

The main goal of epilepsy surgery is to stop seizures. The formerly widely held assumption that cognition – social or otherwise – will improve as a result of the elimination of seizures implied the notion of a causal relation between seizures and cognition. Recent years have witnessed a shift in perspective, away from this ‘epilepsy-centric’ view [35]. Rather than seizures causing cognitive impairments, both seizures and cognitive impairments may cooccur as dual symptoms of an underlying condition. This view is supported by studies that fail to pinpoint a relation between seizure frequency and the severity of impairments in cognitive functions such as ToM [39,47]. Additionally, cognitive and behavioral problems have been observed in children with new-onset epilepsy, before multiple seizures have had the opportunity to cause harm [43,44]. Therefore, cessation of the seizures is unlikely to improve cognition, social or otherwise. An exception may be children with so-called epileptic encephalopathy, in which the seizures contribute to aggravation of cognitive disturbances, more than can be expected on the basis of the underlying epileptogenic disorder alone [48]. There are no studies on social cognition available to confirm this; children with epileptic encephalopathy are mostly very young which complicates performing standard social cognition assessments.

##### 4.2. General social functioning

Although positive changes in general social functioning were reported in about half of the longitudinal studies, clinically meaningful improvements were rare and sometimes unclear. For example, the postsurgical increase in social activities found in one study was based on the ability to engage in activities, rather than by an increase in social interaction with peers [33]. In addition, self-perceived increase of social functioning after surgery was supported by the responses of only a few children whereas the majority reported continued isolation and peer rejection after surgery [23]. In a study on personality, only one of the more negative personality traits that distinguished CwE from healthy peers, i.e., social inadequacy, improved significantly after epilepsy surgery [17].

Explanations for the lack of improvement in general social functioning after pediatric epilepsy surgery may involve factors related to the practical and psychological difficulties that may follow surgery, rather than to the medical consequences of epilepsy and the surgery. Epilepsy, particularly drug-resistant epilepsy, is a severely debilitating disorder and demands many patients and their families to live restricted lives. Seizure freedom, therefore, marks a huge change in the daily life of the child who once had epilepsy and calls for often drastic readjustments that may require counseling to be implemented [49]. This is in line with what was described in some of the included studies on general social functioning. Even when epilepsy surgery is successful, behaviors that have become entrenched in the habits of the child and her/his environment over the course of development may be difficult to overcome once the child is seizure-free [20]. The current available literature does not prove that longer follow-up periods would entail more positive change in social functioning compared with shorter follow-up. Many CwE grow up with feelings of being different or

misunderstood, and such feelings may not disappear spontaneously after surgery [23]. Also, growing up under continuous supervision hampers children to develop self-dependence. Furthermore, deprivation from social situations due to seizures, fatigue, hospital visits, etcetera, may lead to decreased social learning opportunities, which could lead to underdeveloped social cognition and underdeveloped social skills. In addition, the child's social environment may not change in response to her/his changed health condition after epilepsy surgery [20]. In one of the included studies, it was noted that although the children's perceptions of themselves and their own social ability changed after surgery, the negative attitudes of their peers towards them did not necessarily change, the remaining stigma hampering their integration. Seizure-free children evaluated persistent stigma as the greatest barrier to improve social functioning. One child who had become seizure-free after surgery and had changed school reported no problems making friends, suggesting that a change in environment may be a protective factor in the child's reintegration and adjustment after surgery [23].

The 'burden of normality' has previously been introduced to explain the difficulty of adjusting to the expectations that come with newly found health. Growing up as a chronically ill child, needing and receiving extra care and protection may make the child feel insecure and dependent. Abandoning this illness role, accepting more responsibilities, and abandoning dependence may therefore be challenging for the child [49]. This 'burden of normality' may also apply to parents who had adjusted to having a sick child. They had provided continuous surveillance and concern, left their jobs, put their social lives on hold, and even disregarded their own health. All of these factors change once the child is no longer in constant danger of having seizures [50]. Fear of fits, persistent over-protection, and continuously treating the child as though she/he was ill can strongly hinder the child's social readjustment after surgery [7,49].

#### 4.3. Limitations

The heterogeneity of variables such as age, intelligence, etiology, and side and site of the surgery, but also the scarcity of studies on social cognition, as well as the wide variety of instruments used in the assessment of general social functioning are major limitations for drawing general conclusions. While admitting that reproduction of a literature review on a larger sample of prospective studies, including critical evaluations on the quality of the studies, is desirable in the future, we believe this paper to provide a complete overview of the current available literature on social functioning of children after epilepsy surgery.

With only four papers of which only two had a longitudinal design, the dearth of research on the effects of surgery on social cognition is surprising and contrasts to the large amounts of research on other functional domains, such as intelligence, language, and memory [46,51]. Neuropsychologists have rather recently added social cognition to their primary focus [52]. Moreover, since social skills are practiced in social contexts, they are more difficult to operationalize in an ecologically valid manner for use in the conventional test setting.

With a sample of 20 papers, general social functioning, evaluated through questionnaires, interviews, and observational screening, was more frequently the topic of studies in children before and after epilepsy surgery than social cognition. However, the instruments used varied widely between the studies, and the methods were rather indirect, relying largely on informants. In one study, parents of CwE reported social problems, but their teachers did not. The teachers, however, reported more severe signs of anxiety and depression [23]. These conflicting reports from parents and teachers render interpreting the results difficult. Perhaps, the children behave differently at school and at home. A disadvantage of the current self-report questionnaires could be that reflecting on one's social functioning relies on the insight that children have into their own behavior, which may be specifically unreliable in children with deficits in ToM.

#### 4.4. Suggestions for further research

Longitudinal long-term studies using standardized neuropsychological assessments including social cognition, in combination with repeated evaluations of general social functioning, should be performed in sufficiently large groups of children, in order to obtain a better understanding of the child and adolescent with drug-resistant epilepsy and the factors that might improve her/his social functioning.

#### 5. Conclusion

Epilepsy surgery does not seem to solve the problems in social functioning associated with having drug-resistant epilepsy. Social cognition and general social functioning should be recognized as important aspects of development and should be addressed longitudinally during the treatment of CwE and their recovery after surgery.

#### Declarations of interest

None.

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