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Pediatric epilepsy surgery patients show normal psychosocial development at long-term follow-up despite dissatisfying family dynamics

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ABSTRACT

Drug-resistant pediatric epilepsy involves unpredictable seizures and long-term medical management. Both factors can alter a child's psychosocial development and the dynamics of the family, to the detriment of patient and family wellbeing. While drug-resistant pediatric epilepsy can be successfully treated by neurosurgery in some cases, the outlook for psychosocial and family functioning after surgery remains unclear. A total of 163 participants across four groups took part in the current study: these were (i) individuals who had undergone surgical treatment of drug-resistant focal seizures approximately five years prior as children, and were now largely adolescents or young adults ('Patients'; n = 23), (ii) their caregivers ('Patient Caregivers'; n = 27), (iii) healthy individuals of similar age and gender to the Patients ('Controls'; n = 53), and (iv) their caregivers ('Control Caregivers'; n = 60). Based on similar software validated in adults, we built an interactive computer program, 'Living with Epilepsy', to evaluate the achievement of age-specific developmental tasks in Patients relative to their peers. The Family Adaptability and Cohesion Scale measured family dynamics. The findings showed that in the context of seizure freedom, after pediatric epilepsy surgery, Patients are similar to their healthy peers in terms of attaining developmental tasks, with no differences between the Patient and Control groups ($P > .05$). Family dynamics, however, seemed resistant to postsurgical adaptation, with Patients reporting lower levels of balanced family dynamics (cohesion, flexibility) and higher rates of unbalanced family dynamics (disengagement, chaos, rigidity, enmeshment) relative to Patient Caregivers ($P < .001$–0.041), and the Controls ($P = .011$–0.034). Patients also reported reduced family satisfaction compared with that of Patient Caregivers ($P = .002$), which was associated with polytherapy prior to surgery; that is, more drug-resistant seizures. These findings suggested that childhood-onset epilepsy has a lasting effect on family functioning, even when the child has an optimal medical and psychosocial outcome. These initial findings have significant implications for the provision of pre- to postoperative family support in pediatric epilepsy cases.

1. Introduction

Pediatric epilepsy disrupts the development of brain networks that subserve cognitive and psychological processing [1,2]. As such, the disease is linked to high rates of neuropsychological and behavioral disorder [3,4], which beget poor academic, vocational, and social outcomes [5]. Poor psychosocial outcomes are also worsened by the school absenteeism, medication side effects, and stigma that accompany epilepsy [6]. For the 8% of children with epilepsy who have drug-resistant seizures [7], persistent psychosocial disadvantage looms large [8].

Neurosurgery renders 50–70% of drug-resistant children seizure-free [9]. Growing evidence suggests that early surgical treatment is optimal for reducing long-term morbidity [10], although psychosocial gains may not become apparent for years and require significant psychological adjustment [10]. For example, a prospective, longitudinal cohort study of childhood-onset temporal lobe epilepsy (TLE) found that a decade after epilepsy onset, patients who progressed to surgery and became seizure-free were still experiencing difficulties associated with defining a new identity outside of epilepsy [8,11,12].

Developmental tasks provide a useful way to measure outcome, as they represent normative indicators of the psychosocial challenges that

Abbreviations: AEDs, Antiepileptic drugs; FACES-IV, Family Adaptability and Cohesion Scale — Fourth Edition; TLE, Temporal Lobe Epilepsy.

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typically emerge at particular phases of development. By adolescence, most individuals have made educational gains, formed vocational aspirations, and established friendships, leading to career direction, financial independence, and close relationships by young adulthood [13]. In our longitudinal study of childhood-onset TLE, we demonstrated the utility of developmental tasks for assessing long-term psychosocial outcomes of epilepsy by revealing three distinct developmental trajectories [14]:

1. 'Normal' (52%) mastered most of their developmental tasks and outperformed the other groups on a range of cognitive tasks;
2. 'Altered' (37%) achieved some;
3. 'Delayed' (11%) achieved few.

Good seizure control and intellectual functioning discriminated the Normal group from the other two, while having surgically remediable epilepsy, and female gender primarily discriminated the Altered from the Delayed group. This study showed that neurosurgery is a protective factor for children with TLE, producing better developmental trajectories relative to medical treatment.

The psychosocial functioning of a child with epilepsy is also shaped by family dynamics, which reflect patterns of interpersonal interactions between family members. These dynamics guide the way young people perceive themselves and the world, influence their subsequent relationships, and affect wellbeing [15]. Psychosocial maturity is fostered by low family conflict, less parental intrusiveness, and reduced psychological dependence on family members [16]. With childhood epilepsy, however, such dynamics may not be achieved. The family must accommodate a chronically sick child requiring daily medication and regular medical reviews, whose seizures can unpredictably disrupt routines as well as cause injury. A child with epilepsy heightens worry in parents and siblings [17], focuses parental attention on the patient at the expense of siblings, and in some cases, limits a caregiver's capacity to work, thereby elevating financial strain and restricting the caregiver's personal and professional growth [18]. Cumulatively, these issues can undermine caregiver quality of life [18,19]. In turn, lowered parental wellbeing erodes patient quality of life and may heighten their feeling of being a burden [20,21].

The archetype of maladaptive family dynamics in pediatric epilepsy is that of an enmeshed child–parent relationship [22], characterized by age-inappropriate behaviors like cosleeping, overprotectiveness, or dispensing medication into adolescence [23]. Clinical reports also suggest that epilepsy may engender excessive rigidity in some families [24], with inflexible rules and roles imposing order in an environment subject to random disruption by seizures. It remains unclear, however, whether family dynamics that originally evolve to support a sick child normalize if seizure freedom is achieved.

This initial study sought to examine the psychosocial development and family dynamics of people who had undergone epilepsy surgery as children, with the unique perspectives of caregivers and healthy controls contrasted to that of the patients. The first aim of this study was to examine the long-term psychosocial outcomes of young people who had undergone pediatric epilepsy surgery. We compared their attainment of various developmental tasks to that of healthy controls to identify whether their psychosocial development approximated that of healthy peers. Our second aim was to examine characteristics of family functioning following childhood epilepsy surgery, comparing the patient's perception of family dynamics to that of their caregivers, as well as to the family functioning of healthy peers and their caregivers. This initial investigation also asked whether postsurgery family dynamics influence the achievement of developmental tasks.

2. Methods

2.1. Participants

Using a quasi-experimental design, four groups were recruited (N = 163): individuals who had undergone surgical treatment for drug-resistant focal seizures as children ('Patients'), their caregivers ('Patient Caregivers'), and independent samples of healthy individuals of similar age and sex to the Patients ('Controls') together with their caregivers ('Control Caregivers'; see Table 1). Inclusion criteria were an intellectual capability sufficient to complete the computer program based on neuropsychological impression or parental report, and functional English. In addition, participants in the Control and Control Caregiver groups had no history of serious disease in their immediate family.

The Patient group comprised 23 individuals (57% female) who underwent surgical treatment for epilepsy as children in the Comprehensive Epilepsy Programs of Austin Health or The Royal Children's Hospital in Melbourne, Australia. They formed part of a larger study on psychosocial outcomes after childhood epilepsy surgery [8]. Inclusion criteria for the Patients were as follows: (i) aged 6–18 years at the time of epilepsy surgery; (ii) focal cortical resection; and (iii) epilepsy surgery at least 12 months prior to recruitment to allow for neurological stabilization. A minimum age at surgery of six years was chosen to minimize cases with very large resections typically characterizing young children [25], and optimize the validity and reliability of their responses [26]. Cases who had undergone palliative procedures (corpus callosotomy, vagal nerve stimulators), hemispherectomy, multiple subpial transection, or removal of a hypothalamic hamartoma were excluded as these procedures differ from selective cortical resections in terms of their surgical approach and associated neurological issues. Patients who had undergone previous epilepsy surgery were also excluded, although cases who had previous neurosurgery unrelated to their epilepsy were included to increase the representativeness of the sample. In accordance with international practice [27], both centers use standard clinical, electroencephalogram, and imaging techniques for seizure characterization, and standard surgical approaches to the resection of epileptogenic foci. On average, Patients were aged 7.30 years (SD = 4.36) at the time of seizure onset and 13.09 years (SD = 2.81) at the time of surgery. Their age at follow-up spanned 11–25 years (M = 18.00 ± 4.45), and they were 1.16–10.95 years postsurgery (M = 5.43 ± 2.83). Twenty-one of the Patients were deemed seizure-free following the procedure (91%), defined as without seizures (excluding auras) and taking no antiepileptic drugs (AEDs) for a minimum of two years at follow-up. Clinical information relating to the surgical group is summarized in Table A of Supporting Information.

To incorporate a caregiver's perspective of family dynamics following surgery, a group of 27 caregivers were recruited from participating families. The Patient Caregivers were aged between 34 and 60 years (M = 46.89 ± 6.22; 89% female) and comprised parents (Mothers n = 24; Fathers n = 3). The two healthy control groups were recruited from the broader community in Victoria via snowball sampling of persons known to the research team, who broadly matched age and sex characteristics of Patient and Control Caregiver dyads/triads. The Controls comprised 53 healthy individuals aged 11–26 years (M = 18.34 ± 3.75; 64% female). They did not differ in age or sex to the Patients, providing a broadly matched sample ($P > .05$). Sixty Control Caregivers were 26–66 years (M = 50.37 ± 5.94; 62% female) and comprised parents and one grandmother who was the child's primary caregiver (Mothers n = 35; Fathers n = 24; Grandmothers n = 1). Control Caregivers did not differ in age, sex, or role to the Patient Caregivers ($P > .05$).

The study was approved by the relevant Human Research Ethics Committees, and all patients or their guardians (where participants were <18 years of age) gave written, informed consent. Caregivers and children were assessed independently to minimize response bias.

2.2. Materials

2.2.1. The pediatric 'Living with Epilepsy' program

In our work with the adult epilepsy population, we purpose-built and validated an interactive computer program, 'Living with

Table 1
Demographic profiles of Patient, Control, and Caregiver groups (N = 163).

	Patients n = 23	Controls n = 53	Patient Caregivers n = 27	Control Caregivers n = 60
Gender, Female	13 (57%)	34 (64%)	24 (89%)	37 (62%)
Age (years), M ± SD	18.00 ± 4.45	18.34 ± 3.75	46.89 ± 6.22	50.37 ± 5.94
Range	11–25	11–26	34–60	26–66
Current developmental period				
Middle childhood (9–12 yrs)	2 (9%)	2 (4%)		
Adolescent (13–18 yrs)	10 (43%)	19 (36%)		
Young adult (19–30 yrs)	11 (48%)	32 (60%)		

Epilepsy', for use with patients with epilepsy and their caregivers to assess the impact of epilepsy on their psychological functioning, family dynamics, and expectations for life after surgery [28]. The pediatric version incorporates the achievement of developmental tasks.

The program first asks participants for demographic information, with the Patient version also collecting information about seizures (see Fig. 1, Panel A). It then asks Patients and Controls to rate their attainment of age-expected developmental tasks (see Fig. 1, Panels B & C). These spanned a range of psychosocial domains (see Table 2) and were specific to either adolescence or young adulthood (preadolescent participants do not complete this section). Developmental tasks and their age for mastery were identified from a detailed review of large-scale normative studies from the developmental psychology literature [13,29]. Participants were required to rate their attainment of each task using a 5-point Likert scale (0 = *not at all*… 4 = *fully*). To maximize statistical power, a revised 3-point scale comprised 'not achieved' (0–1), 'somewhat achieved' (2), and 'achieved' (3–4). Overall percentage of tasks achieved for an individual ('Percentage Achieved') was derived from the number of tasks scored as 'achieved' on the 3-point scale, in relation to the number of tasks expected of that individual (ten for adolescents; 19 for young adults).

2.2.2. Family dynamics

Family dynamics have been characterized in terms of their *cohesion* (emotional bonding) and *flexibility* (in roles and relationships), with a balance across these two domains considered ideal [15]. The Family Adaptability and Cohesion Scale Fourth Edition — (FACES-IV) [15] is a self-report assessment of family functioning consisting of 84 items across six scales; two that measure 'balanced' dynamics (cohesion, flexibility), and four 'unbalanced' scales (disengagement, enmeshment, rigidity, chaos). Participants respond to questions for each of the domains on a 5-point Likert scale (1 = *does not describe my family at all*…5 = *very well describes our family*), with scores converted into percentiles. Percentiles ≤ 26 are considered 'Very Low', 30–40 'Low', 45–60 'Moderate', 64–75 'High', and ≥ 80 'Very High'. Additional scales assess satisfaction with family functioning and communication between family (1 = *very dissatisfied*… 5 = *extremely satisfied*). The FACES-IV is a widely-used research tool with high levels of concurrent, construct, and discriminant validity [15].

2.3. Statistical analyses

Analyses were run using IBM SPSS Statistics 22.0 with a statistical significance criterion set at P ≤ .05 (two-tailed). Where parametric

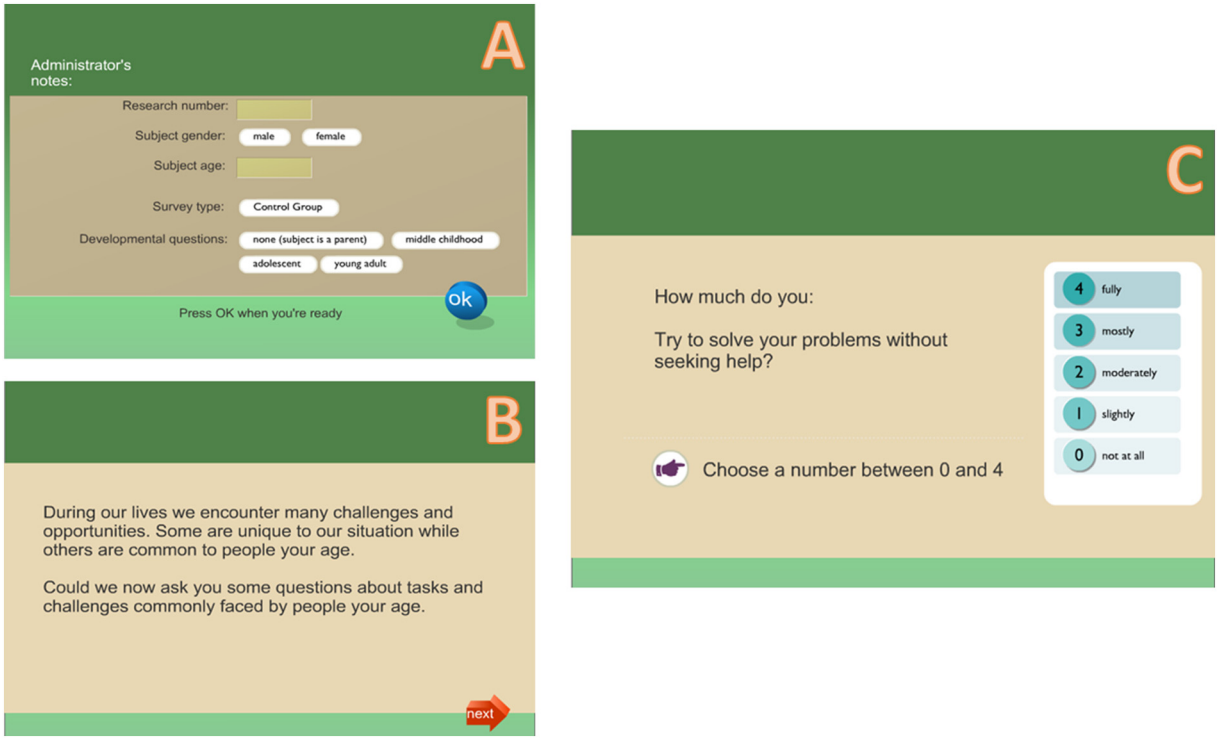

Fig. 1. Example screens captured directly from the pediatric version of 'Living with Epilepsy'. ***Panel A*** shows the collection of basic demographic information; ***Panel B*** shows the instructions given to young people regarding their attainment of developmental tasks; ***Panel C*** shows an example of how participants are asked to rate their attainment of a specific developmental task.

Table 2
Developmental tasks examined in Patient and Control groups.

Developmental period	Maturational domain	Developmental task
Adolescence (13–18 years)	• Physical needs • Emotional development • Peer group membership • Autonomy • Life goals	• Providing support and friendship to others • Having close and confiding friendships • Having close and supportive relationships • Trying to solve problems without seeking help • Accepting the way you are • Having realistic goals for life • Living the life you want • Needing approval of parents[a] • Finding yourself unable to live up to responsibilities[a] • Awareness of body needs
Young adult (19–30 years)	*All of the tasks for adolescence above, as well as*:	
	• Internalized morality • Romantic relationships • Work/career choices	• Working on establishing a career • Enjoy stable relationships • Committed to a long-term romantic relationship • Actions motivated by your own values and beliefs • Able to recognize when you need help • Able to draw upon resources you need • Confident in ability to cope with whatever happens • Confident in ability to achieve what you set out to do • Achieving life goals?

[a] Negatively worded items, where stronger endorsement reflects a failure to achieve a more mature level of development.

assumptions were not upheld, nonparametric alternatives were employed. Given that FACES-IV data were missing for nine Patients, we also ran Little's missing completely at random test, which showed a strong trend for nonsignificance [χ^2 (1) = 4.02, p = .05, ψ = 0.03, i.e., very small effect size], indicating that missing data likely did not have a systematic impact on our results. In confirmation of this interpretation, further inspection of the data indicated that patients with missing FACES values did not significantly differ from patients without missing data on any clinical or psychosocial variables (P > .05 for all comparisons; nonparametric statistics used given small samples sizes).

Differences in psychosocial status between patients and controls at the time of follow-up (employment, relationship status, level of education, independence in living) were assessed using Chi-squared tests with a continuity correction for 2 × 2 tables and effect size estimated using Phi (ϕ). To assess the attainment of developmental tasks captured by our purpose-built computer program, the frequency with which each developmental task was rated as 'achieved' by Patients and Controls for each psychosocial domain was first inspected. Chi-squared tests of independence then statistically compared the rate of task achievement between the groups. Should results indicate statistical differences, Cramer's V will be used as a metric of effect size as it accounts for degrees of freedom, with inspection of standardized residuals as a means of posthoc analysis. In order to highlight any trends in the relative frequency of achievement for different psychosocial tasks across different age groups, frequency metrics such as percentages were calculated separately for Adolescent patients and Young Adult patients (as stated previously, preadolescent participants in the Middle Childhood period of development did not complete this component of the computer program).

To assess family dynamics after surgery, we performed an analysis of variance (ANOVA) on the eight FACES-IV scales using planned contrasts to compare (i) Patients and Patient Caregivers, (ii) Patients and Controls, and (iii) Controls and Control Caregivers. Partial eta squared (η_p^2) was the measure of effect size. Finally, to identify factors associated with Patient-reported family (dis)satisfaction (taken here as a subjective measure of overall family dynamic), Pearson product–moment correlations were calculated between the FACES-IV score and relevant demographic, seizure, and developmental task variables. Univariate ANOVAs or independent samples *t*-tests were used to assess the strength of relationships between relevant FACES-IV family dis(satisfaction) scores and dichotomous variables. Variables that were significantly associated were then entered into hierarchical multiple regression equations to examine their relative importance in predicting family dissatisfaction scores in the Patient group.

3. Results

3.1. Pediatric surgery patients go on to attain normal psychosocial milestones

Adolescents or young adults who had epilepsy surgery as children and are now largely seizure-free are comparable to their peers across common demographic markers of psychosocial functioning. In particular, most Patients and Controls were single (87% and 93% respectively), and continued to live with their parents (87% and 75%). In terms of scholastic and vocational attainment, there were no significant differences for educational achievement and employment status (P > .05 for all comparisons; see Supporting Information Table B).

Moreover, inspection of frequency plots for the developmental tasks (Fig. 2) indicates that adolescent Patients (n = 10) 'largely achieved' tasks such as forming supportive relationships (90%), being aware of their own needs (80%), accepting themselves (80%), supporting others (80%), having close friendships (70%), and living life the way they want (70%; see Fig. 2). Statistical analyses did not show any significant differences between adolescent Patients and adolescent Controls in their task attainment for any domains of psychosocial functioning (P > .05). Similarly, overall adolescent Patients achieved around 68% of their developmental tasks (SD = 26.16) as compared with around 80% of the adolescent Controls (SD = 10.79; $t_{(10.64)} = -1.451$, P > .05).

In young adults (n = 11), the tasks most commonly achieved by Patients included having close friendships (91%), forming goals (82%), living life the way they want (82%), being aware of their own needs (82%), supporting others (82%), accepting themselves (73%), forming supportive relationships (73%), establishing a career (73%), acting according to their beliefs (73%), feeling confident in their coping skills (73%), and confident in achieving their goals (73%; given the large size of this figure, see Supporting Information Fig. A). There were no significant differences between Patients and Controls in the rate of task attainment for any domains of psychosocial functioning (P > .05). Similarly, overall adult Patients achieved around 62% of their developmental tasks (SD = 24.736) as compared with around 65% of the adult Controls (SD = 16.561; $t_{(41)} = -0.590$, P > .05). Although cross-sectional in nature, these data suggest that Patients self-report attaining normal developmental milestones after having successful epilepsy surgery as children.

3.2. Altered family dynamics after childhood epilepsy surgery

A summary of Patient family functioning relative to the perceptions of their Caregivers and Controls is depicted in Fig. 3.

3.2.1. Childhood epilepsy surgery patients describe unbalanced family dynamics

Patients who had undergone childhood epilepsy surgery reported less balanced family dynamics on the FACES-IV relative to Controls and Patient Caregivers (see Table 3). In particular, planned comparisons revealed that relative to Controls, Patients reported lower family cohesion ($F(1,144) = 4.59$, P = .034, $\eta_p^2 = 0.031$, small effect) and lower family flexibility ($F(1,144) = 5.80$, P = .017, $\eta_p^2 = 0.039$, small effect). Patients also reported poorer family cohesion than their Patient

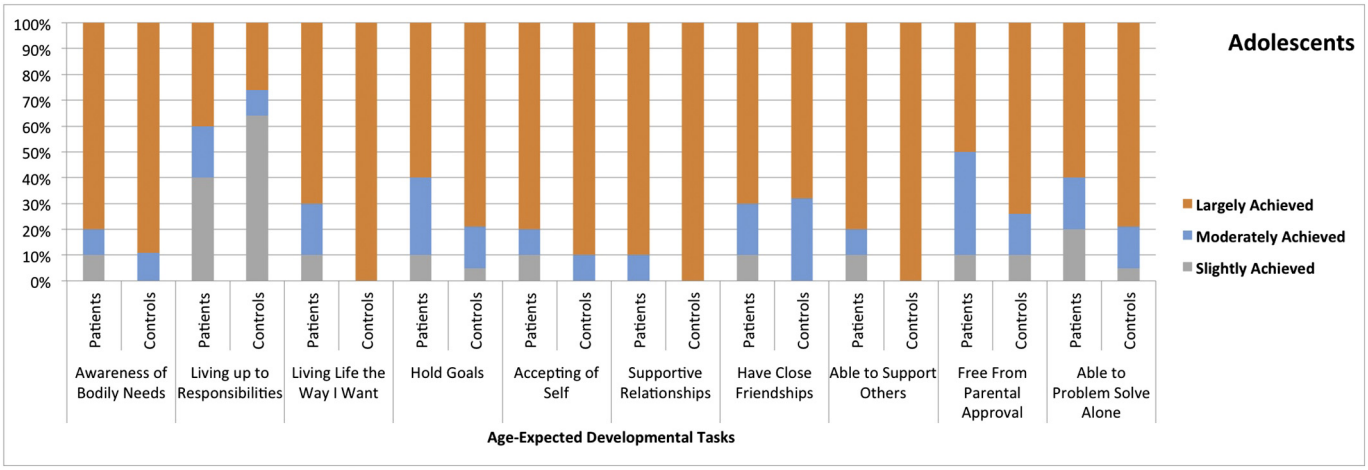

Fig. 2. People who had epilepsy surgery as children attain a similar number of psychosocial milestones to their healthy peers by adolescence. Patients who were now in adolescence (n = **10**) attained a similar number of psychosocial milestones relative to Controls of the same age and gender (n = 19). *Orange refers to the % who largely achieved the task; blue refers to the % who moderately achieved the task; gray refers to the % who had not achieved the task.*

Caregivers ($F(1,144) = 13.21$, $P < .001$, $\eta_p^2 = 0.084$, medium effect), however no significant difference existed between the patient and caregiver flexibility. Interestingly, there was a significant difference in cohesion reported by Controls relative to Control Caregivers ($F(1,144) = 4.26$, $P = .041$, $\eta_p^2 = 0.029$, small effect), suggesting that adolescents and young adults generally feel their family is less cohesive than their caregivers, but that this feeling is heightened in patients.

3.2.2. Elevated family dysfunction felt by childhood epilepsy surgery patients

In addition to the lower flexibility felt by Patients relative to their peers, planned contrasts revealed a significant difference between Patients and Controls regarding perceived levels of disengagement and chaos (see Table 3). On average, Patients reported *High-Very High* levels of disengagement ($F(1,144) = 6.57$, $P = .011$, $\eta_p^2 = 0.044$, small effect)

Fig. 3. Maladaptive family dynamics reported by Patients relative to their caregivers and peers. The ***top panel*** shows group level differences in the groups' self-reported family dynamics, with Patients endorsing lower balanced dynamics and higher unbalanced dynamics compared to peers and caregivers; labels on the right hand side indicate the severity of the dynamics (higher scores are considered healthy regarding the domains of cohesion and flexibility; higher scores are considered maladaptive for the four unbalanced domains). Error bars represent 5% standard error. The ***bottom panel*** summarizes the specific comparisons of Patients versus Controls and Patient Caregivers.

Table 3
FACES-IV family functioning for Control and Patient groups (N = 148).

	Patient (n = 14)[a]	Controls (n = 51)	Patient Caregiver (n = 23)	Control Caregiver (n = 60)
Balanced scales				
Cohesion, M ± SD	33.4 ± 18.3[*,§]	49.6 ± 27.6[^]	64.3 ± 24.2	59.4 ± 24.4
Flexibility, M ± SD	42.7 ± 28.1[*]	61.9 ± 28.7	53.0 ± 28.7	68.0 ± 22.9
Unbalanced scales				
Disengaged, M ± SD	78.1 ± 21.1[*,§]	60.5 ± 22.9	42.2 ± 22.1	55.1 ± 23.2
Enmeshed, M ± SD	76.1 ± 17.1[§]	64.1 ± 21.7	58.1 ± 26.0	65.5 ± 22.9
Rigid, M ± SD	61.0 ± 29.9[§]	51.1 ± 29.2	39.1 ± 29.6	52.4 ± 28.9
Chaotic, M ± SD	69.9 ± 20.1[*,§]	52.4 ± 25.0	40.6 ± 22.1	50.8 ± 24.4
Family satisfaction, M ± SD	29.43 ± 22.90[*,§]	48.92 ± 29.27	64.78 ± 21.56	59.20 ± 27.14
Family communication, M ± SD	36.93 ± 23.74[§]	48.15 ± 29.38[^]	63.39 ± 18.71	64.47 ± 27.13

For the unbalanced indices, percentile scores of ≤26 are considered 'Very Low', 30–40 'Low', 45–60 'Moderate', 64–75 'High', and ≥80 'Very High'.
[a] Nine cases of missing data: six patients did not return the FACES-IV questionnaire to researchers, two patients had a mild intellectual disability that precluded completing the questionnaire, one patient was too young (11 years old).
[*] Patients significantly different from Controls (P ranges .011–.034).
[§] Patients significantly differed from their Patient Caregivers (P ranges <.001–.029).
[^] Controls differed significantly from *their* Control Caregivers (P < .05).

and chaos ($F(1,144) = 5.91$, P = .016, $\eta_p^2 = 0.039$, small effect) as opposed to their peers, who reported *Moderate* levels on both scales. No significant differences in levels of enmeshment (*High-Very High;* P = .081) or rigidity (*Moderate*; P = .265) were observed between the groups.

Patients also reported significantly higher levels of unbalanced family functioning relative to their caregivers, given that they generally endorsed *High-Very High* scores on all four scales, while Patient Caregiver scores fell in the *Low-Moderate* range. In particular, Patients reported significantly higher levels of enmeshment ($F(1,144) = 5.50$, P = .020, $\eta_p^2 = 0.037$, small effect), rigidity ($F(1,144) = 4.88$, P = .029, $\eta_p^2 = 0.033$, small effect) disengagement ($F(1,144) = 1.7$, P < .001, $\eta_p^2 = 0.131$, large effect) and chaos ($F(1,144) = 13.1$, P < .001, $\eta_p^2 = 0.083$, medium effect). In contrast, Controls and Control Caregivers did not differ on any of the four 'unbalanced' scales of family functioning (P > .05; see Table 3). Together, these results suggest that following epilepsy surgery, Patients generally perceive their families to be more unbalanced and dysfunctional than either their caregivers or their peers.

3.2.3. Patients are dissatisfied with their family dynamics

There was a significant difference in the level of family satisfaction perceived by the four groups (Brown-Forsythe's $F(3,103) = 7.53$, P < .001; see Table 3). Planned contrasts showed significantly lower Patient family satisfaction levels in comparison to Controls ($F(1,25.9) = 7.00$, P = .014, $\eta_p^2 = 0.046$, small effect) and compared to their own caregivers ($F(1,26.3) = 21.7$, P < .001, $\eta_p^2 = 0.131$, large effect). In contrast, Controls and Control Caregivers reported similar levels of family satisfaction (P = .059). This may indicate that high levels of unbalanced family dynamics specific to patients might result in overall family dissatisfaction.

There was a significant difference in the perceived effectiveness of family communication between the four groups (Brown-Forsythe's $F(3,97.6) = 7.66$, P < .001; see Table 3). Planned contrasts showed that although Patients report similar levels of family communication to Controls (P = .149), they report significantly lower levels of communication in comparison to their Patient Caregivers ($F(1,22.8) = 12.6$, P = .002, $\eta_p^2 = 0.080$, medium effect). This is analogous to the relationship between Controls and their Control Caregivers ($F(1,105) = 9.22$, P = .003, $\eta_p^2 = 0.068$, medium effect), suggesting that adolescents and young adults generally feel that their family communication is poorer than their caregivers perceive it to be. It also indicates that the difficulties with disengaged and chaotic family dynamics reported by Patients may not specifically relate to poor communication.

3.3. Predictors of dissatisfaction with family dynamics after childhood epilepsy surgery

Exploratory multiple regression assessed predictors of low family satisfaction in Patients. Based on literature outlined in the Introduction, a number of epileptological predictors were evaluated including age at seizure onset, duration of epilepsy, number of AEDs prior to surgery (an indirect marker of disease severity), age at surgery, and years since surgery. In line with our hypotheses, we also considered whether family dissatisfaction was predicted by developmental tasks achieved by patients.

Variables significantly associated with lower family satisfaction included increased number of AEDs presurgery (r = −0.718) and greater number of years elapsing since surgery (r = −0.526). These two variables accounted for 65% of the variance in Patient family satisfaction scores ($F(2,11) = 10.40$, P = .003). Inspecting the unique contribution of these two variables indicated that only a greater number of AEDs presurgery was a significant predictor of reduced family satisfaction (β = −0.63, $t_{(11)} = -3.47$, P = .005), uniquely accounting for 47.6% of the unadjusted variance in family satisfaction scores and indicating that more drug-resistant seizures prior to surgery predicted reduced family satisfaction at follow-up.

4. Discussion

This study followed up individuals around five years after they underwent pediatric epilepsy surgery, mapping their success in attaining normal developmental milestones as well as the dynamics of their family. These outcomes were compared to the experiences of their caregivers, as well as a sample of healthy control children and their caregivers. It revealed that in the context of seizure freedom, pediatric epilepsy surgery patients went on to achieve similar developmental milestones to healthy peers. Family dynamics, however, were more resistant to postsurgical adaptation, with patients reporting lower levels of balanced family dynamics and higher rates of unbalanced dynamics relative to their caregivers and their peers. Patients also felt reduced family satisfaction compared with their caregivers and peers, an experience linked to a marker of more severe disease preoperatively, i.e., taking a higher number of AEDs prior to surgery. While these are preliminary findings that need to be replicated in a larger sample, they indicate that childhood-onset epilepsy has a lasting effect on family functioning even when the child has an optimal medical and psychosocial outcome.

4.1. Children with epilepsy attain normal psychosocial function after surgery

Developmental tasks provide real-world markers of an individual's competence in daily life [29], and in epilepsy are a useful way to gage whether improved seizure control translates into improved psychosocial functioning [14]. Normalized psychosocial functioning is an explicit or implicit goal of nearly all epilepsy treatment plans; if a child of normal intellectual capability were to be rendered seizure-free but

nonetheless failed to mature in an age-appropriate manner, this would be a dissatisfying outcome for many families.

The current study illustrates that after undergoing epilepsy surgery, children who are free of any serious intellectual disability typically go on to attain the normal developmental milestones expected for their age. This includes gains in emotional and physical maturation, establishing friendships, becoming autonomous, creating life goals, and for older individuals, developing an internalized sense of morality, forming romantic relationships, and making vocational decisions. Such findings lead to the question: did these children have abnormal psychosocial development presurgery and then use seizure freedom to "catch up" to their healthy peers, or were they always on track to achieve all their psychosocial milestones regardless of surgery? Our previous longitudinal work in children with TLE suggests that normal achievement of developmental tasks in pediatric epilepsy is linked to having surgically remediable disease, alongside intact cognitive functioning, less frequent seizures, and female gender [14]. Together with our data, these findings suggest that surgery likely has a protective effect on psychosocial outcome.

A normal psychosocial trajectory after pediatric epilepsy surgery may prove to be important information for children and caregivers to consider when weighing up surgical options. Informed consent for surgery requires a clear appreciation of the risks, processes, and consequences of the procedure [30], including its potential benefits. Following replication of our findings, future presurgical counseling might encourage families to weigh the medical and cognitive risks of surgery against the likelihood that psychosocial maturation may normalize after the procedure. Given our previous finding that preexisting cognitive limitations are linked to a poorer psychosocial outcome after pediatric epilepsy surgery [14], in replicating the current findings efforts should also be made to explore whether a cognitive decline *after* surgery also counteracts potential psychosocial gains.

4.2. Patients perceive abnormal family dynamics after successful childhood epilepsy surgery

Against a background of good seizure control and a positive psychosocial outcome, patients who had epilepsy surgery as children nonetheless continue to complain of dissatisfying and unbalanced family dynamics. Specifically, patients perceive their family's interpersonal dynamics to be less flexible, more disengaged, and more chaotic than either their caregivers or healthy peers, and additionally report higher levels of family enmeshment and rigidity relative to their caregivers. Together, these findings would suggest that following pediatric epilepsy surgery, patients experience their family interactions as dysfunctional.

It is important to note that given the intrinsically interdependent nature of family dyads, each dyad's broader family unit may have influenced their scores on our questionnaires and could give rise to statistical dependency between groups. However, the concept of statistical dependency is typically raised in relation to critiques of clinical trial methodology [31]; while we acknowledge it as a potential limitation here, we do not feel that it detracts from the current behavioral study. In particular, given our finding of significant group differences in the way that people with childhood epilepsy surgery perceive their family's functioning relative to the perceptions of their caregivers, there is good evidence of separability in patient and parent responses. Moreover, enforcing such a strict concept of independence would misconstrue the fundamental concept of this study's investigation; namely, to explore the subjective impressions of patients perceptions of family functioning. Nevertheless, future research should endeavor to replicate and extend these initial findings within a more systematic exploration of family dynamics in pediatric epilepsy.

Low family satisfaction from the patients after surgery was linked to taking a higher number of AEDs prior to surgery and – to a lesser extent – more years passing since surgery. This may indicate that young people with more severe disease going into surgery either become increasingly dissatisfied with changed family dynamics that typically emerge after the procedure, or else were dissatisfied before surgery and remain so despite their good medical outcome. Speaking to the former scenario, after epilepsy surgery family roles and routines must change. Typically, the patient's health ceases to be the focus of family life and in the context of seizure freedom, is expected to discard the sick role and 'step up' to a more age-appropriate level of family engagement [8]. In parallel, caregiver attention is typically redistributed more equitably to their own neglected needs, and those of other siblings. Although the lack of a presurgical assessment of family functioning precludes direct observation of how family dynamics change as a consequence of surgery in this initial study, it is reasonable to speculate that our data suggest that young patients with epilepsy may not like these changes. Dissatisfaction captured by the current study may stem from a tendency for children with epilepsy to be more dependent on their caregivers than either healthy children or those with other chronic illnesses like diabetes [32]; that is, they may view the expectation to become more autonomous at home as a sign of familial disengagement, chaos. This would be commensurate with caregiver reports of increasing independence promotion within the family in the year after pediatric epilepsy surgery being accompanied by a decline in the child's satisfaction with family life [33].

Future research should seek to extend these preliminary findings using a long-term longitudinal methodology, measuring family functioning, and its correlates both pre- and postsurgery. For instance, the current sample of patients and their controls are still young at follow-up (on average, around 18 years of age), and living at home with their parents. An interesting aspect to future research will be to investigate whether the dissatisfying family dynamics observed here persist as the cohort of childhood epilepsy surgery patients mature into independent adults with their own families. Future studies may also consider the influence of the age of the child at surgery on later family dynamics and psychosocial maturation (e.g., under the age of 10 versus in adolescence), as well as whether children who experience ongoing seizures after surgery also show abnormal family dynamics at follow-up.

A limitation of the current work is the exclusion of patients with serious intellectual disability and the absence of psychometric data with which to examine the influence of patient cognitive capability on postsurgical family dynamics. Intellectual disability and cognitive impairments are observed to cause additional psychosocial stress in families, above and beyond the stressors of seizures or postsurgical adjustment. In particular, individuals with epilepsy and a comorbid intellectual disability require specific representation in research, to ensure the generalizability of findings across the population with epilepsy [34].

Clinically, these findings suggest that pre- and postoperative counseling might include time spent normalizing or flagging family adjustment processes that can be triggered by seizure freedom after surgery. In addition to psychoeducation, families may benefit from help developing strategies to smooth the transition from an 'epilepsy' family to a 'healthy' family. For instance, a clinician may work with the patient and family to map shared family values, and workshop age-appropriate behaviors, routines, and responsibilities for all family members that are in line with these values [35]. In these cases, the role of clinicians may extend to helping to bridge the perceived communication gap between patients and their caregivers, and to empower them to develop more adaptive patterns of family communication. In this way, curating more adaptive family dynamics after epilepsy surgery may help to translate a successful medical outcome into improved patient quality of life [36].

4.3. Conclusions

Deciding whether a child with drug-resistant seizures should undergo epilepsy surgery is a big decision for families. While the normal attainment of age-appropriate psychosocial milestones is a pleasing outcome to note in this long-term follow-up, these findings are tempered by the emergence or persistence of dissatisfying family dynamics in the years following surgery. In practice, these unbalanced and

disappointing family dynamics perceived by former patients signals that for some families, it may be important for clinicians to provide supportive counseling to anticipate or identify changes to family functioning, and work with the child and family to develop adaptive strategies to smooth this process so that the full benefits of seizure freedom can be enjoyed.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2019.01.004.

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