

‘Functional mushrooms saved my daughter’s Life’: A preliminary mixed methods survey study of Reishi (*Ganoderma lucidum*) and lion’s mane (*Hericium erinaceus*) for epilepsy

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ABSTRACT

A significant proportion of epilepsy patients are resistant to conventional treatments. Functional mushrooms such as Reishi (*Ganoderma lucidum*) and Lion’s Mane (*Hericium erinaceus*) have recognized health benefits, including neuroprotective and anti-seizure effects. This mixed-methods study investigates the use of these mushrooms as adjunctive therapies for epilepsy among 19 participants, including caregivers on behalf of a minor. The majority (n = 14) met criteria for drug-resistant epilepsy (DRE). Participants completed surveys and structured interviews addressing functional mushroom use, quality of life (QoL), sleep quality, health outcomes, seizure activity, and caregiver burden. Qualitative data underwent thematic content analysis. Compared with the general population, participants utilizing functional mushrooms noted comparable scores in physical health, psychological health, social relationships, and environmental health. Self-report responses indicated improvements in seizure control, including reduced seizure frequency and severity, cognitive and developmental outcomes, and overall quality of life since starting use of functional mushrooms. Caregivers emphasized both benefits and ongoing challenges in managing epilepsy. Functional mushrooms are a sustainable and widely available resource, and the findings presented here suggest they could complement existing treatments for epilepsy, particularly in DRE, though further clinical trials are needed to establish efficacy, optimize dosing, and clarify mechanisms of action.

1. Introduction

Epilepsy is a common and complex neurological disease characterized by recurrent seizures, affecting more than 70 million people worldwide. [1] Despite the prevalence of epilepsy and the many available treatments, which include surgical, pharmacological (synthetic drug), non-pharmacological (diet), and complementary therapies, epilepsy remains a significant cause of disability and mortality in children and adults. [2] Healthcare services for epilepsy, such as long-term treatment, hospitalization, and surgery, along with social services, including social support and health education, result in high costs and significant economic burdens for individuals with epilepsy, their

families, and healthcare systems. [3] Quality of life (QoL) is defined by the World Health Organization (WHO) as “individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. [4] QoL is worse in patients with epilepsy than in the general population. [5,6] Compared with patients with other chronic conditions, patients with epilepsy experience more disability days, face greater activity limitations, have lower annual incomes, and are high users of healthcare resources. [5] Additionally, approximately one third of epilepsy patients do not achieve seizure control with currently available anti-seizure medication (ASM). [7] Despite the development of many new epilepsy drugs with differing mechanisms of action over the

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past two decades, long-term outcomes in epilepsy patients have not improved, and the probability of achieving seizure freedom diminishes sharply with each unsuccessful treatment. [8] Drug-resistant epilepsy (DRE) occurs when seizures persist despite the use of at least two tolerated anti-seizure medications (ASMs). Since standard treatments often fail, managing DRE frequently requires alternative strategies, such as neuromodulation, dietary therapies, or experimental treatments. [9] Patients with DRE are at increased risk of earlier death, poorer cognitive development, and reduced QoL. [10–12] In these patients, the chance of reaching seizure freedom is lower than 15 %. [13]

Caregivers of individuals with epilepsy also face significant emotional, financial, and physical challenges due to the chronic nature of the condition, associated disabilities, and the stigma surrounding it. [14–16] When epilepsy is well-controlled, QoL is comparable to healthy individuals both in adults and children. [17,18] However, these treatments are not suitable for all patients and intensive surgical and pharmacological treatments can cause an onset of adverse effects and worsening QoL. [19] A paradigm shift in treatment and research strategies is needed to improve long-term outcomes in epilepsy, which includes the evaluation of nonpharmacological therapies. [8] Consequently, there is a critical need for continued research and development of new, low-cost therapeutic approaches utilizing complementary therapies used in concert with traditional/conventional treatments. [20]

Various edible mushrooms have been recognized globally for their nutritional and healing properties, dating back thousands of years. In recent years, these mushrooms have gained increased attention for their therapeutic potential, and a growing body of literature has sought to better understand the therapeutic efficacy of certain species of mushrooms. These species, often referred to as functional or medicinal mushrooms for their functional and beneficial health properties following ingestion, may hold therapeutic potential in the treatment of epilepsy. For example, *Ganoderma lucidum* (known as “Ling Zhi” in China or “Reishi” in Japan) is a culinary mushroom belonging to the family *Ganodermataceae* that has been used in traditional Chinese medicine for more than six millennia for strengthening the immune system, treatment of hypertension, and other disorders. [20–23] *G. lucidum* also has demonstrated antimicrobial properties. [24] In human studies, *G. lucidum* spore powder has been shown to reduce seizure frequency and improve QoL as measured in patients with epilepsy. [25–27] *Hericium erinaceus* (commonly known as “Lion’s Mane”), a culinary mushroom belonging to the *Hericiaceae* family, is one of the most studied functional mushrooms. It is known for its potential in immunotherapy and improving cognitive impairment. [28] *H. erinaceus* has demonstrated various health benefits, including antimicrobial, anticancer, antihyperglycemic, anti-fatigue, antihypertensive, antihyperlipidemic, antisenescence, cardiovascular protective, hepatoprotective, neuroprotective, and nephroprotective effects. [27–34] It may also reduce the impact of traumatic brain injury (TBI) by preventing neuroinflammation. [35] In rodent studies, *H. erinaceus* demonstrated an anti-epileptic effect by protecting hippocampal neurons from pilocarpine-induced neurotoxicity and reducing seizures. [36] Other naturally-occurring medicinal substances such as *Commiphora myrrh* have similar documented neuroprotective, anti-inflammatory, antimicrobial effects, [37] and anti-epileptic effects. [38] Despite this wealth of existing evidence for some level of therapeutic action among several naturally occurring substances for epilepsy and other chronic conditions, the dearth of current clinical evidence is glaring.

Although functional mushrooms are widely available, sustainably grown, easily accessible, and common dietary supplements and gourmet ingredients, there is currently limited evidence to support their use as a complementary treatment strategy in children or adults with epilepsy. Given the limitations and adverse effects of current epilepsy treatments, however, functional mushrooms may offer benefits as a complementary treatment option. Only one prior report has addressed the use of a functional mushroom product blend to treat treatment-resistant epilepsy

(TRE). Within a recent case study, a child with TRE experienced marked decreases in seizure frequency and duration. Before initiating functional mushroom use, the patient had three to five seizures a day, each lasting 30–60 s. After initiating the use of functional mushrooms, no seizures were observed in the patient for two months. The patient has since experienced one to two seizures every two months, lasting 5–15 s each. [39] This preliminary evidence indicates the possibility of achieving success in seizure relief and QoL improvements in the treatment-resistant (or DRE) epilepsy population. Research into these natural compounds could lead to more effective, affordable, and holistic approaches to managing epilepsy, ultimately improving QoL for patients. Preliminary investigations are needed to gather information required to develop a hypothesis-driven approach to experimental and longitudinal investigations of health outcomes related to the ingestion of functional mushrooms.

Using a mixed methods design, we investigated the use of functional mushrooms as a potential treatment option for epilepsy among a convenience sample of epilepsy patients. The current study was conducted to gather data on contemporary functional mushroom use, primarily Reishi (*G. lucidum*) and Lion’s Mane (*H. erinaceus*), and health outcomes among epilepsy patients and their caregivers. Specifically, the study aims were to: (a) characterize respondent demographics and self-reported functional mushroom use patterns including factors such as substance, dose, and product; (b) characterize self-reported QoL in comparison to the general population, including physical and mental health, (c) characterize health outcomes including wellbeing, caregiver burden, sleep quality, healthcare utilization, and seizure events, (d) determine associations between caregiver burden, severity of seizure symptoms, and perceived stress, (e) and gather narrative data to understand the underlying reasons, motivations, and contexts behind self-reported patterns of functional mushroom use among epilepsy patients. The current study differs from prior work by utilizing an in-depth investigation including both quantitative and qualitative data from human subjects on the health outcomes of functional mushroom use among epilepsy patients.

2. Methods

2.1. Study design

This mixed methods investigation enrolled caregivers responding on behalf of minors with epilepsy and adults with epilepsy. All participants included English-speaking adults aged 18 years or older and caregivers who responded on behalf of minors who were currently using or planning to use the functional mushrooms Reishi (*G. lucidum*) and Lion’s Mane (*H. erinaceus*) for the treatment of epilepsy. We employed a mixed methods design to gain insight into the experiences of individuals using functional mushrooms to treat epileptic seizures. Participants completed an informed consent document, followed by an extensive survey addressing relevant concepts such as functional mushroom use, medical history, and a series of validated instruments used to assess various health outcomes. The study concluded with a structured interview. All participants who completed the survey were encouraged to complete the interview. Participants meeting all criteria were recruited online through a convenience sample from the non-profits Lily’s Lighthouse, Unlimited Sciences, and Realm of Caring Foundation. Data collection occurred between March 4, 2024 and July 25, 2024.

2.2. Informed consent and demographic information

Participants were invited to participate in the study if they: (a) were at least 18 years old or were caregivers who were participating on behalf of a minor, (b) could read and write English fluently, (c) have an epilepsy diagnosis, (d) currently use or plan to use functional mushrooms Reishi (*G. lucidum*) and Lion’s Mane (*H. erinaceus*), (e) and were willing to complete a single survey, an optional interview, and share their email

address for study reminders and compensation. 20 individuals completed the study; however, one was removed for not meeting all study criteria. Participants were asked to complete a short survey that began with the informed consent document. Participants were also asked to provide demographic information and a brief history of their epilepsy diagnosis and treatment.

2.3. Survey

After completing informed consent, participants were invited to complete a single survey with an average completion time of 54 min. Participants answered several quantitative, standardized measures to capture various relative concepts (see Table 1). [4,40–48] Participants were also asked to complete questions assessing demographic information, personal history, substance and product use, impact on epilepsy, and impact of functional mushrooms.

2.4. Interviews

After completing the survey, participants were asked to complete an optional structured interview via online meeting room or phone. Participants consented to have audio recorded and transcribed and were asked five questions addressing: (a) what led them to begin the therapeutic use of functional mushrooms, (b) how use has helped them, (c) how use has harmed them, (d) reasons for participation and desired outcomes of the study, and (e) perception of whether Reishi (*G. lucidum*) and Lion's Mane (*H. erinaceus*) has been more beneficial to their epilepsy and/or overall wellbeing. Participants were also provided time to discuss anything about their experience using functional mushrooms that had not been addressed. Audio was recorded and transcribed using Otter.ai, an AI-based audio transcription tool. Three independent raters verified data validity and removed protected health information (PHI).

2.5. Data analysis

Analyses and descriptive statistics were generated using IBM SPSS (v. 29) statistical software, and results were cross-verified in R Statistical Software (v4.4.0; R Core Team 2021). Descriptive statistics were generated for all standardized measures, individual questionnaire items, and demographic information. Comparisons were calculated for standardized measures with documented, suggested population means

Table 1
Summary of Standardized Measures Used.

Measure	Details
Patient-Reported Outcomes Measurement Information System (PROMIS–10) Global Health	A 10-item global health quality of life scale with two subscales: physical health and mental health []
World Health Organization Quality of Life-BREF (WHOQOL-BREF)	A 26-item quality of life scale with four subscales: physical health, psychological health, social relationships, and environmental health []
Hospital Anxiety and Depression Scale (HADS)	A 14-item scale measuring anxiety and depression symptoms []
Pittsburgh Sleep Quality Index (PSQI)	A questionnaire developed to assess adult sleep quality []
Children's Sleep Habits Questionnaire (SF-CSHQ)	The short-form version of this scale was used to assess child sleep quality. []
Scale for Estimating Prognosis of Epilepsy (SEPE)	A 6-item scale developed to estimate prognosis outlook of epilepsy []
Caregiver Burden Scale (CBS)	A 22-item scale assessing caregiver burden []
Seizure Severity Questionnaire (SSQ)	A 22-item scale assessing perceived severity and bothersomeness of seizures []
Perceived Stress Scale (PSS–10)	A 10-item scale assessing recent personal stress levels []

Note. Participants were asked to consider their answers since initiating use of functional mushrooms.

(PROMIS-10; WHOQOL-BREF) using one-sample *t*-tests. Six *a-priori* one-sample, two-way, *t*-tests [Cohen's *d*; 95 % CI] were conducted to assess QoL and overall health. Test values were set at respective population means. [49] Effect sizes (Cohen's *d*) and 95 % confidence intervals were calculated. Most quantitative data were characterized using descriptive statistics and standardized cut-off scores (CBS; SEPE; HADS; PSQI; PSS-10; LAEP). For other standardized measures, higher scores indicate stronger connection to the concept being captured (SF-CSHQ; PGIC).

Qualitative data was collected from two sources: responses to open-ended survey questions (*N* = 19) and responses to interview questions (*n* = 14). Data from both sources were converged, and a thematic content analysis approach was used to determine meaning. Three independent researchers reviewed the data to code content, and themes were identified and developed to capture meaning and nuance most effectively. Inter-coder reliability was also calculated.

3. Results

3.1. Participant demographics

Following informed consent, 19 participants completed the survey (*N* = 19). 14 participants completed the interview (*n* = 14). For a visual summary of study completion and exclusion, see Fig. 1. Most participants were caregivers (*n* = 16) participating on behalf of a minor aged 17 years or younger (*n* = 14; mean age = 6.6 years) or an adult care recipient (*n* = 2; mean age = 28 years). The remaining participants were adult respondents (*n* = 3; mean age = 49.3 years). Most participants were White (*n* = 17), female (*n* = 16) and residing in the United States (*n* = 16). Other participants reported from Canada (*n* = 1), Australia (*n* = 1), and Ireland (*n* = 1). For detailed information about epilepsy history and demographics, see Table 2.

3.2. Functional mushroom use

For a dosing summary of how functional mushrooms were used, see Table 3. Duration of use is summarized in Fig. 2.

3.3. Perceived impact of functional mushrooms

A summary of perceived impact of functional mushrooms can be seen in Table 4. Most participants (*n* = 17) reported at least a somewhat better impact with noticeable changes on activity limitations, symptoms, emotions, and overall QoL since beginning use of Lion's Mane and/or Reishi mushrooms. Most participants (*n* = 17) reported at least a somewhat positive impact on the way Lion's Mane and/or Reishi

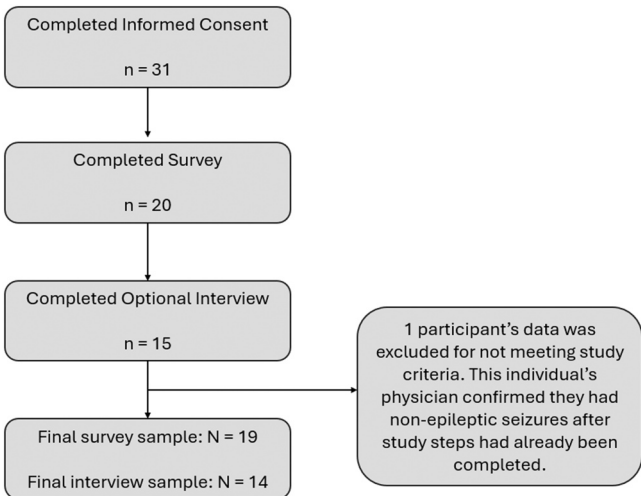


Fig. 1. Summary of Study Completion and Exclusions.

Table 2
Demographic and Medical History.

Demographic & Medical History	Pediatric (n = 14) Medians (range); n (%)	Adult (n = 5) Medians (range); n (%)	Total (N = 19); n (%)
Sex			
Male	2 (14.3 %)	1 (20.0 %)	3 (15.8 %)
Female	12 (85.7 %)	4 (80.0 %)	16 (84.2 %)
Age			
At onset of seizures	1.67 (.02–10)	31.00 (.75–59)	2.50 (.02–59)
Weight (kg)	22.97 (9.98–81.65)	74.84 (47.63–83.01)	27.22 (9.98–83.01)
Comorbidities			
Count of participants	7 (50.0 %)	3 (60.0 %)	10 (52.6 %)
Count per participant	1 (1–3)	4 (3–6)	2 (1–6)
Developmental delay	9 (64.3 %)	2 (40.0 %)	11 (57.9 %)
Epilepsy Etiology			
Genetic	4 (28.6 %)	0 (0 %)	4 (21.0 %)
Unknown	4 (28.6 %)	2 (40.0 %)	6 (31.6 %)
Structural	6 (42.9 %)	2 (40.0 %)	8 (42.1 %)
Post-Traumatic	0 (0 %)	1 (20.0 %)	1 (5.3 %)
Current Seizure Treatments			
Ketogenic diet	4 (28.6 %)	0 (0 %)	4 (21.0 %)
Vagal Nerve Stim (VNS)	0 (0 %)	0 (0 %)	0 (0 %)
Deep Brain Stim. (DBS)	0 (0 %)	0 (0 %)	0 (0 %)
Cannabidiol (CBD)	5 (35.7 %)	0 (0 %)	5 (26.3 %)
ASMs previously used			
Frequency	11 (55.0 %)	3 (60.0 %)	14 (73.7 %)
Per participant	3 (1–17)	2 (1–10)	3 (1–17)
ASMs currently used			
Frequency	9 (64.3 %)	2 (40.0 %)	11 (57.9 %)
Per participant	2 (1–3)	2 (2)	2 (1–3)
Treatment Resistant (≥2 ASMs)	12 (85.7 %)	2 (40.0 %)	14 (73.7 %)

Table 3
Dosing Summary.

Mushrooms Used	Brand	Form Ingested; mean amount (g/mL per day)	Average Frequency (times taken per day)*
Lion's Mane; n = 19	Naturealm; n = 9	Scoopable Powders; n = 14	3.6 2.1
Reishi; n = 17	Vita Life; n = 1	Tinctures; n = 4	1.1 1.25
Chaga; n = 11	Health Ranger; n = 1	Capsules; n = 3	1.3 2.0
Cordyceps; n = 11	Real Mushrooms; n = 2	Whole mushrooms; n = 2	10.0 1.5
Maitake; n = 11	Host Defense; n = 1		
Shiitake; n = 11	Om; n = 1		
Turkey Tail; n = 9	Gaia Herbs; n = 1		
Himematsutake; n = 1	SuperFeast; n = 1		
Antrodia; n = 1	Home-grown/sourced organically; n = 2		
King Trumpet; n = 1			

* Participants were also asked to report how many days of the last 30 mushrooms were used (M = 25.1). Most reported using mushroom products everyday (n = 13).

mushrooms affected seizure impact on life, with 68.4 % (n = 13) experiencing a change in both the frequency and severity of seizures following administration of Lion's Mane and/or Reishi mushrooms that included at least some reduction in the severity (n = 13) and frequency (n = 13) of seizures. For those who reported information on seizure type (n = 12), this change was observed across multiple seizure types: generalized motor seizures (n = 4), focal motor seizures with or without impairment of awareness (n = 2), focal non-motor seizures with preserved awareness (n = 2), and those with multiple seizure types (n = 4). For participants in our sample who met criteria for DRE (prior use of ≥ 2 anti-seizure medications; n = 14), 42.1 % (n = 8) reported a significant reduction in the severity of seizures and 15.8 % (n = 3) reported some reduction in the severity of seizures following administration of Lion's Mane and/or Reishi mushrooms. Additionally, 36.8 % (n = 7) reported a significant reduction in the frequency of seizures and 31.6 % (n = 6) reported some reduction in the frequency of seizures. Only one participant reported an adverse reaction resulting in increased gas/gastrointestinal discomfort. The perceived severity of this side effect was mild.

3.4. Quantitative measures of health outcomes

3.4.1. Quality of life (WHOQOL-BREF)

For the four aspects of WHOQOL-BREF, no significant differences were identified for physical health (M = 69.63, SD = 23.70, p = .486; t = -.711; df = 18, 95 % CI [-.614,.292]), psychological health (M = 68.63, SD = 18.27, p = .644; t = -.470; df = 18, 95 % CI [-.557,.345]), social relationships (M = 66.53, SD = 13.83, p = .134; t = -1.568; df = 18, 95 % CI [-.820,.110]), or environmental health (M = 73.84, SD = 21.09, p = .789; t = -.260; df = 18, 95 % CI [-.509,.391]). Test values were set at 73.5, 70.6, 71.5, and 75.1, respectively (Fig. 3).

3.4.2. Global health (PROMIS-10)

For the PROMIS-10, the test value was set at 50.0 for both dimensions. [36] No significance was found for physical health (M = 50.75, SD = 10.41, p = .756; t = .315; df = 18, 95 % CI [-.379,.522]) or mental health (M = 46.65, SD = 9.35, p = .136; t = -1.562; df = 19, 95 % CI [-.818,.111]) (Fig. 3). For descriptive statistics and cut-off range summaries for SEPE, PSQI, PSS-10, CBS, LAEP, and HADS, see Table 4.

3.4.3. Patient's global impression of change scale (PGIC)

The PGIC is a 7-point Likert scale which measures a patient's subjective impression of change. Using a cut-off score of 5 (Moderately better, and a slight but noticeable change), 84.2 % of participants (n = 16) indicated a noticeable improvement (mean = 5.8) in activity limitations, symptoms, emotions, and overall QoL since beginning use of functional mushrooms.

3.4.4. Sleep quality

Using a modified version of the Children's Sleep Habits Questionnaire (SF-CSHQ), all caregivers of minors who completed the scale (n = 12) reported scores above the threshold (> 30), indicating the presence of a pediatric sleep disorder (mean = 40.7). For the Pittsburgh Sleep Quality Index (PSQI) for adults (n = 5), 60.0 % reported scores over a threshold of 5, indicating worse sleep quality (mean = 8.2). Two participants declined to answer.

3.4.5. Caregiver burden, seizure severity, and perceived stress

Using a Pearson correlation analysis, total scores on the Caregiver Burden Scale (CBS; mean = 32.2) were significantly positively correlated with total scores on the Seizure Severity Questionnaire (SSQ; mean = 7.60) (p = 0.23, r = 0.57, n = 16), indicating a significant association between caregiver burden and seizure symptom severity. Total scores on the CBS were also significantly positively correlated with total scores on the Perceived Stress Scale (PSS; mean = 15.4) (p < 0.001, r = 0.84, n = 16), indicating an association between higher caregiver burden and perceived stress.

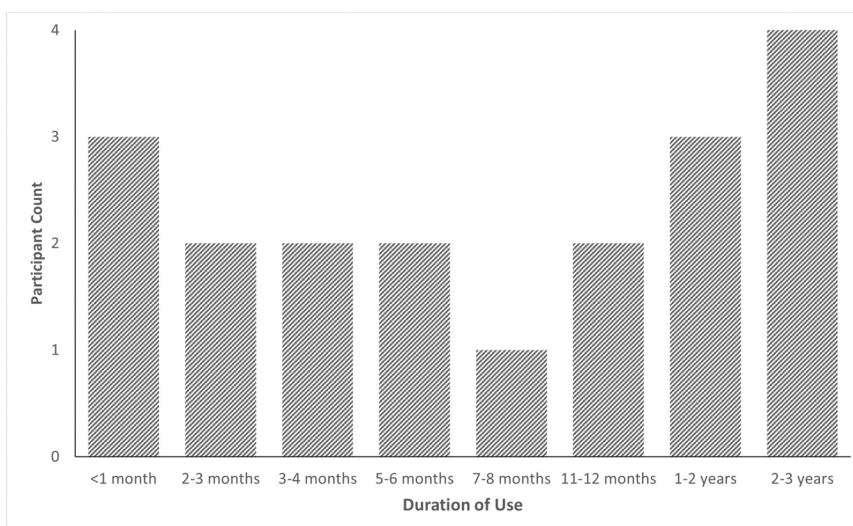


Fig. 2. Duration of use of Lion's Mane and/or Reishi mushrooms (N = 19), median = 5–6 months.

3.5. Qualitative thematic analysis

We utilized a thematic coding approach for the qualitative analysis portion of this mixed-methods investigation. [50] After compiling all qualitative data from participant interviews and surveys, three independent raters read through all qualitative data to determine a list of codes. Raters then read through all qualitative data again and applied codes to the text. Themes were allowed to arise organically, and six major themes were identified (see Table 5). Example excerpts from all themes and subthemes can be seen in Table 6. The percentage agreement between the three raters was 90.96 %, and Fleiss' kappa was also used to report inter-rater reliability. [51] Agreement between the three raters was very good, $\kappa = 0.888$, 95 % CI [0.824, 0.953], $p < .0005$. Minor adjustments have been made to the interview transcripts to enhance readability while maintaining an accurate representation of the participant's meaning.

3.5.1. Theme 1: improved seizure control

Participants consistently highlighted that functional mushrooms, specifically Lion's Mane and Reishi, have helped reduce the frequency, intensity, and duration of seizures. This was often noted within weeks of use, and caregivers point out that even if seizures were not completely eliminated, improvements were significant. In the interview or open-ended survey responses, all participants (N = 19) reported at least some reduction in the frequency, duration, or severity of seizures or that their seizures stopped completely after beginning use of functional mushrooms (n = 11, 57.9 %).

"My daughter's seizures completely stopped and haven't returned after the introduction of using Reishi mushroom powder." (Caregiver for minor with epileptic seizures)

"I would say, about six weeks after introducing the mushrooms twice a day, we found [seizure] freedom, and we have had over 16 months of [seizure] freedom, so no seizures." (Caregiver for minor with epileptic seizures)

"There is a significant decrease in severity, duration and frequency of my seizures and I am feeling my mental health get better!" (Caregiver for minor with epileptic seizures)

Seizures stopped completely for varying periods of time for most participants. Although some reported seizures returning later, they noted that they still experienced noticeable improvements in overall seizure control (n = 10, 52.6 %).

"She had tonic-clonic [seizures] every day, every night. When I started trying the mushrooms, she stopped, completely. Later, she started having some [seizures], but it's not every day. It's some days. She's doing better." (Caregiver for minor with epileptic seizures)

"It's increased her seizure threshold significantly. If she does have a seizure now, it's shorter in duration. It's short. It's less severe. The jerks are smaller. Her recovery time - she would usually sleep for three, four hours after a seizure - But now she doesn't do that. Her recovery time is, you know, she just gets straight back to life and she doesn't have any deficits, you know, which is pretty huge." (Caregiver for minor with epileptic seizures)

"At that time, she had been having other types of seizures and started having tonic-clonic seizures. And when we started the Lion's Mane, it stopped the tonic-clonic [seizures] and went back to spasms and/or focal seizures." (Caregiver for minor with epileptic seizures)

3.5.2. Theme 2: cognitive and developmental gains

A recurring theme was improvements in cognitive functions, including mental clarity, memory, and focus (n = 9, 47.4 %). Many caregivers observed notable cognitive gains in their children after introducing functional mushrooms. Improvements in speech and the ability to process information were commonly reported, with some children achieving developmental milestones that had previously been delayed. Both adults and caregivers noted consistent cognitive gains. For some, cognitive gains improved further with each increase in functional mushroom dose. Adults noted noticeable improvements in memory, specifically word searching and short-term recall.

"My memory is better... I can concentrate on one thing for a longer amount of time." (Adult with epileptic seizures)

"I truly feel like it's giving her more mental clarity... like her brain can function better." (Caregiver for minor with epileptic seizures)

"I noticed massive explosions and jumps in her speech and cognitive gains after increasing the dosage." (Caregiver for minor with epileptic seizures)

Caregivers noticed improvements in attention and felt that their child recovered more quickly cognitively after experiencing a seizure or absence.

"What difference do you see? I say the biggest one is this. When he would start a sentence, he would say 'Mommy, at school today we had a test' and let's say the absence would happen, right? He would have his little absence, and then you would come back, and he would restart the

Table 4
Perceived impact of functional mushrooms.

Question	Count (n); Percent (%)
Since beginning Reishi and/or Lion's Mane mushrooms, how would you describe the change (if any) in activity limitations, symptoms, emotions, and overall quality of life?	n = 2; 10.5 % A little better, but no noticeable change n = 1; 5.3 % Somewhat better, but the change has not made any real difference n = 1; 5.3 % Moderately better, and a slight but noticeable change n = 9; 47.4 % Better, and a definite improvement that has made a real and worthwhile difference n = 6; 31.6 % A great deal better, and a considerable improvement that has made all the difference
Please select the answer which best describes your belief on the impact of Lion's Mane and/or Reishi mushrooms on the way seizures affect my life.	n = 1; 5.3 % ...significant negative impact on the way seizures affect my life n = 1; 5.3 % ...no impact on the way seizures affect my life n = 8; 42.1 % ...somewhat positive impact on the way seizures affect my life n = 9; 47.4 % ...significant positive impact on the way seizures affect my life
Did you experience a change in the frequency of seizures following administration of Lion's Mane and/or Reishi mushrooms?	n = 13; 68.4 % Yes n = 1; 5.3 % No n = 5; 26.3 % I don't know
Please indicate the answer that best describes this change in frequency.	n = 7; 36.8 % Significant reduction in the frequency of seizures n = 6; 31.6 % Some reduction in the frequency of seizures
Please indicate which seizure type you experienced a change of seizure frequency in (select all that apply).	n = 4; 21.0 % Generalized motor seizures n = 2; 10.5 % Focal Motor Seizures with or without impairment of awareness n = 2; 10.5 % Focal non-motor seizures with preserved awareness n = 4; 21.0 % More than one seizure type (please list) n = 1; 5.3 % I don't know.
In terms of severity, have the seizures changed in appearance following administration of Lion's Mane and/or Reishi mushrooms?	n = 13; 68.4 % Yes n = 3; 15.8 % No n = 3; 15.8 % I don't know
Please indicate the answer that best describes this change in severity.	n = 11; 57.9 % Significant reduction in the severity of seizures n = 2; 10.5 % Some reduction in the severity of seizures
Please indicate which seizure type you experienced a change of seizure severity in (select all that apply).	n = 4; 21.0 % Generalized motor seizures n = 3; 15.8 % Focal Motor Seizures with or without impairment of awareness n = 2; 10.5 % Focal non-motor seizures with preserved awareness n = 3; 15.8 % More than one seizure type (please list) n = 1; 5.3 % I don't know
Please select the answer which best describes your belief on the impact of Lion's Mane and/or Reishi mushrooms on your physical health.	n = 1; 5.3 % ...significant negative impact on my physical health n = 1; 5.3 % ...no impact on my physical health n = 7; 36.8 % ...somewhat positive impact on my physical health n = 10; 52.6 % ...significant positive impact on my physical health
Please select the answer which best describes your belief on the impact of Lion's Mane and/or Reishi mushrooms on your mental health.	n = 1; 5.3 % ...no impact on my mental health n = 7; 36.8 % ...somewhat positive impact on my physical health n = 11; 57.9 % ...significant positive impact on my quality of life
Please select the answer which best describes your belief on the impact of Lion's Mane and/or Reishi mushrooms on your quality of life.	n = 2; 10.5 % ...no impact on my mental health n = 5; 26.3 % ...somewhat positive impact on my quality of life

Table 4 (continued)

Question	Count (n); Percent (%)
	n = 12; 63.2 % ...significant positive impact on my quality of life n = 1; 5.3 % Definitely, yes n = 2; 10.5 % Somewhat, yes n = 4; 21.0 % Probably, yes n = 3; 15.8 % Might or might not n = 2; 10.5 % Probably not n = 1; 5.3 % Somewhat, no n = 6; 31.6 % Definitely not
Have you seen a change in the use of prescription medication since starting use of Lion's Mane and/or Reishi mushrooms?	n = 1; 5.3 % -5.00 n = 2; 10.5 % -2.00 n = 3; 15.8 % -1.00 n = 4; 21.0 % 0.00
Please use the slider to indicate the increase or decrease in medication use (-5 to +5, whole integers with "-" indicating a decrease and "+" indicating an increase).	
Have you seen a change in the frequency of hospital or physician-related visitation since starting use of Lion's Mane and/or Reishi mushrooms?	n = 9; 47.4 % Definitely, yes n = 1; 5.3 % Somewhat, yes n = 1; 5.3 % Probably, yes n = 3; 15.8 % Might or might not n = 3; 15.8 % Probably not n = 2; 10.5 % Definitely not n = 3; 15.8 % -5.00 n = 3; 15.8 % -3.00 n = 2; 10.5 % -2.00 n = 2; 10.5 % -1.00 n = 3; 15.8 % 0.00 n = 1; 5.3 % 5.00
Please use the slider to indicate the increase or decrease in hospital or physician visits (-5 to +5, whole integers with "-" indicating a decrease and "+" indicating an increase).	
Do you think the use of Lion's Mane and/or Reishi mushrooms has helped treat the main medical problem or related issues?	n = 9; 47.4 % Definitely, yes n = 4; 21.0 % Somewhat, yes n = 3; 15.8 % Probably, yes n = 1; 5.3 % Might or might not n = 2; 10.5 % Probably not

sentence ‘Mommy, today at school on the test.’ After starting him on the Lion’s Mane and now within three weeks after being on Lion’s Mane he will be like ‘Mommy, we had a test today...’ He would pause here for a second. ‘...And I did really well’ and he would continue his sentence.” (Caregiver for minor with epileptic seizures)

“Using Lion’s Mane, I have found less intensity of seizures, faster post-ictal recovery, both physically and cognitively. Some days you would never know there had been lots of seizure activity through the previous night.” (Caregiver for adult with epileptic seizures)

These improvements allowed some children to meet previously delayed developmental milestones (n = 3, 15.8 %).

“So, when we started mushrooms the first week, [participant] hit three developmental milestones she’d never been able to hit before and these were reports from, you know, specialists, occupational, speech, physical. Eight weeks before starting mushrooms in her IEP, which is an Individualized Education at preschool. Her physical therapy goal was [participant] will navigate her own environment and only fall once a day, and she was falling 10 times a day covered in bruises. You know, she couldn’t navigate stairs by herself. Eight weeks after starting mushrooms, she was assessed developmental age for physical therapy and hasn’t required that service since in almost three years. In eight weeks. She went from not being able to stand up by herself basically to developmental age. So huge, very quick improvements in fine gross motor. You know, she had more speech, fluidity, she was able to communicate her needs. She just quickly started doing things. She could, you know, put her own shoes and socks on. She’d never been able to do that before.” (Caregiver for minor with epileptic seizures)

3.5.3. Theme 3: better quality of life

Alongside cognitive gains, participants experienced improvements in prosocial behavior, fatigue, and mood. Some participants reported that they began using functional mushrooms to improve their cognition and mood, finding the effects especially beneficial for anxiety and fatigue (n = 5, 26.3 %).

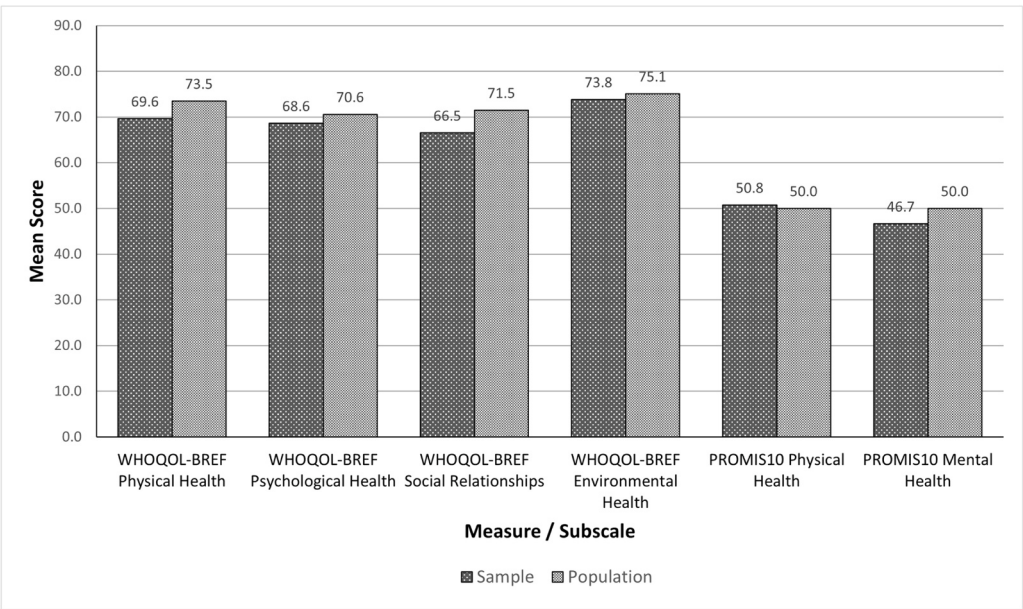


Fig. 3. A comparison of epilepsy sample and general population means for the WHOQOL-BREF and PROMIS-10. Sample mean values have been rounded to the nearest tenth for visual consistency.

Table 5
Summary of quantitative scores.

Measure	mean (SD)	Percent of sample; cutoff ranges
SEPE (n = 19)	4.4 (2.3)	31.6 %; ≤ 3 likely to become seizure-free without AEDs 52.6 %; ≤ 4 may have a positive outcome 31.6 %; ≥ 6 indicates a poor outcome
PSS–10 (n = 19)	15.4 (6.3)	42.1 %; 0–13 low stress 52.6 %; 14–26 moderate stress 5.3 %; 27–40 high stress
CBS (n = 16)	32.2 (16.7)	18.7 %; 0–20 = little to no burden 50.0 %; 21–40 = mild to moderate burden 25.0 %; 41–60 = moderate to severe burden 6.2 %; 61–88 = severe burden
LAEP (n = 19)	32.5 (12.6)	21.0 %; > 40 indicates mental health risk
HADS (n = 19)	Anxiety 8.5 (3.3) Depression 5.5 (4.9)	36.8 %; 0–7 normal 42.1 %; 8–10 borderline abnormal 25.0 %; 11–21 abnormal 73.7 %; 0–7 normal 21.0 %; 8–10 borderline abnormal 21.0 %; 11–21 abnormal
PGIC (n = 19)	5.8 (1.2)	84.2 %; ≥ 5 moderately better, and a slight noticeable change
SF-CSHQ (n = 12)	40.7 (4.3)	100.0 %; > 30; a score greater than 30 indicates the presence of a pediatric sleep disorder
PSQI (n = 5)	8.2 (5.1)	60.0 %; > 5; higher scores indicate worse sleep quality

“Better mood and less foggy. She used to have horrible crying fits upon waking in the morning and from naps every single day. These have drastically reduced, and she is not taking nearly as long to recover when she does have slight moodiness upon waking. She seems generally happier overall.” (Caregiver for minor with epileptic seizures)

Caregivers also noted great improvements in mood, fatigue, and prosocial behavior, saying that their child’s disposition seems overall happier. They reported that their child initiates eye contact more and initiates play (n = 3, 15.8 %).

“I feel like on top of helping cut the seizures in half, which obviously we still want to continue to try to cut them down because 15 a day is still a lot, but we did also see like a lot more smiles. Some eye contact, facial expressions... She has many different types of therapists and so she really

knows her and she was just like, “Look at her, she’s just so happy” like it was hard work for her and yet she was thrilled she was smiling the whole time like even a couple of little vocalizations. So, a lot of positive.” (Caregiver for minor with epileptic seizures)

“She would initiate play with her siblings, which she would never really do before.” (Caregiver for minor with epileptic seizures)

Participants also noted longer awake periods and more energy due to reduced severity in seizures (n = 3, 15.8 %). These effects have allowed for more success at school and more family outings accompanied by less fear and seizure triggers.

“More awake windows have allowed for more days attending school, therapies and family activities.” (Caregiver for minor with epileptic seizures)

“...Just overall improvement in our whole family unit as a quality of life, right? Because of [participant’s] you know, improvements, we’ve been able to do lots of other things that we’ve never done. I mean, we went to a water park when on water slides for the first time, you know, a couple of days ago, that never would have been even on our radar to do anything like that with her. Just getting her in and out of water. She’d have a seizure because of the temperature change. You know, the fact that chlorine would trigger her. So just the fact that we can do these things now is pretty amazing.” (Caregiver for minor with epileptic seizures)

3.5.4. Theme 4: uncertainty in functional mushroom dosing and overall effectiveness

Participants frequently discussed the importance of adjusting the dose to find the right balance for effectiveness. Many noted that it took some experimentation to find the optimal dosage for reducing seizures and improving cognitive function. Uncertainty when dosing functional mushrooms and determining the cause of these positive outcomes was common. Many participants expressed a desire for more information on how to dose functional mushrooms and determine the therapeutic range (n = 4, 21.0 %).

“One of the things I found challenging with it was finding a good dosage for and then also there was that uncertainty of if it was going to cause something. I didn’t realize that I went really slow. I think I wasted a lot of time on a really low dose and it helped. I think it was benefiting her. But I

Table 6
Themes.

Theme 1: Improved seizure control
1.1 Cessation of seizures
1.2 Reduction in seizure frequency
1.3 Reduction in seizure severity
1.4 Reduction in seizure duration
Theme 2: Cognitive and developmental gains
2.1 Improvements in memory
2.2 Improvements in attention
2.3 Meeting delayed developmental milestones
Theme 3: Better Quality of Life
3.1 Improvements in mood
3.2 Improvements in fatigue
3.3 Increased prosocial behavior
Theme 4: Uncertainty in functional mushroom dosing and overall effectiveness
4.1 Dosing uncertainty
4.2 Coinciding changes in diet/medications/supplements
4.3 Uncertainty in determining Lion's Mane VS Reishi effectiveness
Theme 5: Dissatisfaction with current treatment options
5.1 Desire to decrease or stop pharmaceuticals
5.2 Dissatisfaction with current treatment options
5.3 Feeling hopeless with managing symptoms
5.4 Lack of physicians' knowledge of complementary natural therapies
Theme 6: Positive beliefs about functional mushrooms and holistic natural complementary therapies
6.1 Learning about functional mushrooms from online sources
6.2 Desire for empirical research
6.3 Desire for increased awareness of natural therapies
6.4 Belief in holistic approach to natural and traditional therapies

did find for my daughter we did need to go up to a pretty healthy dose, I think, and I'm not sure. I'm not sure. We're still playing around with it, but I'm not sure, you know, I would love more information on, kind of where that therapeutic range is, kind of thing, too. That was a challenge I had with it." (Caregiver for minor with epileptic seizures)

"It took some trial and error, but once we found the right dose, the seizures decreased, and her cognition improved." (Caregiver for minor with epileptic seizures)

Many participants began using functional mushrooms alongside new treatments, diets, and supplements, which made it challenging for them to determine the cause of their success in seizure control (n = 7, 36.8 %).

"So, it wasn't like we just introduced the mushrooms. We were introducing a new pharmaceutical combination for her as well. As well as figuring out we hired a cannabis pediatrician, and just trying to figure out everything, we were kind of just throwing it all out there." (Caregiver for minor with epileptic seizures)

Few participants were able to determine whether they believed Lion's Mane or Reishi mushrooms to be more effective in treating seizures because many exclusively use a blend that includes both mushrooms or both types were introduced at the same time (n = 8, 42.1 %).

"Yeah, that one's a rough one to answer, just because we've implemented them both at the same time, they actually combine the two tinctures into just one syringe. So, I feel like I don't really have an appropriate answer for that." (Caregiver for minor with epileptic seizures)

3.5.5. Theme 5: dissatisfaction with current treatment options and a desire for natural or holistic treatment alternatives

Dissatisfaction with current treatment options, including pharmaceuticals and surgeries, was regularly expressed. There was a strong preference for natural remedies over pharmaceuticals, with several participants expressing frustration over the side effects of conventional medications. Many used functional mushrooms to reduce their dependence on pharmaceutical treatments or to wean their children off entirely. Several participants communicated a desire to stop or decrease the use of pharmaceuticals due to harmful side effects (n = 6, 31.6 %).

"It's a trial and error and it's nerve-wracking to put my son on a medication that caused a massive increase in seizures. It's like every time I'm changing the medication because we're on the fifth one right now." (Caregiver for minor with epileptic seizures)

"I had been wanting to wean my daughter off her seizure med and I did get the okay from her neurologist to do that. He was supportive and I came across her using that to help with seizures. And I was like, oh well I'm going to add that. So, at the time we weren't seeing active seizures. So, I was adding it because I was hoping to wean the med and the med at the time was kind of like keeping her seizures away kind of deal. So, I was hoping to add this as something that would keep them gone and be able to wean the med." (Caregiver for minor with epileptic seizures).

Caregivers often expressed dissatisfaction with the intrusive nature of many seizure treatments (n = 7, 36.8 %), and some noted dissatisfaction with physicians' lack of knowledge and support of natural complementary therapies (n = 3, 15.8 %).

"I wasn't getting anything from the neurologist, the neurologist at the Children's Hospital that we go to, like that they didn't have anything else. They just had more medications to try, even though she was having severe reactions and surgery." (Caregiver for minor with epileptic seizures)

When discussing treatment options, some caregivers expressed how hopeless they've felt while attempting to improve their child's symptoms, especially among those with medically resistant epilepsy types (n = 4, 21.0 %).

"Well, you know [participant] had uncontrolled seizures for seven years straight since the onset of her epilepsy at five weeks old, and she had failed every available treatment option to her and her life, outlook on life, wasn't that good. You know, we were using rescue medicine three times a week to intervene and I was running out of time with her, you know. I was concerned that we were going to lose her and I was seeking alternative therapies." (Caregiver for minor with epileptic seizures)

3.5.6. Theme 6: positive beliefs about functional mushrooms, a holistic approach to natural complementary therapies, and social support and advocacy

Many participants found other parents and online research to be

Table 7
Summary of subthemes.

Subthemes	Subtheme Description	Most Representative Quote	Count
Theme 1: Improved seizure control			
1.1 Cessation of seizures	Participants reported seizures completely stopping after beginning use of functional mushrooms.	"My daughter's seizures completely stopped and haven't returned after the introduction of using Reishi mushroom powder."	n = 11
1.2 Reduction in seizure frequency	Participants reported experiencing reductions in seizure frequency after beginning use of functional mushrooms.	"[There were] decreases in seizures from up to 50 per day to months between seizures."	n = 9
1.3 Reduction in seizure severity	Participants reported experiencing reductions in seizure severity after beginning use of functional mushrooms.	"Although I still get my aura it seems to be now staying there and not peaking into a total seizure. It feels as though it's so close to turning into a seizure, but it doesn't fully become a seizure."	n = 10
1.4 Reduction in seizure duration	Participants reported experiencing reductions in seizure duration after beginning use of functional mushrooms.	"In duration, it's short, it's less severe. The jerks are smaller. Her recovery time, she would usually sleep for three, four hours after a seizure. But now she doesn't do that."	n = 5
Theme 2: Cognitive and developmental gains			
2.1 Improvements in memory	Participants reported improvements in short-term memory recall and word searching after beginning use of functional mushrooms.	"My memory is better... the head injury happened. And it, you know, memory, short term memory and coordination was the worst, basically, short term memory and coordination was terrible, because after that injury, and when I went back to try to play them again, I was not even the same. Totally worse by a long shot. But then the Lion's Mane..."	n = 2
2.2 Improvements in attention and overall cognition	Participants reported improvements in focus and attention after beginning use of functional mushrooms.	"Her slow processing is not as slow with the mushrooms. You know what I'm saying? She has so much better clarity. You know what I mean? And she is able to focus better."	n = 9
2.3 Meeting delayed developmental milestones	Caregivers reported meeting previously delayed developmental milestones after beginning use of functional mushrooms.	"In week 1 **** hit three developmental milestones for occupational therapy, physical therapy, and speech. Eight weeks into mushrooms, **** was assessed at developmental age for physical therapy and no longer required this service. She was	n = 3

Table 7 (continued)

Subthemes	Subtheme Description	Most Representative Quote	Count
Theme 3: Better Quality of Life			
3.1 Improvements in mood	Participants reported improvements in mood: including less anger, anxiety, and an overall happier demeanor after beginning use of functional mushrooms.	falling on average 10 times a day." "Better mood and less foggy. She used to have horrible crying fits upon waking in the morning and from naps every single day. These have drastically reduced, and she is not taking nearly as long to recover when she does have slight dizziness upon waking. She seems generally happier overall."	n = 5
3.2 Improvements in fatigue	Participants reported improvements in fatigue, with longer wake-periods between seizures, and overall increased energy after beginning use of functional mushrooms.	"More awake windows have allowed for more days attending school, therapies and family activities."	n = 3
3.3 Increased prosocial behavior	Caregivers noticed more eye contact and instances of initiated play after beginning use of functional mushrooms.	"...but we did also see a lot more smiles. Some eye contact, facial expressions... She has many different types of therapists and so she really knows her, and she was just like, "look at her, she's just so happy" like it was hard work for her. And yet she was thrilled she was smiling the whole time like even a couple of little vocalizations." "She would initiate play with her siblings, which she would never really do before."	n = 3
Theme 4: Uncertainty in functional mushroom dosing and overall effectiveness			
4.1 Dosing uncertainty	Participants expressed confusion and uncertainty when dosing functional mushrooms.	"...One of the things I found challenging with it was finding a good dosage for and then also there was that uncertainty of if it was going to cause something. I didn't realize that I went really slow. I think I wasted a lot of time on a really low dose and it helped. I think it was benefiting her."	n = 4
4.2 Coinciding changes in diet/medications/supplements	Participants reported coinciding changes in diet/medications/supplements use alongside introducing functional mushrooms.	"I kind of brought in a lot of things at once, which I know is not good because then you don't know what is contributing what's working, what's not or is it a combination of everything. But basically when we	n = 7

(continued on next page)

Table 7 (continued)

Subthemes	Subtheme Description	Most Representative Quote	Count
		were in this rough patch, we started the ganaxolone, the pharmaceutical drug. We only lasted a couple of weeks and that immediately stopped given her reaction. I started red light therapy. I also bought this product called Nirvana, which is a VNS...So I had been doing all of that all at once, and then I brought in the mushrooms."	
4.3 Uncertainty in determining Lion's Mane VS Reishi effectiveness	Participants often reported uncertainty in determining whether Lion's Mane or Reishi is responsible for the success in managing seizure symptoms. Many participants use a blend or initiated use of both mushrooms at once.	"Yeah, that one's a rough one to answer, just because we've implemented them both at the same time, they actually combine the two tinctures into just one syringe. So it's just easy so I feel like I don't really have an appropriate answer for that."	n = 8
Theme 5: Dissatisfaction with current treatment options	Participants expressed the desire to decrease or stop using pharmaceuticals.	Q: Why did you choose to begin the therapeutic use of Lion's Mane and/or Reishi mushrooms? "In the hope that we would be able to reduce the amount of medications that my son was on for seizure control."	n = 6
5.1 Desire to decrease or stop pharmaceuticals			
5.2 Dissatisfaction with current treatment options	Participants were dissatisfied with current treatment options due to their invasive nature or harmful side effects.	"It's a trial and error and it's nerve wracking to put my son on a medication that caused a massive increase in seizures. It's like every time I'm changing the medication because we're on the fifth one right now."	n = 7
5.3 Feeling hopeless with managing symptoms	Participants expressed hopelessness when describing medical history and attempts to manage seizure symptoms.	"Well, you know **** had had uncontrolled seizures for seven years straight since the onset of her epilepsy at five weeks old, and she had failed every available treatment option to her and her life. outlook on life. Wasn't that good. You know, we were using rescue medicine three times a week to intervene. And I was running out of time with her, you know, I was concerned that we were going to lose her, and I was seeking alternative therapies."	n = 4
5.4 Dissatisfaction with physicians'	Participants reported	"And I mean literally, like a team of 15	n = 3

Table 7 (continued)

Subthemes	Subtheme Description	Most Representative Quote	Count
	knowledge or attitude concerning complementary natural therapies	dissatisfaction with physicians' lack of knowledge or attitude regarding natural complementary therapies	
Theme 6: Positive beliefs about functional mushrooms and holistic natural complementary therapies	Participants reported learning about functional mushrooms from online connections (i.e., other caregivers for a child with epilepsy) and online research rather than health professionals.	"Research first. I was trying to deal with my blood sugar levels and looking around for various research around epilepsy and functional mushrooms and kind of the journey started from there. I ran into a lovely website. That became helpful. They gave me an idea to give it a shot. To give it to my son." "I think that parents have actually provided more insight into some of the things that they've seen, [the] benefits."	n = 7
6.1 Participants heard about functional mushrooms from online sources			
6.2 Desire for empirical research	Participants expressed a desire for more empirical research on functional mushrooms.	"The one thing that has always been, you know, with your neurologist and everything, it's like when I bring up CBD or frequency therapy or red light therapy, they're like, well, there isn't enough clinical data. There isn't enough studies, you know, I hate that, so I want to contribute to those, you know, provide those that data."	n = 6
6.3 Desire for increased awareness of natural therapies	Participants expressed a strong desire for increased awareness of complementary natural therapy options when treating seizures.	"To this I mean, you know if these are the side effects of mushrooms, cognitive gains, I just think that is incredible. You know, when you can have a side effect that's cognitive gains from a medicine because I fully believe that this is a medicine, right? When we're talking about mushrooms for epilepsy, you know who wouldn't want that? Who wouldn't want cognitive gains over the side effects of pharmaceuticals?" "I would love to just help spread the word so that anybody that could be suffering and have the possibility for it to help, then they hear about it."	n = 9
6.4 Belief in holistic approach to natural	Participants reported a strong	"And I will say that just from my own	n = 7

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Table 7 (continued)

Subthemes	Subtheme Description	Most Representative Quote	Count
and traditional therapies	belief in a holistic approach to managing symptoms, including both natural complementary therapies and traditional approaches.	personal beliefs from the past. It is just trickled down into this. I feel like any positive responses she's ever had, has been to more holistic approaches...So, chiropractor, the frequency therapy, the red light therapy, you know it's always been the diets. Things like that have been the one thing to give her some form of relief."	

more helpful in learning about functional mushrooms and complementary therapies than health professionals (n = 7, 36.8 %). Parents and caregivers who had positive experiences with functional mushrooms often shared their stories with others, advocating for broader use of natural treatments. They also sought information from other parents, creating a support network around natural remedies for epilepsy

"I think that it's just so hard when you're a parent faced with a rare genetic disease or, you know, anything really to find support. That's not just traditional medicine, and we were kind of led down a not great path in the beginning of her diagnosis, and it took a lot of us researching and talking with parents and as much as we've now found an incredible doctor, as much as doctors have helped us, I think that parents have actually provided more insight into some of the things that they've seen—benefits of—so I would love for information like this to be out there." (Caregiver for minor with epileptic seizures)

Many stated the desire for more research (n = 6, 31.5 %) and more awareness of functional mushrooms and complementary natural therapies. This desire for awareness was especially strong among those who found no success after trying several medications and treatment options prior to finding information about functional mushrooms (n = 10, 52.6 %).

"We obviously want to help with any form of potential treatment for families in the future so that they don't struggle the way we've struggled." (Caregiver for minor with epileptic seizures)

Though functional mushrooms were consistently acknowledged as an important piece of the puzzle, or instrumental in the improvements in seizure control, many participants were uncomfortable with attributing success solely to functional mushrooms (n = 7, 36.8 %).

"I feel like at least for me I don't know. I do a lot for my daughter. So many alternative things, and I feel like each one has definitely benefited her. But I don't know if I could ever say that this is definitely 100 % what this has done and what this has helped. We still have not seen any seizures and I feel like [mushrooms] play a part in that. I feel like she has made cognitive improvements. She had made just overall improvements. Now we are doing other things as well. So, I don't know if I can say, yes, absolutely this has definitely helped her, because it's just a piece of the puzzle." (Caregiver for minor with epileptic seizures)

Many participants expressed a holistic belief in the combination of natural complementary therapies alongside traditional treatments, finding functional mushrooms to be an important factor in seizure control success (n = 7, 36.8 %).

"I do believe that there are a lot of options outside of the Western world in which we can really, maybe not treat everything naturally, but definitely

aid and reduce the harmful effects of the Western medicine and pharmaceuticals that we're administering to children or adults." (Caregiver for minor with epileptic seizures)

"Functional mushrooms saved my daughter's life." (Caregiver for minor with epileptic seizures)

4. Discussion

Using a mixed methods design utilizing a single survey followed by a structured interview, the present study investigated the use of functional mushrooms as a potential treatment option for epilepsy among a sample of 19 individuals (mostly children) with epilepsy, including a subset of participants meeting criteria for drug-resistant epilepsy (DRE). Participants utilizing functional mushrooms, specifically Reishi (*G. lucidum*) and Lion's Mane (*H. erinaceus*), reported a positive impact on how these substances impacted their seizures, mental health, and quality of life (QoL) and exhibited comparable physical health, psychological health, social relationships, and environmental health to the general population. Decreased perceived stress and seizure severity was also associated with lower caregiver burden. Thematic content analysis of qualitative data collected from structured interviews revealed the emergence of several major themes, including improved seizure control and severity, cognitive and developmental gains, and better QoL.

4.1. The potential of functional mushrooms as a complementary treatment for seizures in epilepsy

Epilepsy is a progressive and chronic neurological disorder characterized by recurrent seizures, and currently available anti-seizure medications (ASMs) are known to produce a variety of cognitive, psychiatric, and motor adverse effects. [52,53] Therapies that show low potential to increase adverse effects liability are in significant clinical demand. In search of better tolerated treatments, recent studies have demonstrated the acute anti-seizure potential of plant-derived cannabidiol (CBD) in rodents, [54] and initiatives are ongoing to assess outcomes of CBD treatment in human populations, such as The BEhavior, COgnition, and More with Epidiolex® (BECOME) study. [55] These studies suggest plant-derived approaches to seizure management may represent a viable next-step in determining potential complementary approaches to currently available ASMs. In our study, the majority (73.7 %) of participants in our sample reported they had been using functional mushrooms for three months or more, and some (36.8 %) as long as one year or more, for the treatment of epilepsy. The median duration of use (5–6 months) suggests these participants had ongoing seizure and non-seizure benefits persisting over months or even years, indicating potentially sustainable benefits. Indeed, 94.7 % of participants in our study reported a positive impact of functional mushrooms on the way seizures affected their life, with the majority (68.4 %) reporting at least some reduction or a significant reduction in both the severity and frequency of seizures (across different seizure types and including patients with DRE). 57.9 % reported a change in the frequency of hospital or physician-related visits. The Patient's Global Impression of Change (PGIC) scores, which was used to determine cutoff values for change scores that distinguish patients who have clinically improved from those who have not, [46] indicated 84.2 % of respondents reported a moderate to significant improvement in their diagnoses. Similarly, the Scale for Estimating the Prognosis of Epilepsy (SEPE), a tool used to predict the outcome of epilepsy for a patient, [44,47] indicated at least a positive outcome for 52.6 % of our sample, with 31.6 % likely to become seizure-free without the use of ASMs.

These generally positive, but preliminary, findings suggest that Reishi (*G. lucidum*) and Lion's Mane (*H. erinaceus*) have potential as a complementary/adjunctive treatment for epileptic seizures and supports earlier studies describing their neuroprotective and anticonvulsant properties and their implications in seizure outcomes. Prior research has

explored the efficacy of Reishi spore powder for treating epilepsy patients and found reduced average weekly seizure frequency, [25] and several research studies have shown that Reishi may reduce seizure frequency and improve QoL in patients with epilepsy. [25–27] Lion's Mane has demonstrated the ability to regenerate peripheral nerves in the early stages of recovery, as shown in a study on injured rat peroneal nerves. [56] Further investigation into the potential regenerative effects of Lion's Mane in the central nervous system in humans is therefore critical, especially as it relates to central neuronal regeneration or circuit reorganization in the context of epilepsy. Should further research corroborate these findings and provide a neurobiological basis for its use in epilepsy, it would substantiate long-term sustainable change in epilepsy patients which may hold potential as a breakthrough therapy.

4.2. Functional mushrooms as a potential treatment for improving non-seizure outcomes

The results of this study underscored improvements in non-seizure outcomes using several quantitative measures. The World Health Organization Quality of Life (WHOQOL-BREF) and Patient-Reported Outcomes Measurement Information System (PROMIS-10) Global Health scales, used to capture various aspects of wellbeing, did not reveal significant deviations from general population norms in physical, psychological, social, and environmental health. In a meta-analysis of 68 studies, Berto and colleagues found all studies agreed that psychological and social dimensions associated with epilepsy worsen QoL. [6] Furthermore, QoL improves when better seizure control is achieved by surgical or antiepileptic treatment, regardless of age. While epilepsy typically lowers QoL due to its impact on daily functioning, participants reported perceived benefits that allowed them to maintain QoL standards observed in the general population. These results resonate with studies that have linked improved seizure control to better mental and physical health outcomes. [40,49] However, participants generally reported poor sleeping habits with strong evidence of a sleep disorder, indicating that functional mushroom use in individuals with epilepsy may not be effective in improving sleep quality. Overall, functional mushrooms may provide additional benefits for individuals with complicated epilepsy, improving both seizure-related and non-seizure outcomes alongside standard epilepsy treatment. Although these findings are promising, further clinical evidence is required to validate these results.

Notably, we also observed a significant correlation between reduced perceived stress, reduced seizure severity, and decreased caregiver burden, as measured by the Perceived Stress Scale (PSS-10), Seizure Severity Questionnaire (SSQ), and Caregiver Burden Scale (CBS), respectively. These associations highlight the broader impact of improved seizure management on family dynamics and caregiver wellbeing which could support sustainable benefits for epilepsy patients and their families. Prior studies have shown that caregiver stress is directly influenced by the severity and frequency of seizures, [15] reinforcing the relevance of these findings.

4.3. Potential of functional mushrooms to produce seizure-freedom in drug-resistant epilepsy

Approximately one third of patients with epilepsy will become drug-resistant and continue to have seizures. [9] DRE remains a major clinical challenge associated with severe consequences on quality of life and prognosis, including higher mortality and morbidity, restriction on social activities, and caregiver burden. [57] Patients diagnosed with DRE have less than a 15 % chance of achieving seizure freedom. [13] 73.7 % of participants in our sample met criteria for DRE (prior use of ≥ 2 anti-seizure medications). Notably, of those 73.7 % ($n = 14$), 8 reported a significant reduction in the severity of seizures and 3 reported some reduction in the severity of symptoms following the administration of Lion's Mane and/or Reishi mushrooms. Further data collected from the

SEPE indicated at least a positive outcome for 52.6 % of our sample, with 31.6 % likely to become seizure-free without the use of ASMs. Considering the low likelihood of drug responsiveness of a patient with DRE, these preliminary reports warrant further research on the efficacy of functional mushrooms as a potential complementary treatment strategy for individuals diagnosed with DRE.

4.4. Qualitative outcomes support the therapeutic potential of functional mushrooms

The qualitative data complemented quantitative insights by providing detailed personal accounts which aligned well with descriptive data. Despite our quantitative data indicating that 68.4 % reported they experienced a change in the frequency and severity of seizures since beginning use of Lion's Mane and/or Reishi mushrooms, all qualitative reports included indications of overall reductions in frequency, duration, or severity of seizures in qualitative data. The discrepancy between these results may indicate uncertainty in which treatment was effective, since many participants employed several approaches to their treatment regimes. Improved seizure control emerged as one of the major themes from this analysis, with some participants noting a complete cessation of seizures or significant decreases in frequency and severity after beginning use of functional mushrooms. Cognitive and developmental improvements were frequently reported, particularly among children. Caregivers noted better memory, attention, the achievement of previously delayed developmental milestones, decreased fatigue, fewer anxiety episodes, greater emotional regulation, and increased prosocial behavior, suggesting that functional mushrooms may contribute positively to overall well-being and QoL. Together, these qualitative insights provide a compelling rationale for further investigation into the beneficial properties of these mushrooms, including anti-seizure properties, [25,37] neuroprotective function and cognitive enhancement, [29,34] and anxiolytic and antidepressant-like effects. [26,33] Additionally, with several reports in the current study of individuals achieving seizure freedom attributed to functional mushroom use, further investigations into these claims should be considered of utmost importance.

Participants often cited difficulties in determining effective dosages and attributing outcomes solely to functional mushroom use, as many were simultaneously implementing other therapies. This highlights a gap in standardized dosing information, suggesting the need for controlled clinical trials to establish therapeutic ranges and isolate specific effects. [32] The dissatisfaction expressed by participants regarding conventional epilepsy treatments also aligns with existing literature, highlighting the limitations of current pharmacological approaches due to efficacy or adverse events. [19] The study participants' motivation to seek complementary therapies is consistent with the growing interest in natural and complementary treatment modalities that offer fewer side effects and holistic benefits. [20]

Overall, a significant proportion of participants emphasized the need for more research and awareness of functional mushrooms as viable treatment options. This advocacy reflects the increasing patient-led push for integrating complementary therapies into mainstream healthcare. The holistic approach reported by participants, involving both natural and traditional methods, is consistent with findings that suggest synergistic effects when combining complementary therapies with standard treatment. [23]

5. Limitations and future research

This study has several limitations that should be considered when interpreting the findings. The study relied on a non-random convenience sample of individuals self-administering Lion's Mane and/or Reishi mushrooms to treat epilepsy recruited through specific non-profit organizations, which limits the generalizability of the findings. With only 19 participants (14 completed the interview), the study's small sample size further reduces the ability to generalize results to larger

populations. Furthermore, the use of a retrospective survey design and interview presents inherent limitations, as it relies on participants' past recollection of events and experiences, which may not be entirely accurate or detailed. The absence of a control group makes determination of causality between functional mushroom use and reported improvements not possible to infer. Self-report data is further subject to multiple biases wherein participants may report more favorable outcomes to align with perceived expectations. Since participants were already using or planning to use functional mushrooms, some inherent self-selection bias due to pre-existing beliefs or expectations regarding their effectiveness is expected. This could have resulted in overreporting positive outcomes and underreporting adverse effects. Additional potential limitations include placebo effects, lack of blinding, and generalizability to a broader population. This study provides preliminary insights into the potential benefits of functional mushrooms for epilepsy. Randomized controlled trials (RCTs) are necessary to establish causality, determine appropriate dosages, identify the distinct mechanisms of Lion's Mane and Reishi mushrooms, and assess safety and efficacy more rigorously. Clinical studies would allow for the control of confounding variables, such as how concurrent treatments or lifestyle changes influence these outcomes. These limitations highlight the importance of interpreting the study's findings as hypothesis-generating, preliminary, and exploratory. Future research should include larger, more diverse samples, use prospective designs, and incorporate clinical trials to validate these initial observations and provide more definitive conclusions.

5.1. Conclusions

The findings from this mixed-methods exploratory study underscore the potential benefits of using functional mushrooms, specifically Lion's Mane and Reishi, as an adjunct therapy for epilepsy management and drug-resistant epilepsy. Participants reported noticeable improvements in seizure control, cognitive gains, and QoL. Efforts to further understand how the incorporation of functional mushrooms as low-cost, underutilized, and sustainable materials for the treatment of epilepsy may potentially bolster global research initiatives and collaborations such as the World Health Organization global action plan on epilepsy and other neurological disorders. Limitations of the study design emphasize the need for future randomized controlled, large-scale clinical trials to establish the efficacy of these findings, optimal dosages, and safety of these mushrooms as part of epilepsy treatment regimens.

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CRediT authorship contribution statement

Heather Jackson: Writing – review & editing, Validation, Supervision, Resources, Funding acquisition, Conceptualization. **Sasha Kalcheff-Korn:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Funding acquisition, Data curation, Conceptualization. **Sarah-Kate Boylan:** Writing – review & editing, Validation, Resources, Methodology, Investigation, Funding acquisition, Data curation, Conceptualization. **Evan Cole Lewis:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Investigation, Conceptualization. **Todd Boylan:** Writing – review & editing, Funding acquisition, Conceptualization. **Hugo R. Seguin:** Writing – review & editing, Validation, Formal analysis, Data curation. **Quinn A. Darby:** Writing – review & editing, Writing – original draft, Visualization, Validation, Methodology, Investigation, Formal analysis,

Data curation, Conceptualization. **Matthew X. Lowe:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Matthew X. Lowe reports financial support was provided by Lily's Lighthouse. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

Data will be made available on request.

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