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# The feasibility, acceptability, and effectiveness of the multimodal, community-based LoveYourBrain Retreat program for people with traumatic brain injury and caregivers

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## ABSTRACT

**Purpose:** To evaluate the feasibility, acceptability, and effectiveness of the LoveYourBrain Retreat program using a pre-post, retrospective, concurrent triangulation mixed methods study.

**Materials and methods:** A 5-day, multimodal, residential Retreat intervention was designed to improve quality of life among traumatic brain injury (TBI) survivors and caregivers through mindfulness, movement, nutrition, art, and community-building. Eligibility included being a TBI survivor (>2 years post-injury) or caregiver, 18+ years old, independently mobile, able to communicate verbally, and a first-time participant. Self-reported quantitative and qualitative data were collected via electronic surveys pre- and post-retreat, analyzed separately, then combined. Paired t-tests assessed mean differences in scores on Quality of Life After Brain Injury Overall scale (QOLIBRI-OS) and NIH TBI/Neuro-QOL Resilience, Cognition, Positive Affect/Wellbeing, and Emotional/Behavioral Dysregulation scales. We assessed feasibility using sample characteristics and program frequency and retention, and acceptability using quality ratings. Content analysis explored perceived benefits and improvements.

**Results:** 68 People—53 with TBI and 15 caregivers—participated in one of three LoveYourBrain Retreats. Significant improvements were found in QOLIBRI-OS (6.91, 95%CI 1.88–11.94), Resilience (2.14, 95%CI 0.50–3.78), Cognition (2.81, 95%CI 0.79–4.83), and Emotional/Behavioral Dysregulation (2.84, 95%CI 0.14–5.54) among TBI survivors ( $n=41$ ). Mean satisfaction was 9.6/10 (SD = 0.64). Content analysis revealed community connection, reframing TBI experience, self-regulation, and self-care themes.

**Conclusions:** The LoveYourBrain Retreat is feasible, acceptable, and may be effective complementary rehabilitation to improve QOL among TBI survivors.

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Traumatic brain injury; caregiver; resilience; retreat; community-based rehabilitation; quality of life

## ► IMPLICATIONS FOR REHABILITATION

- Ongoing, holistic rehabilitation services are critical to quality of life for people with chronic traumatic brain injury (TBI).
- Residential retreats are a type of holistic, multimodal, community-based rehabilitation.
- LoveYourBrain Retreats improved quality of life, resilience, cognition, and emotional dysregulation among people with TBI.
- The integration of community connection, reframing TBI experience, self-regulation, and self-care may support adjustment to TBI.

## Introduction

Traumatic brain injury (TBI) is a serious public health concern with both short- and long-term consequences for the individual, family, and society. It is estimated that 5.3 million people are currently living with a TBI-related disability in the United States [1]. Cognitive and behavioral impacts to memory, attention, executive function, behavior management, and mood regulation make it particularly difficult for patients to engage in meaningful and productive life activities [2]. The physical challenges associated with TBI such as balance impairments, dizziness, fine motor deficits, visual changes, headaches, and chronic pain are often recurrent and long-term [3]. Mental health conditions (e.g., anxiety, depression, post-traumatic stress) also develop in people with no history of

psychopathology, and pre-existing conditions often intensify [4]. It is common for people with TBI to experience long-term psychosocial challenges from social isolation [5] and loneliness [6]. Despite participation in rehabilitation services, such disabilities often undermine a person's ability to participate in work, school, leisure activities, and their community [7], and result in low quality of life. A needs assessment of people with TBI and their caregivers concluded that more research is needed on rehabilitative interventions to improve quality of life [8].

Due to the complex and chronic nature of TBI, access to community-based rehabilitation that incorporate physical, psychological, social, emotional, and motivational components is important for improving quality of life among this population [9,10]. Residential retreats are one type of community-based

rehabilitation that present opportunities to improve the acquisition and application of skills in a variety of areas critical to functioning (e.g., mobility, social integration, perception of self, interpersonal relationships, and independent living skills) while in natural environments where they are used in daily activities. They also are conducive to the inclusion of multimodal therapies, which are intended to optimize treatment by delivering different types of therapeutic interventions together. Holistic, multimodal approaches are often necessary for complex conditions like TBI that impact multiple dimensions of functioning [11,12] and have been shown to be effective [13,14]. A systematic review on the effectiveness of residential retreats found sustained improvements in psychological, physiological, cognitive, and metabolic outcomes, including for people with chronic or complex conditions with neurological impacts [15]. For example, among people with multiple sclerosis, health-related quality of life increased by 11.8 and 19.5% at one year and five years, respectively, after a five-day residential retreat [16]. Similarly, a seven-day retreat improved quality of life and reduced psychological stress among breast cancer patients [17]. However, to our knowledge, no studies have investigated the effectiveness of holistic residential retreats for improving quality of life among people with TBI.

To fill this gap, the LoveYourBrain Foundation designed a five-day, multimodal, community-based residential retreat for people with TBI and their caregivers. The goal of this intervention is to improve participants' quality of life through the integration of psychosocial and mindfulness-based components, including mindfulness meditation, yoga, nutrition, art, and community building. The LoveYourBrain Retreat offers mindfulness meditation [18–20], gentle yoga [21,22], brain health nutrition [23,24], and art therapy [25,26] to improve mental, physical, and cognitive health. Community building processes and activities are designed to increase social connectedness based on McMillian's theory that sense of community is represented by membership, influence, integration and fulfillment of needs, and shared emotional connection [27]. Ultimately, research is needed to better understand the potential benefits of the LoveYourBrain Retreat program as a multimodal, community-based, complementary rehabilitation intervention for people affected by TBI. The aim of this study was to evaluate the feasibility, acceptability, and effectiveness of the LoveYourBrain Retreat program on quality of life for individuals with TBI and their caregivers.

## Materials and methods

The study was reviewed by the Dartmouth College Committee for the Protection of Human Subjects (#02000421). We adhered to the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines for cohort studies [28].

### Design

This pre-post, retrospective, concurrent triangulation mixed methods study evaluated data collected by the LoveYourBrain Foundation before and after people participated in a five-day residential LoveYourBrain Retreat program. Using a concurrent triangulation mixed methods design, both quantitative and qualitative data were collected simultaneously, analyzed separately, and then combined to provide a more nuanced understanding of acceptability and effectiveness [29].

### Participants

Participants were eligible for the study if they had participated once in a LoveYourBrain Retreat program in 2019 and gave permission to LoveYourBrain for their data to be used for research purposes. People were excluded from the study if they had withdrawn from a program before it commenced, were a repeat participant, and/or did not give permission for their data to be used for research purposes.

The LoveYourBrain Retreat program is open to adults 18 years of age or older who self-identify as having sustained a TBI, defined as a bump, blow, or jolt to the head that disrupts the normal functioning of the brain [1], are at least two years post injury, are independently mobile with or without assistive devices, can follow directions and communicate verbally, and agree to participate in interactive, group workshops. The program is also open to adult caregivers of people with a TBI, which includes non-parental family members, close friends, or partners/spouses who provide direct support with activities of daily living (e.g., driving, cooking, organizing, hygiene, socializing, etc.). LoveYourBrain Retreats follow a peer-support model [30–32], thus parents are not permitted to attend in a caregiving role. To facilitate greater diversity in TBI severity levels among participants, applicants with more severe impairment are encouraged to bring a caregiver to provide consistent support during the retreat. All participants must be able to communicate in English and be capable of traveling to and participating in a multi-day, overnight experience. LoveYourBrain generally prioritizes first-time participants to ensure equity of access, however, will allow people to attend more than once to support their rehabilitation goals and achieve the minimum threshold needed to operate a Retreat (i.e., 25 participants).

As part of the application process, potential participants submit an eligibility application for a specific retreat location. LoveYourBrain staff review each application to confirm eligibility and then invite each applicant to a 30-min video conference interview with the Retreat Manager. During the interview, applicants are asked to share about their TBI history, motivations for attending a LoveYourBrain Retreat program, what they are proud of about themselves, and what feels most challenging to them at the moment. This interview serves two primary purposes: to confirm that the information shared on the application is accurate and provide space for a member of the LoveYourBrain staff to clarify any confusion or questions about the program, and to help confirm suitability for LoveYourBrain Retreat by determining participants' readiness for an overnight, group-based immersive experience (e.g., emotional regulation, level of independent functioning, mobility, etc.).

### Setting

LoveYourBrain partners with residential facilities in diverse geographic regions of the United States (e.g., East, West, Midwest) that meet Americans with Disabilities Act accessibility standards. Facilities must be located in rural, natural environments (e.g., in mountains or lakeside) to minimize external stimulation and optimize the healing benefits of nature. They also must have proximity (i.e., within 60 miles) to a hospital and/or urgent medical facility and airport.

### Intervention

Beginning in 2014, the LoveYourBrain Foundation began offering a free, five-day, residential Retreat program for groups of 25 individuals with TBI and their caregivers in Vermont once a year.

Since that time, the curriculum was developed iteratively based on participant and health professional feedback and trauma-informed service best practices [33]. It became manualized in 2018 in preparation for scaling up implementation in 2019 to new locations (i.e., Maine and California). To remove financial access barriers, LoveYourBrain funds the program through annual fundraising initiatives so that participants can attend at no cost. Participants are invited to fundraise towards a goal of the true cost of attending (\$1,000 USD (at time of the study)). LoveYourBrain supports participants to conduct peer-to-peer fundraising through the secure platform, Classy. Participants are responsible for the costs of travel, so LoveYourBrain also offers limited travel scholarships up to \$200 USD to further support financial accessibility.

### **Staff and volunteers**

Each five-day program is staffed by a team of 2–3 Lead Facilitators, 1 Retreat Manager, 1–2 Support staff, 2 LoveYourBrain Ambassadors, 1 Head Chef, 3–4 Kitchen volunteers, 1 Mental Health Professional, and 1 Medical Professional. The ratio of participants to staff is approximately 4:1. LoveYourBrain trains and supports a growing pool of Retreat staff and volunteers to ensure sustainability and facilitate growth of the program. Lead Facilitators have professional expertise and/or personal commitment to the pillars of the LoveYourBrain Retreats (i.e., mindfulness, movement, nutrition, art, community building). They have received specialized training in TBI-specific group facilitation skills, hatha yoga, mindfulness, and/or brain injury from the LoveYourBrain Foundation. Lead Facilitators are responsible for setting the tone, leading the curriculum workshops, teaching yoga and mindfulness, and supporting the overall Retreat operations. The Retreat Manager oversees all day-to-day logistics, scheduling, participant and volunteer needs, and venue coordination. The Support staff work with the Retreat Manager to provide general assistance as needed. The Head Chef and Kitchen volunteers are responsible for providing all culinary needs, meals, and brain health nutrition education. The Mental Health and Medical Professionals include a mental health expert (e.g., social worker, neuropsychologist, clinical counselor) and physician or nurse who are responsible for supporting the psychosocial needs of participants and medication distribution. LoveYourBrain Ambassadors have a lived experience of TBI, strong leadership skills, exemplify what it means to live by the core components of the LoveYourBrain Retreats, and have attended a previous Retreat as a participant. They serve as peer mentors and take on a variety of leadership roles to support participants to deepen their understanding of the curriculum and connection to the community (e.g., proactively share insights during workshops, engage participants with a focus on those who may be less social, lead Breakout Group Workshops, and serve as residential assistants).

### **Curriculum**

The manualized curriculum blends experiential learning, didactic workshops, and structured rest time based on four areas: mindfulness, somatic movement, nutrition, art, and community building, as described below. Participants are encouraged to participate in as many of the activities as feels supportive, and are also empowered to opt out and rest, if necessary (e.g., symptomatic). The manual is available upon request, and the schedule outline is described in [Supplementary Material 1](#).

### **Mindfulness**

Mindfulness is the practice of paying attention to the present moment with an attitude of curiosity and kindness [34]. Practicing mindfulness has been shown to increase quality of life [19], improve perceived self-efficacy [18], reduce depression symptoms [19,35], improve attention [36], decrease PTSD symptoms [36], reduce fatigue [20], better regulate attention [18,36], and enhance working memory [37] among the TBI population. The LoveYourBrain Retreat offers a variety of opportunities for participants to learn about and practice mindfulness, including a 60-min experiential *Mindfulness Workshop* that educates participants about mindfulness, why it is beneficial for healing from TBI, and how to practice it using a guided mindfulness meditation and a mindful eating exercise. A 60-min *Intention Setting Workshop* educates participants about mindfulness and intentions as tools for skillfully working with automatic negative thoughts, and provides a step-by-step exercise for how to set intentions relevant to adjusting to life post-TBI. Finally, 45 min yoga nidra guided relaxation is offered twice as an evening activity to support relaxation, quality sleep, self-awareness, and anxiety management [38,39].

### **Somatic movement**

Somatic movement is movement that is consciously performed to promote body-mind integration [40]. In the TBI population, research on yoga as a somatic movement practice has found improvements in quality of life, physical (i.e., balance, strength, endurance [41], respiratory, [42]), and psychological functioning (mood [21]), and cognitive health [21,22,41–43]. LoveYourBrain Retreats offer two morning 60-min gentle hatha yoga classes adapted from the LoveYourBrain Yoga curriculum [21]. Classes are led by Facilitators who are experienced, certified yoga teachers with specialized training from the LoveYourBrain Foundation in accessible yoga for TBI.

### **Brain health nutrition**

Brain health nutrition encompasses an understanding of how a healthy relationship with food and food choices can impact brain health. People with TBI whose diets fail to meet the Recommended Daily Allowance by the Food and Nutrition Board at the Institute of Medicine of the National Academies are more likely to experience worse neurobehavioral scores [23]. The LoveYourBrain Retreat serves all meals communally, with staff and participants gathered in small groups to support intimate conversation and community building. The menu is designed specifically to support brain health with an anti-inflammatory emphasis, dense in nutrients, including polyphenols to enhance brain-derived neurotrophic factor [24,44], and elimination of processed sugar. The Head Chef educates participants about the key ingredients that support brain health before every dinner, and also offers a 30-min experiential *Brain Health Nutrition workshop* to inform participants about gut health, anti-inflammatory eating, and practical at-home cooking techniques. Two silent breakfasts are offered as opportunities to practice mindful eating, followed by 15 min of facilitated discussion to reflect on and deepen participants' understanding about their experience.

### **Art therapy**

Throughout the week, participants engage in a three-session, project-based *Art Inquiry Workshop* to create a mask, symbolic of the masks they wear to both reveal and conceal elements of their identities as they navigate their TBI journey. Participants are asked to reflect on the following prompt to guide their mask making process: "In your TBI journey, what aspects of yourself do you

share with others and what do you hide?" Participants first work collaboratively with a partner to create the plaster mask, and then, in the following session, work independently to decorate it. In the third session on the final day, participants are invited to share their reflections to the full group on the process of making their mask and what it reveals about their identity in this stage of their healing journey. The process of working with a partner intimately and over time, then having a common symbol (i.e., mask) to frame conversations about the TBI experience, is designed to deepen the felt-sense of shared emotional connection [27], normalize and validate TBI and caregiving experiences, and further self-understanding [25,26].

### **Community building**

Community building is defined as creating a sense of belonging, shared values, fulfillment of needs, and emotional connection among a group [27]. The LoveYourBrain Retreat offers a structure and range of activities to generate a deep and lasting sense of community. For example, the Retreat is structured so that participants are assigned a daily "contribution" (e.g., clearing plates after meals, setting up and cleaning up yoga mats, ringing a bell for time management) to create a culture where everyone feels able and willing to help one another and receive help in return. On the first full day, the participants are invited as a full group to join *Our Stories Matter Workshop* to share their story about their TBI experience and their superhero. The intimacy, emotional vulnerability, and expression of shared experiences is designed to facilitate a deep bond between participants [27]. Also, to give participants power to shape what happens in the Retreat environment, participants are asked to choose topics for a range of 30-min *Breakout Workshops* (e.g., navigating relationships after a TBI (e.g., communication strategies, connection support), the role of caregiving (e.g., setting boundaries), sexual and reproductive health (e.g., intimacy), and accessibility tools (e.g., dictation apps, social connectivity apps)) that are facilitated by LoveYourBrain Ambassadors. Participants then select which *Breakout Workshops* they find meaningful to attend. Finally, to further a sense of personal relatedness and identification with the group, the LoveYourBrain Retreat includes a midweek *Fire and Music Night* where participants gather around a campfire to sing songs and connect with one another organically. On the last night, participants join a *Talent Show* to showcase their diverse abilities (e.g., music, arts, performance, photography, athletics) and celebrate the Retreat experience together.

### **Recruitment**

Recruitment to this study was based on whether prospective participants granted written consent for their data to be used for research purposes when completing the LoveYourBrain Retreat program electronic eligibility and feedback forms. Specifically, participants must have responded "yes" (instead of "no") to the following question "Do you give LYB permission to use the information you provide for research purposes? (LYB will never share your name or contact details)."

Recruitment to the LoveYourBrain Retreat program includes a range of methods LoveYourBrain uses to raise awareness and promote referral, with particular emphasis on facilitating equitable participation among people with mild, moderate, and severe TBI. First, LoveYourBrain has established connections with a network of health professionals across the United States, including physical therapists, neuropsychologists, physicians, occupational therapists, social workers, and clinical psychologists, serving patients across

the continuum of TBI severity. Medical professionals refer their patients to the Retreat as an opportunity to learn new tools for supporting quality of life after TBI. Second, LoveYourBrain leverages its relationships with brain injury advocacy organizations (e.g., Brain Injury Associations/Alliances, brain injury and caregiver support groups) to disseminate information about the program to their members through their newsletters, conferences, and websites. Third, LoveYourBrain advertises the Retreat program through its own social media, newsletters, and other programming.

### **Data collection and measures**

Data included in this study comprised self-reported quantitative and qualitative data collected electronically in eligibility and feedback form surveys pre- and post-retreat. Specifically, prospective participants are required to complete an electronic eligibility form up to six months before the start of the program. This form takes approximately 10–15 min to complete and includes questions about eligibility, demographic characteristics, injury-related history, five clinical outcomes (see below in *Effectiveness*), motivations for signing up, permission to use data for research, and a waiver of liability. After the program is over, participants are asked to complete an electronic feedback form within two weeks. This form includes the same five clinical outcomes as well as other quantitative and open text qualitative questions about program quality, benefits, and areas for improvement. LoveYourBrain sends two reminder emails one week apart if the feedback form has not been submitted within that time period.

### **Sociodemographic characteristics and injury history**

Sociodemographic (i.e., race, ethnicity, age, gender, self-identification as a TBI survivor or caregiver) and injury-related questions (i.e., injury severity (i.e., mild, moderate, severe), time since injury) were collected in the eligibility form. People who experienced a TBI were asked to respond to the question, "Do you currently experience any of the following conditions?" with an option to select any of the following symptoms: light sensitivity, hemiparesis, post-traumatic stress or PTSD, paralysis on one side of the body, post-concussion syndrome, and/or seizures.

### **Feasibility**

To assess feasibility, the extent to which an intervention can be successfully conducted within a specific setting [45], we described the number and location of programs using data provided by the LoveYourBrain Foundation. We also described the number of people who signed up, completed (i.e., attended 3 or more out of the 5 days), and did not complete (attended less than 3 out of the 5 days) each program, and TBI severity characteristics of our sample.

### **Acceptability**

To assess acceptability, the perception that components of the intervention (e.g., content, complexity, or comfort) are satisfactory [45], participants were asked in the feedback form to respond to the question, "On a scale from 1 to 10, how would you rate this program?" (1 "poor" to 10 "excellent"). Participants were also asked whether they would recommend attending a LYB Retreat to a friend with response options including "Definitely yes," "Probably yes," "Probably no," and "Definitely no."

For the qualitative analysis, data was analyzed from participant responses to three out of the four open text questions in the feedback form: "Please provide any feedback on the activities. What would you change? What would you want more or less of?";

"If you could pick one moment that was the most meaningful to you at the retreat, what would it be?"; and "What else would you like us to know?"

### **Effectiveness**

To assess effectiveness, five quantitative outcomes were collected in the eligibility and feedback forms using the *Quality of Life After Brain Injury overall* scale [46], the *Emotional and behavioral dysregulation* scale from the Neurology Quality-of-Life measurement initiative (Neuro-QoL), a set of self-report measures that assess the health-related quality of life of people with neurological disorders [47], and *Positive affect and well-being, Resilience, and Cognition: General Concerns* from the TBI-QoL, a set of self-report measures adapted from the Neuro-QoL measures specific to the TBI population. TBI-QoL item banks have demonstrated validity [48], responsiveness to change, and measurement stability [49].

**QOLIBRI overall scale.** The primary outcome was quality of life, as measured by the Quality of Life After Brain Injury overall scale (QOLIBRI-OS) (Cronbach's  $\alpha=0.85$ , test-retest reliability = 0.81) [46]. Participants were prompted to respond to six questions with a rating using a 1–5 Likert Scale (1 "Not at all," 2 "Slightly," 3 "Moderately," 4 "Quite," and 5 "Very"). The questions were presented with the opening statement, "These questions are about how you feel overall now (including in the past week)". The six ratings were then summed for each individual to give a total, then divided by the number of responses to give a scale mean (range 1–5), and finally converted to a 0–100 scale.

**Emotional and behavioral dysregulation v1.0 (Neuro-QoL).** To assess emotional regulation which is described as a "set of disease and/or treatment related to manifestations including disinhibition, emotional ability, irritability, impatience, and impulsiveness," participants responded to the Emotional and Behavioral Dysregulation v1.0 SF8 from the Neurology Quality-of-Life measurement initiative (Neuro-QoL). The Neuro-QoL psychometrically measures outcomes in clinical trials research assessing Physical, Emotional, Cognitive, and Social Health of people with neurological disorders (i.e., stroke, MS, ALS, Parkinson's disease, epilepsy, and muscular dystrophy) [47]. Participants are presented with an opening statement, "In the past seven days..." and asked 8 questions rated on a 1–5 Likert scale (1 "Never," 2 "Rarely (once)," 3 "Sometimes (two or three times)," 4 "Often (about once a day)," and 5 "Always (several times a day)"). The raw scores are summed and then converted to a T-score. A lower score represents lower emotional and behavioral dysregulation which is described as higher functioning.

**Positive affect and well-being v1.0 (TBI-QoL).** Positive affect, defined as "aspects of a person's life that relate to a sense of well-being, life satisfaction or an overall sense of purpose and meaning," was measured using the Positive Affect and Well-being v1.0 SF 9a from the TBI Quality-of-Life measurement system (TBI-QoL). The TBI-QoL consists of adapted self-report measures from the Neuro-QoL for the TBI population with demonstrated validity [48,50], responsiveness to change, and measurement stability [49]. Participants were presented with an opening statement, "Lately..." and rated 9 questions on a 1–5 Likert scale (1 "Never," 2 "Rarely," 3 "Sometimes," 4 "Often," and 5 "Always"). The raw scores are summed and then converted to a T-score. A higher score represents more positive affect and well-being and therefore, better functioning.

**Resilience v1.0 (TBI-QoL).** Resilience, defined as the ability to adapt to and/or overcome adversity [51], was measured utilizing the Resilience v1.0 SF 10a from the TBI-QoL. Participants were presented with an opening statement, "Lately..." and rated 10 questions on a 1–5 Likert scale (1 "Never," 2 "Rarely," 3 "Sometimes," 4 "Often," and 5 "Always"). The raw scores are summed and then converted to a T-score. A higher score represents more resilience representing better functioning.

**Cognition: general concerns v1.0 (TBI-QoL).** Cognition, which includes "perceived difficulties in cognitive abilities (e.g., memory, attention, and decision making), or in the application of such ability to everyday tasks (e.g., planning, organizing, calculating, remembering and learning)," was evaluated using the Cognition: General Concerns v1.0 SF10a from the TBI-QoL [50]. After being presented with the opening statement, "In the past seven days..." participants rated 10 questions on a 1–5 Likert scale (5 "Never," 4 "Rarely (once)," 3 "Sometimes (two or three times)," 2 "Often (about once a day)," and 1 "Always (several times a day)"). The raw scores from the TBI-QoL are summed and then converted to a T-score. A higher score represents more cognition which relates to better functioning.

For the qualitative analysis, data was analyzed from participant responses to three out of the four open text questions in the feedback form: "What were your top three learnings from the retreat?"; "If you could pick one moment that was the most meaningful to you at the retreat, what would it be?"; and "What else would you like us to know?"

## **Data analysis**

### **Quantitative analysis**

Descriptive statistics were used to describe the measures of feasibility and acceptability. We analyzed sample characteristics, and considered LoveYourBrain Retreats to be feasible if there was >10% representation of each category of mild, moderate, and severe TBI. Feasibility was also demonstrated if programs met the minimum threshold of at least 25 participants with  $\geq 15$  first-time participants and >90% completing each program. We analyzed the mean quality rating for the full sample and also separately for participants who identified as TBI survivors and caregivers. We considered LoveYourBrain Retreats to be acceptable if the mean satisfaction rating was at least 9.0 overall and per subgroup.

To assess effectiveness, paired t-tests were performed to analyze differences in mean scores from baseline to post-retreat for each outcome. Analyses of effectiveness comprised non-missing, linked outcome data in eligibility and feedback forms from participants. If people had missing outcome data (e.g., due to failure to submit a feedback form, permission not granted for data to be used for research on either the eligibility form or the feedback form) participants were excluded pairwise. Statistical significance was assessed at a  $p < 0.05$  level. All analyses were conducted using Stata/IC 16.1.

### **Qualitative analysis**

To further assess acceptability and effectiveness, we used conventional content analysis to analyze qualitative data from open text responses about perceived benefits and areas for improvement [52]. Two members of the research team (SZ and KZD) immersed themselves in the data and collaboratively developed the initial coding structure. The research team met periodically to compare findings, share perspectives, and reconcile discrepancies in order to iteratively expand, refine, and agree upon the coding structure and emergent themes. The findings were then integrated into the

quantitative results by using the qualitative data to illustrate, triangulate, and further expanded upon quantitative findings [53]. To enhance the trustworthiness of our analysis [54], we provided thick descriptions of the LoveYourBrain Retreat program delivery context and process and maintained an audit trail to keep notes about decisions made during analysis [54]. Dedoose version 8.1.8 was used to facilitate qualitative data analysis by managing the data.

## Results

### Feasibility

The LoveYourBrain Retreat program was successfully offered three times in 2019, including twice in Maine and once in California. No programs were canceled due to low enrollment (i.e., <25 participants). Of the 85 participants who had completed the eligibility form, 17 people were excluded because two people did not give permission for their data to be used for research and 15 people were second-time participants. The final sample of 68 first-time participants included 53 people with TBI and 15 caregivers. Of the 68 eligible participants, 27 people participated in a program in May 2019, 15 people participated<sup>1</sup> in a program in September 2019, and 26 people participated in a Retreat in November 2019, all of which met the threshold to be considered feasible. Only two out of the 68 participants (2.9%) did not complete the program (i.e., attended less than 3 out of the 5 days). These participants were both individuals with TBI.

Demographic and injury-related characteristics of participants with TBI are described in Table 1. There was comparable proportions of mild, moderate, and severe TBI, suggesting that feasibility was met. Of the list of current conditions presented to participants, 26.4% reported experiencing light sensitivity, 22.6% reported post-concussion syndrome, 15.1% reported PTS or PTSD, 1.9% reported paralysis on one side of the body (hemiplegia),

**Table 1.** Demographic and injury-related characteristics of people with TBI ( $n = 53$ ).

Characteristic	Freq. (%)
Mean years post-injury	6.3 (SD 6.2)
Severity	
Mild	13 (24.5)
Moderate	14 (26.4)
Severe	20 (37.7)
Missing	6 (11.4)
Age	
18–34	23 (43.4)
35–54	17 (32.1)
55–70	6 (11.3)
Missing	7 (13.2)
Gender	
Male	16 (30.2)
Female	35 (66.0)
Genderqueer, neither exclusively male nor female	1 (1.9)
Missing	1 (1.9)
Race	
White	44 (83.0)
Black or African American	2 (3.8)
Asian	2 (3.8)
American Indian or Alaska native	1 (1.9)
Some other race(s)	1 (1.9)
Two or more races	2 (3.77)
Missing	1 (1.9)
Ethnicity	
Hispanic	0 (0.0)
Not of Hispanic, Latino, or Spanish origin	52 (98.1)
Missing	1 (1.9)

5.7% reported weakness on one side of the body (hemiparesis), and 13.2% reported none.

### Acceptability

Nearly all participants (98.3%,  $n = 59$ ) responded “Definitely yes” when asked whether they would recommend a LoveYourBrain Retreat to a friend. The mean quality rating was 9.6 (SD 0.64) out of 10, which was similar for participants with a TBI (9.7 SD 0.57) and caregivers (9.3 SD 0.75), and thus demonstrated acceptability.

Content analysis revealed that the program was highly acceptable, particularly the activities and group dynamics. Specifically, participants commonly described the opening *Our Stories Matter Workshop* as very impactful and important for setting a tone of vulnerability, inclusion, and connection for the remainder of the Retreat. They also found the art project and mindfulness workshop, yoga nidra meditations, and the intention setting exercise as particularly useful for self-exploration and self-expression. One participant shared that, “Intention setting was valuable for me. I don’t normally quiet myself enough to figure out what my intentions for myself are.” [ID 85, female, caregiver]. A majority of participants (78.3%,  $n = 47$ ) expressed that they valued the opportunities to connect with others in multiple formats, including one-on-one conversations, smaller groups, and with the full group. A participant shared how “all people are different, community is important, LYB creates communities” [ID 52, male, TBI]. Finally, participants often noted that the welcoming and supportive environment of the Retreat staff was instrumental to their experience and enhanced their sense of safety and empowerment to advocate for their needs. One participant shared that “not being afraid to ask for what I need (quiet, a break, support, love)” [ID 3, female, TBI] was meaningful to her healing process.

About half of participants offered suggestions for improvement ( $n = 36$ ), including, most commonly, changing the order of activities in the schedule, more breakout sessions, and more breaks in general. For example, some participants shared that they would have appreciated more time to connect with others within the community while others had hoped to have more yoga and meditation practice available. Also, participants sometimes felt that breakout sessions were rushed or not available, so suggested allocating more opportunities to participate and offering them for a longer duration.

Breakout sessions on different topics – need more; perhaps each night have a topic. I was frustrated due to wanting to attend more than 2 topics + allow the space to chat with all not just 30 min [ID 5, female, TBI]

While participants universally shared that they valued the scheduled activities, some suggested more formal breaks were necessary. These individuals shared that due to cognitive fatigue it was hard to find energy to socialize after a full day of activities. Some participants also found it difficult to sufficiently rest during the day when they felt that the break time was the primary opportunity to socialize outside of the scheduled activities.

I found it a bit challenging to socialize as many of the opportunities to do so were in the evening or later in the day once my energy was lowered. Perhaps could have been helpful for me if some of the learning sessions were switched to later as interacting with people takes much energy/brain power than solo thinking/listening/contributing [ID 83, female, TBI]

### Effectiveness

#### Quantitative analysis

A total of 41 participants with TBI completed both pre- and post-intervention assessments and were included in analyses of

**Table 2.** Mean scores in pre- and post-intervention periods for participants with TBI ( $n = 41$ ).

Outcome	Pre Mean (SD)	Post Mean (SD)	$p$
QOLIBRI-OS	52.4 (14.8)	59.3 (15.7)	0.008
Resilience	49.1 (6.6)	51.2 (6.8)	0.012
Cognition*	35.8 (6.5)	38.6 (5.9)	0.008
Emotional and behavioral dysregulation	50.0 (5.6)	47.2 (7.1)	0.039
Positive affect and wellbeing	51.8 (6.2)	53.3 (6.6)	0.095

\*Note Four participants had missing data on cognition, so the sample comprised 37 participants for this analysis.

effectiveness. Significant improvements from pre- to post-Retreat were found in the QOLIBRI-OS (6.91, 95% CI 1.88 – 11.94), Resilience (2.14, 95% CI 0.50 – 3.78), Cognition (2.81, 95% CI 0.79 – 4.83), and Emotional and Behavioral Dysregulation (2.84, 95% CI 0.14 – 5.54), as shown in Table 2. Although not significant, trends in improvement in Positive Affect and Wellbeing were also observed (1.57, 95% CI 0.28 – 3.42).

### Content analysis

Perceived improvements among people with TBI and caregivers were found in four themes: community connection, reframing TBI experience, self-regulation, and self-care.

**Community connection.** Both caregivers and individuals with TBI found that the LoveYourBrain Retreat program provided a unique opportunity to connect with individuals with similar circumstances. Nearly all participants shared that the felt-sense of community connection was one of the most meaningful parts of their experience. As one participant put, “I am not alone in this brain injury journey” [ID 8, female, TBI]. Many participants reflected on the growth and strength of community building as the week went on with a majority noting the opening *Our Stories Matter Workshop* as a strong bonding experience. For example, a participant expressed how “the most impactful was group share first night. It was essential to the success of the retreat. Once participants were able to be vulnerable, healing and open dialogue could begin. It set a tone of community for the week” [ID 78, male, TBI]. Another participant observed that the authenticity in how people connected fostered a depth of community connection.

I went into the retreat not knowing anyone and left feeling like family. It was so cool to see how each person was accepted and appreciated for exactly who they were and what they had gone through. There was something so powerful in spending the week with 50 people engaged in that level of authenticity. [ID 81, female, TBI].

Similarly, caregivers found that being in an immersive space with other caregivers and people with TBI was beneficial. Most caregivers noted that connecting with this community gave them a chance to relate to others in a similar caregiving dynamic, validate their experience, and feel less alone. They also shared the value of seeing a diversity in the severity and manifestations of TBI, which gave them more context to better understand their loved one’s experiences.

**Reframing the TBI experience.** Some people with TBI and caregivers expressed that the LoveYourBrain Retreat provided them with new tools to reframe the TBI experience to see greater possibility. For example, people with TBI ( $n = 16$ ) shared that they learned how to become more accepting of themselves and their healing journey, and began approaching life with greater resilience and optimism. One participant shared that “resilience is absolutely possible. It’s okay to mourn the ‘old me’ as long as I

learn to accept the ‘new me’” [ID 46, female, TBI]. People with TBI also described feeling motivated by learning about different healing modalities, such as brain health nutrition, mindfulness, gentle yoga, and creating a strong community. For example, some participants reflected how they were unaware of the importance of nutrition on their brain health and they appreciated learning about the effects of different foods on the brain. Many participants also shared that learning how to be mindful throughout the day rather than just during formal meditation enhanced their ability to focus, be more present, manage their emotions, and respond instead of impulsively react to their circumstances, which contributed to a greater sense of self-efficacy.

Most caregivers shared that the LoveYourBrain Retreat provided them with a unique perspective to view the varying impacts of brain injury. In particular, they described how they felt increased empathy for and understanding of a broader range of TBI experiences, and recognized the need to shift priorities and become more accepting of the people they care for.

I learned about the vastness of TBI’s. Everyone’s struggles are different even with the same type of injury. I will have more understanding and patience for people, understanding that not all TBI’s are visible on the surface. [ID 75, female, caregiver].

**Increased self-regulation.** About a quarter of participants described the positive impact of practicing mindfulness, gentle yoga, and yoga nidra meditation on their ability to regulate emotions and negative thought patterns. For example, participants felt that learning how to incorporate practical mindfulness tools (e.g., awareness of breath, body, thoughts, environment) into their daily routine at the LoveYourBrain Retreat helped them better regulate feelings of anxiety or discomfort both during and following the Retreat. Indeed, some participants described that they felt outside of their comfort zone at the LoveYourBrain Retreat, but that “coming back to the breath” made it easier to manage situations that would typically cause anxiety. For example, one participant shared how she felt empowered by her new mindfulness skills to more effectively manage her anxiety and participate in the talent show performance with less intimidation.

I am noticing my thoughts more, how some are positive and others contribute to anxiety and unhelpful patterns, and working on loving myself and allowing myself to be loved for the person I am now... As anxious as I get and was performing [at the Talent show], it was important to me to do so in front of others as vulnerability was respected and honored and I LOVED all the performances. Filled me with such awe, joy and love. [ID 6, female, TBI]

**Improvement in self-care.** About a quarter of people with TBI expressed that the LoveYourBrain Retreat instilled new, practical, and diverse habits for improved self-care that were sustained following the program. These participants felt that they could rely on the range of new tools learned at the Retreat to achieve “better self-care through yoga, rest & nutrition” [ID 10, female, TBI]. For example, learning how to make simple, brain health recipes during the *Brain Health Nutrition workshop* with common foods that could be repurposed in different ways motivated and enabled people to try them at home.

I learned so much about nutrition – discovered I was already drawn to some of the foods at home but learned new foods as well as new combinations of foods I was familiar with. [ID 18, female, TBI]

These participants also shared that, for the first time, they felt capable of both determining what they needed to recharge and attending to their needs. For example, participants expressed that they had a better sense of when they needed to step away from



a group event to preserve energy and felt more empowered to choose to go to bed earlier or take a midday nap to recuperate.

## Discussion

The major finding of this study suggests that participating in the LoveYourBrain Retreat significantly improved Quality of Life, Resilience, Cognition, and Emotional and Behavioral Dysregulation among people with TBI, and led to perceived benefits among people with TBI and their caregivers in community connection, adaptive reframing of the TBI experience, self-regulation, and self-care. To the best of our knowledge, this study is the first to investigate the impact of a multimodal, community-based residential retreat for people with TBI, and therefore starts to fill an important gap in understanding the potential of this type of complementary intervention for this underserved population.

Before discussing the implications of our results, the limitations and strengths of this study are important to note. First, the pre-post, single-arm, design is subject to confounding, so we suggest future research include a non-intervention control group to draw more reliable inferences into the causality of potential effects. We also recommend exploring innovations in trial designs (e.g.,  $2 \times 2$  factorial designs) to more accurately detect and quantify the synergistic or additive effects of the intervention components [11,12]. Second, the use of self-reported measures may have introduced response bias, so we suggest using more reliable data collection methods for brain injury severity (e.g., medical record review) and symptoms (e.g., objective measures), which would not have been feasible in this study design. Third, the survey data was collected outside of the research setting, which may have contributed to higher frequency of missing data for some demographic characteristics (i.e., loss of consciousness and symptoms for the first retreat program). Also, data was not obtained on ineligible participants who did not give permission for their data to be used for research, so we were unable to examine if this introduced selection bias. Yet, by conducting our study in a “real world” setting, we maximized ecological validity and thus avoided bias inherent in clinical trials (e.g., limited reproducibility of intervention, highly selective study population, rigid intervention protocols that are not applicable to everyday life) [55]. Also, our choice to use a concurrent triangulation mixed methods design, which combines quantitative and qualitative analysis, allowed for a richer understanding of the results. Fourth, our sample was homogenous in terms of race/ethnicity and thus the results are not generalizable to racially underrepresented groups. Given the disparities in the risk and outcomes of TBI among Black and Hispanic communities [56], it is critical to design and investigate holistic, multimodal interventions for these marginalized groups. In contrast, our sample was diverse in terms of TBI severity, which enhances the generalizability of the results to people across the continuum of mild-moderate-severe TBI. Finally, we were unable to perform long-term follow-up of TBI outcomes to assess if effects were sustained, nor investigate any differences in how subgroups responded to the intervention, and therefore suggest these areas as important for future research.

Our results have several important implications. First, the significant improvements in a range of patient-reported health outcomes suggest that the LoveYourBrain Retreat may be an effective means of multimodal, community-based rehabilitation among people with chronic TBI. Notably, our sample’s QOLIBI-OS baseline mean (i.e., 52.4) is consistent with the threshold for impaired QOL (i.e., <52) [57], suggesting participants may have experienced meaningful changes in their QOL with the significant

increase in post-retreat scores to above this threshold. Data on minimally important difference thresholds for the TBI-QOL measures are limited, so we recommend further investigation to better assess if the score changes are meaningful and perceptible to participants [58]. Yet, our qualitative data suggests that participants perceived improvements in cognitive, emotional, and social functioning, all core aspects of QOL [50]. Our results are also consistent with other evidence that gentle yoga and mindfulness modalities can meaningfully improve a range of health and QOL outcomes for people with TBI [59]. However, to our knowledge, our intervention expands upon previous research in that it combines the delivery of mindfulness and gentle yoga with other evidence-based modalities, including brain health nutrition [23,24], art therapy [25,26] and community building [60]. This is important given emerging evidence that a combination of different modalities, rather than the individual components, may produce additive or synergistic effects on neuroplasticity underpinning rehabilitation from brain injury [61–63]. The high satisfaction ratings also suggests that this particular combination of psychosocial and mindfulness-based modalities was not only acceptable, but also dovetailed in such a way that participants could integrate and apply the skills from each component across all five day to optimize learning. However, we recommend future interventions of this nature include more formal breaks and opportunities for rest to mitigate cognitive fatigue and thus maximize retention and overall benefit.

Our qualitative results suggest that participants’ with TBI experienced meaningful community connection and a renewed sense of self, which may enhance adjustment to TBI and life satisfaction [64]. This is consistent with society identity theory, which posits that groups with shared experience give us a sense of belonging and self-esteem [65]. Previous research has found that following brain injury, people make sense of themselves in terms of the meanings and felt experiences of social activity, which contrasts the more traditional medical model of defining identity by impairments and abilities [66]. The Retreat’s emphasis on activities that facilitate self-reflective meaning making in a group with shared lived experiences may be a means to positively influence sense of self and identity [67], life purpose, and motivation and goals for future behavior [68]. This is important given that TBI survivors’ ability to positively cope with and adapt to trauma, known as post-traumatic growth, are facilitated by changes in self-views (e.g., appreciation of personal strengths and greater awareness of new possibilities for one’s life) and depth of connection in relationships [69]. Caregivers also perceived benefits to adjusting to TBI, community connection, personal self-care, and self-regulation. This is promising given that interventions designed to support or involve caregivers of people with TBI have demonstrated variable benefits [70], even though caregivers’ wellbeing directly corresponds to TBI survivors’ wellbeing [71]. Further research that examines quantitative caregiver-specific outcomes is an important area of future research.

Because facilitating adjustment and emotional re-integration is central to the holistic model of rehabilitation, LoveYourBrain Retreats may be a useful complement to rehabilitation models that emphasize other strategies (e.g., compensatory [72]) to improve outcomes based on patients’ goals and needs [73]. Indeed, our findings that the LoveYourBrain Retreat was feasible to implement in different environments and for a sample with diverse TBI severity levels and time since injury has important implications on expanding access to holistic, community-based rehabilitation services. Despite calls for ongoing support programs that focus on mental health, emotional support, and leisure to

enhance quality of life for TBI survivors decades after injury [74], significant access barriers remain [75]. However, the LoveYourBrain Retreats are designed to be scalable (i.e., manualized design for fidelity [76]), sustainable (i.e., growing the pool of human, technical, and organizational resources [77], a funding model independent of insurance coverage), and accessible (i.e., inclusive of diverse TBI severities, racial/ethnic backgrounds, and socioeconomic statuses (SES)) so that it has potential to be part of a continuum of services to benefit people with TBI and their caregivers. To further support accessibility among disproportionately underserved groups (e.g., Black and Hispanic [56], LGBTQIA+ [78], and lower income communities [79]), we recommend strategies for improving relational coordination between LoveYourBrain and key stakeholders (e.g., churches, Pride Centers, public housing agencies) [80], increasing representation of underserved groups in retreat staff and volunteers [81], integrating group-specific needs in the intervention design [82], and offering additional financial support (e.g., greater travel scholarships).

In conclusion, high satisfaction and significant improvements in health outcomes from participating in the LoveYourBrain Retreat suggests this type of multimodal, community-based, complementary intervention may improve the quality of life of people affected by TBI. It appears to create a sense of belonging, fulfillment of needs, and shared emotional connection, which may facilitate adjustment to TBI and have a lasting impact on well-being. Further research using a randomized design and caregiver-specific and longitudinal outcomes is warranted.

## Note

1. 30 people participated in this Retreat, however, 15 people were second-time participants so were excluded from this study.

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## Author contributions

Kyla Z Donnelly: conceptualization; data curation; investigation; methodology; project administration; software; supervision; writing – original draft; writing – review & editing. Jenna Nelson: software; formal analysis, writing – original draft; project administration. Shilo Zeller: formal analysis; writing – original draft. Amber Davey: project administration; writing – original draft. Drew Davis: writing – original draft.

## Disclosure statement

No potential conflict of interest was reported by the author(s). All authors have reviewed the ICMJE uniform disclosure form and declare: KZD is employed by the LoveYourBrain Foundation, a non-profit, for whom she led the design of the curriculum for the LoveYourBrain Retreat program. KZD is married to the Executive Director of the LoveYourBrain Foundation. JN, SZ, AD, and DD have no relationships or activities that could appear to have influenced the submitted work.

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