

Original Article

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
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From “surviving to thriving”: Mood Lifters – a wellness program for parents of medically complex children

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Abstract

Objectives. Parents of medically complex children juggle unique demands associated with caring for chronically ill children, many of which negatively impact their mental wellbeing. Despite this, parents of medically complex children often forgo mental health support due to concerns with costs, time, stigma, and accessibility. There is limited research on evidence-based interventions addressing such barriers for these caregivers. We piloted an adapted version of Mood Lifters, a peer-led wellness program, to equip parents of medically complex children with evidence-based strategies to manage their mental health while also reducing barriers to support. We hypothesized parents would find Mood Lifters to be feasible and acceptable. Further, parents would experience improvements in mental wellbeing upon program completion.

Methods. We conducted a single-arm prospective pilot study to assess Mood Lifters for parents of medically complex children. Participants included 51 parents in the U.S. recruited from a local pediatric hospital providing care for their children. Caregiver mental wellbeing was assessed through validated questionnaires pre-intervention (T1) and post-intervention (T2). Repeated-measures analysis of variance was conducted to evaluate change between T1 and T2.

Results. Analyses from T1 and T2 ($n = 18$) revealed improvements in parents' depression ($F(1,17) = 7.691, p = 0.013$) and anxiety ($F(1,17) = 6.431, p = 0.021$) after program completion. Improvements in perceived stress and positive and negative emotion were significant at $p < 0.0083$.

Significance of results. Parents of medically complex children experienced improved mental health upon participating in Mood Lifters. Results offer preliminary support for the feasibility and acceptability of Mood Lifters as an evidence-based care option that may also alleviate common barriers to care.

Introduction

In 2020, 14.1 million caregivers provided care to children with complex needs, a 38% increase from 2015 (AARP 2020). Among these caregivers, experiences of emotional distress are widespread and well-documented, including increased levels of stress, anxiety, and depression related to parents of healthy children (Cohen 1999; Cohn et al. 2020; Cousino and Hazen 2013; Sultan et al. 2016). This also impacts their children, as greater levels of parental stress are associated with negative health outcomes in their children (Barakat et al. 2007; Emerson and Bögels 2017; Helgeson et al. 2012).

While their need for support is evident, there is limited research focused on parents of medically complex children and a lack of established psychological interventions available to them (Edelstein et al. 2017; Law et al. 2019). Although some interventions demonstrate promise in reducing parental stress (e.g., mindfulness, problem solving, cognitive behavioral therapy), several meta-analyses cite insufficient data to make claims about the most effective interventions (Edelstein et al. 2017; Law et al. 2019). Further, among the currently established interventions, there are significant limitations. One program is Promoting Resilience in Stress Management for Parents (PRISM-P; Rosenberg et al. 2019). PRISM-P combines multiple approaches, including problem solving, cognitive reframing, and stress-and-coping theories. However, randomized clinical trials indicated that only the one-on-one setting, not the group setting, was effective in improving symptoms (Rosenberg et al. 2019). Providing one-on-one treatment is resource-intensive and may not be accessible for all families. Another program, Bright IDEAS

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(Sahler et al. 2013), is a problem-solving skills training intervention for mothers of children with cancer. While participants in these randomized clinical trials saw improvements in group settings, this intervention employed only 1 framework to address mental health (i.e., problem solving skills training), neglecting other crucial domains. A final program, Surviving Cancer Competently: An Intervention Program (SCCIP), is a 1-day family-based intervention for adolescent cancer survivors and their families (Kazak et al. 2004). Although participants in SCCIP displayed decreases in post-traumatic stress and anxiety, the more distressed families tended to drop out of the program, suggesting it may not be feasible for families experiencing the highest levels of stress. In addition, all 3 programs were intended for and evaluated in parents of children with cancer diagnoses only, not parents of children with other conditions. Finally, these programs do not specifically address barriers to care (i.e., costs, time, stigma, and accessibility) often experienced by this population. In summary, these limitations highlight a need for interventions that (a) are easily scalable to increase availability, (b) take a comprehensive approach, (c) are inclusive of parents with children experiencing other chronic illnesses or medical complexities, and (d) address parents' barriers to obtaining care for themselves.

Many current interventions are not accessed by caregivers due to limited time and financial resources (Aldrich 2011; Kuo et al. 2011; Smith et al. 2003). Some family caregivers further report expectations to have the emotional strength for handling caregiving stress on their own or with informal supports, such as family and friends (Mosher et al. 2015). However, research on peer caregiver groups suggests that caregivers value the opportunity to connect with others in similar situations (Serwe et al. 2019). Moreover, many interventions are delivered in person, which may present challenges for parent caregivers who are required to provide around-the-clock care. Interventions using remote technology offer a more accessible approach that research suggests is also feasible and well-received by caregivers (Eagar et al. 2007; Reinhard et al. 2015). Considering these factors, more accessible and appealing care options that address these concerns are necessary.

The Mood Lifters program was developed as an evidence-based mental wellness program to address widely endorsed barriers to obtaining care (Prakash et al. Under review; Roberts et al. 2022; Votta and Deldin 2022). This intervention consists of weekly peer-led remote meetings during which participants learn evidence-based strategies to improve stress, depression, and anxiety in a group setting. It follows a biopsychosocial approach to mental health, combining skills from cognitive behavioral therapy, dialectical behavior therapy, and acceptance and commitment therapy to address multiple areas contributing to mental health difficulties. Further, Mood Lifters follows the dimensional framework of the Research Domain Criteria, focusing on improvement in various symptom levels rather than diagnostic criteria. By combining these approaches, Mood Lifters offers a more efficient, lower-cost, and less stigmatizing evidence-based option than traditional care.

In addition to greater accessibility, research suggests that Mood Lifters improves mental health. In the randomized controlled trial of the original program, participants experienced significant reductions in anxiety, with additional reductions in perceived stress and depression experienced by participants with the highest program engagement (Votta and Deldin 2022). Following the successful results of the trial, Mood Lifters LLC was established. Participants in groups run by Mood Lifters LLC report further improvements, including decreased negative emotion and

increased positive emotion, social functioning, and flourishing (Prakash et al. Under review).

The current study presents an adaptation of Mood Lifters for parents of medically complex children. Our objective was to pilot the adapted program, assess for feasibility and acceptability, and evaluate the preliminary impact of the program on the mental health of parents of medically complex children. We hypothesized that Mood Lifters would be a feasible and acceptable form of care for parent caregivers and that program participation would result in improvements in depression, anxiety, perceived stress, social functioning, positive and negative emotion, and flourishing.

Methods

Participants and procedures

Inclusion criteria required participants to be adult parents of chronically ill or medically complex children receiving care at a local academic pediatric hospital in the US. Chronic illness and medical complexity were defined as requiring at least 3 medical and/or surgical subspecialists in the child's ongoing care. Conditions experienced by the children included genetic or congenital anomalies, neuromuscular disorders, and cancer. Many children were dependent on medical technology (e.g., wheelchairs, feeding tubes, or respiratory support) and required multiple medications per day.

Families were approached about Mood Lifters by pediatric professionals (e.g., physicians, nurses, and social workers) involved in the care of chronically ill or medically complex children at 1 of 3 local pediatric hospitals serving as recruitment sites for the program. Interested participants were assessed for eligibility, which involved screening for psychosis, mania, and suicidal ideation. Any participants endorsing active psychosis (i.e., a score of 1 or more on the hallucination items of the Community Assessment of Psychic Experience Questionnaire), mania (i.e., a score of 7 or higher on item 1, a response of "Yes" on item 2, and a response of "Moderate" or "Serious" on item 3 of the Mood Disorder Questionnaire), or suicidal ideation (i.e., a response other than "Not at all" on item 9 of the Patient Health Questionnaire [PHQ]) were to be excluded and referred to other resources (Hirschfeld et al. 2000; Kroenke et al. 2001; Mossaheb et al. 2012). However, no interested participants were excluded by these criteria in the current study. Fifty-one eligible participants provided consent and agreed to have their anonymized data shared for research. The Mood Lifters program was conducted remotely via videoconferencing.

Measures

Participants completed a set of online measures 2 weeks prior to the start of the intervention (T1) and again in the final week (T2) to evaluate outcomes. T1 and T2 measures consisted of the PHQ-9, Generalized Anxiety Disorder-7 (GAD-7), Perceived Stress Scale (PSS), Scale of Positive and Negative Experience (SPANE), Flourishing Scale (FLO), Social Functioning Questionnaire (SFQ), and a brief demographics form. T2 measures also included a participant feedback form. Measures at each timepoint required approximately 30 minutes to complete based on trials conducted by research assistants and estimates from the online survey platform used to complete the measures.

Patient Health Questionnaire-9 (PHQ-9)

Depressive symptoms were assessed using the PHQ-9, a self-report instrument assessing depression severity. The PHQ-9 demonstrates good internal reliability in the validation study (Cronbach's $\alpha = 0.86\text{--}0.89$) and in our sample (Cronbach's $\alpha = 0.90$ at T1 and $= 0.78$ at T2) (Kroenke et al. 2001). Cutoffs for the PHQ-9 are 5 = mild, 10 = moderate, 15 = moderately severe, and 20 = severe depression. The minimal clinically important difference (MCID) for the PHQ-9 is a 21% reduction in symptoms (Kounali et al. 2022).

Generalized Anxiety Disorder-7 (GAD-7)

Anxiety was measured with the GAD-7, which shows evidence of excellent internal consistency, with a Cronbach's $\alpha = 0.92$ (Spitzer et al. 2006). This was replicated in our sample (Cronbach's $\alpha = 0.88$ at T1 and $= 0.90$ at T2). Cutoffs for the GAD-7 are 5 = mild, 10 = moderate, 15 = severe anxiety. The MCID for the GAD-7 is a 26.8% decrease in symptoms (Kounali et al. 2022).

Perceived Stress Scale (PSS)

Perceived stress was assessed by the PSS, a questionnaire designed to quantify levels of perceived global stress. This shows good internal consistency with a Cronbach's α of 0.85 reported in the validation paper (Cohen et al. 1983). The PSS demonstrates good consistency within our sample (Cronbach's $\alpha = 0.84$ at T1 and $= 0.86$ at T2). The MCID for the PSS is estimated to be a 28% reduction (Eskildsen et al. 2015).

Scale of Positive and Negative Experience (SPANE)

Frequency of positive and negative emotions was measured using the SPANE. The SPANE demonstrates high internal consistency, with the validation paper reporting a Cronbach's $\alpha = 0.89$ (Diener et al. 2010). The SPANE also demonstrates decent reliability within our sample (At T1 for positive, Cronbach's $\alpha = 0.92$, Cronbach's $\alpha = 0.85$ for negative. At T2, Cronbach's $\alpha = 0.86$ for positive emotion and $= 0.90$ for negative emotion).

Flourishing Scale (FLO)

The FLO assessed flourishing (i.e., self-perceived success). The FLO shows high internal reliability in the validation paper (Cronbach's $\alpha = 0.87$) and decent reliability within our sample (Cronbach's $\alpha = 0.55$ at T1 and $= 0.67$ at T2) (Diener et al. 2010).

Social Functioning Questionnaire (SFQ)

The SFQ was used to measure the levels of self-perceived social functioning. The SFQ has good validity and reliability (Tyrrer et al. 2005). Within our sample, Cronbach's $\alpha = 0.68$ at T1 and $= 0.77$ at T2.

Feedback form

A feedback form was developed to assess reception of the program and acceptability. The form included items on how useful participants found the program to be (i.e., Usefulness score; "On a scale of 1–10, how useful did you find Mood Lifters?" with 10 = extremely useful and 1 = not at all useful) and participants' program recommendation ratings (i.e., Recommendation score; "On a scale of 1–10, how much would you recommend Mood Lifters to someone else?").

Mood Lifters

The original Mood Lifters content and delivery were adapted for parents of chronically ill and medically complex children by a

multidisciplinary team including a pediatric palliative care doctor (KP), decision scientists who have worked with parents of medically complex children (PD, HY), a clinical psychologist (PD), and a clinical science graduate student (CV). Adaptations to the program were guided by current research and clinical expertise and included changes to the manual to reflect relevant examples and skills for this population (e.g., challenging thinking traps about their child's illness, self-compassion).

The program consisted of 15 weekly 1-hour group meetings conducted remotely via Zoom. Groups were facilitated by peer leaders who had previously participated in the Mood Lifters program and obtained certification by completing an 8-hour clinical skills and content training (e.g., review of program content and procedures) developed by the director of clinical training at a local university (PD). Group leaders also received in vivo training through gradually transitioning to full facilitation across the course of leading their first Mood Lifters program with an experienced facilitator and through continued weekly supervision sessions with a PhD level supervisor. Leaders were trained to manage and refer during potential crisis and/or distress situations that may arise for parents during the program. Referrals for individual providers in the area at an alternate level of care were on hand for leaders to provide to members who needed additional support.

Each meeting centered on 1 of 6 biopsychosocial domains (i.e., behavior, mind, mood, body, sleep, and social). Following each meeting, participants were encouraged to earn points by practicing the skills introduced throughout the program. Participants logged their points on an accompanying app between meetings. At the following meeting, participants had the opportunity to discuss their practice from the previous week. Participant progress was monitored through a weekly "check-in" questionnaire via the online survey platform, Qualtrics, and participants completed the same measures at T1 and T2. Participants in this version of Mood Lifters had their program participation costs covered by donations. However, Mood Lifters typically costs about US\$16 per meeting, approximately 12% of the cost of a standard group therapy session without insurance (Sidecar Health 2019).

Fidelity monitoring

After each meeting, both facilitators independently completed a self-report fidelity assessment covering all required components based on that meeting's protocol. Fidelity scores in the original semi-randomized control of Mood Lifters were 97.51–100%, suggesting high treatment fidelity throughout the program (Votta and Deldin 2022). See Votta and Deldin (2022) for further detail on fidelity monitoring procedures.

Program feasibility

Program feasibility was defined a priori as participant attendance at meetings and engagement in program activities outside of meetings (i.e., earning and tracking points after practicing skills; Votta and Deldin 2022).

Program acceptability

Program acceptability was defined a priori as positive participant attitudes toward the program as assessed by the feedback form (Sekhon et al. 2017).

Table 1. Mean participant scores pre- and post-intervention

Measure	Score range	Pre-intervention M (SD)	Post-intervention M (SD)
Depression (PHQ-9)*	0–27	8.47 (5.551)	5.33 (3.896)
Anxiety (GAD-7)*	0–21	6.95 (4.314)	5.00 (4.627)
Perceived Stress (PSS)**	0–40	18.26 (7.859)	14.17 (7.270)
Social Functioning (SFQ)	0–24	7.61 (3.415)	6.78 (3.964)
Positive Emotion (SPANE-P)***	6–30	19.79 (4.171)	22.11 (3.984)
Negative Emotion (SPANE-N)***	6–30	18.37 (4.728)	14.50 (4.997)
Flourishing (FLO)	8–56	44.89 (4.999)	46.89 (4.028)

* $p < 0.05$, ** $p < 0.005$ *** $p < 0.001$.

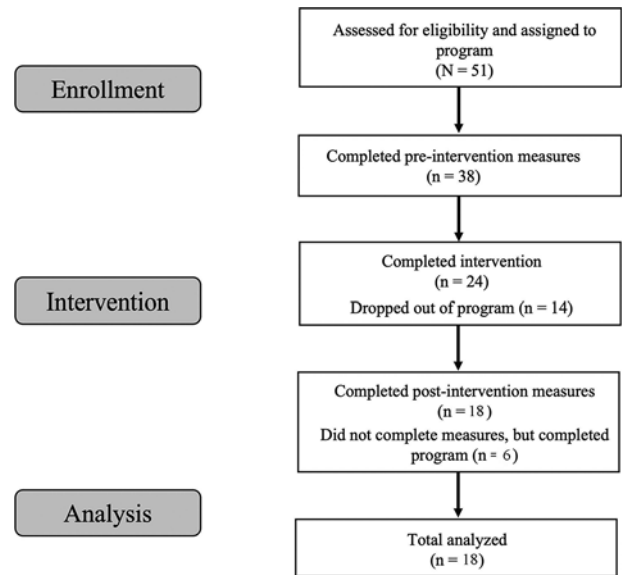
Analyses

Frequencies were obtained for demographic variables. Mean participant age was also calculated. Mean values and standard deviations of scores on all measures were calculated at both pre- and post-intervention (see Table 1). Repeated-measures analysis of variance (ANOVAs) were conducted to evaluate change between the start (T1) and finish of the program (T2). Due to multiple comparisons, a Bonferroni correction was used to determine the appropriate p -value for the ANOVAs ($0.05/6 = 0.0083$). The significance threshold was thus set at $p < 0.0083$. Usefulness and recommendation ratings were obtained by averaging the response values of the feedback questions (i.e., Usefulness Score and Recommendation Score). All analyses were conducted using SPSS.

Results

Participants

A total of 51 participants enrolled in the program, with 38 of those completing the T1 pre-intervention measures and participating in 1 of 5 program groups based on availability (see Figure 1 for information on participant flow). All participants were parents ranging from 20 to 67 years (mean, 42.3 years) providing care for their chronically ill or medically complex children. Thirty-three participants identified as female (see Table 2 for T1 and T2 participant demographics). Eighteen participants completed T2 measures and were included in subsequent analyses. Of note, participants were not required to complete measures to participate in this program, especially considering undue burden on this specific population of caregivers. As such, some participants ($n = 6$, 15.8% of the total sample) completed the program but did not complete T2 measures needed for inclusion in final analyses. Several other participants were unable to finish the program due to the unpredictable nature of caregiving and were lost to follow-up. One parent was excluded from analyses due to their child's death during the program and the extreme impact of this experience on their mental health in consideration of outlier data in our analyses of the program's impact on symptoms. Analyses revealed no significant differences at T1 in age ($p = 0.92$), sex ($p = 0.63$), race ($p = 0.61$), education level ($p = 0.19$), or baseline mental health (e.g., depression: $p = 0.34$; anxiety: $p = 0.23$) between participants who completed the program and those who did not.

**Figure 1.** Mood Lifters participant flow diagram**Table 2.** Baseline demographic information for Mood Lifters participants

Variable	Full sample (N = 51) M (SD)	Time ₁ (N = 38) M (SD)	Analyzed sample (n = 18) M (SD)
Age	42 (10)	42 (10)	42 (9)
Sex			
Male	6	4	2
Female	44	34	16
Not specified	1	0	0
Race			
Black/African American	2	1	0
Caucasian/White	48	36	18
Hispanic/Latino	1	1	0
Education			
Graduated high school	5	5	1
Some college(including associate's degree)	15	10	3
Bachelor's degree	17	13	7
Graduate degree	14	10	7

Impact on presenting symptoms

Data from participants who completed measures at both T1 and T2 ($n = 18$) showed improvements in depression, anxiety, perceived stress, and positive and negative emotions (see Table 1 for means). Following the intervention, caregivers experienced an average 37.66% reduction in depressive symptoms ($F(1,17) = 7.691$, $p = 0.013$) that trended toward significance under the Bonferroni correction and exceeded the MCID for the PHQ-9. Participants experienced a 21.54% reduction in perceived stress

($F(1,17) = 9.223, p = 0.007$) and average 21.15% reduction in negative emotion ($F(1,17) = 27.916, p < 0.001$). Reductions in anxiety symptoms among caregivers trended toward significance with an average 27.42% decrease in symptoms ($F(1,17) = 6.431, p = 0.021$), which met the MCID. Caregivers also experienced increased positive emotion (average 10.56% increase; $F(1,17) = 13.141, p = 0.002$). No significant main effects emerged for social functioning ($F(1,16) = 1.528, p = 0.234$) or flourishing scores ($F(1,17) = 3.752, p = 0.069$), though flourishing trended toward significance.

Feasibility and acceptability

In total, 24 of the 38 caregivers completed the program, demonstrating a dropout rate comparable to standard therapeutic interventions (Olfson et al. 2009). Caregivers attended 11.3 meetings on average ($SD = 2.2$). Although participants often communicated with peer leaders when they would need to miss meetings, they did not always provide reasons why. As such, we do not have data on reasons for non-attendance. On a scale from 1 to 10, participants rated the average usefulness score of the program as 8.8 and the average program recommendation score as 9.3. Overall, participant attendance, engagement, and feedback suggest Mood Lifters to be both feasible and acceptable to this group.

Discussion

This pilot version of Mood Lifters was adapted for parents of chronically ill and medically complex children by a multidisciplinary team of providers and researchers with the goal of creating a comprehensive and inclusive form of mental health care that alleviates the widely endorsed barriers of stigma, time, cost, and accessibility associated with traditional forms of treatment. Mood Lifters uses a combination of psychological frameworks to offer an evidence-based approach to improving mental health that is inclusive to parents of children with various chronic illnesses and medical complexities. The program's peer leaders and group members allow parents to connect with individuals in similar circumstances, while its remote delivery provides flexibility and makes it more feasible for parents to receive care without sacrificing additional time, energy, and finances to travel. Further, Mood Lifters offers a relatively low-cost option, averaging a fraction of the cost of standard group therapy.

Our preliminary study results suggest Mood Lifters to be beneficial, feasible, and acceptable to caregiver participants. On average, parents saw significant improvements in perceived stress, positive emotion, and negative emotion upon program completion. Further, participants rated Mood Lifters as a useful program they would strongly recommend to their peers, with 1 parent describing the program as “the ultimate framework to take an experience that is life-altering and give parents the opportunity to move beyond surviving and into thriving.”

Program completion and dropout rates were comparable to those of other therapeutic groups (Olfson et al. 2009) and were not predicted by baseline characteristics such as mental health. However, the reasons for participant drop out were unable to be obtained, as participants were lost to follow-up. Future studies on Mood Lifters with parents of medically complex children should include an exit survey to clarify what factors contribute to participant dropout so the program can be further adapted to meet the unique needs of this population and increase program accessibility. Similarly, reasons for meeting non-attendance should

be collected to inform program adaptations that will encourage engagement while considering caregiver bandwidth (e.g., changing the points logging system to further reduce program burden for this population).

Interestingly, parents in our sample did not demonstrate improvements in flourishing or social functioning as seen with participants of the original program. However, they did experience changes in anxiety and depression that met the MCID on the GAD-7 and PHQ-9 despite these improvements not reaching statistical significance. This could be due to several factors. First, the Bonferroni correction conducted for multiple comparisons is widely considered to calculate overly conservative thresholds for significance (Streiner and Norman 2011). Further, our study was relatively underpowered, with power analyses suggesting at least 24 participants to be sufficiently powered at 0.8 power and a moderate effect size of 0.3. It is also possible that this subgroup may not be expected to experience as significant of reductions in symptoms as the general population. In fact, studies consistently suggest that caregivers experience elevated levels of depressive symptoms and other mental health concerns relative to noncaregivers from chronic caregiving stress (Pinquart and Sörensen 2003). Moreover, certain symptom domains may be more difficult to address in this population. For example, some aspects of social functioning may relate to more general and consistent issues for parent caregivers that are not typically addressed by mental health interventions (e.g., financial trouble, feeling isolated; Kuo et al. 2011; Ross et al. 2020).

It is important to note that these data are preliminary and should be interpreted in the context of study limitations. Due to the nature of a pilot program for local parent caregivers, our sample is relatively small and lacking in terms of racial, ethnic, and sociodemographic diversity, which may limit the generalizability of these findings. It is crucial to thoroughly investigate this program in more inclusive samples of caregivers, including historically marginalized and underrepresented populations, before drawing conclusions with clinical implications. Further, conclusions about program efficacy are limited by the single-arm study design and 1 timepoint assessment of symptom change following program completion. Future studies on Mood Lifters in this population would benefit from using a randomized controlled trial design and follow-up assessments to examine how the program impacts caregiver mental health over time.

In summary, our results offer preliminary support for the feasibility and acceptability of Mood Lifters adapted for parents of medically complex children. Based on reported improvements in mental health and program feedback, parents benefited from their participation in the program and found it useful. The peer-led remote format of groups allowed for a more accessible and cost-effective form of care that promotes scalability. Future studies should be conducted with larger and more diverse samples to expand on these findings and further adapt the program to this population's unique needs to increase program acceptability and accessibility. We hope that future research will build upon this study to further demonstrate Mood Lifters as a comprehensive, inclusive, and evidence-based option that concurrently alleviates common barriers to care in this community.

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Competing interests. CV and PD are co-owners of Mood Lifters LLC and may profit in the future from groups run by the company. No profits are made through research on Mood Lifters or from publications regarding Mood Lifters programming. The other authors have no competing interests to declare.

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