

Reducing Distress in Mothers of Children With Autism and Other Disabilities: A Randomized Trial



WHAT'S KNOWN ON THIS SUBJECT: Mothers of children with neurodevelopmental disabilities often experience poor health, high stress, anxiety, and depression. Highly stressed parents are less effective in their parenting roles, risking their children's developmental progress.



WHAT THIS STUDY ADDS: Evidence-based interventions in mindfulness and positive psychology significantly reduce distress in mothers of children with disabilities. Well-trained peer-mentors are effective interventionists. Adult-oriented services are needed for these mothers to improve their mental health and sustain their caregiving over the long-term.

abstract



BACKGROUND: Compared with other parents, mothers of children with autism spectrum disorder or other neurodevelopmental disabilities experience more stress, illness, and psychiatric problems. Although the cumulative stress and disease burden of these mothers is exceptionally high, and associated with poorer outcomes in children, policies and practices primarily serve the identified child with disabilities.

METHODS: A total of 243 mothers of children with disabilities were consented and randomized into either Mindfulness-Based Stress Reduction (mindfulness practice) or Positive Adult Development (positive psychology practice). Well-trained, supervised peer mentors led 6 weeks of group treatments in 1.5-hour weekly sessions, assessing mothers 6 times before, during, and up to 6 months after treatment. Mothers had children with autism (65%) or other disabilities (35%). At baseline, 85% of this community sample had significantly elevated stress, 48% were clinically depressed, and 41% had anxiety disorders.

RESULTS: Using slopes-as-outcomes, mixed random effects models, both treatments led to significant reductions in stress, depression, and anxiety, and improved sleep and life satisfaction, with large effects in depression and anxiety. Mothers in Mindfulness-Based Stress Reduction versus Positive Adult Development had greater improvements in anxiety, depression, sleep, and well-being. Mothers of children with autism spectrum disorder improved less in anxiety, but did not otherwise differ from their counterparts.

CONCLUSIONS: Future studies are warranted on how trained mentors and professionals can address the unmet mental health needs of mothers of children with developmental disabilities. Doing so improves maternal well-being and furthers their long-term caregiving of children with complex developmental, physical, and behavioral needs. *Pediatrics* 2014;134:e454–e463

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KEY WORDS

autism spectrum disorders, developmental disabilities, maternal stress and mental health, mindfulness based stress reduction, positive psychology

ABBREVIATIONS

ASD—autism spectrum disorders
BAI—Beck Anxiety Inventory
BDI—Beck Depression Inventory
ES—effect size
MBSR—Mindfulness-Based Stress Reduction
PAD—Positive Adult Development
PSI—Parenting Stress Index-Short Form

Dr Dykens developed the study rationale, aims, and design, led and supervised the implementation of the study, and drafted and revised the final manuscript; Dr Fisher managed data entry and quality, conducted preliminary descriptive statistics, completed Figure 1's Consolidated Standards of Reporting Trials flow diagram, and critically reviewed the final manuscript; Dr Taylor assisted with data analyses and interpretation, drafted the results section, constructed and revised Tables 2 and 3, and critically reviewed the final manuscript; Dr Lambert conducted data analyses by using slopes as outcomes, drafted the power analysis and statistical approach sections, created and revised Figures 2 and 3, and reviewed the final manuscript; Dr Miodrag assisted with data interpretation, provided background literature on maternal stress and mindfulness practice, conducted preliminary analyses in mothers of children with autism, and reviewed the final manuscript; and all authors approved the final manuscript as submitted.

This trial has been registered at www.clinicaltrials.gov (identifier NCT01110343).

(Continued on last page)

Compared with mothers of typically developing children, mothers of children with neurodevelopmental disabilities experience more stress, psychiatric problems, and poorer health.¹ Higher levels of stress in these parents are predicted by economic hardship,² insufficient supports,^{3,4} and such child problems as aggression, self-injury, and social or communicative deficits.^{5,6} Although the positive aspects of raising children with disabilities are increasingly recognized,⁷ studies in this population consistently find maternal susceptibility to depressive and anxiety disorders or symptoms,^{8,9} insomnia, poor sleep quality,¹⁰ and stress chronicity marked by blunted diurnal cortisol trajectories,^{11,12} reduced immune functioning,¹³ and accelerated telomere shortening.¹⁴ Because neurodevelopmental disorders are prevalent, comprising the top 5 chronic medical conditions affecting US children,¹⁵ the cumulative disease burden of these parents is alarmingly high, adding to the growing costs to society of autism spectrum disorders (ASD) or other developmental disabilities.¹⁶

Highly stressed parents are less able to implement interventions for their children with disabilities, and their children make less developmental progress.¹⁷ Even so, services for families of children with disabilities primarily focus on the child's needs. Thus, parents may be taught strategies to facilitate their children's cognitive, linguistic, physical, or social development or to manage their difficult behaviors.¹⁸ Parent interventions also include anticipatory guidance about the child's disability, advocacy training, involvement in disability-specific organizations, and respite care or "short breaks" from round-the-clock caregiving.¹⁹

Although parent training can lead to modest collateral benefits on maternal stress,²⁰ and disability organizations provide support and advice, these programs were not developed to treat

parental mental health. Similarly, respite care provides parents a welcomed reprieve,¹⁹ but does not teach them how to cope with stress once the break is over.

This study instead treated parental distress directly, with business as usual for children. Although treating parents is much less common than child-oriented interventions, cognitive-behavioral therapies can effectively reduce distress in mothers of children with developmental disabilities or chronic health problems.²⁰ Individual psychotherapies, however, rely on professionals, which may prove costly, and do not necessarily reach at-risk mothers who are stressed but do not seek formal clinical care. This study thus used peer-mentors (well-trained mothers of offspring with disabilities) to lead group interventions in community settings, thereby taking advantage of naturally occurring parent-to-parent rapport.

Parents were randomly assigned to either Mindfulness-Based Stress Reduction (MBSR), which has demonstrated efficacy across both clinical and healthy populations,^{21,22} or Positive Adult Development (PAD), which incorporated evidence-based interventions from positive psychology.^{23,24} These interventions were selected because they were conducive to group formats led by trained mentors, and controlled studies find that they effectively enhance well-being and reduce anxiety, depression, and sleep problems in other clinical populations.²⁵ Further, mindfulness practice has been piloted in other parent groups,²⁶ and concepts in positive psychology, such as maximizing virtues, abilities, and optimism, resonate with the disability community.⁷

This study's first aim tested whether it would be beneficial to treat parents in groups led by peer-mentors by using adult-oriented curricula. In the second aim, we tested our expectation that

even though both interventions would be effective, MBSR would confer some advantages over PAD. MBSR has a larger literature supporting its efficacy, and even beginners show robust neural changes linked to mindfulness practice.²⁷ Third, because mothers of children with autism (versus with other disabilities) often report more stress, illness, and psychiatric symptoms,^{8,28} we determined if mothers of children with ASD responded differently to treatment.

METHODS

Identifying and Enrolling Participants. Parents of any age were recruited as long as they were the primary caregivers of offspring with developmental disabilities. Eligibility criteria also included willingness to be randomized into groups, and no previous training in mindfulness or positive psychology practices. Current or past psychiatric problems were not used as eligibility criteria. The study was advertised via Web sites and announcements to local and state disability organizations. To maximize enrollment, treatment sessions were offered during the day or evening in an accessible community setting, with optional, on-site child care for offspring with disabilities or siblings. Parents who used child care services (42.1%) did not differ from other participants at baseline or treatment response.

As shown in Table 1, mothers averaged 40 years of age, and most were married (73%) and white (70%). Similar numbers of participants had either high or low annual incomes, with 38% falling below the US median income level. Offspring with disabilities averaged 10 years of age, 65% had ASD, and 35% had other developmental disabilities.

Randomization. All participants provided written, informed consent using institutional review board–approved procedures. After completing baseline measures, they were randomly assigned via

TABLE 1 Participant Demographic Features and Baseline Outcome Measures

Demographic features		
Age, mean (SD), range	40.87 (8.92), 23–76 y	
Married %	73	
Number in household, mean (SD), range	4.07 (1.34), 2–9	
Employed outside home, %	47.5	
Race, %		
White	69.6	
African American	14.7	
Hispanic	9.2	
Asian, other	6.5	
Education, %		
High school degree	29.9	
2 or 4 y college	44.7	
Professional	25.4	
Annual income \$, %		
<15 000–29 000	18.3	
30 000–49 000	19.3	
50 000–59 000	20.2	
70 000–99 000	23.4	
>100 000	18.8	
Child features		
Age, mean (SD), range	10.85 (7.53) 2–54 y	
Male, %	72.3	
ASD, %	64.9	
Autistic disorder	36.1	
PDD-NOS	14.4	
Asperger disorder	14.4	
Other developmental disabilities, %	35.1	
Genetic syndromes	9.1	
Developmental disabilities	20.0	
Psychiatric disorders	6.0	
Baseline outcome measures		
BDI, mean (SD)	19.99 (10.86)	
BDI clinically significant, % (score \geq 20)	47.3	
BAI, mean (SD)	13.41 (9.56)	
BAI clinically significant, % (score \geq 16)	35.7	
Insomnia Inventory, mean (SD)	12.33 (6.43)	
PSI-Parent Distress, mean (SD)	36.80 (8.51)	
PSI-Dysfunctional Interactions, mean (SD)	30.91 (8.17)	
PSI-Difficult Child, mean (SD)	40.79 (9.53)	
PSI-clinically significant total scores, %	86.5	
Life Satisfaction Scale, mean (SD)	17.59 (6.66)	
Psychological Well-Being, mean (SD)	73.66 (12.73)	

PDD-NOS, pervasive developmental disorders-not otherwise specified.

a computer program to either the MBSR or PAD 6-week group intervention. Parents who attended as couples ($n = 50$) were yoked and randomized together into a treatment arm. No significant differences in baseline characteristics or treatment responses were found between mothers who attended singly or with their spouses. Fathers' treatment responses are analyzed separately later.

Outcome Assessments. Outcomes were assessed in 6 waves at baseline, mid-treatment, at the end of treatment, and

posttreatment at 1, 3, and 6 months. Mothers were thus enrolled in the study for 8 months between March 2010 and December 2012.

Outcomes were standardized measures often in clinical or developmental disabilities research. The primary outcome, the Parenting Stress Index-Short Form (PSI),²⁹ contains 3 domains: Parental Distress, Dysfunctional Parent-Child Interactions, and Difficult Child. Although we report all 3, the PSI Parental Distress domain was most pertinent, as we did not treat children or

expect dramatic changes in child problems. Secondary outcomes included the Beck Depression Inventory (BDI),³⁰ Beck Anxiety Inventory (BAI),³¹ Insomnia Severity Index,³² Ryff Scales of Psychological Well-Being (short form total score),³³ and the Life Satisfaction Scale.³⁴ For each outcome, higher scores indexed more of the measured construct.

Mentor Training, Supervision, and Treatment Fidelity. Four well-trained, supervised peer-mentors, all mothers of children with disabilities, led the group interventions, 2 per treatment arm. Mentors received 4 months of training on the intervention curriculum, role of a mentor, and research ethics. Mentors enrolled in either MBSR classes or online positive psychology training, completed directed readings, and engaged in regular mindfulness or positive psychology practices. A social worker provided instruction on mentorship, including lessons on professional boundaries, confidentiality, and identifying participants in need of professional services. Mentors received institutional review board certification by taking online and university classes on the responsible conduct of research and data integrity.

Subsequent to training, a social worker or psychologist observed mentors during treatment sessions and met with them weekly for supervision. Clinical supervisors also ensured high treatment fidelity based on well-accepted criteria: preparing meeting rooms and materials, establishing group guidelines, adhering to weekly lessons and content, ensuring participant understanding of materials, reviewing homework, and properly collecting data.³⁵

Treatment Groups. Peer-mentors co-led weekly groups, which never exceeded 15 participants. MBSR taught specific breathing, meditation, and movement techniques, including paying attention to the breath; deep belly breathing; the

relaxation response; self-observation without self-evaluation; Qigong (gentle movements); and the sitting, body scan, and loving-kindness meditations.^{22,25} PAD emphasized ways to temper such emotions as guilt, conflict, worry, and pessimism by identifying and recruiting character strengths and virtues, by using strengths in new ways, and by exercises involving gratitude, forgiveness, grace, and optimism.^{23,24} All participants were encouraged to practice specific exercises at home and share these experiences at group meetings. The MBSR and PAD curricula will soon be available at the Vanderbilt Center for Technology Transfer and Commercialization Web site (www.vanderbilt.edu/cttc/).

Statistical Power. We conducted a longitudinal power analysis³⁶ on a hypothetical outcome, assuming an n of 100 per group and traditional standards (power = 80%, 2-sided tests, $\alpha < 0.05$). This yielded a minimum detectable effect size (ES) of $d = 0.33$ at the last wave, or power to detect small- to medium-sized differences in time slopes. Our minimum ES is in the range of treatment effects reported in recent meta-analyses of positive psychology³⁷ (ES = 0.31) and mindfulness³⁸ (ES = 0.51) interventions.

Statistical Analyses. For each outcome, we used a common approach for longitudinal data: a slope-as-outcome, mixed random-effects model.^{36,39} Multi-wave longitudinal modeling takes advantage of all available observations; thus, incomplete cases are not dropped or are missing values imputed. Assuming that the untestable theory of missing at random holds, this strategy yields findings that are not biased.^{36,39}

Mothers had up to 6 unique wave-time observations, with average wave-times for the sample of 0.00, 0.73, 1.32, 2.64, 4.49, and 7.71 months. The first 3 points measured outcomes before, during, and after treatment, and the last 3 points, during follow-up. We used 2,

piecewise slopes that represented 2 study epochs: changes during treatment, and changes during follow-up. As clinical trials often use a single-slope model, we tested the 2-slope against the traditional 1-slope model by using maximum likelihood and Bayesian χ^2 analyses. For all outcomes, the 2-slope model was a significantly better, more accurate fit ($\chi^2(1) > 32.00, P < .001$).

The analytic model was simple, focused only on answering the 3 study aims. Given the high number of possible covariates (eg, maternal age, SES), we used the strength of existing literature^{8, 28} to select just 1 important covariate, child ASD versus non-ASD, to model on intercept and slope parameters. Effect sizes were calculated by using Cohen's d formula⁴⁰ ($M_1 - M_2/SD_{\text{pooled}}$), corrected for dependence among means. All outcomes were standardized to a mean of 0 and SD of 1, allowing further magnitude of change comparisons across measures.

RESULTS

Enrollment

Figure 1 shows that of the 533 assessed for eligibility, 167 did not complete consent procedures, and 123 were not deemed eligible for the study (ie, children did not have developmental disabilities, fathers, already exposed to treatment). This left 243 women who were randomized into MBSR or PAD; no baseline differences were found in mothers or children across treatments. Once enrolled, most women completed treatment ($n = 202$); no adverse events were reported. Reasons for dropping out ($n = 41$) were primarily attributed to life circumstances (eg, family crises, unexpected events). The t tests revealed no significant demographic or baseline differences between those who dropped out versus completed treatment. Follow-up 2 \times 2 ANOVAs (MBSR versus PAD by dropouts versus completers) revealed no sig-

nificant main or interaction effects in baseline assessments or demographics, indicating no apparent differential dropout biases.⁴¹

Baseline Characteristics

Table 1 summarizes mean baseline scores on outcome measures. Even though a positive psychiatric history was not an eligibility criterion, 47% had clinically elevated depression scores on the BDI; 36% exceeded anxiety clinical cut-points on the BAI, and most, 87%, had clinically elevated stress scores on the PSI. These elevations are consistent with participants' descriptions of their previous diagnoses of depressive (48.0%) or anxiety (40.6%) disorders, and use of psychotropic medications (58.0%). Mean Insomnia Severity scores indicated subthreshold insomnia, and mean Life Satisfaction scores were slightly below average.

Aim 1

To determine if maternal distress improved during treatment or follow-up for the sample as a whole, 8 unconditional regression models were analyzed that included only the within-persons time variables. Results are presented in Table 2 and Fig 2. Mothers showed significant improvements during treatment in primary outcomes of parental distress and dysfunctional parent-child interactions as well as in 4 secondary outcomes of anxiety, depression, insomnia severity, and life satisfaction.

Overall, participants continued to improve or maintain gains during follow-up; no outcomes significantly worsened. From baseline through the end of the 6-month follow-up period improvements of large magnitudes were found in anxiety (Cohen's $d = 0.81$) and depression ($d = 0.98$), medium effects in insomnia ($d = 0.67$) and personal distress ($d = 0.49$), and smaller effects in life satisfaction ($d = -0.43$) and dysfunctional parent-child interactions ($d = 0.29$). Psychological well-being, which did not change during

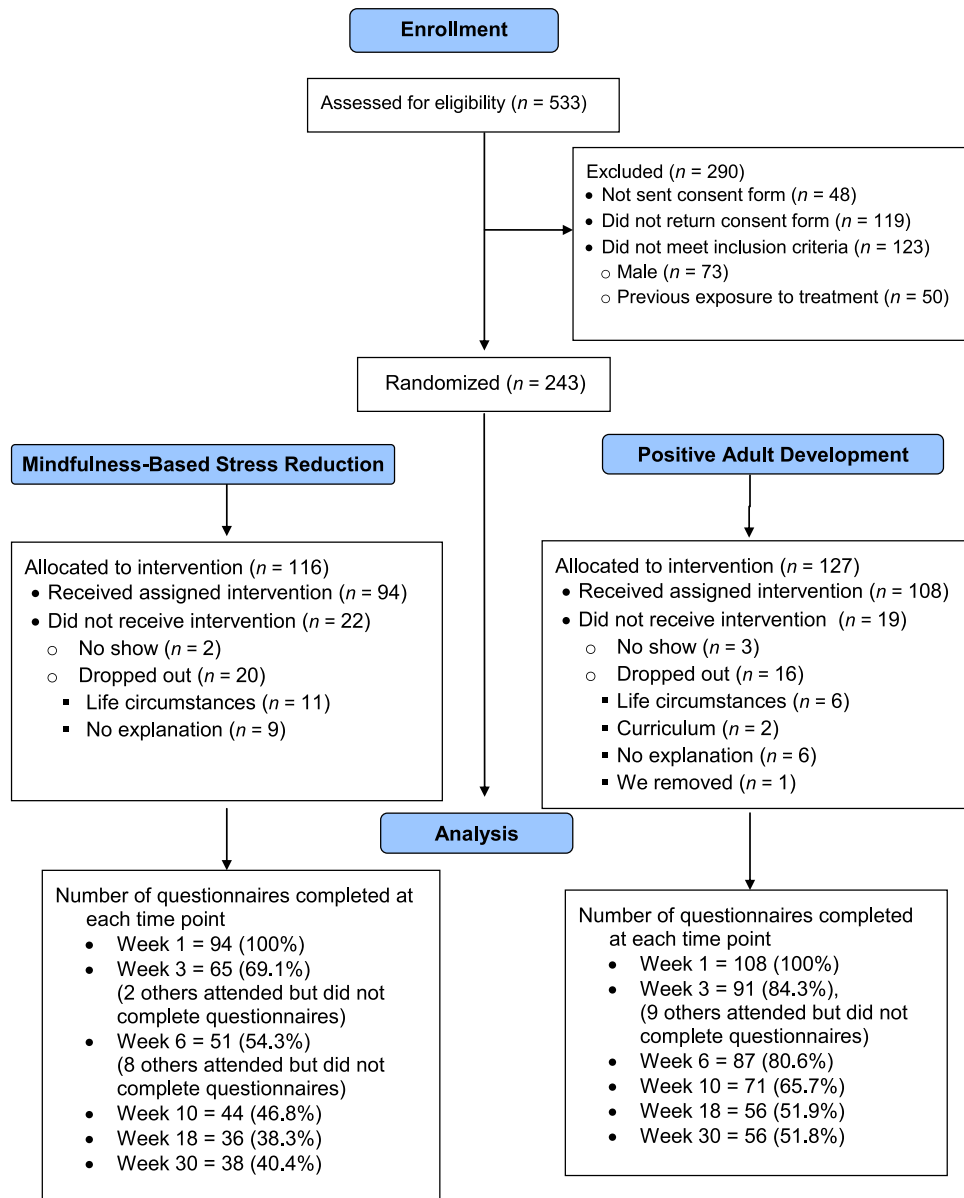


FIGURE 1
Participant enrollment.

intervention, began to improve during follow-up ($d = -0.38$).

Aims 2 and 3

To test if treatment or follow-up responses depended on the type of

treatment or child's disability, between-person's variables of treatment type (MBSR versus PAD) and child's disability (ASD versus other disabilities) were entered into the regression models. Results are shown in Table 3 and Fig 3.

With randomization, no baseline differences were found between treatment groups (intercept findings; Table 3). Mothers of children with ASD scored higher than other mothers on just 1 variable, the PSI's Difficult Child domain.

TABLE 2 Estimates and SEs from "Unconditional" Models With Only Between-Persons Variables

	Anxiety	Depression	Insomnia Severity Total	Parent Distress	Difficult Child	Dysfunctional Parent-Child Interactions	Life Satisfaction	Psychological Well-Being Total
Time 1 Intercept	0.22** (0.07)	0.35** (0.07)	0.24** (0.07)	0.14* (0.07)	0.11 (0.07)	0.12 (0.07)	-0.13 (0.07)	-0.07 (0.07)
Treatment slope	-0.12** (0.03)	-0.29** (0.03)	-0.08** (0.03)	-0.08* (0.03)	-0.05 (0.03)	-0.09** (0.03)	0.08** (0.03)	0.01 (0.03)
Follow-up slope	-0.03* (0.01)	-0.02* (0.01)	-0.04** (0.01)	-0.01 (0.01)	-0.01 (0.01)	-0.00 (0.01)	0.01 (0.01)	0.02* (0.01)

* $P < .05$. ** $P < .01$.

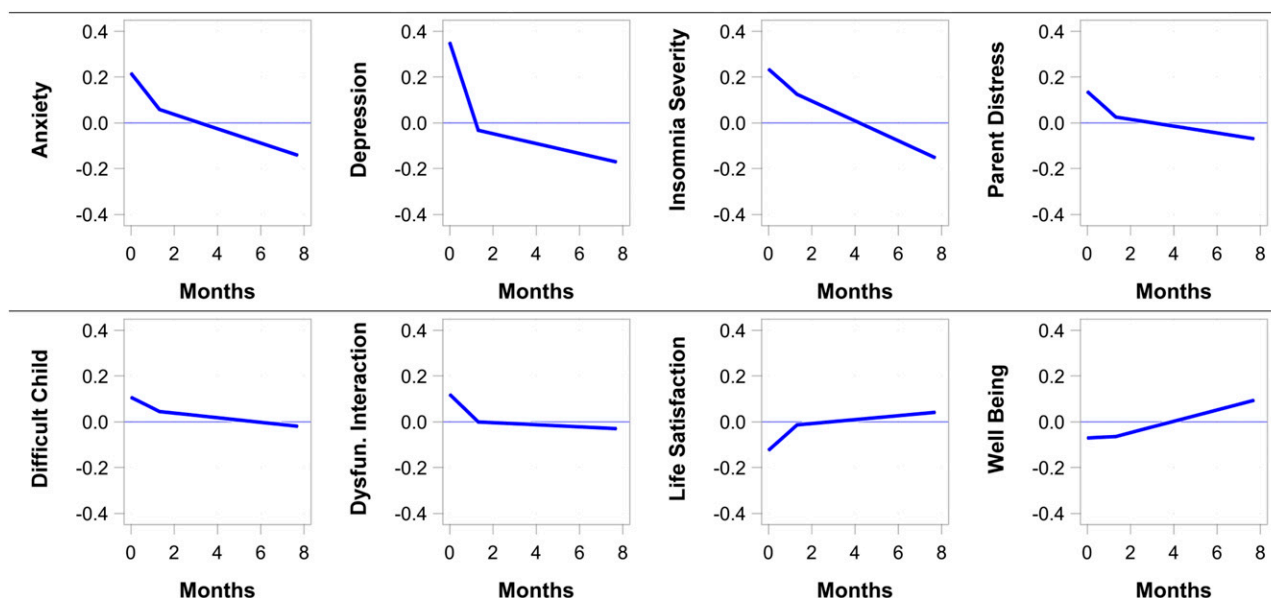


FIGURE 2

Plot of unconditional model score plots showing treatment and follow-up slopes for the whole sample. Note: For Anxiety, Depression, Insomnia Severity, Parent Distress, Difficult Child, and Dysfunctional Parent-Child Interaction, higher scores indicate worse functioning. For Life Satisfaction and Psychological Well-Being, higher scores indicate better functioning.

Figure 3 shows that both groups declined in primary stress outcomes, but participants in MBSR versus PAD showed greater improvements during treatment in anxiety ($d_s = 0.88$ vs 0.44), depression ($d_s = 1.03$ vs 0.58), and insomnia ($d_s = 1.10$ vs 0.26). Only 1 treatment difference emerged between disability groups: mothers of children with ASD improved less in anxiety. Still, from baseline to 6-month follow-up, these mothers showed a large, gradual attenuation of anxiety ($d = 0.94$).

Change at follow-up was generally similar for those in MBSR versus PAD, and

for mothers of children with or without ASD. However, relative to mothers in MBSR, those in PAD experienced more improvement in depression and life satisfaction during follow-up.

DISCUSSION

Chronic stress impairs health, well-being, and the ability to learn and retain information.⁴² But even given the enormous public health cost of stress, we have yet to fully appreciate how chronic stress affects the health and mental health of mothers of children with neurodevelopmental disabilities,

as well as their child-rearing practices. Instead of the usual child-oriented interventions, this study treated parent distress by using adult-oriented, evidence-based strategies.

Mothers in both the MBSR and PAD treatments showed less personal stress and dysfunctional parent-child interactions on the primary outcome, as well as less anxiety and depression, and improved sleep and life satisfaction. Depression, anxiety, and life satisfaction continued to improve during follow-up and improvements in other areas were sustained up to 6 months after treatment.

TABLE 3 Estimates and SEs From “Conditional” Models That Include Treatment Condition and Type of Disability

	Anxiety	Depression	Insomnia Severity	Parental Distress	Difficult Child	Dysfunctional Parent-Child Interaction	Life Satisfaction	Psychological Well-Being
Time 1 Intercept	0.28* (0.14)	0.44** (0.13)	0.21 (0.13)	0.07 (0.13)	-0.14 (0.13)	-0.08 (0.13)	-0.18 (0.13)	-0.04 (0.13)
MBSR (vs PAD)	0.03 (0.14)	0.01 (0.13)	0.17 (0.14)	0.11 (0.14)	0.09 (0.14)	0.13 (0.14)	-0.11 (0.14)	-0.08 (0.14)
ASD (vs DD)	-0.07 (0.15)	-0.08 (0.14)	-0.03 (0.15)	0.02 (0.15)	0.32* (0.14)	0.22 (0.15)	0.13 (0.14)	0.00 (0.14)
Treatment slope	-0.24** (0.08)	-0.36** (0.08)	-0.15 (0.08)	-0.08 (0.08)	-0.01 (0.07)	-0.09 (0.08)	0.16* (0.07)	-0.10 (0.07)
MBSR (vs PAD)	-0.20* (0.08)	-0.26** (0.08)	-0.25** (0.08)	-0.01 (0.08)	-0.08 (0.07)	0.01 (0.08)	0.09 (0.07)	0.17* (0.07)
ASD (vs DD)	0.18* (0.08)	0.14 (0.08)	0.12 (0.08)	0.00 (0.09)	-0.03 (0.08)	-0.00 (0.09)	-0.11 (0.08)	0.08 (0.07)
Follow-up slope	-0.01 (0.02)	-0.04* (0.02)	-0.03 (0.02)	-0.01 (0.02)	-0.03* (0.01)	-0.02 (0.02)	0.03 (0.01)	0.04 (0.02)
MBSR (vs PAD)	0.01 (0.02)	0.04* (0.02)	0.03 (0.02)	0.00 (0.02)	0.03 (0.02)	0.03 (0.02)	-0.03* (0.02)	-0.03 (0.02)
ASD (vs DD)	-0.03 (0.03)	0.01 (0.02)	-0.02 (0.02)	-0.01 (0.02)	0.02 (0.02)	0.00 (0.02)	-0.01 (0.02)	-0.00 (0.02)

DD, other developmental disabilities. * $P < .05$. ** $P < .01$.

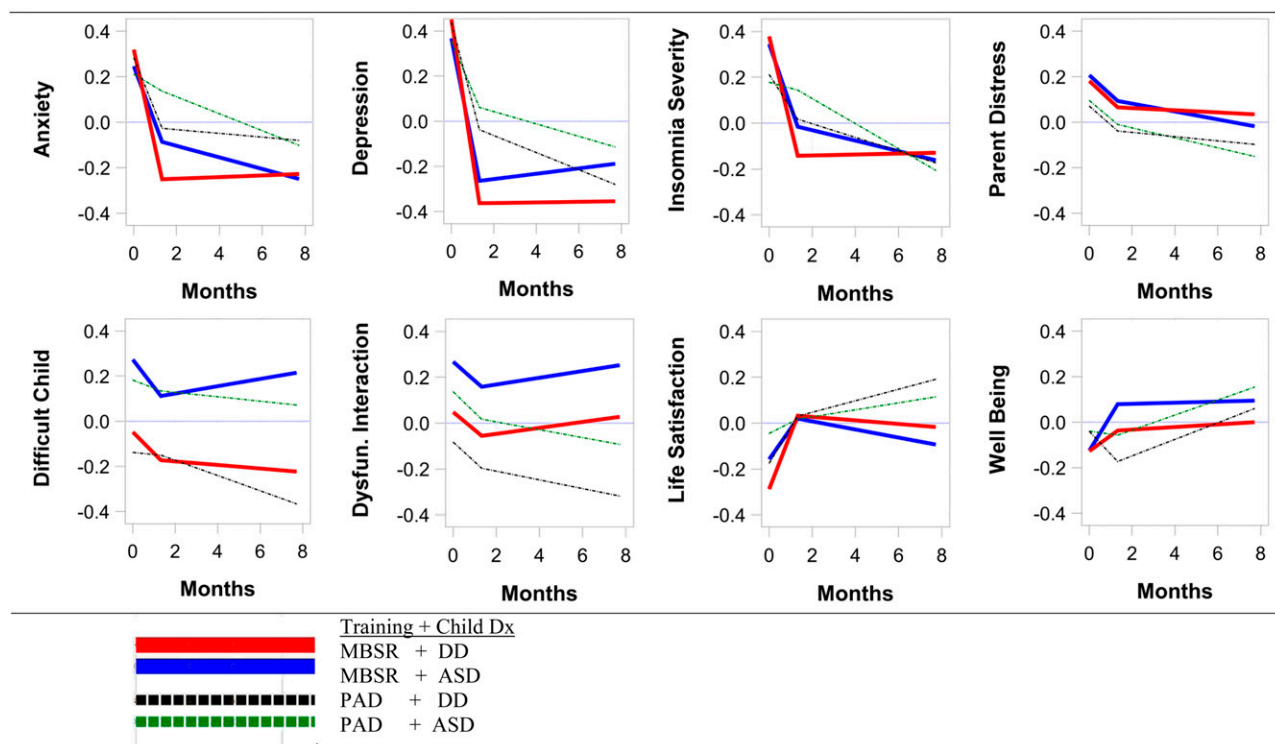


FIGURE 3

Model score plots showing treatment and posttreatment slopes for treatment condition (MBSR versus PAD) and type of disability (ASD versus other developmental disabilities [DD]).

Effect sizes were medium to large for depression and anxiety in both treatments from baseline to 6-month follow-up. Such improvements across groups are likely due to a confluence of shared treatment factors: a group setting with other parents, peer-mentors who could readily understand participants' experiences, and programs that jettisoned traditional parent training and instead met parental needs to be less stressed and more engaged in their own adult development.

Although no differential treatment effects were found in primary stress indices, mothers enrolled in MBSR (versus PAD) showed significantly greater improvements, with larger effect sizes, in depression, anxiety, sleep, and life satisfaction. Such advantages in MBSR may be associated with the immediacy of physiologic relaxation responses incurred in mindfulness practice, including strengthened attention to bodily sensations, and less reliance on rumi-

nation or other automatic emotions.^{21,27} The PAD interventions, however, were more cognitively oriented, with exercises that require more time and reflection (eg, identifying and engaging character strengths, practicing kindness and gratitude).²⁴ Indeed, mothers in PAD versus MBSR reported improved life satisfaction and reduced depression during the longer follow-up period. Both treatments were advantageous, however, and new work aims to integrate features of mindfulness and positive psychology interventions.⁴³

In contrast to previous literature, mothers of children with ASD versus other disabilities did not report more distressful affect. However, no such group differences are also seen when child variables are well controlled,⁴⁴ or when mothers are grouped by a stress biomarker instead of their child's diagnosis.¹² Response to treatment also was similar across diagnostic groups,

although mothers of children with ASD showed less immediate improvements in anxiety. This dampened response may relate to the broader autism phenotype, or presumptive genetic vulnerability to mild social, anxiety, or cognitive symptoms in first-degree relatives of individuals with ASD.⁴⁵ These mothers may thus warrant more intensive or longer anxiety treatments. Taking advantage of parent-to-parent rapport, we found that well-trained, supervised peer-mentors are effective interventionists. This approach meets urgent calls to improve global mental health by training nonspecialists to address unmet mental health needs.^{46,47} These same calls also highlight needs to integrate mental health screening or services into primary health care settings. Although pediatricians are uniquely well positioned to screen mothers of patients with disabilities, multiple challenges remain in doing so.⁴⁸⁻⁵⁰

A limitation of this study is that we did not use an untreated control group, and thus cannot conclude that either intervention was associated with better maternal outcomes than no treatment. However, untreated mothers of offspring with disabilities do not necessarily become less depressed over time; indeed by early old age they experience more health and mental health problems than they did in middle-age, and at higher rates than control parents.⁵¹ Further, meta-analyses of studies from the 1980s onward show no hints of decreased maternal mental health vulnerabilities over the years.^{8,28} Given this historical context, we used a comparative effectiveness design that applies interventions already proven to be effective in controlled studies to real-world settings and high-risk groups.

A second limitation is that we did not test effects of maternal improvements on child functioning. It is well known, however, that maternal depression has detrimental effects on children, and that child outcomes improve when maternal depression is well-treated.⁵² We found modest improvements in dysfunctional parent-child interactions primarily during treatment. Improved maternal mental health may thus set the stage for better child functioning, but these mothers may benefit even further with additional help in parenting strategies.

Other limitations also deserve mention, including that outcome measures relied on self-reports. One could argue, however, that maternal self-perceptions are exactly what treatment aimed to change. Even so, future studies need to include biomarkers of stress and confirmation of medical or psychiatric conditions. Parents in our study may not represent the population of all parents of children with developmental disabilities, but they were more diverse in age, race, and income than those typically included in MBSR or positive psychology interventions.^{21,41} Given the number of study outcomes, significant findings with smaller effect sizes could be due to chance and thus need to be replicated in future work. A final limitation, inherent in “real-world” effectiveness studies, is dropout owing to life circumstances, and in our case to caregiving demands, and dwindling questionnaire compliance during follow-up. These factors also pose challenges to follow-up beyond 6 months. However, we ensured that the study was adequately powered, dropouts versus completers did not significantly differ, and that differential attrition biases did not occur.

CONCLUSIONS

With advances in pediatric care, more children with neurodevelopmental

disabilities are living well into adulthood, and most continue to reside with their aging parents.⁵³ Even so, glaring knowledge gaps exist on the compromised health and mental health of the lifelong parent caregivers of young or adult children with developmental disabilities. This study helps bring these mothers into the research limelight and justifies future efforts to promote their well-being and long-term caregiving abilities.

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