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Mindfulness Based Stress Reduction (MBSR) for Parents and Caregivers of Individuals with Developmental Disabilities: A Community-Based Approach

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Abstract Stress among parents and other primary caregivers of children with developmental disabilities is pervasive and linked to lower quality of life, unhealthy family functioning, and negative psychological consequences. However, few programs address the needs of parents or caregivers of children with developmental disabilities. A mindfulness-based stress reduction (MBSR) program is a well-suited approach for these parents and caregivers, who may be overwhelmed by their children's situation, anticipating future challenges and reliving past traumas. We aimed to develop, implement, and evaluate the feasibility of an MBSR program designed for this population in a community-based participatory setting. Parents and caregivers were equal partners with researchers in curriculum development, recruitment, implementation and evaluation. Two concurrent classes, morning and evening, were conducted weekly in English with simultaneous Spanish translation over 8-weeks. Classes consisted of meditation practice, supported discussion of stressors affecting parents/caregivers, and gentle stretching. Of 76 participants recruited, 66 (87 %) completed the program. All participants experienced a significant reduction (33 %) in perceived stress ($p < 0.001$) and parents (n = 59) experienced a 22 % reduction ($p < 0.001$) in parental stress. Parents/caregivers also reported significantly increased mindfulness, self-compassion, and well-being ($p < 0.05$). Participants continued to report significant reduction in stress 2 months after the program. Our study suggests that a community-based MBSR program can be an effective intervention to reduce stress and improve psychological well-being for parents and caregivers of children with developmental disabilities. Additional research should assess the effect of cultural or socioeconomic factors on the outcomes of the intervention and further expand MBSR programs to include community-based participatory settings.

Keywords Mindfulness · Caregivers · Parents · Developmental disabilities · Community-based participatory research

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Introduction

Stress among parents and other primary caregivers of individuals with developmental disabilities (i.e., intellectual disability, autism spectrum disorders, cerebral palsy, epilepsy and other related conditions) is pervasive and linked to a variety of adverse physical and mental health outcomes (Dyson 1997; Emerson 2003; McKinney and Peterson 1987; Mugno et al. 2007; Schieve et al. 2007). For example, parents of children with Down syndrome experience more fatigue, depression, and anxiety symptoms than parents of children without Down syndrome (Hedov et al. 2000). Parents of children with Asperger's disorder have worse physical health scores and parents of children with autistic disorder experience increased levels of parental stress compared to parents of children without developmental disorders (Allik et al. 2006; Leonard et al.

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1993). Finally, parents of children with cerebral palsy report poorer levels of both mental and physical health (Leonard et al. 1993).

A wide network of interrelated factors contributes to caregiver stress: level of child functional ability and behavior, co-existing health challenges, limited social supports, lack of socio-economic resources, poor family functioning, as well as psychological and physical health (Rubin and Crocker 2006). Current interventions provided to parents and caregivers of individuals with developmental disabilities include respite care and parent support groups. These interventions address certain aspects of caregiver stress, such as caregiving demands and social supports, but do not specifically target development of psychological copings skills that can build resilience to current and future stress.

Mindfulness has been defined as "moment-to-moment awareness" or a "systematic approach to developing new kinds of control and wisdom in our lives, based on our inner capacities for relaxation, paying attention, awareness, and insight" (Kabat-Zinn 1990). This approach has been used in structured, evidence-based group programs called mindfulness-based stress reduction (MBSR), which focus on empowerment, nonjudgmental interpretation of events, and acceptance of the present situation using mindful meditation practices and gentle stretching (Kabat-Zinn et al. 1992). MBSR programs generally include formal mindful meditation instruction, discussion and practices and teach integration of mindfulness into everyday life as a strategy for increased coping and decreased reactivity to physical and emotional difficulties. Originally developed at the University of Massachusetts almost 40 years ago, MBSR programs have been successfully used in multiple controlled trials to improve mental and physical health in depression, anxiety, chronic pain, hypertension and several other chronic illnesses (Kabat-Zinn 1982; Kabat-Zinn et al. 1992, 1985; Sephton et al. 2007). Because mindfulness teaches a different relationship to external stressors and increases emotional regulation skills, an MBSR program may address stress and its consequences among parents and caregivers of children with developmental disabilities. Adapting the typical MBSR program to address caregiver stress appears a well-suited approach for these parents and caregivers, who often state that they are overwhelmed by their children's present situation (Leonard et al. 1993), and may be constantly anticipating future challenges and reliving past traumas.

Very few studies have assessed the effectiveness of an MBSR program for parents and caregivers of those with developmental disabilities. A study of four parents of children with developmental disabilities who were trained in mindfulness techniques revealed that the parents experienced an increased ability to mindfully attend to their children's problematic behavior, higher satisfaction in their own parenting skills, more satisfaction with their interactions with their children and lower caregiving stress (Singh et al. 2007). Though the small sample size limits conclusions that can be drawn from the study, it does provide a direction for research.

The potential for an MBSR program to relieve stress and its consequences and the dearth of literature on its use by parents and caregivers of those with developmental disabilities led us to design the current study. The objectives of the study were (1) to develop an MBSR program adapted for parents and caregivers of individuals with developmental disabilities using a community-based participatory research (CBPR) framework, and (2) to conduct a feasibility study measuring the effects of the MBSR program on stress, mindful awareness, self-compassion and psychological well-being. Based on previous studies (Carmody and Baer 2008), we hypothesized that increases in mindfulness would correlate with decreases in stress, and increases in perceived self-compassion and psychological well-being. A community-based participatory framework was utilized for this study to bring full participation of the affected community members (parents and caregivers) as partners in the research process so that the research could be enriched by all contributions.

Method

This study was a pre-/post- evaluation of participants in an eight-week MBSR program for parents and caregivers of children with developmental disabilities held at a community non-profit organization that used community-based participatory research principles. Self-reported quantitative measures were assessed prior the program, immediately following it and then 2 months after the program was completed. Qualitative assessment was completed using post-intervention interviews.

Participants

Participants were eligible for the program if they were parents or primary caregivers of an individual (or individuals) with a developmental disability receiving services from the local non-profit agency. Parents and caregivers who communicated in English and/or Spanish and cohabitated with the individual (or individuals) were included in the program.

Parents and caregivers were recruited through the engagement of leaders of parent support groups (most notably the Spanish-language and Ethiopian parent support

groups). Ads were also published in the Training and Events Bulletin and the agency newsletter, each of which was distributed to approximately 6,000 parents, care providers, staff and clients. Parent and caregiver participation was facilitated through the provision of multiple class day and time options, CD players, practice CDs available in English or Spanish, simultaneous Spanish translation by headset, at-home respite care, on-site childcare, and taxi vouchers. All services and incentives were provided free of charge.

Demographic characteristics are presented in Table 1. The majority (67 %) of participants participated in English, which they identified as their primary language. Our sample was predominately female (77 %) and married (77 %). The mean age of respondents was 46 years old, with participants as young as 28 and as old as 71 years old. Forty-five percent of respondents were Hispanic, 32 % were Caucasian, 12 % were African-American, and 11 % were another ethnic background. Over half of participants (52 %) reported being college graduates and 18 % reported finishing high school or less. Most participants cared for an individual diagnosed with autism spectrum disorders (60 %), with others caring for individuals diagnosed with intellectual disability (21 %), cerebral palsy (5 %), Down syndrome (3 %), or another diagnosis (e.g., borderline intellectual functioning, epilepsy) (11 %).

Table 1 Demographic characteristics (N = 66)

Sample characteristics	N	%		N	%
Gender			*Race/Ethnicity*		
Male	15	23	Caucasian	21	32
Female	51	77	Hispanic	30	45
Relationship type			African American	8	12
Parent	59	89	Other	7	11
Caregiver	7	11	*Education level*		
Primary diagnosis of child			Completed HS or less	12	18
Autism spectrum DO	36	59	Some college	20	30
Cerebral Palsy	3	5	College degree	17	26
Down syndrome	2	3	Graduate school	17	26
Mental retardation	13	21	*Income level*		
Other	7	11	<$25,000	19	30
Primary language			$25,000–50,000	16	25
English	44	67	$50,001–100,000	19	30
Spanish	22	33	>$100,000	9	14
	Mean (SD)				
Age of participant	45.7 (11.1)				

Community-Based Participatory Research Framework

A parent of a child with a developmental disability initially brought the MBSR program concept to the local community-based, state-funded non-profit organization that provides services to individuals with developmental disabilities, which in turn engaged the academic research team. In this spirit of partnership, the intervention was designed with community-based research principles. Community-based participatory research involves a partnership between community members and researchers in which all of the partners have equal standing, rather than the academic researchers leading as experts. The partners contribute to the entire research process, sharing expertise and accounting for decisions together (Israel et al. 2005). Throughout the research process, community members played an active role, participating as equal partners with researchers on the project planning committee, guiding the program and research concepts, design and implementation. Members of the committee included parents of individuals with developmental disabilities, university researchers, and staff from a mindfulness training institute and the local community-based organization. This committee determined recruitment strategy, developed the MBSR curriculum, delineated incentives to retain participants throughout the eight-week course, defined the desired evaluation questions, and selected evaluation instruments. Prior to the program, in depth interviews with key informants served to establish program interest, to identify the most effective approach to the program and its evaluation and to assist with recognition of potential barriers and means to address them. In addition, the evaluation was piloted to determine preferred length of tools and to ensure appropriate reading levels and understanding. During the program, the entire planning committee was involved in implementation, and participated in interpretation and dissemination of results.

This protocol was approved by the California Committee for the Protection of Human Subjects.

Intervention

The adapted MBSR program consisted of eight weekly 2-h sessions and a 4 h silent retreat. All classes were taught by an experienced MBSR teacher who was trained by the University of Massachusetts Medical School Center for Mindfulness. Qualified Spanish translators, with prior experience in MBSR translation with the program instructor, provided live simultaneous translation of each session. Four sets of eight-week classes in total were provided: two classes running simultaneously (morning or evening sessions) in the spring and again in the fall. Caregivers were assigned to one of the classes based on their preferences, as elicited at their initial orientation

session. They were provided the flexibility to switch between sessions (e.g., from morning to evening) on any given week; though this occurred on only three instances.

Our program followed the structure of the University of Massachusetts' Center For Mindfulness MBSR program (see Table 2), including teaching mindful meditation practices, gentle yoga/movement, mindfulness and stress theory, and group discussion Meditation practices included awareness of breathing, a body scan, a loving kindness intention practice, and other mindfulness practices in everyday life. A sample class would include the following: a discussion on a topic such as "acceptance of the child's developmental disability", an emotional awareness technique concentrating on breathing, a guided exercise (i.e., body scan meditation) bringing awareness to the different parts of the body and homework of a CD-guided body scan meditation and eating one meal mindfully. The planning committee made adaptations to the discussion topics to address parent/caregiver-specific stressors and to highlight strengths gained by parenting/caregiving for a child with a developmental disability. Group discussion topics included common stressors of parents and caregivers, the perception versus reality of caregiving, acceptance of the role of caregiver, mourning the loss of an idealized child, fear for the child's future, mindfulness practice with the child, and feeling compassion for self as caregiver. The half-day retreat included extended practice of various meditations, stretching techniques, and emphasizing practice to deepen the experience of being with one's own experiences as they arise and fall away. Participants received handbooks with information, printed assignments for each week's instruction (including daily half hour mindfulness exercises), and two audio CDs with guided meditations and exercises. Additional adaptations designed to facilitate continued parent/caregiver participation, based on feedback from the planning committee interviews, included shortening the weekly classes from 2.5 to 2 h per session and reducing the CD-guided practices to practice daily at home from 45 to 30 min per day.

Evaluation Procedures

Prior to the intervention, the program committee discussed at length the evaluation methodology. Because this was a feasibility study, a single-group pre-/post- design was chosen. Potential participants attended an orientation during which the instructor explained the goals and timeline of the intervention, as well as briefly previewed the meditation exercises and discussion to be expected in the class. Before the beginning of the first class, participants gave their informed consent and completed self-administered pre-test questionnaires. Post-program evaluations were completed after the final MBSR session at the conclusion of the final session and then again approximately 3 months after program completion to assess persistence of effects. The average time of survey administration was 30 min. Pre-/post- test data was only analyzed for subjects who participated in at least four of the eight sessions.

Measures

Demographics

Demographic information included age, gender, race/ethnicity, primary language, education level, participant's relationship to the individual with developmental disabilities (parent or caregiver), individual's diagnosis and perceived severity of the disability.

Mindful Awareness (MAAS)

Mindfulness, which is the fundamental skill taught in MBSR programs, was assessed using the Mindful Attention Awareness Scale (MAAS; Brown and Ryan 2003). This 15-item instrument measures participant's tendency to be attentive to and aware of present-moment experience in daily life. Items are rated on a Likert scale ranging from 1 (almost always) to 6 (almost never) to rate how often respondents have experiences of acting on automatic pilot, being preoccupied, or not paying attention to the present moment. Items include, "I find myself doing things without paying attention" and "I break or spill things because of carelessness, not paying attention, or thinking of something else". The MAAS has reported internal consistency (coefficient alpha = .82) and expected convergent and discriminant validity correlations.

Stress (PSS10 and ParentSS)

The primary outcome of this study, stress, was assessed using two instruments: the Perceived Stress Scale (Cohen et al. 1983) and the Parental Stress Scale (Berry and Jones 1995).The level of perceived stress was evaluated using the 10-item Perceived Stress Scale (PSS-10). Each item has a 5-point response scale (from 0 = never to 4 = very often). PSS-10 scores are obtained by reversing the scores on the four positive questions and then summing across all 10 scores. Example questions include "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?"

The Parental Stress Scale (PSS) is an 18-item Likert-type scale measure of stress specifically arising from the parenting role. This measure has been shown to be highly reliable, both internally and over time (coefficient alpha = .83 and test–retest reliability = .81 for 6 weeks) and to be equally appropriate for mothers and fathers. Example item are "Since having this child, I have been

Table 2 Adapted MBSR curriculum

Session	Theme	Mindfulness practices/ exercises	Homework
1	"[T]here is more right with you than wrong with you"	Awareness of positive self Moment by moment awareness of eating and breathing Guided body scan meditation	CD—guided body scan meditation Eat one meal mindfully
2	"[H]ow you see things (or don't see them) will determine in large measure how you will respond to them"	Guided body scan meditation Wandering mind—acceptance and refocusing Expanding awareness to identify and solve problems Guided sitting meditation with awareness of breathing	CD—guided body scan meditation Sitting meditation Pleasant events calendar Mindfully engage in routine activities
3	"There is pleasure and power in being present"	Guided mindful yoga Guided sitting meditation with awareness of breathing	CD guided (alternating) body scan meditation and mindful yoga Sitting meditation with awareness on breathing Unpleasant events calendar Capturing present moments Awareness of "automatic pilot" moments
4	"Awareness of being stuck in one's life and how to get unstuck"	Guided sitting meditation with awareness on breathing, sensations, body as a whole Listening and trusting in inner wisdom Awareness of stress and stress reactivity Loving kindness (i.e., compassionate awareness) meditation	CD guided (alternating) body scan meditation and mindful yoga Sitting meditation with awareness on breathing, sensations, and body as a whole Awareness of stress reactions, feeling stuck, and shutting off
5	"Reacting and responding to stress"	Guided sitting meditation with awareness on thoughts and focus on stillness Mindfulness in problem-focused and emotion-focused coping strategies to stress Mindful pain management Loving kindness meditation	CD guided sitting meditation, alternating with body scan meditation or yoga Difficult communications calendar Awareness of moments of reacting Mindful responses to stress
6	"Maintaining your center in interpersonal relationships"	Guided sitting meditation Optional mountain and/ or lake meditation Guided mindful yoga Loving kindness meditation	CD guided sitting meditation, alternating with body scan meditation or yoga Awareness of consumption
7	"How what we take in (diet in the broadest sense of the term) affects our health and well-being"	Awareness of attachment to place Sitting meditation with choiceless awareness Mindfulness of moving out of self-destructive diet practices Mindful communication Loving kindness meditation	Non-guided formal mindfulness practice Informal practices Awareness of consumption
8	"Keeping up the momentum and discipline"	Body scan Sitting meditation Loving kindness meditation Review	Continuing guided and non-guided formal mindfulness practice Informal practices Short- and long-term health goals

unable to do new and different things" and "I expected to have closer and warmer feelings for you child than I do and this bothers me."

Psychological Well-Being (PWB)

Psychological well-being was assessed using Ryff's Psychological Well-Being scales (PWB: Ryff and Keyes 1995). This is a self-rating, 84-item inventory that covers six areas of well-being: Autonomy, Environmental Mastery, Personal Growth, Positive Relations with Others, Purpose in Life, Self-Acceptance. On the PWB scales, subjects respond with a 6-point response ranging from strongly disagree to strongly agree. Responses to negatively formulated items are reversed in the final scoring procedure, so that high scores indicate high self-rating on the dimension assessed. Each scale score ranges from 14 to 84. Item examples include "When I look at the story of my life, I am pleased with how things have turned out" and "I don't have many people who want to listen when I need to talk."

Self-Compassion (SCS)

Self-compassion was measured by the Self-Compassion Scale (SCS; Neff 2003a). Neff (2003b) suggests that self-compassion consists of several elements, including a kind and non-judgmental attitude toward oneself when suffering and the holding of painful thoughts and feelings in balanced awareness, in which they are observed and accepted without judgment, rumination, or self-pity. The SCS has shown internal consistency of .92; test–retest reliability of .93 during a 3-week interval. Using a likert-type scale of 1 for almost never to 5 for almost always, the 26 items on this scale include examples such as "I try to be loving toward myself when I'm feeling emotional pain" and "I'm intolerant and impatient towards those aspects of my personality I don't like".

Self-Rated Physical Health

The first question of the Short-Form 12, a validated, frequently used measure of self-perceived health, was used to evaluate participants' physical health status. This question states "In general, would you say your health is excellent, very good, good, fair or poor?" Each of these states of health was ranked with a number from 1 (excellent) to 5 (poor).

Qualitative Measure

At the conclusion of the eight-week MBSR intervention, subjects were asked to write a response to the question, "Do you feel you got something of lasting value or importance from taking the MBSR program?"

Statistical Analysis

All data analyses were conducted using STATA version 10.0. Total and subscale scores for each of the psychosocial measures were analyzed using paired-samples *t* tests to compare scores of participants who completed the pre- and post-program assessments. Change scores were calculated by subtracting the pre-program score from the post-program score. Negative change scores for the two stress measures (PSS10 and PSS) indicate a decrease in psychological and parental stress, respectively. Positive change scores for the other psychosocial measures (MAAS, SCS, and PWB) indicate measured improvements in mindfulness, self-compassion, and psychological well-being. No more than two participants had missing data for each scale (or subscale). To evaluate the effect of this missing data, each test was rerun with missing data imputed using the overall mean value or the mean value of the subscale with missing data. Since the results were similar, we elected to use the imputed data in our final analyses.

In order to determine whether participants in all four classes could be grouped together, we compared their demographics and then used ANOVA to evaluate whether differences in scores for any of the scales were present based on class timing. To determine whether the program had variable effectiveness based on language, we compared t-tests for changes in all measures between groups taking the program in English or Spanish.

To further explore the relationships between mindfulness and stress, we determined whether there was a correlation between MAAS and PSS-10 scores. Then, multiple linear regression was used to determine whether a change in mindfulness predicted a change in parental stress while controlling for demographic variables.

Results

Ninety-three participants attended an orientation and 76 participants attended at least the first session of the MBSR program, during which they enrolled and gave informed consent for participating in the study. Of those participants, 66 (87 %) completed the pre- and post-program questionnaires. A 2 month follow-up was completed as well, with 39 (59 %) participants completing this questionnaire.

Demographics

All demographic factors were statistically similar based on class timing (morning or evening, first session or second), with the exception of marital status (69 % in the first sessions vs. 84 % in the second sessions). In addition, ANOVA results (not shown) indicated that the scores from the groups at baseline and then at post-test were not statistically different from each other. Thus, analyses include

all participants, regardless of which of the classes attended (Table 1).

Mindfulness

Participants' scores on the MAAS improved following the MBSR program, indicating a 15 % increase in average mindful awareness and attention ($p < 0.001$) (Table 3).

Stress Scores

Parent participants (n = 59) in the program experienced a 22 % reduction ($p < 0.001$) in parental stress following their participation in the intervention (Table 3). The pre- and post-program scores for perceived stress also revealed a significant reduction (33 %) in perceived stress ($p < 0.001$) for all participants.

Self-Compassion and Psychological Well-Being

Scores from the SCS and the PWB Scales improved significantly following the intervention (Table 3). The largest changes observed were seen in increases in self- compassion (20 %). Psychological well-being improved significantly from pre- to post-intervention, with overall psychological well-being increasing 9 %. Each of the PWB sub-scale scores significantly increased as well ($p < 0.05$) (data not shown).

Self-Rated Physical Health

Participants indicated a statistically significant improvement in self-assessed overall physical health, from a mean of 2.8 (SD 0.9), or "good", to 2.5 (SD 0.9), or "very good" (Table 3).

Table 3 Effects of MBSR intervention on mindfulness, parental stress, general stress, self-compassion, and psychological well-being. (N = 66)

	Pre-program	Post-program	
	Mean score (SD)	Change score	% Change
MAAS	3.7 (1.0)	0.5***	15
ParentSS[a]	46.4 (10.2)	−10.2***	−22
PSS-10	22.6 (6.2)	−7.4***	−33
Self-rated health	2.8 (0.9)	−0.4**	−12
Self-Compassion Scale	2.9 (0.7)	0.6***	20
PWB total	230.2 (31.3)	19.6***	9

[a] N = 59, * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

Relationship Between Mindfulness and Stress

Multiple linear regression analysis revealed that for every unit increase in mindful attention, based on the MAAS score, there was a 2.9 unit decrease in perceived stress on the PSS-10 score, holding constant demographic variables, including age, gender, language, and education (Table 4). We also controlled for the pre-test MAAS score and found similar results (model not shown).

Qualitative Measure

Responses to the open-ended question ("Do you feel you got something of lasting value or importance from taking the MBSR program?") are listed in Table 5. Generally, parents and caregivers expressed that they learned strategies to manage their stress better, to be more focused on the present and to improve their relationships with their children.

Persistence of MBSR Effects

Thirty-nine participants completed the two-month follow-up questionnaire. Again, paired sample t-tests indicated that every score besides the personal growth PWB sub-scale remained significantly improved after 3 months (Table 6). Notably, Mindfulness scores for this sub-sample were higher after 2 months (25 % increase) when compared to their post-program scores (20 % increase) immediately following the intervention. Reduction in perceived stress (−27 %) was slightly less than the reduction observed in the post-program

Table 4 Multiple linear regression of effects of mindfulness on stress (N = 66)

	B (SE)
Change in MAAS score (by 1 point)	−2.9 (0.9)***
Language of Program	
English	2.8 (2.1)
Spanish	Referent group
Age at baseline (in years)	−0.1 (0.1)
Gender	
Male	−3.0 (1.9)*
Female	Referent group
Parent education level	
High school degree or less	Referent group
Some college	−1.6 (2.6)
College degree	−5.7 (2.8)
Graduate school	0.1 (2.9)
(constant)	22.5 (3.7)
Adjusted R-square	0.156

* $p \leq 05$; ** $p \leq .01$; *** $p \leq .001$

Table 5 Selected quotes from program participants

Do you feel you got something of lasting value or importance from taking the MBSR program?
"A new way of looking at life and dealing with stress. A way to calm myself down—I have been feeling much better and calmer with my son."
"Balance, calmness, and peace of mind for the family and the rest of my life."
"To be kind to myself. To be mindful about things. And to stay in the moment."
"The idea of constantly thinking about the future or past and at times trying to stop the thinking and appreciate things is a wonderful gift."
"My moments of extreme stress are less stressful."
"Clear the mind of thoughts that are not helpful. Better listening skills."
"The MBSR program help[ed] me to feel better and to have more peace in my mind and body. And my stress level is down. I love the yoga. It helped me very much!"
"I learned to STOP—Stop, Take a breath, Observe, and Proceed—when dealing with my child."
"I become more mindful of myself and others, and I can handle my stress in life better because I learned a lot on how and what to do about it."
"A new orientation to life—more positive feelings about myself and more accepting of others—willing to listen and be present."
"I have thoroughly enjoyed meditation, as it has significantly decreased my stress level. I take more time to live and enjoy the (new) present."
"It taught me patience. Meditation is something that needs constant practice. This isn't something one gets good at in a few days. Connecting with oneself is a valuable tool."
"Different ways of thinking. Able to relax at very stressful moments."
"I feel more capable of dealing [with] and coping with stress. I also feel more comfortable in my own skins."
"I have learned the value of body and mind awareness in my own life—it can teach you so much about one's self."
"A great tool to assist in stressful situations."

results (−30 %). Similarly, participants continued to report a significant reduction in parental stress 2 months after the program; though, the magnitude of the reduction is decreased compared to immediately following the program. Finally, improvement in self-rated physical health on the SF-12 question was not statistically significant immediately following the program or at the 2-month follow-up.

Community-Level Findings

With a community-based participatory research approach, we were able to adapt the traditional eight-week MBSR course to one suited for and tailored parents and caregivers of individuals with developmental disabilities (Table 2). From the very first planning meeting, parents of individuals with developmental disabilities actively directed and participated in the decision-making process alongside researchers, community agency staff and skilled MBSR trainers. This planning committee guided participant recruitment, intervention adaptation and implementation, selection of outcome measures, and evaluation and dissemination of results. Specific actions directed by the committee included the decisions to recruit through parent support groups, to provide the specific incentives of childcare and taxi vouchers, to shorten class duration and guided in-home practice, to provide morning and evening classes, to offer free CD players, to provide simultaneous Spanish translation. Following the program, the committee has been actively involved in disseminating results and considering program sustainability.

Discussion

This study supports the use of an MBSR program to mitigate the effects of stress in parents and caregivers of those with developmental disabilities. Participants completing the 8-week adapted MBSR program experienced significant lasting improvements in all measured outcomes, including mindful awareness, general and parenting stress, psychological well-being, self-compassion, and general health. The improvements in pre- and post-mean scores found in the current study indicate the feasibility of utilizing MBSR-based interventions to decrease stress and its negative consequences for parents and caregivers of those with developmental disabilities.

Table 6 Effects of MBSR intervention on mindfulness, parental stress, general stress, self-compassion, and psychological well-being over time (2 month follow-up). (N = 39)

	Pre-program	Post-program		2 Month follow-up	
	Mean score (SD)	Change score	% Change	Change score	% Change
MAAS	3.5 (1.1)	0.7***	20	0.9***	25
ParentSS[a]	48.2 (11.0)	−9.7***	−20	−6.9***	−14
PSS-10	21.9 (6.6)	−6.6***	−30	−5.8***	−27
Self-rated health	2.6 (0.9)	−0.2	−7	−0.2	−7
Self-Compassion Scale	3.0 (0.8)	0.6***	19	0.6***	20
PWB total	234.1 (32.2)	20.8***	9	22.4***	10

[a] N = 33, * $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

This study used a novel approach to mitigate stress in caregivers of children with developmental disabilities. A mindfulness-based stress reduction program strengthens inner psychological resources, builds psychological resilience, helps with acceptance of current situation and increases tolerance of uncertainty. These coping skills can supplement most traditional interventions for stress-reduction for parents of children with developmental disabilities, which typically address the physically draining aspects of caregiving, such as respite, or provide a social setting for support and knowledge dissemination. In fact, conceptual models describing coping factors for caregiver stress include stress management, in addition to social supports and family functioning, as a key factor leading to psychological and physical health outcomes (Raina et al. 2004). Our intervention successfully targeted this aspect of coping.

We believe that the use of CBPR has enhanced the feasibility as well as the outcomes of the MBSR program in this population. CBPR creates collaborative partnerships, where there is an equality and shared mission between researchers and participants or community representatives (Doherty and Mendenhall 2006; Israel et al. 2005; Minkler and Wallerstein 2003). CBPR by focusing on the fact that families and communities are producers of health and health care, not just clients or consumers, it empowers families and communities to co-create health interventions (Berge et al. 2009), understandings, and influence in partnership with professionals (Minkler and Wallerstein 2003). This methodology would appear to be synergistic with the MBSR program. For example, empowerment, which is used in both models, is related to stress reduction and resilience (Frey et al. 1989). Using the CBPR technique, significant community input shifted the locus of control from the researchers to participants and community representatives. Furthermore, using a CBPR methodology may have increased the value of the research to the participants, creating an environment prepared for the intervention. The success of this program indicates that CBPR methodology should be considered in future research in this population.

Our results confirm the large stress burden in this population. Prior to the intervention, parents and caregivers of children with developmental disabilities reported higher levels of general stress than the general public. In fact, the mean pre-intervention PSS-10 score of 22.6 was comparable to mean pre-intervention scores of women undergoing breast cancer treatment (20.62) or who had been referred to stress-reduction programs due to their symptoms of emotional distress (23.17). The 33 % mean decrease in PSS-10 scores following the program compared favorably with 13–30 % improvements found in other populations participating in mindfulness interventions (Dobkin 2008; Nyklicek and Kuijpers 2008). In addition, the 15 % mean increase in MAAS scores in the present study compared favorably to a no change to 12 % increase from prior studies of MBSR interventions. These scores, in addition to the finding that mindfulness is significantly negatively correlated with stress, indicate that mindfulness mediated stress in our study. In addition, mindfulness, as measured by the MAAS, has been significantly positively correlated with openness to experience, emotional intelligence, and well-being and negatively correlated with anxiety (Brown and Ryan 2003). The 20 % mean increase in Self-Compassion Scale scores mirrored closely a 22 % mean increase found in a study of health professionals who completed a mindfulness intervention (Shapiro et al. 2005). Self-compassion scale scores show significant positive correlations with social connectedness, emotional intelligence, and life satisfaction; and significant negative correlations with self-criticism, perfectionism, depression, and anxiety. Because mindfulness includes awareness and acceptance of all experiences, positive correlations between SCS scores and mindfulness scales were predicted. The 9 % mean increase in overall Ryff's Psychological Well-Being scores fell in line with 4–9 % improvements found in clinical populations (Dobkin 2008; Nyklicek and Kuijpers 2008; Oman et al. 2008; Pradhan et al. 2007; Shapiro et al. 2005; Smith et al. 2008). Although the Parent Stress Scale improvement of 22 % in the present study was significant, we are not aware of any studies reporting comparable results.

As all the improvements in the post-test scores except for the improvement in personal growth persisted for some of the participants 2 months following the intervention, there is some evidence to suggest that parents and caregivers successfully integrated the mindfulness techniques into their daily lives and that these techniques continued to be effective in promoting mindful awareness and psychological well-being, as well as mitigating stress.

Furthermore, the core teaching objectives of the adapted MBSR course were accomplished, as intentional and organic group discussions and practices developed in a manner that fostered greater mindful awareness in parent/caregiver-child relationships. In a recently published article, Duncan et al. proposed a model of mindful parenting centered on five dimensions: listening with full attention, nonjudgmental acceptance of self and child, emotional awareness of self and child, self-regulation in the parenting relationship, and compassion for self and child (Duncan et al. 2009). Based on the improvements on the Parent Stress Scale, parents reported that all five of these dimensions were enhanced through the intervention.

Limitations

This study is subject to several limitations. The participant group was self-selected and may not reflect the diversity of

most parents and caregivers of individuals with developmental disabilities. As such, the results may not be generalizable to the larger population of parents and caregivers. Additionally, this study did not include a control group and, as such, a causal relationship between the intervention and improvements could not be strictly inferred. Nonetheless, this study did show the feasibility of a mindfulness based intervention for parents and caregivers of children with developmental disabilities. A future study should include a control group, preferably in a randomized clinical trial format. In addition to the measures used in the current study, future research should also examine effects impacting the child with developmental disabilities to assess how the intervention may have benefited in this arena.

Conclusion

A community-based MBSR program is a feasible and potentially effective intervention for reducing stress and improving stress-related outcomes for parents and caregivers of individuals with developmental disabilities. Additional controlled studies are needed to replicate the findings and further investigate the effects of a mindfulness intervention on parents and their children with developmental disabilities.

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