Mindfulness, Self-Care, & Participatory Medicine: A Community's Clinical Evidence

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Introduction

Tom Ferguson recognized that the evolving model of healthcare called Participatory Medicine acknowledges patients, caregivers and their networks all as powerful medical resources.[2] He coined the term e-Patients as those who actively collaborate to care for others, work with clinicians, shape research, and most relevant to this study, are active participants in their own self-care. While the emphasis in this evolving model of medicine has often been toward accessible information and computer networking, he recognized that medical information and technology alone might not be helpful. Rather, collaborating and communicating in order to enhance the power of self-care is far more effective. This model recognizes that empowering patients requires a transformation in the patient's level of engagement, their relationship with their caregivers, and with their illness.

Summary:

Background and Objective: Proactive patient self-care is central to the model of Participatory Medicine. Mindfulness-based interventions are proving to be effective self-care learning modalities in a variety of medical and therapeutic settings. This naturalistic study offers a clinical account for the value of mindfulness by measuring enduring positive therapeutic outcomes and a transformation of self-care.

Methods: We followed one clinic's empirical, clinical approach to assess the outcomes for Mindfulness-Based Stress Reduction [1] participants who came with a wide diversity of healthcare concerns.

Findings: We found significant and enduring improvements in participants' perceived stress, self-care attitudes and behaviors, as well as physical, mental and social health status and a long-term engagement in mindfulness practice. A survey of participants' health care providers indicated that they perceived a positive transformation of self-care in their patients.

Implications: With a growing library of studies documenting the effectiveness of mindfulness-based learning interventions our clinical evidence demonstrates the ecological validity of mindfulness practice in the domain of participatory health care.

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Acknowledging the power of this transformation from a different viewpoint, Jon Kabat-Zinn was one of the first to articulate the nature of participatory medicine in the medical literature. [3] He explained that the capacity to engage one's illness and relationships is measurably enhanced via learning the practice of mindfulness meditation. More than three decades of research continue to document the broad effectiveness of this approach in medicine (e.g., [4] [5]). These are two complementary views. While one mainly approaches via information, technology, and networked communities and the other via contemplative practice, what they have in common is their capacity to enhance these "inner resources for learning, growing, healing and personal transformation." [3, p. 239] The e-Patient's strengthened relationships with their network of caregivers and relevant information empower these inner resources. Likewise. via mindfulness practice the patient's transformed relationship with the internal experience of their own life, the enriched relationships with others, and a greater understanding of the context of their illness empowers them toward greater confidence to learn, grow, and heal.

The field of medicine's orientation toward healing has many dimensions and a host of these are touched by mindfulness practice. Rogers et al, [5] review the arc of research about mindfulness practice, its consequences and employment in the domain of medicine and psychotherapy. A host of studies document how mindfulness alters the stress response and a number of physiological markers including immune response, inflammation and blood pressure.

Recent neurobiological studies have shown that learning mindfulness produces significant changes in brain structure and function associated with self-regulation, learning, memory, emotional reguperspective and lation, selfreferential processing. Similarly, numerous studies have documented the impact of mindfulness practice on reducing the suffering associated with a growing number of medical and psychiatric disorders and life challenges: chronic pain, cancer, grieving, insomnia, irritable bowel syndrome, depression and more. It follows that mindfulness has become an integral component of an evolving array of effective interventions.

In the MBSR groups in this study we used the definition offered by "Mindfulness Kabat-Zinn [6]: means paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally." The practice of mindfulness meditation is about enhancing the ability to rest sustained awareness on the direct experiences of life: physical sensations. thoughts, sounds, affective states, and more. Being more capable of sustained attention on the current experience of living enhances one's capacity to discern the experience of unconscious reactivity from our capacity for intuitive, responsive choice. As a consequence there is a tendency to be less reactive. As a result, the physiological, neurological, emotional and social burdens of this reactivity begin to lift. The global medical and psychotherapeutic outcomes noted above are a consequence. Essentially, there is less suffering.

Beyond this, and central to an effective model of participatory health care, is first-person proac-

tive self-care, what Bandura [7] terms the primacy of selfregulation in health care. By its nature mindfulness is participatory and is a form of self-care requiring individual intention and proactive personal engagement. Studies measuring the impact of mindfulness practice on self-care have tended to document mental and physical health status measures along with various tests indexing levels of trait mindfulness or desirable mental states. These often go on to infer self-care as a consequence of improvements in such measures. [8] [9] [10] [11] [12] Moreover, most of these studies involve participant populations of clinicians or college students. To broaden the scope of understanding about the impact of mindfulness practice on self-care we developed and used a self-report direct measure of self-care.[13] Likewise, the naturalistic design of this study broadens this understanding by following participants who learned mindfulness in a community-based clinical setting where most of the participants were referred by clinicians, family and friends during the normal course of health care.

In this research we investigated long-term changes in attitudes and behaviors toward self-care, health status, and continuity of mindfulness practice among MBSR participants in one community clinic (Study 1) and surveyed the health care professionals who cared for them in order to determine what changes clinicians see in their patient's capacity for self-care as a consequence of mindfulness practice (Study 2). We hypothesized that there would be concurrent changes reflecting better health and more personal engagement. Our overall goal was to demonstrate in a learning intervention-oriented clinical setting that mindfulness practice supports the model of Participatory Medicine in two ways:

1) with enduring transformations toward positive medical and therapeutic outcomes via a personal learning intervention, and 2) demonstrating a long-term personal transformation that enhances proactive self-care.

Study 1: MBSR, Health Status, and Self-Care

Method

Participants

Participants were recruited from 8week MBSR courses offered through a stress reduction clinic in a healthcare-oriented yoga studio located in a medium-sized city in the state of Oregon from Fall 2007 through Winter 2011 (14 courses in total). All students who were enrolled in the MBSR courses over the four-year period were invited to complete pre- and post-program self-report measures. A total of 229 participants entered the course; 75% were women and the mean age was 47 (range 16-73, SD = 11.6). Income levels of participants varied from those on public assistance, to retired and fixed income, and the working middle class. Of the 218 participants who completed the program, 185 completed measures at pre- and post-MBSR and data from these participants were included for analyses in this study. Additionally, we sent a follow-up questionnaire packet to all 185 participants in Fall 2011, and we received complete data from 94 participants (51%).

MBSR Intervention

MBSR is a learning intervention requiring proactive personal engagement. It is a particular way of

learning mindfulness meditation that emerged in a hospital system over 30 years ago and was fashioned as a complement to medical care and therapy. [1] During this study we used that well-established program's evaluation instruments and methods. [14] **Participants** completed an application process and interview prior to admission to the program. They committed to 24 hours of classroom instruction and over 30 hours of homework. 45 minutes per day. Each group met for eight 2.5 hour weekly sessions and for one 6.5 hour retreat on the 6th week of the program.

Activities and mindfulness-based skills learned in the program are primarily experiential. principal practices are introduced during the program and constitute most of the homework and classroom time for participants. The body-scan meditation involves step-wise guided attention to sensations across all regions of the body from toes to head. Sitting meditation is introduced as a practice of offering attention toward the experience of breathing with a quality of openness to the various experiences of life, including sensation, thought, emotion, and sound. Mindful yoga is introduced as a gentle, adapted form of mindful movement designed to offer an appropriate level of physical movement emphasizing direct experience. Other principal elements introduced during the program include walking meditation, eating meditation, informal mindfulness of daily actives, and guided meditations such as loving-kindness. Didactic learning includes group interaction, dialogue and inquiry about the experiential practices as well as about the subject of stress management. As noted above, participants were asked to complete evaluations and testing for fourteen 8-week MBSR courses from Fall 2007 to Spring 2011 using the measures described below. The first author (B. R.) was the primary instructor for all 14 courses; he is an MBSR instructor certified by the Center for Mindfulness at the University of Massachusetts Medical School.

Measures

Perceived Stress Scale (PSS-10). The 10-item PSS-10 [15] was used to assess the degree to which situa-

tions in life are perceived as stressful. Items on the PSS-10 are designed to assess how unpredictable, uncontrollable, and overloaded participants find their lives. Items are rated on a 5-point Likerttype scale ranging from 0 = neverto 4 = very often. Four items that are worded in a positive direction are reverse-scored and responses to the 10 items are summed to create a psychological stress score, with higher scores indicating greater psychological stress. The PSS-10 has adequate internal consistency $(\alpha = .78)$ and has demonstrated expected correlations with a variety of constructs. [15]

Duke Health Profile (DUKE). The DUKE [16] is a 17-item, multi-dimensional questionnaire designed to measure self-reported functional health status among primary care populations. This brief, accessible measure was developed to assess multifaceted dimensions of health and well-being in a family medicine setting, which made it ideally suited for the naturalistic design used in this study. We used six DUKE subscales to measure function: physical, mental, social health, general health, perceived health and self-esteem. Three subscales were used to measure dysfunction: anxiety, depression, and pain. Six items that are worded in a positive direction are reverse-scored and the responses to different constellations of items are summed to create the various subscale scores. All items are rated on a 3-point Likert-type scale. The DUKE subscales have demonstrated evidence of criterion, convergent, and discriminant validity, as well as acceptable reliability for the overall scale. [17]

MBSR Follow-up Questionnaire (**FQ**). The FQ [14] [19] is a twopart retrospective self-report questionnaire that has been used for many years to follow results of MBSR courses at the University of Massachusetts Medical School's Center for Mindfulness and has also been reported on in published MBSR research. [20] [21] [22] The eight items in part 1, referred to in literature as the Summary Outcome Questionnaire [23], were used to assess pain frequency, pain severity, medication use, activity levels, energy levels, feelings in general, ability to cope with stress, and blood pressure. When responding to these items participants are instructed to "compare how you are now compared to how you were before taking the MBSR Program". These items are rated on a 6-point Likert-type scale ranging from 1 = much worse to 6 =greatly improved (unless the participant, by choosing 0, indicated that aspect of health was not a problem to begin with).

Part 2 includes 10 items used to measure "how much change, if any, has occurred for you in the following attitudes and behaviors as a direct result of your participation in the MBSR Program." We selected the 5 items from the part 2 scale we believed best assessed

self-care and used them in this study, and a factor analysis of all 10 items (see [13] for details) supported these 5 items loading onto a "mindful self-care" index (MSCI). These items are "knowing I need to take better care of myself," "actually taking better care of myself," "believing I can improve my health," "feeling assertive and able to express my needs," and "correcting negative health habits and behaviors." To further tap the participatory medicine aspect of selfcare we added an additional item to the MSCI at long-term followup, "feeling I am able to communicate my needs effectively to my healthcare provider(s)." These items are rated on a 4-point Likerttype scale ranging from 1 = negative change to 4 = positive change. In the current sample, Cronbach's alpha for the 8 items in part 1 is .69 and for the 6 items in part 2 is .83.

Meditation Practice Questionnaire (MPQ). We included four items in this study to measure how much participants continued the practices they learned in the MBSR program. We asked participants: 1) how often they do formal MBSR practices (e.g., sitting meditation, yoga, body scan), 2) average duration of each formal MBSR practice, 3) how often they do informal MBSR practices (i.e., mindfulness of daily activities like eating, walking, speaking, listening, journaling, etc.) and 4) when engaged in daily activities (e.g., eating, walking, speaking, listening, journaling, etc.) what percent of the time they do them mindfully. All four items were rated on a 7-point Likert-type scale, and the two formal meditation items and the two informal meditation items were summed to form a formal and informal meditation index, respectively. These measures avoid many of the weaknesses of mind-fulness measurement articulated by Grossman [24] by directly assessing participants' practice of mind-fulness skills they learned through their participation in the MBSR program.

Procedure

Participants completed either the PSS-10 or the DUKE pre- and post-MBSR course on the first day of class, last day of class, and at follow-up in Fall 2011. The PSS-10 was completed pre- and post-MBSR by 118 participants over eight courses from Fall 2007 through Summer 2009. The DUKE was completed pre- and post-MBSR by 66 participants over six courses from Fall 2009 to Spring 2011. The FQ was completed Post-MBSR by all 185 participants over the 14 MBSR programs from Fall 2007 through Winter 2011. The PSS-10 or DUKE (depending upon which one they completed at pre- and post-MBSR), SC, and MPQ were completed by 93 participants in the follow-up survey in Fall 2011. For participants who were administered the PSS-10 at follow-up (n =55), the mean duration from post-MBSR to follow-up was 3 years and for participants administered the DUKE at follow-up (n = 38)the mean duration from post-MBSR to follow-up was 1.5 years.

Design and Analyses

This naturalistic study was an empirical, clinical approach to the measurement of outcomes for a large number of MBSR program participants over a course of several years. While excluding a rigorous experimental protocol, the study preserved the real-world dimensions of the clinic's ongoing orientation of open access, brevity

of paperwork, and full participation. The testing instruments and self-reporting measures were applied to each of the 14 MBSR programs with respect to these practical limitations and thus not as a rigid experimental design. To assess pre- and post-MBSR health status change experienced by participants for each outcome, paired t-tests were used and a Bonferroni adjustment was made to control family-wise error rate (i.e., to minimize the likelihood of Type I error with the significance value set at p < 0.005 for each t-test – 10 in total). To determine the magnitude of change, effect sizes (ES) were calculated using Cohen's d. The general magnitude of the change was assessed using percentage change from pre- to post-MBSR levels. Repeated measures one-way analyses of variance (ANOVAs) were used to investigate change in outcome variables over three data points (pre-, post-MBSR, and follow-up). ANOVAs were selected over a combined MANOVA for the dependent variables to conserve power and because homogeneity of variance assumptions were met for all tests, and the significance value set at p

Table 1

Percentage of Participants Reporting Health Status Improvements on Part

1 of the Follow-Up Questionnaire Post-MBSR Training

| Health Status Improvements | Percentage Reporting Improvement | Participants |
|-----------------------------|----------------------------------|---------------|
| Coping with Stress | 99% | n = 183 |
| Feeling Better | 96% | n = 181 |
| Energy Level & Stamina | 66% | n = 169 |
| More Physical Activity | 63% | n = 161 |
| Decreased Medications | 31% | n = 134 |
| Decreased Frequency of Pain | 59% | n = 100 |
| Decreased Severity of Pain | 59% | <i>n</i> = 96 |
| Drop in Blood Pressure | 49% | <i>n</i> = 59 |

Note. n = the number of participants who noted that this aspect of health was an issue for them at the beginning of the program.

< 0.005 for each ANOVA. Partial eta squared was used to evaluate the ES for the ANOVA's. Contrast tests were used to further identify differences in functioning at each time interval (i.e., pre-, post-MBSR, and follow-up) for all outcome measures, and the significance value was set at p < 0.0025 for each contrast test (20 in total – 2 per ANOVA). Pearson's correlations were calculated to assess the relationship between self-care, mindfulness practice, and stress.</p>

Table 2
Percentage of Participants Reporting Positive Changes in Self-Care Attitudes and Behavior at Both Post-MBSR and Long-Term Follow-Up

| Self-Care Attitudes and Behaviors | Post-MBSR $(n = 185)$ | Follow-Up (n = 94) |
|---|-----------------------|--------------------|
| Knowing I Need to Take Care of Myself | 82% | 90% |
| Actually Taking Care of Myself | 83% | 91% |
| Believing I Can Improve My Health | 85% | 90% |
| Feeling Assertive & Able to Express My Needs | 76% | 82% |
| Correcting Negative Health Habits | 88% | 90% |
| Feeling Able to Express Needs to My Health Care Provider ^a | N/A | 72% |

Note. aThis sixth item was added at follow-up.

Results

Table 1 presents results for the eight items on part 1 of the FQ. The vast majority of participants endorsed difficulty coping with stress and feeling poorly upon entering the MBSR course, and nearly all of them (> 95%) indicated that they felt better and were coping better after the 8-week MBSR course. Similarly, most participants came with problems of low physical activity, energy and stamina. The majority of these people (> 60%) reported improvements as well. While 75% of participants entered the program taking medication, nearly one-third (31%) of those reported decreased usage as a result of their participation in the program. Over 50% of participants reported that pain was a problem for them prior to beginning MBSR, and 59% of these participants reported less frequency and severity of pain. Nearly 35% of participants reported having high blood pressure, and of those, 49% reported that it had decreased.

Table 3
Changes in Stress and Health from Pre- to Post-MBSR

| | Pre-M | BSR | Post-N | /IBSR | | | | | |
|---------------------|-------|------|--------|-------|-----------|----------|-----|------|--------|
| Measures | Mean | SD | Mean | SD | Cohen's d | % Change | n | t | p< |
| PSS-10 | 19.8 | 6.4 | 12.3 | 5.3 | 1.29 | -38% | 118 | 12.8 | .0001* |
| DUKE Health Profile | | | | | | | | | |
| Physical Health | 61.7 | 19.6 | 70.8 | 17.8 | 0.49 | 15% | 66 | 5.1 | .0001* |
| General Health | 59.9 | 14.9 | 70.4 | 11.3 | 0.8 | 18% | 65 | 7.3 | .0001* |
| Pain | 67.7 | 27.5 | 56.5 | 25.0 | 0.42 | -17% | 31 | 2.0 | .05 |
| Mental Health | 57.7 | 20.4 | 72.5 | 17.3 | 0.78 | 25% | 66 | 6.6 | .0001* |
| Social Health | 60.8 | 20.2 | 68.3 | 16.3 | 0.41 | 13% | 66 | 3.5 | *8000. |
| Self Esteem | 63.1 | 20.1 | 73.0 | 15.7 | 0.55 | 16% | 66 | 4.2 | .0001* |
| Perceived Health | 70.5 | 27.7 | 78.8 | 27.8 | 0.30 | 12% | 66 | 2.4 | .02 |
| Anxiety | 43.3 | 18.6 | 31.8 | 15.1 | 0.68 | -27% | 66 | 5.5 | .0001* |
| Depression | 44.6 | 19.4 | 31.2 | 15.5 | 0.76 | -30% | 66 | 5.5 | .0001* |

Note: PSS-10 = Perceived Stress Scale. DUKE Health Profile pain sub-scale scores are only included for those participants who reported pain was a concern on entering the MBSR program. *Bonferroni adjusted p < .005

Results for the mindful self-care index (MSCI) are shown in Table 2. A large majority of participants reported positive changes in selfcare attitudes and behaviors as a result of the MBSR program. The pre- and post-MBSR results for the PSS-10 and DUKE subscales are presented in Table 3. On the PSS-10 and a majority of DUKE subscales, participants evidenced statistically significant changes (p < .0008 for 8 of 10 measures, and p = .02 and .05 for the other two) toward improved health. Most Cohen's d values were indicative of medium to large effects across domains. More specifically, participants experienced the largest changes and most robust effects for perceived stress (d = 1.29), general health (d =.80), mental health (d = .78), depression (d =.76), and anxiety (d = .68).

As noted above, 51% (94 out of 185) of program participants who completed the pre- and post-MBSR program testing responded

to the follow-up survey. There were no statistically significant differences between follow-up respondents and non-respondents on any demographic variables and PSS-10 or DUKE scores at post-MBSR. Table 4 presents outcome

over all three periods: pre-, post-MBSR, and follow-up for those that completed all three (n = 93). Similar to the pre- and post-MBSR results, participants endorsed significant improvement on all outcome measures with the exception of pain (p = .122) and perceived health (p = .185). ANOVA results for the three time points (i.e., pre-, post-MBSR, and follow-up) revealed that most of the statistically significant changes that occurred at post-MBSR course were maintained at the follow-up. More spestatistically cifically. significant contrast tests comparing post-MBSR to follow-up scores indicated that participants maintained improvements made during the course on all measures. For example there were no statistically significant differences between post-MBSR and follow-up scores: PSS-10 (t = 2.01; p = .06), physical health (t = 1.73; p = .10), mental health (t = .59; p = .62), social health (t = .33; p = .76), general health (t = .42; p = .69), perceived

Table 4
Scores on Stress and Health at Pre-, Post-, and Long-Term Follow-up After MBSR

| | Pre-M | IBSR | Post-N | //BSR | Follo | w-up | | | | |
|------------------------|-------|------|--------|-------|-------|------|----|------|--------|-----------|
| Measures | Mean | SD | Mean | SD | Mean | SD | n | F | p< | $p\eta^2$ |
| PSS-10 | 19.1 | 6.7 | 11.6 | 5.4 | 12.9 | 6.9 | 55 | 41.6 | .0001* | .44 |
| DUKE Health Profile | | | | | | | | | | |
| Physical Health | 63.4 | 17.0 | 72.1 | 14.7 | 67.6 | 13.8 | 38 | 15.3 | .002* | .15 |
| General Health | 61.7 | 14.2 | 71.6 | 10.7 | 70.9 | 10.0 | 37 | 16.5 | .0001* | .31 |
| Pain | 63.0 | 22.4 | 52.2 | 10.4 | 54.4 | 14.4 | 23 | 2.2 | .122 | .06 |
| Mental Health | 60.3 | 20.6 | 73.7 | 16.7 | 72.4 | 15.7 | 38 | 12.6 | .0001* | .26 |
| Social Health | 62.4 | 20.6 | 70.3 | 15.7 | 71.1 | 15.1 | 37 | 6.1 | .004* | .15 |
| Self Esteem | 65.1 | 21.9 | 74.3 | 15.2 | 73.8 | 15.7 | 37 | 5.6 | .005* | .14 |
| Perceived Health | 71.1 | 25.0 | 80.3 | 24.8 | 73.4 | 27.8 | 38 | 1.7 | .185 | .05 |
| Anxiety | 40.8 | 18.7 | 28.5 | 14.9 | 28.9 | 14.1 | 38 | 12.9 | .0001* | .26 |
| Depression | 42.9 | 19.0 | 28.9 | 14.1 | 30.3 | 15.7 | 38 | 11.5 | .0001* | .24 |

Note: PSS-10 = Perceived Stress Scale. DUKE Health Profile pain sub-scale scores are only included for those participants who reported pain was a concern on entering the MBSR program. *Bonferroni adjusted p < .005. p η^2 = partial eta squared.

Table 5

Continuity of Mindfulness Practice at Long-Term Follow-up After MBSR

| • | • | • | |
|----------------------|-----------------|-------------------|--|
| Frequency | Formal Practice | Informal Practice | |
| Never | 14% | 6% | |
| < 1 Day per month | 22% | 15% | |
| 1-10 Days per month | 37% | 31% | |
| 11-20 Days per month | 14% | 13% | |
| 21-29 Days per month | 7% | 9% | |
| Every Day | 7% | 9% | |
| | | | |

Note. Participants (n = 94) completed the follow-up measures on average 3.2 years after MBSR training.

health (t = 1.21; p = .23), self-esteem (t = .26; p = .83), anxiety (t = .20; p = .84), depression (t = .46; p = .65); and pain (t = 1.13; p = .33).

Frequency of formal and informal meditation practice at follow-up is presented in Table 5. The majority of participants endorsed ongoing mindfulness practice, with only 14% never practicing formally and only 6% never practicing informally. In addition, participants endorsed an average range of duration for each formal meditation practice of 21-30 minutes and when engaging in daily activities, doing them mindfully on average 31-40% of the time. As shown in Table 6, there were a number of statistically significant correlations among variables at follow-up. More specifically, informal meditation practices and self-care were significantly negatively correlated with stress, whereas formal meditation practice was uncorrelated with stress. Additionally, self-care was significantly positively correlated with informal and formal meditation practice, and significantly negatively correlated with stress.

Discussion

The results in this naturalistic study reflect the global nature of the consequences of learning and practicing mindfulness meditation. Simultaneous long-term improvements in measures of physical, mental, personal, and social health underscore the ability of this practice to reduce suffering in a broad sense. [1] [25] Indeed, the intervention used in this study to learn mindfulness, MBSR, is well-suited to the multidimensional nature of healing and particularly suitable for addressing the biopsychosocial dimensions of chronic illnesses with their significant components of comorbidity. [26] Our clinical evidence confirms findings in other studies of enduring positive outcomes. (e.g., [20] [21] [27] [28] [29] [30]). Likewise, the number of recent, well designed quasi-experimental and controlled studies supports our finding of internal validity of MBSR in clinical settings (e.g., [31] [32] [33] [34] [35] [36] [37]).

Unlike other interventions that involve the application of a treatment by a healthcare provider, the learning of mindfulness via MBSR substantiates participants' proactive and participatory self-care. It seems reasonable to hypothesize that the results we provide and those reviewed above provide good evidence for this. To test this we measured levels of self-care and found positive change in MBSR participants' attitude and behavior toward self-care which paralleled findings of improved health status.

Parallel to this transformation in self-care, most participants reported a continuing long-term

Table 6
Pearson Correlations Between Stress, Self-Care, and Mindfulness Practice at Long-Term Follow-Up.

| | PSS-10 | Self-Care | Informal Meditation | Formal Meditation |
|---------------------|--------------|---------------|------------------------|----------------------|
| PSS-10 | - | | | |
| Self-Care | 42* (53) | - | | |
| Informal Meditation | 55** (53) | .44** (89) | - | |
| Formal Meditation | 18 (54) | .29** (90) | .35** (91) | - |

Note. Sample size (*n*) is provided in parenthesis for each correlation. PSS-10 = Perceived Stress Scale; Self-Care = 6-item Mindful Self-Care Index; Informal Meditation = 2-item informal meditation index; Formal Meditation = 2-item formal meditation index. *p < .01, **p < .001

Table 7
Clinicians' Assessment of Patients' Positive Changes in Self-Care Attitudes and Behavior After MBSR Training

| Self Care Attitudes | Clinicians Reporting Positive Changes |
|--|---------------------------------------|
| Patient Knowing They Need to Take Care of Themselves | 100% |
| Patient Actually Taking Care of Themselves | 100% |
| Patient Believing They Can Improve Their Health | 94% |
| Patient Feeling Assertive & Able to Express Their Needs. | 90% |
| Patient Correcting Negative Health Habits | 100% |
| Patient Feeling Able to Communicate Their Needs to You | 90% |

Note. Participants were 31 clinicians who were reporting on a total of 111 of their patients.

practice of mindfulness and for a large portion of the time they continue to be engaged mindfully in the activities of daily living. These findings generally complement those of other studies documenting ongoing mindfulness practice after MBSR training. [20] [28] [30] [38]

Study 2: Health Care Provider Assessment of Patients' Self-Care

The self-reporting of changes in attitudes and behaviors summarized in Table 2 indicates robust positive consequences for MBSR participants long-term. There has been no reporting in the literature of such changes observed by the clinicians who provide care for MBSR participants. We hypothesized that clinicians would observe these same changes. In combination with participant self-reporting, such clinician-reporting would further substantiate mindfulness as a vehicle for enhancing the proactive self-care at the heart of the model of participatory medicine.

Method

Clinicians (n = 118) who were familiar to MBSR participants at the clinic described in Study 1 were sent a short, anonymous survey

about the changes in self-care attitudes and behaviors of their patients after MBSR training. This included the clinicians who referred participants or were otherwise noted in the evaluations and applications as clinicians who might be interested in learning more about MBSR by 300 participants including those in Study 1 from 16 MBSR programs at the clinic during four and a half years from Fall 2007 through Winter 2012. The survey included the same 6 items on the MSCI used in Study 1; however, the items were revised to the third-person plural perspective: the clinician's opinion of how much change had occurred for their patients "in general" as a consequence of MBSR. Also, clinicians were asked how many of their patients had taken MBSR.

Results and Discussion

A total of 31 clinicians out of the 118 who were mailed surveys responded by acknowledging that their patients had attended the MBSR program: 9 primary care medical doctors, 4 psychiatrists or psychiatric mental health nurses, 1 specialist, 6 clinical psychologists, 3 physical therapists, 7 clinical social workers or marriage and

family therapists, and 1 naturopathic physician. Twenty clinicians responded that they did not recall which of their patients had taken MBSR and thus they could not complete the survey, and 67 did not respond to the survey. The 31 clinicians who completed the survey reported that they provide care to a combined total of 111 MBSR participants.

As shown in Table 7, health care providers acknowledged a robust positive change in their patients' willingness and ability to take care of themselves indicating an enhanced participatory dimension of their health care. This is parallel to the results among participants demonstrated in Study 1. It is evident that in addition to the positive health status outcomes and increased personal willingness to care for themselves, these patients and their caregivers also showed a greater capacity for communicating and working together as a consequence of their participation in MBSR.

Overall Discussion and Conclusions

These studies have demonstrated in one community clinical setting that the learning of mindfulness meditation positively affects health in substantial and enduring ways. A number of dimensions of physical, mental, and social health were significantly improved over a twomonth period and this improvement endured over a number of years. In general, those who participated in the MBSR courses continued the practices long-term. Participants' attitudes toward selfcare were transformed to the extent that they are taking better care of themselves and communicating their needs better to those around them. Clinicians noticed the same transformation in their patients who began the practice of mindfulness.

While acknowledging that the trajectory of mindfulness meditation does not point toward the outcomes of supply-side medical and therapeutic modalities intent on curing disease, this study's results parallel a growing library of more sophisticated and controlled studies showing that the practice of mindfulness can be a global, tangible, and enduring path to the relief of measurable suffering. We rely on these to affirm the veracity of the findings we have presented here and to help make the case for the ecological validity of the role of mindfulness in the realm of medical care and therapy.

Despite these findings, this naturalistic study must be interpreted with caution due to a number of limitations. This research was conducted parallel and secondary to an ongoing clinical course and as such, testing and self-reporting were woven into the matrix of the learning intervention with care to minimize distraction for participants: switching from administering the PSS-10 to the DUKE in some groups which limited sample size, follow-up data were collected on a static date (Fall 2011) as opposed to a specific time point post-MBSR (e.g., one year). Without the benefit of a control group, we cannot make claims of causality regarding the impact of the MBSR intervention. Lastly, this was a study based on one clinic and one community with corresponding demographic limitations, so generalizations to other populations will be limited.

We believe these studies have affirmed the value of a number of

important contributions that the practice of mindfulness offers to the model of Participatory Medicine as described by Santorelli [39]: importance of body awareness, awareness of inner experience, a recognition of being 'whole,' the liberation that comes with systematic mental training, self-regulation, and transformation. Our studies build on this line of thinking and parallel recent research suggesting that mindfulness meditation transforms one's intrapersonal relationship to enhance a greater capacity for proactive self-care [40]. Further research regarding self-care, mindfulness and health care will further enhance and fine-tune our ability to care for ourselves via this practice.

The intention of both Tom Ferguson and Jon Kabat-Zinn to plant the seeds for a version of medicine that is truly participatory is unde-Their respective apniable. proaches come from different directions but at the heart they both acknowledged the hunger we all have to be personally and proactively engaged with our life during encounters with illness. Self-care, an engaged community of caregivers, attentive awareness, selfcompassion, good communications, a transformation of attitudes and behaviors, and good information are all necessary ingredients for a successful model of Participatory Medicine.

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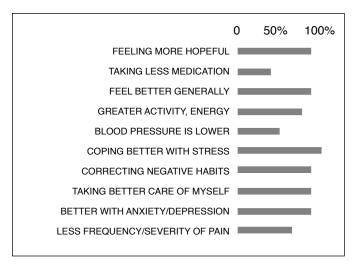
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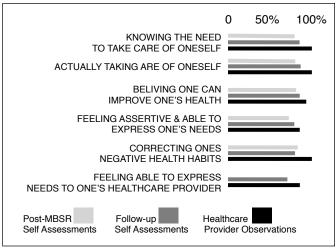
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Addendum: Graphical Summaries

Graphical summaries of the data in the tables of Rogers, Christopher, Sunbay-Bilgen; Mindfulness, Self-Care, and Participatory Medicine: A Community's Clinical Evidence. *Journal of Participatory* Medicine, February 2013.





MBSR Participants' responses on a post-program self-assessment (FQ) ¹¹ as a percentage of the number of such responses for each experience. (n=137). From the data in Table 1.

MBSR participant self-assesment and healthcare provider observations in self-care surveys about the consequences of the program. Compilation of data from Tables 2 and 7.

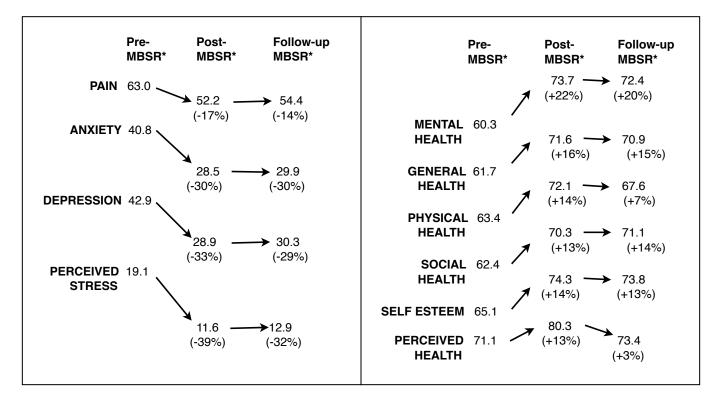
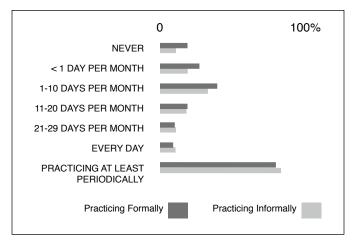
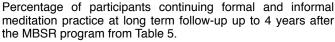
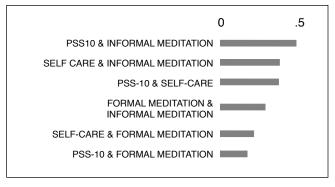


Table Graphics illustrating statistically significant and enduring changes in health status score testing from pre-MBSR through follow-up testing up to 4 years later (n=94) in Table 4. *All scores are DUKE Health Profile subscores with the exception of PERCEIVED STRESS which is the PSS-10.







Size of correlations between participants' modes of meditation practice and the stress (PSS-10) and self-care (MSCI) indices at long-term follow-up after the MBSR program from Table 6.

- "Mindfulness practice teaches my patients to dare to take their health and lives seriously. Carving out time to look within without judgment or agenda helps us all distinguish between the pain and loss that is an irreducible part of being human from the pain we volunteer for by living anywhere but the present, driven by the imperatives of our cultural programming." MD, Psychiatrist, referring physician
- "I find that those of my patients who participated in the MBSR course had better awareness and attitude toward their symptoms. In their own personal ways, this positive internal shift of attention helped them gain new understanding of their symptoms (i.e., pain, anxiety, etc.) and even helped them in times of more severe symptomatology. In some cases, this skill has helped them become less dependent on pharmacologic therapy and more willing to adopt other self-care methods." MD, Internist, referring physician
- "I find that my clients who participated in mindfulness training perceive their bodily sensations in a more healthy way. They have a much enhanced ability to distinguish between the "good" pain of therapeutic movement, and the "bad" pain of illness or injury. This enhances their ability to tolerate and participate fully in treatment, without the increased pain that tension and anxiety provoke." Physical Therapist, referring clinician
- "Overall, I am calmer with my clients and sharing what I have learned with them is helping them to change their views of depression, anxiety, and other mental health challenges." LCSW, MBSR graduate and referring clinician
- "The body aches and discomforts that the medical doctors couldn't even explain, much less fix, MBSR has alleviated." MBSR graduate, public school teacher
- "I had just finished chemotherapy when the class began. Several months later I realized what an impact MBSR had made on my life. I was using so many of the principles as I went about my day to day experiences. I was accepting the limitations of my body and the frustrations. Rather than becoming sad and depressed, I was living in the moment. My job was stressful, but now I had ways to cope." cancer survivor, MBSR graduate

Selected comments from referring clinicians and MBSR participants from Tables 1 & 2 of Rogers, et. al. Mindfulness in Participatory Medicine: Context and Relevance. <u>Journal of Participatory Medicine Vol. 5, February 14, 1013.</u>