The Effect of 20-Minute Mindful Breathing on the Perception of Suffering and Changes in Bispectral Index Score (BIS) in Palliative Care Informal Caregivers: A Randomized Controlled Study

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Abstract
Informal caregivers are at risk of being overwhelmed by various sources of suffering while caring for their significant others. It is, therefore, important for caregivers to take care of themselves. In the self-care context, mindfulness has the potential to reduce caregiver suffering. We studied the effect of a single session of 20-minute mindful breathing on the perceived level of suffering, together with the changes in bispectral index score (BIS) among palliative care informal caregivers. This was a randomized controlled study conducted at the University of Malaya Medical Centre, Malaysia. Forty adult palliative care informal caregivers were recruited and randomly assigned to either 20-minute mindful breathing or 20-minute supportive listening. The changes in perceived suffering and BIS were measured preintervention and postintervention. The reduction in suffering score in the intervention group was significantly more than the control group at minute 20 (U = 124.0, n1 = n2 = 20, mean rank1 = 24.30, mean rank2 = 16.70, z = −2.095, P = .036). The reduction in BIS in the intervention group was also significantly greater than the control group at minute 20 (U = 19.5, n1 = n2 = 20, mean rank1 = 29.52, mean rank2 = 11.48, z = −4.900, P < .0001). Twenty minutes of mindful breathing was more efficacious than 20 minutes of supportive listening in the reduction in suffering among palliative care informal caregivers.

Keywords
mindfulness, suffering, palliative care, end-of-life care, psychosocial care

Introduction
Suffering has been described by Saunders and Baines as “total pain.”1 It is a multidimensional experience which involves physical, psychological, social, and spiritual dimensions.2 Suffering is a state of undergoing pain, distress, or hardship that occurs when the intactness of a person is threatened by an undesirable event.3,4 Although the word “suffering” is commonly used to describe the experience of patients in the health-care literature, it is increasingly recognized in informal caregivers.5 Suffering in informal caregivers is often a reciprocation of the suffering experiences of patients whom they are caring for, and the level of suffering can be as severe as patients, or sometimes even exceed that of patients.5,6 Costa-Requena et al7 found that up to 77% of palliative care informal caregivers have significant suffering. Suffering reported in a qualitative study comprised of the pain of perceiving the patient’s suffering, anticipatory grief, the neurotic desires of giving the best care or keeping patient alive at all costs, the feeling of helplessness and powerlessness, the burden of caregiving, the hindrances, and the repercussion on one’s own

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personal and social life. Many informal caregivers are ill prepared to cope with the toll of caring.

It is important for informal caregivers to attend to their own needs while caring for others. Self-care practices such as eating a balanced diet, getting enough sleep, exercising regularly, taking time off without feeling guilty, maintaining friendships and hobbies, seeking help and advice from health-care providers, and spending time on spiritual activities can be restorative. In the context of self-care, mindfulness interventions may offer added benefits. Mindfulness has been shown to reduce stress, anxiety, and depression and improve sleep. The practice of mindfulness entails paying attention on purpose, in the present moment and without judgment. Although mindfulness has great potential in reducing the proliferation of stressful thoughts, many informal caregivers are unable to attend conventional mindfulness interventions delivered over 6 to 8 weeks. Therefore, we developed a series of mini-mindfulness exercises specifically for patients and family caregivers in the palliative care setting. From the exercises, 20-minute mindful breathing was selected for the study.

In this study, we examined the effect of a single session of 20-minute mindful breathing on the perceived level of suffering, together with the changes in bispectral index score (BIS) among palliative care informal caregivers.

**Methods**

A parallel-group, nonblinded, randomized controlled study was conducted in the University of Malaya Medical Centre, Malaysia, from November 2016 to February 2017, in accordance with the Declaration of Helsinki. Approval was obtained from the medical ethics committee of the University of Malaya Medical Centre. Inclusion criteria were (1) adult informal caregivers of palliative care in-patients and (2) an overall suffering score of 4 or above as measured with the Suffering Pictogram. In our study, an informal caregiver was defined as a non–health-care professional family member or friend providing care for a patient. Caregivers were excluded if they were unwilling to participate in a 20-minute session, had a past history of psychiatric illness, or were taking anxiolytics, hypnotics, antipsychotics, or antiepileptics. Eligible caregivers had the purpose and procedures of the study explained to them and written consent was obtained from recruited participants. The sociodemographic details of participants and the diagnoses of patients were recorded.

Participants were randomly assigned to either mindful breathing or supportive listening based on computer-generated random numbers with a 1:1 allocation ratio. Participants allocated to the mindful breathing group received a 20-minute mindful breathing session guided by 1 of 2 trained research assistants who were medical doctors. They were instructed to relax their body, close their eyes, and focus their attention on their breathing. If they noticed any distractions, they were directed to bring their attention back to their breathing. They were interrupted at minute 5 for outcome measures and then instructed to continue focusing their attention on their breathing until minute 20. During this time, the 2 research assistants then remained quiet. Both research assistants received a single session of training from the primary investigator. This included an introduction to mindfulness, a guided 20-minute mindful breathing exercise, and a supervised practice session where they guided one another paying particular attention to nonverbal cues, paralanguage, and the skilled use of silence.

Participants allocated to the control group received a 20-minute supportive listening session by one of the said research assistants. They were instructed to interview participants with semistructured questions regarding the participants’ caregiving and life experiences and to listen to the participants without interruption. They were also trained to acknowledge the distress of participants appropriately. Outcome assessments were conducted at minute 5, following which participants were facilitated to continue talking, as interviewers listened until minute 20. The instructions to conduct the 20-minute mindfulness breathing session and the semistructured questions for the 20-minute supportive listening session are presented in Table 1.

<table>
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<tr>
<th>Techniques of 20-Minute Mindful Breathing Versus 20-Minute Supportive Listening</th>
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<tr>
<td><strong>Techniques</strong></td>
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<td><strong>20-Minute Mindful Breathing</strong></td>
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<tr>
<td>Instructions</td>
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<tr>
<td>Make yourself comfortable</td>
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<tr>
<td>Relax your body</td>
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<tr>
<td>Close your eyes gently</td>
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<tr>
<td>Take 2 deep breaths slowly through your nose</td>
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<td>Then, breathe naturally</td>
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<td>Notice the flow of air</td>
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<tr>
<td>Rest your attention gently on the breath</td>
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<tr>
<td>If you are distracted by any sounds, body sensations, thoughts or feelings, gently come back to your breath</td>
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<tr>
<td>Be aware of the breath for the next 20 minutes</td>
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Table 1. Techniques of 20-Minute Mindful Breathing Versus 20-Minute Supportive Listening.

<table>
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<tr>
<th>(1) Perceived level of suffering using the Suffering Pictogram</th>
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<tr>
<td>a. Baseline overall suffering score at minute 0 (T1)</td>
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<tr>
<td>b. Average overall suffering score during the 5-minute session as recalled by the participant at minute 5 (T2)</td>
</tr>
<tr>
<td>c. Overall suffering score at minute 5 (T3)</td>
</tr>
<tr>
<td>d. Average overall suffering score during the subsequent 15-minute session as recollected by the participant at minute 20 (T4)</td>
</tr>
<tr>
<td>e. Overall suffering score at minute 20 (T5)</td>
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</table>
(2) Bispectral index score value
   a. Baseline BIS value at minute 0 (T1)
   b. Lowest BIS value during the 5-minute session as recorded from the BIS monitor (T2)
   c. BIS value at minute 5 (T3)
   d. Lowest BIS value during the subsequent 15-minute session as recorded from the BIS monitor (T4)
   e. BIS value at minute 20 (T5)

The primary outcomes analyzed were the within-group reduction in suffering score and the between-group reduction in suffering score measured with the Suffering Pictogram. The overall suffering score is a numerical scale of 0 to 10 (0 = no suffering, 10 = worst possible suffering) at the center of the Suffering Pictogram. The Suffering Pictogram is a brief, reliable, and valid instrument to measure suffering in palliative care. The overall suffering score of the Suffering Pictogram correlated moderately and negatively with the quality-of-life instrument FACIT-Sp total score ($r = -0.448, P < .001$).16

The secondary outcomes analyzed were the within-group reduction in BIS value and the between-group reduction in BIS value recorded from the BIS monitor. Bispectral index score is a validated noninvasive monitoring device used in the intensive care unit and operating theatre to guide anesthesia administration.18-20 It uses a disposable 4-electrode sensor placed on the patient’s forehead to measure the level of consciousness through an electroencephalographic (EEG) signal. The BIS value ranges from 0 to 100 (0 = flat EEG, <40 = deep hypnotic state, 40-60 = general anesthesia suitable for surgery, 60-80 = moderate-to-light sedation, >80 = awake).18 Among the different EEG machines, BIS was selected to provide objective data on the level of arousal due to its portability, ease of application, and interpretation. Mindfulness has been reported to reduce arousal with the increase in low-frequency EEG activities such as $\alpha$ and $\theta$ waves in one systematic review.21

Statistical analyses were performed using SPSS version 16. All participants were included in the analyses. Within-group comparisons were analyzed using the Wilcoxon signed-rank test. Between-group comparisons were analyzed using the Mann-Whitney $U$ test. All tests were 2 tailed, with a significant level of .05.

Results

Of the 53 family caregivers approached and screened, 6 declined participation and 7 were not eligible because of a low overall suffering score of <4. Forty participants were randomly assigned to either a 20-minute mindful breathing session or a
20-minute supportive listening session. The flowchart of participants is illustrated in Figure 1.

Table 2 shows the demographic characteristics of the participants. The mean age of caregivers was 45 years. There were more female (67.5%) than male (32.5%) caregivers and 57.5% of them were married. The majority of participants were of Chinese descent (50%), followed by Malays (35%) and Indians (12.5%). The commonest religion was Buddhism (47.5%), followed by Islam (35%), Hinduism (12.5%), and Christianity (5%). Most had completed tertiary education (60%). Half the caregivers were spouses, nearly half were children, and one was a parent.

All 40 participants completed the study and were included in the analyses. The baseline median suffering score was 7 in the mindful breathing group and 6.5 in the supportive listening group. The baseline BIS value was 98 (BIS > 80 = awake) in both groups. The suffering scores and BIS values at T1 to T5 are presented in Table 3. There was no important harm or unintended side effect observed in both groups.

**Primary Analyses**

A significant reduction in the suffering score was observed in both the intervention group and the control group at T2, T3, T4, and T5 (Table 4). The reduction in suffering score in the intervention group (median = 3.0), however, was significantly greater than the control group (median = 2.0) at minute 20 ($U = 124.0$, $n_1 = n_2 = 20$, mean rank$_1 = 24.30$, mean rank$_2 = 16.70$, $z = -2.095$, $P = .036$, $\eta^2 = 0.11$), as shown in Table 5.

**Secondary Analyses**

There was a significant reduction in the BIS value in the intervention group at T2, T3, T4, and T5 (Table 4). In the control group however, a significant reduction in the BIS value occurred only when caregivers were listened to at T2 and T4 and not during the interruption for outcome assessments at T3 and T5. The reduction in the BIS value in the intervention group (median = -8.0) was significantly more than the control group (median = -0.5) at minute 20 ($U = 19.5$, $n_1 = n_2 = 20$, mean rank$_1 = 29.52$, mean rank$_2 = 11.48$, $z = -4.900$, $P < .0001$, $\eta^2 = 0.62$), as shown in Table 5.
This is the first randomized controlled study that demonstrates the efficacy of a 20-minute mindful breathing intervention in rapidly reducing the perceived suffering among palliative care informal caregivers. The benefit from 20-minute mindful breathing was greater than 20-minute supportive listening. The minimally clinically important difference (MCID) in the overall suffering score that participants perceived as significant that would mandate an intervention was 2.16 In our study, the onset of achieving this MCID of 2 was observed within 5 minutes for mindful breathing and prior to 20 minutes for supportive listening. This rapid onset of therapeutic benefit of mindful breathing was comparable to our previous 2 randomized controlled studies of 5-minute mindful breathing in the rapid distress reduction of palliative care patients.22,23

In terms of EEG activity, 20-minute mindful breathing produced a greater degree of BIS reduction compared to 20-minute supportive listening. There was no correlation between the BIS value and suffering score. Patients may be awake (BIS > 80) without suffering or suffering calmly (BIS 60-80).24 Hence, the suffering reduction with mindful breathing could be due to the calming of the mind when participants focused on their in-and-out breath. A systematic review of the neurophysiology of mindfulness on EEG showed mindfulness consistently increased the amplitude in the α and θ bandwidths, reflecting a state of “relaxed alertness.”21 Our study provides the first subjective evidence of neurophysiological changes of mindfulness from the BIS perspective. As for the listening group, the reduction in BIS at T2 and T4 when caregivers were allowed to speak and ventilate feelings disappeared when they were being interrupted at T3 and T5, possibly indicating an increased level of arousal when they were interrupted.

Although several studies have shown the benefits of mindfulness-based interventions among family caregivers, most of these studies involved family caregivers of people with dementia.9,25-27 Most of these studies utilized mindfulness programs lasting 4 to 10 weeks, of variable duration (1-2.5 hours each session) and that also required daily home practice sessions lasting 10 to 45 minutes.28 Palliative care caregivers may not have the luxury of time to leave patients and participate in these programs. Hence, 20-minute mindful breathing offers an alternative that is easy to administer, has a rapid onset of action,
and can be practiced without leaving the patient. For those who have benefited from the 20-minute mindful breathing, they were encouraged to use it at other times by the research assistants.

This study has several limitations. The study was conducted in a single center and the sample size was small. Community caregivers were excluded for logistic reasons. Of the 53 family caregivers screened, only 75% participated. Most caregivers were female, and the results may not be generalizable to both genders. Similarly, the results may not apply across all educational levels owing to the high level of tertiary education. Allocation concealment was also not performed and the application of electrodes may have affected caregivers’ attentiveness to the breathing exercise. The interruption at 5 minutes to record the suffering experience may also have impacted on the effect of mindful breathing exercise. In addition, this study only examined the immediate effect of a single session of mindfulness practice, but not the sustained effect, as there was no follow-up. Additional studies to examine the longer term durability of response to the intervention should be conducted. Only 1 of the 16 exercises of mindful breathing was applied in our study, and other exercises may be included in future research to examine their effectiveness in addressing suffering in a more comprehensive manner.29

The current study provides preliminary evidence that 20-minute mindful breathing is feasible and beneficial for palliative care informal caregivers and may reduce suffering rapidly. Family caregivers often face no less suffering than patients. Compassion can lead to suffering as well as fatigue in care-givers.8 Through the addition of mindfulness to the provision of compassionate care, caregiver suffering may be reduced. Where caregivers are calm enough after practicing mindful breathing, they may have more space to choose how best to respond to their situations.

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