Research Article

A Novel MBST-Based Intervention for Palliative Care in ALS and Terminal Cancer Patients

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ABSTRACT

Palliative care patients face increased emotional and psychological suffering, including anxiety, depression, suicidal ideations, delirium, anticipatory grief, and fear of death. Hence, an intervention focused on improving the psychological and emotional well-being of terminally ill patients is necessary. This study examines the potential of a novel intervention to enhance the emotional and psychological well-being of terminal patients, specifically with Amyotrophic Lateral Sclerosis (ALS) and terminal cancer. This research is divided into two studies: Study 1a, a set of pilot qualitative interviews (n= 5) to inform the design of a novel mindfulness-based therapy (MBST), and Study 1b, a quantitative experimental intervention to determine the efficacy of the intervention (n=144), to improve the psychological and emotional well-being of palliative patients, along with developing a good coping mechanism. Study 1a revealed information about the problems, needs, and opinions on the intervention of palliative patients, highlighting the demand for effective treatments, through interviews. This information was used to inform the intervention task, which then tested experimentally in Study 1b using the Suffering Pictogram. The analyses, through mixed ANOVA, yielded a significant decrease in all dependent variables tested – overall suffering discomfort, worry, fear, anger, sadness, hopelessness, difficulty in acceptance, and emptiness – for participants in the experimental condition versus the control condition. Hence, study 1b demonstrated the intervention was highly effective to relieve psychological stress. This study highlights the potential of MBST as a practical and efficient tool to improve mental and emotional health in the context of terminal disease and its significant implications for clinical practice, legislation, and future research in palliative care.

Keywords: Palliative care; Terminal illness; Psychological intervention; mindfulness-based therapy; Emotional well-being

INTRODUCTION

Suffering remains as high as 88% in patients with terminally ill diseases (1). Therefore, this intervention aims to reduce suffering, in particular of 8 of its dimensions: Discomfort, Worry, Fear, Angry, Sadness, Hopelessness, Difficulty, and Emptiness, by designing, creating, and developing a novel intervention from ground-up, whilst

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specifically addressing the needs of the palliative care patients, which are generally ignored (physical pain and limitations, psycho-existential suffering, end of life fear).

Terminal illness is defined as an illness or disease process that is not responsive to curative medical treatment and which will worsen, eventually causing death (2). Palliative refers to relieving symptoms without dealing with the condition, and palliative care is a specialized medical care resource for terminally ill patients that focuses on providing relief from the symptoms and stress of the illness. Each year, an estimated 56.8 million people, including 25.7 million in the last year of life, are in need of palliative care (3). Yet, palliative care and, specifically, the relief of suffering for palliative patients are some of the most neglected dimensions of global health (4). Currently, there is Mindfulness-Based Stress Reduction to reduce stress in ill patients, Dignity Therapy to reflect on meaningful aspects of their lives, and Meaning-Centered Psychotherapy to help cancer patients enhance their meaning in life (5). Therefore, this is one of the only solutions that is self-guided, digital, and developed to address holistic coping mechanisms - emotional, psychological, and existential suffering.

Terminal illness influences the patient's psychological and emotional well-being, with risks of anxiety, depression, suicidal ideations, symptoms of delirium, and anticipatory grief and fear of death (6). One important style of intervention for psychological and emotional well-being is mindfulness-based practice. In this paper, I test a novel mindfulness-based intervention I designed and developed which focuses specifically on palliative Amyotrophic Lateral Sclerosis (ALS) and terminal cancer patients and their experiences with terminal illness to aid in alleviating their suffering. by testing patients with Amyotrophic Lateral Sclerosis and Terminal Cancer through a Mindfulness-Based Supportive Therapy (MBST) mindfulness-based intervention was utilized with the goal of reducing emotional and psychological suffering, and increasing positive coping mechanisms.

In order to test patient suffering, we will use the Suffering Pictogram which measures suffering in palliative care to measure the effectiveness of the intervention for emotional and psychological well-being. To do this we will conduct an experiment to test our novel intervention that targets wellbeing to increase the positive coping mechanism and emotional well-being of patients with ALS and cancer.

For the research, 2 studies were conducted. 1 study was the pilot, wherein 5 caretakers of palliative patients were interviewed to understand the psychological and emotional impact their diseases cause and their experience and opinion on implementing a mindfulness-based intervention. This study allowed us to collect primary data to improve the intervention using the feedback. Then, the second study was conducted to investigate the effect of the intervention on emotional and psychological well-being, using the Suffering Pictogram. This study enabled the understanding of the effectiveness of the intervention, by comparing the pre-test and post-test suffering pictogram responses for the control and experimental group.

LITERATURE REVIEW

Previous research has explored methods for the reduction in psychological and emotional well-being due to terminal illnesses. For example, a retrospective study by Majota Kobayakawa *et al*. 2017 showed the psychiatric and psychological symptoms of terminally ill patients. The results of the 532 participants showed that 65% of the patients experienced various symptoms of delirium and 27% of patients experienced suicidal ideations. However, the terminally ill patient has emotional and personal needs other than anxiety and depression that need to be accounted for (6). A study by Wenrich *et al*. (2003) investigated the emotional well-being needs of dying patients through the investigation of two- focus groups with 137 participants. These groups were composed of patients with chronic obstructive pulmonary disease (COPD), acquired immunodeficiency syndrome (AIDS), and cancer. The results showed that focus group participants identified 12 domains related to end-of-life care that are most important to the patients and their families. The findings showed that emotional support was ranked second, following communication and four components emerged essential to emotional support for the patients: compassion, maintaining hope and a positive attitude, providing comfort through touch, and being responsive to patient's emotional needs. Hence, these results suggested the need for the maintenance of emotional well-being for terminally ill patients. Moreover, terminally ill patients also face threats and experience losses which are associated with anticipatory grief and fear of death, along with the loss of previous roles, meaninglessness, and decreased sense of control contributing to demoralization of patients (7).

Coping refers to the thoughts and behaviors mobilized to manage external and internal stressful situations (8), and positive coping mechanisms include actions taken to manage and reduce stress in ways that are not harmful or detrimental in the long run, including preparative

behavior in response to distress (9). Coping strategies are associated with multiple outcomes, including quality of life, symptoms of depression and anxiety, and illness understanding, which are especially useful for end-of-life care (10). One of the coping mechanisms used as a psychological intervention in terminally ill patients is mindfulness. Mindfulness is awareness of one's internal states and surroundings that help people observe their thoughts, emotions, and other present-moment experiences without judging or reacting to them. Mindfulness is used through therapeutic interventions including mindfulness-based stress reduction, and mindfulness meditation (10).

Mindfulness is a cognitive skill of maintaining awareness of one's own mind in the present, and mindfulness practice involves training one's attention to reorient whenever it acquiesces to the absent-mindedness. Some research has demonstrated the efficacy of mindfulness practices among terminally ill patients (11). However, this intervention is important as mindfulness intervention specifically for terminally ill patients is still not created and

These mindfulness-based interventions, as suggested by Lau and Mehta, have been successful in reducing psychological stress, and it's mainly used by non-palliative patients and thus, do not address alleviating psycho-existential suffering of terminally ill patients (12). Moreover, while the aforementioned mechanisms of mindfulness may have great potential in reducing the proliferation of mental events in suffering, palliative care patients may be too sick or emotionally unstable to participate in any psychotherapy and regulate their attention and reactivity (13). Additionally, palliative care patients have needs and requirements: fatigue, breathing constraints, independence, lack of energy/focus, and regulation of reactivity and attention. Hence, this intervention is specifically designed for palliative care and is focused for palliative needs.

Moreover, this is the first designed intervention to our knowledge that tests Mindfulness-based supportive therapy, a psychotherapy, which is a potential therapy primarily for terminally ill patients (14). This theory of suffering in palliative care relies on the framework consisting of 5 components: mindful presence, mindful listening, mindful empathy, mindful compassion, and mindful boundary awareness. The literature review and synthesis of the formation of MBST, Mindfulness-Based Supportive Therapy, is illustrated through the study by Beng *et al*. 2013, which began by formulating the theory of suffering through the 2 thematic analyses of 20 palliative care patients and 15 informal caregivers. Then, the results from a secondary thematic analysis of suffering caused by healthcare interactions were used to conceptualize a psychotherapy framework, followed by the principles of mindfulness being incorporated into the framework for the formation of a mindfulness-based psychotherapy, making MBST a potential therapy for use in palliative care. This theory of suffering in palliative care was formed through the integration of the existential-experiential model of suffering and the model of compassion suffering in palliative care. MBST is centered around 5 themes: presence, listening, empathy, compassion, and boundary awareness, making it one of the only mindfulness techniques for suffering palliative patients (15). However, this technique requires a trained therapist for every session of the therapy. Therefore, this paper also tests the intervention which is completely independent-use, allowing palliative patients to use the intervention without feelings of codependency, and enabling flexibility, feasibility, effectiveness, and free cost.

MATERIALS AND METHODS

Before designing the intervention and conducting a study to test its effectiveness, we conducted a usability-style pilot study in order to test if the intervention was required, what emotional and psychological issues it should target, and what should be improved in the intervention. This information was used to rework the intervention and ensure it targeted the needs of the palliative patients. Next, Sudy 1b aimed to test the effectiveness of the novel, designed, created, and reworked intervention to understand the effect of the intervention on emotional and psychological well-being, measured using the Suffering Pictogram. The intervention was a new, self-designed, mindfulness-based intervention that was designed using the framework of MBST and created as an independent and short mindfulness-based intervention.

To collect information to test the usefulness of the intervention a pilot study was conducted with a small number of participants in the style of usability testing. Common rules-of-thumb in usability research suggest that 4 to 5 participants are sufficient to uncover glaring problems or issues in testing. Thus, over here, we collected 5 participants for our interviews in order to understand the different emotional and psychological effects experienced by palliative patients, with questions asking: the difficulty they experience in their daily routine, the challenges they face mentally/emotionally, what limitations from their disease they feel affect them,

and how the disease affects them emotionally. This information was important to understand the specific emotional and psychological issues the intervention had to target and focus on addressing. Further, we also tested the caretaker's perspective on the novel intervention through questions such as: their initial reaction to it, the logistics of a QR code, how long they would want the intervention, and what features they would prefer. This information was important to understand the features and aspects the caretakers believe would be most important, given their first-hand experience with the palliative patients. Hence, unstructured qualitative interviews were used to collect the data given the additional information it allows the participant to elaborate on, allowing the collection of subjective information, while answering a series of questions to ensure the collection of relevant data.

Using this information, the intervention was informed and reworked. Next, the effectiveness of the intervention was measured by comparing the pre-test and post-test suffering pictogram responses of the experimental and control groups and comparing the results using mixed ANOVA testing. The suffering pictogram is a short, reliable, and valid instrument that measures suffering in palliative care, and hence, can be used as a screening tool to directly detect suffering directly. Therefore, in this study, the suffering pictogram will be used to explore the experience of suffering by the terminally ill patients before and after the intervention was implemented, and in the control and experimental group. The suffering pictogram presents 7 categories of suffering that need to be assessed according to what the patient experiences: discomfort, worry, fear, anger, sadness, hopelessness, difficulty in acceptance, and emptiness. The patient also needs to provide a circle in the center to the overall score of suffering. The patient needs to score their suffering for each of the categories and overall score from between 0-4 to what they most align with. These numbers are noted on the pictogram for each dimension and an area in the middle of the pictogram for overall suffering which needs to be ticked according to the patient's present suffering experience. The patient may indicate their response by pointing.

The intervention was built through an online software - Wix, to create the website through which the mindfulness-based intervention can be implemented. Next, researched mindfulness techniques were developed, and tailored to the principles of MBST. Cards were developed on the website and these tasks were added to it. Through the study, some of the changes made to the intervention were the inclusion of an instruction sheet, the reduction of duration of the mindfulness techniques to 5 minutes longest, and finally, the addition of audio and music to the cards to aid ease.

Study 1a [Pilot]

This study was approved by the Institutional Review Board and informed consent was obtained from all participants. The study included a sample of 5 caretakers of palliative patients. 3 participants were caretakers of patients with ALS and 2 participants were caretakers of patients with cancer. All the patients and caretakers had no prior experience with mindfulness. The participants were recruited through the 'ALS Support Group' through phone calls. The interviews took place online for approximately 5-8 minutes. All the participants are from India and are located in Delhi, Chandigarh, and Mumbai.

The procedure followed a qualitative interview, beginning by drafting a set of 18 questions in a semi-structured interview style. These questions were regarding the emotional and psychological experiences of the palliative patient, experience with mindfulness, and feedback on the mindfulness intervention. The participants were recruited through the 'ALS Support Group' and a mutual time for the interview was set through phone calls. After connecting digitally via phone call or audio call at the set time, the 5 participants, individually, were interviewed using the interview script. The interview call followed the script's standardized introduction, questionnaire, and conclusion, however, modifying some questions based on the responses. Their responses were noted and after the completion of all 5 interviews, the questions and responses were organized into a spreadsheet with questions organized in columns, participants organized by rows, and answers filled in accordingly. The data was then analyzed thematically by count and theme of the open responses collected, analyzing the data to identify patterns and develop findings.

In the interview, questions 1, 2, and 3 (Appendix 1 includes the questions) allowed the caretaker to introduce themselves and provide context - such as the disease and the duration of the patient. Further, questions 4, 5, and 6 discussed how the patients experience mental health in their day-to-day lives, and how it impacts their livelihood, and quality of life. Questions 7 and 9 allowed participants to provide information about any previous engagement with mental-health intervention, its influence, and the patient/caretaker's feedback on the intervention. Moving forward, questions 10, 11, and 12 examined how the participants viewed the idea of the intervention and if they would like to implement it. Questions 15 and 16 asked

specific questions about the intervention on particular features such as audio and visuals. Finally, questions 13 and 14 ensured the features planned to be included in the intervention were user-friendly for the participants.

Study 1b

This study was approved by the Institutional Review Board and informed consent was obtained from all participants. The experiment included 84 palliative patients in the control group and 60 palliative patients in the experimental group. 57 palliative patients in the control group were suffering from a form of cancer and 27 were suffering from ALS. In the experimental group, 34 patients were suffering from a form of cancer and 23 were suffering from ALS. All participants are 40+ years old. The participants were recruited through the ALS Support Group through phone calls, and communication took place through emails. The participants are from India and are located in Delhi, Chandigarh, and Mumbai.

The procedure followed an experiment, with the independent variable being the MBST-based mindfulness technique, and the dependent variable being the effect of the intervention on the wellbeing. The intervention lasted 7 days, and was completed asynchronously by the participants. Firstly, a standardized script was prepared to share with the control group and the experimental group with the instructions. These instructions included 3 documents: the pre-test survey, the post-test survey, and the Google Form as daily check-ins to keep track of the number of cards completed each day. The instructions included information on steps to fill out the pre-test survey, how to follow the intervention, and how to fill out the post-test survey, with general tips. The procedure followed was the participants began by filling the 'Suffering Pictogram' digitally by editing the online copy, and reporting the patient's experiences of discomfort, worry, fear, anger, sadness, hopelessness, difficulty in acceptance, and emptiness, on a scale from 0 to 4, with the intensity increasing in ascending order, according to the patients suffering for each of these 7 categories. The patient is then required to suggest the level of overall suffering they experienced. Once the patient completes the pre-test survey before beginning the intervention, it is sent back via email. Next, the patient follows the intervention every day for 5-10 minutes, approximately 2-3 cards, through the website with all the mindfulness cards. The patient selects a card at random and completes the mindfulness practice by either following the written or audio instructions. To do this, they clicked the 'open' button on the card they preferred. After completing the intervention, the participants fill a Google form inquiring about the day of the intervention and cards completed. The intervention and Google form is completed similarly for 7 days. After the completion of the 7th day intervention and form, the participant fills out the post-survey form, by re-filling the 'Suffering Pictogram' through a new digital copy, following the same procedure as the pre-test, and reporting the current experience of suffering experienced by the patient after the intervention, and sending it back through email. After the pretest and post-test data have been collected, the data will be organized on a Google sheet, with 2 separate tabs of 'Time 1' and 'Time 2', referring to the pre-test responses and the post-test responses, respectively. Then, the columns to be filled in each tab, for every participant in the control and experimental group were their name, number of participant, condition, overall suffering reported through the pictogram, and the suffering reported for each category: discomfort, worry, fear, angry, sadness, hopelessness, difficulty, emptiness, and time point, in the suffering pictogram, in individual columns. After the organization of this data, it is then analyzed and results are derived.

RESULTS

Study 1a [Pilot]

Palliative patients and effect on emotional and psychological well-being. The qualitative interview suggested that patients experienced negative mental well-being, shown through question 3: 'What is the main issue the patient faces in their daily routine?', question 2: 'What are some challenges they face?' and question 5: 'How have the diseases affected their mental and emotional wellbeing?'. 5/5 patients reported facing some mental trouble. 2/5 patients reported that they face anxiety and depression, influencing feelings of hopelessness. Moreover, they noted they feel moody and negative. 3/5 patients also find acceptance of the terminal illness difficult and 2/5 patients report struggling with missing out from daily routine. Further, it was reported that the palliative patients also suffer from physical limitations affecting their quality of life. This is shown through question 6: What are the limitations they are feeling that they believe are affecting their health?' and question 3: 'What is the main issue the patient faces in their daily routine: limited movement, restriction of going outside, etc?'. 5/5 patients reported a form of physical limitation with 3/5 patients suffering from mobility issues and 2/5 patients requiring external assistance with coughing, eating, and breathing. Finally, 2/5 patients also suffer

from hair loss and side effects of medicines.

Previous experience with mindfulness of the palliative patients. No patient had implemented any intervention to improve their mental well-being. Question 7: 'What techniques have they implemented to improve their mental wellbeing?' and question 8: 'Have they engaged in any mindfulness exercises before?' show that 5/5 patients are not engaging with any mindfulness exercises, and only 1/5 patients engaging with music to make themselves feel better.

Caretakers' perspective on the intervention. 1 caretaker demonstrated a desire for an intervention to enable the patient to release their emotions. Additionally, all participants had a positive perspective on the intervention, shown through question 9: 'Do you think this type of mindfulness intervention would be helpful, or unhelpful?', question 10: 'Is there anything that you could imagine would or would not be effective about this intervention on their mental health?', question 11: 'What are your initial reactions to it: do you perceive it to be difficult, boring, ineffective, fun?' and question 15: 'Does this seem unpleasant or confusing at all?'.5/5 participants find the intervention to be helpful, with 2/5 claiming it can bring a sense of normalcy. Further, 5/5 caretakers note the intervention to have no drawbacks with 2/5 caretakers finding it enriching, and 2/5 caretakers finding it fun. However, 1 caretaker noted it could be boring initially. Finally, 0/5 patients find the incorporation of a QR code or using the smartphone inconvenient or confusing.

Study 1b (Figures 1-9)

DISCUSSION

Through the interviews with the terminally-ill patients, the study demonstrated that terminally ill patients experience mental health issues ranging from depression to feelings of sadness and hopelessness. The influence of a terminal disease on the patient's daily life is notable and influences their mood and satisfaction levels. These feelings of irritation and dissatisfaction arise from limited body movement, feelings of dependence, and inability to

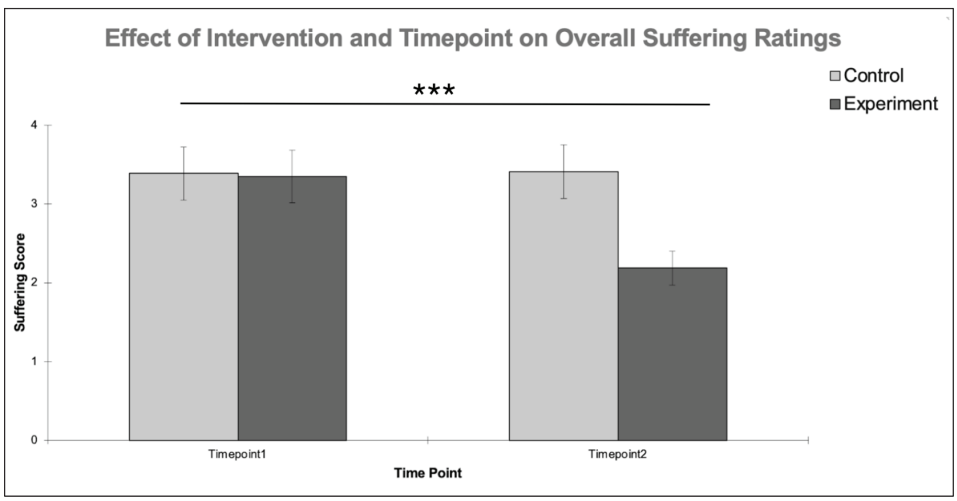

Figure 1. Bar Graph of Effect of Intervention and Time Point on Overall Suffering (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).

Overall Suffering. A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Overall Suffering. The mixed ANOVA yielded a main effect of Intervention, $F(1, 282) = 77.88$, $p < .001$, such that the average Overall Suffering was significantly lower for the experimental group ($M = 2.75$, $SD = 0.87$) than for the control group ($M = 3.4$, $SD = 0.57$). The mixed ANOVA yielded a main effect of time point, $F(1, 282) = 42.18$, $p < .001$, such that the average Overall Suffering was significantly lower for the time point 2 ($M = 2.91$, $SD = 0.84$) than for time point 1 ($M = 3.37$, $SD = 0.61$). However, the interaction effect was significant, $F(1, 282) = 65.82$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Overall Suffering than the control group.

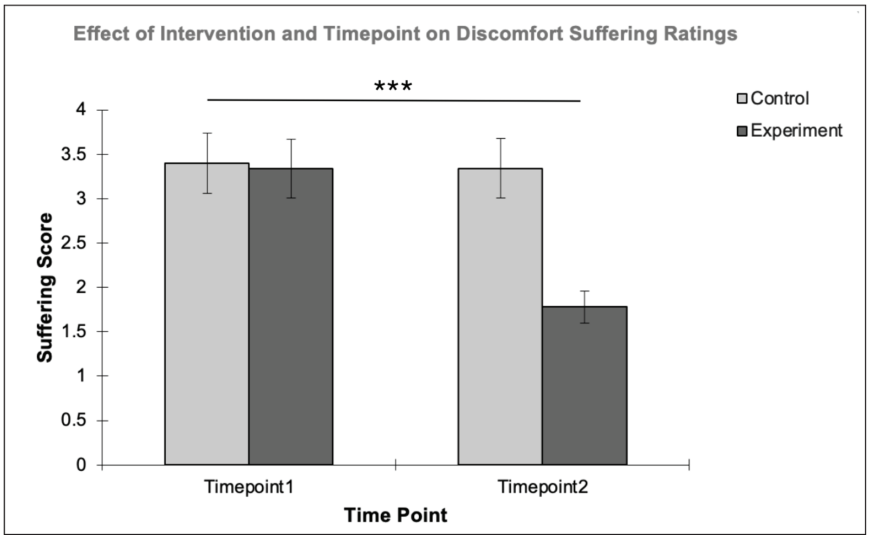

Figure 2. Bar Graph of Effect of Intervention and Time Point on Discomfort (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$). **Discomfort:** A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Discomfort. The mixed ANOVA yielded a main effect of Intervention, $F(1, 284) = 45.84$, $p < .001$, such that the average Discomfort was significantly lower for the experimental group ($M = 2.56$, $SD = 1.09$) than for the control group ($M = 3.37$, $SD = 0.55$). The mixed ANOVA yielded a main effect of time point, $F(1, 284) = 78.06$, $p < .001$, such that the average Discomfort was significantly lower for the time point 2 ($M = 2.7$, $SD = 1.02$) than for time point 1 ($M = 3.37$, $SD = 0.61$). However, the interaction effect was significant, $F(1, 284) = 93.68$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Discomfort than the control group.

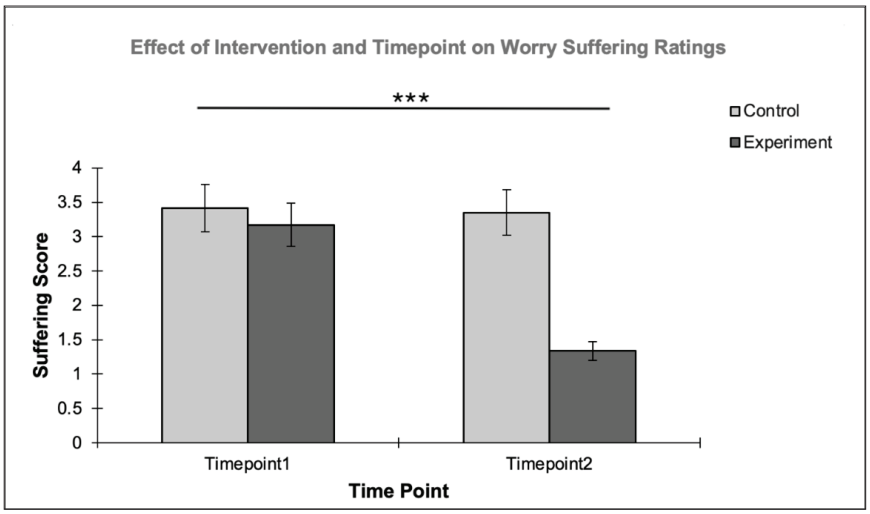

Figure 3. Bar Graph of Effect of Intervention and Time Point on Worry (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$). **Worry:** A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Worry. The mixed ANOVA yielded a main effect of Intervention, $F(1, 282) = 127.81$, $p < .001$, such that the average Worry was significantly lower for the experimental group ($M = 2.24$, $SD = 1.26$) than for the control group ($M = 3.38$, $SD = 0.55$). The mixed ANOVA yielded a main effect of time point, $F(1, 282) = 60.65$, $p < .001$, such that the average Worry was significantly lower for the time point 2 ($M = 2.52$, $SD = 1.23$) than for time point 1 ($M = 3.32$, $SD = 0.66$). However, the interaction effect was significant, $F(1, 282) = 66.93$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Worry than the control group.

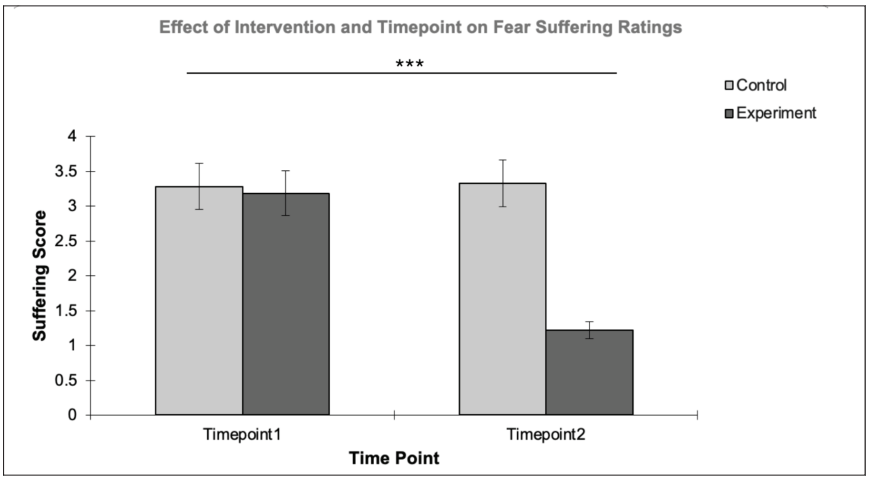

Figure 4. Bar Graph of Effect of Intervention and Time Point on Fear (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).
Fear: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Fear. The mixed ANOVA yielded a main effect of Intervention, $F(1, 284) = 101.83$, $p < .001$, such that the average Fear was significantly lower for the experimental group ($M = 2.2$, $SD = 1.31$) than for the control group ($M = 3.3$, $SD = 0.60$). The mixed ANOVA yielded a main effect of time point, $F(1, 284) = 44.96$, $p < .001$, such that the average Fear was significantly lower for the time point 2 ($M = 2.46$, $SD = 1.28$) than for time point 1 ($M = 3.24$ $SD = 0.69$). However, the interaction effect was significant, $F(1, 284) = 79.62$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Fear than the control group.

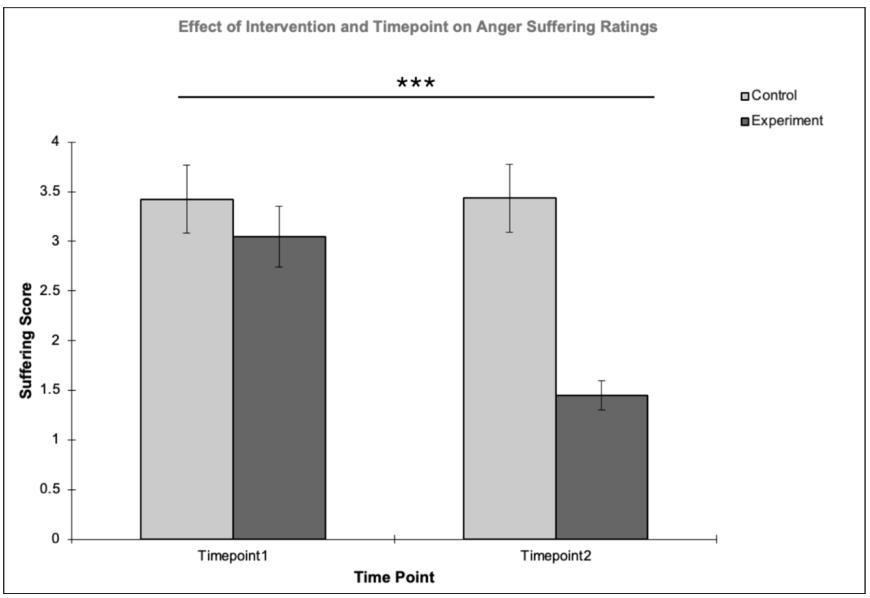

Figure 5. Bar Graph of Effect of Intervention and Time Point on Anger (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).
Anger: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Anger. The mixed ANOVA yielded a main effect of Intervention, $F(1, 284) = 139.27$, $p < .001$, such that the average Anger was significantly lower for the experimental group ($M = 2.26$, $SD = 1.19$) than for the control group ($M = 3.43$, $SD = 0.58$). The mixed ANOVA yielded a main effect of time point, $F(1, 284) = 49.91$, $p < .001$, such that the average Anger was significantly lower for the time point 2 ($M = 2.62$, $SD = 1.23$) than for time point 1 ($M = 3.27$ $SD = 0.71$). However, the interaction effect was significant, $F(1, 284) = 52.61$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Anger than the control group.

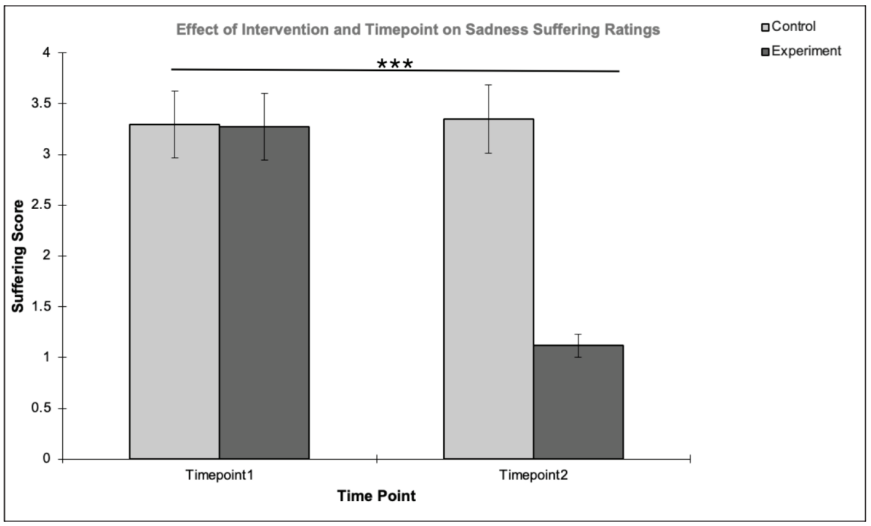

Figure 6. Bar Graph of Effect of Intervention and Time Point on Sadness (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).
Sadness: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Sadness. The mixed ANOVA yielded a main effect of Intervention, $F(1, 282) = 213.51$, $p < .001$, such that the average Sadness was significantly lower for the experimental group ($M = 2.19$, $SD = 1.32$) than for the control group ($M = 3.32$, $SD = 0.52$). The mixed ANOVA yielded a main effect of time point, $F(1, 282) = 128.82$, $p < .001$, such that the average Sadness was significantly lower for the time point 2 ($M = 2.42$, $SD = 1.13$) than for time point 1 ($M = 3.28$ $SD = 0.55$). However, the interaction effect was significant, $F(1, 282) = 202.79$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Sadness than the control group.

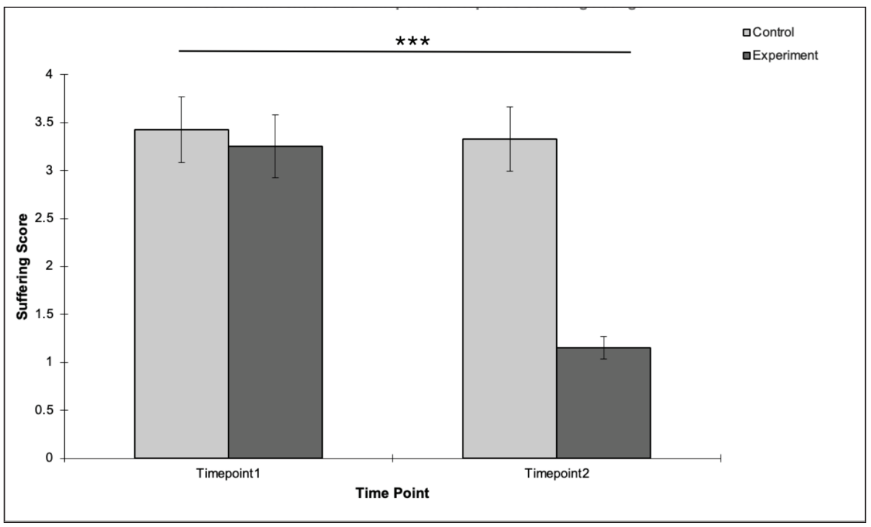

Figure 7. Bar Graph of Effect of Intervention and Time Point on Hopelessness (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).
Hopelessness: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Hopelessness. The mixed ANOVA yielded a main effect of Intervention, $F(1, 283) = 191.07$, $p < .001$, such that the average Hopelessness was significantly lower for the experimental group ($M = 2.20$, $SD = 1.39$) than for the control group ($M = 3.37$, $SD = 0.53$). The mixed ANOVA yielded a main effect of time point, $F(1, 283) = 120.67$, $p < .001$, such that the average Hopelessness was significantly lower for the time point 2 ($M = 2.42$, $SD = 1.28$) than for time point 1 ($M = 3.36$ $SD = 0.70$). However, the interaction effect was significant, $F(1, 283) = 2139.56$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Hopelessness than the control group.

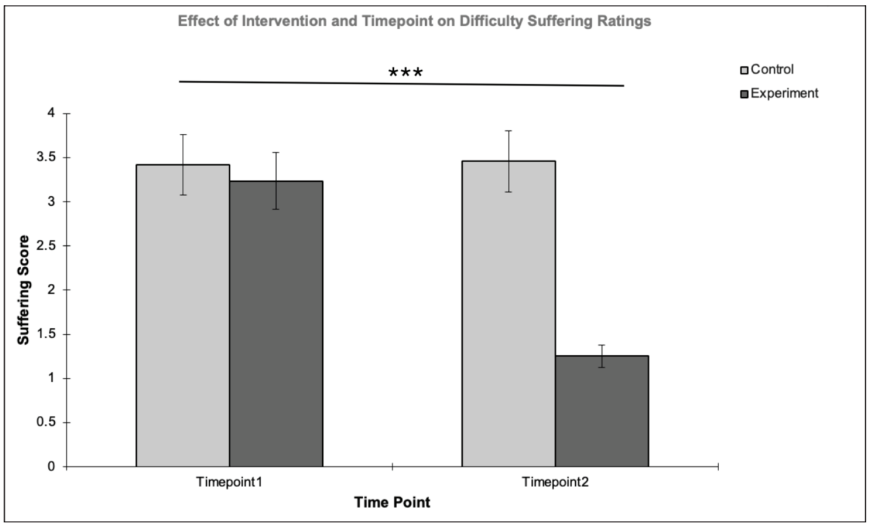

Figure 8. Bar Graph of Effect of Intervention and Time Point on Difficulty In Acceptance (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).

Difficulty In Acceptance: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Difficulty. The mixed ANOVA yielded a main effect of Intervention, $F(1, 284) = 211.39$, $p < .001$, such that the average Difficulty was significantly lower for the experimental group ($M = 2.24$, $SD = 1.29$) than for the control group ($M = 3.44$, $SD = 0.56$). The mixed ANOVA yielded a main effect of time point, $F(1, 284) = 95.83$, $p < .001$, such that the average Difficulty was significantly lower for the time point 2 ($M = 2.42$, $SD = 1.3$) than for time point 1 ($M = 3.35$, $SD = 0.66$). However, the interaction effect was significant, $F(1, 284) = 150.65$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated less Difficulty than the control group.

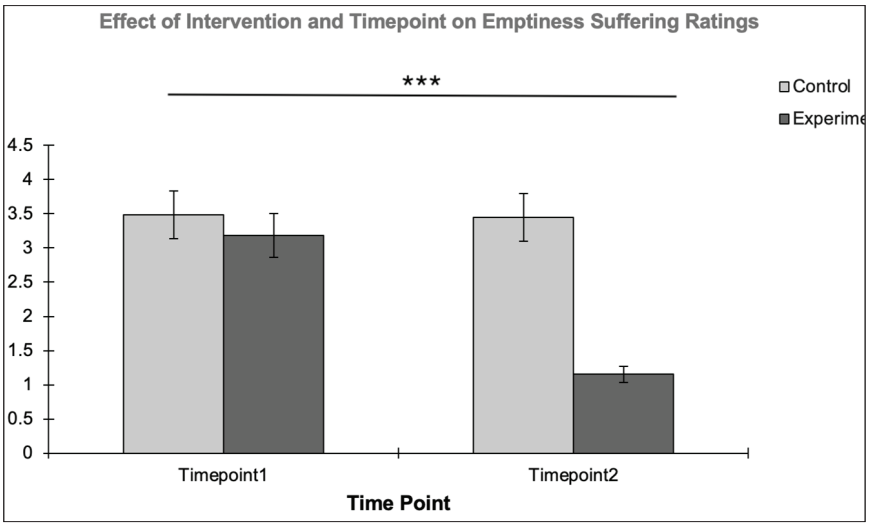

Figure 9. Bar Graph of Effect of Intervention and Time Point on Emptiness (* = $p < 0.05$, ** = $p < 0.01$, *** = $p < 0.001$).

Emptiness: A mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable (Timepoint: Timepoint 1 or Timepoint 2) was conducted to examine the main effect of Intervention, the main effect for Time Point, and an interaction effect of Intervention and Time Point on Emptiness. The mixed ANOVA yielded a main effect of Intervention, $F(1, 283) = 246.17$, $p < .001$, such that the average Emptiness was significantly lower for the experimental group ($M = 2.16$, $SD = 1.14$) than for the control group ($M = 3.46$, $SD = 0.54$). The mixed ANOVA yielded a main effect of time point, $F(1, 283) = 110.73$, $p < .001$, such that the average Emptiness was significantly lower for the time point 2 ($M = 2.50$, $SD = 1.33$) than for time point 1 ($M = 3.36$, $SD = 0.68$). However, the interaction effect was significant, $F(1, 283) = 146.04$, $p < .001$, indicating that in time point 2, but not time point 1, the experimental group rated Emptiness more than the control group.

do normal day activities. Moreover, terminally ill patients have not engaged in interventions to support their mental health. However, terminally ill patients do feel a need to let out their emotions and stabilize their emotions and mental state. Therefore, through the intervention, study b demonstrated how, overall, all the measurements of experimental conditions with time point 2, of Overall Suffering, Discomfort, Worry, Fear, Angry, Sadness, Hopelessness, Difficulty, and Emptiness, had significant effects. That is, in all DVs tested, we saw highly significant results across the intervention, demonstrating that our intervention was an extremely efficacious and useful tool for palliative patients. There was consistency in this finding through all the suffering measurements taken, producing similar results.

These findings align with other research, such as previous research by Block. This study used an evidence-based review and showcased how all patients with progressive life-threatening illnesses require attention to psychological issues and face suffering. By understanding the experiences of patients suffering from cancer, Block's study suggested how the developmental stage of patients' diseases negatively impacted their psychological and emotional responses, and how emotions of sadness, fear, anxiety, and loneliness are present, at times, at least, for almost all patients (13). This study coincides with our findings from the interview of the emotional and psychological damages experienced by the terminally ill patients, and pre-intervention data of the participants. Moreover, a prospective survey conducted by 200-bed palliative care hospitals by Wiliam Breitbard *et al*. used a Scores on the Schedule of Attitudes Toward Hastened Death (SAHD), a self-report measuring tool, and showcased how 17% of the participants were classified as having high desire for hastened death, whilst 16% of the participant met the criteria of a current major depressive episode. They concluded how Desire for hastened death was significantly associated with a clinical diagnosis of depression as well as with measures of depressive symptom severity and hopelessness. Hence, suggests the influence of the satisfaction level of the patients due to facing terminally ill, with being bedridden also influencing their well-being. Hence, these results showcase the negative influence on the satisfaction and usefulness of the patients. Lastly, the study by Back *et al*, 2008 reviewed observational, survey, and qualitative studies from the point of view of oncology clinicians and deduced that for terminally ill, life-limiting, cancer patients, exchanging information, making decisions, fostering healing relationships, managing uncertainty and responding to emotions to provide emotional support and more effective and compassionate care. These results align with our findings of terminally ill patients wanting to release emotions and deal with their mental well-being.

Therefore, after the implementation of the intervention, the analysis yielded that the intervention was highly effective, illustrating a significant decrease in all DVs tested – overall suffering discomfort, worry, fear, anger, sadness, hopelessness, difficulty in acceptance, and emptiness – for participants who were in the experimental condition versus the control condition. These strong statistics demonstrate the effectiveness of the intervention in reducing the emotional and psychological issues experienced by the palliative patients, hence, enabling positive coping mechanisms for the terminally ill patients. This intervention is useful since it is short, allowing patients with bi-pack, who require oxygen for a long time, and those who get tired quickly, to use this intervention. Further, this intervention can be used individually and also with other people, removing the need for the caretaker or a therapist to be needed to use the intervention.

Therefore, these findings showcase that the mindfulness technique developed, after being modified with the interview data, had a positive significant effect in reducing the suffering score, and adds to the literature by showcasing how the psychological and emotional sufferings experienced by terminally ill patients can be reduced through mindfulness technique implementation.

CONCLUSION

Identifying the research area of terminal illness and palliative care, this research paper began by conducting a literature review to explore the different factors influencing the quality of life of patients in palliative care and the role psychological and emotional influences can play in building a healthy coping mechanism with the terminal illness. This enabled the understanding of the role of mindfulness as a potential intervention to reduce the suffering of the patients, and the missing mindfulness intervention for addressing the specific needs of palliative patients. To understand the particular suffering of the patients in terms of the emotional and psychological factors, a semi-structured interview was conducted with the caretakers of patients suffering from terminal illnesses. The interview with the 5 participants enabled the understanding of the specific psychological and emotional suffering experienced by the patients, such as hopelessness and anger, enabling the understanding of the specific needs and limitations of the patients, such as:

immobility, physical pain, breathing constraint, end of life fear, independence, and lack of energy/focus,

Next, the intervention was designed, created and developed from the ground up. Informed to the results from Study 1a, the intervention was created and designed through an online software. Designing adaptability features including mindful music, visuals, and reading/ audio guiding options; creating mindfulness activities for palliative patients and to alleviate suffering; breaking them into small, independent parts; and compiling the online intervention for use, the intervention was built.

Then, the intervention was tested on 84 palliative patients in the control group and 60 palliative patients in the experimental group through the ALS Support Group through phone calls. After the completion of the intervention on the 7th day, the pre-test and post-test suffering pictogram results collected were analyzed using the mixed ANOVA with one fixed variable (Intervention: Experimental or Control) and one repeated-measures variable of experimental conditions with time point 2(Timepoint: Timepoint 1 or Timepoint 2). The results for all measured variables (Overall Suffering, Discomfort, Worry, Fear, Angry, Sadness, Hopelessness, Difficulty, and Emptiness) had a significant effect.

Some of the limitations of this research study include the sample population taken. The sample is small, with only 5 participants in the 1st study, and 144 participants in the 2nd, given the large population of terminally ill patients it is representing - terminally ill patients. Also, all the participants were taken from Northern India - the north - limiting the generalizability of the findings to a large population. Moreover, as the sample of the study only has patients suffering from ALS and cancer, the results may not be generalizable to patients of other illnesses.

Moreover, the sample is homogeneous, as they all have been taken mainly through the same association - ALS Support Group. This may limit the validity due to the possibility of selection bias given that participants in such groups may have demand characteristics in relation to those who are not involved in such support networks. Further, both the studies relied on self-reported data to collect information. This creates risks of response bias, such as demand characteristics of socially desirable responses, and hence, may hinder internal validity. Another limitation of the study was that the mindfulness-based intervention was tested only for 7 days, thus, ignoring the long-term effects of the study which were not captured, providing only short-term results. Further, the data collection was single-method, relying on qualitative interviews and self-reported measures. The study could use data triangulation by incorporating quantitative assessments and physiological measures to increase the understanding of the impact.

For future directions, the study can be looked at as a longitudinal study to evaluate the long-term effect of this intervention on the coping mechanism of palliative patients - allowing the study to showcase the long-term effects of the intervention. Moreover, the research can be expanded to include a more diverse population, such as those of different nations and cultures, that will help increase the generalizability of the mindfulness intervention to a larger sample of terminally ill patients. Moreover, the role of caregivers in facilitating this intervention can be investigated, even involving the caregivers in the intervention to support their emotional and psychological needs. Further, physiological measures, such as cortisol levels and heart rate variability, can be assessed to measure the impact of MBST mindfulness on the physiological well-being of the patient, finding a link between improvement in good coping mechanisms and physiological benefits.

The implications of this study suggest that mindfulness-based interventions have the potential to significantly impact the emotional and psychological well-being of palliative patients. Integrating these interventions into clinical practice and policy can lead to more comprehensive and patient-centered care in the context of terminal illnesses. Mindfulness Integration: Healthcare providers in palliative care settings should consider integrating mindfulness-based interventions, like MBST, into their treatment plans. This may help improve the emotional and psychological well-being of patients facing terminal illnesses. In the clinical setting, caregivers and healthcare professionals can be trained in these mindfulness techniques to support the palliative patients and facilitate these practices for patients. Further, policymakers in healthcare can include mindfulness-based interventions in palliative care guidelines and standards. This can promote the inclusion of such interventions in routine care protocols. Next, the education and training of healthcare professionals in mindfulness practices can be supported, ensuring they are equipped to provide effective support to palliative patients. It can also facilitate collaboration between healthcare professionals, psychologists, and mindfulness practitioners to develop and deliver the intervention to the population.

In conclusion, this study provides an encouraging fresh understanding of a potential intervention specifically for palliative patients to alleviate suffering, developing a positive coping mechanism.

Healthcare practitioners and policymakers can improve the quality of life for those facing the challenging path of terminal illness by understanding the emotional and psychological challenges faced by palliative patients and this intervention providing a potential solution for it There is a chance for a meaningful and thorough treatment for palliative patients in the future thanks to research that evaluates and improves mindfulness-based treatments. The ultimate aims of palliative care continue to be the reduction of pain and the enhancement of emotional and psychological well-being, and mindfulness-based interventions and therapies like MBST provide a promising path ahead.

DECLARATION OF CONFLICT OF INTERESTS

The author(s) declare that there are no conflicts of interest regarding the publication of this article.

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