TO EVALUATE THE EFFECTS OF AN EIGHT WEEK MINDFULNESS BASED STRESS REDUCTION (MBSR) PROGRAMME ON QUALITY OF LIFE IN PALLIATIVE CARE CANCER PATIENTS.

"..Lest I come to the end of my life at death, and find I have not lived."
Henry David Thoreau

By Dr Patricia Lück

DISSERTATION SUBMITTED TOWARD PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MPHIL IN PALLIATIVE MEDICINE, UNIVERSITY OF CAPE TOWN (UCT)

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DECLARATION

I, **Marie Patricia Lück,** declare that this dissertation is my own work. It is being submitted for the degree of Master of Philosophy in Palliative Medicine at the University of Cape Town. It has not been submitted before for any degree or examination at this or any other University.

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15th day of March, 2006

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ABSTRACT

This study assesses the impact on the quality of life of palliative cancer patients participating in a pilot MBSR programme for Hospice Witwatersrand in Houghton, Johannesburg. Interest has been shown by the staff of Hospice Witwatersrand in the use of mindfulness tools in caring for the patients and how these can be taught and be of value to the patients and staff. Before a training programme for the staff can be planned and implemented it is necessary to assess the value and benefit of such a programme for the patients. The research question asked if an eight week MBSR programme improves the quality of life of palliative care cancer patients. Quality of life is closely affected by physical function, emotional or psychological function, social function and symptoms of disease or its subsequent treatment. The aim of the study was to evaluate if an MBSR programme benefits palliative care cancer patients. The objectives were to: explore and adapt the use of an eight week MBSR programme in a palliative care setting; assess the value of such a programme to palliative care cancer patients; and assess impact on various dimensions of the quality of life of living with terminal cancer using the EORTC QLC-C30 which measures physical and psychological functioning and symptoms, including dyspnoea, sleep disturbance, appetite loss, constipation, diarrhoea, irritability, depression, loss of memory, and financial impact.

Despite the many methodological challenges that this study presented regarding sample size, attrition rate, and unevenly matched active and control group, there are a few valuable insights. There was an increase for the active MBSR group in the quality of life score and in the overall functional scores and a matching decrease in overall symptoms. The control group, on the other hand, showed a decrease in the quality of life score, overall functional scores and an increase overall in reported symptoms.

The most significant result was that of the increase, greater than the standard deviation, in role function which showed that an MBSR programme for palliative cancer patients makes a difference in how these patients define themselves and how they integrate into family and societal structures. As QOL is not an absolute quantity but is relative to a person's expectations, being able to adjust to or accept their new limited role function has impact on expectation and subsequent QOL for these patients as shown by the increase in the global QOL score.

The answer to the research question "Does an eight week MBSR programme improve the quality of life of palliative care cancer patients?" is yes it does. Palliative care cancer patients' expectations and biopsychosocial correlates can be positively modulated through participation in an eight week mindfulness based stress reduction programme. Given the challenges of this study, and limited treatment effect, further research is needed to fully answer this question.

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GLOSSARY

MBSR	Mindfulness Based Stress Reduction
Hospice Witwatersrand	Hospice Association of the Witwatersrand
Houghton Hospice	Hospice Association of the Witwatersrand at Houghton
Mofolo, Soweto Hospice	Hospice Association of the Witwatersrand at Mofolo, Soweto
EORTC	European Organization for Research and Treatment of Cancer
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency Syndrome
WHO	World Health Organization
QOL	Quality of Life
Palliative Care	Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[17]
CFM	Center for Mindfulness
QL2	Global quality of life score
PF2	Physical Function score
RF2	Role Function score
EF	Emotional Function score
CF	Cognitive Function score
SF	Social Function score
OFA	Overall Function Average score
FA	Fatigue

NV	Nausea and vomiting
PA	Pain
DY	Dyspnoea
SL	Insomnia
AP	Appetite loss
CO	Constipation
DI	Diarrhoea
FI	Financial difficulties

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CHAPTER ONE: Introduction

Background

This MPhil dissertation explores the use of a specific interventional and behavioural medicine programme, called the Mindfulness Based Stress Reduction programme (MBSR). The MBSR programme is a stress reduction programme that has been offered at the University of Massachusetts Medical Center for the past 25 years. It offers patients with chronic pain, stress, and illness, specific mindfulness tools for the relief of their suffering. The MBSR has been widely taught, documented and researched for many years at hospitals and clinics in many parts of the US, Canada, and Europe, and is now being taught in Johannesburg and Cape Town. It is commonly taught with a heterogeneous mix of patients exhibiting a wide range of stress reactions, chronic pain and illnesses. The MBSR has also been taught and researched within homogeneous patient groups, as for instance with some types of cancer patients, but there is no published research yet in its use with palliative care cancer patients.

MBSR is one programme in the area of complimentary health that specifically addresses the reduction in chronic pain, stress, and illness through being part of a group process that fosters improved individual coping skills through present moment awareness. In recent years there has been a growing interest in the therapeutic benefits that mindfulness brings to the arena of research into mind-body interactions. "Mindfulness has to do with certain qualities of attention and awareness that can be cultivated and developed through meditation. An operational working definition of mindfulness is: the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by

moment."[1] Mindfulness is the non-judgemental observation of the ongoing stream of internal and external stimuli as they arise [2]. "All of us have the capacity to be mindful. All it involves is cultivating our ability to pay attention in the present moment," [3] and "Mindfulness is really about bringing awareness to virtually any situation or any circumstance or any mental state."[4] Mindfulness encourages becoming more in touch with the present moment.

In the past thirty or more years the health sciences community has learned much about the body-mind-immunity interplay and have recognised the importance of personal hardiness factors and coping styles and attitudes on our health and perception of well-being [5, 6, 7]. This increasing body of knowledge points toward the patient being an active participant in their own healing process. This healing process does not just address that of physical health but includes psycho-social health as well, and is not confined solely to curative medicine but also to the area of preventative health, as well as palliative care. In palliative care the aim is not necessarily for a physical cure but to facilitate healing at a physical, emotional and psychological level thereby positively impacting on quality of life.

Facing up to one's own mortality and death from terminal illness can be a time of emotional adjustment, distress and turmoil. There may be an increase in psychological distress and pain as death approaches necessitating particular attention to end-stage intervention [8]. Block and Czosnowski in their case study of an artist dying with cancer presented the work of this patient's experience of the suffering that all-consuming pain can cause [9]. They ask "what is the value of our professional medical care without emotional, social and spiritual support?" They also noted that "physical pain dominates only one picture, while the remainder show us loneliness,

isolation, anxiety, fear, frustration, religious struggle, lack of friendship, helpless, fight for autonomy, despair, resignation, longing for emotional closeness, intimacy and erotic experience and other powerful emotions and feelings."

Coping skills vary from patient to patient and these are generally divided into good copers and poor copers. Good copers display skills that help them overcome the challenges of cancer and are generally optimistic and self-confident, even in difficult times [10]. The capacity to face stressors in our lives with greater equanimity and stability of mind and body, that is a defining quality of good copers, is a large part of the concept of resilience that is attracting growing attention world-wide including its significance in the arena of palliative care (though not a focus of this study) [11]. Qualities of resilience shown to be fostered by the MBSR programme are an increased self-awareness, an enhanced sense of control, positive coping skills, and competent functioning despite the challenges encountered [12].

David Spiegel in his ground breaking work with group therapy for cancer patients found the group support for cancer patients resulted in significantly enhanced survival times and measurably greater quality of life [13, 14]. Others such as Rosenbaum et al [15] and Koopman et al [16] have also found that various supportive groups address the physical and emotional well-being of cancer patients and improve their quality of life.

The MBSR programme takes the patients through eight weeks of various mindfulness meditation approaches and techniques, including guided meditations, gentle stretching and yoga, discussions of mind-body mechanisms that influence the relationship we have to ourselves, our health and the internal and external stressors we experience. The participants usually meet for classes once a week for 2 to 2.5 hours and

participate in a one day long class of approximately seven hours on the week-end of the sixth week. Homework, in terms of daily practice, listening to meditation tapes, and paying attention to specific tasks, is assigned for each day.

Defining Palliative Care and QOL

Hospice Witwatersrand is a palliative care organisation that aims to improve the quality of life of patients and families being faced with terminal illness. The World Health Organization's August 2002 definition of palliative care [17] states that "Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." This directs all of us working in the field of palliative care to pay special attention to the issue of quality of life of our patients. This is done by managing the patient as well as their family within a holistic healing framework that encompasses all physical, psychological, social, and spiritual parameters of this paradigm. The WHO definition of palliative care itself equates quality of life with the prevention and relief of suffering, assessing and treating pain, as well as other problems whether physical, psychosocial or spiritual.

Quality of life (QOL) as a concept can be framed in many different ways [17]:

- Calman [18, 19] describes QOL as the inverse relationship to the size of the gap between an individual's expectations and the reality of the situation. Consequently it follows that the smaller the gap the better the QOL. Thus QOL is not an absolute measurement but is relative to a person's expectations.

Most QOL questionnaires assume the individual assesses their function based on what is normal for their life. Therefore an adjustment to or acceptance of functional limitations has an impact on a person's expectations and subsequent QOL.

- The utility concept concerns itself with making trade-offs in terms of value or utility gained compared to normal function. The utility concept is more of a narrow physiological construct of QOL. An example in palliative care could be an adolescent's choice of having a hind quarter amputation for an aggressive sarcoma of the thigh as apposed to chemotherapy. A choice between possibly longer survival with disfigurement and loss of mobility versus shorter survival while retaining mobility and body image [18, 20].
- The reintegration model proposed by Wood-Dauphinee and Williams [18, 21] concerns itself with the concept of rehabilitation. It looks at how well-adjusted living can be resumed after an incapacitating illness. It is applicable to palliative care in that an individual can and does resume certain roles they may have neglected at work or in the family once pain and certain symptoms have been adequately controlled. This resumption of *role function* has been shown to correlate well with QOL measures.
- The concept of QOL is usually defined as being patient centered and does not take the broader impact on the community into account. Ware [22] includes the greater impact on patient and community in his definition. This is structured like the ripples of a pond after dropping a stone with the concentric rings moving ever outward while new ones form in the center. His concept includes effect on physiology, physical functioning, psychological functioning, general health perception and social role functioning emanating from the impact on the individual but eventually impacting the community at large.

- Many QOL tools have attempted to measure the meanings that patients associate with their illnesses. These also measure the perception of how much the disease is impacting on an individual's life. There is agreement in defining how the various areas affecting QOL interrelate and that the key areas affecting QOL are those of physical function; emotional or psychological function; social function; and symptoms of disease or its subsequent treatment. Quality of life questionnaires, such as that developed by the European Organization for Research and Treatment of Cancer (EORTC)[23], attempt to incorporate these core items. A module specific to patients with advanced disease is still being developed.

MBSR Literature Review

Since the inception of the MBSR programme in 1979 at the Stress Reduction Clinic at the University of Massachusetts Medical School, Worcester, Massachusetts by Dr Jon Kabat-Zinn, the programme as a clinical intervention has been evaluated, documented and studied. Initial research has been qualitative relying on pre and post intervention instrument questionnaires. There have been many methodological weaknesses [24], as well as difficulties in exactly defining what quality of mindfulness is being measured by assessing the MBSR programme [25, 26]. The literature, however, does suggest that mindfulness interventions may lead to reduction in a variety of problematic conditions [27], including chronic pain, [28, 29] stress and anxiety disorders [30, 31], chronic heart failure [32], breast cancer [33], fibromyalgia [34, 35], psoriasis [36], depressive relapse [37, 38], sleep disturbance of cancer patients[39, 40], and disordered eating [41]. Enhancement of health-related quality of life with improved vitality, less bodily pain, fewer role limitations

caused by physical health, greater social functioning, and decreased anxiety and depression have also been demonstrated in a heterogeneous patient population [42].

A recent published controlled study has offered some very exciting glimpses into the potential value of the MBSR programme. Davidson et al [42] showed, by measuring brain electrical activity, that the MBSR can demonstrably change the set point for negative affect activation in the prefrontal cortex. He showed that participating in an eight week MBSR programme significantly increased the activation of the left prefrontal cortex, previously associated with positive affect [43, 44], in MBSR participants as opposed to the control group. These same participants were vaccinated with influenza vaccine after the MBSR programme and the participants where found to have a significantly increased antibody titre as opposed to the control group.

Carlson et al [45] looked at the MBSR programme in relation to quality of life, mood, symptoms of stress, and immune parameters in breast and prostate cancer outpatients. Although this was not a controlled study it did show enhanced quality of life and decreased stress symptoms in breast and prostate cancer patients. It also showed changes in cancer-related cytokine production associated with participation in the MBSR programme. Speca et al [46] showed in a controlled study that an MBSR programme was effective in decreasing mood disturbance and stress symptoms in cancer outpatients. In a follow-up study of these same participants it was found that participating in an MBSR programme continued to be effective with reductions in mood disturbance and stress symptoms still being maintained at the 6-month follow-up review[47]. Smith et al [48] in a recent systematic review of MBSR for cancer supportive care concurred that MBSR has potential as a clinically valuable intervention for cancer patients.

Brown and Ryan [49] studied levels of mindfulness relative to levels of mood disturbance and stress in cancer patients before and after an MBSR intervention. They found increased levels of mindfulness correlated with an increase in well-being.

Jordhøy et al [50], using the EORTC QLQ-C30 questionnaire assessed the impact of comprehensive palliative care on patient's quality of life and showed no significant differences on any of the quality-of-life scores. Their conclusion was that "to achieve improvements on a group level of the various dimensions of quality of life, specific interventions directed toward specific symptoms or problems may have to be defined, evaluated, and included in the program". This MBSR study is researching the benefits of one such specific programme.

As described by Calman [19] QOL is not an absolute measurement but is relative to a person's expectations and has consequently more to do with the *perception* of reality and how one *responds* or *reacts* to it than the actuality of that reality itself. An individual's ability to manage stressors in life is largely driven by unique perceptions of those stressors which vary from person to person and which consequently determine the impact on quality of life. Mindfulness as a concept and a structured training programme addresses how an individual responds to the external and internal stressors that are an inevitable part of life and even more so when facing a life threatening illness. The MBSR programme provides tools necessary to deal with the continual stream of external and internal stimuli with equanimity. Carlson et al[51] showed in her research that patients with breast and prostate cancer participating in an MBSR programme had enhanced QOL and a decrease in stress symptoms. It is hoped that a programme such as the MBSR can enable the coming to terms with this last

phase of life by improving the perception of the physical and psychological challenges that influence the quality of this remaining time.

Purpose of Research

The purpose of this study is to assess, by use of the EORTC QLQ-C30 questionnaire, the impact on the quality of life of palliative cancer patients participating in a pilot MBSR programme for Hospice Witwatersrand in Houghton, Johannesburg. Interest has been shown by the staff of Hospice Witwatersrand in the use of mindfulness tools in caring for the patients and how these can be taught and be of value to the patients and staff. Before a training programme for the staff can be planned and implemented it is necessary to assess the value and benefit of such a programme for the patients.

Research Question

Does an eight week Mindfulness Based Stress Reduction (MBSR) programme improve the quality of life of palliative care cancer patients?

Aim and Objectives

The **aim** of the study is to evaluate if an MBSR programme benefits palliative care cancer patients.

The **objectives** are to:

- Explore and adapt the use of an eight week MBSR programme in a palliative care setting.
- Assess the value of such a programme to palliative care cancer patients.
- Assess impact on various dimensions of the quality of life of living with terminal cancer using the EORTC QLC-C30 which measures physical and psychological functioning and symptoms, including dyspnoea, sleep disturbance, appetite loss, constipation, diarrhoea, irritability, depression, loss of memory, and financial impact.

CHAPTER TWO: Research Methodology

Research Design

For the purpose of this research hospice cancer patients were recruited into an eight week MBSR participatory programme for palliative care cancer patients. The Houghton homecare palliative nursing staff of Hospice Association of Witwatersrand (from here on referred to as 'Hospice Witwatersrand') was asked to identify and approach patients from those in their care. (See memo to homecare palliative nursing staff - Appendix One)

An active control group was drawn from the same patient population which also met once a week for support but without the specific intervention of the MBSR programme. Pre and post participation in the MBSR programme, as well as pre and post participation in the control group, was evaluated using the EORTC QLQ-C30 questionnaire.

Study Population

The study population was drawn from palliative care cancer patients that form part of the Hospice Witwatersrand patient population. The Hospice Witwatersrand commenced as a hospice organisation in 1975. The scope of care at the Hospice Witwatersrand includes medical and psychosocial departments that manage a homecare team, provide in-patient and out-patient care, operate an onsite pharmacy and a daycare programme. There are two in-patient units, one situated in Houghton, Johannesburg which can accommodate ten adult and five paediatric patients, and another situated in Mofolo, Soweto which can accommodate eight adults. The Hospice Witwatersrand also trains health professionals and medical students, as well

as other allied professionals such as teachers, in palliative medicine, palliative care, and counseling and bereavement skills. This is enabled through the Hospice Witwatersrand Center for Palliative Learning which also ensures ongoing staff training. All relevant professional staff at Hospice Witwatersrand have specialist palliative knowledge training, or are in the process of completing training in palliative care.

For the year of April 2003 to March 2004 the Hospice Witwatersrand looked after 1,887 patients. Roughly half of these were cancer patients and the other half HIV/AIDS patients, with a minority having other terminal conditions such as end stage organ failure, motor neuron disease, and severe chronic obstructive lung disease. At any one time Houghton Hospice looks after 200-300 patients and the Mofolo, Soweto Hospice looks after 300-400 patients. The average time of being registered with Houghton Hospice is 60 days prior to death [52].

- ***Sample Selection***

This was a sample of convenience. Participants were sought through requests for participation from the palliative care team. As patients are referred to Hospice Witwatersrand once all active avenues of curative treatment have been exhausted, and usually with an average life expectancy of 60 days [52], most of the potential participants are relatively ill. It was necessary to keep the sample of the study population broad, including all cancer types, as opposed to limiting the study to a particular cancer type or stage. This was in an attempt to ensure enough of a response for this pilot study. Participants needed to fulfill the following criteria for inclusion in the study:

Inclusion Criteria

- Patients of the Hospice Witwatersrand at Houghton or patients of a Hospice Witwatersrand locum palliative care doctor.
- Palliative cancer patients no longer on any active curative seeking treatment.
- Life expectancy of at least three to six months.
- Willing to participate in an eight week MBSR programme or be part of the active control group for the duration of the programme.
- Consenting to have specific data collected to be used for research purposes and possible publication.
- Participants who are sufficiently fluent in English without the need for a translator.
- No evidence of organic brain disease or significant mental disorders (excluding depression).

Exclusion Criteria

- Too frail or ill to tolerate coming to a group session weekly for eight weeks.

There was further information sought, as outlined in the Patient Participant Profile in Appendix Three, to help the researcher and facilitator (Dr Patricia Lück) to tailor the programme to the individual concerns of the patients involved.

- ***Demographic Profile***

The nature of this population of palliative cancer patients with regard to available numbers and accessibility, and subsequent small sample size, did not allow for random assignment to active MBSR or control group. All participants volunteered to be part of the active MBSR group.

A control group was sought from the existing day care programme at Houghton Hospice, which meant that the two groups did not commence the group intervention process at the same time. This may influence the data in unforeseen ways as the control group has already had the non-specific effects of being part of a supportive group process which were already in effect before the beginning of this research.

- ***Demographic Data***

Data was collected by use of a patient information questionnaire that included the demographic information sought. (Appendix Four)

The following demographic information was requested from the patient participants:

- Cancer type
- Cancer stage – not all patients knew their cancer stage
- Time since cancer diagnosis – not all patients were able to give adequate history of time since diagnosis
- Other co-morbid illnesses present
- Age
- Gender
- Education level
- Ethnicity
- Religion
- Social and family support structure
- Prior exposure to meditation or yoga
- Involvement in any other group or individual therapeutic sessions offered by Houghton Hospice
- Involvement in any other group or individual therapeutic sessions other that those offered by Houghton Hospice.

MBSR Group

Active Group	Patient 1	Patient 2	Patient 3	Patient 4
Cancer Type	malignant mesothelioma	metastatic colon	metastatic breast	metastatic colon
Cancer Stage	stage 4	stage 4	stage 4	stage 4
Time since diagnosis	Dec-04	Aug-99	Nov-99	Jan-04
Co-morbid	nil	nil	depression	cardiac
Age	46	48	40	72
Gender	male	female	female	male
Home language	English	English	Afrikaans	English
Education	university	university	university	university
Religion	Christian	Jewish	Christian	Christian
Prior Meditation/Yoga	nil	nil	yes	nil
Other groups - Hospice	nil	nil	nil	nil
Other groups or personal psychotherapy	nil	nil	Yes – personal psychotherapy	nil
Alive 3 months post-programme	no	yes	no	yes

Volunteers for the study were identified and requested to participate by the homecare sisters or doctors. The intention was to randomly assign patients to an MBSR programme group and to an active control group that would attend the existing Hospice Witwatersrand day care programme. Eleven possible patients were identified from homecare by the homecare palliative sisters, and one by a Houghton Hospice locum doctor from her patient base. Three of these patients, following initial contact

per telephone with the researcher to further explain the MBSR programme and transport options, opted not to participate in the study and did not come for an initial interview. Nine patients came for initial interviews: two died prior to the programme commencing; a third became too terminal and frail to be included in the study. This left the study with six participants who satisfied all inclusion criteria and were all assigned to the active MBSR group.

The recruited number of six participants in the MBSR group was very small due recruitment and attrition challenges, and also due to the nature of the physical challenges that the patients were facing. This is not unusual for palliative care research [46] and will be further discussed in chapter four. Three patients recruited for the programme died, or became very terminal, before the first session even started. Six patient participants were eventually recruited for the MBSR active group. One participant died in the sixth week of the programme and one participant came to only the first and last session due to personal, physical and transportation constraints. Four of these, as shown in the graph above, completed the eight week programme and will have results from this programme discussed.

There was an even gender distribution of two males and two females.

All four participants were over forty, one was seventy-two.

Two participants had metastatic colon cancer, one malignant mesothelioma, and one metastatic breast cancer. Two of the four participants died within three months of the end of the programme. One further participant died early in 2006.

All four participants were educated to university level. Only one had prior meditation or yoga experience. None belonged to any other group intervention.

Participants for the study needed to be well enough to attend a group class once a week for approximately two hours, for eight weeks. They also needed to attend a short half day class on the Saturday of the sixth week for four hours. Participants in the active group would be asked to do daily homework.

Only one participant of the active MBSR group is still alive at time of writing.

Control Group

Control Group	Patient 1	Patient 2	Patient 3
Cancer Type	stomach/ multiple myeloma	malignant melanoma	sarcoma
Cancer Stage	unknown	unknown	grade 4
Time since diagnosis	unknown	Apr-92	unknown
Co-morbid	nil	hypertension	nil
Age	50	87	77
Gender	female	female	female
Home language	afrikaans	english	english
Education	grade 12	grade 12	college
Religion	Christian	Christian	Christian
Prior Meditation/Yoga	nil	nil	nil
Other groups - Hospice	share care	share care	share care
Other groups or personal psychotherapy	nil	nil	nil
Alive 3 months post programme	yes	yes	yes

The intention was for the control group to be randomly assigned from the original volunteers for the study. However, due to only six patients being recruited, these participants formed the MBSR active group. A further four patients were then recruited from the existing day care programme to form the control group. One patient of the control group died before the end of the programme.

The participants for the control group were asked to continue to attend a weekly day care group meeting. This is an existing program of patient support and social gathering time at the Houghton Hospice. The research facilitator and instructor, Dr Patricia Lück, was present at these morning meetings for a short period to interact with and observe the nature of the day care activities. This provided for the non-specific effects of social support, therapeutic attention and positive expectancy that are part of being in a group [10-16]. These four patients for the control group met all inclusion criteria. The control group was asked to complete the patient participant information as well the pre and post evaluation questionnaires.

Of the four participants in the control group that were identified from the existing Hospice Witwatersrand day care programme (share care) three were still alive at the end of the programme.

All three participants were women and the average age distribution was higher than that of the active group. None of the control group participants had a university education, and none had prior meditation or yoga experience.

All three participants are still alive at time of writing.

MBSR Programme Details

A guideline to the adapted eight week MBSR programme for this pilot programme is set out in Appendix Three. This programme is closely modeled on the MBSR programme of the Stress Reduction Clinic at the Center for Mindfulness, University of Massachusetts in Worcester, Massachusetts, USA [3, 53]. As detailed in the

introduction, this is a programme commenced by Kabat-Zinn in the 1970's and is being widely studied as a therapeutic mind-body intervention.

The standard MBSR programme consists of three primary components during the eight weeks [51].

- Theoretical input on mindfulness, meditation, stress, and the mind-body connection. Class input, discussion, and written homework was supported by brief notes in a homework folder.
- Experiential practice of mindfulness meditation and yoga in the classroom setting and continued with homework for home based practice.
- Group process which focused on discussing the experience of the classroom situation and homework to overcome any difficulties and barriers to practice.

The programme was tailored in length and intensity to the individual needs of the patient population. Traditionally the classes, which in the model set out by the Center for Mindfulness [3, 53] are 2.5 to 3 hours, were shortened to 1.5 to 2 hours. The all day silent retreat class during the sixth week was adapted from the usual seven hours to four hours. The homework CDs, usually being 30 to 45 minutes, were adapted to be between 15 to 30 minutes. There was an intentional option included in the homework CDs to end at a halfway mark if the participant found it necessary to do so. Participants were asked to practice daily. No record was kept of how much daily practice was done and there was no penalty attached to not doing any homework.

All four participants in the active group attended at least six of the eight weekly sessions and the half day retreat. All participants reported doing some homework on a

daily basis; albeit if only informal attention to mindfulness practice and homework worksheets and not necessarily use of the homework CDs on a daily basis.

Setting

The classes were conducted at Hospice Witwatersrand using the library training room. Participants were asked to bring a blanket and cushions if floor sitting and yoga was possible, given their physical limitations. Chairs and extra blankets were provided for all participants to use for the group sessions including meditations and chair yoga.

Patients referred to Hospice Witwatersrand in Houghton come from the Northern and Southern suburbs of Johannesburg, excluding Soweto, the Eastern and Western Suburbs. These patients are mostly first language English speakers or reasonably comfortable with conversing in English. All the participants were comfortable and fluent with conversing in English even though four out the ten participants were not first language English speakers.

Access

Permission had been sought and granted by the Hospice Witwatersrand at Houghton. (Appendix Two)

Consent

Hospice patients were approached and made aware of the study programme through the palliative care teams of intake staff, homecare sister, share care staff, social workers, home care counselors, staff doctors. Confidentiality was assured and a consent form signed. (Appendix Four)

Data Collection

- ***Evaluation Questionnaires***

The evaluation questionnaire used is the well known and widely validated EORTC QLC-C30 [23]. Permission was sought and granted from the EORTC Quality of Life Group for its use in this research. (Appendix Six)

"The EORTC QLC-C30 is a thirty item quality of life questionnaire that assesses three different areas. It is composed of both multi-item scales and single-item measures. These include five functional scales, three symptom scales, a global health status/QOL scale, and six single items. Each of the multi-item scales includes a different set of items – no item occurs in more than one scale." [23]

- The EORTC QLC-C30 assesses physical symptoms using three scales: fatigue (3 items), nausea (2 items), and pain (2 items), as well as six single items assessing dyspnoea, sleep disturbance, appetite loss, constipation, diarrhoea, and financial impact of symptoms. All these items are rated on a 4-point scale from 1 (not at all) to 4 (very much).
- The EORTC QLC-C30 assesses five functional domains of quality of life which are scored as: physical function, role function, emotional function, cognitive function, and social function. These items are rated on a 4-point scale from 1 (not at all) to 4 (very much).
- The EORTC QLC-C30 assesses global quality of life with two items using a 7-point scale from 1 (very poor) to 7 (excellent).

The use of the EORTC QLQ-C30 has been researched in palliative care [54, 55] but not during the final stage of a patient's life [55]. Kaasa himself notes: "There are few

reliable and valid tools for use in measuring quality of life during end-of-life care." [55] Studies are showing, however, that addressing symptom care leads to improvement in quality of life scores [56]. Strömgren [57] researched the feasibility of using the EORTC QLQ-C30 questionnaire in patients receiving palliative care in the palliative inpatient, outpatient, and homecare setting. Despite the difficulties of poor patient condition, poor patient recruitment and attrition due to death, she concluded that it is possible to carry out a questionnaire-based study of symptomatology in palliative care cancer patients.

- ***Reporting***

For the purpose of this thesis and discussion the global quality of life (QL2), the five functional domains: those of physical functioning (PF2); role functioning (RF); emotional functioning (EF); cognitive functioning (CF); and social functioning (SF); as well as the overall functional average (OFA) and the symptom average will be reported. The small number of patients made it difficult to draw any conclusions relating to individual symptoms.

Data will be presented using excel spreadsheet, graph functions, and statistical tools.

Analysis

The questionnaires were evaluated according to the particular scoring process used for the EORTC QLC-C30 [23]. This was assessed to see if there was any statistical and significant change in the pre and post evaluation assessments. These results will be discussed in chapter three.

Biases and Limitations

- *Despite an inclusion criterion of life expectancy of at least three to six months, the very nature of a palliative cancer population group makes life expectancy an unpredictable factor.* This was borne out by three patients becoming very terminal before the programme even started and by the small number that was able to be recruited for the eight week programme. Two recruited participants died during the course of the eight week research programme.

- *Participants must be well enough to get to hospice and this may vary with the patients from week to week.* Two of the participants died during the course of the programme, one from the active group and one from the control group. One of the participants needed to attend hospital and moved his residence to get more care during the programme resulting in him only attending the first and last session. This participant's results were not included in the data.

- *Transport difficulties may also interfere with attendance and participation in the programme.* Financial aid for transport costs was made available to participants in need. A hospice vehicle was available but limited resources meant that this service was restricted to certain areas and therefore not available to all possible recruits. This limited the number of participants.

- *The language of the programme instruction is English which may cause understanding difficulties in those that do not speak English as a first language.* Six out of the ten participants were first language English speakers. Three were first language Afrikaans speaker and one Tswana speaking. Due

to the multilingual nature of our society and the participants there was little difficulty experienced by the participants in the classes being held in English. All the participants were conversant in English, able to speak, read and write it fluently.

- *The sample size may be too small to draw any significant conclusions.* A sample size of four from the active group and three from the control group is very small. Significant conclusions can not be reached and the results may only point in a particular direction of further study. This was a pilot study to assess the value and impact of such a programme.

- *The sample size was smaller than expected.* This was certainly so with only four participants fully completing the active group and three the control group.

Ethical Considerations

Ethical principles guiding this research were those of:

1. *Autonomy*. The rights of the patients were respected and ensured by the following means:
    - Informed consent was obtained in writing.
    - All individual information is confidential and participants are not identified in the research data.
    - Participants were fully informed of the nature of the programme in an initial interview and were given feedback in a follow up interview at the completion of the programme.
    - The rights of the participants who were already in day care and wanted to stay there were respected by accordingly dividing the group into the existing day care group and the new participants into the active group.
    - The participants were never pressurized to attend a session if they were unwell or not able to attend.
    - At the initial interview it was made clear that this was not a religious or spiritual practice, and not associated with a particular belief system or dogma. It was emphasized that the meditation techniques are used as tools to access our inner capacity for greater strength and stability of mind and body. The belief systems and spirituality of participants were respected at all times.

2. *Beneficence*. Due to this being a participatory research programme that studied the benefits of implementing an MBSR programme with palliative

care cancer patients it was hypothesized that such a programme would be valuable in improving the quality of life of palliative care cancer patients.

3. *Non-Maleficence.* Even though much was asked of this particular patient population, they were not required to do anything with which they were not comfortable. Adjustments were made to accommodate any physical limitations, and emotional issues that arose were handled with appropriate sensitivity.

This study did not compromise the quality of care in the terminally ill participants, particularly those participants that died during the course of the programme; they were given special attention to their palliative care needs and the needs of their families, and were actively returned to the care of their relevant palliative homecare sister.

Ethical considerations were in line with the World Medical Association Declaration of Helsinki (2000/2) that governs medical research involving human subjects [58].

CHAPTER THREE: Results

Data presentation

The following tables and figures will present the results of the pre and post intervention scores using the EORTC QLQ-C30 questionnaire with the Active MBSR Group and the Control Group.

Data scores will be presented for the following:

1. Quality of Life (QL2)
2. Physical Functioning (PF2)
3. Role Functioning (RF2)
4. Emotional Functioning (EF)
5. Cognitive Functioning (CF)
6. Social Functioning (SF)
7. Overall Functional Average (OFA)
8. Change in QL2 and Functions
9. Symptom Average
10. Change in symptoms

Due to the small number of participants no statistical significance can be concluded. Individual symptom data will not be presented or discussed due to the small number of participants. The individual symptom data can be viewed in Appendix Seven.

1. *Quality of Life* (QL2)

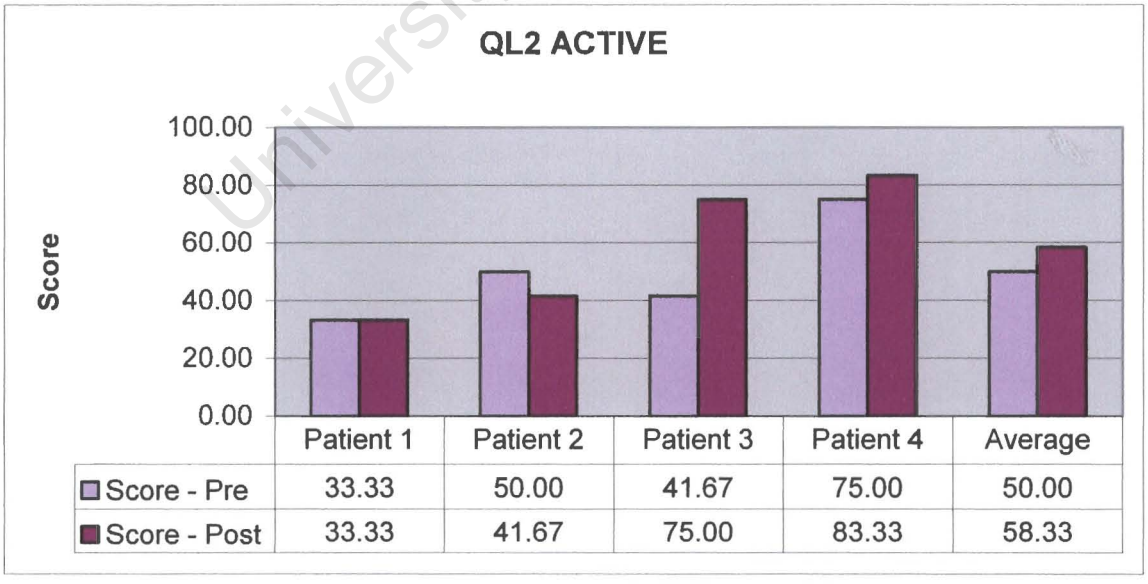
- **Active MBSR Group**

Table 1: QL2 Active: Shows the global quality of life scores before and after the MBSR intervention

QL2 Active						
	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	33.33	50.00	41.67	75.00	50.00	18.00
Score - Post	33.33	41.67	75.00	83.33	58.33	24.53

The mean score prior to the intervention was 50.00 and post intervention increased to 58.33. One participant had no change at 33.33 and one declined from 50.00 to 41.67. Two participants showed an increase in their global quality of life score from 41.67 to 75.00 and from 75.00 to 83.33.

Figure 1: QL2 Active: Shows the global quality of life pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

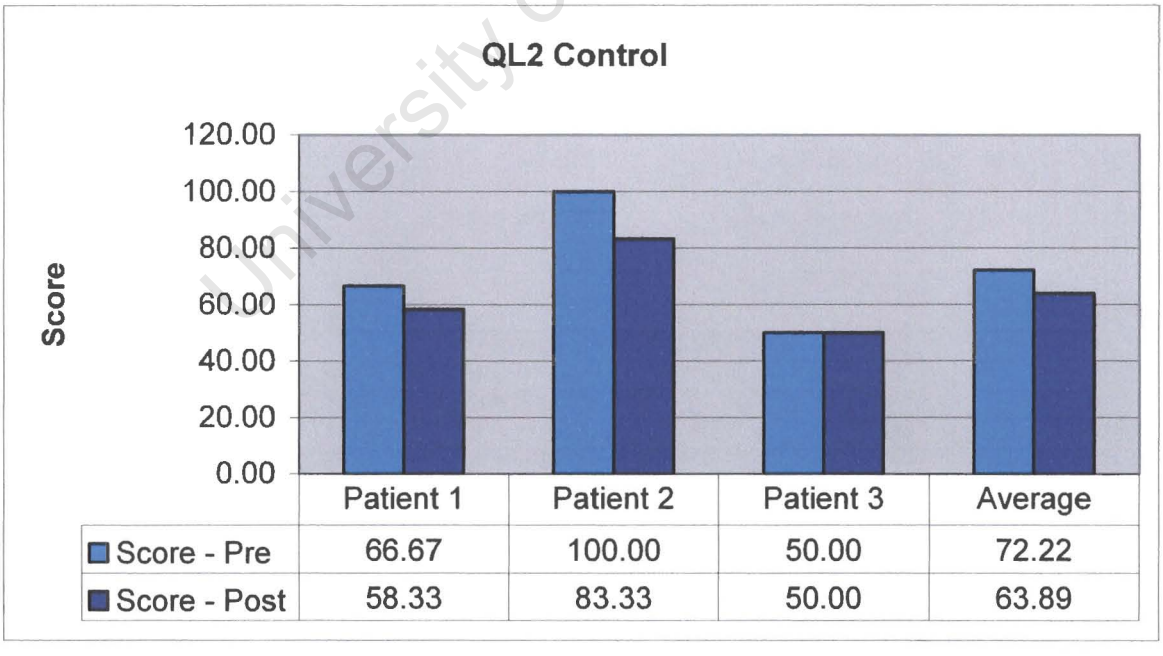
Table 2: QL2 Control: Shows the global quality of life scores before and after the MBSR intervention for the control group that attended day care

QL2 Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	66.67	100.00	50.00	72.22	25.46
Score - Post	58.33	83.33	50.00	63.89	17.35

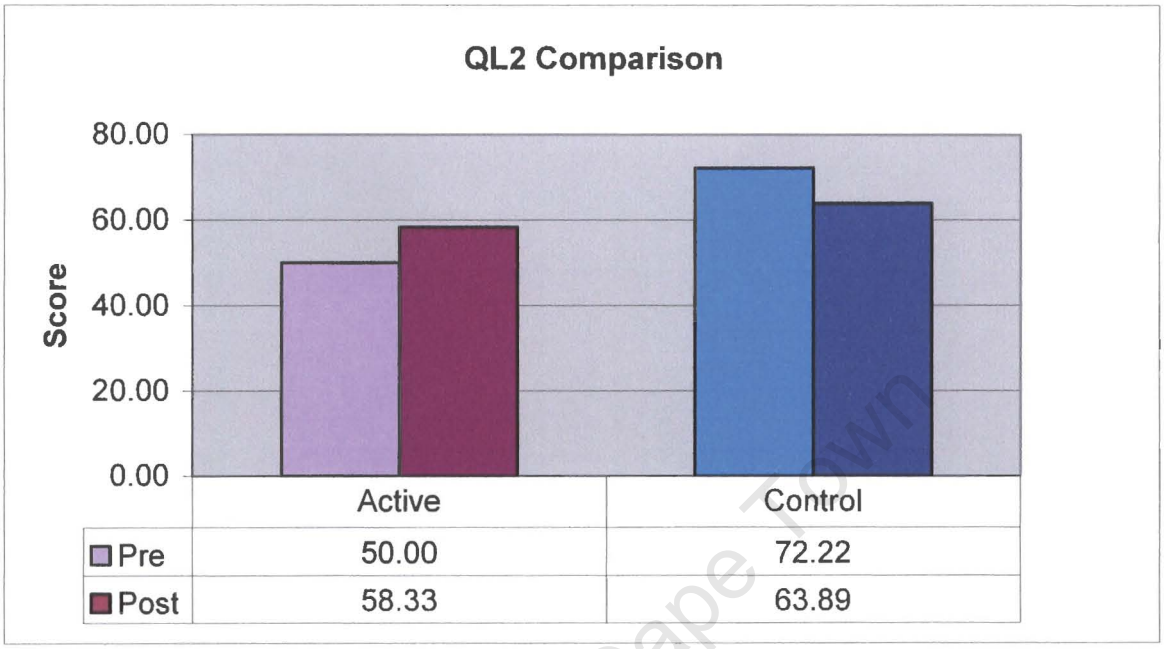
The mean score prior to the intervention was 72.22 and after 63.89. One participant had no change at 50.00 and the other three declined. It is of interest to note that the control group started at a higher baseline mean score for quality of life than the active group but declined over the course of the following eight weeks.

Figure 2: QL2 Control: Shows the global quality of life pre and post intervention scores for the control group in graph format



- **Comparison of QL2 score**

Figure 3: QL2 Comparison: Compares the mean global quality of life scores for the active and the control group



2. *Physical Functioning (PF2)*

- **Active MBSR Group**

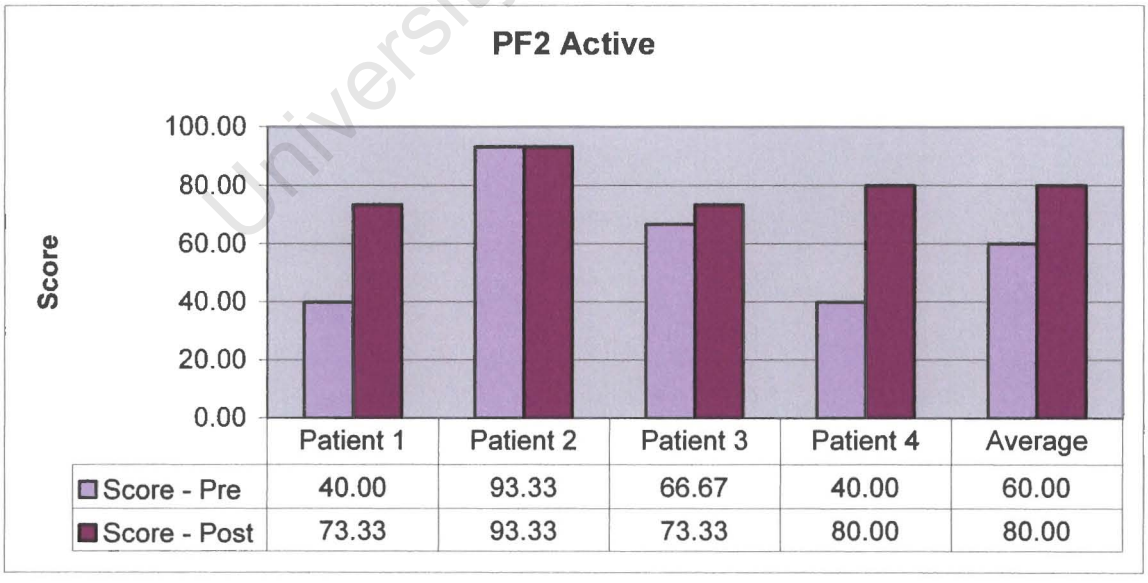
Table 3: PF2 Active: Shows the physical function scores pre and post intervention for the MBSR active group

PF2 Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	40.00	93.33	66.67	40.00	60.00	25.53
Score - Post	73.33	93.33	73.33	80.00	80.00	9.43

The mean physical function score at the beginning of the intervention was 60.00 and at completion of the MBSR programme was 80.00. One participant stayed the same at a high functioning score of 93.33 while all others increased their PF2 score, two of them well beyond the standard deviation.

Figure 4: PF2 Active: Shows the physical functioning pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

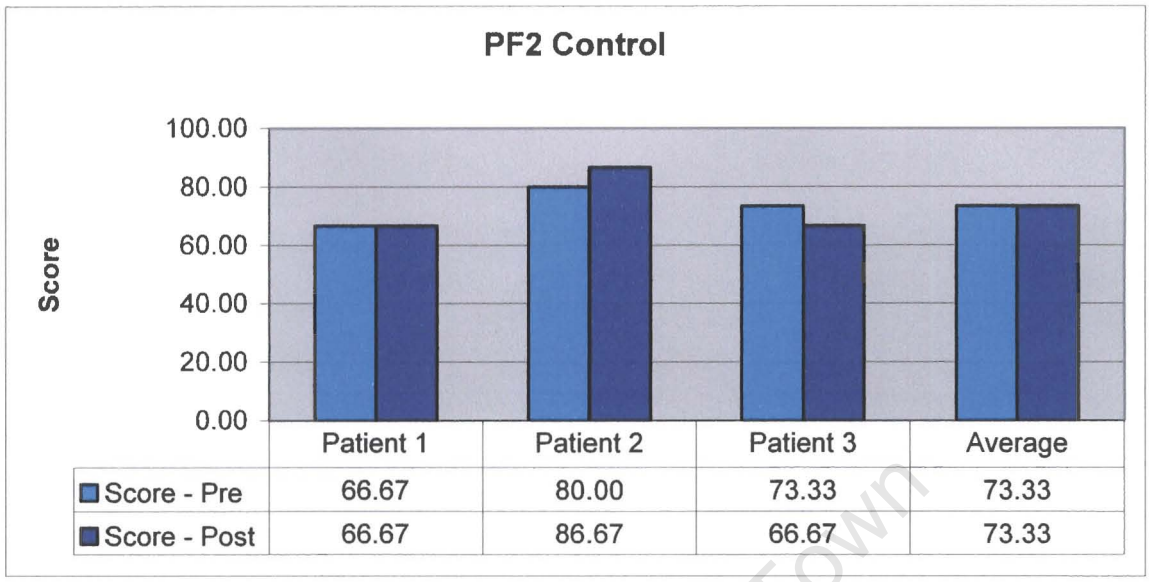
Table 4: PF2 Control: Shows the physical function scores pre and post intervention for the control group

PF2 Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	66.67	80.00	73.33	73.33	6.67
Score - Post	66.67	86.67	66.67	73.33	11.55

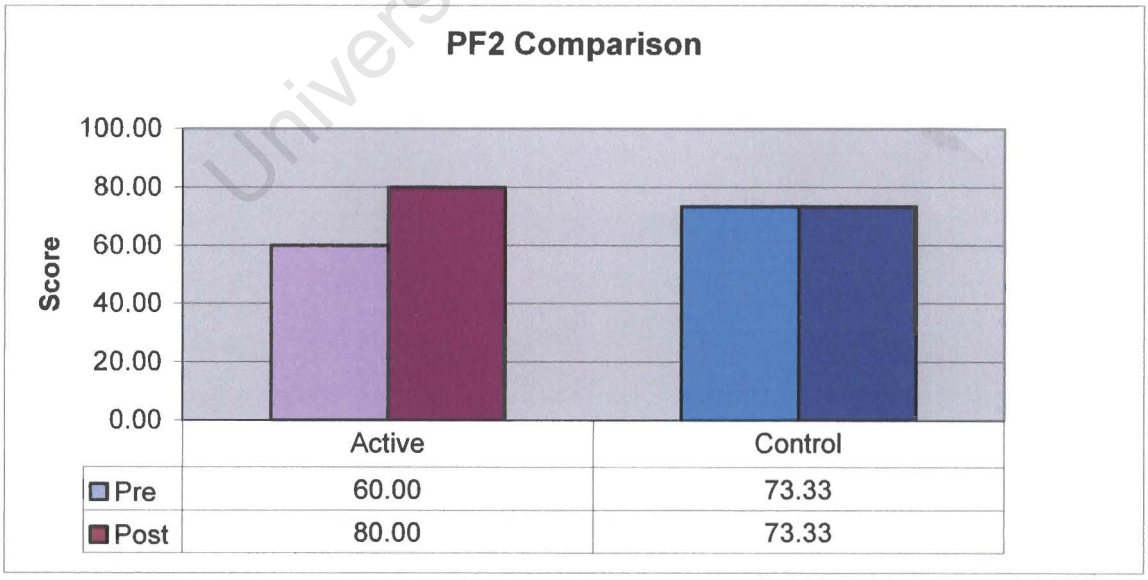
The mean physical function score at the beginning of the intervention was 73.33 and at completion of the programme also 73.33. One participant showed no change, one participant showed improved physical function and one showed decreased function. This variable result within a small sample makes it difficult to draw any significant conclusions.

Figure 5: PF2 Control: Shows the physical functioning pre and post intervention scores for the control group in graph format



- **Comparison of PF2 score**

Figure 6: PF2 Comparison: Compares the mean physical functioning scores for the active and the control group



3. Role *Functioning (RF2)*

- **Active MBSR Group**

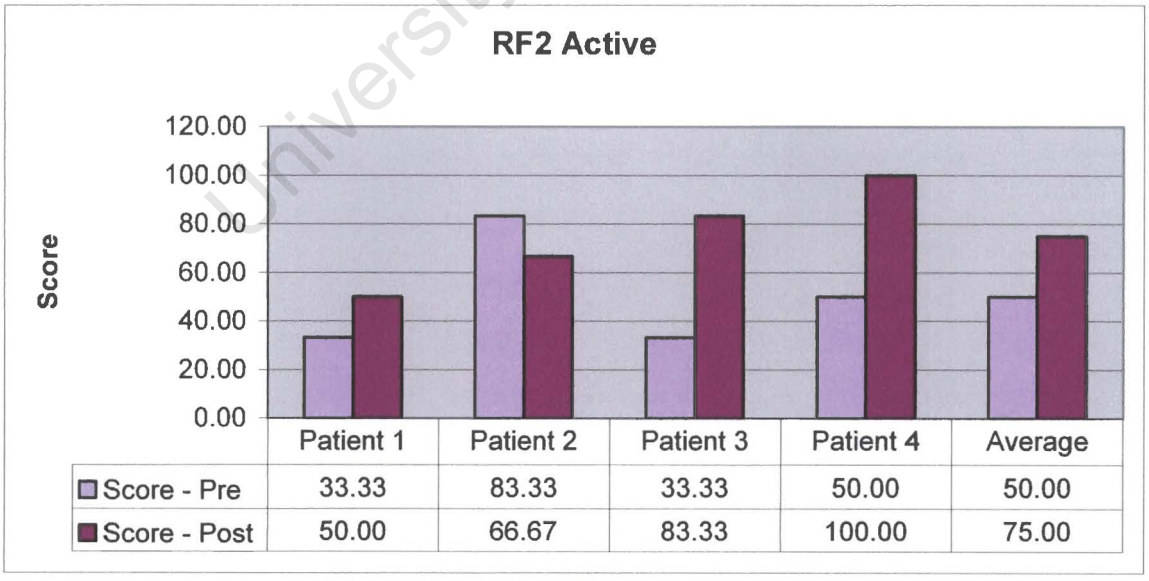
Table 5: RF2 Active: Shows the role function scores pre and post intervention for the MBSR active group

RF2 Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	33.33	83.33	33.33	50.00	50.00	23.57
Score - Post	50.00	66.67	83.33	100.00	75.00	21.52

The mean role function score at the beginning of the intervention was 50.00 and at completion of the MBSR programme was 75.00. There was a significant increase in the mean role functioning of the participants on the programme. One participant showed a decrease in their role functioning. The other three participants showed significant increases.

Figure 7: RF2 Active: Shows the role functioning pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

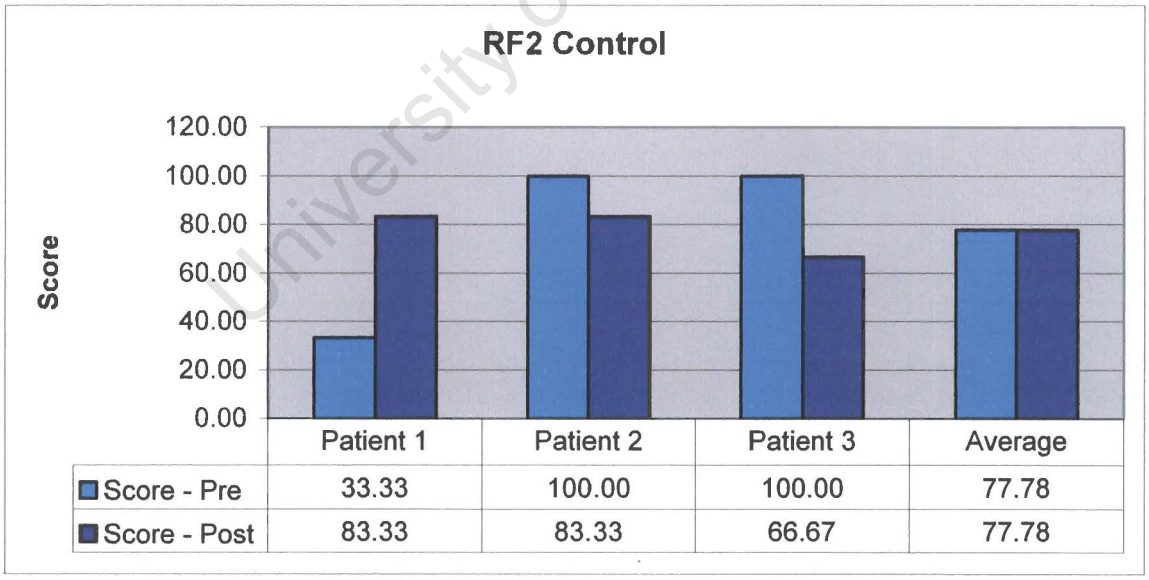
Table 6: RF2 Control: Shows the role function scores pre and post intervention for the control group

RF2 Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	33.33	100.00	100.00	77.78	38.49
Score - Post	83.33	83.33	66.67	77.78	9.62

The mean role function score for the control group did not change over the duration of the intervention and stayed at 77.78. One participant showed an increase in their role functioning from 33.33 to 83.33 but the other two showed declines in role functioning.

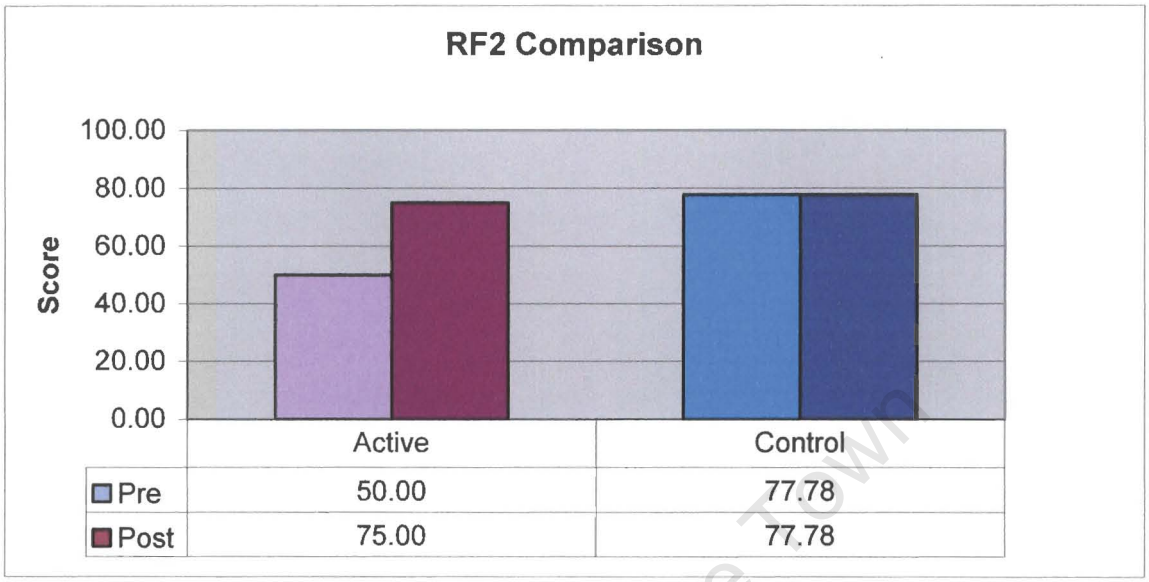
Figure 8: RF2 Control: Shows the role functioning pre and post intervention scores for the control group in graph format



- **Comparison of RF2 score**

Figure 9: RF2 Comparison

Compares the mean role functioning scores for the active and the control group



4. *Emotional Functioning (EF)*

- **Active MBSR Group**

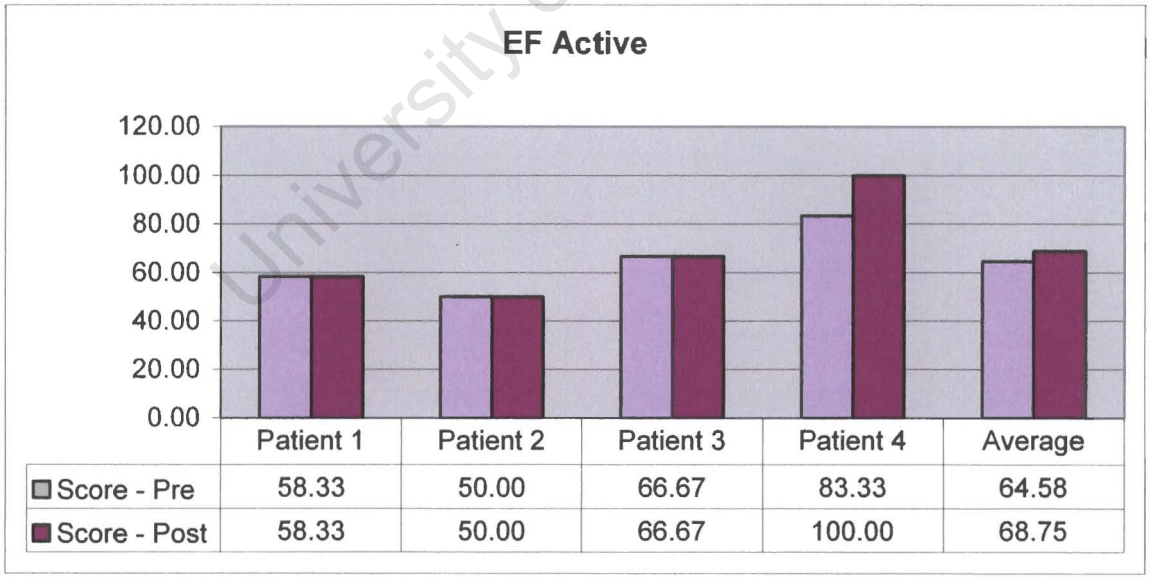
Table 7: EF Active: Shows the emotional function scores pre and post intervention for the MBSR active group

EF Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	58.33	50.00	66.67	83.33	64.58	14.23
Score - Post	58.33	50.00	66.67	100.00	68.75	21.92

The mean emotional function score at the beginning of the intervention was 64.58 and at completion of the MBSR programme was 68.75. Only one of the four participants showed any change with an increase from 83.33 to 100.00.

Figure 10: EF Active: Shows the emotional functioning pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

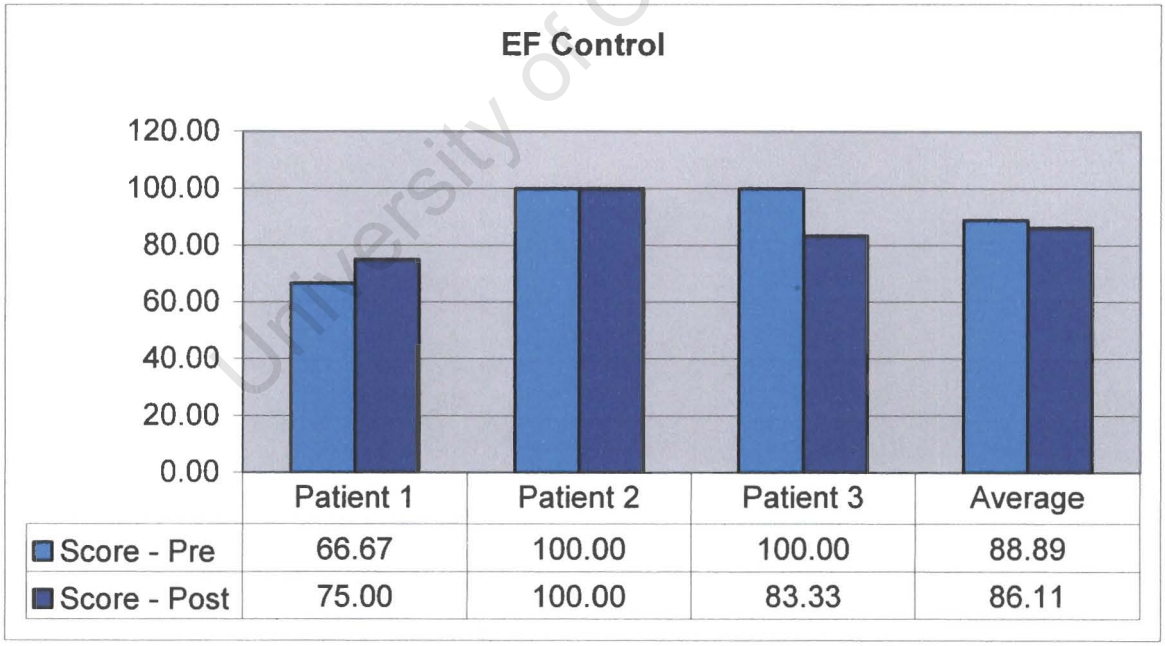
Table 8: EF Control: Shows the role function scores pre and post intervention for the control group

EF Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	66.67	100.00	100.00	88.89	19.25
Score - Post	75.00	100.00	83.33	86.11	12.73

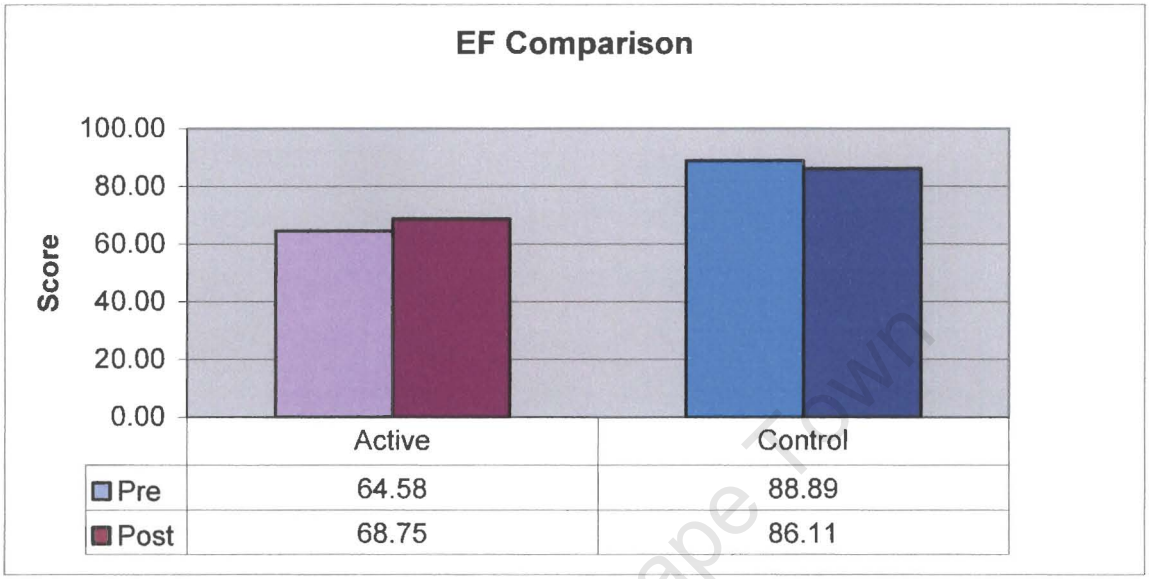
The mean role function score for the control group decreased over the duration of the intervention from 88.89 to 86.11. Again there was one participant who stayed the same, one who declined, and one who increased their score.

Figure 11: EF Control: Shows the emotional functioning pre and post intervention scores for the control group in graph format



- **Comparison of EF score**

Figure 12: EF Comparison: Compares the mean emotional functioning scores for the active and the control group



5. *Cognitive Functioning (CF)*

- **Active MBSR Group**

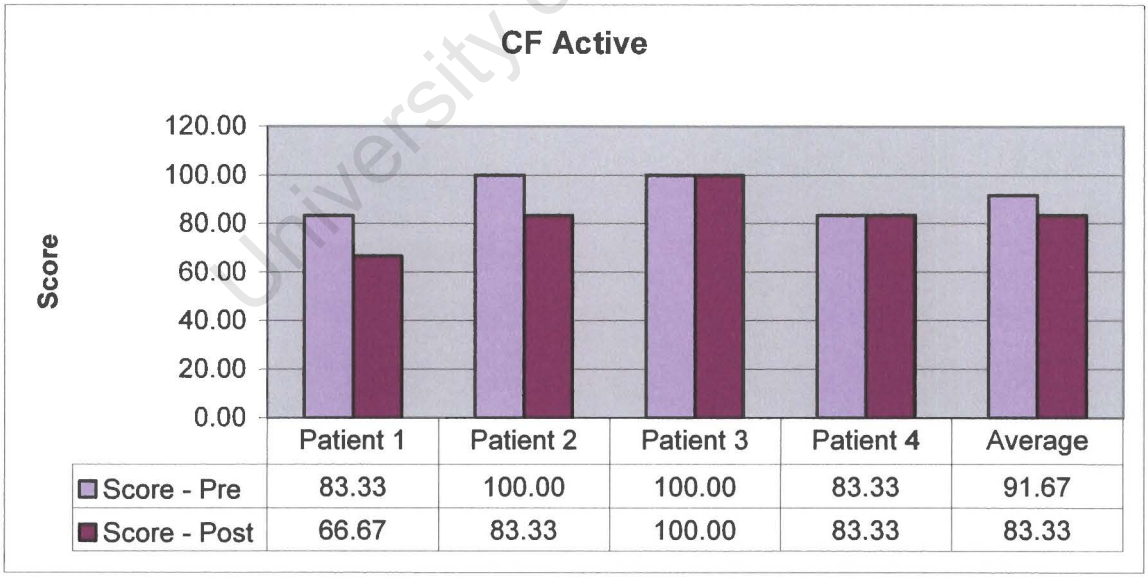
Table 9: CF Active: Shows the cognitive function scores pre and post intervention for the MBSR active group

CF Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	83.33	100.00	100.00	83.33	91.67	9.62
Score - Post	66.67	83.33	100.00	83.33	83.33	13.61

The mean cognitive function score at the beginning of the intervention was 91.67 and at completion of the MBSR programme was 83.33. Two participants showed no change at 100.00 and 83.33 respectively. The other two participants declined to 66.67 from 83.33 and to 83.33 from 100.00 respectively.

Figure 13: CF Active: Shows the cognitive functioning pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

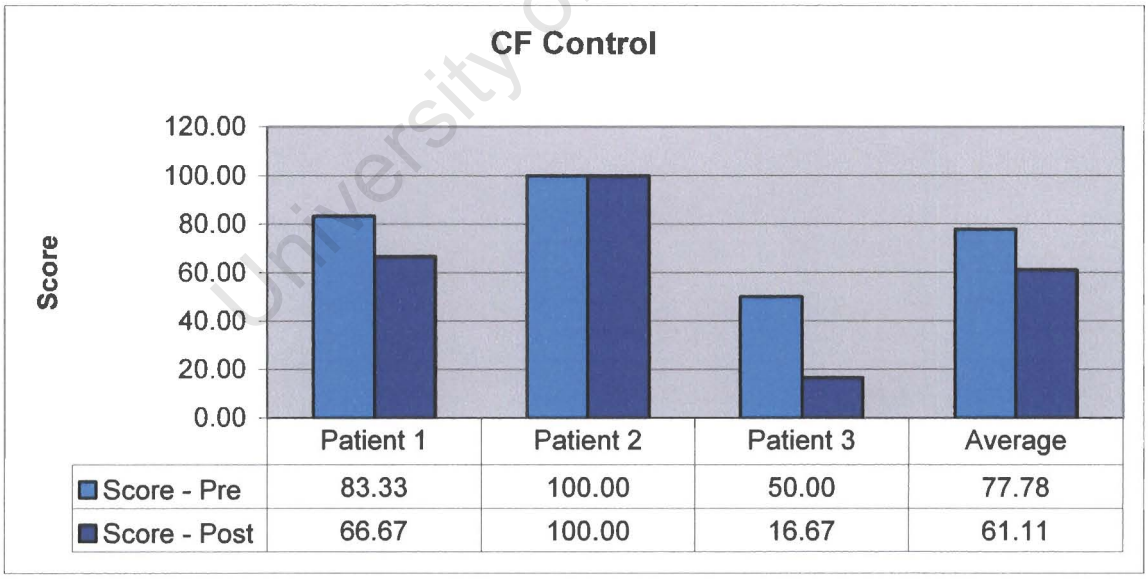
Table 10: CF Control: Shows the cognitive function scores pre and post intervention for the control group

CF Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	83.33	100.00	50.00	77.78	25.46
Score - Post	66.67	100.00	16.67	61.11	41.94

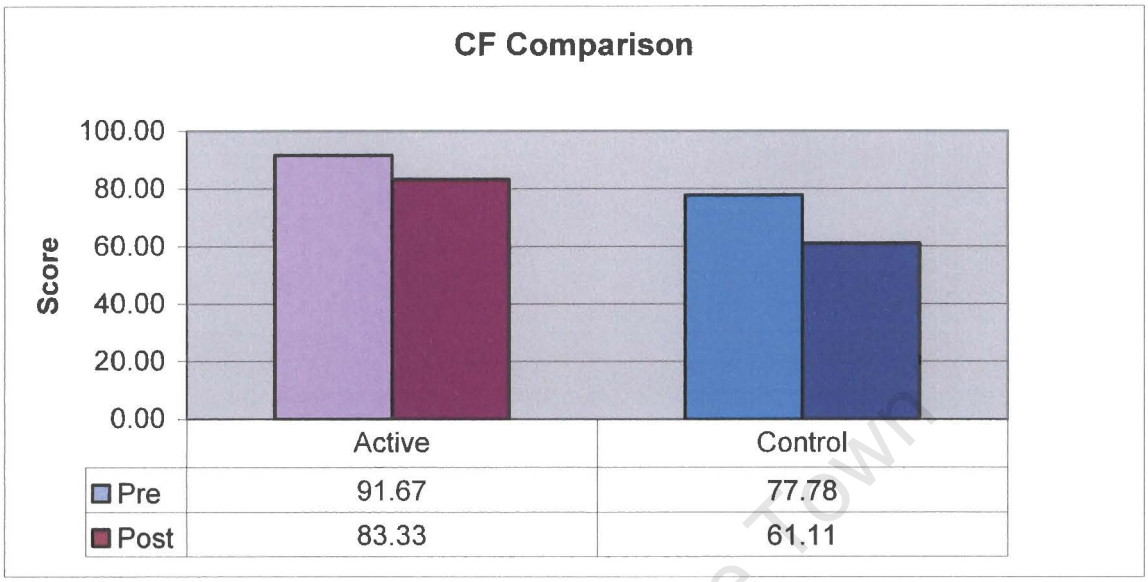
The mean cognitive function score for the control group also decreased over the duration of the intervention from 77.78 to 61.11. One participant stayed the same while the other two declined to 66.67 from 83.33 and to 16.67 from 50.00 respectively.

Figure 14: CF Control: Shows the cognitive functioning pre and post intervention scores for the control group in graph format



- **Comparison of CF score**

Figure 15: CF Comparison: Compares the mean cognitive functioning scores for the active and the control group



6. *Social Functioning (SF)*

Active MBSR Group

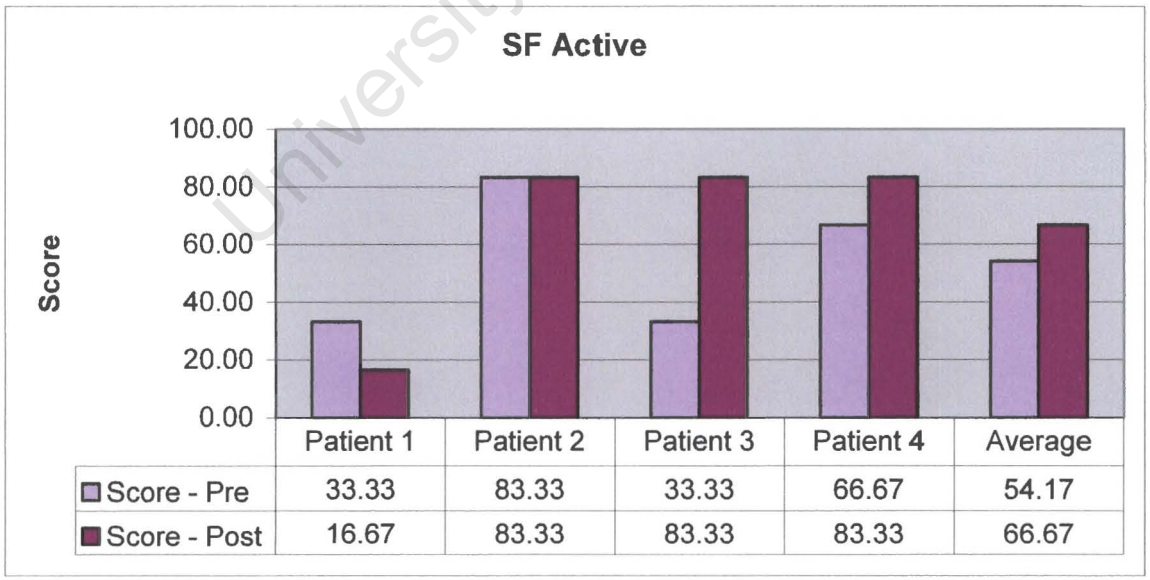
Table 11: SF Active: Shows the social function scores pre and post intervention for the MBSR active group

SF Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	33.33	83.33	33.33	66.67	54.17	25.00
Score - Post	16.67	83.33	83.33	83.33	66.67	33.33

The mean social function score at the beginning of the intervention was 54.17 and at completion of the MBSR programme was 66.67. One participant showed no change staying at 83.33. One participant's social functioning declined from 33.33 to 16.67. The other two participants increased to 83.33 from 33.33 and to 83.33 from 66.67.

Figure 16: SF Active: Shows the social functioning pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

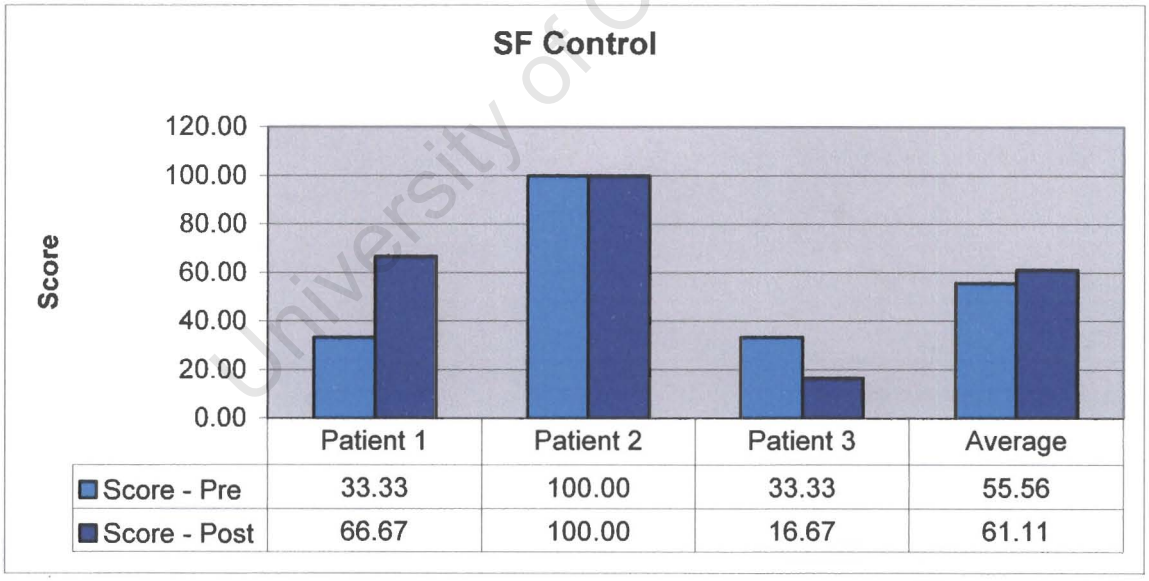
Table 12: SF Control: Shows the social function scores pre and post intervention for the control group

SF Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	33.33	100.00	33.33	55.56	38.49
Score - Post	66.67	100.00	16.67	61.11	41.94

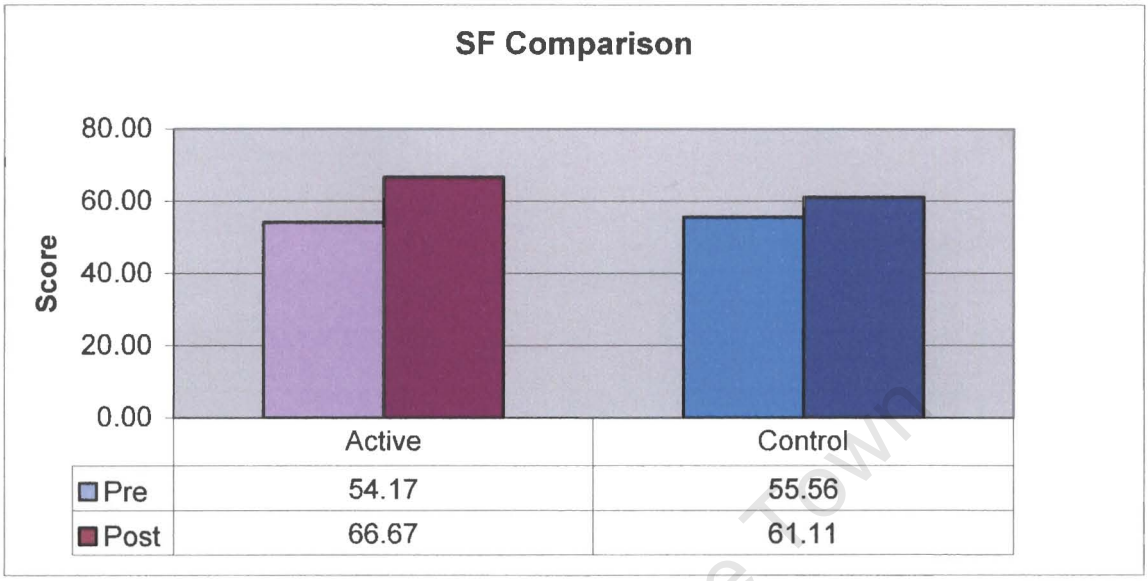
The mean social function score for the control group also increased over the duration of the intervention to 61.11 from 55.56. One participant stayed the same, one declined, and one increased their score.

Figure 17: SF Control: Shows the social functioning pre and post intervention scores for the control group in graph format



- **Comparison of SF score**

Figure 18: SF Comparison: Compares the mean social functioning scores for the active and the control group



7. *Overall Functional Average (OFA)*

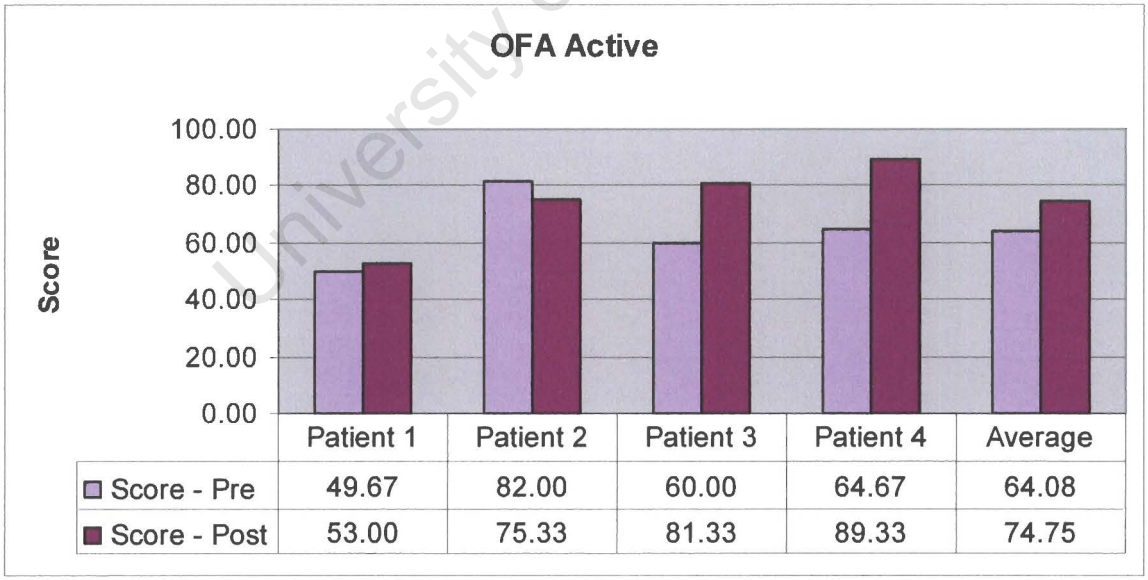
- **Active MBSR Group**

Table 13: OFA Active: Shows the overall functional average scores pre and post intervention for the MBSR active group

OFA Active						
	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score - Pre	49.67	82.00	60.00	64.67	64.08	13.49
Score - Post	53.00	75.33	81.33	89.33	74.75	15.59

The mean OFA score at the beginning of the intervention was 64.08 and at completion of the MBSR programme was 74.75. One participant's overall functional average declined from 82.00 to 75.33. The other three participants all increased their scores.

Figure 19: OFA Active: Shows the overall functional average pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

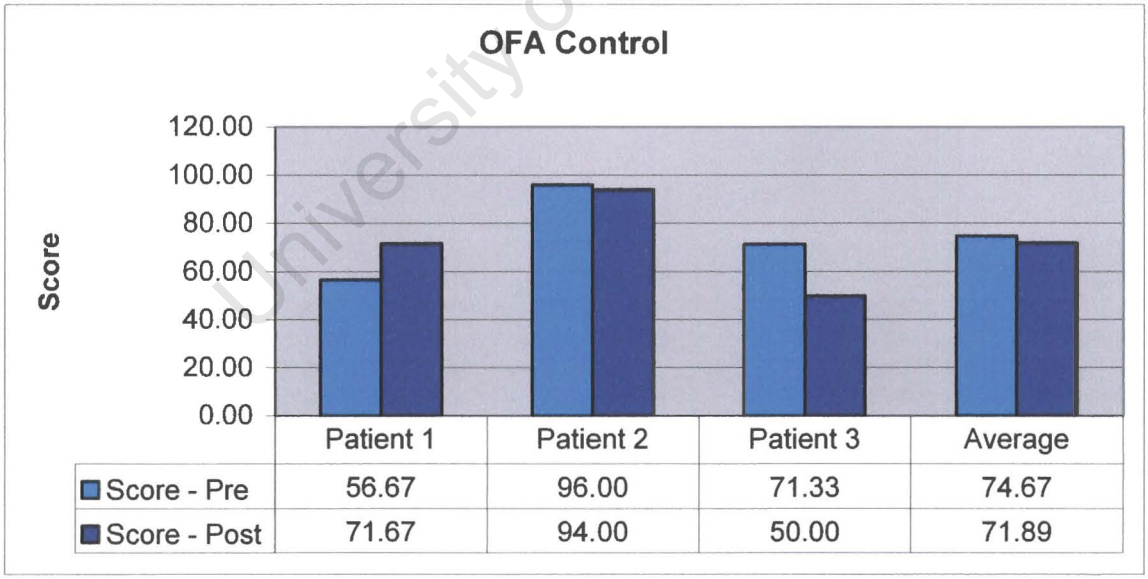
Table 14: OFA Control: Shows the overall functional average scores pre and post intervention for the control group

OFA Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score - Pre	56.67	96.00	71.33	74.67	19.88
Score - Post	71.67	94.00	50.00	71.89	22.00

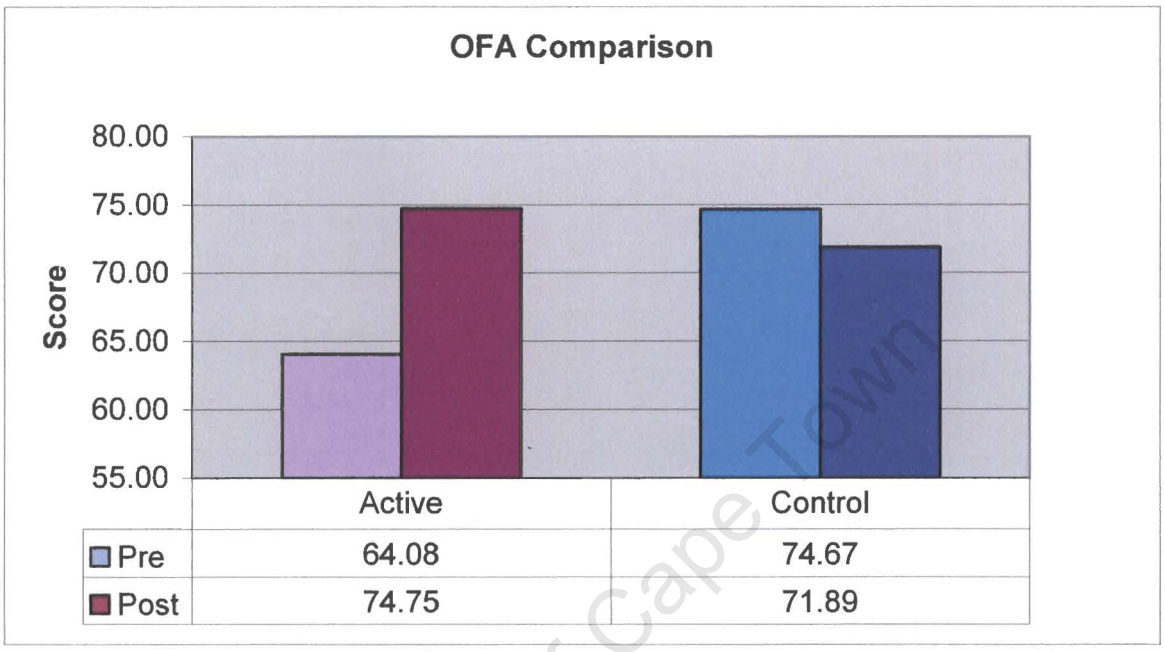
The mean overall functional average score for the control group decreased over the duration of the intervention to 71.89 from 74.67. There was one participant who increased their score from 56.67 to 71.67. The other two participants declined on their overall functional average score.

Figure 20: OFA Control: Shows the overall functional average pre and post intervention scores for the control group in graph format



Comparison of OFA score

Figure 21: OFA Comparison: This score compares the mean overall functional average scores for the active and the control group



8. *Symptom Average*

- **Active MBSR Group**

Table 15: Symptom Average Active: Shows the symptom average scores pre and post intervention for the MBSR active group

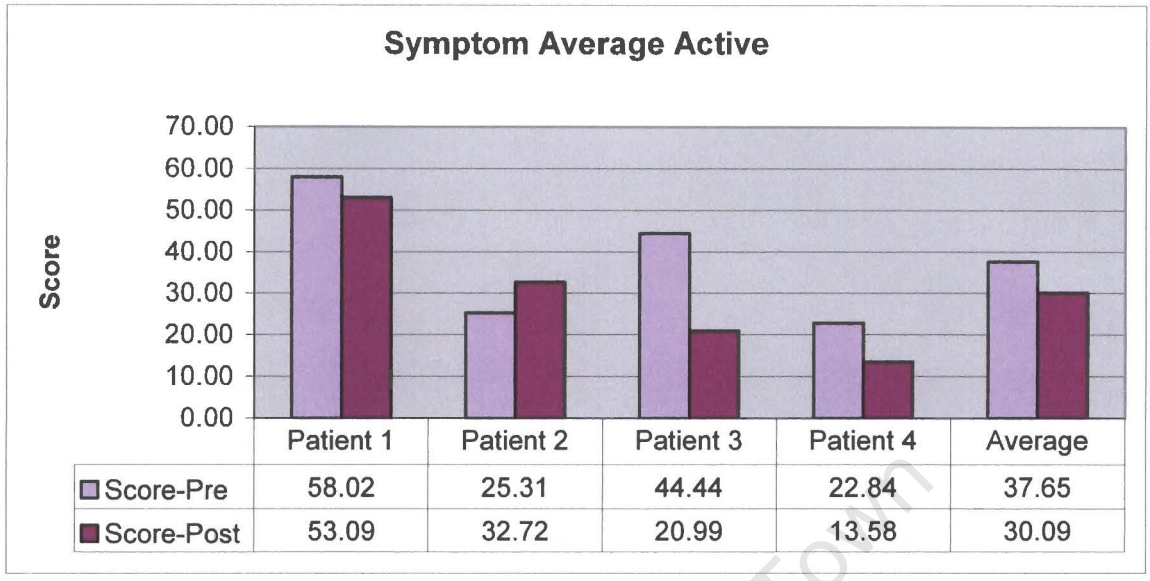
Symptom Average Active

	Patient 1	Patient 2	Patient 3	Patient 4	Average	STDev
Score-Pre	58.02	25.31	44.44	22.84	37.65	16.66
Score-Post	53.09	32.72	20.99	13.58	30.09	17.24

This score is a composite of all the symptom questions on the EORTC QLQ-C30 questionnaire. These include fatigue, nausea and vomiting, pain, dyspnoea, insomnia, diarrhoea, appetite loss, constipation, and financial difficulties.

For the active group the mean symptom average score at the beginning of the intervention was 37.65 and at completion of the MBSR programme was 30.09. One participant's symptom average increased from 25.31 to 32.72. The other three participants all decreased their scores. This shows that despite being terminally ill three of the four participants in the MBSR programme saw a global decrease in all their symptoms.

Figure 22: Symptom Average Active: Shows the symptom average pre and post intervention scores for the active MBSR intervention group in graph format



- **Control Group**

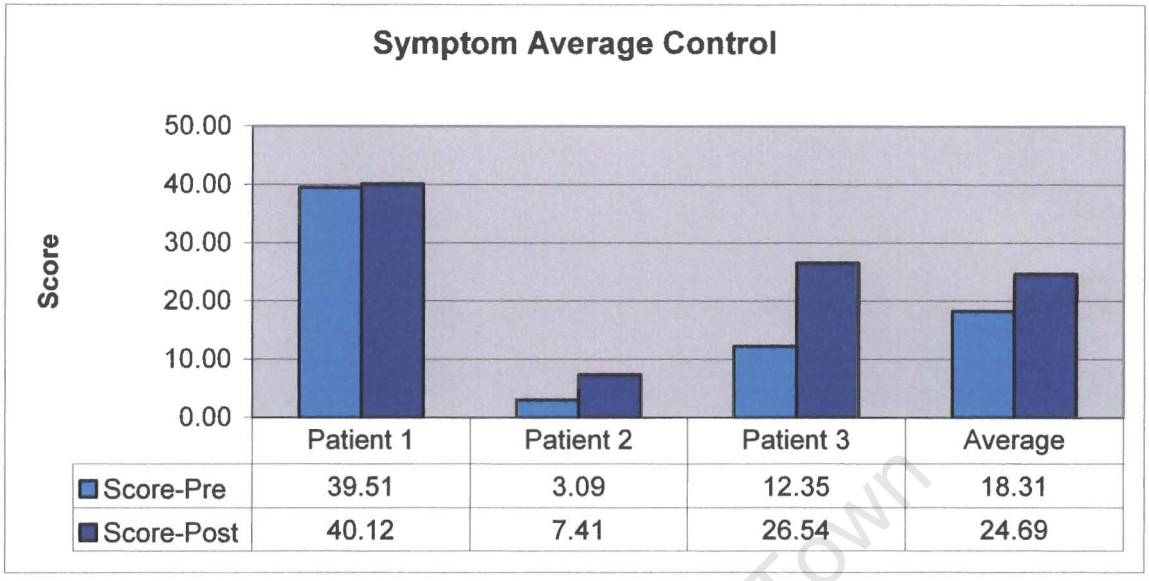
Table 16: Symptom Average Control: Shows the symptom average scores pre and post intervention for the control group

Symptom Average Control

	Patient 1	Patient 2	Patient 3	Average	STDev
Score-Pre	39.51	3.09	12.35	18.31	18.93
Score-Post	40.12	7.41	26.54	24.69	16.44

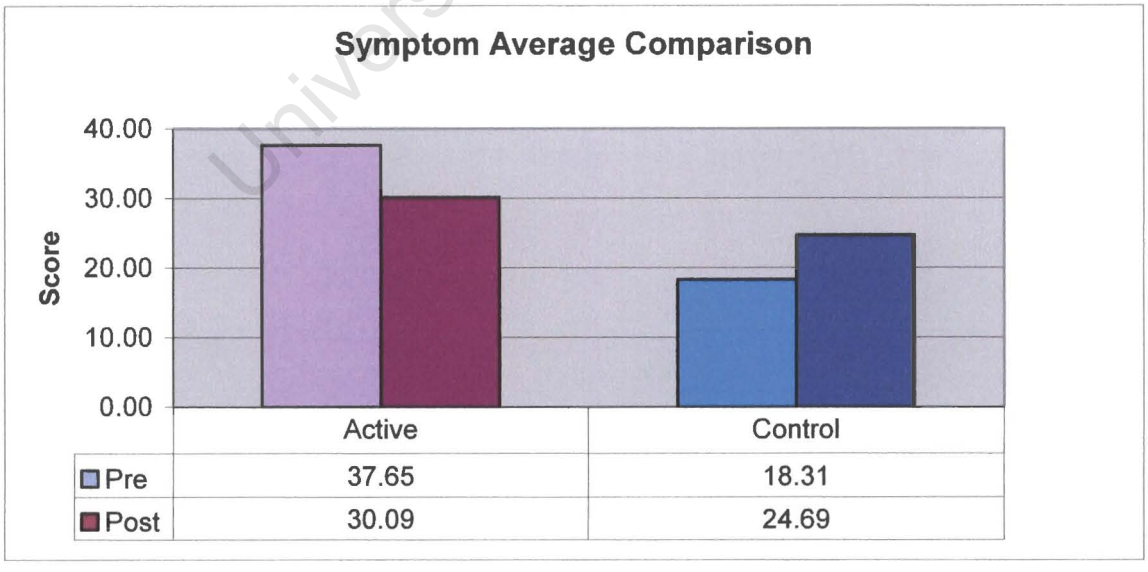
The mean symptom average score for the control group increased over the duration of the intervention to 24.69 from 18.31. All three participants in the control group experienced an overall increase in their symptoms.

Figure 23: Symptom Average Control: Shows the symptom average pre and post intervention scores for the control group in graph format



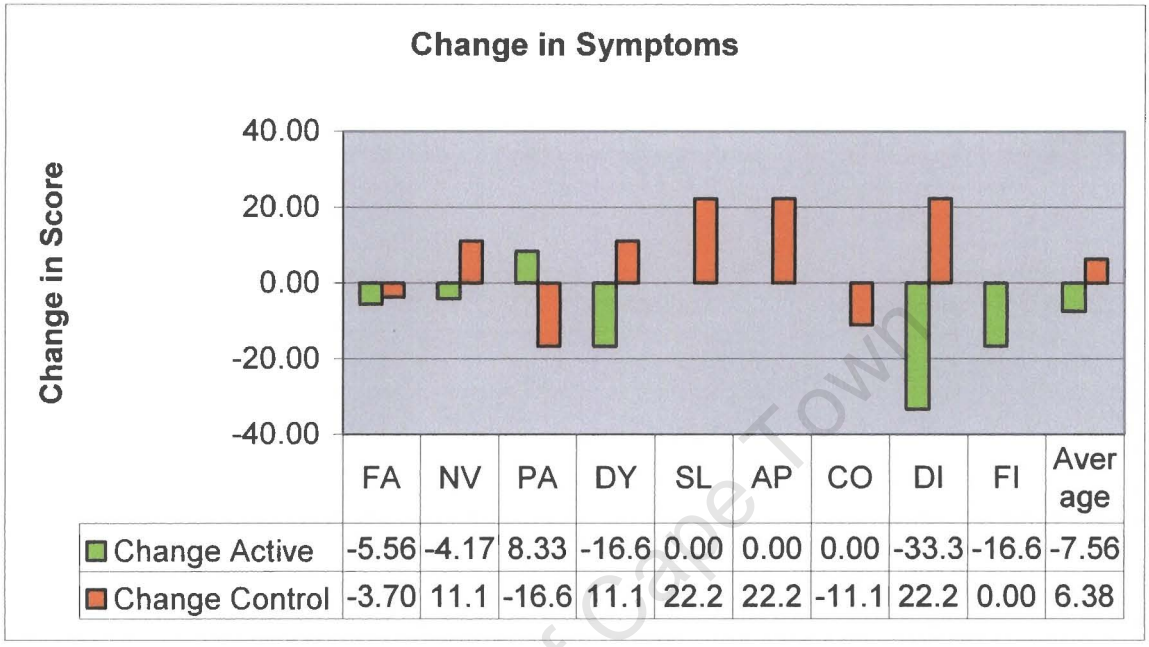
- **Comparison of Symptom Average score**

Figure 24: Symptom Average Comparison: Compares the mean symptom average scores for the active and the control group



- **Change in symptoms**

Figure 25: Change in symptoms: This graph plots the changes in the mean symptom scores of individual symptoms that were recorded by the pre and post intervention data.



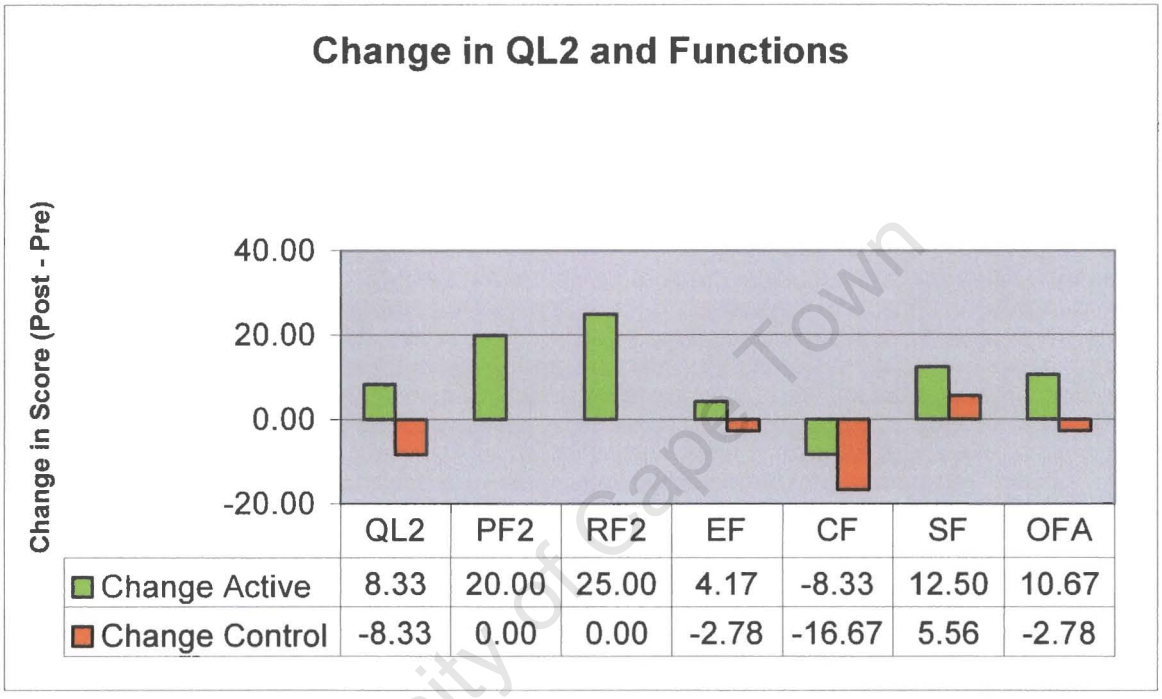
	FA	NV	PA	DY	SL	AP	CO	DI	FI	Average
Change Active	-5.56	-4.17	8.33	-16.6	0.00	0.00	0.00	-33.3	-16.6	-7.56
Change Control	-3.70	11.1	-16.6	11.1	22.2	22.2	-11.1	22.2	0.00	6.38

(FA = fatigue; NV = nausea and vomiting; PA = pain; DY = dyspnoea; SL = insomnia; AP = appetite loss; CO = constipation; DI = diarrhoea; FI = financial difficulties.)

Figure 25 shows the general trend of decreasing symptoms in the active group and increasing symptoms in control group over the eight week period which is confirmed by the symptom average score.

9. *Change in QL2 and Functions*

Figure 26: Change in QL2 and Functions: This graph plots the changes in the mean global quality of life score (QL2), the five functional scores (PF2, RF2, EF, CF, and SF), as well as the overall functional average (OFA) that was recorded by the pre and post intervention data.



(QL2 = QOL; PF2 = Physical Function; RF = Role Function; EF = Emotional Function; CF = Control Function; SF = Social Function; OFA = Overall Functional Average.)

Figure 26 shows the change in the various scores detailed. This shows that for the active

MBSR group there was a positive change, in other words an increase in score recorded by the pre and post intervention questions namely scores recording quality of life, performance function, role function, emotional function, social function, and overall functional average. The only negative change was for cognitive function but was still less of a negative change than that shown by the control group.

Figure 26 also shows that the control group has a negative change in score for quality of life, emotional function, cognitive function, and in the overall functional average. There was no change recorded in either of the performance or role functions for the control group. Interestingly these two functions show the greatest change for the active MBSR group. There was a positive change shown in the control group for social functioning but less again than that of the active group.

Statistical Analysis

Due to the small number of participants in the active and control group it is not possible to apply any statistical analysis to the above data. The following discussion will highlight some of the points of interest that the data raises and point to opportunities for further investigation and research.

CHAPTER FOUR: Discussion

Methodological difficulties

As documented in chapter two, four participants completed the eight week MBSR programme and three completed the eight week control group. From the start the active MBSR group and control group were not randomly assigned. As only six patients were able to be recruited from the population of hospice patients these were assigned to the active group to ensure sufficient numbers to facilitate a group experience. This meant that participants for the control group were sought from the already existing day care group at hospice. The already existing day care group consisted of patients that were on the whole less in need of active nursing intervention and were not on the weekly list of homecare patients that were being regularly seen by the palliative care professional nurses. This may have already introduced a bias with the control group having less physical symptoms than the active group and also having a higher baseline functional level for role function, social function, and emotional functioning, and therefore a better QOL score. Due to the very nature that these two groups were not randomly assigned into active and control group and the very small numbers of this study no statistical significance can be concluded. It is, however, still of significant interest to discuss the various findings, especially given the fact that the active group turned out to be more sick and terminal than the control group, yet had more positive results overall.

This difficulty in research methodology was highlighted by Strömgren [57] who found that recruiting terminally ill patients to a formal study is fraught with difficulties such as poor patient condition, poor patient recruitment and attrition due to death. Jordhy et al [59] further supports difficulties around randomized controlled trials in palliative

cancer care. Rinck et al [60] found in a review of randomized clinical trials that, "without exception, methodological problems were experienced". In two studies reviewed this resulted in no results being reported. Problems found by Rinck et al [60] were very similar to those found by both Strömgren [57] and Jordhy et al [59]. Rinck et al [60] concluded that effective research in palliative care is complex, with many pitfalls.

Faithfull [61] addresses the issue of how many subjects are needed in a research sample in palliative care. She asserts that while sample size is important, "it is only one of the four factors that increase the statistical power of the study". In her opinion effect size – "the size of the proposed treatment response in the intervention group will have an important influence on the likelihood of attaining statistical significance." Many link statistical power and sample size so closely that it may be assumed that sample size is the only important factor needed to test treatment effectiveness. Faithfull argues that treatment effect is closely linked to statistical power and consequently statistical power of a study can be enhanced without needing to resort to large sample studies. As large sample numbers are not practical in palliative medicine for many of the methodological reasons given by Rinck et al [60], Jordhy et al [59], and Strömgren [58], other factors that enhance design sensitivity are useful. Faithfull [61], in her article, outlines numerous factors that work to increase design sensitivity. The factor most relevant to this particular study is that of strong treatment effect. This strong treatment effect will be elaborated in the specific discussions of the measurements of mean global quality of life measure, physical function, role function, overall functional average and the change in symptom average. Other factors that may be relevant are 'consistency in measurement procedures', 'timing of measurement to coincide with the peak response', and 'measurement of effect closer to the intervention rather than longer term effects'. To be consistent both the active MBSR

and control were given the EORTC QLQ-C30 questionnaire in the first and last week of the study. Measurement was also close to the intervention with the post intervention questionnaires being completed at the last class. Given the above it is this researcher's assertion that this study still holds relevant data to be discussed, despite the very small number of participants.

Quality of Life (QL2 score)

Despite starting at a lower mean global QOL score (QL2) the active MBSR group's mean QL2 score increased in comparison to the control group which showed a reduction in score over the course of the eight weeks. The active MBSR group began with a mean global score of 50.00 which increased during the course of the eight weeks to 58.30. The control group started at a higher mean global score of 72.22 but this decreased over the course of the eight weeks to 63.89.

According to Carlson et al [51] scores of 60s and 70s reflect a good QOL. In their study of breast and prostate patients they reported on a pre-intervention mean global QL2 score of 66 using the EORTC QLQ-C30 questionnaire. Carlson et al also noted that other cancer patient groups studied using the EORTC QLQ-C30 questionnaire scored in the 50s for the mean QL2 score[51].

When the follow-on results of this study are discussed they will show a decrease in the symptomatology and an increase in overall function for the active MBSR with a corresponding increase in symptomatology and decrease in overall function for the control group. As QOL is a composite concept affected by physical function, emotional or psychological function, social function, and symptoms of disease or its

subsequent treatment it is clear that changes in make up of the components of QOL will improve the measurement of QOL itself.

Deng and Cassileth [62] in their review of complementary therapies, which included meditation and MBSR, for pain, anxiety, and mood disturbance, confirm that 'because some complementary therapies can reduce mood disturbance as well as physical symptoms they can improve quality of life in general'. Steer et al [56] in his editorial review supports the view that "QOL issues are of paramount importance to patients and are closely related to a reduction in physical symptoms". Analysis of the other results from the EORTC QLQ-C30 questionnaire will shed more light on why the mean global score of the active MBSR group increased and that of the control group decreased. It will be shown that, as in the reintegration model proposed by Wood-Dauphinee and Williams [18, 21], the resumption of or increase in role function has an impact on QOL.

Physical Functioning (PF2 score)

Participating in the MBSR programme and being exposed to the mindful meditation and yoga presented the active MBSR group with a realization that they could still move their bodies no matter how limited this may be. The active MBSR group showed an increase in the mean physical function score from 60.00 at the beginning of the intervention to 80.00 on completion of the MBSR programme. One participant remained unchanged with a high functioning score of 93.33 while all others increased their PF2 score. Two of the participants increased their score well beyond the standard deviation of 25.53. On the other hand the mean physical function score of 73.00 for the control group remained unchanged from the beginning to completion of

the intervention. This is not significant in terms of a strong treatment effect as the mean change in score is not greater that the standard deviation of the scores.

This finding shows that eight weeks of MBSR training had some impact on the physical functioning of the active group, even given that this is a group of terminally ill cancer patients. This is supported by previous studies on MBSR, as discussed in chapter one, that show a reduction in physical symptomatology after having participated in an eight programme. Lindemalm et al [63] found that cancer patients who belonged to a structured support group improved their QOL, physical, and psychological functions. Bower et al's study [64] on cancer patients found that the practice of yoga (which is an integral part of the MBSR programme) resulted in 'modest improvements in sleep quality, mood, stress, cancer-related distress, cancer-related symptoms, and overall quality of life'. This further supports findings of improved physical functioning with MBSR interventions in cancer participants.

Role Functioning (RF score)

The role functioning score demonstrates the most significant change of all the functional scores. The active MBSR group showed a mean score change from 50.00 to 75.00. This was greater that the standard deviation of 23.57 and shows the significance of treatment effect. The control group on the other hand showed no change with a mean score of 77.78 at beginning and completion of study. In fact two of the control group participants had a decline in role function as opposed to only one of the active group.

Role function is closely linked to identity and is a reflection of a person's sense of self. This sense of self is not independent of our relationship with the world we inhabit. We understand much about the way disease impacts on people and their feelings but we pay little attention to how these events influence people's perceptions of themselves and the way they live in the world. [65] Berger and Luckmann [66] describe identity as "a person's sense of self....that involves a 'positioning' of self in reality, a symbolic placement that situates the person in the world". Cayoun [67, 68] describes the discovery of a "clearer, more authentic and more consistent sense of self, and a shift from external to internal locus of control" by patients who undergo mindfulness training.

Impaired role functioning is one of the determinants of great distress in palliative care cancer patients. There may be significant difficulty in performing one's normal activity within one's career, as a family member, as a member of society, a social group, religious activity, and friendships.[69] As stated above in the description of the reintegration model of QOL [18, 21] individuals can and do resume certain roles that have been neglected once certain symptoms are controlled. This resumption of role function has been shown to correlate well with QOL measures.

Role function measures the given role a person assumes in a given situation. The MBSR programme encourages participants to examine assumptions made about oneself and habitual patterns that are followed mindlessly. Bringing mindful attention and non-judgemental awareness to thought, emotion, and sensation breaks the constraints of the mind that places limits on how we identify roles for ourselves. Reibel et al's [12] study of MBSR in a heterogeneous patient population also showed a moderate decrease in role limitation due to physical symptoms on completion of an

eight week MBSR programme. It is interesting to note that role function was one of the more significant changes in measurement for the active MBSR group and that there was no change in this score for the control group. This suggests that the active MBSR group learnt to identify less with themselves only as dying cancer patients and more as people with choices.

Jon Kabat-Zinn in his book *Full Catastrophe Living* [3] devotes a complete chapter to role stress. He highlights how, through unawareness, we are stuck in our various roles and "feel helpless to break out of the rigid constraints [we] impose on our attitudes and behaviors". This lack of flexibility in our roles can cause suffering and impede any form of growth. The participants on the MBSR programme spoke of the constraint of being locked into the role of a terminal cancer patient. The participants spoke about how being assigned this role (that of a terminal cancer patient) meant they became much less active participants in their lives and that it constrained their view of themselves. It also seemed, in their opinion, to give their families implicit permission to make assumptions and decisions on their behalf, something which they would not have ordinarily done in the past. Having brought mindful attention to how constraining this view of themselves had become one of the participants, with extensively metastasized stage 4 breast cancer, signed up for a year's gym membership even though she knew she would not be able to enjoy its full benefit. The benefit it gave her in the present moment was enough to make a difference to how she perceived herself and permitted her to adopt a revised and improved role function.

Emotional Function (EF score)

In this study, emotional function shows little variability. The active MBSR group had a slight increase from 64.58 to 68.75 and the control fell from 88.89 to 86.11. Previous studies on MBSR consistently reported mood elevation [12, 27, 30, 31, 32, 33, 37, 38, 40, 45, 46, 47, and 48] yet in this group of palliative cancer patients there was little change from the baseline level. One possible explanation for this are that this particular population is facing the reality of death with all its accompanying thoughts, concerns, and anxiety regarding one's eventual death. The control group's decrease in emotional function and mood may be due to worsening symptoms as reflected by the increase in the symptom average. Depression is a common symptom in palliative care patients with the incidence of depression increasing with the severity of illness.[69] Agrawal [70] in his editorial review noted that "more than one third of dying patients may be depressed, and more than one half of patients with advanced cancer feel sad, anxious, and irritable." It is possible that being so close to death, with so much suffering, emotional mood elevation is not necessarily one of the factors affected by this programme. In essence, however, the number of participants in this study is too small and this question will warrant further investigation.

Cognitive Function (CF Score)

For both the active MBSR group and the control group the CF score decreased. The MBSR group dropped from a score of 91.67 to 83.33 and the control group from a score of 77.78 to 61.11. The MBSR programme purposefully encourages participants to observe the process of thinking[3], and perceive thoughts as "events" arising in the mind without being caught up in them. Though this may contribute to the decline in cognitive function the more likely explanation may be due to the declining health of

the patients themselves who are terminally ill making active cognition more and more difficult.

Social Function (SF score)

Both the active MBSR group and the control group had increases in the mean SF score however one of the active MBSR group as well as one of the control group had a decrease in social function. The active MBSR group increased from a mean score of 54.17 to 66.67 and the control group from a mean score of 55.56 to 61.11. The active MBSR group had a slightly greater improvement in social function but not statistically significantly relevant.

One of the areas covered in the MBSR programme is that of 'people stress' and communication difficulties [3]. The MBSR programme encourages participants to examine their current relationships and also to reflect on the way they relate to people in general. Most of the participants spoke of the relationships they had with family, friends, and work colleagues, and how these had been influenced since their being diagnosed with terminal cancer. The MBSR programme supports and facilitates a non-judgmental and transparent exploration of 'people-stress'.

Social function is related to role function and an increase for the active MBSR group correlates with the significant increase seen in role function.

Overall Functional Average (OFA)

The average OFA increased for the active MBSR group from 64.08 to 74.75 as opposed to the control group that had a slight decrease from 74.67 to 71.89. The OFA is the mean result of all the function scales. As the control and active MBSR group were unevenly matched with the control group starting the study at a higher baseline functional level for role, social, emotional function as well as QOL, little can be concluded from comparisons of the group on OFA. Of note is that the active MBSR group increased their average OFA over the eight weeks of the MBSR programme whereas the control group essentially had little change. Notable is that the active MBSR group increased their OFA to the level of the control group at initiation of the study. If, as stated before, the control group was less terminal than the active MBSR group, this may mean that the MBSR group increased their OFA to a level they were at prior to becoming so ill.

Symptom Average

It is interesting to note that for the active MBSR group the symptom average declined from 37.65 to 30.09 whereas the control group symptom average increased from 18.31 to 24.69. This shows an increase in physical symptoms for the control group and a decrease for the active group. This is clinically significant considering that the active group, on average, was closer to the terminal stage. This is supported by the fact that eight months post study all of the control group participants are still attending the day care programme, with no need yet for attention from the homecare palliative nurse team, whereas three of the four active MBSR group participants have died. Butler et al [8] as well as others [9, 10] showed that psychological distress and pain increases as the terminal phase approaches. Despite this the active MBSR group

showed a decrease in symptoms apart from one participant who reported increasing pain levels over the course of the eight weeks. This participant died two months after the programme ended suffering increasing pain due to his disease of malignant mesothelioma with extensive pleural involvement and difficult to control neuropathic pain.

Figure 24 illustrates the change in individual symptoms for both groups. This graph reflects that the active control group had a greater overall decrease in symptoms to that of the control group which had an overall increase in symptoms. This is very much in line with other MBSR research that shows a decrease in physical symptoms after completion of an eight week MBSR programme. Being a heterogeneous palliative cancer care group there were differences between participants in terms of cancer type, cancer stage (although most were stage 4 cancer), treatment regimes, treatment side effects, and consequently the experience of individual symptoms. It is of interest to note the trend of a decrease in symptoms for the active MBSR group and a trend of an increase of symptoms for the control group.

Change in QL2 and Function

Figure 25 plots the changes in the mean QOL score (QL2), the five functional scores, as well as the overall functional average that was recorded by the pre and post intervention data. This graph shows, despite the small numbers, a general trend that correlates with that seen in the symptom average. A decrease in symptoms should result in an increase in QOL given that these are so closely related. This is supported by the increase, however slight, in QL2 and overall function for the active MBSR group and a decrease in QL2 and overall function for the control group.

Conclusion

Despite the methodological challenges that this study presented regarding sample size, attrition rate, and unevenly matched active and control group, there are a few valuable insights.

It is notable that for the active MBSR group there was an increase in the quality of life score and in the overall functional scores and a matching decrease in overall symptoms. As already stated quality of life is closely affected by physical function, emotional or psychological function, social function and symptoms of disease or its subsequent treatment.

The control group, on the other hand, showed a decrease in the quality of life score and in the overall functional scores as well an increase overall in reported symptoms.

The most significant result was that of the increase in role function which showed that an MBSR programme for palliative cancer patients makes a huge difference in how these patients define themselves and how they integrate into family and societal structures. As QOL is not an absolute measurement but is relative to a person's expectations; being able to adjust to or accept their new limited role function has an impact on expectation and subsequent QOL for these patients as shown by the increase in the global QOL score.

The answer to the research question "Does an eight week MBSR programme improve the quality of life of palliative care cancer patients?" is yes it does. Palliative care

cancer patients' expectations and the biopsychosocial correlates can be positively modulated through participation in an eight week mindfulness based stress reduction programme. Given the challenges of this study already noted, however, and limited treatment effect, further research is needed to fully answer this question.

CHAPTER FIVE: Recommendations, The way forward

"...don't turn your head
Keep looking at the bandaged place.
That's where the light enters you...."
Rumi

Study aim & objectives

The **aim** of this study was to evaluate if an MBSR programme showed a positive benefit to palliative care cancer patients. As described in the previous chapters, participating in an eight week MBSR programme did show benefit to the active MBSR participants compared to the control group. The most important benefit to the MBSR participants was that of a shift in their perception of self with a subsequently improved sense of self and capacity in the making choices in defining their roles. There was also an increase, on average, in global quality of life, physical functioning, social functioning, and a decrease in the average reported symptoms.

This shift in patient perception, QOL, and functioning scores requires further investigation.

The **objectives** of this research were to:

1. Explore and adapt the use of an eight week MBSR programme in palliative care cancer patients.

   It was found that, despite the small numbers, it is possible to run an eight week MBSR programme, which stays within the original Center for Mindfulness

guidelines of the programme, for palliative care cancer patients. The classes were shortened to two hours and the guided homework meditations shortened from forty-five minutes to thirty minutes with opportunity to stop at fifteen minutes. The participants were able to attend class for at least six of the eight classes as well as the four hour day class (shortened from the usual seven hours) in the sixth week. They coped well with the homework, using their own wisdom to guide their own tolerance levels. All the participants were able to adapt according to their own limitations and follow the guided meditations and gentle stretching yoga exercises without much difficulty.

2. Assess the value of such a programme to palliative care cancer patients.

The value shown by this programme has already been discussed. Observations made that were not documented by the questionnaire were those of enthusiasm, trust, and camaraderie among participants during the classes; participants also shared support for each other during these sessions. The group fulfilled traditional group outcomes of support and positive expectation, but also provided a safe environment within which to explore their own response to being faced with a terminal illness within the boundaries of moment to moment non-judgemental attention.

It had been hoped that a programme such as the MBSR would enable the coming to terms with this last phase of life, and with improving the perception of the physical and psychological challenges that influence the quality of this remaining time. In this regard, this study, despite its limited sample size, has demonstrated clinically significant results with an improvement in QOL, role

function, and decrease in symptoms. Further research with MBSR in this patient population is needed to expand on these findings.

3. Assess impact on various dimensions of the quality of life using the EORTC QLC C30 which measures physical and psychological functioning and symptoms, including dyspnoea, sleep disturbance, appetite loss, constipation, diarrhoea, irritability, depression, loss of memory, and financial impact of symptoms.

   As discussed in chapter four there was an increase in QOL and in the overall functional average as well as a decrease in symptoms for the active MBSR group. For the control group there was a decrease in QOL and in the overall functional average as well as an increase in symptoms.

Staff

As indicated in the introduction to this dissertation interest has been shown by the staff of Houghton Hospice in the use of mindfulness tools and their benefits for both patients and caregivers. As this research has shown promise in terms of value and benefit in going through an eight week MBSR programme for palliative care cancer patients a similar programme for staff will be offered. A pilot staff MBSR programme is already being taught. It is hoped that by participating in such a programme the staff will benefit three fold:

- Derive their own stress reduction and self-care benefits
- Be able to use mindfulness skills with patients in their care
- Refer appropriate patients to future MBSR programmes.

In-service training

There will be feedback to Hospice Witwatersrand at one of its monthly in-service training to educate the general professional staff as to the value of this research and how this can be carried forward into staff MBSR programmes and patient MBSR programmes.

Conference presentations

Initial results of this research have been presented as part of a conference presentation on traditional and complementary health use in palliative care by the author in August 2005 to a Palliative Nursing Conference in Johannesburg, South Africa.

This research will also form the basis of a presentation on 'MBSR research with palliative care cancer patients' by the author at the *4th Annual Conference of Integrating Mindfulness-Based Interventions into Medicine, Health Care, and Society* March 30 – April 2, 2006 hosted by the Center for Mindfulness in Medicine, Health Care, and Society, University of Massachusetts Medical School, at Worcester, Massachusetts, USA.

This research will contribute to the growing knowledge in the use of mindfulness meditation skills in medicine, health care and society, specifically to its use in palliative care cancer patients. To the author's knowledge this is the first study that investigates the use of an MBSR programme within palliative care. This has been researched extensively on the internet, discussed in mindfulness discussion groups on the internet, and is also the informed opinion of Saki Santorelli, current director of the

Center for Mindfulness in Medicine, Health Care, and Society, University of Massachusetts Medical School, at Worcester, Massachusetts, USA.

Conclusion

I would like to conclude by quoting a medical colleague who teaches MBSR in the US: "In the end, we stand together with our patients, facing the uncertain challenges of the future, dealing with the problems of now, and reflecting on the events of the past, with a mysterious and very human kind of bond." Mic Krasner, from his article titled *'The Gift of Mindfulness'* [75].

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APPENDICES

Appendix One

Memo to homecare palliative nursing staff

Dr Patricia Luck
Memo to homecare nursing staff, Hospice Witwatersrand

I will be running a research programme for my master's research I am doing for the Mphil Palliative Medicine through UCT. I am studying the effects of a stress reduction programme that incorporates meditation, gentle stretching, and discussion around stress reducing mind-body tools. It is hoped that this program will help patients deal with the daily stressors they encounter in dealing with cancer, pain, and terminal illness.

This will be an eight week programme starting Friday, May 6th and meeting for eight consecutive Friday mornings until the 24th June. There will also be a meeting on Saturday morning the 11th June. The Friday mornings typically will last about one & half hours. The one Saturday morning will be about four hours. Patients will be asked to do an amount of daily homework for programme of about half an hour to forty-five minutes in length.

As this is a pilot study to evaluate the effects of such a program for palliative care cancer patients and therefore we are not certain yet of its value, I will divide half of the participants to be a control group and to come to share care for the duration of the eight weeks. I will also be at the share care program and will interact with the control group. If these participants want to have the programme run for them, I will do so after the eight weeks.

Please could you speak to suitable patients of yours for this exciting study. Patients must not be on any active curative regime; they must have at least a three to six month prognosis and be able to come to hospice weekly for the eight weeks. They must also be reasonably comfortable with English. Patient information will be kept confidential. Every effort will be made to adjust the program to the requirements of the patients.

If you have interested patients please give me their details and I will contact them to discuss this further. I will make an appointment for an initial interview with each one of the interested patients for the study. Patients are under no obligation to participate if they decide not to do so after meeting with me. If you have any questions please be in contact with me. I have included a short summary of my research proposal to give you some more information.

Thank you, Trish. 15th March, 2005.

Appendix Two

Hospice Witwatersrand Research Study Permission

HOSPICE
association of the Witwatersrand

P.O. Box 87600, Houghton, 2041. 50 Second Avenue, Houghton Johannesburg.
Tel: (011) 483-9100. Fax: (011) 728-3104. E-mail: offices@hospicewitwatersrand.org.za

4TH AUGUST 2004.

THIS LETTER SERVES AS AUTHORISATION FOR DR. PATRICIA LÜCK TO ACCESS HOSPICE PATIENT FILES SHOULD SHE REQUIRE ANY INFORMATION REGARDING SUCH PATIENTS FOR HER MASTERS RESEARCH WHICH SHE IS DOING THROUGH THE UNIVERSITY OF CAPE TOWN.

PERMISSION IS ALSO GRANTED FOR HER TO RUN AN MBSR PRORAMME FOR HOSPICE PATIENTS, USING THE HOUGHTON HOSPICE FACILITIES.

SHOULD ANY FURTHER ASSISTANCE BE REQUIRED PLEASE DO NOT HESITATE TO CONTACT ME.

DR. DANIELLE LINCOLN

MEDICAL DIRECTOR

Appendix Three

MBSR Programme Guidelines

MBSR Programme Guideline

The following is a brief outline of the eight week MBSR course, covering nine sessions. Themes will be developed upon more fully within the class programme. Each class will be for 1.5 to 2 hours.

Session One: Class One - Introduction to MBSR. Begin to establish group rapport; Introduce MBSR and guidelines for participation; Allow time for personal introduction including name, expectation of the programme and positive things about themselves; Introduce 'eating' meditation; Introduce and practice body scan; Discussion of homework; Theme is the present moment and that is more right with one than wrong, no matter the problems.

Session Two: Class Two - Perception and Appraisal. Practice body scan; Discussion of homework experiences; Discussion of perception homework and concept of appraisal; Mental factors in assessment of stress; Short sitting meditation with awareness of breathing; Theme is perception and creative responding, kindness and compassion.

Session Three: Class Three - Being Present. Short sitting meditation with awareness of breathing; Gentle mindful yoga and stretching session either seated in chair or on floor if wish; Discussion of progress and homework experiences; Theme of mindfulness in everyday life.

Session Four: Class Four - Responding to Stress. Sitting meditation with focus on breath, body sensations, sound, and the body as a whole; Introduction to walking meditation; Discussion of homework; Discussion of stress reactivity versus responding with awareness; Theme is around dealing with loss.

Session Five: Class Five - Commitment. Guided sitting meditation with breath, body, sounds, emotions, thoughts, as 'events' in consciousness, distinguishing the event from the content, with emphasis on stillness; Standing and sitting yoga; Review fundamentals of mindfulness; Discussion of homework; Theme is around creating space, being open to and having flexibility to deal with whatever arises in our lives within the present moment.

Session Six: Class Six - Communication. Guided seated meditation with less guided instruction: breath, body, sounds, emotions, thoughts, choiceless awareness; Discussion of homework; Discussion of stressful communication; Discuss upcoming half-day session on week-end; Theme is around communication and needs.

Session Seven: Half-Day Class. This session emphasizes the deepening and continuing development of the various practices in a more flexible and refined capacity; This four to five hour session will include seated meditation, yoga exercises, walking meditation, body scan. The day is held in silence and the tea/coffee break mid-session will be a time to experience 'eating' meditation in silence.

Session Eight: Class Seven – Feeling at Home Wherever We Are. Sitting meditation with choiceless awareness using breath as anchor; Seated yoga; Walking meditation; Discussion of homework and half-day class; Theme is around recognition and choices.

Session Nine: Class Eight – Making This Our Own. Review of body scan, yoga, sitting meditation; Discuss progress, benefits, what learned, obstacles encountered; Review programme; Theme around endings being beginnings.

References:

Mindfulness-Based Stress Reduction Professional Development Program Resource Manual: Center for Mindfulness in Medicine, Health Care, and Society, University of Massachusetts Medical and UMass Memorial Health Care, Worcester Massachusetts. Compiled and Edited by Saki F. Santorelli, Ed.D and Jon Kabat-Zinn, PhD. © 2003

Appendix Four

Patient Consent Form

Mindfulness Based Stress Reduction Programme- Informed Consent

Dr Patricia Luck
Hospice Association of the Witwatersrand, Houghton, South Africa

The risks, benefits and possible side effects of the Mindfulness Based Stress Reduction programme were explained to me in detail. This includes skill training in relaxation and meditation methods as well as gentle stretching (yoga) exercises. I understand that if for any reason I am unable to, or think it unwise to engage in these techniques and exercises either during the weekly MBSR sessions or at home, I am under no obligation to engage in these techniques, nor will I hold the above named facility liable for any injury incurred from these exercises or techniques.

I understand that I am expected to attend each of the eight weekly sessions, the short day-long session, and to practice the home assignments for 15-30-45 minutes per day for the duration of the training programme. The venue that it will be held at is the Houghton Hospice.

I understand that this programme is a pilot research study run by Dr Patricia Luck toward her Mphil dissertation in Palliative Medicine, and that my needs as a palliative care cancer patient have been taken into account. I understand that my participation in this study is entirely voluntary and that if I refuse to participate or withdraw from participation at any time there will be no prejudice to the quality of my subsequent clinical management and care from Houghton Hospice.

Date_____ Time_____

Print Name_____

Participant Signature_____

Witness_____

Thank you for your attention to filling out this questionnaire. This helps me ensure that I can take account of your individual needs and tailor the programme accordingly. All information is private and highly confidential. The information given will be used for research purposes but no personal details will be made public.

Sincerely,
Dr Patricia Luck
Hospice Association of the Witwatersrand, 2005

Appendix Five

Patient Participant Profile

Strictly Confidential

Patient Profile, History & Consent Form

Today's Date: ____/____/2005

First Name:
_____Surname:_____

Name you wished to be called by: _____

Postal Address: _____

_____

Postal Code: _____

Physical Address: _____

_____

Telephone: (H)_____(W)_____

(Fax)_____(C)_____

(Email)_____

Medical Aid Details:_____

Age: _____years Date of Birth: _____

Gender: (Male or Female) _____

Ethnic Grouping _____

Relationship Status: _____
(single, married, divorced, separated, widower, committed relationship, etc)

Occupation/Profession: _____

Monthly Income: _____

Highest educational level achieved till now:_____

Do you have close friends? _____

Do you have close family support? _____

Religious Affiliation_____

Sleep quality_____ **Ave Hours of sleep per night**_____

Weight_____ **Height**_____

Do you smoke? _____ **No. of Caffeinated drinks per day**_____

Do you eat a balanced diet?_____

Do you exercise? _____ **What kind?** _____

How much? _____

What do you care about most? _____

_____

What gives you most pleasure in your life?_____

_____

What are your greatest worries?_____

_____

What is your main reason for participating in this programme? _____

_____

Have you had any prior experience of meditation or yoga? If so please describe._____

_____

Are you involved in any other group or individual therapy sessions outside of Houghton Hospice? If so please describe._____

_____

MEDICAL INFORMATION

Cancer Type _____

Cancer Staging _____

Year and Month of diagnosis _____

Treatment Received for Cancer To Date _____

_____

_____

_____

_____

Do you have a heart problem? _____

Do you have blood pressure problems?_____

Do you have epilepsy?_____

Do you have diabetes? _____

Do you have chronic pain? _____

Do you have any physical limitations? Please specify? _____

_____

Do you have any mental health problems? _____

_____

Any previous overnight hospitalisations (year) _____

Medical/Surgical_____

Psychological_____

Do you take prescription medication? (please list)_____

_____

_____

_____

_____

_____

_____

_____

Please note any over the counter medication, vitamins, and natural remedies you are presently taking_____

_____

_____

_____

_____

_____

_____

Appendix Six

EORTC QLQ-C30 User's Agreement

EORTC QLQ-C30 USER'S AGREEMENT

The EORTC Quality of Life Group grants permission to Dr Patricia Luck to employ the EORTC QLQ-C30 in an academic quality of life study entitled:

Does an eight week MBSR (mindfulness based stress reduction) programme improve the quality of life of palliative care cancer patients?

The Group will supply Dr Patricia Luck, with (1) the QLQ-C30 in the currently available languages; and (2) the standard algorithms for scoring the QLQ-C30. Use of the EORTC QLQ-C30 in the above-mentioned investigation is subject to the following conditions:

1. Dr Patricia Luck confirms that this study is being conducted without direct or indirect sponsorship or support from pharmaceutical, medical appliance or related, for-profit health care industries.

2. Dr Patricia Luck will grant the EORTC Quality of Life Group limited access to the trial database. Access will be limited to the following: (a) the EORTC QLQ-C30 and module data; and (b) additional data will be made available to the EORTC at the sole discretion of Dr Patricia Luck as deemed appropriate for the purpose of validation of the QLQ-C30.

3. Dr Patricia Luck will not modify, abridge, condense, translate, adapt or transform the QLQ-C30 or the basic scoring algorithms in any manner or form, including but not limited to any minor or significant change in wording or organization of the QLQ-C30.

4. Dr Patricia Luck will not reproduce the QLQ-C30 or the basic scoring algorithms except for the limited purpose of generating sufficient copies for its own use and shall in no event distribute copies of the QLQ-C30 to third parties by sale, rental, lease, lending, or any other means Reproduction of the QLQ-C30 as part of any publication is strictly prohibited

5. Analysis and reporting of QLQ-C30 data by Dr Patricia Luck should follow the written guidelines for scoring of the QLQ-C30 as provided by the EORTC Quality of Life Group.

6. This agreement holds for the above-mentioned study only. Use of the QLQ-C30 in any additional studies of Dr Patricia Luck will require a separate agreement.

Signed and dated by:

28 July 2004

Dr Patricia Luck signature removed
University of Cape Town(research toward Mphil in Palliative Medicine)
P O Box 620, Riverclub
Gauteng, South Africa
2149
South Africa

Appendix Seven

Individual Symptom Data

Individual Symptom Data

	A. Active MBSR Group Mean Score Pre Intervention	B. Active MBSR Group Mean Score Post Intervention	C. Control Group Mean Score Pre Intervention	D. Control Group Mean Score Post Intervention	E. Change In Mean Score Active MBSR Group (B-A)	F. Change In Mean Score Control Group (D-C)
Fatigue (FA)	47.22	41.67	25.93	22.22	-5.56	-3.70
Nausea/Vomiting (NV)	37.50	33.33	0.00	11.11	-4.17	11.11
Pain (PA)	45.83	54.17	38.89	22.22	8.33	-16.67
Dyspnoea (DY)	41.67	25.00	33.33	44.44	-16.67	11.11
Insomnia (SL)	33.33	33.33	22.22	44.44	0.00	22.22
Appetite Loss (AP)	25.00	25.00	0.00	22.22	0.00	22.22
Constipation (CO)	33.33	33.33	22.22	11.11	0.00	-11.11
Diarrhoea (DI)	33.33	0.00	0.00	22.22	-33.33	22.22
Financial Difficulty (FI)	41.67	25.00	22.22	22.22	-16.67	0.00
Average	37.65	30.09	18.31	24.69	-7.56	6.38