Bangor University

DOCTOR OF PHILOSOPHY

Accessing and assessing fibromyalgia through pain drawings

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Award date:
2010

Awarding institution:
Bangor University

Link to publication

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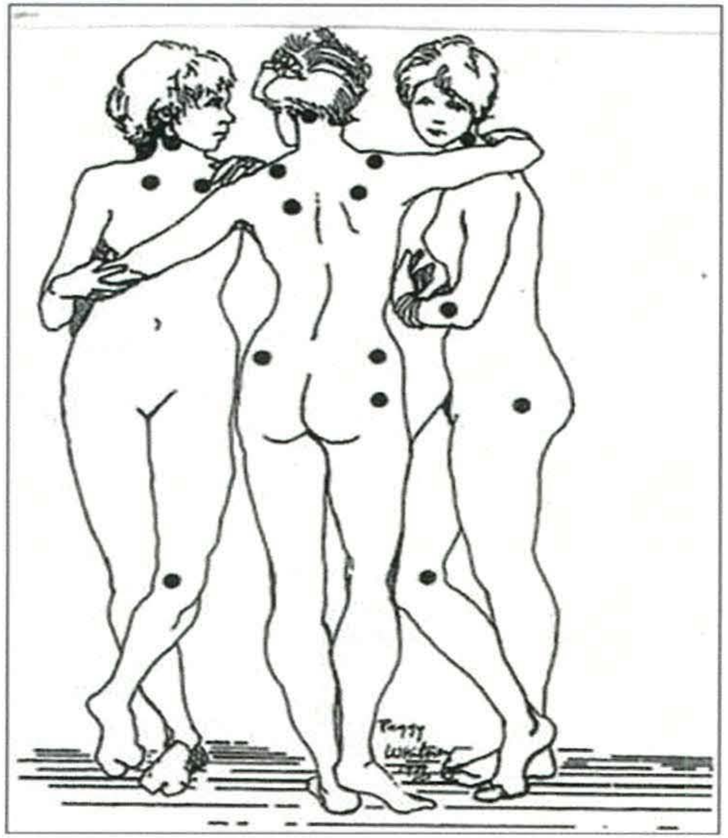

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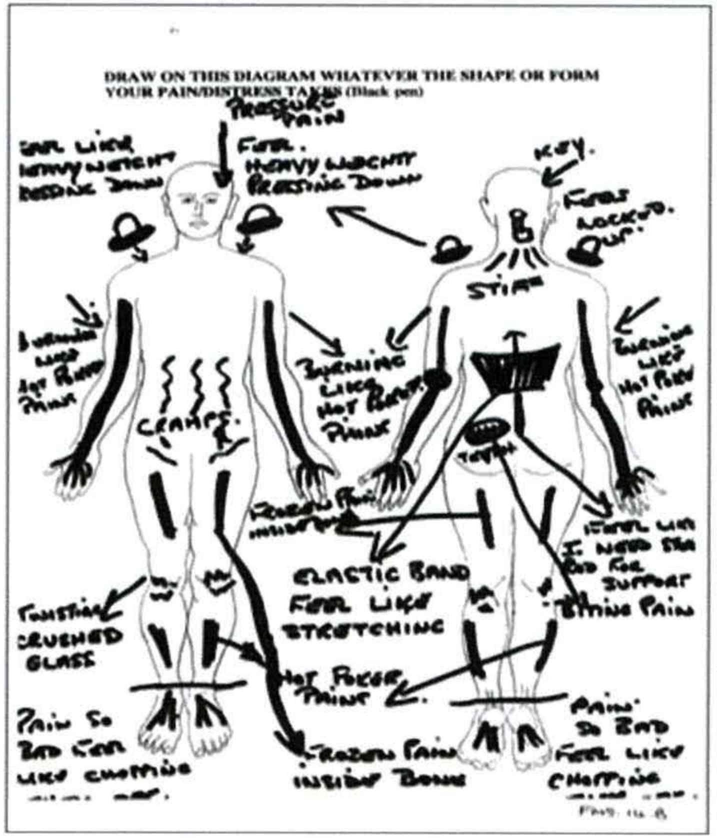


霊気

The human being is designed primarily to function from spiritual information, meaning that the actions and desires of people derive in spirit, and the energy to move forward with actions and desires is first and foremost a spiritual energy. The highest intensity and structure of spiritual energy will flow in a life that is most highly aligned with a Divine spiritual intention which can be viewed as a contract between a power higher than the self (God) and the higher aspect of each self (soul or higher self).

ACCESSING AND ASSESSING FIBROMYALGIA THROUGH PAIN DRAWINGS

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Thesis submitted to the University of Wales in fulfillment of the requirements of the Degree of Doctor of Philosophy at the Bangor University, Wales

December 2010

ABSTRACT

Simple body outlines are commonly used in the documentation of pain in rheumatology clinics. However, the explicit guidelines given to patients when completing these often restrict the potential for patient communication and expression of pain and distress. This research program explored an innovative method that used the simple body outline as a means for patients to express and communicate their symptoms of pain and distress more freely. *Chapter One* provides a general overview of the historical use of the simple body outline in clinical practice. More specifically, a focus on the use within rheumatology clinics is presented. The study in *Chapter Two* compares the drawings of women with either fibromyalgia (FM) or osteoarthritis (OA). The results of this study indicated differences between the two groups. Indeed, visual assessment alone identified distinct and dramatic differences. The FM group's drawings are more creative and dramatic, suggesting this would be a good method of communicating pain for this patient group. Given that individuals with FM were able to utilize this innovative method in order to communicate their pain and distress, *Chapter Three* aims to explore the process and meaning ascribed by these participants when completing the simple body outline, by use of a semi-structured interview. Previous research has found that a proportion of patients diagnosed with Rheumatoid Arthritis (RA) also have co-morbid FM. This co-morbidity has implications for the management and treatment of these conditions. Consequently, the study presented in *Chapter Four* further explores the application of the simple body outline specifically to highlight its clinical utility in identifying the presence of FM. The drawings on the simple body outline were compared to clinical diagnostic methods for identifying FM. The results from this study provide evidence that the use of the simple body outline can differentiate between these two conditions. *Chapter Five* reports a series of case studies where the simple body outline and other standardized measures were used as outcomes following a course of six sessions of a Complementary Alternative Medicine (CAM) therapy. The results of this study indicated that patients with FM benefited more from CAM than patients with RAFM and patients with RA only. The final chapter in this thesis brings together all of the findings from the previous chapters to provide some overall conclusions regarding the clinical utility of the simple body outline in rheumatologic conditions. Additionally, the strengths and weaknesses of the research programme are addressed along with directions for future research.

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ACKNOWLEDGEMENTS

There are many who helped me along the way to achieving my PhD, many to whom I owe a debt of gratitude. It is a great pleasure to now thank everyone who helped me to complete my thesis successfully, from those who aided with the organisation and execution of the work itself to those who provided important emotional support, encouragement and friendship. I would like to thank them for their patience with my inability to attend so many social occasions during the years of this research due to my also living with M.E.

First and foremost on this list are my parents Norman and Mafona Kirkham to whom I owe my deepest gratitude. Without their practical and continual support it would not have been possible for me to even consider attempting this work. Their faith in me and my work gave me the strength I needed when the work required seemed daunting. I would also like to thank the rest of my close family – Uncle John, my brother Huw, his wife Emma and their children Morgan, Harry and Imogen.

Sincere thanks to Huw Kirkham whose skills as an editor/proof reader was of great assistance during the many revisions and early drafts of this thesis. Most of all I would like to thank him for his continual encouragement and unwavering belief in me and my work.

I am truly indebted to my fiancé Thom Gilligan for his unending patience, assistance and computer expertise in helping me to bring together the culmination of my years of research in the professional format presented here.

Special thanks to Bangor University who in conjunction with the European Social Fund (ESF Objective 1 West Wales and the Valleys Programme) provided the main funding for this project alongside the contribution given by the Reverend Barbara Occleshaw (owner of Cennin Herbs). I would like to say thank you to Sal Roberts who brought this opportunity for PhD funding to my attention and for her friendship over the past years.

Acknowledgement and sincere gratitude goes to SSHES (School of Sports, Health and Exercise Science). I was helped by Nigel Gleeson PhD who originally agreed to be my supervisor for this work, prior to his move from Bangor University. Particular thanks to Rheumatologist Jeremy G Jones MD, FRACP, FAFRM for agreeing to be my supervisor at short notice. I am sincerely grateful for his knowledge of fibromyalgia, and for his early support, encouragement and belief in my work. I appreciate Sue Walsh PhD for agreeing to be my secondary supervisor - her advice in the beginning was very reassuring. David Markland PhD, Dr. Clinical Psychology, replaced Sue Walsh as my secondary supervisor following her early retirement. His patience, support and assurances were very important in the later stages of the work. I thank Professor Lew Hardy and Andrew Lemmey PhD, my two thesis chairs.

Gratitude and a special thank you also goes to Angela Gliddon M Phil, MA for the many hours she spent independently assessing the pain drawings in this research and for the interest she showed in the work during the hours we spent identifying and discussing patterns and themes in the drawings.

To my good friend and fellow PhD-candidate-traveller Bryan (now Dr Bennett) for his invaluable input and support throughout the times of stress and frustration this journey entailed for us both. Thank goodness we managed to keep a sense of humour and perspective (most of the time!).

A special heartfelt gratitude goes to Pat Thomas for being a very efficient secretary of the department at the beginning of my journey. She so often went beyond the call of duty in helping me and others. I am truly grateful for the support she gave and glad to still know her as a good friend.

For assistance in recruiting volunteers for the studies, I would like to thank Dr. Jeremy Jones, Catherine (Cath) Jones RGN, Anne Breslin RGN and the nursing staff at the rheumatology departments of Ysbyty Gwynedd and Llandudno hospital. I thank Rossella Stoicescu, PhD (North West Wales NHS) for her time and guidance on the completion of Ethics approval for these research studies.

A very warm thank you to my friends who have offered support and encouragement along the way, in particular: Pat Antares, Ailsa Bannister, Lina Conlan, Margaret Jones, Eiko Klimant MD, Hazel Lee, Delyth McRae, Sandra Makin, Damian Nola, Juli Rogers and Dawn Wafer.

A sincere thank you goes to the patients who participated in these studies, for their willingness and openness in sharing their experience of living with chronic pain. This work is dedicated to all the participants and all fibromyalgia sufferers who have to live with this vastly misunderstood, disabling condition.

My list of thanks would not be complete without a mention to my two most faithful companions throughout this time, my two poodles (Mr) Thomas and (Miss) Tula, always there to uplift and comfort me – priceless!!

My ability to live the last 20 years with M.E. and to successfully complete an MA degree in Counselling and Therapy and now achieve a PhD would not have been possible without the all-encompassing and fully unconditional support of a long list of Angels, Archangels, Masters and Spirit Guides. The science of today does not yet want to recognise the importance of their hands in our world, but the science of tomorrow, required now to rescue our planet from the hand of mankind, will be rooted in communication with them. They have already accepted my gratitude even before I thanked them.

CHAPTER ONE

GENERAL INTRODUCTION

GENERAL INTRODUCTION

The simple body outline is a rudimentary anatomical drawing used by rheumatologists to record the location and nature of pain when treating classic arthritis and rheumatism (Margoles, 1983). The drawings are mostly completed by the medical professional, not by the patient. This work is about the use of pain drawings in the clinical assessment of the rheumatologic conditions of osteoarthritis (OA), fibromyalgia (FM) rheumatoid arthritis (RA) with a specific interest in FM. As will be shown in the studies presented in subsequent chapters of this thesis, additional information about each patient's pain became available by having patients personally participate in drawing on the simple body outline as a representation of their personal, subjective experience of pain. The participants of these studies are all women; because, although men indeed suffer from FM, the syndrome occurs significantly more in women (Yunus, 2001). The prevalence of FM in the United States is 2% with a higher rate in women (3.4%) than in men (0.5%) (Wolfe, Ross, Anderson, Russell, Hebert, 1995; Clauw, 2008).

History of Fibromyalgia (FM)

Fibromyalgia (FM), also known as fibromyalgia syndrome, and fibrositis, is a common form of non-articular rheumatism associated with chronic generalized musculoskeletal pain, fatigue and non-restorative sleep (Wolfe, 1994). Prior to the syndrome being given the nomenclature FM, patients with its distinctive symptoms were often diagnosed as having 'muscular rheumatism' or 'soft tissue rheumatism'.

FM is not a new syndrome, and it has had a long and troubled journey to recognition. Descriptions of conditions with similar characteristics date back to 1843 when Frioriep and Lawrence attempted to characterize it in their work 'On the Therapeutic Application of Electromagnetism in the treatment of Rheumatic and Paralytic Affections' (Frioriep, Lawrence, 1850). FM has since undergone a 'conceptual evolution' (Bennett,1981) and is now officially classified and accepted as a chronic condition by the medical establishment (Wolfe, Smythe, Yunus, Bennett, Bombardier, Goldenberg et al 1990).

FM has similar characteristics to myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) (Clauw, 1995; Jason, Taylor, Kennedy, 2000). The conditions share an array of identical symptoms ranging from fatigue, impaired cognitive and memory functions, musculoskeletal pain, headaches, sleep disturbance and digestive disorders. They have causative and potentiating factors that are remarkably similar (Yunus 1989A; Luc, Maclean, Moldofsky 1991; Goldenberg, 1993). However, the exact aetiology and pathogenesis of the conditions are still unknown (White, Harth, 2001).

In 1869, perhaps facing what is now called FM, neurologist George Beard identified a significant correlation between modern social organization and nervous illness and referred to a condition believed to be caused by the environment as 'American nervousness'. It was a disease more common amongst the educated than the unskilled which caused the patient to experience severe fatigue. Beard believed that the malady was the diagnostic predecessor of fibrositis and FM. He claimed that it was caused by "the sufferer's commitments in life", and that its onset was the result of the nervous system being taxed beyond its capacity. He believed that the condition was precipitated by stress factors such as emotional upsets, bad experiences or too much work. He later referred to this condition as 'neurasthenia', for which the recommended treatment was rest in bed - or hospital if necessary - nourishing food, general "tender loving care" from relatives, and consideration from employers and co-workers. In fact some medical historians consider neurasthenia to be the diagnostic predecessor of chronic fatigue syndrome (CFS). "When we come to study the symptoms of neurasthenia, we find that they are essentially those of chronic fatigue syndrome" (Musser, 1912). CFS is a condition with symptoms and characteristics that overlap with those of FM (Jason, Taylor, Kennedy, 2000; Winfield, 2007).

In 1904 pathologist Ralph Stockman used the term 'fibrositis' to describe inflammatory changes in the 'fibrous intra-muscular septa'. The failure of subsequent studies to reproduce Stockman's findings led to the term being considered inaccurate; but later in the same year Sir William Gowers introduced the term 'fibrositis' to describe the inflammation of fibrous tissue in his description of lower back pain (Gowers, 1904). A few years later, Osler emphasized "it is by no means certain that the muscular tissues are the seat of the disease" (Osler, 1909). In subsequent years similar ailments were named such as psychogenic rheumatism, psychosomatic rheumatism and muscular rheumatism. These conditions mystified physicians for years and a simple and workable diagnostic explanation for the wide range of symptoms proved elusive. The most common symptoms were fatigue, stiffness, aches and pains and disturbed sleep patterns.

In the interim numerous studies were conducted; the investigations carried out by Lewis and Kellgren during the 1930's being amongst the most influential. Their work provided an experimentally reproducible method to study the phenomena of referred pain and musculoskeletal tenderness, which led to a hypothesis on the nature of various conditions with similar symptoms to fibrositis (Kellgren, 1938; Lewis and Kellgren, 1939). The term 'fibrositis' was first introduced by Hench in 1976 to describe a condition where "muscle as well as ligamentous and tendonous connective tissues are usually subjectively involved" (Hench, 1976). It eventually became used mainly to denote the more specific syndrome of soft tissue rheumatism which has a "characteristic diffuse musculoskeletal pain associated with multiple areas of localized tenderness" (Smythe 1989; Smythe, Moldofsky, 1978). The definition has also been the basis of several objective studies on the pathogenesis of fibrositis. (Moldofsky 1975; Moldofsky, Scarisbrick 1976; Moldofsky and Lue 1980; Moldofsky, 1989; Yunus, Masi, Calabro, 1981; Russell, Vipraio, Morgan, Bowden, 1986) and has become "...synonymous with idiopathic local or diffuse musculoskeletal pain of any type" (Campbell, Clark, Tindall, 1983; Wolfe, Cathay, Kleinheksel, 1984; Wolfe, Cathay, 1985).

It was the work and studies of Smythe and Moldofsky that finally determined the aetiology of fibrositis (Moldofsky et al 1975; 1976). The work reported in their seminal paper 'Two contributions to understanding of the fibrositis syndrome' determined the most aetiologically significant symptoms in fibrositis patients to be the presence of tender points, which upon palpation are extremely sore. However, biopsies of these locations consistently failed to reveal pathology (Smythe, Moldofsky, 1978).

Later, Smythe determined that the position of the tender points appeared to be the same in all FM patients and, according to Smythe, study of the tender points (TP) was essential in uncovering the cause of FM. He wrote "because the points are localized, prospectively predictable in location, and largely unknown to the patient, they rule out exaggeration operating at the psychological level" (Smythe, 1989). The ongoing efforts of Smythe to identify the diagnostic criteria on tender points generated revived interest in the long known, but generally rejected, syndrome of fibrositis, resulting in the publication of over sixty research papers and consequently an increasing clinical acceptance of the syndrome, which was eventually renamed as fibromyalgia (Ablin, Clauw, 2009). Dr Muhammad Yunus furthered the understanding of fibromyalgia by proposing the need for a unified classification system as well as the first diagnostic criteria (Yunus, 1984). Later studies were also pivotal in the categorizing of symptoms and tender points (Wolfe, Hawley, Cathey, 1985; Bennett, 1989; Yunus, 1989A; Yunus, 1989B).

In 1986 the American College of Rheumatology (ACR) sponsored a landmark study that identified criteria with which to better study patients displaying the symptoms of FM. This resulted in the formation of today's accepted criteria for the classification and diagnosis of fibromyalgia which was finally established and published in 1990 by the American College of Rheumatology (Wolfe, Smythe, Yunus, Bennett, Bombardier, Goldenberg et al 1990). The ACR Criteria was based on a blinded, multi-centre study of 558 age and sex matched patients: 293 patients with fibromyalgia and 265 control patients. The study investigated eleven symptom variables such as sleep disturbance and frequent headaches; and modulating factors such as stress and weather changes.

There were two critical findings: 97.6% of the FM patients had widespread pain in comparison to 69.1% of the control group; and 88.4% of FM patients suffered widespread pain in combination with pain, upon digital palpation, in at least 11 of 18 tender points defined in the ACR Criteria. Other findings were that 76% of the patients suffered morning sickness; 78% reported being fatigued; and 76% suffered from 'unrefreshing sleep'. However even though these symptoms are suggestive of FM they are common and non-specific and only 56% of patients were found to suffer from all three. Therefore the diagnosis of fibromyalgia relies heavily on the history of widespread pain (98%) and finding of discreet 'tender points' on physical examination.

In a review a decade later, Goldenberg discussed the diagnosis of FM, psychiatric and central nervous system factors, therapy and outcome, compensation and disability. He stated "It is important to recognize the social factors that distinguish patients with FM from persons in the community who meet criteria for the syndrome but who do not seek medical care. Such factors may be among the most important in long-term treatment" (Goldenberg, 1999).

Despite substantial interest and investigation, FM continued to provoke and cause controversy (Goldenberg, 1995). There is a considerable degree of overlap between many of the symptoms of FM, ME and CFS (Wolfe, 1997; Moldofsky, MacFarlane, 2005; Yunus, 2007; Yunus 2008); and many people who are diagnosed by rheumatologists as having FM might also receive a diagnosis of ME or CFS from a different specialist (Aaron, Buchwald, 2001). Furthermore, in recent years the importance of tender points as the major criteria in the diagnosis of FM has increasingly been questioned (White, Harth, Speechley, Ostbye, 2000; Wilke, 2009) with a new criteria now being proposed by Dr Frederick Wolfe and his colleagues (Wolfe, Clauw, Fitzcharles, Goldenberg, Katz, Mease et al 2010).

Today FM is typically recognized by primary care physicians by whom the condition is diagnosed and treated, to the best of their ability, before being referred to specialists (Ablin, Clauw, 2009). Indeed it is because of the consistently growing frequency with which FM is being encountered in clinical practice (Branco, Bannwarth, Failde, Carbonell, Blotman, Spaeth, 2009) that there is much more time being given to research into this complex and illusive syndrome (Crofford, Clauw, 2002).

Overview of Fibromyalgia (FM)

FM is a chronic condition characterized by widespread pain and a reduced pain threshold with hyperalgesia and allodynia. Symptoms are sporadic and diverse. Associated features include fatigue, depression, anxiety, sleep disturbances, headache, variable bowel habits, migraine, abdominal pain, and urinary frequency (Carville, Arendt-Nielsen, Bliddal Blotman, Branco, Buskilla, 2008). Although the pathogenesis of FM is unknown, it shares clinical features with irritable bowel syndrome (IBS) and chronic fatigue syndrome (CFS) (Abeles, Solitar, Pillinger, Abeles, 2008). Its occurrence increases with age (Wolfe, Ross, Anderson, Russell, Hebert, 1995; Lindell, Bergman, Peterson, Jacobseon, Herrstrom, 2000; Abeles, Solitar, Pillinger, Abeles, 2008). The condition was formalized by the ACR

(Wolfe et al 1990). However, to date its relationship to true rheumatologic conditions has not become more clearly defined, and it remains a mysterious syndrome about which there is still controversy (Wolfe, 1994; Wolfe, 1997: Wolfe, 2000; McBeth, Chiu, Silman, Ray, Morriss, Dickens et al, 2005; Winfield, 2007; Wolfe, Michaud, 2009; Buskila, 2009).

How Is Fibromyalgia (FM) diagnosed?

The modern diagnosis of FM typically incorporates a physical examination by the doctor to determine the status of known 'tender points'; and the completion of a questionnaire to determine 'subjective' information about the patient's pain (Wolfe et al 1990). Currently there are no laboratory tests available for diagnosing fibromyalgia. Routine laboratory tests for osteoarthritis or rheumatism do not detect the widespread pain of FM. When light pressure is applied to the surface of the muscles throughout the body, patients with FM find this painful, especially at the tender points (TP's) used for diagnosis. Doctors must rely on patient histories, self-reported symptoms, a physical examination and an accurate manual tender point examination. Proper implementation of the examination determines the pain sensitivity at a multiple of tender points at characteristic locations. The classic examination to determine FM is based on the standardized American College of Rheumatology (ACR) Criteria (Wolfe et al, 1990).

American College of Rheumatology (ACR) Fibromyalgia (FM) Classification Criteria (1990)

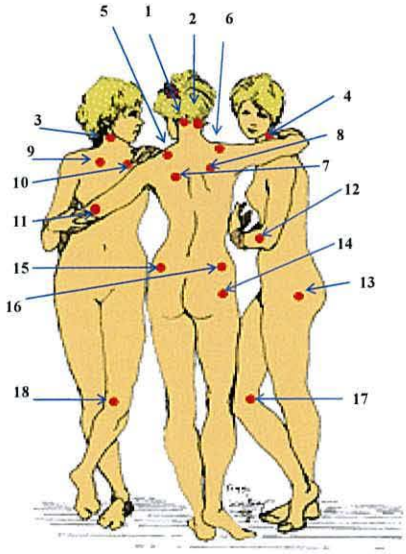
While many chronic pain syndromes display symptoms that overlap with FM, the 1990 American College of Rheumatology (ACR) multi-centre criteria study consisted of interviews and examinations performed by trained, blinded assessors. In total, 558 patients matched for age and sex were evaluated, 293 with primary FM and 265 classified as controls. Control patients for the group with primary FM were limited to patients with disorders that could be confused with primary FM such as: neck pain syndrome, low back pain, local tendonitis, trauma-related pain syndromes, rheumatoid arthritis, lupus, osteoarthritis of the knee or hand, and other painful disorders. The control patients all had some symptoms that mimic FM; however, the criteria performed equally well for patients with and for patients without concomitant rheumatic conditions, and the trained examiners/assessors identified the primary FM patients with 88% accuracy. A combination of widespread pain and mild or greater tenderness in greater than or equal to 11 of 18 tender point sites yielded a sensitivity of 88.4% and a specificity of 81.1% in this patient group (Wolfe et al, 1990).

The then newly proposed ACR criteria for the classification of FM were:

- Chronic, widespread, musculoskeletal pain lasting longer than three months in all four quadrants of the body.
- Axial skeletal pain in the cervical spine, anterior chest, thoracic spine, or low back.
- The above criteria in combination with tenderness at 11 or more of the 18 specific tender point sites.

The finger pressure that must be applied to the tender point areas during a palpation exam' is roughly equivalent to the amount of pressure that causes the finger nail bed to blanch or start to become white (approximately four kilograms of pressure), and the patient must indicate that the tender point locations are painful. The 18 sites used for the FM diagnosis are clustered around the neck, shoulder, chest, hip, knee, and elbow regions (Figure 1.1). Over 75 other tender points have been found to exist, but are not used for diagnostic purposes.

Figure 1.1 The American College of Rheumatology (ACR) Tender Points for Fibromyalgia (FM)



Although the ACR FM diagnosis focuses on the tender point count, a consensus of 35 FM experts published a report in 1996 claiming that a person does not need to have the required 11 tender points to be diagnosed and treated for FM (Wolfe, Hawley, Wilson, 1996). The ACR criterion was created for research purposes and many people may still have FM whilst having less than 11 of the required tender points as long as they have widespread pain and many of the commonly associated symptoms.

The ACR Criteria recommends the diagnosis of FM based on the history of a patient's symptoms, and the examination of the eighteen areas of the tender points (TP's). The three principal symptoms of FM are pain, sleep disturbance and fatigue. The diagnostic criteria for FM do not require the simultaneous presence of these three symptoms. Wolfe et al reported only 56% of patients had all three symptoms, and 81%

had two out of three (Wolfe et al, 1990). Other symptoms include: cognitive and memory dysfunction; irritable bowel syndrome; headaches (tension and migraine); numb, tingling or burning feelings (especially in hands and feet); feeling 'spaced out'; muscle weakness; intolerance of bright light; intolerance of alcohol; depression; anxiety; mood swings; sinus and other allergies; weight change; dry eyes and mouth; cold hands and feet; irritable bladder; heart palpitations and chest pain. Unexplained rashes are less common but are reportedly seen to be more common in FM patients than in the control groups. The physician often makes the diagnosis after reviewing the patient's medical history and checking for chronic widespread pain according to the ACR Criteria where pain has persisted for over three months (Wolfe et al, 1990).

Limitations of the ACR Criteria for diagnosis of Fibromyalgia (FM)

Since there were no reliable diagnostic laboratory tests for measuring and diagnosing FM, the ACR diagnostic criteria were an important forward step in the clinical understanding and further research in FM. With the ACR diagnostic criteria, researchers and clinicians in different countries could identify and study FM patients using a standardized criteria. As time went on, it did become apparent that the ACR diagnostic method has its own limitations. The tender point assessment for FM tended to suggest to doctors that FM patients may only experience pain in the anatomically localized sites on the body described. Further research shows patients with FM experience sensitive painful reactions to stimuli throughout the body outside those indentified by the ACR diagnostic criteria. The ACR diagnostic criteria were questioned even as soon as 1993 by researchers who studied the pressure pain threshold in pain-free subjects, patients with chronic pain and patients with FM (Granges, Littlejohn, 1993).

It has become evident that the tenderness experienced by patients with FM is not consistent; the extent of the pain varies from day to day and month to month. As a result of this a patient could qualify for the diagnosis of FM by having the pre-requisite eleven or more tender point count on one examination and fall short of the required number at another time. Another important consideration is the tender point examinations performed by medical professionals are subject to human error. When performed incorrectly (at the wrong anatomical point or with an incorrect amount of digital palpation), they yield erroneous results.

Although the ACR diagnostic criteria for FM have become used by rheumatologists around the world and patients with FM are being identified and given opportunities for participation in treatments and therapies of various kinds (Burckhardt, 2002; Arnold, 2006), the ACR Criteria do not easily identify certain important and common symptoms such as fatigue, forgetfulness and episodes of reduced mental clarity, sleep disorders as well as reduced ability to function in normal everyday activities (Wentz, Lindberg, Hallberg, 2004).

Why is diagnosing fibromyalgia (FM) difficult?

There are no abnormalities in blood tests, x-rays or imaging methods which would indicate the presence of FM (Vanhoudenhove, 2003). Initially doctors dismissed problems suffered by FM patients as being psychosomatic (all 'in their heads); or diagnosed those patients were suffering a form of depression or hypochondriasis (Asbring, Narvanen, (2002). However, many studies and psychological tests have since shown these impressions to be unfounded and by today FM is recognised as a condition that needs an accurate diagnosis and appropriate treatment (Chakrabarty, Zoorab, 2007). It is accepted that laboratory tests are not useful by themselves for diagnosing FM and that the diagnosis of FM to a large extent should be based on a doctor-patient discussion of the symptoms present (Rothman, Wagner, 2003). This discussion should address what the patient feels and their response to the tender point examination.

Nevertheless, since FM may be co-morbid with other rheumatologic diseases, such as arthritis, then classic laboratory tests may be useful, but mainly in identifying the co-morbid condition, not in identifying FM itself (Coury, Rossat, Tebib, Letroublon, Gagnard, Fantino, 2008). In such a situation the doctor will use some lab testing to rule out other serious medical conditions. For example, he/she may use a complete blood count to measure the haemoglobin, red cells, white cells and platelets which could identify other common blood disorders such as anaemia that cause fatigue. In addition the doctor may ask for tests on the liver and the kidneys to check the blood chemistries, level of cholesterol and other fats in the blood and calcium levels. He/she may also ask for thyroid tests for overactive or underactive thyroid. The red blood cell sedimentation rate provides a rough index of inflammation in the body. In rheumatoid arthritis and other types of arthritis, this test is abnormal, but this abnormality could also be caused by the presence of some infections. In cases of FM and OA, however, it is usually normal.

Another test is one for anti-nuclear antibody (ANA). Like the rheumatoid factor, ANA is an abnormal antibody in the blood. It is commonly found with systemic lupus. Lupus is more common in women, especially younger women, and can cause pain and fatigue. Lupus may also cause internal organ problems, such as kidney disease, heart disease, or problems in the brain.

FM pain fluctuates, which can affect the number of tender points, and the tender point test may not adequately measure symptom severity or the effectiveness of treatments (Katz, Wolfe, Michaud, 2006). They also recognized a gender bias in the tender point test since men may report widespread pain but are not generally as tender as women. It is even hypothesized that this bias of sensitivity seen in women has created an over-diagnosis of FM in women with an under-diagnosis of FM in men. Katz and colleagues also believe there is confusion regarding the tender point test and that many primary care doctors either are not checking tender points after an initial diagnosis or they are checking them incorrectly. A proposal for new criteria has recently been presented in *Arthritis Care and Research*, to standardize symptom based diagnosis so that the process used by doctors is more consistent (Wolfe, 2010). This new proposal by Wolfe along with new patient-centered approaches such as the pain drawing methods studied in this thesis create a new body of work that may change the way rheumatologists look at FM and its treatment.

Treatments for Fibromyalgia (FM)

FM is a complicated syndrome with many symptoms and there are no treatments which appear to treat the cause of FM (Rossy, Buckelew, Hagglund, McIntosh, 1999; Sarzi-Puttini, Buskila, Carrabba, Doria, Atzeni, 2008); that is as yet unknown (Staud, 2004). Although there are to date three drugs which have been approved for FM, i.e. pregabalin, duloxetine, milnacipran (Clauw, 2010; Häuser, Petzke, Sommer, 2010) in addition to the standard anti-depressants (O'Malley, Balden, Tomkins, Santoro, Kroenke Jackson, 2000). Research in FM continues to attract funding with the number of papers published (concurrent with the ACR Criteria) growing from about 200 in 1990 to nearly 5000 today. The main focus for the treatment of FM is the management and reduction of its symptoms (Richards, Cleare, 2000; Cedraschi, Desmeules, Rapiti, Baumgartner, Cohen, Finckh, 2004). Patients who have enough motivation and who continue to educate themselves on developments in FM research continue to have an expanding repertoire of ways to work with the symptoms of FM beyond drug prescription (Burckhardt, Bjelle, 1994), and in many cases have experienced significant improvements in their symptoms as well as in their general quality of life (Nicassio, Radojevic, Weisman, Schuman, Kim, Schoenfeld-Smith, 1997).

Available treatment options, such as drugs and surgery, provided to patients with classic rheumatologic diseases, for example osteoarthritis (OA) and rheumatoid arthritis (RA) have not been successful in the search for a cure or solution for FM (Staud, 2004; Staud, 2006). There are no surgical solutions; and drugs prescribed to some FM patients mainly treat symptoms such as general pain, depression, or insomnia (Clauw, 2010; Häuser, Petzke, Sommer, 2010).

Nevertheless, there have been many studies involving the psychological, social and emotional aspects of patients' suffering and the nature of their pain (Mehl, 1988; Rosenblum, 1997; Epstein, Kay, Clauw, Heaton, Klein, Krupp, 1999; Wentz, Lindberg, Hallberg, 2004; Meeus, Jijs, 2007; Wachholz, Pearce, Koenig, 2007). Furthermore, a strong FM patient advocacy movement, facilitated by websites and support groups, has helped to raise sympathetic public awareness. There is also a clearer understanding and better acceptance of the disabilities associated with FM (White, Speechley, Harth, Ostbye, 1999A; Sansone, Levengood, Sellborn, 2004). As a result, many more people are now diagnosed with FM, which leads to more usage of healthcare resources, raising the cost of care (White, Speechley, Harth, Ostbye, 1999B; Hughes, Martinez, Myon, Taieb, Wessely, 2006; Sicras-Mainar, Rejas, Navarro, Blanca, Morcillo, Larios, 2009). Insurance coverage of FM treatment costs and legal claims for compensation for injuries resulting in FM symptoms have increased (Wolfe, 1996; Wolfe, Anderson, Harkness, Bennett, Caro, Goldenberg, 1997).

Appropriate diet and regularity of food intake (Arranz, Canela, Rafecas, 2010), good exercise, counselling and psychotherapy are common approaches (Abeles, Solitar, Pillinger, Abeles, 2008), but successful treatment depends heavily on the individual. Psychological and emotional issues are primary in FM patients, although sometimes hidden by the patient or overlooked by the medical profession (Walker, Keegan, Gardner, Sullivan, Bernstein, Katon, 1997; Wentz, Lindberg, Hallberg, 2004). Many FM patients learn 'coping strategies' to overcome the negative effects of the symptoms whereas other FM sufferers do not look beyond the conventional medical system, and drug-based treatment for inflammatory pain and depression. FM sufferers may first present themselves to general practitioners, many of whom prescribe medication, before referral to rheumatologists or pain clinics, not all of whom recognize FM as distinctively different from OA or RA (Wolfe, Michaud, 2009). Early intervention and diagnosis of FM may allow various forms of symptom management and coping strategies to be learned in order to slow progression, or even, in some cases, to reverse FM progression. The use of non-invasive, patient-based diagnosis of early FM through analysis of emotional and subjective pain depicted on a simple body outline is studied in this thesis.

Recently, a multidisciplinary task force which included nineteen experts from eleven European countries - reviewed the literature and presented nine recommendations for the management of FM (Carville, Arendt-Nielsen, Bliddal et al, 2008). These included tailored exercise; cognitive-behavioural therapy (CBT); hydrotherapy; relaxation; rehabilitation; and pharmacotherapy with tricyclic antidepressants, SNRIs, and the alpha-2-beta ligands pregabalin and gabapentin. Reviews of pharmacologic and nonpharmacologic treatments (Clauw, 2008; Abeles, Solitar, Pillinger, Abeles, 2008) have reported tricyclic and SNRI antidepressants to be beneficial. However, until recently when both duloxetine and milnacipran were added, pregabalin was the only US Food and Drug Administration (FDA) approved treatment for FM in the United States (Clauw, 2010; Häuser, Petzke, Sommer, 2010). They also concluded that a multidisciplinary approach was most useful because no single agent or class of drugs is broadly efficacious, although the hypothesis of a multidisciplinary approach has yet to be fully tested and proven.

Dr. Robert Bennett, one of the original researchers interested in FM, has recently summarized the extent of hope and confusion in the field of FM, persisting after his thirty-year career. The entire article is found in appendix D. Bennett ends his review by pointing out that the growing understanding of the physiological roots of chronic pain is that the nervous system is not 'hard wired' and that sensation can be 'wound up', or progressively increased over time. He also highlights that the mechanism called central sensitization (Yunus, 2007) is being studied at the forefront of the field.

According to Yunus Central Sensitivity Syndromes (CSS) may share a common aetiology that involves hyperexcitement of the central neurons. He proposes that the following conditions may be members of a CSS family: Fibromyalgia (FM); Chronic Fatigue Syndrome (CFS); Irritable Bowel Syndrome (IBS); Tension-type Headache (T-T headache); Temporomandibular Disorders (TMD); Myofascial Pain Syndrome (MPS); Regional Soft-tissue Pain Syndrome (RSTPS); Periodic Limb Movements in Sleep (PLMS); Multiple Chemical Sensitivity (MCS); Female Urethral Syndrome (FUS); Interstitial Cystitis (IC); Post-traumatic Stress Disorder (PTSD). If the hypothesis of CSS being an umbrella for a large number of pain syndromes is substantiated in the future a more integrated approach, incorporating drugs and complementary/alternative therapies may be possible.

Fibromyalgia (FM) and Complementary and Alternative Medicine (CAM) Therapies

People are most likely to seek CAM therapies for conditions that are chronic and do not have an effective single remedy (Buchbinder, Gingold, Hall, Cohen, 2002; Ernst, 2003). FM meets both of these criteria and FM is more likely to be self-treated with CAM than other rheumatologic diseases, such as OA and RA (Holdcraft, Assefi, Buchwald, 2003; Wahner-Roedler, Elkin, Vincent, Thompson, Oh, Loehrer, 2005). At one tertiary FM treatment program (Wahner-Roedler, Elkin, Vincent, Thompson, Oh, Loehrer, 2005) 98% of participants with FM reported use of at least one CAM therapy during the previous six months. The most frequently used CAM therapy was exercise for a specific medical problem (48% of respondents). The next most frequent therapies were prayer (45%), massage (44%), chiropractic treatment (37%), and vitamin C, vitamin E, magnesium, or vitamin B complex (ranging from 25% to 35%).

Another study (Breuer, Orbach, Elkayam, Berkun, Paran, Mates, Nesher, 2005) found that despite participant perceptions that CAM therapies were less effective than conventional treatment, there was a high rate of CAM utilization. Interestingly this corresponded with participants' using their own funds to pay for 'treating' FM. Participants in rheumatology outpatients clinics used a mean of two CAM treatment modalities, the most popular being acupuncture and homeopathy (41% and 44%, respectively). An older review (Berman, Ezzo, Hadhazy, Swyers, 1999; Berman, Swyers, Ezzo, 2000) found that the most popular CAM therapies for FM were mind-body techniques (biofeedback, hypnosis, and cognitive-behavioral therapy), manipulative therapies (chiropractic and massage therapy), and acupuncture.

According to a survey of ACR members (Berman, Bausell, Lee, 2002) rheumatologists reported knowing enough about an average of ten out of twenty-two listed CAM therapies to be able to discuss them with patients. On average, the surveyed rheumatologists considered that nine of the twenty-two modalities were legitimate, and had actually referred patients for eight of the twenty-two CAM therapies listed. In this study, the most commonly endorsed therapies by medical practitioners were acupuncture, biofeedback, counselling/psychotherapy, trans-cutaneous electrical nerve stimulation (TENS), exercise, and massage. The therapies least endorsed were spiritual healing (meditation and prayer), manipulation, hypnotherapy, energy healing, and homeopathy. Self-use of CAM therapies by medical practitioners, rather than demographic factors, disease condition, or current evidence base, was the strongest predictor of practitioner referral for that CAM therapy.

Medical rehabilitation professionals who were surveyed (Schoenberger, Matheis, Shiflett, Cotter, 2002) specifically about their endorsement of prayer and meditation were more likely to choose meditation than prayer. Again, personal use of the modality by the medical professionals was a strong predictor of likelihood of recommendation to participants in this study. Practitioner age, sex, and other factors did not influence the decision to recommend the CAM modality to participants. As would be expected, CAM practitioners are more likely than other practitioners to recommend CAM modalities (Long, Huntley, Ernst, 2001). When asked about the likelihood of recommending CAM for specific conditions, respondents from different CAM organizations chose seven common conditions most likely to benefit from twelve therapies. These therapies included aromatherapy, Bach flower remedies, Bowen technique, chiropractic, homeopathy, hypnotherapy, magnet therapy, massage, nutrition, reflexology, Reiki, and yoga. The conditions being treated were - in order of the frequency in which they occurred- stress/anxiety, headaches/migraine, back pain, respiratory problems, insomnia, cardiovascular problems, and musculoskeletal problems. The likelihood of participants with FM being referred for CAM therapies would be expected to increase as they see more CAM practitioners.

There have been a number of systematic (Berman, Ezzo, Hadhazy, Swyers, 1999; Sim, Adams, 2007) and general (Holdcraft, Assefi, Buchwald, 2003) reviews of the evidence for the efficacy of CAM therapies for FM. For acupuncture in particular more recent reviews are available on its use as a specific modality for FM. These reviews concur and despite higher-quality studies of acupuncture and electro-acupuncture for FM being available there remains no significant beneficial effect from its use (Mayhew, Ernst, 2007; Martin-Sanchez, Torralba, Diaz-Dominguez, Barriga, Martin, 2009). Therefore caution should be exercised when recommending this modality as stand-alone therapy (Assefi, Sherman, Jacobsen, Goldberg, Smith, Buchwald, 2005) for participants with FM. However, one study reported that acupuncture might be useful as an adjunct to other therapies (Targino, Imamura, Kaziyam, Souza, Hsing, Furlan, 2008). In this study, women with FM were randomly assigned to tricyclic antidepressants and exercise with or without acupuncture. After six months, the acupuncture group showed significant improvement in the number of recorded tender points in their mean pressure pain threshold, and in their quality-of-life measures, with this effect diminishing between one and two years after treatment.

Caution is also recommended for homeopathic treatments (Edwards, Blackburn, Christie, Townsend, David, 2000); anthocyanins (McCarty, Csuka, McCarthy, Trotter, 1994); topical capsaicin (Wahner-Roedler, Thompson, Luedtke, 2008); coenzyme Q, and ginkgo biloba (Lister, 2002). Few well-conducted studies are available for these modalities. They often have inadequate blinding, power, or objective endpoints (De Silva, El-Metwally, Ernst, Lewith, McFarlane, 2010). Indeed, only moderate exercise is fully supported as having a beneficial effect on FM, according to the most recent systematic review and meta-analysis (Sim, Adams, 2002).

The Fibromyalgia (FM) Personality

Vanhoudenhove explored the idea that women with FM and CFS (Chronic Fatigue Syndrome) seemed to have a high commonality in certain personality traits. In general, they observed that FM and CFS women suffer from chronic stress, caused by an overactive lifestyle, tended to have a nearly pathological need for perfectionism, and often exhibited self-sacrificing, care-giving behaviour (Van Houdenhove, Neerinckx, Ohghena, Lysens, Vertommen, 2001A). These women tended to lead busy lives, placing the needs of others before themselves (Van Houdenhove, Neerinckx, Ohghena, Vingerhoets, 2002), and were often driven by very creative abilities in art or design and vivid imaginations. They were also very sensitive to the emotional aspects of social and family situations (Perrot, Winkelmann, Dukes, Xu, Schaefer, Ryan, Chandran, Sadosky, Zlateva, 2010). Although these attributes would seem unrelated to pain, it is possible that the inability to control all outcomes or make all people happy eventually leads some such women down a path of anxiety and eventually depression (VanHoudenhove, Egle, Luyten, 2005). In many cases this seems to be caused by feelings of being trapped in social systems. In other cases, they hold their pain away from society as a form of withdrawal (Nordahl, Stiles, 2007) and eventually move over into the role of defining their personal experience around their unwanted and mysterious pain i.e. non-organic pain not easily identified by diagnostic tests used in standard medicine (Werner, Malterud, 2003).

According to Vanhoudenhove, unresolved emotions and conflicts related to past trauma make a major contribution to the onset and persistence of FM. Trauma can derive from various forms of experience, including physical trauma such as injury, social trauma such as workplace or family environments, psychological trauma such as unresolved emotional issues, as well as sexual trauma related to abuse in childhood or sexual assaults (White, Carette, Harth, Teasell, 2000). Various researchers have also proposed that CFS and FM sufferers can fall into the role of 'victimization', with a higher than average tendency to view themselves as victim (Van Houdenhove, Neerinckx, Lysens, Vertommen, Van Houdenhove, Ohghena, 2001B).

The FM personality appears to also be easily dissatisfied with the simplicity of a medical system which mainly understands pain from the mechanism of injury or inflammation, and which mainly medicates the pain, or relies on the general belief that pain diminishes with time, through tissue healing; or the expectation that chronic pain may eventually be treated by surgery (Nielson, Jensen, 2004; Nishiyama, Urrutia, Walitt, Rodriguez, Bonfill, Alegre, 2008).

This research work uses the pain drawing in a novel way by exploring its potential as a form of complex vs. simple pain expression. By allowing the patient freedom to depict their pain and distress it may be possible to identify patients more likely to be entering into complex chronic pain as found in FM.

Patient Doctor Communication

After the onset of a chronic illness a woman must learn a new language – the language of her body (Simonton, 1984; Simpson, 1997; Siegel, 1990A; Siegel, 1990B) the language of symptoms (Simpson, 1997). With virtually no preparation she must discuss the most detailed aspects of the physical pain she is living with doctors and health care providers. Doctors and patients often describe important symptoms such as pain and fatigue, using very different terms. The differences in language used by the trained practitioner and the lay person, can pose challenges when the patient is trying to describe their symptoms, in particular when attempting to describe difficult or medically unexplained conditions such as FM (Begum, 1999, Thorne, Harris, Mahoney, McGuinness, 2004).

Sometimes the women's descriptions of the type of pain they experience is misunderstood by doctors because patients and health care practitioners describe pain using different "interpretive frameworks and conceptual worlds" (Johansson, Westman, Lindgren, 1999). A significant implication of this miscommunication is that a patient's symptoms may not be taken seriously, or will be delegitimized due to the difference in understanding of pain (Asbring, Narvanen, 2002). In addition since experiences of such pain impact the women in so many important spaces of daily life, lack of recognition of its significance and/ or a misjudgment of its magnitude may result in either incorrect or no actions being taken in terms of treatment regimens and referrals (Soderberg, Lundman, Norberg, 1999). Miscommunications or a lack of common understanding within the space of care provision has implications for woman's lives and their abilities to manage the symptom of pain in key areas of everyday life at home and at work (Werner, Malterud, 2003).

Legitimization is something many chronically ill and disabled women seek within the health care system, particularly those with less well understood diseases such as FM. Illnesses which are controversial or difficult to diagnose can be delegitimized by health care practitioners in two ways: The first is where the symptoms can be treated as being insignificant in that 'we all have aches and pains, they're a fact of life'. The second is where the illness can be viewed as psychosomatic and not physically present (Ware, Sherbourne, 1992). Patients expect to be legitimized by their doctors and health care advisors; they want it to be acknowledged that their symptoms are real and that what they are experiencing is in fact a recognized or legitimized disease or illness (Asbring, Narvanen, 2002).

Art Therapy

The primary interest in using pain drawings to assess FM is based on a diagnostic approach where the patient expresses through drawing imagery related to their experience of pain in order to facilitate a more detailed understanding for the doctor. It is not possible to draw a distinct line between patients drawing for diagnosis purposes and patients' experience of completing the simple body outline having the aspects of a treatment or a therapy. Moreover, the methods developed for this work are asking the patient to be expressive in a way that asks them to access emotional content.

Although this work is not in of itself to be considered art therapy, it is worthwhile to examine the broader field of art therapy briefly.

The mode of action of art therapy is well expressed by Luzzatto (1998) as the "externalization of the mental content of the patient onto visual images". Art therapy is based on the idea that visual image making is an important part of mental functioning. It works on the deep mental, emotional and spiritual effects that illness may have on a patient; helping them to come to terms with major adjustments to their lives (Luzzatto, 2000). For example, women who progressively suffer the symptoms of pain, depression, sleep disturbance associated with chronic fatigue or FM, have typically overtime made major adjustments in their behaviour. A potential role for art therapy is helping the patient and the therapist identify ways to create new behaviours with positive outcomes.

Art therapy enables patients to project their internal worlds, both consciously and unconsciously into visual forms, and allows them to grow on a personal level. In the 1980's a number of art therapists began to work with people with life threatening illnesses and today this approach is being developed in hospitals, hospices and in the community throughout many countries. Although some art therapists have used traditional scientific research methods to measure the effectiveness of art therapy (Rosal 1993; Neale and Rosal, 1993), it is still difficult to quantify the effectiveness of art therapy since the creation and the perception of art is greatly influenced by aesthetic and subjective experience, as well as by culturally based viewpoints on art and its usefulness to therapy or personal growth in healing. This problem has been addressed to some extent by innovative art therapists who have used their creative ingenuity to develop new research paradigms that more accurately convey the art therapy process (Junge, Linesch 1993). Since the late 1980's extensive case studies in North America, the U.K. and Europe have demonstrated the value of art therapy. They have shown its positive effects when treating emotional and psychological disturbances including psychotic illnesses, severe learning difficulties, eating disorders, and alcohol and drug abuse, while providing relief to AIDS victims and patients with Alzheimer's disease and terminal illnesses such as cancer (Reynolds, Nabors, Quinlan, 2006).

Art therapy may be used in crisis intervention and in pain relief, where the effects of even a single session can be dramatic and/or cathartic depending on the exact nature of the situation. Art therapy is in many cases an intimate experience which can be both rewarding and psychologically nourishing for the patient (Appleton, 2001). As well as relieving certain types of pain, art therapy may be used to treat trauma, nausea, headaches, tinnitus, tension, anxiety, anger and fear, feelings of isolation and sense of meaninglessness and boredom (Feen-Calligan, Washington, Moxley, 2008: Gannt, Tinnin, 2008). For example when diagnosed as having cancer a patient's primary concern is his/her body and understanding what is taking place within it and around it. Whilst hospitals offer treatment and, in many cases, a cure for their cancer, it is not just the physical / physiological impact that has to be addressed. In that man is both psyche and soma, the emotional impact of such an illness is inestimable (Junge, Linesch, 1993). Cancer diagnosis reawakens a patient's memories of past events and experiences, and art therapy helps him/her unravel his/her life history and place the events within it in context. Patients diagnosed with terminal illness, for example, could suffer mental and psychological stress or pressure felt as a direct result of reflecting on the inner state of their experience (mental/emotional). This pressure could appear either at the time of the first diagnosis of the disease or when symptoms or illness return. At such times the patient could feel that every aspect of his or her life and lifestyle is threatened. Such feelings cause distress and often lead to deeper self-analysis and reflection. It is in such cases that patients respond to art therapy (Puig, Lee, Goodwin, Sherrard, 2006) to deepen their exploration of mental and emotional patterns and life events that art therapy often proves to be a very therapeutic tool, providing in depth information on emotional thoughts and feelings which previously may not have been accessed or explored (Appleton, 2001). After successful treatment, the need for therapy may diminish quite naturally, as life resumes a new healthier pattern. However, patients who have experienced and benefitted from art therapy, may continue to use its techniques to improve their lives (DePetrillo, Winner, 2005).

The healing influences transmitted by art, literature and music are proven to be of profound help in arousing a patient's capacity for responding to an innate and finer area of perception within themselves (Pizzaro, 2004). They enable him/her to reach a deeper understanding of the direction which their life has taken, and creating positive outcomes for new directions. It can be therapeutically beneficial when used alongside conventional treatments as part of the complete healing process. When art therapy is used in cancer care, it is typically patient led; it is normally the choice of the patient whether or not to participate. Art therapy can address the patient's need to communicate, articulate and share their responses and reactions to the conditions which are imposed on them by their illness. In this respect it is one of the few therapies that invite and encourage the patient to be active rather than passive (Reynolds, Vivat, 2006). Whilst major healing responses in cancer are the result of the actual drug, chemotherapy and surgical treatments, full recovery from cancer usually involves positive changes of emotional and existential or spiritual nature (Puig, Lee, Goodwin, Sherrard, 2006).

Art therapy can be used to relieve pain, whether the cause of pain is physical, mental, emotional or spiritual. During such intervention, art therapy provides an outlet for the patient to express their inner-most emotions and feelings (Luzzatto, 1998; Luzzatto, 2000). Although modern science has typically attempted to separate the physical world - which is objective and collectively observed from the spiritual world - which is subjective and individualized, it should be remembered the traditional social systems of human cultures around the world typically contain a religious teaching or doctrine. In times of modernizing, it is common for people to individually face their religious roots and to compare them to other religions or to contrast them to the materialization of life as seen in most modernizing economies. In many cases women in particular are faced with new roles which contrast with the traditional roles for women and are based on the equalizing effects of modernization on gender roles. When their traditional roles are associated with religious practice, the contrasts and struggles for new meaning can take on a spiritual meaning within each of them individually.

How does the need for spiritual meaning translate into pain, particularly chronic physical pain? Perhaps the more relevant question is related to the ability of the human spirit to use pain and distress signals to alert and inform the emotional and mental capacities of the human being to the behaviours or conditions which are not aligned with the needs of the individualizing human spirit. Many of those suffering from FM symptoms have already experienced a long journey of spiritual inquiry, even if they do not openly discuss it. The understanding that pain and physical distress signals may be an intimate part of personal development (road signs from Spirit) will emerge more in the future. The field of chronic non-organic pain, as exemplified by FM is certainly a fertile ground for these new understandings to emerge.

The methods used in this work to access and assess FM using pain drawings involve asking the patient to focus on the expression or visual depiction of their pain and emotional distress. It is impossible to completely separate the study of these patients as a group (statistical modality) from the individual personal realities expressed in each of them at the time they participated in the study.

An interesting example of the artistic depiction of pain may be found in the paintings of Frida Kahlo (1907-1964). She is known as an intense and emotive artist, who depicted her own pain in dramatic self-portraits. At the age of 18, Frida was in a traffic accident where a streetcar struck the bus that she was riding in. She suffered multiple bone fractures, severe damage to lumbar vertebrae, and had a serious abdominal wound from a metal rod piercing through her body. She was confined for several months in a plaster cast surrounding her torso. From that time on, Frida suffered severe, widespread pain and profound fatigue. She endured generalized pain and exhaustion for the remainder of her life. Over the following years, different diagnoses were offered to explain her chronic pain. Tuberculosis and syphilis were mooted but ruled out later. She received many types of treatments, including medications and long periods of immobilized confinement in metal or plaster casts. She underwent several orthopaedic operations on her spine, but without improvement in her symptoms.

Although her painting skills were mainly self-taught and her artwork has a naturally expressionist and surrealist appeal, it drew the attention of the famous Mexican muralist Diego Rivera, whom she married. In spite of terrible chronic pain Frida was engaged in an open social life, travelled internationally and came to know many of the leading politicians and artists of her time. Not only has her life been documented by her paintings of pain, but also her life has been studied by art therapists as a spontaneous expression of art therapy. In the book 'A Biography of Frida Kahlo' (Herrera, H. F., 1983) the author points out that Frida described her own paintings as "the most frank expression of myself". Her self-portraits are striking and full of passion. Anguish and pain are the common themes in her paintings, with emotions being dramatically expressed. A popular example is the painting, 'The Broken Column' (Figure 1.2).

Figure 1.2

As Herrera observed, Frida's determined impassivity creates an almost unbearable tension. Pain is made vivid by the image of nails driven into her naked body. A gap resembling an earthquake fissure splits her torso. The opened body suggests surgery. Inside her torso, we see a cracked ionic column. The corset's white straps accentuate her beautiful body. Her hips are wrapped in a cloth suggestive of Christian martyrdom. She stares straight ahead with dignity. Tears dot her cheeks; but her features refuse to cry. An immense and barren plain in the background conveys physical and emotional suffering.

Frida lived well before the field of rheumatology defined the diagnosis of FM. It can never really be proven if she would have been diagnosed with FM. However, what is certain is that Frida's self-portraits convey widespread pain and anguish with the emotional overtones that FM patients frequently use to describe their illness. Her anatomically devoted paintings even show pain located close to the conventional FM tender points. Her life story reflects her struggle with chronic pain, chronic fatigue and sleep disorders.

Pain Drawings

Early History of the Pain Drawing

The prototype of the pain drawing is the pain map drawn by the German print-maker, painter and designer, Albrecht Dürer. In the early part of the 16th century, when sending for a physician to visit him he illustrated his own pain by drawing it onto his self-portrait (see Figure 1.3). Dürer drew his finger pointing to the part of his body where he felt discomfort/pain, and highlighted it using the colour yellow. On it he wrote: "Do wo der gelb fleck is und mit dem finger drawff dewt do is mir we". (*There where the yellow spot is located, and where I point my finger, there it hurts*; Schott, 2004).

Fig 1.3 The Sick Dürer, by Albrecht Dürer (1471-1528)

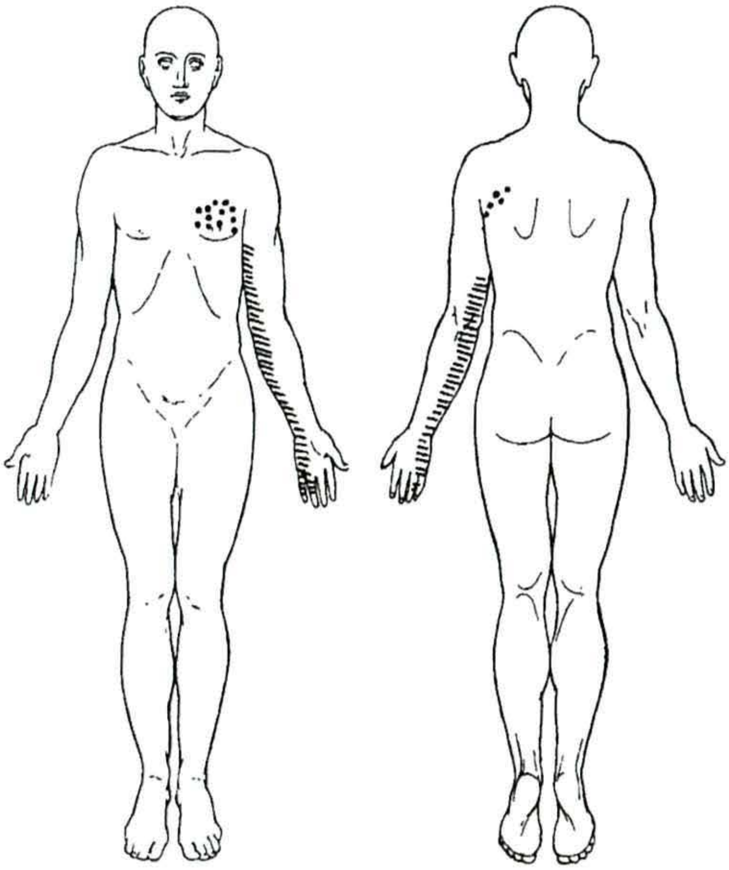
Medical literature has many other examples of drawings used in the observation of patients. One early example is the highlighting of tender areas on a body-diagram/outline to indicate pain suffered because of acute pleurisy. This was drawn by Sir Henry Head when observing a patient. Sir Henry was an English neurologist who conducted pioneering work in the somatosensory system and sensory nerves which was published nearly a century ago (Head, 1922).

The pain drawing templates used today originate from the work of Harold Palmer who in 1949 introduced the use of pain drawings when observing his patients. Palmer used their pain drawings to distinguish between organic and functional pain (Palmer, 1949). He provided his patients with colouring pens and an outline diagram of the human body. The patients were asked to identify the areas where they experienced pain using the pens to mark corresponding areas on the outline diagram of the human body. Palmer was interested in the correlation between the resulting pain drawings, and the anatomical locations highlighted, in relation to what would be expected in organic disease.

Palmer found that in most instances patients drew simple features such as lines or symbols that primarily identified the locations of organic pain. He postulated that in some cases the extent and distribution of pain marked by patients on the pain body outline could "identify a tendency to a good deal of psychological content" (Palmer, 1949). However, despite this speculation on the reason for extensively marked drawings, Palmer, in a later article, cautioned physicians "not to place too much emphasis on the value of the pain drawings" in the identification of a psychological underlay; but rather to use them as ancillary tools in patient care (Palmer, 1960). Palmer's work was important in highlighting the potential of the pain drawing as a tool that was simple for the patient to use to describe complex pain experiences.

Another example of a pain drawings being used by an observer is found in the work of Whitty and Willison (Figure 1.4). They used different symbols in one drawing to depict a variety of symptoms caused by the presence of two conditions in one patient. (Whitty and Willison, 1958). They used hatched markings to represent referred pain from effort-induced angina, and dots to represent the occurrence of persistent post-herpetic neuralgia.

Figure 1.4 - Pain drawing by Whitty and Willison (1958)



In 1975 Melzack used the pain drawing in conjunction with the adjective questionnaire. This consists primarily of three major classes of word descriptors: sensory, affective and evaluative. It is used by patients to specify a subjective pain experience. It also contains an intensity scale and other measures to determine the properties of pain experience. It provides quantitative information that can be treated statistically, and is also sufficiently sensitive to detect differences between various methods of relieving pain.

The pain drawing and the adjective questionnaire are both part of what is known as 'The McGill Questionnaire' (Melzack, 1975). Since Melzack, there has been interest in the use of the pain drawing as a screening tool for the quantification of the physiological and psychological experience of pain.

Concurrent to Melzack's work, research by Pawl put it "patient markings that indicate multiple and diffuse areas of pain suggest a good deal of psychological content, whilst distinct line drawings suggest mainly organic problem" (Pawl, 1973). A study by Margolis, Tait and Krause suggested that visual representations of pain distribution could differentiate somatic and sympathetic nerve problems thus possibly help the clinicians decide on rational forms of treatment (Margolis, Tait, Krause, 1986). However, the question of psychological involvement in the pain experience, and the possibility of using pain drawings as a means of identification has caused controversy and evolved into a major area of research. Indeed, it is an ongoing theme in the consideration of the use of pain drawings for this purpose.

Pain drawings as a measure of physiological and psychological pain

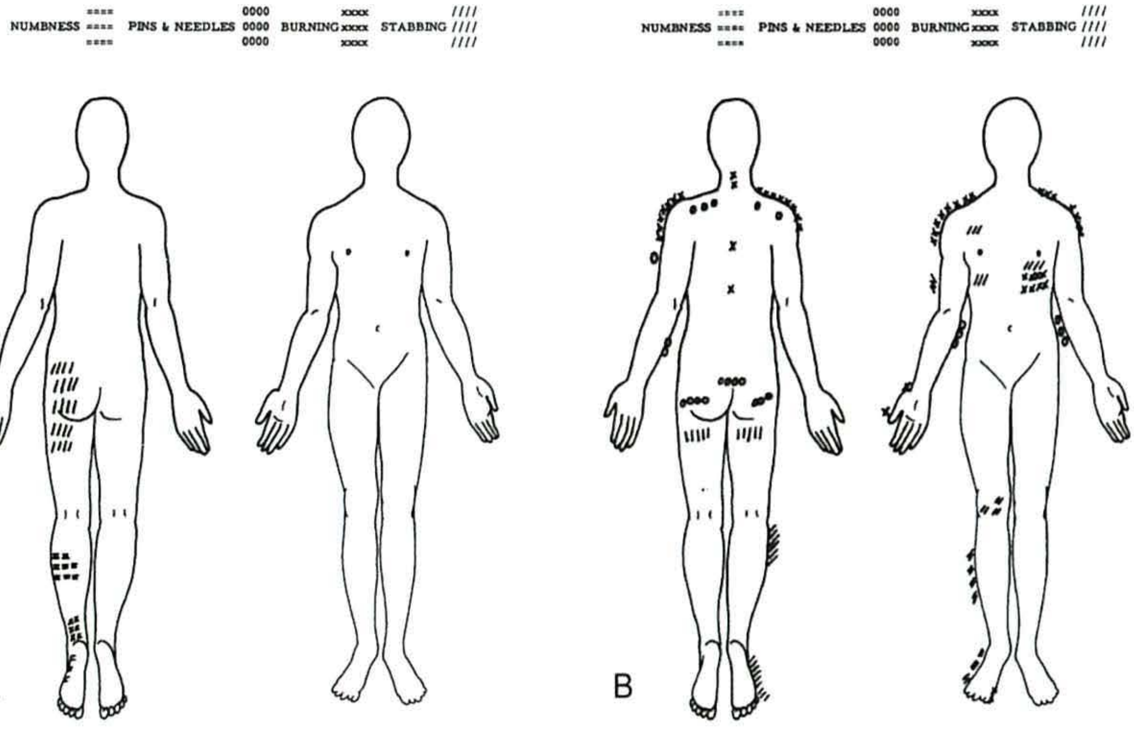
Many studies have investigated the standard pain drawing as a possible diagnostic measure of the severity of physical pain - as opposed to psychological pain - comparing them to other measures of mental health, such as the Minnesota Multiphasic Personality Inventory (MMPI) (McKinley, Hathaway, 1940).

Ransford and colleagues first proposed the use of pain drawings to assess back pain and sciatica. Their study evaluated the possibility of using the pain drawings of patient's with low-back pain as a screening test to determine whether further psychological evaluation was necessary (Ransford, Cairns, Mooney, 1976). The study was based on the correlation of the distribution of pain drawn on pain drawings with hypochondriasis and hysteria scales on the MMPI. The results reported showed that the pain drawing predicted a high or low hypochondriasis or hysteria in 97 of 109 (89%) patients. This suggested that pain drawings could be used to predict psychological overlay by their organic or nonorganic features.

According to Ransford organic pain is represented by clearly defined areas that are logical results of potential pathology; whereas non-organic pain is characterized by diffuse, global, poorly defined patterns that are not a logical result of pathology. To identify a pain drawing as being non-organic the observer would consider the reasonableness of the anatomic distribution of the markings in addition to considering whether they reflect magnification of pain; i.e. the presence of indicators indicating 'I particularly hurt here!' and other information signaling 'Look how bad I am!'

From the results of their study they proposed a scoring system that entailed awarding points for diffuse, non-anatomical (nonorganic) features in order to assist the interpretation and quantification of pain drawing. Additionally penalty points were awarded for nonorganic drawings i.e. drawings with poor localization features indicating magnification or expansion of pain and the highlighting additional body areas or the whole body to indicate 'how bad I am" (Fig 1.5). In this scoring system two or more penalty points on the pain drawing predicted a high hypochondrias or hysteria scores on the MMPI (Ransford et al, 1976).

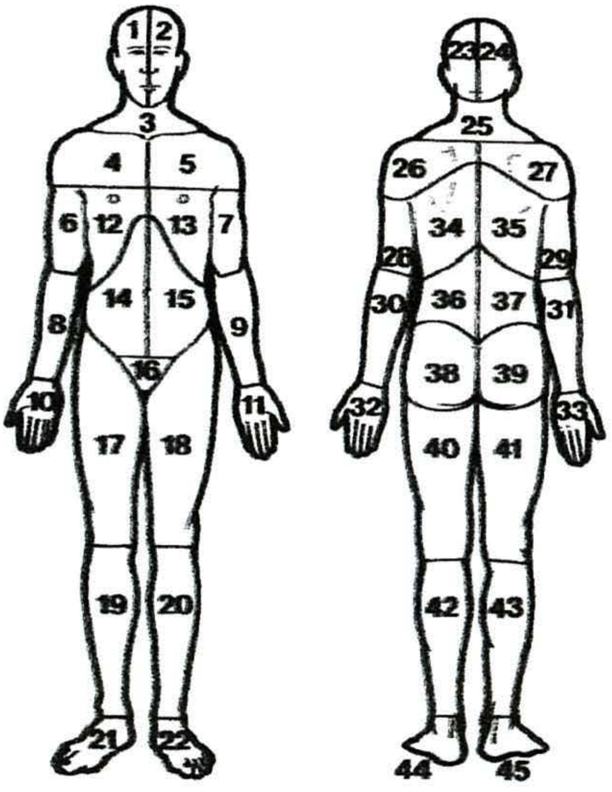
Fig 1.5 Ransford's scoring of (A) Organic pain (B) Nonorganic pain



Margoles also noted the unusual distributions found in chronic pain syndromes, and suggested that using pain drawings in a "diagnostic battery can reduce the likelihood of mistakenly giving a patient a psychiatric diagnosis" (Margoles, 1983). Von Baeyer and his colleagues were amongst the first to explore Ranford's methodology and to question the use of pain drawings as a screening technique for psychological involvement in low back pain complaints (Von Baeyer, Bergstrom, Brodwin, Brodwin, 1983). In their study the pain drawings of 212 patients; over half of the patients meeting the MMPI criteria for psychological involvement were incorrectly identified as normal, as the ratings did not discriminate reliably between patients with and patients without significant psychological involvement in their pain conditions. Von Baeyer was not able to validate Ransford's findings, and in contrast concluded that pain drawings were not sufficiently sensitive for use in screening and predicting psychological involvement in patients with low back pain.

A quantitative system of scoring the pain drawings was proposed by Margolis et al (1986). In a study consisting of a 101 patients presenting with chronic lower back pain, they explored the use of pain drawings to identify a connection between the area of body surface marked as painful on the drawing and the measured level of the patients' psychological distress or dysfunction. The scoring system consisted of a transparent body outline template demarcated into 45 sections (see Fig 1.6) being placed over the patient drawing and being scored to reflect the extent of pain.

Figure 1.6 Margolis Scoring Template (1986)



A point was awarded for each area marked by any shading, regardless of how extensive the shading was in each individual area. This was a simple form of quantifiable scoring which resulted in a high rate of inter-rater agreement. The correlation between body surface area and psychological distress or dysfunction in chronic pain patients was found to be high (Margolis, Tait, Krause, 1986). The body surface area scores obtained through this method were also shown to have high correlation with the penalty point system devised by, in which certain features of the chart were held to signify psychological underlay (Ransford, Cairns, Mooney 1976).

In a study of 328 pain patients at the London Psychiatric Hospital, London Ontario, Canada, charts of patients who had completed the pain chart series used by Merskey and his colleagues in 1987 (Merskey, Lau, Russell, Brooke, James, et. al. 1987) were analyzed and correlations were found between the percentage of body surface area involved in pain and four different psychological instruments (Ginzburg, Merskey, Lau, 1988). The Ontario patients were also sub-grouped into four different clinical settings: Anaesthetist's Clinic; Dental Clinic; Psychiatric Clinic; and Rural Clinic. This study required the patients to draw their pain onto full view i.e. front and back, body outlines, which were scored using the method of Margolis (Margolis, Tait, Krause, 1986). In addition a questionnaire on demographics was completed.

The pain drawing scores were compared to the patients self-rated responses in four psychological instruments: The General Health Questionnaire-28 (measuring psychological disorder with respect to somatic symptoms, anxiety and insomnia, social dysfunction, and severe depression)(Goldberg,Hillier,1978:Lobo,Perez-Echeverria,Artal,1986);the Irritability/Depression and Anxiety Questionnaire (measuring depression, anxiety and inward and outward irritability) (Snaith, Constantopoulos, Jardine, McGuffin, 1978); the Parental Bonding Index (assessing bonding with respect to either parental care, or lack of parental care; and/or as well as overprotection, from the patients perspective) (Parker, Tupling, and Brown,1979); and the Hysteriod/Obsessoid Questionnaire (measuring the patients tendency to be outgoing or reserved and obsessional) (Hope, Caine, 1968).

The Ontario Study attempted to add definition to a field of opinion on the reliability of pain drawings when used to identify psychological states. It noted the observation of Pawl that "patient markings that indicate multiple and diffuse areas of pain suggest a good deal of psychological content, while the distinct line drawings limiting it to trunk and single extremity suggest a mainly organic pain problem" (Pawl, 1973). The Ontario Study also noted that Ransford proposed that correlation of the distribution of pain in charts of patients with hypochondriasis and hysteria scales on the MMPI can be predictive of a patient's psychological state (Ransford, Cairns, Mooney, 1976). It also noted that Margolis et al. (Margolis, Tait, Krause, 1986), using the above-mentioned method of Ransford et al. (Ransford, Cairns, Mooney, 1976) found a high correlation between body surface area and psychological distress or dysfunction in chronic pain patients. However, it expressed concern that the correlations could be tautological. It is interesting that the authors of the Ontario Study (Ginzburg, Merskey, Lau, 1988) view the potential tautology as a function of the 'crossing of boundaries' between the anatomical sections of the pain chart as drawn by the patient who in turn leads to higher scoring of the pain drawing. This could be reconsidered in that patients where pain crosses anatomical boundaries (diffuse pain) could well find it to be a greater challenge to understand or to express in detail their pain. Such challenges could thus derive from, or lead to psychological pathologies. The authors of the Ontario Study also note the work of Schwarz and DeGood (Schwartz, DeGood, 1984) who proposed that the degree of bodily involvement, non-anatomical pain, and number of body parts reported painful do seem to be related to psychopathology.

The Ontario Study found a very low correlation between the pain drawing scores and the chosen psychological instruments. It was therefore possible that the patients who had covered more extensive areas of the body with pain markings would be found to be more distressed. However, they found "no indication that primary psychiatric illness predisposes to involvement of more body area than does physical illness" concluding "it seems inappropriate to rely on the amount of body area involved as any sort of proof that the patient has either a current psychological or a long-standing personality disorder." It is worth noting that the Ontario Study published in 1988 somewhat preceded the publication of the ACR Criteria for FM (Wolfe et al, 1990). Accordingly, the categorization of the pain patients in the Ontario Study as having FM or not having FM would not have been considered.

In 1988 Uden used 264 pain drawings obtained from two groups of patients with back pain and one non-patient group (Udén, Åström, Bergenudd, 1988). They rated the pain drawings into four grades according to the degree of non-organic and extended pain. They found the reliability of the drawings to be excellent with an intra-and interrater agreement of 80 and 70% respectively. Three-quarters of the non-patient group had dull aching pain in the lower back only, whereas widespread or non-anatomical pain was prevalent in patients responding poorly to treatment. They concluded that pain drawings afforded an important clue to nonorganic factors in the assessment of back pain but found no correlation to psychiatric illness.

Chan and colleagues explored the reliability of psychological assessment by comparing the pain drawing to Waddell non-organic physical signs (Chan, Goldman, Ilstrup, Kunselman, O'Neill, 1993). Waddell Signs (WS) are a group of eight physical findings divided into five categories. The Waddell Signs are: malingering gain, secondary gain, hysteria, psychological distress, magnified palpation, abnormal illness behaviour, abnormal pain behaviour and somatic amplification (Waddell, McCulloch, Kummel, Venner, 1980) Waddell, 1980). Pain drawings were obtained from a group of 651 patients who had chronic low-back pain. Pain drawings were put into one of four grades according to the degree of organic and non-organic pain drawn as was previously done in the study of Uden et al (1988). A correlation found between the pain drawings and Waddell's non-organic physical signs demonstrated that a large proportion of patients with high Waddell scores had drawn non-organic pain drawings. Experienced and inexperienced evaluators were used and the reliability was reported as excellent with inter-evaluator reliability between 73% and 78%. A correlation between pain drawings and Waddell's non-organic physical signs demonstrated that a large proportion of patients with high Waddell scores had drawn non-organic pain drawings. Chan et al concluded that pain drawings afford an important adjunct in the physician's assessment of chronic low-back pain (Chan, Goldman, Ilstrup, Kunselman, O'Neill, 1993).

Parker and colleagues also researched the use of the pain drawing as a screening measure to predict psychological distress in chronic low back pain (Parker, Wood, Main, 1995). Their study tested the effectiveness of three new methods of scoring the pain drawing in order to predict psychological distress. In two cohorts of 100 patients suffering from chronic low back pain. The participants completed a pain drawing and filled in questionnaires aimed at measuring psychological distress. In addition they were given a standard physical examination. The relationship between the three new scoring systems and measures of distress, physical factors, and disability were investigated. It was found that the new scoring methods had high reliability, and they concluded that pain sites were a more accurate predictor of distress. However, the pain drawing did not correlate with physical disability measures. Therefore using the new scoring systems, it was not possible to identify distressed patients with sufficient specificity also, it was and not possible to differentiate between organic and nonorganic pain patterns. These studies show the variance in the validity of pain drawings for this purpose.

Ohnmeiss used a variety of scoring methods to evaluate the pain drawings of a group of patients with chronic low back pain (Ohnmeiss, 1995, 2000). They investigated the patients' repeatability in completing the drawings alongside intra-evaluator repeatability of the scoring systems requiring subjective interpretation. The results of this study found acceptable repeatability for most scoring methods of pain drawings that were completed on occasions separated by a relatively long period of time. This finding supports the use of the pain drawing as a stable instrument for assessing pain in this patient group.

The use of colour in pain drawings

In general, pain drawings provide pre-defined symbols and colours to represent the varying sensory pain experience. The symbols include dots, crosses, circles and hatchings. Each symbol, colour either relates to a different symptom or indicates either sensory disturbance, such as numbness, pins and needles, stabbing, burning or other painful feelings. The patient needs to observe the correct symbols and colours in their own representation of their pain (Palmer, 1949; Margoles, 1983; Masferrer, Prendergast, Hagell, 2003).

Research by Williams interestingly reported that different cultures tend to associate different colours with various emotions and therefore found it likely that a different colour scheme would be used in different cultural and/or ethnic groups (Williams, 1996). Previous studies using colours in conjunction with pain drawings had been limited to psychiatric and pediatric settings (Unruh, McGrath, Cunningham, Humphreys, 1983). Abnormal black and white pain drawings have been associated with multiple, non-organic physical signs, and dysfunction. Chan and colleagues found that 81.7% of patients with three or more WS's drew a non-organic pain drawing (Chan, Goldman, Ilstrup, Kunselman, O'Neill, 1993). Ohlund and colleagues found that abnormal pain drawings were associated with a tendency to somatise (Öhlund, Eek, Palmbald, Areskoug, Nachemson, 1996).

In 2003 Masferrer and colleagues aimed to retrospectively explore the use of coloured pain drawings in patients with neck, low back pain or radicular pain, who attended a community-based neurological practice for evaluation (Masferrer, Prendergast, Hagell, 2003). Out of the 359 patients who depicted their pain on a pain body outline, using colours to represent various pain characteristics, 109 were selected for the study (55 patients who had drawn abnormal pain drawings and 54 patients who had drawn normal pain drawings). The use of medications by those patients was recorded in addition to findings of physical examination and radiographic findings, activity levels, and Waddell Signs. The findings for patients with normal pain drawings were compared to the findings for patients who had drawn abnormal pain drawings and assessed according to the Ransford penalty point system (Ransford, 1976).

Patients with abnormal pain drawings demonstrated a greater use of medications, more non-focal clinical findings, WS, impaired activity levels, involvement in pending litigation, and fewer pathological radiographic findings than patients with normal pain drawings. This indicated that coloured pain drawings were equally as effective as the black and white drawings in providing similar data to those obtained by Ransford's penalty point system (Ransford et al, 1976). It was suggested that further exploration into the usefulness of coloured pain drawings, when predicting outcomes or when determining treatment, would be beneficial for future research (Masferrer et al, 2003).

Masferrer and colleagues based on their clinical experience, reported that when more than one symbol was used to represent 'pain characteristics in a monochromatic fashion' it became difficult to interpret. Their study substituted colours for traditional black and white symbols in the use of pain drawings. In this work is found the first description of the use of coloured pain drawings to help patients with spinal disorders. Their findings agreed with previous observations using black and white pain drawings. Clinical observations appeared to show that both the traditional black and white and the coloured pain drawings showed signs of non-organic overlay to be significantly more common among patients with abnormal pain drawings (Masferrer et al, 2003).

Fishbain and colleagues carried out a structured, evidence-based review of all available studies on the principle of non-organic pain (Fishbain, Cole, Cutler, Lewis, Rosemoff, Rosemoff 2003). The aim was to find if evidence existed to support the various interpretations of the identification of WS during physical examination. The review found there to be consistent evidence for WS being associated with decreased functional performance, poor non-surgical treatment outcome as well as greater levels of pain. It found consistent evidence that WS were not associated with psychological distress, abnormal illness behaviour or secondary gain. It also found consistent evidence that WS are an organic phenomenon and that they cannot be used to distinguish organic from nonorganic problems. In addition it found inconsistent evidence that WS do demonstrate inter-rater reliability; do not correlate with the neurotic triad of the MMPI; are associated with poorer surgical treatment outcome; and are associated with non-return to work. Finally, the review found little or no evidence that WS demonstrate test-retest reliability, reliable factors, or that they are associated with self-esteem problems, catastrophizing, or the non-organic pain drawing.

As a result of these findings Fishbain et al concluded that WS do not correlate with psychological distress, do not discriminate organic from nonorganic problems, that they may represent an organic phenomenon, that they are associated with poor treatment outcome, that they are associated with greater pain levels, and that they are not associated with secondary gain (Fishbain et al, 2003). These findings show that WS like pain drawings are not totally reliable when determining psychological underlay in a patient's pain experience.

A novel form of pain drawing was depicted by Moseley. Six examples illustrating where the patient experienced their back pain also showed an area in which the patient was unable to delineate part of their trunk as well as other perceptual changes. Cartography was relied upon to depict the "co-localizing of pain with unexpected disruptions of body image" (Moseley, 2008).

Summary of Pain Drawings

The standard pain drawing consists of a human body outline which can be marked with various pre-defined symbols to represent different sensations of pain. Pain drawings have been used in a variety of applications. These include the documentation of symptom location, the diagnosis of a condition, and psychological screening. The main purpose of the pain drawing is providing a way for the patient to pinpoint and describe the area of their pain as part of their assessment at pain clinics. The pain drawing enables the patient to transfer their subjective experience into an objective format to be viewed by a third party, normally their physician. Patients entering treatment for chronic benign pain are often asked to complete drawings indicating the intensity and location of their pain as part of the diagnostic process.

Although the pain drawing was initially introduced as an aid to document the patient's symptoms, it soon became apparent that it could also prove useful as an aid to identify the patient's psychological status. There have been several methods suggested for interpreting the pain drawings, and several studies have investigated the evaluator's abilities to replicate their results.

Various methods have been used to score and interpret the pain drawing. Whilst, several methods are similar to each other they generally fall into four categories (Ohnmeiss, 1995). The first category is the penalty point system for psychological assessment (Ransford, 1976; Sivik, Gustafsson, Klingberg-Olssson, 1992). The second is the visual inspection for diagnosing lumbar disc herniation (Von Baeyer et al, 1983); both of these categories require subjective interpretation. The third category is the documentation of body regions in pain (Margolis, Chibnall, Tait 1988; Escalante, Lichtenstein, White, Rios, Hazuda, 1995; Ohnmeiss, 1995). Finally, the fourth category is the grid method in which drawings are divided into square regions to be counted (Mann, 1992; Bryner, 1994; Ohlund, 1996). The third and fourth categories involve simply recording the presence or absence of pain within defined regions.

In studies of pain drawings many researchers have made inferences regarding the relative contributions of physiological and psychological factors to the patient's experience of pain expressed through this medium (Palmer, 1949; Pawl, 1973; Ransford, 1976; Margoles, 1983; Schwartz, 1984; Von Baeyer et al 1983; Hildebrandt, Franz, Choroba-Mehnen, Temme, 1988; Parker, Wood, Main, 1995; Albert, Godskesen, Westergaard, 2002). Further, numerous studies have attempted to explore possible ways of identifying the psychological aspect of pain and the role it plays in the pain experience through the use of the pain drawing.

The use of pain drawings to distinguish between organic/functional pain, and non-organic pain/psychological pain to assess the contribution of non-organic or psychological aspects of pain has provided a wide area of research, especially in the case of back pain (Ohnmeiss, 2000). Pain drawings have been studied extensively with this patient group. The main purpose of such studies is the assessment of adverse psychological factors which could contribute to a surgical outcome not being successful. There are a wide range of opinions, for some pain drawings afford an important clue to non-organic factors in the assessment of back pain (Uden et al 1988); for others it is not "possible to differentiate between organic and nonorganic patterns" (Parker et al., 1995). In addition Von Baeyer considered pain drawings to be invalid tools for psychological screening (Von Baeyer et al, 1983). The conclusion of a systemic review by Carnes and colleagues states that there is no high quality evidence to support the use of the pain drawing as a psychological assessment tool, therefore pain drawings are not recommended for this purpose (Carnes, Ashby, Underwood, 2006).

Whether or not anatomical pain drawings are a reliable method of identifying psychological issues in addition to the physiological location of pain has been one of the most controversial issues throughout the recent history of pain drawings. A comprehensive answer is yet to be fully agreed upon. Some have used them to document symptom location and to diagnosis lumbar disc disease (Ransford et al, 1976; Uden et al, 1988; Von Baeyer et al, 1983; Sorensen, 1992; Parker et al, 1995; Ohnmeiss, 1999). Whereas

Ohnmeiss used them to evaluate changes in pain (Ohnmeiss, 1996), others have researched their use for the prediction of treatment outcome (Dzioba, and Doxey, 1984; Sorensen, 1992; Takata, 1995).

The pain drawing may be useful in assessing the location and distribution of pain at a point in time, and in assessing the changes in this distribution over a period of time. The pain drawings could serve as a permanent record of a patient's pain; and, as a convenient, speedy source of reference. Their visual representation helps to facilitate the recognition of both common and unusual disease patterns which might otherwise be missed. It is suggested that such visual representations of pain distribution helps the clinicians decide on rational forms of treatment and also, differentiate somatic and sympathetic nerve problems.

Although currently the pain drawing is predominantly used in the treatment of back and lower back pain there is a wider scope for utilizing this simple measure in other conditions where pain is a contributory symptom. The pain drawing as an assessment tool to measure the patient's pain experience has thus proved useful. However, there remain limitations to its application, partly due to the restriction of its use to pre-defined symbols.

Two main philosophies within medicine

There are currently two main philosophies within medicine, both of which aim to bring back the optimum health to a sufferer: a) The conventional, orthodox, reductionist approach of western technological medicine; b) The alternative, complementary, holistic philosophical approach of eastern medicine. Although both approaches are successful in treating and rehabilitating patients, there are specific differences to their practices and treatments born of dissimilar viewpoints towards the subject of health, illness and disease. Within conventional medicine health is defined as the absence of disease and is based upon the theory that a person becomes sick due to pathogens-bacteria and viruses or biochemical imbalances. Doctors and patients are taught that their chief concern is the diagnosis and treatment of illness. The body is viewed as a machine and disease is regarded as an independent entity which can be fully understood without regard to the personality of the patient or the environment in which it occurs, and which can be combated with a conventionally prescribed remedy. This normally entails the use of pharmaceutical drugs and surgical procedures as primary treatment options which are based on the foundations of the theory of reductionism.

In contrast the complementary/alternative or holistic practitioner views health as a state of complete physical, mental, spiritual and social well-being; believing in nurturing and nourishing the 'entire-being'- the body, the mind and the spirit. The approach is fundamentally supportive, cause based, and preventative in nature, viewing the body as a complex interrelated system; acknowledging that if one of these areas is ignored it can lead to an imbalance, an incomplete state or a lack of 'wholeness'.

This holistic approach to health is fundamentally embracing all influences upon a human being, both internal and external. It does not seek to fragment or impose artificial limitations upon human knowledge and learning. Rather than dissect the body into numerous separate and independent functional areas, this approach recognizes the interdependence of various bodily systems. Holistic medicine is often used as an umbrella term to describe the approach of complementary and alternative therapies. The term holistic originates from a principle called 'holism' which means a 'state of wholeness', in which all aspects of a person are seen as interrelated. Whilst use of the term is comparatively recent the concepts underlying it go back at least 2500 years. Holistic practitioners treat the 'whole person', the mind and body as one, as opposed to treating the individual organs of the body where symptoms occur in isolation.

> *"The cure of the part should not be attempted without treatment of the whole, no attempt should be made to cure the body without the soul, and therefore if the head and the body are to be well you must begin by curing the mind; that is the first thing.... For this is the great error of our day in the treatment of the human body; that physicians separate the soul from the body." (Plato. Chronicles 156e)*

Holistic View of Illness

The holistic practitioner recognizes that there are numerous causes and contributions to the development of an illness beyond infection and virus. Illness is viewed as one of the final stages of disease. It is seen as the result of a breakdown in the communication systems of the whole person, due to mental, emotional or environmental factors both internal and external; for example these can include diet and heredity factors.

Holistic medicine works to address the concept that physical pain in a specific area of the body often corresponds to particular inner conflicts. The healing process teaches people to recognize and understand pain as a message from their body relating to their wellbeing and their lifestyles. This 'feedback system' informs the individual that something could be wrong. Therefore, healing the illness and stopping the pain is supported by searching for the root cause by deciphering the symbolic messages represented in the symptoms.

Whilst immediate physical surgical intervention is needed in many cases, arguably, people have become over dependent on what is too often regarded as 'the miracle cure' of traditional medicine. They have relinquished their personal responsibility by not considering the part their lifestyles and beliefs play in their own health. Bernie Siegel M.D. writes:

> *"Patients vary enormously. Some will do almost anything rather than alter their lives to increase their chances of a cure. When I offer them a choice between an operation and a change in lifestyle, eight out of ten say 'Operate it hurts less. That way all I have to do is get a babysitter for the week I'm in hospital."* (Siegel, 1990 p.3)

As a result, in today's society, 'sick' people are under tremendous pressure to overcome their ailments quickly and return to 'normal life' in a fast-moving, money-oriented world. From this perspective, individuals and modern society have yet much to learn about illness and disease and how it should be treated. People with serious, sometimes incurable, illnesses often develop the ability to make a profound assessment of their lives, and to rededicate themselves to a better future should they be cured. For example, promising to spend more time with their family or more time developing their creativity.

> *"Ultimately, all healing is a personal journey. Sometimes it seems to come from without, sometimes from within, sometimes it does not come at all. In any case, healing comes when illness motivates a person to seek change. Though the process may seem long and chaotic at times, it always begins with intention towards a more satisfying life."* (Jonas & Jacobs, 1996 p.xvii)

Many people, who have survived great traumas or even death, describe the wonderful experience of seeing the interconnectedness of life; in many cases it is often through chronic or life threatening illnesses that people actually make a conscious connection to the divine. This appears to fill them with a new compassion for humanity, a respect for all life and the precious gifts it has to offer the evolving human spirit. Illness sometimes provides an opportunity to bring another dimension into life that gives strength and hope in otherwise futile circumstances. One of the basic differences between holistic therapies and orthodox medicine is the interpretation of symptoms and perhaps the most important characteristic that discriminates between the two approaches is the means by which they seek to obtain changes in health.

A closer look at orthodox medicine reveals that various problems result from the inability of many practitioners to fully understand the fundamental healing ability of the body. Although conventional medicine does recognize that many symptoms have mental components, for example it accepts that emotional stress might promote the development of an ulcer or chronic headaches; as a rule, its approach is to suppress symptoms, both physical and psychological. Illness is considered to be something that happens to people as a result of exposure to an infectious bacterium or virus, a trauma to the body, a toxic chemical ingestion, or an inherited abnormal gene.

As the first natural warning signs of disease, pain symptoms are either viewed negatively as a problem or remain unrecognized, with any deterioration in condition viewed as something which should be avoided. Therefore, attempts are made to abate or suppress symptoms via the use of pain-killers or anti-depressants. In contrast, holistic practitioners possess a fundamental respect and concern for the normal restorative processes of the body which makes the mechanisms behind symptom causation of the utmost importance. To fight against disease they use a range of therapies to bolster the body's own defenses and restore balance. The symptoms which occur as a part of the healing process are recognized to be the body's attempts to detoxify and restore balance.

Holistic practitioners understand when symptoms become more extreme before any abatement of the illness occurs; described as a 'healing crises' this apparent deterioration is respected as a natural part of the healing mechanism. In fact the recovery process often involves such an exacerbation of symptoms which occurs as an inevitable result of the correct treatment of many diseases. In fact, temporary worsening symptoms are often deliberately brought about by naturopaths, and holistic practitioners.

Another major difference between the two approaches is the way they understand symptoms and illness. For example a cold virus or bacteria causes the body to increase the blood flow to the nose, producing an influx of white blood cells and other infection fighting substances such as histamines which increase the mucus and drainage from the nose.

> *"In conventional medicine, we control the symptoms of a cold by taking a drug such as an antihistamine or decongestant that stops the stuffy nose. This brings relief from the symptom but often blocks the self-healing action of the body."* (Jones & Jacobs, 1996 p.5)

Therefore the healthy response to the infection is what actually produces the symptoms that are identified as a cold, such as a stuffy nose and headache; the illness is also part of the healing response of the body. Both Hahnemann the founder of homeopathy and Dr Bach realized the significance of treating the patient and not the disease. They recognized the importance of treating the characteristics, the temperamental side of the patient, using these as a guide to the treatment required irrespective of the physical complaint.

> *"...the rational physician will judge every case of illness brought under his care according to its individual characteristics...he will treat it according to its individuality...with a suitable individual remedy."* (Hahnemann; Organon, Para 48)

Dr. Bach, who was an orthodox trained physician practicing in the prestigious medical community of Harley Street in London before taking on an additional post of pathologist and bacteriologist at the London Homeopathic Hospital, believed that surgery could rarely do more than 'palliate and relieve'. Bach became disillusioned by the limited healing success of the purely 'academic' therapies. He felt this failure was due to the fact that the majority of medical men had little opportunity to study their patients, they were too busy to think of the human side, concentrating too much upon the physical body. Physicians were:

> *"...taught to be so concerned with disease that they ignored the personality of the human being"* (Weeks, 1983 p.19)

This again echoes Hippocrates writings upon which modern medicine is founded, this is why it is a paradox how medicine has travelled so far down the road of reductionism to the exclusion of these basic holistic values that have been recognized by so many great doctors throughout the course of medical history. Bernie. S Siegel M.D., a noted physician who after working a lifetime with orthodox medicine became more interested in the holistic aspect of illness wrote:

> *"Despite the insights of these eminent doctors, medicine still focuses on disease, giving it a failure orientation. Its practitioners still act as though disease catches people, rather than understanding that people catch disease by becoming susceptible to the seeds of illness to which we are all constantly exposed."* (Siegel, 1990 p.2)

> *"Users of alternative health care are more likely to report having had a transformational experience that changed the way they saw the world...They find in [alternative therapies] an acknowledgment of the importance of treating illness within a larger context of spirituality and life meaning....The use of alternative care is part of a broader value orientation and set of cultural beliefs, one that embraces a holistic, spiritual orientation to life."* (Astin, 1998)

Discoveries in the field of 'quantum physics' that describe the underlying nature of the physical world indicate that if western orthodox medicine was to investigate the basis of this 'vital life force' it would very likely find the answers to many of its questions about the mystery of healing. Perhaps one of the major problems for orthodox medicine is its non-recognition of this 'vital energy', of a person's innate healing ability being an inherent part of nature, and the natural healing mechanism of the body.

> *"Alternative medicine regards nature as a 'force' which one works with rather than against; orthodox medicine on the other hand regards nature as something which must be 'categorized and controlled".* (Whitelegg, 1998 p.129)

Since World War Two more money has been available for research and great advances have taken place in most areas of medicine. Orthodox treatment is the most spectacular system of medicine in the history of human kind for relieving suffering; nothing provides immediate relief from pain as efficiently and quickly as allopathic medicine.

Most doctors reject the concept of holistic medicine because it cannot be measured by scientific methods. They make the assumption that since science cannot measure vital energy today it will never be able to do so. Yet there are in fact things which science still cannot measure; many human diseases and death itself are still beyond science! Nevertheless, many enlightened doctors are beginning to acknowledge their limitations when treating a specific disease. Recognizing there is much more to the origin and causes of ill health than the physical symptoms it eventually displays Dr. Bernie Siegel states:

> *"My role as a surgeon is to buy people time, during which they can heal themselves. I try to help them get well and at the same time try to understand why they became sick. They can go on to true healing, not merely a reversal of one particular disease."* (Siegel, 1990 p.4)

For holistic medicine to be fully effective and for healing to proceed, the patient must realize and accept that every illness carries a message. It recognizes there to be an untold story behind every symptom, an entire human drama surrounding every illness, and only the person who is sick can unravel that story. This understanding is based on a belief that life is a learning journey of the spirit, which evolves and grows stronger through its earthly experiences, trials and tribulations.

> *"Every illness, minor or major, is a crucible that tries our mettle and tests our limits."* (Duff, 1996 p.15)

This does not imply that illness is a punishment; or that a person needs to be ill to evolve; but it does suggest that growth of the spirit does happen, as a direct result of recovering from a disease or ill health. It suggests that the physical challenges faced enable a person to balance and heal in ways of which they are not always consciously aware. Illness is seen as an opportunity for a person to step back and evaluate what is currently happening in their lives, be it an emotional conflict or a physical limitation.

Other cultures have always respected the fact that those born with illness and infirmities that have learnt to accept and live with its pain and discomforts have much to teach the rest of their society. They are recognized for their ways of understanding sickness and their ability to relate to those who are afflicted and suffering. This enables everyone - the sick and the well, the young and the old to find the deeper meaning of life. This aspect does not come into consideration in the conventional view of illness, may be this could be an important piece of the jigsaw that is needed on the road to achieving full health.

> *"Traditional Cherokee, for example, understand sickness to be a purifying experience intended to return us to our path of destiny and of spirit."* (Mehl, 1998 p.137)

They ultimately believe that life is a spiritual journey, and illness is counted as one of the challenges people face on their earthly quest.

Orthodox medicine insists that pain is unnecessary because it can be eliminated by the use of drugs and other conventional treatments. Symptoms are often divorced from the patient and their personal circumstances. In contrast the holistic practitioner believes that by being secularized as mechanical mishaps, illnesses are stripped of their stories, their history, and the very things that could provide crucial information to precipitate their healing; the so called 'sacred space' of North American Indian medicine is disregarded.

In the healing systems of other cultures such as China and India and Indigenous people, the effects of vital energy seems obvious, their whole healing criteria being based on the existence of a 'vital life force'. This is the same inner vitality that was noted by Hippocrates more than 2000 years ago as the 'vis medicatrix', meaning the 'inherent wisdom of the body'. In Chinese medicine it is described as 'Qi', in Indian Ayurvedic medicine it is known as 'Prana'.

The innate ability of the body to resist disease and heal is recognized to be due to this 'vital force', vitality, yet mainstream healers gave up the theory of vital energy a long time ago considering it to be an outdated concept. There are now an ever-increasing group of pioneering researchers embracing a view of healing that combines the best of the ancient and modern world; bringing the knowledge of the eastern holistic philosophy to work alongside the more technological approach of orthodox medicine used in the western world.

Mounting scientific evidence is being discovered that endorses the value and importance of ancient healing systems even though their views of physiology are very different from the present mainstream health paradigm. Dr. Candace Pert has taken a giant step toward changing some cherished beliefs held sacred by Western Scientists for more than two centuries (Pert, 1997; 2000). Her research has provided evidence of the biochemical basis for awareness and consciousness, validating what Eastern Philosophers, Shamans, Rishis, and alternative practitioners have known and practiced for centuries i.e. that 'the body is not a mindless machine; the mind and body are one'. It is being discovered that these 'mystical viewpoints' may hold the key to understanding why people become ill, and how they can go about regaining their health. It is being suggested that important information could be found by reappraising ancient wisdoms, enough to result in a revolution in the field of medicine and healing.

The latest discoveries by Dr. Candace Pert prove there is a body-mind relationship to health in addition to the presently acknowledged mind-body connection. In essence Dr Pert's discovery corroborates the philosophical thinking of the ancient healing systems on which the complementary/holistic view of health and disease is formed. The scientific evidence she has found calls into question the present non-acceptance of many alternative therapies by the conventional medical system.

> *"There is a growing disbelief in a reductionistic science and an increased interest in the ancient wisdom of earlier cultures and ancient "sciences" as well."* (Rogers, 1980 p.347)

The majority of modern medicine still distances itself from the ideas of 'Spirit' and 'life-force energy'; refusing to consider that such concepts may be able to solve some of their unanswered questions. For example why do people with identical medical problems receiving the same treatments still recover at varying rates? Even within groups that are medically and physically the same there are variations in resistance to infections and the time taken to heal from similar illnesses, traumas and surgery.

> *"Western medicine still makes serious distinctions between mental, emotional, and physical roots of illness despite the amassing of research that finds that mind and*

> *body are so interwoven that such distinctions are not only artificial, they're unscientific."* (Benson, 1996 p.50)

Overview of the Research Programme

This research programme aims to investigate and explore an innovative method of using the simple body outline as a means for patients to express and communicate the symptoms of their pain and/or distress. Specifically, in chapter two the simple body outline will be used in order to establish whether there are any differences between the drawings of patient groups with FM and to those of patient groups with OA. Furthermore, if there are differences, it will be explored whether the novel use of the simple body outline can be used to help diagnose if a patient has FM or OA.

Previous research has already identified that patients with FM find it difficult to communicate their pain and/or distress, and this might have implications for their clinical management (Sayar, Gulec, Topbas, 2004). Consequently, the focus of chapter three will be to expand on the use of a simple body outline with the goal being to establish whether this method could be used as a form of communicating pain and or distress. This will be investigated by comparing the visual drawings and using the semi-structured interviews of patients with FM and patients with OA.

Approximately 17% of patients diagnosed with RA are thought to have co-morbid FM (Wolfe, Michaud, 2004; Naranjo, Ojeda, Francisco, Erausquin, Rua-Figueroa, Rodriquez-Lozano, 2002). Continuing with the novel experimental use of the simple body outline, the purpose of chapter four is to identify patients diagnosed with RA who may also have co-morbid FM.

Chapter five explores the potential benefits of using the simple body outline as an outcome measure for patients diagnosed with FM, RA and RAFM following a six-week intervention of a complementary therapy.

The final chapter of this thesis will provide overall conclusions concerning the novel use of the simple body outline explored in the research programme. The strengths and weaknesses of the current research and clinical implications are discussed, together with proposals for future research.

CHAPTER TWO

DO WOMEN WITH FIBROMYALGIA (FM) IMAGE/DRAW THEIR PAIN DIFFERENTLY TO WOMEN WITH OSTEOARTHRITIS (OA) OF THE HIP/KNEE?

This research was presented as an oral presentation at the annual conference of the British Society of Rheumatology (BSR) in May 2007. The abstract was accepted for publication: Kirkham & Jones (2007), Women with Fibromyalgia (FM) produce dramatic and distinctive pain drawings, *Rheumatology 46* (suppl 1)

Abstract

Objective: Fibromyalgia (FM) patients often find it difficult to express their feelings; communicating the severity of their pain/distress to their doctors is often a challenging ordeal (Sayar, Gulec, Topbas, 2004). This study explores whether a novel method of using the simple body outline provides an effective way for patients to communicate their pain/distress. It compares the pain drawings of women with FM to the pain drawings of women with another chronic pain condition, specifically osteoarthritis (OA).

Methods: Thirty two participants were recruited for the study: 16 women from a FM clinic who satisfied the ACR Criteria for FM; 16 women from a pre-operative assessment clinic for hip/knee replacement who had severe osteoarthritis (OA). Using a simple body outline diagram participants were asked to (1) 'draw your pain on this body outline' (i.e. its location); (2) 'draw the shape or form of your pain/distress on this body outline' (both body outlines were filled in with a black pen); (3) 'draw your pain/distress on this body outline' (using coloured pens); (4) 'draw the image/shape/form of your pain/distress' (plain sheet of paper, using coloured pens). The McGill adjective questionnaire and visual analogue scales were used to measure emotional and physical pain.

Results: Both FM and OA drawings were easily identified by visual assessment. Drawings by women with FM contrasted starkly with those of women with OA. The FM drawings were creative, dramatic and frequently drawn outside the body outline. In contrast, the OA participants' drawings were anatomical, limited and precise. All FM participants drew expressive images on the blank page whilst not one of the OA participants drew an image. The FM participants related well to this method of expressing their pain/distress.

Conclusions: Women with fibromyalgia (FM) produce dramatic and distinctive pain drawings which have diagnostic and therapeutic possibilities. The contrast between the drawings of patients with FM and the drawings of patients with OA is so striking that they could be used to identify the two diagnoses. Notably the creative and dramatic images drawn by women with FM, when asked to convey their pain and distress, could be used as a focus for therapy.

Introduction

FM is a complex and debilitating condition that causes much pain and suffering. Despite considerable research investigating the aetiology of this disease, its exact cause remains unresolved. Indeed, the lack of any underlying pathology in FM poses a particular challenge in conceptualising the disease within a biomedical model. Consequently, medical and pharmacological interventions are rarely successful in isolation (Carette, Bell, Reynolds, 1994). More recently, studies have shown that painkillers in isolation are of little benefit and neuro-active drugs which regulate sensory processing are now being recommended (Dadabhoy, 2006). In part, as a result of the ineffectiveness of orthodox medicine in improving this condition, people with FM use alternative treatments. (Haanen, Hoenderdos, van Romunde, Hop, Mallee, Terwiel,1991; Kaplan, Goldenberg, Galvin-Nadeau, 1993; Creamer, Singh, Hochberg, Berman, 2000).

A biopsychosocial perspective of FM acknowledges that physical, psychological and social factors play an important role in the development and persistence of this condition (Van Houdenhove, 2003). Many patients have psychological difficulties, for example anxiety and depression has been identified as being more common in this patient group than in the normal population (Van Houdenhove, 2003; Walker, Keegan, Gardner, Sullivan, Bernstein, Katon, 1997). From a biopsychosocial perspective it is assumed that psychosocial interventions could positively influence outcome. Indeed, in 2004 Goldenberg and colleagues conducted a meta-analysis of 500 peer reviewed articles published on FM in order to identify the most effective management. The results of this meta-analysis indicate a stepwise approach where pharmacological interventions (e.g. low dose tricyclic anti-depressants) are used in conjunction with non-pharmacological interventions (e.g. cardiovascular exercise and cognitive behavioural therapy). Although Goldenberg and his colleagues suggest, from their meta-analysis this particular approach is the most effective management of FM there are limitations which need addressing (Goldenberg, Burckhardt, Crofford, 2004). The authors fail to report any effect sizes for the interventions and outcomes; therefore, the strength and magnitude of the relationship between intervention type and outcome is statistically unknown. Furthermore, within their meta-analysis do not consider how robust their findings are in the context of file drawer threat (Rosenthal, 1979; Rosenthal, 1991; Scargle, 2000).

A critical challenge for the successful treatment of FM is the dilemma that many patients face in being unable to effectively communicate the severity of their condition to their doctor (Sayar, Gulec, Topbas, 2004) and the corresponding difficulty in comprehending the patients' descriptions of their condition experienced by their physician. This study used pain drawings in a novel way to explore the effectiveness of using drawings, images and colours to represent pain and distress with the two patient groups of FM and OA in order to explore the efficiency and effectiveness of this method.

In a clinical setting pain drawings are usually used to separate organic from non-organic pain. Pawl states that pain markings indicating multiple and diffuse areas of pain suggest a good deal of psychological content (Pawl, 1973); whilst distinct line drawings suggest mainly organic problems. Ransford and colleagues originally used the pain drawing as an adjunct to patients' verbal description of their pain (Ransford, Cairns, Mooney, 1976). They described the pain drawing as an aid to psychological evaluation of patients with chronic benign low back pain. Furthermore, they proposed the use of pain drawings with this patient group after noting an association between their condition and abnormal psychological profiles. They suggested that pain drawings could be used to predict psychological overlay. A scoring system was proposed of awarding penalty points for diffuse and non-anatomical features in an attempt to interpret and quantify pain drawings (see Method, page 56).

Many people who develop FM have a nurturing personality type with a tendency to either perfectionism or to self-sacrificing care-giving behaviours. They often live an overactive life style in their search of the approval of others (Van Houdenhove, 1992, 2001A). In many cases a serious physical or psychological traumatic event has preceded and possibly triggered the condition (McBeth, 1999; Houdenhove, B, 2001B). Often the person has either consciously or subconsciously refused to acknowledge the impact of this event on their life and has tried to suppress it with varying degrees of success. The pain and muscle tenderness of FM has also been closely linked to distress (Wolfe, 2000)

Researchers are discovering that imagery is the 'body-mind's' internal form of communication (Archteberg, Simonton-Matthews, Simonton, 1977; Simonton, 1984; Benson, 1996; Gerber 1996; Whitfield, Greenfield, 1997). The visual language of images can access a deeper, unconscious connection to the pain. The drawing of images often externalizes the person's inner experience enabling him/her to view it objectively. It has been shown that adding a visual dimension to the narrative is an aid to communication for those with unspeakable pain (Padfield, Hurwitz, Pither, 2003). It could be that this is a way for patients to release blocked emotions that are distorting the intended meaning of their words.

Verbal psychotherapy is the traditional way of releasing negative thoughts and fear based emotions. However, in a recent study it was shown that writing about an important either current or past, traumatic event, together with emotional expression and cognitive reappraisal, produced short term improvement in patients suffering pain and fatigue and engendered better psychological well-being (Broderick, Doerte, Junghaenel, Schwartz, 2005).

Increasingly interest is being shown in the use of expressive art as a way of exploring the mental, emotional and spiritual effects of illness or trauma (Puig, Lee, Goodwin, Sherrard, 2006). Based on the idea that visual image making is an important part of mental functioning, art therapy enables the externalization of the mental content of the patient into visual images (Luzzatto, 1998). Such therapy often provides a person with previously untapped in depth information on emotional thoughts and feelings (Talwar, 2007).

Osteoarthritis (OA) is the most common type of arthritis. It is associated with the breakdown of cartilage and is characterized by joint pain that may occur in any joint in the body, but is most often found in the fingers, hips, knees and spine (Bellamy, Kirwan, Boers, Books, Strand, Tugwell et al, 1997).

The OA group was chosen as the second group for this study. In terms of the biomedical model, the condition is easily identified because the pain experienced by the patient is the result of organic damage. The medical evidence of a deteriorating joint is easily identified by x-rays, and the pain thus caused is not disputed. This patient group is given a clear explanation of the cause of their pain/discomfort; and if the condition is considered serious enough surgery is offered in order to replace the damaged joint as a solution. This patient group has the comfort of knowing that the medical profession recognises the pain they are experiencing and able to offer the clear possibility of an end to their pain.

To the author's knowledge there has not been a study to date that has explored the way in which patients with FM and OA 'image' or draw their pain. Neither has there been one that researches the differences between these two groups of patients. Prior to this study the researcher interviewed 6 people, using the pain drawing, in order to explore whether the idea that people with FM draw their pain and distress in a distinct way warranted further investigation. The group consisted of 2 female and 1 male FM sufferers; 1 male emphysema sufferer; 1 female suffering with severe OA of the hip; and 1 male suffering from severe OA of the knee.

As an exploratory exercise the participants were asked to complete pain body outlines by following the protocol described in the procedure section of this study. The results identified that the FM sufferers found it easier to convey their pain/distress by using different colours to draw on the body outlines in a very creative and expressive way that often involved the use of dramatic images. In contrast the results showed that the OA and emphysema sufferers found it difficult to relate to the instruction 'draw your pain/ distress'. They did not think it was possible to draw pain. It was decided that this idea was worth further exploration.

One of the aims of this research was to find out if, when given the freedom to express and draw their pain experience using their own images, the FM group would be able to relate to this method easier than the traditional method that restricted them to using specific symbols and markings to depict the pains and discomfort they were experiencing. During this research the participants had total freedom to draw any image or shape that they believed best described and expressed their pain. No restrictions on or suggestions to the participants were made during the completion of this exercise.

The author hypothesizes that the drawings by FM patients will show a non-organic pattern. This pattern will be easily identifiable when compared to the drawings made by the patients with OA that will most likely show an organic pattern. It is also anticipated that women with FM will relate well to this method of expressing their pain and distress.

Method

Participants

Sixteen female patients attending the weekly FM Clinic of the North West Wales NHS Trust who had been previously diagnosed with FM were recruited by the resident rheumatologist. Sixteen female participants with osteoarthritis (OA) who were awaiting hip or knee replacement were recruited from the pre-operative joint replacement clinic at Ysbyty Gwynedd - a district general hospital in North Wales - by the researcher. The inclusion criteria for the FM group were that they met the American Rheumatology College (ARC) diagnostic criteria for FM (Wolfe et al., 1990) The inclusion criteria for the OA group were that they had OA of either the knee or hip, which was severe enough to warrant joint replacement, and, they were in their final pre-operative evaluation i.e. just prior to surgery. The age range was from 18 to 75 years. Participants with systemic diseases likely to produce pain (e.g. rheumatoid arthritis or other inflammatory forms of arthritis) were excluded.

Procedure

All participants received an information sheet detailing the purpose of the study; and signed informed consent was taken more than 48 hours later. Every potential participant who read the information sheet agreed to take part in the study. Recruitment of both groups took place simultaneously. Participants attended in order of recruitment and were allocated consecutive numbers from one to thirty-two. The interviews were conducted either in a private room at the local hospital or in the participants' own home. Each participant was interviewed once for approximately 90 minutes, or longer if the participant needed more time. During the interview participants were asked to complete the following:

Pain drawings

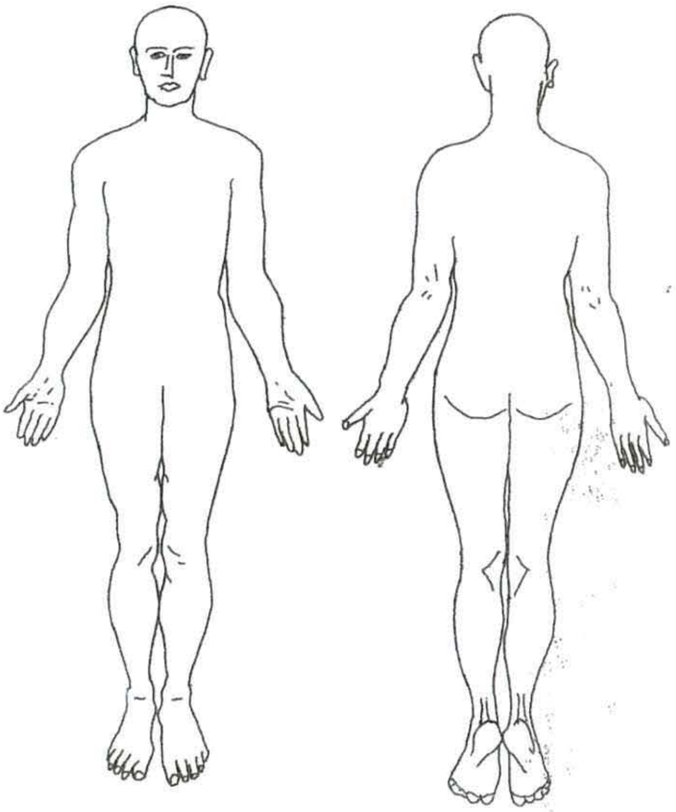
Participants were invited to draw their pain. Each participant was given four pages of paper. On three of these pages was a simple body outline diagram as shown in figure 2.1, the remaining one page was blank. Participants were also given coloured pens - black, red, orange, yellow, green, blue, purple and magenta - with which to complete the 'pain drawings'.

Each participant was given pages numbered one to four. On each of pages one to three there was a simple body outline diagram. Page four was blank. Specific instructions were written on each of the pages as follows:

1. Page one - Simple body outline diagram 'Draw your pain on this diagram' (black pen)
2. Page two – Simple body outline diagram 'Draw on this diagram whatever shape or form your pain/distress takes (black pen)
3. Page three – Simple body outline diagram 'Draw your pain/distress in the colours of your choice' (coloured pens)
4. Page four – blank page 'Draw the image/shape form of your pain/ distress using the colours of your choice'. (coloured pens)
5. Those participants who had drawn an image on page four were requested to 'Describe your image explaining what it means to you'. The researcher recorded the response in writing.

After completing the pain drawings on the simple body outline diagram (Figure 2.1), participants were asked to complete two separate questionnaires. This was followed by a semi-structured interview with the researcher. The questionnaires are described below while the semi-structured interview is reported in chapter three.

Figure 2.1 Simple Body Outline Diagram



McGill Adjective Questionnaire and Visual Analogue Scale

Participants were then asked to complete the McGill Adjective Questionnaire (Melzack, 1984) and Visual Analogue Scales (VAS) (Huskisson, 1983) for emotional and physical pain. Forms used for McGill Adjective Questionnaire and the Visual analogue scale are in Appendix E.

Measurements

Pain Drawings

The researcher and an independent assessor* separately examined each participant's four pages of pain drawings in order to see whether they could identify, from the drawing itself, which patient group the participant was from i.e. was the participant a pre-operative OA patient or a recently diagnosed FM patient. The independent assessor evaluated all drawings from the thirty two participants at one time was 'blind' to all other medical information about the participants; and had no contact with any of the participants. The researcher in that she had interviewed the subjects was not 'blind'. However, two months had elapsed between the interviews and the drawings analysis. Each set of 4 drawings was assessed by both the researcher and the assessor. The order in which they were assessed was based on the date that each participant, regardless to which group they belonged were recruited and interviewed.

The drawings were assessed and scored using three methods:

(a) Visual Assessment

(b) Margolis scoring system (Margolis et al, 1984)

(c) Ransford scoring system (Ransford et al, 1976)

*The independent assessor used for this study was on the research staff of the School of Sport, Health and Exercise Science, University of Wales, Bangor, UK.

a) Visual Assessment

The researcher and the assessor visually assessed each set of four drawings. The first three drawings used were on the simple body outline diagram while the fourth drawing was on a blank page. The objective with each assessment was to place the patient in one of the three categories shown below.

(i) Fibromyalgia participant

A set of drawings was categorized as having been drawn by an FM participant if the pain drawings and markings were non-organic; i.e. if the drawings contained diffuse, global, poorly defined patterns that were not considered to be a logical result of pathology; and/or if the drawings used words, phrases or images to emphasize pain.

(ii) Osteoarthritis participant

A set of drawings was categorized as having been drawn by an OA participant if the pain markings were organic; i.e. anatomically precise. Consideration was given to the likelihood of the image or marking corresponding with an anatomical distribution of pain which would be indicative of an OA diagnosis.

(iii) Non-classifiable participant

A set of drawings was categorized as non-classifiable if using the above classification it was not possible to allocate the drawings to either the FM or OA groups.

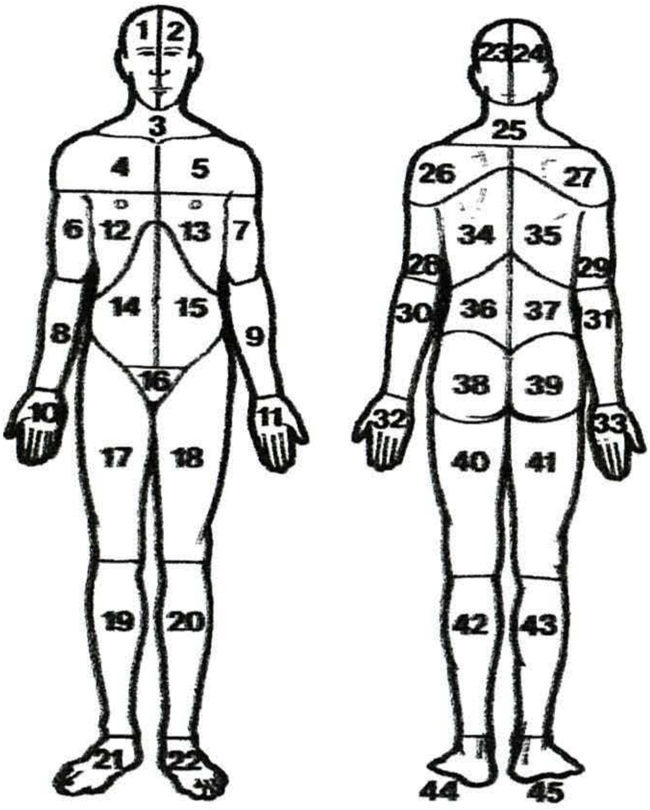
b) The Margolis scoring system.

The Margolis Scoring system bases its results on the total body area recorded as being painful by the participant (Margolis et al 1986, 1988). The system was used to score the first two drawings of each participant i.e. their responses to the instruction 'Draw your pain on this diagram' (black pen) and to the instruction 'Draw on this diagram whatever shape or form your pain/distress takes' (black pen).

The Margolis scoring system uses a clear plastic template which is divided into 45 anatomical areas. The boundaries between these areas are drawn at anatomical landmarks such as joints) as shown in Figure 2.2 below. The template is placed over each completed pain drawing.

A score of one was recorded for each of the areas where the participant placed a mark to indicate the presence of pain. No score was recorded where the area was left unmarked. For the purpose of this study any area shaded or marked, no matter how slightly, scored as one. No score was recorded for any additional markings outside the body outline. The final scores for each participant were calculated by adding together the total number of body areas that they had marked (range of scores 0-45).

Figure 2.2 Margolis Scoring Template



c) The Ransford scoring system.

The Ransford Scoring System (Ransford, Cairns, Mooney, 1976) uses a penalty point system to segregate organic from non-organic drawings. Organic pain is characterised by clearly defined markings in areas that are reasonably associated with typical pathologies such as joint rheumatism or muscular injury. Non-organic pain is characterized by diffuse, global, poorly defined markings, with patterns that are not easily localised (Figure 2.3).

The four descriptors used in the Ransford scoring system as guidelines for awarding penalty points to the non-organic drawings were:

- The reasonableness of the anatomic distribution.
    - (poor anatomical localization scores 2)

- The degree to which they reflect any magnification of pain.
    - (each scores 1)
- The presence of indicators like 'I particularly hurt here!'
    - (a score of 1 for single or multiple markings)
- The presence of information signaling 'Look how bad I am!'
    - (score of 1 if limited to small areas otherwise scores 2)

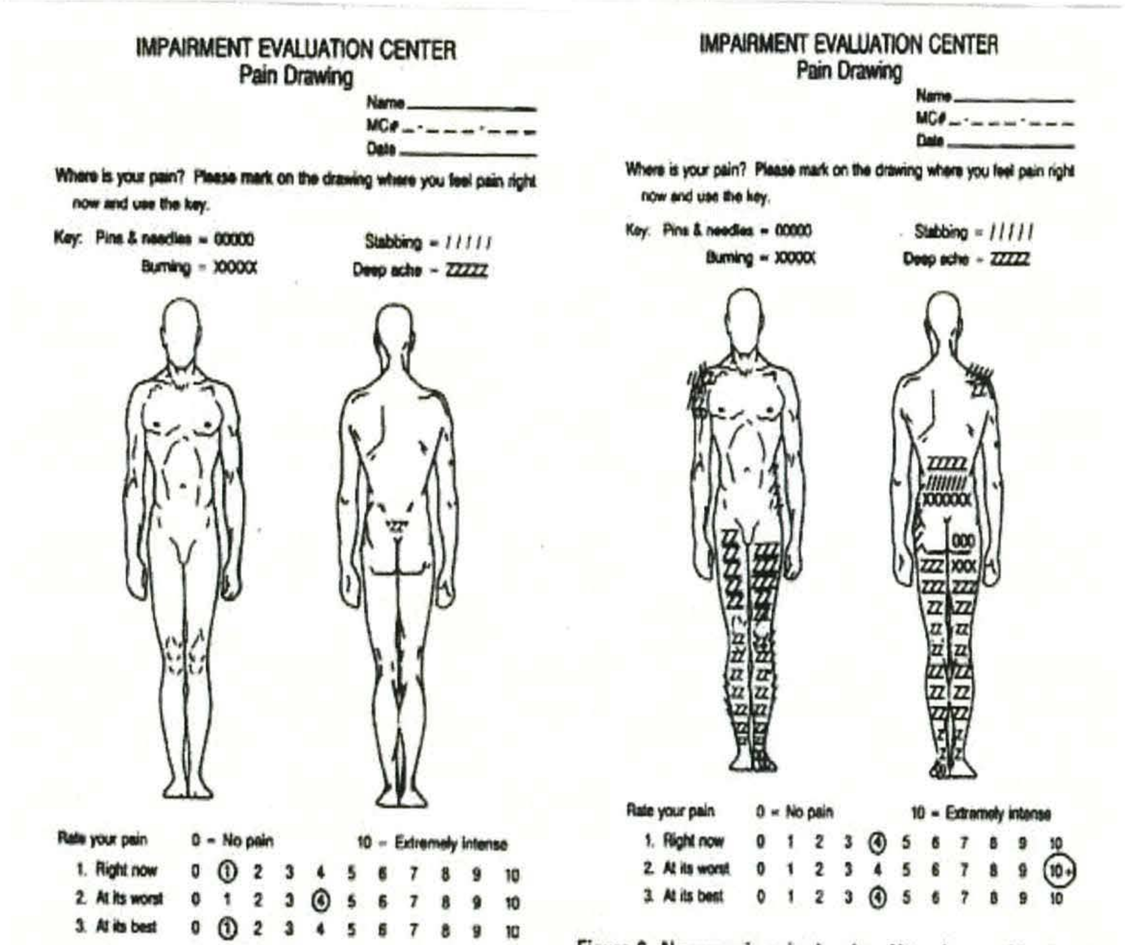
Each different pattern shown in these four groups was awarded points. A score of greater than two points indicated non-organic pain.

Applying the original Ransford scoring system to the drawings was difficult because of the way some participants illustrated their pain i.e. because of the tendency of some participants to draw or write extensively outside the body outline. For the purpose of this study the Ransford Scoring system was modified to include awarding one penalty point for each occurrence within the following categories:

- Any area of pain marked that was not typical of OA of the hip or knee.
    - (each scores 1)
- Several spots or marks in one area e.g. all the fingers and toes on a single hand or foot scored as one.
    - (each scores 1)
- Out of Body - Indications of pain outside the body e.g. marks outside of the body outline.
    - (each scores one)
- Phrases or written descriptions.
    - (each scores 1)

The above modified scoring system was applied to the first two drawings of each participant i.e. their responses to both the instruction 'Draw your pain on this diagram' (black pen) and to the instruction 'Draw on this diagram whatever shape or form your pain/distress takes' (black pen). The final score for each drawing was counted and recorded independently by both the researcher and the assessor. Both sets of scores were then compared.

Figure 2.3 Ransford Scoring System



IMPAIRMENT EVALUATION CENTER
Pain Drawing

Name ________
MC# _-____-___
Date ________

Where is your pain? Please mark on the drawing where you feel pain right now and use the key.

Key: Pins & needles = 00000 Stabbing = /////
Burning = XXXXX Deep ache = ZZZZZ

Rate your pain 0 = No pain 10 = Extremely intense
1. Right now 0 [✓ 1] 2 3 4 5 6 7 8 9 10
2. At its worst 0 1 2 3 [✓ 4] 5 6 7 8 9 10
3. At its best 0 [✓ 1] 2 3 4 5 6 7 8 9 10

IMPAIRMENT EVALUATION CENTER
Pain Drawing

Name ________
MC# _-____-___
Date ________

Where is your pain? Please mark on the drawing where you feel pain right now and use the key.

Key: Pins & needles = 00000 Stabbing = /////
Burning = XXXXX Deep ache = ZZZZZ

Rate your pain 0 = No pain 10 = Extremely intense
1. Right now 0 1 2 3 [✓ 4] 5 6 7 8 9 10
2. At its worst 0 1 2 3 4 5 6 7 8 9 [✓ 10+]
3. At its best 0 1 2 3 [✓ 4] 5 6 7 8 9 10

Figure 1. Organic pain drawing. Note the use of only one symb to show the anatomic distribution of pain.

Figure 2. Nonorganic pain drawing. Note the graphic display of almost complete total body pain in a nonanatomic distribution. Multiple pain symbols have been used.

McGill Adjective Questionnaire

The McGill adjective questionnaire is a section of the widely used self-report pain inventory (Melzack, 1987). The method provides a list of twenty pre-defined groups of adjectives with between two and six adjectives in each group. Participants were asked to select one adjective from each group, but only if they felt it described their pain. A score of between one and six was given for adjectives chosen from each group. If no adjective was chosen from a group it scored as zero. Final scores for each participant ranged between zero and seventy-seven. The McGill adjective questionnaire has proven to be a useful instrument for assessing a patient's pain quality and intensity. It has been used in diverse clinical situations and proved to be a reliable and valid measure of pain both for patients with FM and for patients with OA (Marques, 2008).

Visual analogue scale (VAS)

The VAS is a way of measuring by asking a person to put a mark on a line, for example a 100 mm VAS, without scale indication. Only the endpoints are given, for example: no pain at all and extreme pain. In this way you can measure different criteria, like morning stiffness, fatigue or general well being. A VAS can be made by the consultant as well as by the participant. The VAS is widely used in pain research and has been found to have good validity and reliability (Huskisson, 1983). Participants were asked to indicate the severity of their emotional and their physical pain by marking points on two separate lines, one for physical pain, one for emotional pain, where the end points of the lines were:

Left - 'None'

Right - 'As bad as it could be'

They were given the instruction: 'Please mark the lines below at the point which you think best represents your emotional or physical pain'.

Ethics

The study was approved by the North West Wales NHS Trust Ethics Committee. The study interview had the potential to address sensitive issues as well as to give the patient an opportunity to disclose potentially distressing emotions. Thus psychological support was made available to the participants. The patient information sheet invited participants to contact either the principal investigator who is a trained and registered counsellor, or the North West Wales Rheumatology Helpline.

Sample Size

The size of this pilot study was not designed to use a statistically significant population size since no similar studies had been reported. Unpublished results of a similar exploration had led to the expectation that a pilot study using sixteen individuals from each patient group would show important differences.

Data analysis

Margolis/Ransford Scoring

The scores for each of the dependant variables were examined to investigate whether the assumption of normality had been violated. Where the assumption of normality had not been violated as indicated by a Kolmogorov-Smirnov statistic with a probability value greater than 0.05 independent samples t-tests were conducted to examine possible differences between the two groups. In cases where normality had been violated as indicated by a Kolmogorov-Smirnov statistic with a probability value less than 0.05 the non-parametric equivalent of independent samples t-test, the Mann-Whitney U Test was conducted. In all cases a probability level of 0.05 was accepted.

McGill adjective questionnaire

Means and standard deviations were calculated for each of the two groups. Depending on normality either an independent samples t-test or a Mann-Whitney U test was conducted to investigate possible differences between the OA and FM groups.

Visual analogue scale (VAS) for emotional and physical pain

Means and standard deviations were calculated for each of the two groups. Depending on normality either an independent samples t-test or Mann-Whitney U test was conducted to investigate possible differences between the OA and FM group.

RESULTS

Thirty two females (16 FM; 16 OA) completed interviews for this study. Every potential participant asked to take part in the study agreed to do so. See table 2.1 below for patient characteristics.

Table 2.1 Mean Questionnaire Scoring Values for FM and OA Participants

	FM		OA			Sig
	(n=16)		(n=16)			
	M	SD	M	SD	t/z	p
Age	*52.7*	*7.31*	*68.6*	*5.33*	*-7.02*	*0.000#*
VAS Emotional	8.0	3.04	5.7	3.41	-2.47	0.012 ##
VAS Physical	8.3	1.49	8.7	1.32	-0.79	0.044 ##
McGill Adjective	47.9	12.78	22.4	10.78	6.09	0.001#

normally distributed data - Independent Sample t-test

##non-normally distributed data – Mann-Whitney U test

The age of the OA group was significantly higher than the age of the FM group. Both groups showed very high scores on the VAS physical, indicating strong physical pain with the OA group scoring a little higher than the FM group (p =0.044). The FM group scored very highly for emotional pain both on the VAS (8.0 +/- 3.04) and on the McGill adjective questionnaire (47.9 +/- 12.78) (see table 2.1). However the OA group also scored highly on the McGill pain score (Mean 10.78 +/- 6.09) confirming the presence of severe pain.

Pain Drawings

As a form of summary, the images for all 32 participants are shown in Figures 2.4, 2.5, 2.6 and Figure 2.7 as indicated below:

1. Figure 2.4 – Drawing 1 - 'Draw your pain on this diagram' (black pen
2. Figure 2.5 – Drawing 2 - 'Draw on this diagram whatever the shape or form your distress takes' (Black pen)
3. Figure 2.6 – Drawing 3 - 'Draw your pain/distress in the colours of your choice'
4. Figure 2.7 – Drawing 4 – 'Draw the image/shape/form of your pain/distress using the colours of your choice'

Larger versions of these images are located in Appendix A.

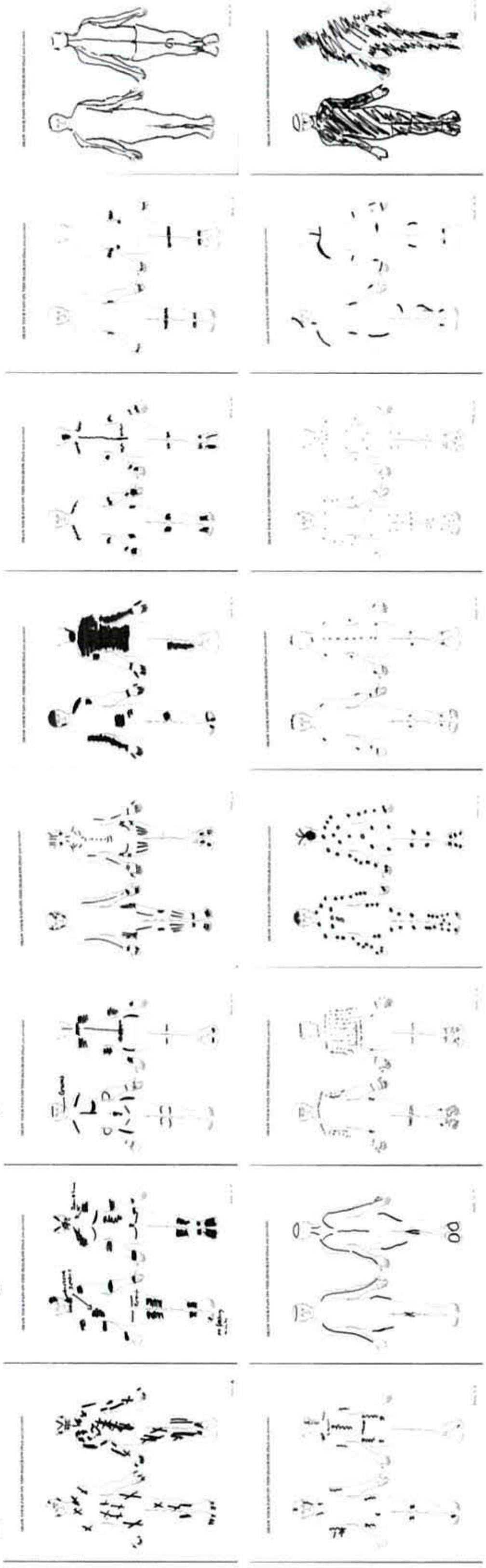


Figure 2.4 FM Participants - Drawing 1

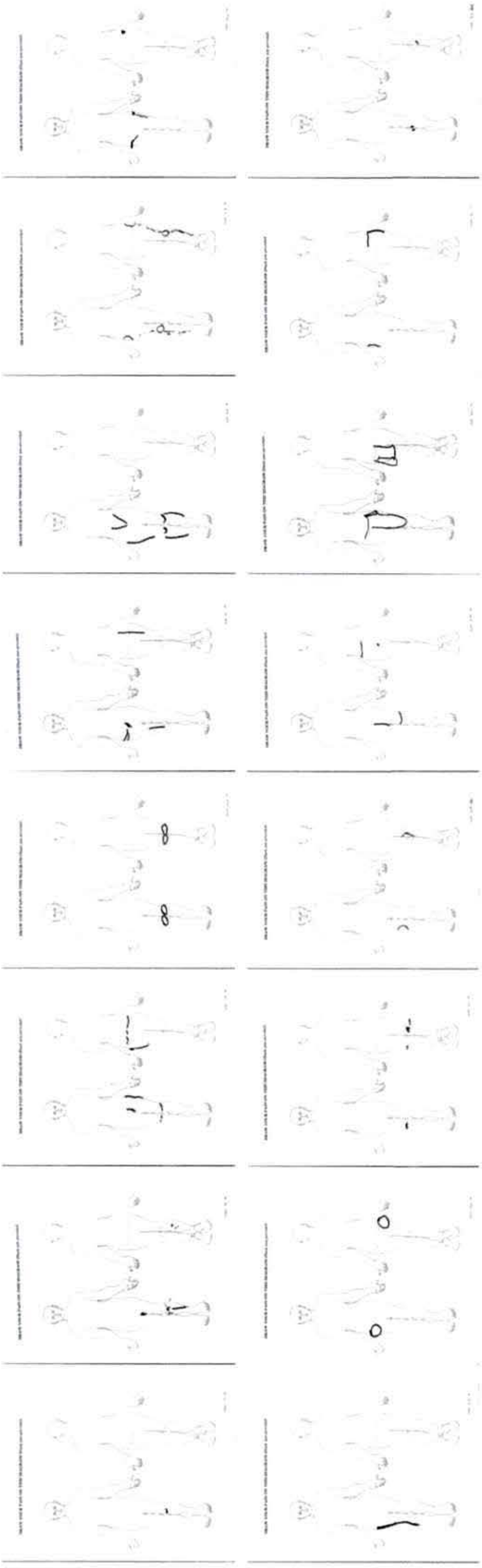


Figure 2.4 OA Participant s – Drawing 1

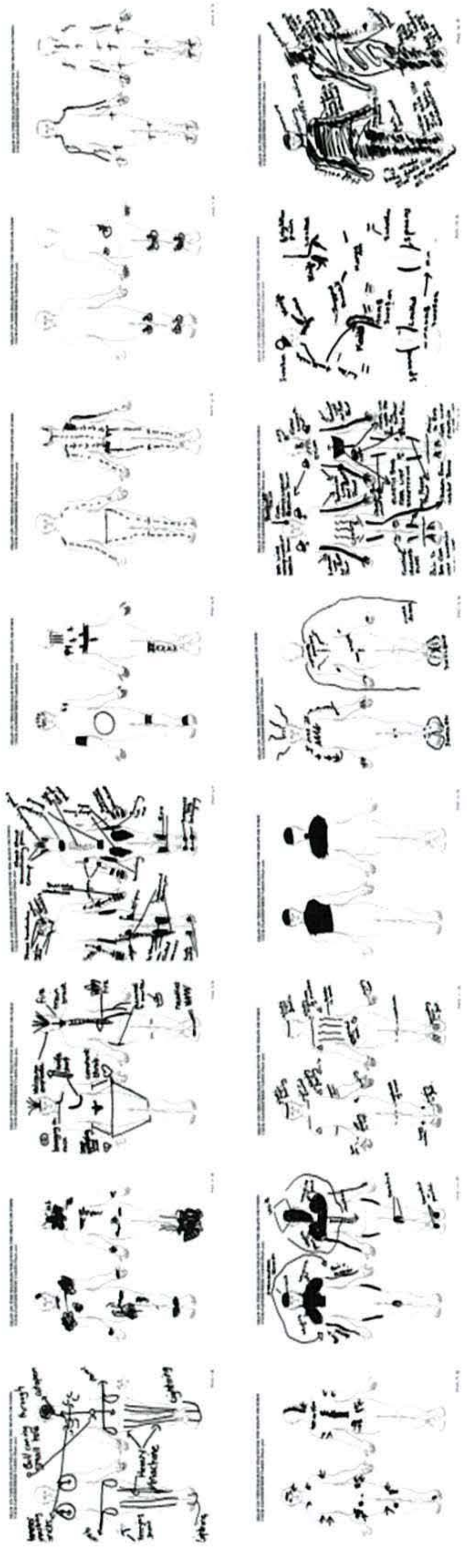


Figure 2.5 FM Participants - Drawing 2

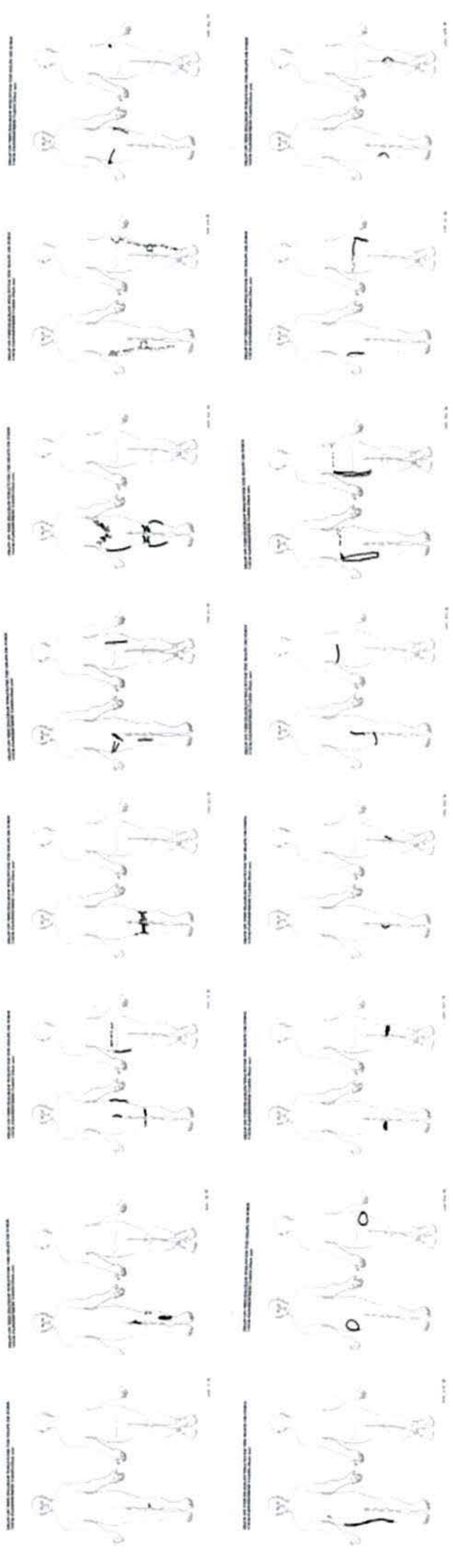


Figure 2.5 OA Participant s – Drawing 2

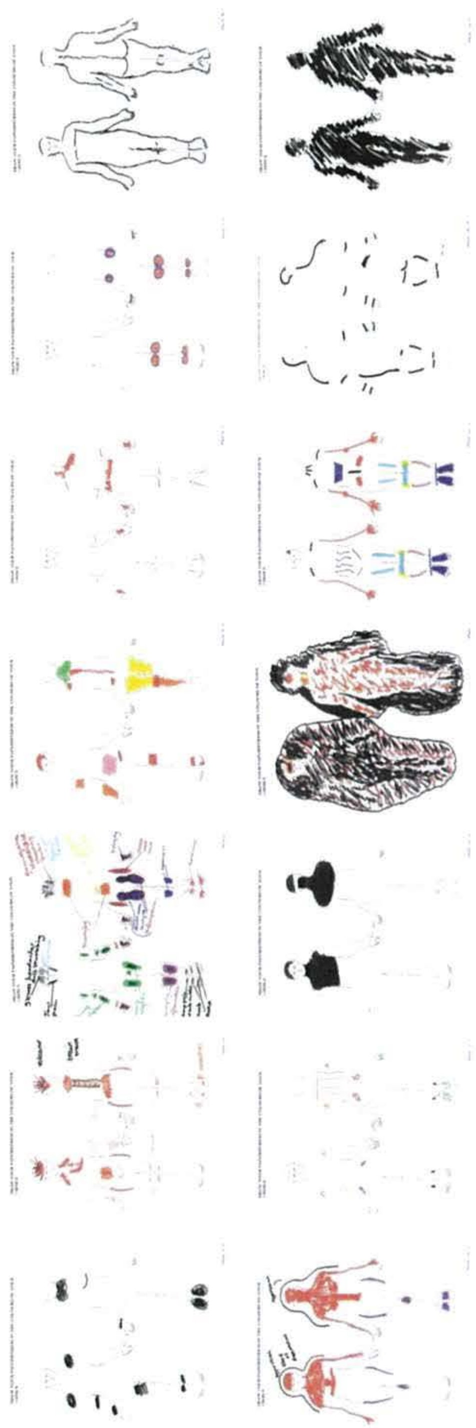


Figure 2.6 FM Participants - Drawing 3

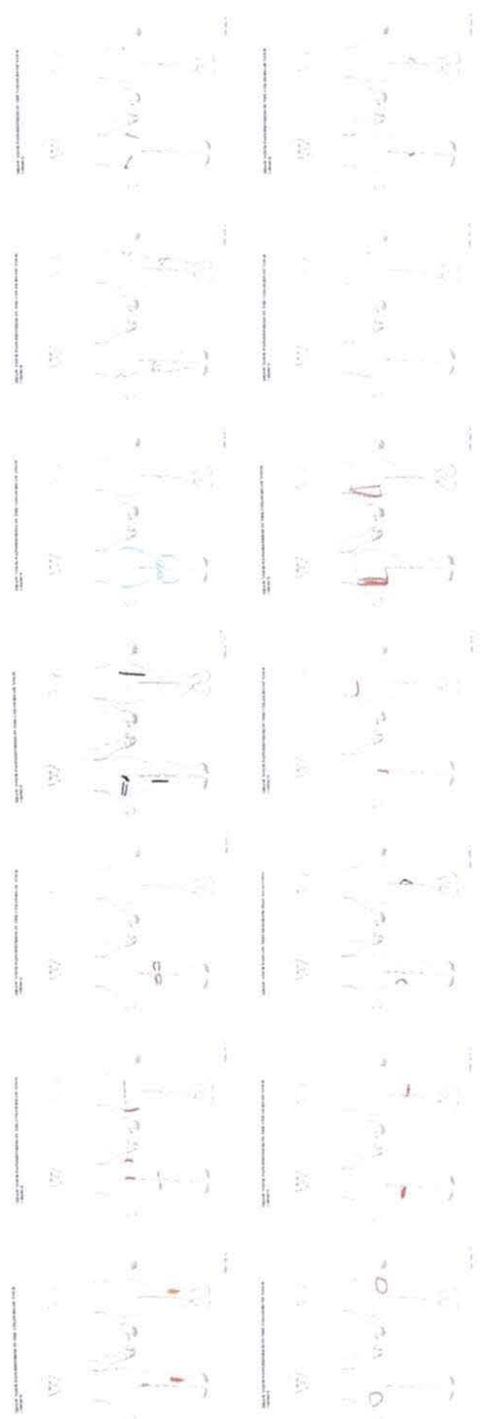


Figure 2.6 OA Participant s – Drawing 3

Figure 2.7 FM Participants - Drawing 4

Figure 2.7 OA Participant s – Drawing 4

Visual assessment

Independent assessment by the researcher and the assessor of each set of three silhouette/body outline drawings and an image drawn on a blank sheet showed that the drawings could be easily identified and categorised as having been drawn by either FM or OA participants. No drawing was unclassifiable. The researcher and assessor agreed in every case. (Table 2.2)

Table 2.2 Participant Categorization Based on Visual Assessment of all 4 Drawings.

	FM	OA
FM Drawing (Organic)	16	0
OA Drawing (Non-Organic)	0	16
Non-classifiable	0	0

Assessment of the blank pages (Figures 2.7) showed that an image was drawn by fourteen out of the sixteen FM participants. Of the two remaining FM participants, one gave a written description with no image and one was unwilling or disinclined to describe or draw an image to represent his/her pain experience. In contrast, not a single OA participant was able to draw or even to think of an image to represent his/her pain.

Descriptive observations on Pain drawings

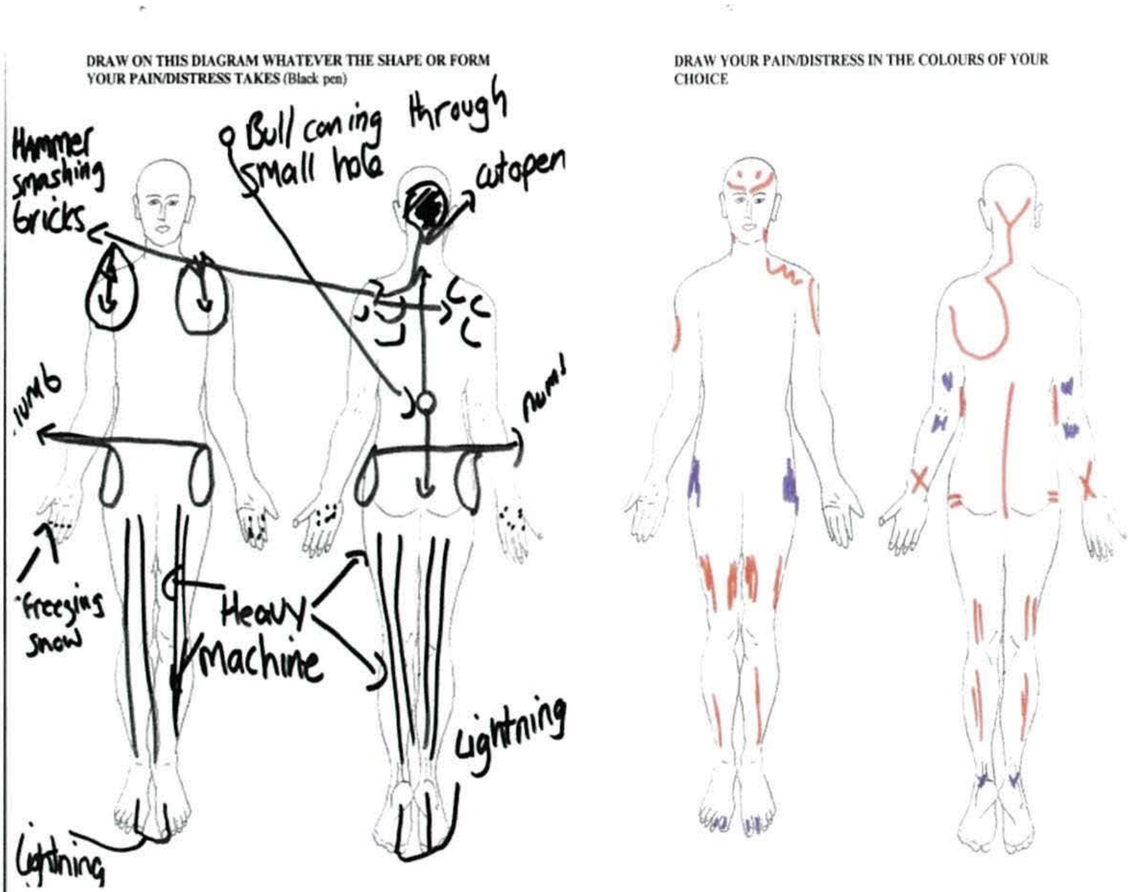
Figures 2.4, 2.5 and 2.6 show that the drawings of the FM participants are very flamboyant, expressive, detailed and were often drawn outside the framework of the body outline. This is in distinct contrast to the drawings by the OA participants, who typically used anatomically precise (organic) markings to represent their pain/distress. In addition, Figure 2.7 demonstrates the FM participants' ability or willingness to visualise and draw their pain on a blank sheet, producing dramatic images to convey the extent of their pain and distress. In contrast, Figure 2.7 shows that in the OA group none of the participants were either able to or inclined to draw an image of their pain.

Observations on individual FM drawings

Figures 2.8, 2.9 and 2.10 (below) are examples of the creative, expressive and flamboyant images drawn by the FM participants. They are characteristic of the way the FM participants drew their pain, and have been selected to illustrate the dramatic use of images, words and colours.

Figure 2.8 below drawn by FM participant 01 shows images of hammer smashing bricks; bull coming through small hole; heavy machine; cut open; freezing snow; lightning.

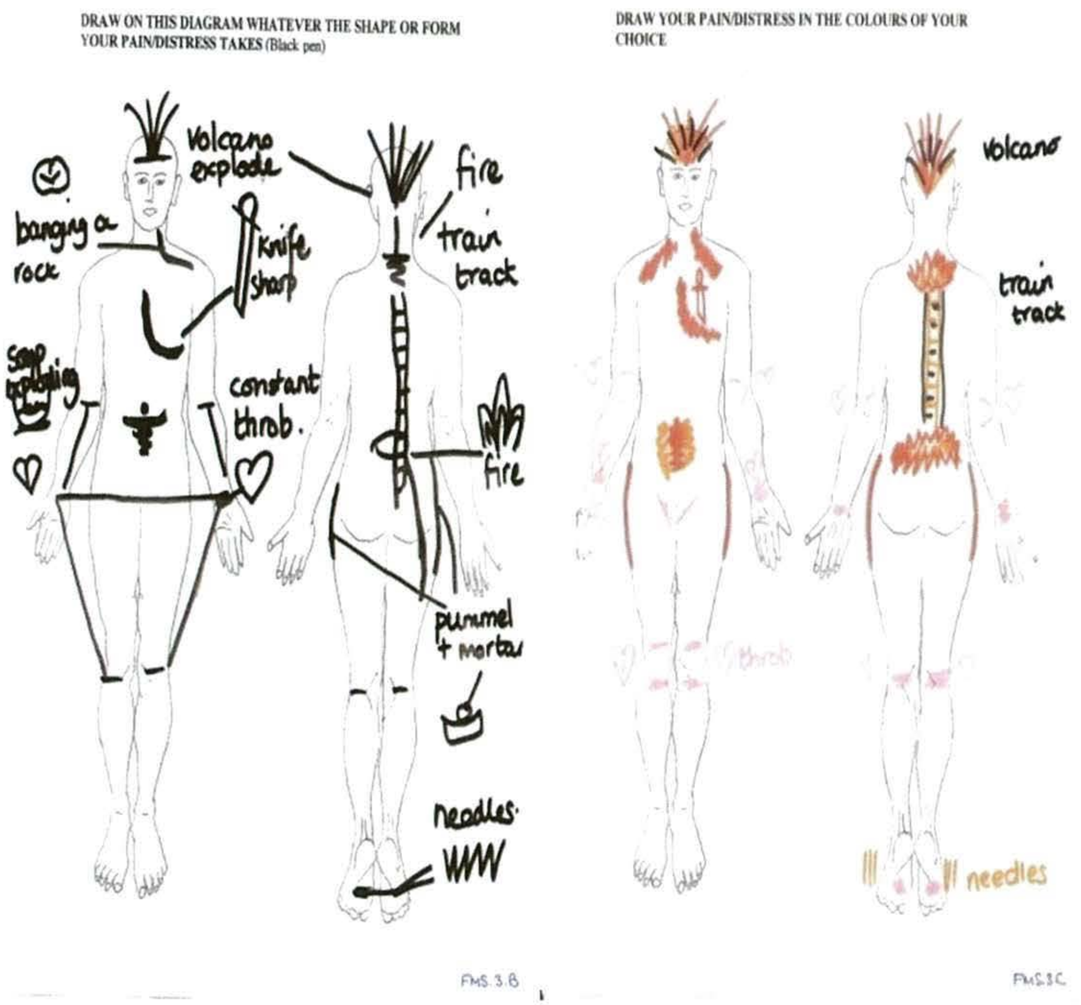
Figure 2.8 FM Participant (01) - Drawings 2 and 3


DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

Figure 2.9 below drawn by participant 07, uses very different but still dramatic images to express her pain and distress; i.e. volcano explode; banging on rock; fire; knife sharp; soup exploding; pummel and mortar; needles and a constant throb illustrated with the image of a heart.

Figure 2.9 FM Participant (07) - Drawings 2 and 3

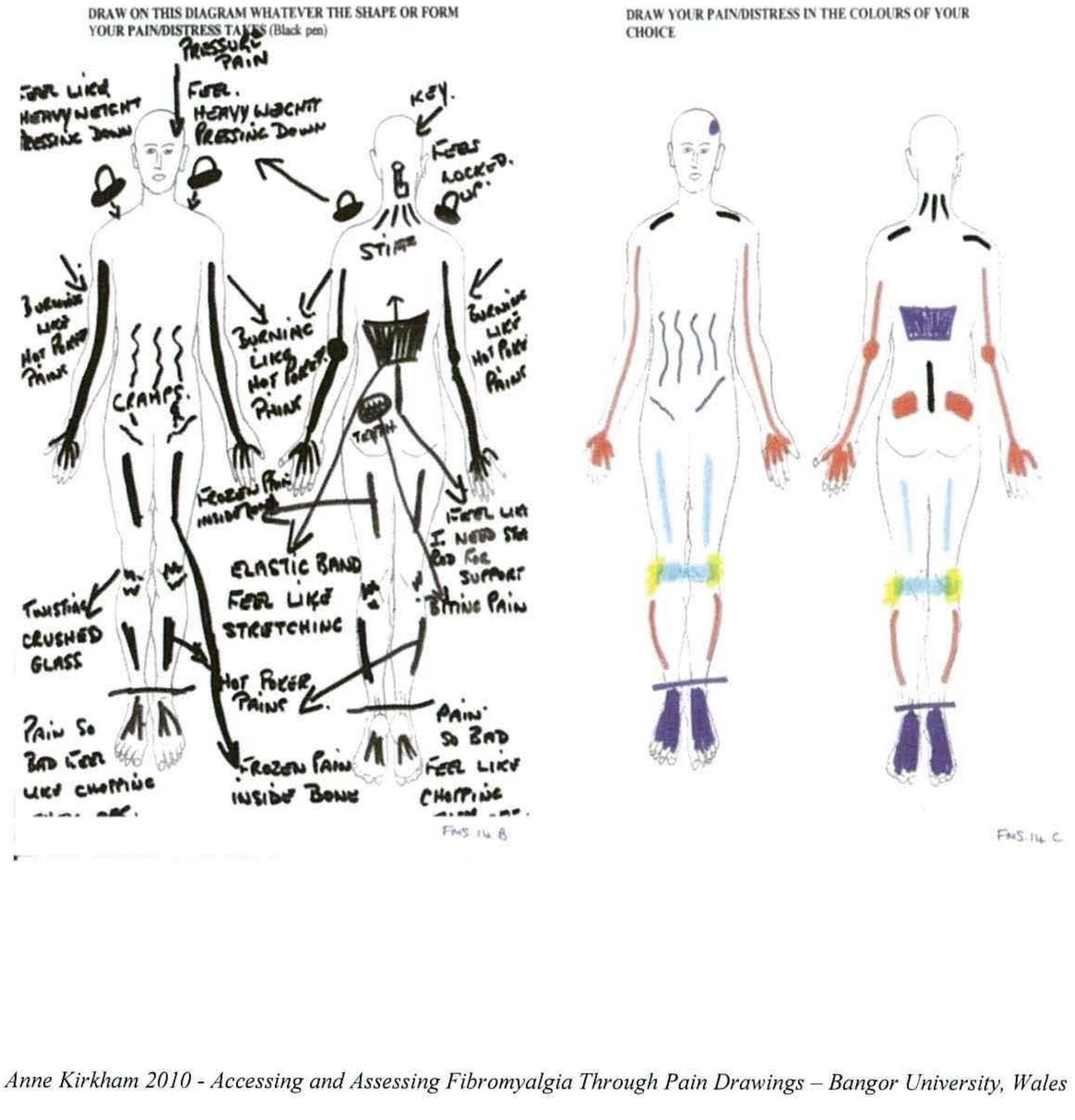


DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

Fig 2.10, below, was drawn by participant 30 who uses images of weights for heavy pressure; a lock and key for her neck feeling locked up; a hot poker for burning pains; twisted crushed glass for knees feeling twisted; elastic band across back to show the feeling of a need for stretching; back feeling like it needs metal rod for support; frozen pain inside bones; pain so bad in feet wants to chop them off; left buttock feels like teeth biting pain to express her pain and distress.

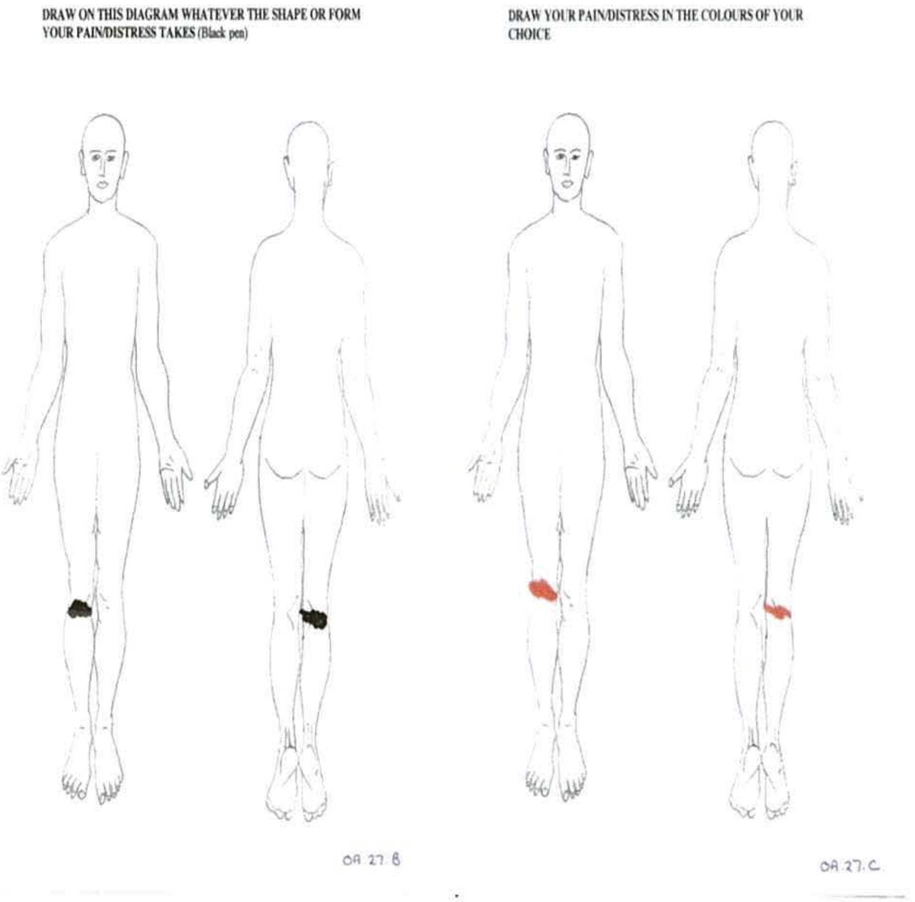
Figure 2.10 FM Participant (30) - Drawings 2 and 3



Observations on individual OA drawings

Figure 2.11 below shows the drawings of participant 16 who has OA of the knee. Figure 2.12 below shows the drawings of participant 20 who has OA of the hip. Note that all the markings are organic, in that they are simple lines, drawn on either the hip or the knee area, that correspond with the osteoarthritic joint that is going to be replaced. These two drawings are representative of the way in which all participants in the OA group drew their pain.

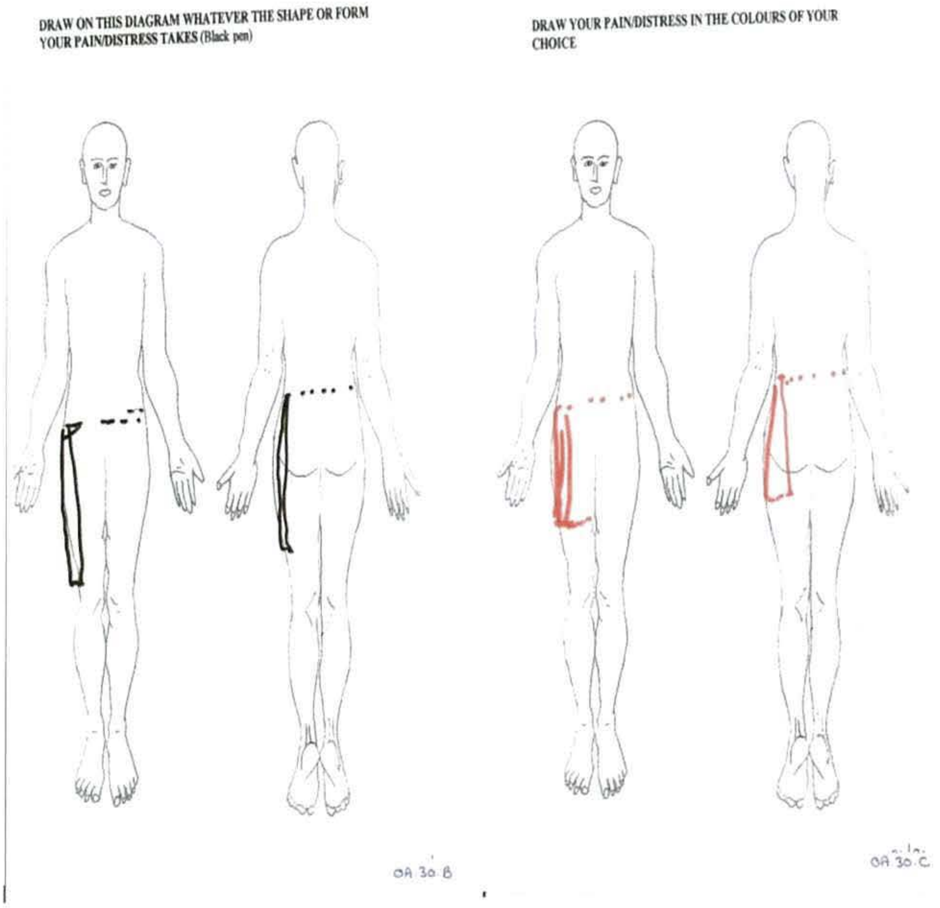
Figure 2.11 OA Participant (16) - Drawings 2 and 3



DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

Figure 2.12 OA Participant (20) - Drawings 2 and 3



DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

Representative Sample of Complete set of FM and OA drawings – individual patients:

Figures 2.13 below show the complete set of 4 drawings by FM participant 10. Figure 2.14 shows the complete set of 4 drawings by OA participant 22. The figures are representative of the drawings made by all participants in each patient group.

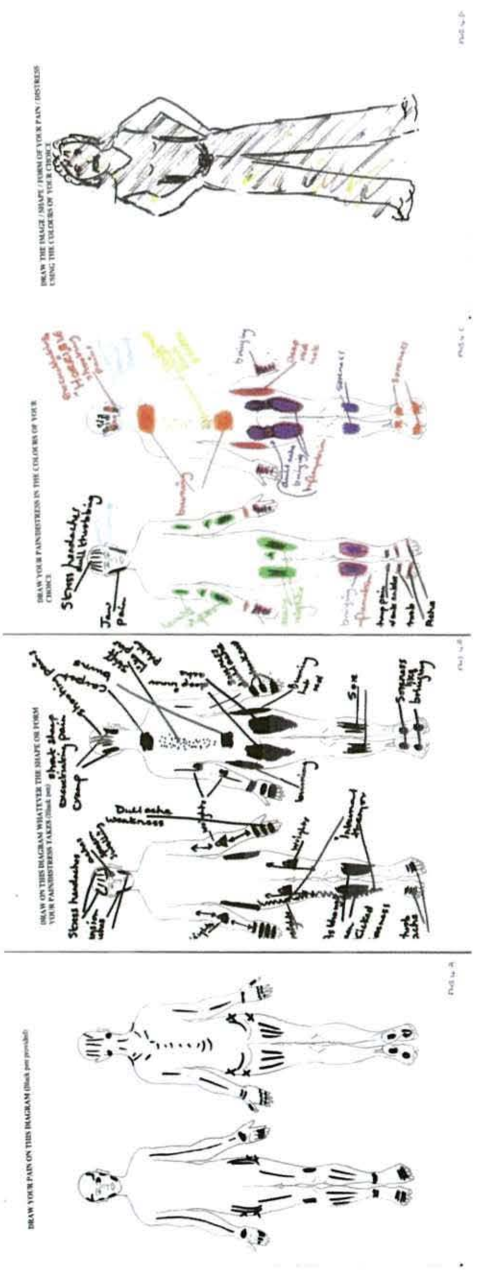


Figure 2.13 Drawings of FM participant 10

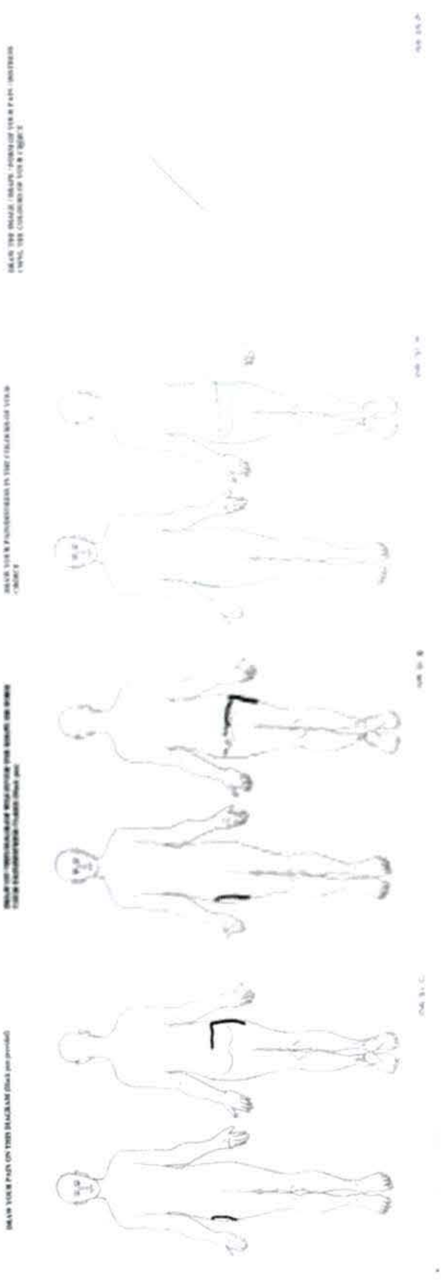


Figure 2.14 Drawings of OA participant 22

Observations of images drawn on blank page by FM participants:

Fourteen of the sixteen FM participants drew an image of their pain on the blank page. Assessment of these images by the researcher and independent assessor identified that there were three distinct themes. Twelve of the drawings could be classified into one of the following groups: Imprisonment; Knives/stabbing; Black depression. These are shown in Figures 2.15, 2.16, 2.17 below.

Figure 2.15 Images of FM Participants Depicting Imprisonment/trapped in body

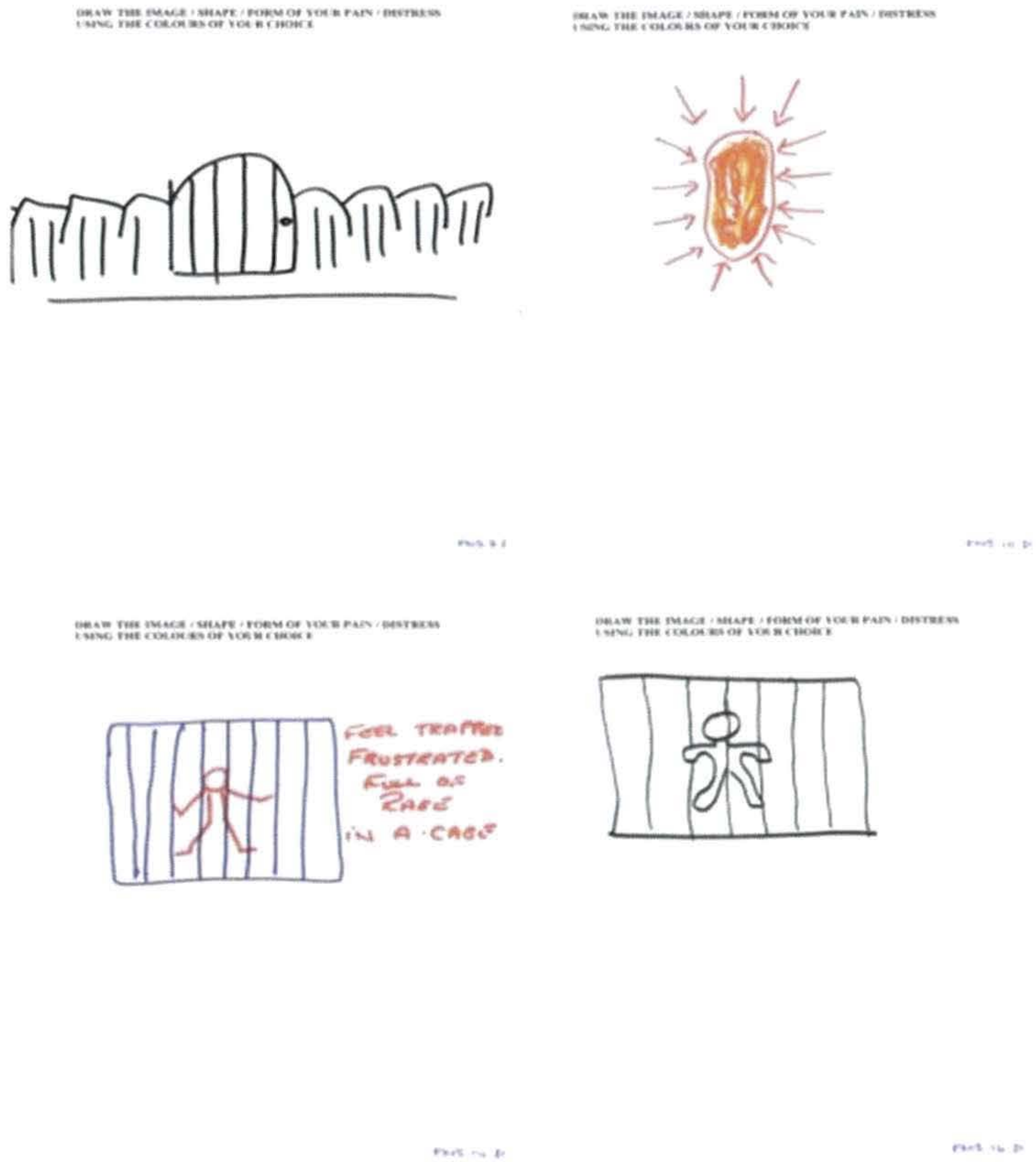


Figure 2.16 Images of FM Participants Depicting Knives

Figure 2.17 Images of FM Participants Depicting Depression

Observations of images drawn on a blank page by OA participants

No images were drawn by any of the OA participants as they were either unable to relate to the concept of 'drawing' pain or not motivated enough to do so.

Margolis and Ransford Scoring

Inter-observer reliability analysis

Inter-observer reliability analysis was performed on the Margolis and Ransford pain drawing scores recorded by the researcher (observer 1) and by the independent assessor (observer 2). Inter-observer means and standard deviations for the Margolis and Ransford scores of the pain drawings; the out-body markings and phrase counts as measured by intra-class correlation coefficient (Chronbach's alpha) and independent t-test on actual overall differences between scores on each rating category are shown in Table 2.3 below.

TABLE 2.3

Inter-observer agreements for Margolis, Ransford and Visual assessment systems

Scoring System	Mean Diff Obs1-Obs2	sd	Sig t	95%CI	ICC(alpha)	Sig. F<
Margolis 1	-0.16	1.139	0.444	0.998 to 0.999	0.999	0.001
Margolis 2	-0.22	0.751	0.109	0.951 to 0.988	0.976	0.001
Ransford 1	2.90	10.36	0.119	0.831 to 0.960	0.921	0.001
Ransford 2	0.38	2.166	0.335	0.987 to 0.997	0.993	0.001
Out-Body 1	3.80	6.626	0.003	0.369 to 0.885	0.789	0.001
Out-Body 2	2.40	3.435	0.001	0.508 to 0.939	0.891	0.001
Phrases 1	0.13	0.421	0.103	0.767 to 0 .945	0.892	0.001
Phrases 2	-0.16	2.034	0.667	0.985 to 0.969	0.985	0.001

Margolis 1 – Includes the scoring of drawing 1 from all 32 participants.

Margolis 2 – Includes the scoring of drawing 2 from all 32 participants.

Ransford 1 – Includes the scoring of drawing 1 from all 32 participants.

Ransford 1 – Includes the scoring of drawing 1 from all 32 participants.

Out-Body 1 refers to the number of occurrences of images being drawn outside the simple body outline on drawing 1 from all 32 participants.

Out-Body 2 refers to the number of occurrences of images being drawn outside the simple body outline on drawing 2 from all 32 participants

Phrases 1 refers to the number of phrases written on or around the simple body outline on drawing 1 from all the 32 participants

Phrases 2 refers to the number of phrases written on or around the simple body outline on drawing 2 from all the 32 participants

*(Phrases refer to the number of uses of text i.e. words or phrases).

Agreement between the researcher's scores and those of the assessor is more than 90% valid in most cases. However, there was some disagreement with the 'out body' rating reliability reflecting the subjective nature of this score. Intra-class correlation was employed as opposed to Cohen's kappa as the data table was asymmetrical.

Table 2.4 below shows the results of the normally distributed data. It is clear that the FM participants scored significantly higher than the OA participants with both the Margolis and Ransford scoring systems on drawings one. This identifies the non-organic drawings of the FM group from the organic drawings of the OA participants. The FM participants scored significantly higher than the OA group with the Ransford scoring system on drawing two and on the out of body markings on drawing two. This further indicates the difference between the non-organic drawings of the FM participants and the consistent organic drawings of the OA group.

Table 2.4 Normally Distributed Data – FM/OA Margolis and Ransford Scores

Scoring System	FM		OA			Sig
	m	sd	m	sd	t	p<
Margolis 1	36.1	6.042	4.6	2.25	19.52	0.001
Margolis 2	34.4	8.603	4.7	2.04	13.45	0.001
Ransford 2	35.8	12.774	4.1	2.17	9.78	0.001
Out Body 2	08.2	5.427	1.3	0.95	5.01	0.001

Table 2.5 (see below) shows the results for the non-normally distributed data. The FM participants scored significantly higher than the OA participants with the Ransford scoring on drawing two; the out of body scores on drawing one and the phrases used on drawing two. There was no significant difference recorded between the two groups for the scores of phrases used on drawing one.

Table 2.5 Non-Normally Distributed Data – FM/OA Margolis and Ransford Scores

Scoring System	FM		OA			Sig
	M	SD	M	SD	z	p
Ransford 1	26.0	9.94	3.7	1.99	-4.63	0.001
Out Body 1	9.5	8.55	1.6	1.16	-3.57	0.001
Phrases 1	0.3	0.89	0.0	0.00	-1.79	0.381
Phrases 2	9.0	9.74	0.0	0.00	-3.67	0.002

Discussion

FM patients often find it difficult to verbally communicate their pain. Correspondingly, doctors find it difficult to understand/comprehend their explanations. The assumption in this study is that accurate communication of pain improves diagnosis and treatment. The study uses a simple body outline diagram in a novel way to explore how drawings and images with or without colour, to represent and reflect pain allows patients to express their pain and distress to their doctors. The task of drawing inner distress and pain is accessed to increase the options available for doctors when diagnosing FM.

The main objective of this study was to identify and explore the differences between the ways in which women with FM and women with OA of the hip/knee use images and drawings primarily within a simple body outline diagram to express their pain/distress. It was hypothesised that women with FM would relate to this method of expressing their pain and distress in a different way to the one in which women with OA would react. The results of this study confirmed the hypothesis, in that there were significant differences between the two patient groups reflected in the way they used images and drawings to express their pain. Specifically, it was clearly shown that women with FM illustrated their pain and distress more expressively in comparison to women with OA who used simple markings only in the drawings. Indeed, both the author and independent assessor were in full agreement as to which category of diagnosis each pain drawing belonged; and it was not necessary to place any of the drawings into the third 'unclassifiable' category.

Each of the three methods of assessment i.e. Visual, Margolis and Ransford identified and separated the two patient groups. In addition to being 100% accurate in identifying whether drawings were by FM or OA patients, the visual assessment of drawings provided the most comprehensive information on the patient's pain experience.

The results of this study show that the drawings of pain and the images chosen to represent pain by the FM group were markedly different in appearance to those chosen by the OA group. Whilst some FM participants found it difficult to actually draw a picture, the results show that they all chose an image to describe their pain. Fourteen of the sixteen

FM participants drew expressively on the blank page; whilst all the OA participants were unable to draw anything on the blank page. The FM drawings were creative and dramatic. Images of knives, daggers, volcanoes, lightning and crushed glass was drawn inside and outside the body outlines. These images were often accompanied by written descriptions.

All FM participants were able to draw images and pictorial representations to express their pain/distress; with many knowing immediately what colours they wanted to use to represent the different characteristics of their pain. The only difficulty for some of the FM participants was in being able to draw the image they had in mind as well as they would have liked. To compensate for their 'not having the drawing skills' many FM participants included a description of the image they had drawn or wanted to draw.

In contrast, the OA participants found the concept of drawing an image to depict their pain difficult to comprehend. Strikingly, not one of the OA group could think of an image in relation to their pain. The OA participant drawings are anatomical and precise, they used simple lines to identify the areas of pain, and these markings were identical on each of the three body outlines. However, despite their inability to draw images of their pain and distress, all OA participants were able to choose a colour to represent the area of their pain. Twelve of the patients chose red or black, another three chose green or blue only one used more than one colour choosing both red and orange. It is not clear from this observation why none of the women with OA was able to draw a single image or even to suggest an image that would help describe their pain. The dramatic simplicity of their drawings could indicate the OA participants did not feel the need to use dramatic pain drawings to express their pain experience. The reason could be that having their condition medically been diagnosed and knowing the source of their pain and that soon they would receive a cure for it by having a joint replacement.

The FM group scored significantly higher than the OA group on the VAS for measuring emotional pain (8.0 v 5.7); whereas the OA group scored slightly higher on the VAS for physical pain (8.7 v 8.3) (Table 2.1). These results show that the differences between the ability of the two groups to draw an image of their pain are not accounted for by the subjective scores for the severity of the physical pain experienced. However, it is suggested that the impetus for FM participants to draw so extensively, stems from the level of emotional distress caused by their condition. Further, the lack of medical understanding of their condition may be contributory factor in the FM patients' greater willingness to explain their pain.

The use of the Margolis scoring system in this study showed a distinct difference between the two patient groups. The Margolis system was limited in its quantitative analysis of drawings by FM patients. Because the Margolis system does not formerly score regions outside the body outline it fails to accurately score drawings by FM patients whose perception is that the pain they experience and the sensitivity they feel is outside their body. They draw using imagery such as flames, lightning bolts, volcanoes and streams of dots, outside the body. The Margolis system is also limited in the types of non-organic pains experienced by FM - such as throbbing, pulsations, energy surges, cold and hot episodes, sudden fatigue - are not typically localised at a single joint, vertebra, muscle group or tendon insertion point. As a consequence the drawing of such types of pain will commonly cover a large number of the Margolis regions for one pain type.

From Table 2.4 it can be seen that FM participants in this study scored an average of 35 Margolis points; while the OA participants in the study scored an average of 4 points. The very large difference in Margolis points is intuitively obvious by simple observation of the FM drawings. In a world which prefers to quantify as many aspects of the patients diagnosis, the Margolis point scoring of these types of drawings for patients with different pain conditions, may allow a simple quantified value for the extent of pain, with high scores indicating patients who might best be further diagnosed by other FM related methods such as the ACR criteria for FM.

This study also used a modified Ransford scoring method. The classical Ransford scoring system neither incorporates the measurement of individual markings drawn outside the body line nor does it give much weight to the use of words or phrases. In the modified Ransford scoring system used in this study a value point was assigned to each individual marking outside the body line and a point to each phrase used. The results of the modified Ransford scoring method clearly showed a significant difference between the FM and OA participant groups. It is worth noting that, for the FM group, the modified Ransford scores for drawing one produced normally distributed data; while the data from drawing two was non-normally distributed. In addition the Mean Ransford score for drawing one was about 26 points while the score for drawing two was nearly thirty-six points (Table 2.6)

Table 2.6 Modified Ransford Scores

Scoring System	FM		OA			Sig
	M	SD	M	SD	distrib	P
Ransford 1	26.0	9.94	3.7	1.99	-4.63(z)	0.001
Ransford 2	35.8	12.77	4.1	2.17	9.78 (t)	0.001

This difference in mean modified Ransford scores for drawings one and two in the FM group must be attributed as follows: the difference in the set of instructions given on each page; the patients understanding of the instruction; and the type of expression used. Specific instructions were written as follows: Page one – 'Draw your pain on this diagram' (black pen); Page two – 'Draw on this diagram whatever shape or form your pain/distress takes' (black pen) i.e. on page two, participants are instructed not only to draw their pain, but also to draw their distress. In doing so and they were told to use any shape or form. Drawings on pages were done in black ink only. The first page gave simple instructions; the second page gave broader creative license to draw pain. This shows two things. Firstly, within the FM group the level of complexity of drawings, as measured by the modified Ransford scoring system, reflects the instructions given. Secondly, it shows that FM participants are far more likely than OA participants to be encouraged by the instructions to use form and image in any way they liked. It is interesting to note that in contrast to the Ransford scoring the Margolis scoring system did not record much difference between drawing one and drawing two.

Thus there is potential for deeper diagnosis of individual FM patients where the individual difference in modified Ransford score for drawings one and two can be compared (as a ratio, for example) to identify patients who have a strong tendency to be expressive with image or text, when given an opportunity.

The McGill Adjective questionnaire identified a significant difference between the two groups. Table 2.1 shows that the FM group had a mean score of about forty-eight. This is more than double the OA groups mean score of about twenty-two. The McGill adjective questionnaire offers a long list of adjectives for the patient to use to describe their pain. Many of these adjectives describe emotional states and it is generally understood that high McGill adjective scores correlate with pain conditions that are not only complex and extensive, but also emotionally perceived. Because the McGill scores in the FM group indicated high levels of emotional and physical pain it could be that the dramatic and distinctive pain drawings of FM patients reflected their need to communicate the distress and anguish they experience as a result of their pain not being fully recognised or taken seriously. A perceived lack of understanding, compounded by the absence of available medical evidence i.e. an explanation based on a specific diagnostic test- such as x-ray or blood tests – could explain why FM sufferers are experiencing a catalogue of symptoms, creating a deep anxiety for FM sufferers and equally frustration for medical professionals.

Previous use of the pain body outline involved the patient marking the body outline with a selection of predefined symbols which represented certain pain sensations i.e. pins and needles, numbness, burning, stabbing and aching. This work explores the use of pain drawings in a unique way by allowing the patient the freedom to include images and words to better describe their pain/distress. A blank body outline was used but the participant was neither restricted to using pre-defined symbols nor given explicit guidelines. Thus freedom of expression was encouraged to help the patient communicate their pain and distress. The scoring systems of Margolis and Ransford quantified markings to provide a numerical score for each drawing enabling it to be classified as either organic or non-organic. FM participants were easily able to relate to this new method of expressing their pain distress. They immediately knew what they wanted to draw despite sometimes not being able to draw very well, i.e. not being 'good artists'. This method clearly offered FM sufferers a new means of expression. It enabled them to 'open up'; it freed them to explore and communicate their pain distress, emotions and feelings. In contrast, the OA group, despite finding it easy to mark the areas of their pain found it 'impossible' to think of an image that represented their pain. Many asked "How can you draw pain?"

This method of expression not only allowed patients the freedom to draw the various body regions affected by each pain but also gave them the opportunity to express the qualitative and emotional nature of the symptoms. For FM patients these symptoms are numerous and greatly varied in nature and in terms of times and locations throughout the patient's body.

Certain limitations to this study should be considered: All thirty-two participants in this study were interviewed using the same format and by the same researcher. By standardising the format of the assessment and by having only one interviewer the effects of the researcher on the results cannot be determined. In addition, all sixteen FM participants were recruited from the same clinic, where their FM diagnosis had been determined by one specialist. Accordingly, an area for future research might be larger studies using the same methods with more than one interviewer. Such studies would allow the interviewers to be blinded with respect to the diagnosis of FM or non-FM.

It could be considered that another limitation of this study was that the use of medication by the participants was not recorded. Therefore, it might be that some members of each group were on medications such as steroidal anti-inflammatory drugs (NSAIDs), muscle relaxants and non-narcotic analgesics. It is possible that participants of the groups were taking more pain medication than the other. This would be affecting the self-reported levels of pain. It might, therefore, be suggested use of medication and its effect on levels of physical pain influenced the participants' tendency to draw elaborate pain representations.

The reliability of the results of the present study could also be limited in that participants were not age matched. The women in the OA group were significantly older than the women in the FM group. The average age of the OA group was over sixty-eight; years whereas the average age of the FM group was fifty-four years. Nevertheless, this does not itself explain the demonstrated ability of the FM patient group to draw graphic images in order to express their pain and distress.

Further research is required into this method of expressing pain/distress. A larger sample size of FM participants could be used and their pain drawings could be compared with those drawn by a different patient group. This different group should also suffer from a condition that causes severe and chronic full body pain i.e. rheumatoid arthritis. Why FM participants image, visualise and draw their pain/distress in such a way, and whether or not this way is unique to them as a patient group, is most definitely an area worthy of further research.

In conclusion, the results show that women with FM clearly draw/image their pain in a distinctive way that contrasts to the way in which women who suffer with OA draw/image their pain. The OA patient group was specifically chosen for this study because of the organic nature of their condition was easily identified. The probability that the OA sufferers' pain would be restricted physiologically to the expected locations was also a contributing factor in their selection. Identifying FM patients from their distinctive pain drawings is an area that should be explored further as it has the potential to enhance communication between the patient and the physician which is proven to lead to greater satisfaction and an increased adherence to and compliance with medical treatment (Mead, Bower, 2000).

CHAPTER THREE

A QUALITATIVE STUDY EXPLORING THE USE OF PAIN DRAWINGS AS A FORM OF EXPRESSION FOR WOMEN WITH FIBROMYALGIA (FM) AND OSTEOARTHRITIS (OA)

Abstract

Objective: Previous research suggests that a 'fibromyalgia personality' exists, and that it is closely linked to chronic stress resulting from overactive lifestyles. Sufferers typically display characteristics such as pathological perfectionism, selflessness/self-sacrifice and willingness to care for others (Van Houdenhove, Neerinckx, Ohghena, Lysens, Vertommen, 2001A, 2002). In many cases a traumatic physical or psychological event triggers the condition (McBeth, McFarlane, Benjamin, Morris, Slimam, 1999). Suppressed feelings or emotions in many cases add to the pain and distress suffered (Van Houdenhove et al, 2002; Nordahl, Stiles, 2007). FM patients often find it difficult to communicate these feelings (Sayar, Gulec, Topbas, 2004) and to express the severity of their pain and distress. This study explores a novel method for women with FM and OA to use the simple body outline (pain drawing) to express and communicate pain/distress.

Method: Thirty two participants were recruited for the study: 16 women from a fibromyalgia clinic who satisfied the ACR criteria for FM; 16 women from a pre-operative assessment clinic for hip/knee replacement who had severe osteoarthritis (OA). Using a simple body outline (pain drawing) participants were given the following instructions: (1) 'draw your pain on this diagram' (2) 'draw the shape or form of your pain/distress on this diagram' (both diagrams were filled in with a black pen); (3) 'draw your pain/distress on this diagram' (using coloured pens); (4) 'draw the image/shape/form of your pain/distress' (plain sheet of paper, using coloured pens). A semi structured interview was then conducted to discuss their pain drawings and feelings experienced whilst completing this exercise.

Results: There were significant differences between the two patient groups in the way they used images/drawings to express their pain. Qualitative analysis of their responses taken from the semi-structured interviews revealed that women with FM were better able to relate to this method of using the pain drawings in order to describe their pain than were women with OA, finding the process therapeutic.

Conclusion: The main observation of this study is that FM participants given the opportunity to express their pain/distress using this method gave an emotional response. FM sufferers related well to this exercise in comparison the OA group. Not only were the

FM group able to image and draw representations of their pain they were also able to relate well to this method as a means to vocalise and communicate their emotional distress. In other words this exercise enabled the FM patient group to 'connect' with their pain in a way that they had not previously experienced; and in turn freed them to speak about the traumatic impact of this condition on their daily lives during the semi-structured interview. Most important is the potential of this method for women with FM to clearly express and communicate the symptoms of their pain to their doctors and care providers.

Introduction

This chapter presents and discusses the findings of the semi-structured interview conducted with the participants after the completion of the drawing exercise reported in chapter two. The study was looking at a new method of using the simple body outline that allowed women with women with fibromyalgia (FM) and osteoarthritis (OA) a freedom of expression when drawing their pain and distress. The study explored the possibility that drawing the images or representations of their pain and distress on the simple body outline could prove to be a therapeutic process for women with FM and OA and a form of communicating more accurately their symptoms, pain and often emotional distress to their doctors and care providers.

Fibromyalgia (FM)

FM is a chronic, complex pain condition for which there is neither an obvious physical explanation nor a single identifiable causative agent. The pain associated with FM is described as a diffuse aching or burning, and the intensity of the pain can vary from day to day, in addition to changing location, becoming more severe in the parts of the body that are used the most (i.e. the neck, the shoulders, and the feet). Women with FM also have a heightened sensitivity to pain (hyperglesia) and may present with a wide range of comorbid conditions such as tension headaches, migraine, irritable bowels syndrome, overactive bladder, pelvic pain, premenstrual tension syndrome, and restless leg syndrome. The combination of pain and multiple other symptoms leads to more extensive medical investigations, the results of which are nearly always normal.

One of the main challenges of women with FM is the lack of credibility that confronts them as they seek diagnosis and confirmation of their illness from the medical profession. Despite extensive research and official recognition of the existence of the condition since 1990 when the ACR set diagnostic criteria, there is still often a lengthy process from the onset of a person's symptoms to their receiving a authoritative diagnosis. The miscommunication or a lack of understanding in the provision of care has serious implications for woman with FM. Their lives and their abilities to manage the symptom of pain in key areas of their everyday life both at home and at work are deeply impacted.

Pain drawing

The simple body outline (pain drawing) is a tool frequently used in pain clinics to assess the location and severity of a patients' pain. Previous studies using the simple body outlines have been concerned mainly with identifying the sensations and areas of pain. During this study the participants had total freedom to draw any image or shape that they felt best described and expressed their pain and distress on the simple body outline; it was for the patient to draw an image which would more accurately express her experience of pain. No restrictions or suggestions whatsoever were placed onto the participants during the completion of this exercise. In addition, each participant was allowed to write a description of their image by the body outline if they felt a further explanation was needed (see chapter two).

Prior to this study the simple body outline was mainly used for the patient to note the area and pain sensation where a choice of symbols representing different pains are pre designated (Melzack, 1975), or the patient simply shades the affected area (Udén, Åström, Bergenudd, 1988). The latter is a method widely used for identifying the location of back pain before deciding on the best form of treatment, and to establish whether surgery would be beneficial to the patient. Alternatively to find out whether the psychological content of the condition was high enough to indicate that the patient would not respond to surgery and that other forms of treatment could be considered a better option (Udén, Åström, Bergenudd, 1988). In using the standard method the patient's choice in how to express and draw their pain and distress is restricted.

Emotional expression

Within the fields of psychology and psychotherapy, the expression of emotion has been an important area of focus, one of the earliest examples of this is 'Gestalt' therapy (Perls, Hefferline, Goodman, 1951). Exploration of emotional disclosure outside of the interpersonal context of therapy has received more attention in recent years i.e. the use of prescriptive and creative tasks to encourage emotional expression of the individual as in writing about a traumatic or stressful experience (Pennebaker, Beall, 1986).

The therapeutic value of emotional expression through journaling has proven itself to be valuable in treating a range of patient populations (Esterling, Antoni, Fletcher, Margulies, Schneiderman, 1994). For example, emotional expression and written emotional disclosure has been well researched in the treatment of various cancers. It has been found to be of particular benefit in the treatment of breast cancer (Stanton, noff-burg, Sworowski, 2002; Walker, Nail, Croyle, 1999). A random controlled trial (RCT) where 234 patients with cancer were randomized into three groups to explore whether narratives in which patients either (1) spent at least twenty minutes, once per week, writing about how cancer affected their lives; (2) completed the McGill pain questionnaire; (3) control group in which patients attended weekly medical visits during which they received usual customary care. They found that pain intensity and sense of well being were similar in all groups before and after treatment. Analysis of subgroups showed that patients whose narratives had high emotional disclosure had significantly less pain and reported higher well being scores than patients whose narratives were less emotional (Cepeda, Chapman, Miranda, Sanchez, Rodriguez, Restrepo et al, 2008).

The benefit of psychological and physical health using these interventions is well documented (Esterling, L'Abate, Murray, Pennebaker, 1999; Francis, Pennebaker, 1992: Greenberg, Wortman, Stone, 1996; Pennebaker, Kiecolt-Glaser, Glaer, 1988). A meta-analyses that examined the effect of writing on health found that doing so improved physical symptoms, but the magnitude of effect was small (Frising, Borod, Lepore, 2004; Smythe, 1998). In most studies included in this analysis the patients wrote about stressful experiences or their suffering and how their diseases affected their lives (Richards, Beal, Seagal, Pennebaker, 2000; Pennebaker, 1999; Francis, Pennebaker, 1992; Pennebaker, Barger, Tiebout, 1989).

The high rates of trauma observed in FM patients (White, Carette, Harth, Teasell, 2000) suggest that an intervention targeting cognitive and emotional processing of past traumas might be particularly effective for this patient population. The writing referred to as 'emotional writing' or 'emotional disclosure' where the patient writes about a traumatic or stressful event has proven to be an effective intervention in the treatment of some people suffering with both FM and RA (Broderick, Doerte, Junghaenel, Schwartz, 2005). However, for other people in this population this therapeutic intervention might not be as effective as some find the use of words may be a greater obstacle than catalyst for accessing feelings.

Although simply drawing is a method frequently used within art therapy, its use as an independent intervention to elicit emotional expression is an area that has not been extensively researched. The possibility that drawing might offer an alternative or complementary approach as a means of processing stressful experiences was explored in a study comparing both journaling and drawing. The study by Pizarro highlighted the value of examining various factors that might influence the effectiveness of drawing interventions i.e. number and length of sessions, content of instructions, type and range of art media included (Pizarro, 2004). It could be argued that because traumatic events are stored in memory as imagery, expressive art processes may provide a particularly effective method for processing and working through such experiences. Indeed, some would argue that art provides a more powerful method of catharsis than words alone (Appleton, 2001). A review of seventeen studies by Reynolds provided good evidence supporting its effectiveness for emotional expression which resulted in reducing psychological symptoms (Reynolds, Nabors, Quinlan, 2000).

Patient Doctor Communication

Many chronically ill and disabled women seek confirmation of their condition within the health care system, particularly those with less well understood diseases such as FM. These women need their symptoms to be acknowledged as being 'real' and to have what they are suffering be recognised as a legitimate disease or illness by their doctor and health care providers. Illnesses which are often ill-defined or difficult to diagnose are delegitimized when the patients are patronized and their symptoms not taken seriously as they are treated as being insignificant 'everyday aches and pains; or viewed as being psychosomatic (Ware, Sherbourne, 1992).

The difference in language used by doctors and patients often poses particular challenges when attempting to diagnose difficult or medically unexplained conditions (Begum, 1999). After the onset of a chronic illness such as FM the sufferer with virtually no preparation is forced to discuss the most detailed aspects of their physical reality with their medical providers. Since there is often no common language of pain between medical professionals and lay people it can be difficult for patients to explain or describe the impact of a particular symptom.

Sometimes women with FM are misunderstood by their doctors because patients and health care practitioners describe pain using different "interpretive frameworks and conceptual worlds" (Johansson, Hamburg, Westman, Lindgren, 1999). Doctors and patients even describe important symptoms such as pain and fatigue, using very different terms (Johansson, Hamburg, Westman, Lindgren, 1999). Therefore communicating pain verbally can be a challenge for FM patients.

A significant implication of miscommunication is that a patient's symptoms may not be taken seriously, or possibly delegitimized as a result of this difference in understanding of pain (Hellstrom, Bullington, Karlsson, Lindqvist, Mattsson, 1998). Further, because such experiences of pain impact on the women in so many aspects of daily life, a misjudgment of its magnitude can result in incorrect actions being taken in terms of treatment regimens and referrals or of no action at all.

It was shown in chapter two that women with FM related well to the method of expressing their pain and distress through drawing images and representations of pain on a simple body outline. The result being that the drawings by women with FM were very expressive, flamboyant and representative of a non-organic pattern of pain that could be easily identified when compared to the drawings made by the women with OA whose drawings consisted of simple lines following an organic pattern (Ransford et al, 1976).

This chapter explores and reports, the feelings and thoughts of the participants during the completion of the drawing exercise on the simple body outline. In addition to discussing their opinions of this method as a form of patient-doctor communication (This information was recorded during a semi-structured interview immediately following the drawing exercise).

Method

Participants

Sixteen female patients with FM attending the weekly Fibromyalgia Clinic of the North West Wales NHS Trust were recruited by the consultant rheumatologist running the clinic. Sixteen female patients with osteoarthritis (OA) awaiting hip or knee replacement were recruited from the preoperative joint replacement clinic at Ysbyty Gwynedd - district general hospital - by the researcher.

The inclusion criteria for the FM group were that they met the American Rheumatology College (ARC) diagnostic criteria for FM (Wolfe et al., 1990). The consultant rheumatologist assessed this. The inclusion criteria for the OA group were that they had OA of either the knee or hip which was severe enough to warrant joint replacement. The age limit was between 18 and 75 years old inclusively. Participants with systemic diseases likely to produce pain (e.g. rheumatoid arthritis or other inflammatory forms of arthritis) were excluded.

Study Design

Qualitative data was collected using a semi-structured interview schedule, with the aim being to extract in-depth free responses revealing the participant's experiences, perceptions, opinions and feelings (Appendix E). Participants were asked to describe the experience of completing the pain drawings and meanings were elicited from their individual responses. These interviews were recorded and later transcribed verbatim to ensure no loss of data. Because of the individual nature of the study, which sought to identify individual experience and meaning, the preferred qualitative method employed is Interpretative Phenomenological Analysis (IPA).

IPA is an idiographic approach to psychological qualitative research (Smith, 1996). The central objective of IPA is to offer insights and to gain a deeper understanding of how a person makes sense of a personally significant phenomenon (Reid, Flowers, Larkin, 2005). Therefore, the principle concern in IPA is the meanings which those significant experiences hold for the individual (Smith, Osborne, 2003). It has its theoretical origins in phenomenology and hermeneutics, and key ideas from Husserl Heidegger, and Merleau-Ponty are often cited (Smith, Eatough, 2007).

Smith and Osbourne provide an excellent suggestion for analysis qualitative data using IPA (Smith, Osbourne, 2008). First, they recommend that emergent themes are extracted from detailed analysis of the first case. Then connecting themes are drawn together, this may involve clustering themes in a more analytical or theoretical manner rather than chronologically ordering themes. These emergent themes can then be used to orient subsequent cases. Analysis of subsequent cases also permits the extraction of other emergent themes not identified in the first case. Finally, the themes are translated into a narrative account where the researcher plays an important role in interpretation.

In qualitative research the interviewer can be viewed as an instrument. During each interview, the researcher maintains empathic neutrality and is non-judgmental. However, the researcher is also responsive to verbal and non-verbal cues from each participant (Guba, Lincoln, 1981). The researcher is also adaptable to the diversity of narratives during each interview, and, hence, greater flexibility is allowed to gain a holistic view of the participants' experiences. As there are no standardized instruments developed to help us understand the phenomena of pain in FM and the intervention employed within this study i.e. the simple body outline, a qualitative methodology was used in the study design, data collection and analysis.

This naturalistic approach permitted flexibility in design thus reducing bias from predetermined constraints on the findings. Second, the key processes of empathic neutrality and mindfulness ensured that participants were shown openness, respect and vicarious understanding without judgment. Furthermore, inductive analysis and creative synthesis were crucial to discover emergent themes and interrelationships throughout the data, which were guided by analytical principles rather than rigid rules.

The study was approved by the Local Ethics Committee of North West Wales NHS Trust. All participants gave written informed consent before taking part in any interviews.

Procedure

All participants who met the inclusion criteria received an information sheet detailing the purpose of the study and what they would be asked to do if they decided to participate. After a period of no less than 48 hours participants were contacted by the researcher, and if they agreed to participate were sent a consent form for them to sign and to return to the researcher. Recruitment of both groups took place simultaneously. Participants were interviewed in order of recruitment and were allocated consecutive numbers from one to thirty-two. A choice of times and locations for the interviews was offered. The interviews were conducted either in a private room at the local hospital or in the participants' own home. Each participant was interviewed once and for no longer than 90 minutes. During the interview participants were asked to complete the following:

Pain drawings

Participants were invited to draw their pain. Each participant was given four pages of paper. On three of these pages was a silhouette/ body outline (see Figure 2.1) the remaining one page was blank. Participants were given coloured pens - black, red, orange, yellow, green, blue, purple and magenta - with which to complete the pain drawings.

Each participant was given pages numbered one to four. On each of pages one to three there was a simple body outline diagram. Page four was blank. Specific instructions were written on each of the pages as follows:

1. Page one - Simple body outline diagram 'Draw your pain on this diagram' (black pen)
2. Page two – Simple body outline diagram 'Draw on this diagram whatever shape or form your pain/distress takes (black pen)
3. Page three – Simple body outline diagram 'Draw your pain/distress in the colours of your choice' (coloured pens)
4. Page four – blank page 'Draw the image/shape form of your pain/ distress using the colours of your choice'. (coloured pens)

Those participants who had drawn an image on page four were requested to 'Describe your image explaining what it means to you'. The researcher recorded the response in writing.

A semi-structured interview (Appendix F) was completed where participants were asked a further thirteen questions on their personal experience of the pain drawing method as a way to communicate their pain and distress.

Data Analyses

All the interviews were recorded and transcribed. The present author listened to each interview while reading each transcript to ensure that the data was accurate and no data was missing. The transcripts were analysed using an Interpretative Phenomenological framework (IPA).

Results

The results of this study are presented in two sections. The images drawn and colours used by each participant are presented in Appendix A. The results from the semi-structured interview are then presented sequentially in order of the questions that were asked to each participant. OA participants not only drew very simple, limited markings depicting specific organic pain, they also did not find the review of the drawing process animating. The results discussed below are primarily those of FM patients. Throughout the analysis of the results the common themes are presented which were identified throughout the interview. Although in qualitative research it is common practice to discuss and interpret the results within the results section (Knafl, Howard, 1984), interpretation of these results will be discussed throughout the discussion section.

Summary Results of Participant Narratives:

Q. What do the images you have used represent to you?

After completing the drawings each participant was asked what the images they had drawn represented. This question allowed participants to further explore and identify the meaning attributed to their image. Four main themes arose from their narratives. These were action, quality of pain, cause of pain and emotional and cognitive effect of pain.

Action:

Participants described their image as being dynamic and containing some movement. Although the images were static two-dimensional images on a piece of paper, the meaning and interpretation was given form.

> *It's like a hammer smashing bricks. The back of my neck being cut open with a knife.*
>
> *Heavy machine rolling up leg.*
>
> *It is moving all of the time, it doesn't feel very safe.*
>
> *Angry frustrated with myself, almost like being forced into a smaller space, compression.*

Participants describe the movement of what they were experiencing, the quality of information they expressed, thus would not have been obtained by standard questionnaires used in routine practice.

Quality:

Another theme which emerged related to patients description of the quality of their pain. The rich descriptions related to the type of pain the individual was experiencing and their personal interpretation.

> *The pain is like lightning strikes.*
>
> *Fire in the head like a volcano ready to erupt.*
>
> *Spiky pain, not smooth or smooth running. There are no smooth lines – it is just chaotic – just chaos!*

Cause:

Not only did these participants describe the quality of their pain, they also were able to identify a cause, the cause again is their own personal meaning and not reflective of any anatomical reasons for the pain they were suffering at the time of the interview.

> *The image of a dagger in a cushion.*
>
> *Feet kicked in back, stabbing knives in hips.*

Affect:

Participant's narratives revealed expressions of thoughts and emotions. Here participants describe how the pain affects them emotionally and cognitively.

> *Feel trapped because of so much pain cannot do the things I want to. Trapped in a cage, my body and doesn't allow me to do the things I want – not just the pain but the fatigue.*
>
> *Me in prison...no way out constant...My body is a prison...my mind doesn't work...everything looks black...the sun is shining out there but I don't see it because I haven't got the strength.*

> *No escape from the pain... you hate your body... you want to control it and it controls you...the lack of control is what I hate most.*

From the first question participants express their pain in a new way. Such rich descriptions of the quality of pain and its affect on them as sufferers would be impossible to represent using conventional clinical measures of pain.

Q. What are the most important emotions feelings that your drawings/colour represent for you?

Two of the main themes presented through the participant narratives were emotion and reasons.

Negative Emotion:

Here participants describe a powerful and negative emotion that represents the image and the colours they used to represent their pain.

> *I feel as if I am fighting all of the time but I cannot see what I am fighting. Dark/black means there is no way out of the pain. I can't see it.*
>
> *Hate for the pain.*
>
> *Anger, definitely frustration, depression...ultra sensitivity... anxiety...tearfulness...and the feelings of being so limited.*
>
> *Frustration...fed up... annoyed with it all and yet I get very depressed but basically frustration and the feeling it will never go away.*

In reading the participants' narratives one gains a sense of fear and anger. This fear and anger often ends up in depression, which was referred to by many of the participants as they reflected on the image that they had drawn.

Reasons:

Many participants also felt the need to provide descriptions of and a rational as to why they felt a particular emotion.

> *I mean it obviously restricts me from doing things I might be able to do and the fear is it will get worse to the point where I won't be able to do things that I want*

to do. I kind of have an image of me at 55 or something just not being able to take the dog out for a walk and being immobile and confined.

It is not what a normal body should look like – I just feel that the body should be quite clear.

Not knowing how to deal with it. Emotions – very tearful – I don't think any of the day is normal from one minute to the next.

Many of the reasons they cited for drawing their image related to a sense of 'normality' and how when they compare what they have drawn they see something that is not normal.

Q. What are your thoughts as you look at your drawing?

Two main themes arose from participant narratives. These were negative emotions and a sense of realisation. Interestingly, participants were asked what their thoughts were as they looked back at their drawing, yet the many of the narratives contained emotions.

Negative Emotions:

Feel sorry for myself.

Sad. Very sad, that is how I have made my drawings.

See somebody that is in pain – there's nothing positive about it, it affects every part of the body.

Realisation:

Interesting in a way as I haven't ever given it that amount of thought. I mean initially when I first had the diagnosis I was worried because of the exhaustion that comes with that.

I suppose I realise how littered I am with pain. I suppose I'd never connected them up before…they've just been different… that must be that and that must be well you know.

Looking at the drawings brings it home to me. If I wasn't on pain killers the whole thing would be coloured.

Asking participants to reflect on what they had completed started a process of interpretation. This is discussed further at a later stage. Emotions were dominant rather than thoughts; this is also discussed further in relation to patient-physician communication.

Q. How do you feel as you look at your drawings?

When participants were asked how they felt, as opposed to what they thought, as they reviewed their drawing, three themes were identified from their narratives. These were; negative emotions; and a sense of dissociation from their drawing pain and 'unrealistic thinking style'.

Negative Emotions:

All of the participants identified negative emotions as they reviewed their drawings. The spectrum of negative emotions ranged from simple sadness to depression, and anger.

> *Sad really... horrible upset because I don't want to feel like it.*
>
> *I am afraid... the word I always use to describe it is a 'burden' a heavy burden that you carry around every day.*
>
> *Very cross, frustrated, angry, sad.*

Sense of Dissociation:

Many of the participants' narratives reflected a sense of their trying to distance themselves from the pain they were experiencing, and the image they had drawn.

> *Slightly embarrassed... um...it feels a bit strange sitting down and talking to you about it in these terms; I have to think about it on a completely different plane.*
>
> *I don't know whether I am accepting of it. No man's land. I feel like I am in no man's land!*

Unrealistic Thinking Style:

A common theme with many chronic conditions is non-acceptance/denial and an unrealistic belief in the existence of a 'miracle cure' or the vain hope that it might just disappear or cease to affect them. This theme was clearly apparent in some of the participant narratives.

> *I know it's there but tend to not dwell on it and just believing that one day the pains will go away.*
>
> *I kind of keep hoping if I keep mobile and keep doing all of my physiotherapy and all this kind of thing it might just all go away.*
>
> *I feel I have got to find a cure.*

Q. What emotions did you experience whilst you were drawing?

Not surprisingly, participants referred to negative emotions as they revisited the experience of creating their image. However, it became apparent that there was a dynamic process occurring during the creation of their image. Although most participants started the process with negative emotions, many changed during the creation of their images to more positive emotions and even a sense of acceptance of their condition. The themes identified from the participant narratives for this specific question were; negative emotion, positive emotion and acceptance.

Negative Emotions:

The negative emotions mentioned were the same as those identified from previous questions. They will not be repeated here.

Positive Emotions:

> *I felt in control as I was drawing a good feeling.*
>
> *That is just how it is - I'm matter of fact about it.*

Acceptance:

> *I was concentrating too hard on what I was doing but I don't think until I actually drew it that I accepted it – Red - burning partly and the intensity – Black – cloud of depression that comes with the pain it is like a feeling of imprisonment – Purple – areas of pain less intense I can live with those.*

From here we can still see that the most dominant discourse is that of negative emotion. However, as before in the last question there are also elements of the discourse evolving into something more positive. We can see the beginning of acceptance. By this stage in the interview process it is becoming more apparent that there is a process happening.

Q. What would you say your drawings are telling me about how you feel about your life at this moment in time?

When asked to reflect on what the images participants drew disclosed about their life at that present time, four major themes were elicited from their narratives. These were feelings of being trapped; negative emotions and feelings; self-blame; and a sense of relief. It is interesting that for some participants the focus of their narratives was on negative themes whereas for others their narratives were based on more positive themes.

Feelings of Being Trapped:

> *I feel as though I have still got my physical mind and body but I can't go forward in anyway.*
>
> *Sad trapped angry frustrated.*
>
> *I feel like I am stuck in a time warp and stuck in a black cloud like people describe for depression except it's not depression it's a pain thing.*

Negative Emotions and Feelings:

> *I am not happy I suppose – I am and I am not it's a bit weird. I am not happy with me if you like so dark represents me – dark I suppose!*
>
> *That I am feeling down*
>
> *Depressed*

Self Blame:

> *I think I am angry at myself the way I take it all on board – the way I perceived things that have happened in my life and why haven't I been able to deal with things in a better way.*
>
> *So angry with myself for making this happen to me; if I had dealt with things in a different way I would have been a stronger person. The body wouldn't have resulted in this mess.*

Sense of Relief:

> *Nice to be able to tell someone I've got all of the pain in all of these places.*
>
> *I suppose I am trying to tell you something I had not thought of before in terms of words or images.*

Q. Have you ever expressed your pain/emotions in this way before?

The answer to this question was unanimous and unequivocal. None of the participants had previously had the opportunity to give meaning to their pain/distress using drawings and images.

Q. How did it feel to be able to use colours and drawings to convey the pain/distress of your condition?

From the answers to this question it was clear that most of the participants found the experience of using drawings and colours to convey their pain to be a therapeutic experience. Whilst the majority of the participants simply answered with a affirmative, a few offered more elaborate answers.

> *A little bit therapeutic really.*
>
> *Was good – quite cleansing quite nice – good.*
>
> *It has made me feel better.*

One particularly interesting answer that emerged from this question, was offered without any prompting from the interviewer.

> *It makes me feel as if I am not on my own in the wilderness screaming out and nobody listening. I feel like I have gained a friend, I feel people like you who have suffered understand. I feel you understand. Someone who hasn't experienced the pain listens but they don't really understand.*

The participant expressed how the process of having someone 'listen' to them trying to explain their experience of living with pain had been like gaining a friend.

Q. Has taking part in this exercise made you think about your pain/distress in a different way?

The majority of participants agreed that taking part in this exercise had made them think about their pain and distress in a different way. Two main themes emerged from the answers to this question: The use of cognitive strategies to deal with pain; and the perception that pain had been reduced by the taking part in this exercise.

Cognitive Strategies for Dealing with the Pain:

> *Yes, now I will visualise the whole whereas before I would just visualise an area, never dwell on it for very long.*
>
> *Maybe to focus more to where the pain actually is rather than just saying all over. To say where it is otherwise I would just colour the whole thing. I really felt like colouring the whole thing – that is how it feels.*
>
> *Yes it has. It made it clearer by identifying it more than anything. Because I have had it for such a long time it has just been I have that...that hurts...and that hurts. I just kind of assumed that other people hurt like that too. You don't tend to think that other people are quite normal without it...that's odd.*

Reduction in Pain:

> *Different approaches to pain. Think of colour and lights to release.*
>
> *Yes – blocked off pain – not thought about it like this before.*
>
> *Yes, I think it has, it is linking it to everyday life – just different to things you see and know about, helps to deal with it.*

Q. What insights if any have you gained about yourself by completing this exercise?

Participants gained both positive and negative insights related to coping with their pain, and being able to communicate their pain in a way that could be understood in the knowledge that it was manageable. However, negative insights in the form of concerns about the future and whether the condition would deteriorate to a point where they could not cope.

> *I suppose it makes you think there is a lot more to it than what you imagine really. There are a lot more people going through these things but probably they have a*

> *lot worse than I have. I know I cope with it. There are a lot of people who are housebound.*
>
> *I am going back to the health aspect when I was in Eryri Hospital. I really did a lot of thinking about it then. It was the recurrence of the pain rather than the exhaustion. I am now able to manage it.*
>
> *If I was healing and visualising now that is what I would use whereas before I haven't. I have never given myself enough time to do it always been distracted by something.*
>
> *It worries me that will happen to me. I keep on thinking 'oh my god what am I going to be like in five years from now?' As long as I can live with it and not think am I going to get worse.*

Q. Did you find it therapeutic to express your pain/distress emotions using this method?

The vast majority of the participants found it therapeutic to express their pain using the pain diagrams and colours. Although not many of them said why they found it therapeutic, several did. In particular, it was noted that this method gave participants a new way to express their pain. It gave them greater opportunity to be understood. It gave them hope in that they felt that someone was able to listen to them, and to understand what they were going through.

> *It was interesting to think about it in a different way. The insight came when you asked me the question was it easy to describe it using colours, drawings or words – it actually made me realise how reliant I am on words but I am not very good at using other methods to describe things.*
>
> *Yes it did. It was good to talk about them and trying to put feelings and colour down where I had never done that before.*
>
> *I found it therapeutic to be able to discuss it rather than just being given tablets.*

Q. Did your response to this exercise surprise you?

This question confirmed that participants found this method of communicating their pain more effective than words. The participants' narratives support this hypothesis.

The participants in this study generally found it more effective to communicate their pain using pain diagrams and images/colours rather than trying to find the correct words that a medical professional might not fully understand.

> *No, I mean I haven't ever used it before and when I first spoke to you I thought I can never possibly do it and that I can actually visualise it in image rather than thinking about it in words... so, yes.*
>
> *How easily I could access images to describe the pain.*
>
> *I surprised myself being able to do it because I am not very demonstrative about myself.*

Q. Would you say this exercise has helped you in anyway? If so, how?

The narratives provided as answers to this question demonstrate that using images and colours to communicate pain was found by participants to be effective. However, the range of efficacy is varied. For some relief was momentary, whilst for others it normalised their experience and left them feeling reassured that they were not going mad. The answers to this question also reinforced the perception that communication between patient and doctor certainly from the patients perspective need to improve drastically.

> *Yes, it's been therapeutic for not feeling so alone in the pain.*
>
> *Yes – I think so, because it is the first time I have discussed the pain with anyone else other than the consultant, and not in the same way.*
>
> *Very much – it has been very therapeutic to be able to talk about it. Yes because you know someone else has got it and you are not going mad.*
>
> *Yes, I feel that someone is willing to help and that I am not a nuisance, because when I go to surgeries most Doctors don't want to know!*

Another element to this study is demonstrated by looking at participant responses and how a process evolved throughout the semi-structured interview based on participant responses. The results presented in both the images drawn and the narratives demonstrate that participants found this exercise to be more useful and a therapeutic way to describe their pain and distress than the use of words.

Discussion

The simple body outline has not previously been used to collect data in this way (using the freestyle drawing of images with black and/or coloured pens). The researcher is currently unaware of any study which has analysed the content or meaning of such non-organic pain drawings drawn on the simple body outline. This study participation experience was found to be beneficial to all FM participants. This study intended to view the pain experience from the patient's perspective. This innovative form of expression could prove to be a useful tool to identify the best course of treatment for a patient at a specific point in time.

The pain drawings completed using this method would allow the patient the opportunity to describe their pain symptoms prior to their appointment with the Doctor. Many of the participants related well to freedom of expression that the pain drawings offered them. This was reflected in the dramatic images drawn by the FM participants (see Appendix A). Had they not been asked to express their pain/distress by drawing images on a body outline, many of the patients would not have known how to provide such visual descriptions to help their doctors understand/diagnose their condition.

The pain drawing would then be an effective, time efficient method that would allow the doctor an insight into the pains their patient is experiencing. It would better enable them to decide the best course of treatment in the limited time allotted to the appointment.

Emotional disclosure through writing and drawing

Emotional disclosure when the patient writes about a traumatic or stressful event has been shown to improve pain and well being. This is thought to happen through the increased insight gained by the patient; this has been linked to improved health status (Pennebaker, Seagal, 1999; Suedfield, Pennebaker, 1997; Pennebaker, 1993). Looking at an illness from the perspective that pain is a message from the body which is attempting to enlighten the sufferer to situations and attitudes that are unhealthy in their life are worth consideration (Pert, 2000).

One of the most common themes in the drawings of the FM group was one of being trapped; of being imprisoned by the physical manifestation of their condition. The overwhelming fatigue and physical restrictions imposed by the condition was very prominent in their drawings. The fatigue alone leads to feelings of depression and hopelessness. Such feelings are further compounded by the frustration felt at the condition having no medical explanation and consequently the sufferer having no hope of any immediate solution or prospect for recovery.

The use of writing and the use of drawing within the context of individual psychotherapy and group therapy (Parr, Haberstroh, Kotter, 2000) have increased in popularity (Theorell, Konarski, Westerlund, Engstroem, Lagercrantz, 1998). Nearly all the FM participants reported that this drawing exercise had a therapeutic value in that it had enabled them to discuss their difficulties and pain; and opened them up to speaking about the often traumatic impact of this condition on their daily lives.

The main observation of this study was the emotional response of the FM participants when given the opportunity to express their pain and distress using the simple body outline in this way. This activity enabled FM patients in particular to 'connect' with their pain in a way that they had not previously been able to do. It allowed the women an opportunity to explore and express emotions to a deeper more intense level. It enabled women with FM to 'vocalise' their emotional distress and frustration found to be inherent to living with FM. This method therefore holds the capability to reveal hidden traumas that could be playing a role in the continuation of FM. In contrast OA patients did not seem to benefit from discussing pain drawings in a semi-structured interview.

Patient-doctor communication

For many women with FM coping is perpetually challenged, and sustaining a reasonable quality of life requires a focus that demands constant attention and modification to the ever-present impact of pain. The women with FM in this study discussed the struggle in finding medical support for their manifested symptoms, and the discomfort they experienced when interacting with medical professionals with whom they felt the need to justify their pain. Such interactions for these individuals typically include coping with physicians who have perceived power and control over treatment decisions and endorsing the diagnosis of FM. This finding is supported by other researchers (Schaefer, 1997; Hellstrom et al, 1999).

All FM patients who participated in this study were appreciative of the opportunity to talk about their symptoms. One of the most prominent observation/ comments was that they felt they were being listened to and understood. They felt that they were given the opportunity to express and help others understand and appreciate the condition with which they had to live. This in itself proved therapeutic to them; they all felt they had been able to release some tension and had learnt something new about themselves. They had been able to use the simple body outline (pain drawing) as a tool to give them a new perspective on their condition. As a result of their participation in the study they felt more in control although some were surprised at the amount of anger and frustration they were feeling and had expressed. Such emotions suppress the immune system and in turn not only compound the pain experience but also contribute to the condition becoming more severe.

There is a lack of understanding by many in the medical profession who fail to comprehend the extent of the pain of women with FM. This patient group often suffers pain throughout their bodies. The pain fluctuates on a daily basis and is often more severe in different areas and at different times. Because of the complexity and variety of the pains they experience the FM patient finds it difficult to know where to begin when trying to describe the extent of their pain.

For the patient with complex health issues the time constraint of a doctor's appointment is very stressful. One of the reasons that women with FM draw such detailed and dramatic images of their pain could be their frustration at experiencing such debilitating physical symptoms that as yet cannot be tested for and measured or proved to exist by conventional procedures. This study highlights the need to hear and listen to the voices of women such as those who participated in this study; and most important is to understand what FM does to them and what effect it has on their lives.

This work in part has attempted to give a voice to the FM patient; to give the women an opportunity to explain and express their feelings and experiences of illness. It has attempted to give the FM sufferer an alternate form of expression to describe how he/she is truly feeling. Very often as time spent with her doctor or consultant is restricted it becomes almost impossible for the patient to be able to explain all of her various pains. The expressive and at times dramatic images of the pictures and images drawn by FM participants in comparison to those drawn by OA participants could be an indication of the need for the FM patient group to have the real extent of their pain/distress understood. It must be remembered that the FM sufferer lives with a condition for which, they are still told, there is no cure and that it is a condition they simply have to live with and endure. This is in contrast to the OA patients experience as they were pre-operative patients nearing the time of their joint replacement, and therefore hopeful of a large improvement to their pain and possibly a full cure.

Therapeutic value

The pain drawings can open up an avenue of communication with the body. Interviews conducted in this study corroborated this perception. The pain drawing experience was found to be beneficial to all FM participants. They had been able to use the simple body outline (pain drawing) as a tool to give them a new perspective on their condition. As a result of their participation in the study they felt more in control although some were surprised at the amount of anger and frustration they were feeling and had expressed. A common theme amongst the FM participants was that completing the pain drawings was a form of therapeutic release. It is hoped that this modality will provide a new key to accessing the trauma the trauma and emotional content that underlies the patient's pain and distress that could be contributing to the continuation of their condition.

The researcher believes that exploring the possible underlying emotional causes of FM, with FM patients as the lead contributors, will provide a deeper insight into how FM sufferers can be helped. This insight could prove to be the key to FM sufferers understanding their condition. In turn the consequence of this conscious understanding might be the alleviation of their pain/distress. The 'pain drawing' appears to be an effective tool in facilitating this process. Through its use many FM sufferers gained new insights into how their bodies were expressing their emotional pain/distress. Expressing pain using this method could also prove beneficial to other patient groups suffering from chronic pain.

Instead of perceiving pain or depression as an enemy to be blocked, it should be perceived as a message from the body notifying the sufferer that something in their life or lifestyle needs to be changed. When one component of the myriad of systems of the body is compromised the others are affected as well. The pain drawing appears to be an effective tool in facilitating patients' ability to identify the underlying emotional issues of their condition. Many sufferers gained new insights into how their bodies were expressing their emotional distress through pain. Using this method could prove beneficial with other patient groups with chronic pain.

The drawings of the women with FM clearly show that even though common themes emerge in the final images of the overall FM experience the individual drawings on the pain body outline show they all draw /express their pain experience in very unique format. Each individual has their own pain experience. This could explain why it is not possible to use one treatment as a cure all for FM. Each patient has their own story. Often complex, emotional history and life experiences which has brought him/her to this state of health. For each individual if this story is unraveled the root of his/her emotional psychological trauma can be reached.

Limitations of Study

Although the results of the present study highlight some important issues and could have an impact on the diagnosis and clinical management of FM there are several limitations which should be considered. Within the research the assessments were conducted by the author, additionally the follow-up interviews were conducted by the same researcher. Therefore there is a possibility that experimenter expectancies may have contaminated the results. The risk of experimenter expectancy is also increased by the fact that the researcher of this study has suffered from and lived with FM for twenty years. This might be considered as being either strength or a weakness or both. However, all thirty-two participants in this study were interviewed using the same format and by the same researcher. By standardizing the format of the approach to assessment it was hoped that the risks associated with experimenter expectancies would be reduced. It is, therefore, equally argued that the researcher's influence on the data gathered in this study was minimal.

It could be argued that the researcher's natural empathy towards this patient group influenced the response of the FM participants to this exercise; and that her personal experience may have influenced the content of the data gathered when interviewing. Her ability to be an empathic listener could have played a role in the patients' willingness to communicate their pain experience openly and effectively. However, this does not explain the demonstrated ability of the FM patient group to draw graphic images in order to express their pain and distress.

Future research

What are not captured in the medical approach are the experiences of the person who suffers and the attitudes of doctors and others who see no abnormalities on x-rays or specific laboratory tests and no obvious physical defect. For FM participants, talking to their doctors is mostly a difficult experience. Very often the diversity of pain experiences occurring simultaneously or intermittently means there is not enough time during their appointments for them to fully describe their symptoms. A future use for this method of using the simple body outline is a visual assessment of the drawings prior to an appointment could help provide a quicker and more efficient method for a doctor to understand the subjective pain/distress the individual FM patient is experiencing.

In recent years more attention has been given to the voice of the person with the illness, their experience of living and ability to cope with suffering. With a condition like FM - where there is no definitive answer to the cause of the condition, hence no present cure - any avenue of exploration that provides hope to a sufferer is worthwhile. The researcher hopes her work will lead to a new form of information collection that will allow patients to express and communicate their pain and distress more effectively to their doctors. This is an area that warrants further exploration and should be the subject of future research.

Another area for future research might be the exploration of the use of the pain drawings using the same format but with a larger population of FM patients. In addition it is suggested that the interviewer have no personal experience of the condition to ensure an objective approach.

CHAPTER 4

THE USE OF PAIN DRAWINGS AS A DIAGNOSTIC TOOL TO DIFFERENTIATE BETWEEN RHEUMATOID ARTHRITIS (RA) AND RHEUMATOID ARTHRITIS COMORBID WITH FIBROMYALGIA (RAFM)

Abstract

Objective: In the first study on fibromyalgia (FM) and osteoarthritis (OA) (Chapters 2 and 3) it was demonstrated that women patients with FM related well to using the simple body outline diagram to express and communicate their pain and distress. The second study broadens the research in pain drawings to include women patients with rheumatoid arthritis (RA). It is significant that a proportion of RA patients also has FM (RAFM) and can therefore benefit from therapies and treatments recommended for FM patients. The study set out to see if pain drawings can be used to identify patients with RA but without FM (RA) and patients suffering from both RA and FM (RAFM).

Methods: Eighty participants were recruited for the study. All were women diagnosed with RA. The volunteers agreed to be screened by a FM consultant, who used the classic ACR diagnostic criteria of the tender point count (TP) for FM, in addition to completing the procedure to determine a DAS28 (disease activity scale) score for each of them. Each participant was independently interviewed by the researcher. Using a simple body outline diagram they were asked to (1) 'draw your pain on this body outline' (i.e. its location); (2) 'draw the shape or form of your pain/distress on this body outline' (both body outlines to be completed with a black pen); (3) 'draw your pain/distress on this body outline' (use coloured pens); (4) 'draw the image/shape/form of your pain/distress' (use the plain sheet of paper and use coloured pens). In addition they completed the Regional Pain Scale (RPS) and a semi-structured interview.

Results: The percentage of participants in the RA group who were shown by the ACR criteria to have FM (20%) corresponds closely to the results of the larger studies of FM co-morbidity within an RA population. In contrast, the RPS questionnaire method and the visual assessment of pain drawing method identified 47% and 39% of these participants to be within the RAFM group, respectively. Analysis of individual components of the DAS28 show compelling evidence that the pain drawing method is an effective way to differentiate between women patients diagnosed with RA and those who have RA with comorbid FM (RAFM).

Conclusion: Use of the pain drawing method to diagnose FM comorbid with RA is a new and interesting approach. It provides the medical profession the opportunity to better understand the pain RAFM sufferers have to contend with. This improved understanding will extend to the families of women diagnosed with RAFM as well as members of the communities in which they live. It is nevertheless, an area of research that should be investigated further; either as part of a larger/broader study or as a study of FM specifically.

Introduction

This study is incorporated into an ongoing set of studies, the aim of which is to determine whether the use of subjectively based pain drawings, by patients suffering from chronic pain syndromes such as FM, could be reliably used in differential diagnosis. These studies place a particular emphasis on delineating between those suffering simple forms of arthritic pain localized to specific joints (OA), and those suffering more complex arthritic conditions such as rheumatoid arthritis (RA) and FM (Wolfe, Michaud, 2004: Wolfe, 1999). Whilst the simple forms of arthritic pain like OA are commonly treated by appropriate medications, in many cases, for FM sufferers, medication does not always adequately reduce pain (Kleinman, Harnett, Melkonian, Lynch, Machlis, Silverman, 2009; Wolfe, Michaud, 2009; Kim, Lipton, Deodhar, 2009). This study involving eighty patients looked at the possibility of using pain drawings to identify women who were already being treated for rheumatoid arthritis (RA) who may have been entering into or already experiencing FM.

The social/medical hypothesis driving this research was that syndrome pain like seen in FM is complex, develops over time and is best treated using forms of therapy either with or without medications i.e. psychotherapy, counselling, group sharing (Spaeth, Briley, 2009). 'Self-mapped' pain images drawn by the patient during the course of treatment could identify at an early stage, patients being treated for RA who should also be receiving treatment for 'pain syndrome problems'. It is also proposed that such early detection by this method could reduce the severity and the duration of the traumatic pain experiences such as RAFM or FM.

This study researches the pain drawings drawn by women with RA. A proportion of these patients also have FM (RAFM) and this may influence how they present to their doctors and often how their doctors react to their pain and distress (Coury, Rossat, Tebib, Letroublon, Gagnard, Fantino, Tebib, 2008; Makinen, Hannonen, 2009; Pollard, Kingsley, Choy, Scott, 2010). This study set out to see if pain drawings using the simple body outline can differentiate between patients with RA but without FM (RA) from patients with both RA and FM (RAFM). It also compared the reliability of this method to the primary and currently accepted clinical methods of diagnosing FM. The most commonly used is the tender point count (TP) as stated by the ACR Criteria of 1990 (Wolfe et al, 1990). The second is the Regional pain scale questionnaire (RPS) devised by Frederick Wolfe (Wolfe, 2003). If it were possible to differentiate patients with RAFM from those with RA alone by a simple test of them completing a pain drawing, it would be extremely helpful to health professionals and equally beneficial to the patients.

It was hypothesised this study would show a striking difference between the pain drawings of the RAFM sufferers, and the drawings of those who suffered from RA alone. It was hypothesized that the pain drawing test would prove to be a useful clinical tool when used to identify the sub-group RA sufferers. It would enable clinicians to identify those RA patients with superimposed FM (co-morbid FM) (Mease, Arnold, Crofford, Williams, Russell, Humphrey et al, 2008). It would also help them reinterpret the subjectively high Disease Activity Scale (DAS) (Van der Heijde, Van der Hof, Van't Rijswijk, Vande Putte, 1993). The information it provides could lead to a reduction in the prescription of either re-use or different drugs and to facilitate the management of the symptoms on a more appropriate bio-psycho-social basis (Garcia,-Campayo, Magdalena, Megallon, Fernandez-Garcia, Salas et al, 2008). The treatment would be more beneficial and the patient's exposure to potentially toxic drugs would be reduced. Another not insignificant benefit would be a considerable savings in the cost of treatment (Sicras-Mainar, Rejas, Navarro, Blanca, Morcillo, Larios, 2009).

Despite all the latest scientific and medical information about FM with its severe muscle pain, unrelenting fatigue and sleep problems, as well as feelings of anxiety and depression (McBeth, 2005; Mease, Arnold, Bennett, Boonen, Buskila, Carville, 2007), FM is regularly misunderstood and doctors are still misdiagnosing this common pain condition (Haugli, Strand, Finset, 2004). The chronic pain diagnosis a person first receives is often coloured by their chief symptom complaint. Chronic widespread muscular pain is often diagnosed by rheumatologists as FM (Kato, Sullivan, Evengård, Pedersen, 2006). A person who is overcome by extreme fatigue and flu-like symptoms might consult an infectious disease expert and receive the diagnosis of chronic fatigue syndrome (CFS); whereas a person who has severe jaw pain might see a dentist and be told that they have temporomandibular joint disorder (TMJD); whereas people who appear to have allergictype symptoms to a number of chemicals, foods, or odours may consult an allergist for multiple chemical sensitivity (MCS). All of these conditions come under the dysregulation spectrum syndrome (DSS) described by Dr Yunus (Fitzcharles, Yunus, 2010); and since a person may often suffer from more than one it is important to keep these overlapping syndromes in mind because this could impact on the course of treatment prescribed (Martinez-Lavin, 2001; Cohen, Neumann, Haiman, 2002). Many symptoms are similar to other illnesses and FM is not always identified when another disease such as RA is the primary reason for consultation. This subgroup of RA co-morbid FM patients often have different needs to those with RA only (Gaston-Johannsson, Gustafsson, Felldin, Sanne, 1990). Therefore early diagnosis would allow a more efficient and beneficial service to the patient ensuring they receive the appropriate treatments. Previous studies have estimated that about 15-17% of patients with RA also have FM (Wolfe, Michaud, Pincus, 2005; Wolfe, Michaud, 2004; Naranjo, Ojeda, Francisco, Erausquin, Rua-Figueroa, Rodriquez-Lozano, 2002).

It is often difficult to determine how much of the disability, pain and distress of these patients are due to RA and how much is due to FM (Pollard, Kingsley, Choy, Scott, 2010). When compared with RA patients without FM (RA), patients with RA and FM (RAFM) rate themselves to be more disabled (Hidding, van Santem, DeKlerk, Gielen, Boers, Geenan, 1994). However, objective measures of their ailments suggest that the arthritis is milder (Viitanen, Ronni, Ala-Peijari, Uoti-Reilama, Kautiainen, 2000). The rheumatoid arthritis/Fibromyalgia (RAFM) group uses more disease modifying drugs (Naranjo et al, 2002) and seems to respond less well to the new expensive biological anti-rheumatoid drugs (Stern, Wolfe, 2004).

Laboratory and x-ray testing are routinely performed when compiling a complete medical history and physical examination crucial for a correct diagnosis of FM. FM symptoms mimic several other diseases: for example, systemic lupus, polymyalgia rheumatica, myositis/polymyositis, thyroid disease, rheumatoid arthritis and multiple sclerosis and it is necessary to rule out these conditions before a FM diagnosis is made. While a diagnosis of FM does not preclude the co-existence of another condition, it is important to ensure that no other condition is mistaken for FM so that appropriate treatment may be given (Makinen, Hannonen, 2009).

Rheumatoid Arthritis

Rheumatoid Arthritis is an inflammatory disorder of unknown aetiology that primarily involves joints all over the body. The arthritis is symmetrical. It may, occasionally, go into remission; but, especially if uncontrolled, leads to progressive destruction of joints with resulting pain, disability and deformity (Aletaha, Neogi, Silman, Funovits, Felson, Bingham, 2010). It is a chronic, progressive, systemic disease which causes fatigue and malaise as well as pain and stiffness. (Lee, Weinblatt, 2001)

The progress and symptoms of the disease can often be controlled by the use of disease modifying anti-rheumatoid drugs (DMARDs). A composite measure called the Disease Activity Score (DAS28) is commonly used when making the decision whether or not to start treatment using these drugs and then when monitoring their progress (Prevoo, Van't Hof, Kuper, Van Leeuwen, Van de Putte, Van Riel, 1995). The Disease Activity Score (DAS28) test is designed to give a composite score of RA activity; and is the outcome measure most frequently used to decide when to start anti-rheumatoid treatment and once treatment commences to monitor its effectiveness. The DAS28 score is made up of four measures, two objective and two subjective. The objective measures are a blood test measuring the acute phase reaction and a clinical assessment of the number of swollen joints. The two subjective measures are a count of the number of tender joints, and the patient's own assessment of the global arthritis activity.

Fibromyalgia (FM)

FM is a common and debilitating illness. It is characterized by widespread chronic musculoskeletal pain, sleep disturbances, tender points, fatigue, distress and depression (Wolfe et al, 1990). It has not been possible to find a unique underlying medical explanation for this disabling condition; but it is known that physical, social and psychological factors play important parts in its development as well as in its persistence and its management. However despite considerable research into these three areas, FM remains a problem which needs to be better understood.

Medications alone are rarely successful when treating FM (Carette, Bell, Reynolds, 1994). Wider success is achieved using cognitive behavioural therapy and the bio-psycho-social self management model (Goldenberg, Burckhardt, Crofford 2004). There is strong evidence that intensive patient education is an effective treatment in FM (Burckhardt, Bjelle, 1994; Nicassio et al, 1997). Thus the management of the patient with FM is different from the management of the patient with RA. While DMARDs (disease-modifying antirheumatic drugs) are active against the joint swelling and inflammation found in RA, these potentially toxic drugs have no effect on the symptoms of FM. In some cases, FM patients experience no benefits whatever; effects varying in severity often confound the treatment.

The current diagnostic criteria for FM, which the American College of Rheumatology (ACR) put forward in 1990, include several main features. Firstly, this is a chronic widespread, painful condition with pain affecting many areas of the body. It is associated with the demonstration of pain occurring in at least eleven out of eighteen defined areas of the body (TP), above and below the waist and on both sides of the body. Many people confuse tender points with trigger points. A trigger point is a term used in the evaluation of myofascial pain, which is a localized area of abnormality, not to be further discussed right now. A tender point is any area where palpation with 4 kg/cm^2 of pressure or less is perceived as painful by the individual. When a group of rheumatologists worked together to examined patients in a very standardized fashion. These 18 tender points, again, above and below the waist and on both sides of the body, were highlighted as the areas that were most specific and sensitive when making the diagnosis of FM. Even though the tender point count is still used as the prime diagnostic method for FM there has been controversy surrounding the effectiveness of this method as an accurate measure for the presence of FM for a long time (Croft, Schollum, Silman, 1994; Croft, Burt, Schollum, Thomas, MacFarlane, Silman, 1996; Cöster, Kendall, Gerdle, Henriksson, Henriksson, Bengtsson, 2007; Harth, Nielson, 2007).

Many doctors who have FM patients now realise that FM is not only pain but it also leads to fatigue, sleep disturbances, cognitive disturbances, and other co morbidities (Martinez-Lavin, 2001). For this reason these criteria are now being revised. As a result, the newer ACR criteria for diagnosis of FM will include some of these non-pain-related features when making the diagnosis (Wolfe, Clauw, Fitzcharles, Goldenberg, Katz, Mease et al, 2010).

Although the exact aetiology of FM is still not known, recent research in central nervous system chemistry supports the hypothesis that FM is associated with a process defined as central sensitization (CS) which is an augmented response to sensory processing through what is primarily believed to be centrally enhanced hypersensitivity (Arendt-Nielson, Graven-Nielsen, 2003). For example, a normally non-painful stimulus is augmented by the central nervous system (CNS) such that it is experienced by the person with FM as painful i.e. it becomes a tender point (TP) (Bennett, 1999). A pressure of 4 kg/cm^2 would not normally be expected to cause pain in a person without FM. There are scientific studies that emphasize the role of the central nervous system (CNS). Numerous studies have shown people with FM truly experience pain at a lower pain threshold (Bennett, 1999; Desmeules, Cedraschi, Rapiti, Baumgartner, Finckh,, Cohen, Yunus, 2007).

In a functional MRI (magnetic resonance imaging) study carried out at the NIH (National Institute of Health) patients with FM identified a level of stimulus as painful that was not considered painful in a non-FM control group. Both groups showed metabolic activity in similar areas of the brain known to be associated with pain processing. However, more areas of metabolic activity were present in the FM patients (Gracely, Petzke, Wolf, Clauw, 2002). The importance of this is observation that even though on average a patient with FM experienced pain at a much lower threshold than a control patient, the FM patient's experience of pain at a lower threshold still resulted in metabolic activity showing up in areas of the brain associated with pain processing on the fMRI.

Lack of information on FM mean that many doctors and other health professionals are uncomfortable when dealing with the distress it causes those who suffer. As a result of this discomfort, the medical profession tends to over compensate and react in the only way it knows how, in a medical way, i.e. by changing drugs, ordering tests, and physiotherapy. Drugs, apart from amitriptyline are largely ineffective (Goldenberg, Mayskiy, Mossey, Ruthazer, Schmid, 1996; Nishiyama, Urrutia, Walitt, Rodriguez, Bonfil, Alegre, 2008). Cognitive behavioural approaches have been shown to help FM patients (White, Nielson, 1995), it is reasonable to expect future treatments for FM to avoid or reduce the use of drugs and their associated side-effects, while incorporating integrated medicine (Conventional and CAM).

In the first study (OA compared to FM) the florid drawings of the people with FM could easily be identified from the drawings of people with osteoarthritis of a single joint. It was hypothesized that this study would show a similarly striking difference between the pain drawings of women with RAFM and the drawings of women with RA alone. It was hypothesised that the pain drawing test would prove to be a useful clinical tool when used to identify the sub-group of patients with RAFM out of the eighty RA patients. This study also explored how patients with RA visualized and depicted their pain. Visualisation of pain as this could be an additional outcome measure of the bio-psycho-social effects of rheumatoid arthritis. In addition the pain drawings could possibly provide a starting point for a psycho-social-spiritual intervention for people living with RAFM.

Method

Participants

All 80 participants in this study (RAFM study) were women between the ages of 18 and 75 in treatment for RA and who were attending one of the Rheumatology clinics in the North West Wales NHS Trust. Prospective participants were either offered the opportunity to take part in the study whilst attending their routine clinical appointments, or were recruited by the researcher or the rheumatology nurses by examination of their patient records. Each prospective participant underwent a short interview with the researcher in person or by telephone, and was provided with a patient information sheet giving detail of the study and a consent form to sign. Each patient was then allowed a minimum of 48 hours to consider her choice whether or not to participate. Patients were told that the purpose of the study was to understand the question: “How do people with RA draw/image their pain?” The patients were not aware that they were being screened for FM.

Study Design

This study used both qualitative and quantitative analysis. Qualitative analysis was used to visually assess the ‘pain drawings’. Quantitative analysis was used on the regional pain scale; tender point count and disease activity scale. Eighty volunteer RA patients were recruited. This number was selected because previous studies by Wolfe and colleagues estimate that about 15-17% of patients with RA also have FM (Wolfe, F.2005; Wolfe, F., Michaud, K.2004; Naranjo, Ojeda, Francisco, Erausquin, Rua-Figueroa, Rodriquez-Lozano, 2002). Therefore it was expected this study would produce thirteen or fourteen patients with RAFM. In fact, this is likely to be an underestimate because the two studies by Wolfe included male patients and FM is much less frequent in males than females whereas this study only has women patients.

Inclusion criteria

- Rheumatoid Arthritis patients satisfied the American College of Rheumatology classification Criteria of 1987 for diagnosis of Rheumatoid Arthritis (Arnett et al, 1988).
- Participants were be female and aged between 18 – 75 years (Informed consent was given).
- Patients had to be able to understand English

Exclusion criteria

- Patients suffering severe pain which did not originate in the musculoskeletal system i.e. nerve pain.
- Patients with other severe co-morbidities which might impinge on the way subjects draw their pain.
- Male participants were not included in this study.

Procedure

Each participant completed their interview with the researcher prior to the examination by the resident rheumatologist who was the FM consultant for the district. The interview with the researcher, which lasted no longer than ninety minutes, was carried out in a private examination room at the rheumatology clinic. The examination by the FM consultant followed immediately afterwards. If this was not possible, an appointment was arranged for examination within four weeks of the date of the original interview.

The following procedures were conducted by the researcher in the first appointment with each participant:

Pain drawings

Participants were invited to draw their pain. Each participant was given four pages of paper. On three of these pages was a simple body outline diagram as shown in figure 2.1, the remaining one page was blank. Participants were also given coloured pens - black, red, orange, yellow, green, blue, purple and magenta with which to complete the pain drawings.

Each participant was given pages numbered one to four. On each of pages one to three there was a simple body outline diagram. Page four was blank. Specific instructions were written on each of the pages as follows:

1. Page one – Simple body outline diagram 'Draw your pain on this diagram' (Black pen)
2. Page two – Simple body outline diagram – 'Draw on this diagram whatever shape or form your pain/distress takes (Black pen)
3. Page three – Simple body outline diagram 'Draw your pain/distress in the colours of your choice'
4. Page four – Blank sheet of paper – 'Draw the image/shape form of your pain/distress using the colours of your choice'.

After completing their 'pain drawings' each participant was asked to complete the Regional pain scale questionnaire (see Appendix E), and a semi-structured interview with the researcher.

The DAS28 and TP examination were done by a single rheumatology consultant who specializes in FM.

Measurements

Pain Drawings

The researcher and an independent assessor* separately examined each participant's four pages of pain drawings. The drawings were assessed and categorised using Visual Assessment. (*The independent assessor used for this study was on the research staff in the School of Sport, Health and Exercise Science, University of Wales, Bangor, UK.)

Visual Assessment

The researcher and the assessor visually assessed each set of four drawings. The aim was to identify which group each participant belonged and placing them in one of four categories as shown below (each category was agreed upon during consultation between both assessors):

(A) Rheumatoid Arthritis (RA)

A set of drawings was placed into this category if the images were generally simple and precise, with anatomical markings, typically symmetrical and most commonly at joints or articulations. In particular participants in this category did not draw on page two where participants were asked to draw the shape or form of their pain; and they typically only used words without images i.e. they did not draw an image on page four.

(B) Rheumatoid Arthritis (RA)

The drawings in this category satisfied the same criteria as the drawings placed in the previous category (A). However, a simple image was drawn on page four.

(C) Rheumatoid Arthritis with Fibromyalgia (RAFM)

A set of drawings was placed in this category if they were clearly non-organic i.e. they contained diffuse, global, poorly defined patterns that were not a logical result of pathology, and/or used words, phrases or images to emphasize pain (as identified in Study one FM v OA reported in chapter two).

(D) Rheumatoid Arthritis with possible fibromyalgia (RAFM)

The drawings in this category satisfied the same criteria as the drawings placed in category (A) and the drawings placed in category (B). However, they also included use of non-organic markings similar to the drawings placed in category (C).

The final decision as to which category each drawing was placed was jointly agreed upon by the two assessors. For simplification of data analysis these four groups were combined into two groups. One group comprised of categories (A) and (B), and was labeled 'The RA Group'. The second group comprised of categories (C) and (D) and was labeled 'The RAFM Group'.

Regional Pain Scale (RPS)

The RPS was developed to diagnose FM, and measure its severity, either as a condition on its own or co-morbid state with RA or OA (Wolfe, 2003). The patient is presented with thirty two anatomical locations which have symmetry (right v left) and six locations which do not have symmetry on head, neck or torso. The patient is asked to categorise the pain and tenderness experienced in each of these locations as either none, mild, moderate or severe over the past seven days. An example of the form used for this measurement is in Appendix E. Although participants provided information for thirty eight anatomical locations, only nineteen locations were used for the FM measurement. The locations used are as follows: left shoulder, right shoulder, left hip, right hip, left jaw, right jaw, lower back, upper back, neck, left upper arm, right upper arm, left lower arm, right lower arm, left upper leg, right upper leg, left lower leg, right lower leg, chest and abdomen. A zero point value was given to any location where the patient reported no pain. A point value of one was given for any location where the patient reported mild, moderate or severe pain. The sum total of these values was added to the VAS fatigue score, and the total was divided by two to determine the final RPS score for each participant. Participants with an RPS score between 0 and 5.75 were classified as RA, while participants higher than 5.75 were classified as RAFM.

Semi-structured interview

For the questions asked by the researcher in the semi-structured interview (Appendix E).

The first appointment with the researcher included the completion of the above. During the follow-on appointment with the FM consultant the following procedures were conducted with each participant:

Tender point examination (TP)

The tender points test was performed by the FM consultant. Since all participants already satisfied two out of the three ACR criteria for FM, namely, pain in all four quadrants of the body, and such pain having been experienced for three or more months, a score of 11 or higher for the tender points test was deemed to qualify the participant as having FM co-morbid with RA. Tender points chart is given in Appendix E.

Disease Activity Scale (DAS28)

The disease activity scale (DAS28) final value is derived from four separate components; these results are collected on one examination and scoring sheet (Prevoo, Van't Hof, Kuper, Van Leeuwen, Van de Putte, Van Riel, 1995; Leeb, Andel, Sautner, Nothnagl, Rintelen, 2004). An example is given in Appendix E. The four components are:

Swollen Joint Count

The FM consultant examined twenty eight joints for physical swelling in each patient and recorded the location of each swollen joint. The extent of swelling for each joint was not documented. This is considered an objective measurement.

Tender Joint Count

The FM consultant asked each patient whether they experienced tenderness as a result of being touched or when articulating each of the twenty eight joints on each patient. Each patient's impression of tenderness was reported. However the extent of this tenderness or pain for each joint is not documented. This is considered a subjective measurement.

Patient's Global Assessment of Disease Activity

In the presence of the FM consultant, participants were asked how active their pain (disease activity) was overall. They were asked to mark a point on a 10cm visual analogue scale. The left hand side of the scale represented 'not active at all' and the right hand side represented 'extremely active'. This is considered a subjective measurement.

Erythrocyte Sedimentation Rate (ESR)

The ESR test is a standard low cost test done on a blood sample. All patients at the rheumatology clinic were tested for the ESR during most of their visits. This test was performed by medical staff. The most recent ESR test was determined by examining the patient's records.

This study was submitted to the North West Wales NHS Trust Ethics Committee for approval. Patients expressing interest in the study were given an information sheet to read. See Appendix E. They were given the opportunity to discuss the study with significant others i.e. family and close friends if they wished. If the patient agreed to participate in the study, each participant was asked if they fully understood what was required of them, and if they had any further questions, before consent was obtained.

Results

From the visual assessment of the pain drawings it was seen that participants with only RA were very aware of the places in their body where they felt pain, mainly. They were therefore, able to use the simple body outline diagram to accurately depict the locations of their pain. The visual assessment also showed that participants with RAFM were less able to identify specific points where they felt pains. They were more likely to experience pain that required imagery to describe it. For the individualized examination of a each patient, the visual assessment of the drawings, and individualized semi-structured interviews were powerful tools that facilitated a better understanding of the nature of the complex pain for sufferers that is synonymous with FM.

When reviewing a large number of such pain drawings the broad diversity of an image and varying intensity in drawings by different patients is immediately striking. The florid drawings of FM sufferers contain rich information. Whilst, some of the images are drawn by participants who also have the painful condition RA; many interestingly are not drawing the RA aspects of their condition.

The following are some examples of the information contained in arguably the most florid RAFM drawings (see Appendix B for individual drawings):

Participant 2

I. Tightness and constriction in front side of arm and upper chest – pain drawn going up into neck lending to feeling of strangulation. This sensation could be associated with poor breathing and anxiety.
II. Reference in the region of the heart to palpitations, nausea, and dehydration. These feelings could either be related to an actual heart condition, such as congestive heart failure; or related to an emotional loss, a struggle or social anxiety.

III. Reference to nerve pain in the vertebrae from the lower thoracic to the lumbar extending into right the hip and the thigh. This pain could be caused by sciatica.

IV. Description of feelings like ripples and waves throughout the front of the torso. In this case the patient does not state whether this is actually a painful feeling or whether it is simply a disconcerting feeling. Indeed, the regularity of the pulses implies a rhythmic structure. It is more likely to be a nerve pulse pain rather than the rhythm of the heartbeat.

V. Referring to pain in the back of the head, extending down cervical vertebrae in with feelings described as a tingling extending into both shoulders.

VI. Reference to tender heavy feet Tender heavy feet with the sensations of energy movement out of (or into?) the feet. The drawing here is in black ink implying negative dark feelings.

VII. Description of drawings – red heat or pressure at the top of the scalp and the bottom of the spine. This reflects a blockage of energy.

An additional interview would be required to go further into the root causes and inter-relationships of the complex pain images drawn by this participant. From a first analysis, based on this set of images the participant's body energy system (spinal chakra system) is blocked at both ends. The participant has difficulty in keeping emotionally balanced. She is giving a lot of loving support to someone or something (energy moving from the front of her body at levels below her heart), however she is not fulfilled socially, mentally or spiritually i.e. at levels higher above her heart. This participant could benefit from bio-energy therapy (foot reflexology, reiki, polarity) and spinal manipulation (chiropractic, osteopathic), followed by homeopathic and counselling therapies.

Participant 15

Most of this participant's drawing indicated she was an RA participant; but the distinctive drawing of blockages in the cervical spine (explosive) with illustration of painful energy "flashing" and radiating upwards from the head identified her as a RAFM sufferer. This participant could probably be helped by cranial-sacral manipulation or by delicate chiropractic adjustments done by a highly experienced chiropractor or osteopathic doctor. This treatment should be supported by yoga, tai chi, as well as by some simple meditation.

Participant 26

This participant's drawings indicate clearly that she suffered from pain in her major joints of articulation from the torso (shoulders and hips) and knees. She visualised this pain with images of tigers/monsters and compared them to members of her family. She also perceived that her joints were in communication with each other; as pain fades from one joint it is passed to the next. The participant was obviously retaining pain as a result of being surrounded by unhealthy parasitic family and work based relationships. It was also probable that she was addicted to the pain killers prescribed to her.

This participation could be helped by psychotherapy, re-birthing or soul regression therapy, and family counselling.

Participant 34

This participant's drawings depicted some joint pain typical of a RA sufferer but showed extensive unlocalised pain and hot flashes typical of RAFM sufferers. She would be helped by further examination of her endocrine functions, particularly her thyroid. She could also be suffering menopausal complications. The firm lines she drew indicated a strong psychological balance and suggested her condition would improve the more information she was given and that she would willingly comply with recommended treatment.

Participant 39

This participant's drawings pointed to classic RA symptoms in the ankles – reflecting a need to move forward – and in the wrists and knuckles reflecting a need to get things done. The florid drawings highlighted a potential problem with the right kidney- reflecting the participant's anger and frustration. However, they showed the major non-RA problem to be in the shoulders and neck. The pain in the back and shoulders is caused by heat not stress or tension, and the energy exchange at the top of the head appears to be blocked. The participant drew a spiral of pain down the arm. This pain probably has its main root in an injury and in a lingering, connected problem with vertebra 1st thoracic, there and some fascial adhesions in the cervical spine.

This participant could benefit from deep tissue massage such as Rolfing followed by emotional therapy in the term of counselling or family counselling.

Participant 49

This participant's drawings indicated 'heavy' pain in the major joints. This pain's intensity was exaggerated far more than that depicted by 'typical' RA participants. The extremely complex mixture of pains that she drew for example sore throat, dry skin, "gnawing", chicken pox like lesions, showed a tendency to over identify with her illness. Despite having legitimate organic problems - mostly related to endocrine, primarily light adrenal and thyroid imbalances – she used sheer force of personality to drive herself into more pain than she needs. She is in desperate need of attention and craves her prescription as if it were love letters from the doctor. Ironically many of her deepest problems are caused by sensitivity to the drugs she is taking. This participant cannot be significantly helped much until she chooses to change her worldview.

Participant 73

The four main images drawn by this participant did not place her in the RA group. The way these four images tie together underpins the diagnosis. The participant draws a darkness /heaviness/dullness of the forehead – this is her third eye (chakra)(see Appendix G). She also draws a cold or non-heated pain in the heart that radiates along a constriction in her back parallel to the throat and up into the occiput. This can be interpreted as the participant opening up to a new heart i.e. emotion and contextual wisdom; and to new throat i.e. assertion and perseverance – energies. However, she is neither supporting these new energies from the fundamental i.e. existential regions of her pelvis, nor is she integrating these new energies into her higher centres i.e. mental and spiritual.

This participant probably has problems at home and needs to have a more supportive environment and better eating and exercise habits. She is probably frustrated by the imbalance of higher order problems, and is not taking enough care of the basics. Simple pastimes such as carpentry or gardening would prove therapeutic.

Participant 76

The drawings of this participant were very florid and displayed aspects not typical of the RA group. Indeed, it was surprising to learn that she had RA. Her images of pain include a lot of arrows that indicate the feeling of energy flowing better - properly or improperly - and the 'hot-right-cold-left' feelings show that she does not do well in her efforts to balance the energy that is moving in her body.

She could make progress - albeit slowly - by working with experts in Reiki.

Participant 78

This participant is not satisfied with her life and her pain is the progressive result of this dissatisfaction. Nevertheless, she continues to take the pain killers in the forlorn hope that they will be the answer to what she calls her "problems at home and at work". Her condition is so desperate that she occasionally overdoses on NSAIDs sold to her 'over the counter'. If she were helped to recognise the deeper underlying causes of her pain her rehabilitation could begin. The first treatment recommended would be to reduce the amount of "problems" she has both at home and at work. Once a stable living environment is created, psychotherapy would help. She should also adopt an appropriate exercise regime.

The above are based on the visual assessment of the patients' drawings as well as intuitive knowledge derived from them. In these cases the suggestions were put as propositions and adapted to each individual patient interview. Nonetheless, an interesting use of this drawing system would be as an aid for medically intuitive workers to personalized treatments and therapies for sufferers of FM. Such intuitive information is commonly held by people with many years of experience. However, the number of medical professionals - such as doctors, nurses, counsellors and therapists - in direct contact with patients and working with highly intuitive information may be far higher than is currently thought.

Statistical Analysis of RA v RAFM

The average age of the 80 participants in this study was 60 years (SD = 11.8 years). Average disease duration was 168 months (SD = 133.5 months). Participants in this study had an average of 5.7 swollen joints (SD = 3.0) and 5.4 tender joins (SD = 5.0). Participants reported an average score of 41.9 (SD = 26.6) on the Patient Global Assessment (PGA). The clinical measure of disease activity indicated by the erythrocyte sedimentation rate (ESR) was 27.3mm/hr (SD = 17.2). Finally, the overall average disease activity score (DAS28) was 4.5 (SD = 1.1). Additionally, when broken into two groups based on tender point count ten or less for RA and eleven or more for RAFM, analysis of age, disease duration, the number of swollen joints and the ESR indicated no statistically significant differences between the groups (RA and RAFM). When broken into two groups, analysis revealed no significant difference in age, swollen joints or ESR. However, there were significant differences in Tender Joints (TJ), PGA and DAS28 composite scores with RAFM scoring significantly higher than RA in all three domains.

Table 4.1 shows the distribution of clinical measures in the population separated based on the results of the tender points test for FM.

Table 4.1 Patient Characteristics and Baseline Clinical Measures of Disease

Baseline Measure	Rheumatoid Arthritis N=64	Rheumatoid Arthritis and Fibromyalgia N=16	Significance levels
Age (yrs)	58.4 (12.5)	64.2 (7.0)	*Ns*
Disease Duration (months)	159.4 (125.2)	204.1 (162.5)	*Ns*
Swollen Joints	5.8 (3.2)	5.2 (2.4)	*Ns*
Tender Joints	3.6 (3.0)	12.5 (5.1)	$t(17.8)=6.72$, $p<0.005$
PGA	36.8 (24.2)	62.1 (25.7)	$t(78)=3.66$, $p<0.005$
ESR	27.3 (16.8)	27.4 (19.3)	*Ns*
DAS28	4.3 (1.0)	5.6 (1.0)	$t\ (78)=4.73$, $p<0.005$

(Standard Deviation)

Inter-rater reliability in categorizing the visual assessment Pain Drawings

Two researchers independently categorised the pain drawings to RA only (RA) or RA with FM (RAFM). The value of Cohen's kappa was 0.62. This value indicates substantial agreement between the two researchers.

Diagnosis from the three different Methods

Table 4.2 below identifies the number of participants given a diagnosis of RA or RAFM depending on the method of diagnosis.

Table 4.2 Comparison of different methods of diagnosis

Diagnostic Method	Rheumatoid Arthritis	Rheumatoid Arthritis and Fibromyalgia
Tender Point Count	64 (80%)	16 (20%)
Regional Pain Scale score	42 (53%)	38 (47%)
Pain Drawing	49 (61%)	31 (39%)

Inter-Rater Reliability between the three different Methods.

Table 4.3 Levels of inter-rater reliability between the three methods of diagnosis.

	% Agreement	% random probability	Cohen's kappa value
Tender Point Count v Regional Pain Scale score	66	52	0.30*
Tender Point Count v Pain Drawings	72	57	0.36*
Regional Pain Scale score v Pain Drawing	74	50	0.47**

* indicates fair agreement between methods of diagnosis

** indicates moderate agreement between methods of diagnosis

Exploring differences in diagnosis depending on method used.

The non-parametric test, Wilcoxon Signed Ranks Test (see table 4 below) revealed that there was a statistically significant difference in the diagnosis given to participants by:

1. Tender Point Count and Pain Drawings ($p<.005$), with Pain Drawings diagnosis statistically more RAFM than Tender Point Count diagnosis.
2. Tender Point Count and Regional Pain Scale score ($p<.005$) with Regional Pain Scale scores diagnosing statistically more RAFM than Tender Point Count.

The results of the analyses also indicate there was no statistically significant difference between the number of participants diagnosed with RAFM using the Regional Pain Scale score and the Pain Drawings ($p>.05$).

Table 4.4 Statistical comparison by type of diagnosis method

	Diagnosis from TP count v Pain Drawing	Diagnosis from TP count v RPS score	Diagnosis from RPS score v Pain Drawing
Z	-3.128	-4.158	-1.528
Asymp. Sig. (2-tailed)	.002	.000	.127

Method of diagnosis and the individual components of disease activity score

Table 4.5 Individual components of Disease Activity Score by Tender Point Diagnosis (mean, *95% CI lower-upper limits*)

	Rheumatoid Arthritis *(n=64)*	Rheumatoid Arthritis and Fibromyalgia *(n=16)*	Significance
Tender Joint Count	3.58 *(2.81-4.36)*	12.50 *(9.80-15.20)*	$t(78)=8.99, p<0.005$
Swollen Joint Count	5.89 *(5.09-6.68)*	5.19 *(3.92-6.45)*	*Ns*
ESR	27.54 *(23.31-31.77)*	27.44 *(17.17-37.70)*	*Ns*
PGA	36.76 *(30.67-42.85)*	62.06 *(47.84-76.28)*	$t(78)=3.66, p<0.05$
DAS28	4.27 *(4.02-4.52)*	5.58 *(5.05-6.11)*	$t(78)=4.73, p<0.005$

Comparing the two groups by the tender point (TP) diagnosis analysis revealed significant differences in the following: tender joint count (TJ), Patient Global Assessment (PGA) and Composite Disease Activity Scores (DAS28). The RAFM scored significantly higher than RA in all these domains.

Table 4.6 Individual components of Disease Activity Score by Regional Pain Score Diagnosis (mean, *95% CI lower-upper limits*)

	Rheumatoid Arthritis (*n=42*)	Rheumatoid Arthritis and Fibromyalgia (*n=38*)	Significance
Tender Joint Count	3.44	7.50	*t*(78)=3.87, *p<0.005*
	(*2.48-4.40*)	(*5.56-9.44*)	
Swollen Joint Count	6.00	5.47	*Ns*
	(*5.06-6.94*)	(*4.47-6.84*)	
ESR	27.80	27.21	*Ns*
	(*23.08-32.53*)	(*20.79-33.62*)	
PGA	36.78	47.39	*Ns*
	(*28.43-45.12*)	(*38.86-55.95*)	
DAS28	4.27	4.82	*t*(78)=4.73, *p*<0.005
	(*3.96-4.58*)	(*4.42-5.22*)	

Comparing the two groups by the Regional Pain Score (RPS) diagnosis analysis revealed significant difference in Tender Joint Count (TJ) and the Disease Activity Score (DAS28) Composite Score and the RAFM scored significantly higher than the RA in these two domains.

Table 4.7 Individual components of Disease Activity Score by Pain Drawing Diagnosis (mean, *95% CI lower-upper limits*)

	Rheumatoid Arthritis (*n=49*)	Rheumatoid Arthritis and Fibromyalgia (*n=31*)	Significance
Tender Joint Count	4.79 *(3.28-6.30)*	6.32 *(4.60-8.04)*	*Ns*
Swollen Joint Count	6.25 *(5.33-7.16)*	4.97 *(3.99-5.94)*	*Ns*
ESR	27.77 *(23.72-32.27)*	27.12 *(19.86-34.40)*	*Ns*
PGA	39.94 *(31.88-48.00)*	44.90 *(35.52-54.00)*	*Ns*
DAS28	4.48 *(4.16-4.81)*	4.62 *(4.21-5.03)*	*Ns*

Comparing the two groups by the pain drawing analysis revealed no significant differences in any of the categories.

Discussion

The aim of this study was to determine whether the use of subjectively based pain drawings drawn by patients suffering from chronic pain syndromes such as FM could be reliably used in differential diagnosis. A particular emphasis was placed on delineating between patients suffering with RA and patients who have RA with co-morbid FM (Coury, Rossat, Tebib, Letroublon, Gagnard, Fantino, Tebib, 2008; Makinen, Hannonen, 2009; Pollard, Kingsley, Choy, Scott, 2010). Patients with RA can be diagnosed using the revised American College of Rheumatism Criteria (EULAR, 2010; Arnett, Edworthy, Bloch, McShane, Fries, Cooper, 1988) and treated with prescribed medications; but syndromes such as FM are more complex and diagnosis is more difficult and often inaccurate (Fitzcharles, Boulos, 2003), where emotional and cognitive imbalances appear to be causative or contributory, and, in many cases, medication does not adequately alleviate pain.

The social/medical hypothesis driving this research is that syndrome related pain is complex, develops over time, and cannot always be treated by medications alone. Psychotherapy, counselling and group sharing are often helpful. Pain images drawn by the patient as part of a consultation/course of treatment may provide early identification of patients who are being treated for RA who should also be receiving treatment for pain syndrome related problems such as FM. Earlier recognition of FM may reduce the severity and the duration of the traumatic pain syndrome experience.

It was expected, based on results from the earlier study on FM verses OA (Chapter Two) that this study would show a difference between the pain drawings of patients with RAFM, and those of patients with only RA. Thus, it was explored if the pain drawing test would prove to be an effective clinical tool to identify two subgroups: RA only and RA with superimposed FM. For RA patients developing FM it is common that the increasing levels of non-localized pain (non-organic pain with emotional content) leads to higher scores on the disease activity scale (DAS28). In that the DAS28 is used to decide whether or not to increase or decrease pain medication, it is possible that the subset of RA sufferers who begin to develop FM may become over-medicated for pain. This study asks the question whether this new method of identifying RAFM will help cast a new light on the subjectively high DAS28 results in RAFM. Better understanding of this type of pain might lead to less drugs being prescribed. The patient's exposure to potentially toxic drugs and the cost of treatment would be reduced; and the patient could be introduced to a treatment that is more likely to be beneficial.

The study also explored how patients with RA and RAFM visualised their pain. This could be helpful as an outcome measure of the bio-psycho-social effects of rheumatoid arthritis. It may also provide a starting point for a psycho-social-spiritual intervention for people who live with RAFM.

From the visual assessment of the four pages of pain drawings both the researcher and the independent assessor identified and grouped the drawings into two categories. The most common division of styles were Type I (RA only) which displayed limited and localized pain imagery, within the body outline, densely depicted into spots corresponding mostly with joints. Type II (RAFM) drawings were much more vivid, commonly using more colour, and use of shape, use of shape neither localized to joints nor bounded within the body. In many cases the imagery was related to the spine and the head. These drawings were categorized as RAFM.

From a limited body of 320 of drawings analysed (see Appendix B), it is seen that if the general population were studied, it would be reasonable to assume that it would be possible to designate which of the 2 above-stated groups individual patients fall into. This is particularly true for RA only sufferers. The pain drawing method (self-mapping) appear to be an interesting method to produce objective information (to add to patients medical charts) that may allow other medical professionals or persons to whom the patient did not present personally to make estimates of the extent of the syndrome pain in a patient.

The differences between individual drawings must be considered with the caveat that not all patients are either comfortable with or capable of drawing. Therefore there is a difference between the relative mapping of true internal (subjective) pain experience and self-mapped (objective) drawings. The statistical correlation of pain drawing images to the objective measurement of a pain test would appear to be possible with a larger number of patients. It remains unknown how to quantify the images in a manner that allows correlation studies with clearly objective measures.

The body of evidence not only supports this aspect of the study but also points to many encouraging possibilities for future research. Many of the participants reported to have gained a therapeutic benefit from their participation in this study. They reported feeling better after completing the pain drawing exercise. Being given the opportunity to freely express their pain, to speak to an independent party - empathic towards their physical and psychological distress, -relieved the feelings of frustration caused by living with a chronic condition. This area of research is unique; as there is no written evidence that a similar study using pain drawings in this way has been conducted.

The pain drawings allowed the patient freedom in their choice of how to draw, image, or describe their pain. It allowed them ample time to assess what they were feeling. This entails the patient 'listening inside' to arrive at a purposeful analysis of the different parts of their bodies in which they were experiencing pain.

When analyzing the results, it must be remembered that the pain drawings are providing two tiers of information from the patient. The primary tier represented by the diagnosis if the RA patient has FM as a comorbid condition. In this case, the answer is mostly a 'yes/no', however there are some cases where the answer is a 'maybe'. If one or two drugs or therapies worked for most FM patients, then this yes/no decision could translate into the prescription of an additional drug for FM; however, there are no drugs, and even limited understanding of non-drug therapies that can work for FM. Therefore, the diagnosis of FM needs to be followed by an open –minded approach allowing the patient access to up to date information about their condition and how to live with it.

The second most revealing tier of information is found in the imagery and colour chosen by the patients, as well as in the phrases they uses to describe their pain. Each set of drawings uniquely describes a specific patient at a specific point in time. Depending upon the method used to identify FM within an RA population, it appears that about 15-30% of women with RA also have FM to varying degrees of severity. Some of the patients in this study had very severe FM symptoms. They were clearly diagnosed as FM, and drew florid images – full of information for the researcher and any rheumatologist with sufficient experience analysing such patient drawings. However, it will prove more of a challenge to identify FM a few years ahead of the condition becoming severe.

The thinking of the modern western medical establishment is anatomically based. Its analysis of the body is based mainly on the study of the organs (mainly the brain and the torso), the musculoskeletal system, (the neck, the legs, the arms, the hands, and feet). In addition, western medicine overlays 'systems' i.e. circulatory, endocrine, nervous, digestive, immune, lymphatic, which map across locations. Western science has already spent billions of pounds of research funding looking for the molecular or systemic problem that underlie FM problems, with limited success. Whilst not yet fully accepted in western medical institutions, the eastern (Oriental) medical system, is also anatomically based, considers aspects of the body that are useful, often essential in managing FM. It is particularly interesting to look at the pain drawings of some patients who show pulses of energy along their spine or appendages represented by arrows of heat, travelling up their lumbar region being emitted from their head. Some drawings clearly depict the sense of having internal blockages (dams stopping a flow, or reflecting stagnation, heavy dense sensations and numbness, or intense pain of pressure).

Practitioners of eastern medicines in the subcategory of 'energy medicine' are becoming very familiar with diagnosing and treating i.e. balancing or opening, the flow of energy in the body called 'ki'. The sciences of Meridian Energy (acupressure, acupuncture) and Kundalini (chakra flow) (Appendix G) are some of the most advanced treatments. Knowledge and experience of energy medicine science coupled with some intuition enable us to understand from patients drawing the possible causes of their pain.

For the analysis of individual patient pain drawings and the discussion and meaning of the drawings, it could even be that the field of energy medicine can adopt such analysis as a meaningful contribution to patient care. It is expected that this method studied here will be used within such a field. The combination of energy medicine, pain drawings, and western clinical practice is a field with much potential for complementary therapy.

Evaluation of Statistical Results

The cost-effectiveness of any new method such as pain drawing analysis should be considered. The value of a new diagnostic method may be that it can replace an older one, with better information, and perhaps at a lower cost. Better information leading to better use of treatment and therapy resources reduces costs and can be considered a cost benefit. The value of an additional diagnostic method (not displacing an older method) can only create value in providing better information, leading to better allocation of treatment and of therapy resources, as well as to a quicker return of the patient to wellness, and away from being a financial burden on the medical system.

The two most common objective and quantified methods used for FM are the tender points count (TP) and the regional pain scale (RPS). Both these methods are simple, easy to perform, and are typically done by the examining doctor. Table 4.2 shows a comparison of how each of these two methods compared to the pain drawing method in the identification of RAFM within the RA population of women (N=80). The TP count identified only 20% of the population as RAFM; whilst the RPS identified 47% as RAFM, and the Pain Drawing method identified 39% as RAFM. It therefore seems possible that the classical TP method is under-diagnosing FM comorbid with RA. It might also be considered that women who have already been suffering RA for a number of years will tend to score higher on the RPS and Pain Drawing. Another consideration is that patients may initially be screened on the RPS, and those with high scores could enter into a treatment program that uses pain drawings both as a diagnostic method as well as an adjunct to treatment. This would mean using the pain drawing to understand what forms of treatment might be appropriate for different patients, as well as using it as a means to follow the patient's progress over a given period.

There were two persons reviewing the pain drawings for visual assessment, so an inter-rater reliability calculation was made on their individual scoring of patient's drawings. This was documented prior to the reviewers' efforts to reach common agreement in a final analysis. The inter-rater reliability was 0.62. This indicates substantial agreement.

Table 4.1 shows the age breakdown, disease duration of patients as well as the 4 individual components and total value of the DAS28 score, for the patients in both groups. The groups were based on the status of RA or RAFM as determined by the tender points count. Although the standard deviations for age were high, the average age of RAFM (64.2 years) was about 5.8 years more than the average age for RA (58.4 years). Disease duration in the two groups was 44 months (3.7 years) apart. This implies that screening women for FM who have been receiving RA treatment for 3-5 years is cost-effective. Another consideration is that women whom are being treated for RA depending on their age and the duration of their treatment, should be vigilant for certain symptoms of FM, and report them to their GP or rheumatologist immediately.

Analysis of Table 4.1 also shows that the two 'objective' components of the DAS28 test, Swollen Joints (SJ) and Erythrocyte Sedimentation Rate (ESR), show no significant numerical or statistical differences between RA and RAFM. However, the two 'subjective' components of the DAS28 test, Tender Joints (TJ) and Patient Global Assessment (PGA), show very high numerically very high and statistically significant differences between RA and RAFM. In the case of TJ test, the RAFM/RA ratio is 12.5/3.6, while the PGA has a RAFM/RA ratio of 62.1/36.8. This result suggests that when diagnosing FM within an RA population, it is most cost effective to use subjective measures. The principle consideration being that the patient knows his/her own body and can therefore give the most accurate information about it.

Tables 4.5, 4.6 and 4.7 are similar, each comparing an RA group with an RAFM group for both the individual DAS28 components and for the total DAS28 score. The RA v RAFM grouping in Table 4.5 is based on using the TP method. The RA v RAFM grouping in Table 4.6 is based on using the RPS. The RA v RAFM grouping in Table 4.7 is based on using the pain drawing (PD) method presented in this work.

In all cases, the ESR values in both groups are essentially identical indicating that the gross inflammation levels observed in RAFM patients may derive mainly from the inflammation related to RA, and that comorbid FM may cause little additional gross inflammation.

The dramatic difference in PGA value differences seen in the grouping by tender points (Table 4.5) (RA v RAFM, 36.76 v 62.06, Δ 25.30) is less in the grouping by RPS

(Table 4.6) (RA v RAFM, 36.78 v 47.39, Δ 10.61), and dramatically less in the grouping by pain drawing (Table 4.7) (RA v RAFM, 39.94 v 44.90, Δ 4.96). This indicates a very high correlation between the PGA and the PD. The patient asked to place a simple mark on a Visual Analogue Scale (not active - highly active) which asks: 'how active is your disease today?' will on average give the same outcome as using the pain drawing method. Therefore, consideration should be given to screen patients firstly with PGA - this could be done by means of website interviews - and then have those with certain scores (or certain patterns of scores over time) be entered into a treatment program that uses pain drawings both as a diagnostic method as well as an adjunct to treatment.

The dramatic difference in TJ count in the grouping by TP (Table 4.5) (RA v RAFM, 3.58 v 12.50, Δ 8.92) is reduced in the grouping by RPS (Table 4.6) (RA v RAFM, 3.44 v 7.5, Δ 4.06) and dramatically reduced in the grouping by pain drawing (Table 4.7) (RA v RAFM, 4.79 v 6.32, Δ 1.53). This implies that the pain drawing method is better able than the TP test or the RPS to identify women with very low levels of RA comorbid with high levels of FM.

The very small difference in SJ Count in the grouping by TP (Table 4.5) (RA v RAFM, 5.89 v 5.19, Δ -0.70) which is also small in the RPS (Table 4.6) (RA v RAFM, 6.00 v 5.47, Δ -0.53) is the highest in the grouping by pain drawing (Table 4.7) (RA v RAFM, 6.25 v 4.97, Δ -1.28). This implies that women using the pain drawing method, visually assessed by experienced analysts, are more able to accurately depict the true number of SJ's. This also implies the pain drawings are better than the TP method or the RPS method at identifying non-articulated joint pain. This leads to the possibility of online studies being calculated which allow women suffering with pain - who may or may not be receiving treatment for pain - to use pain drawings, RPS, PGA and other 'subjective' information gathering methods to differentiate between joint pain and systemic pain. Of these modalities, the pain drawings provide most information facilitating the engagement of the patient in the process of understanding and managing the complexity of FM.

Since FM treatment does not require the prescription of drugs, insofar as there are not any drugs which educated patients with FM would be willing to rely on, the use of this pain drawing system by medical professionals, not necessarily medical doctors offers the possibility of treatment of FM by a 'community of helpers'.

Implementation of research findings

It was hoped that this study would show a difference between the pain drawings of the rheumatoid arthritis/fibromyalgia (RAFM) and the rheumatoid arthritis alone (RA) and that the pain drawing test would prove to be a useful clinical tool in identifying this subgroup of rheumatoid arthritis sufferers. This would enable clinicians to identify those RA patients with superimposed FM. An important finding revealed that using the pain drawings as a means of diagnosis identified no significant difference in the DAS score of RA and RAFM. However, using the TP count and the RPS, the DAS score was significantly higher in the RAFM group. This highlighted a potential limitation of the DAS28. It would help diagnosticians reinterpret the subjectively high DAS28 in the light of this knowledge; and rather than the prescription of more or different drugs; the symptoms could be managed on a more comprehensive bio-psycho-social basis. This would reduce the patient's exposure to potentially toxic drugs, reduce the cost of treatment and also provide treatment which is more likely to be beneficial.

Pain drawings used as in this research could help to identify the presence of a multitude of symptoms (and comorbid conditions) and assist the physician in deciding upon the best course of treatment to treat the individual patient's immediate concern. The drawings of the FM and RAFM groups in particular indicate the possibility of recognizing other complaints that could be adding to the distress of patients with these conditions. This method could, therefore, be used as an additional screening tool; enabling the doctor to prioritize a certain aspect of the condition by taking into account the patients' description of their current symptoms and concerns. It may also provide a starting point for a psycho-social-spiritual intervention for people living with RAFM.

CHAPTER FIVE

A SERIES OF CASE STUDIES EXPLORING THE POSSIBLE THERAPEUTIC EFFECT OF USING REIKI IN RHEUMATIC DISEASE

Introduction

The studies presented in chapters 2, 3, and 4 all deal with the question of how women with rheumatologic conditions draw their pain. All of the women were attending and recruited from clinics where they were expecting or hoping to have treatment that would reduce their pain. Many of the women participating in these studies, particularly those known or found to have FM, have such severe pain and other symptoms that it causes a significant reduction in their quality of life.

The researcher is a certified counsellor and Reiki (Master-teacher) therapist as well as holding qualifications in a range of alternate therapies. The researcher had also completed a Masters degree for which the topic was integrated medicine. The researcher was interested, if time allowed during the work for this PhD, to see if participants with FM would respond well in experiencing a reduction of symptoms following a structured set of sessions of the complementary therapy Reiki.

Reiki Theory

Reiki was formulated by Mikao Usui (1865-1926) in early twentieth century Japan (www.reikialliance.org). Usui was a practitioner of Tendai Buddhism and his foundation of Reiki in its early years was primarily a system of spiritual practice. Physical, emotional, or mental healing that might occur in those learning Reiki was seen as a natural bi-product (Miles, True, 2003). A Japanese contemporary of Mikao Usui, Morihei Ueshiba (1883-1969) was the founder of a martial arts movement called Aikido. Western practitioners of Aikido have suggested the meaning of 'Aikido' as: "The way of harmonious Spirit" (Westbrook, 1970); or as "The way of unifying with life energy" (Saotome, 1989). The word 'ai-ki-do' can generally be transliterated as 'harmony-energy-way' with the primary teaching of Ueshiba being to control martial arts (violent in nature) with a way of harmonious energetic balance within the action of martial art. In the Japanese language the word for health is 'genki' while the word for illness is 'byoki'. 'Gen' meaning good or flowing, 'byo' meaning ill or stagnant or blocked, are combined with the word 'ki'. Accordingly, the Japanese understand an underlying force of 'ki' and health to be synonymous. Westbrook's translation of 'ki' to mean 'Spirit' was an effort to translate to the Western mind that what the West calls 'Spirit' may also be synonymous with 'ki' (Westbrook, 1970). The name 'Reiki' is made up of the word 'Rei' meaning universal or highest and 'Ki' meaning subtle energy, like the Chinese 'chi or qi' (Chang, 1973). The vibration accessed in Reiki arises from primordial chi, or Tao, (this is different to the bioenergetics level of chi stimulated by therapeutic acupuncture) (Becker, 1976).

The practice of Reiki as a clinical art has become more popular throughout the world as it was adapted, somewhat beyond the early intentions of its founder Usui, to become a treatment modality claiming to have effect upon physical, emotional and mental health. In Usui's original teaching there were no recipients of Reiki who would not be taught the art of Reiki. Usui structured his teachings into three levels:

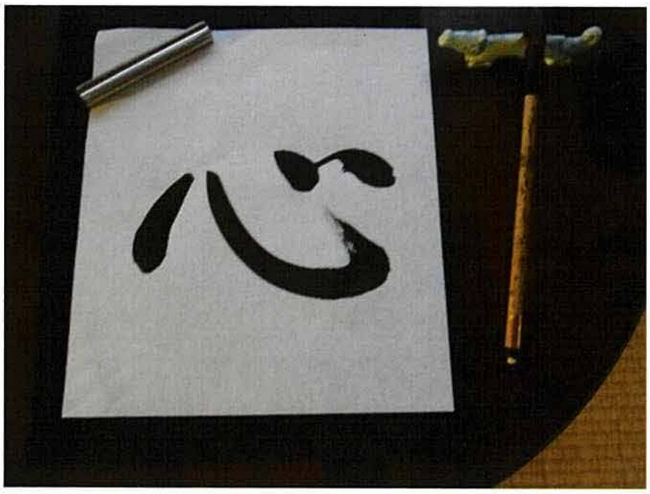
1. Shoden – a process in which the student would be initiated into the reiki energy and learn to give Reiki to others.
2. Okuden – further teachings of the student related to specific symbology for higher order Reiki work along with the teaching on how to practice Reiki at a distance. This level required the student to be sensitive to the energy of others not in their presence.
3. Shinpiden – a Master-teacher level (Sensei) in which further refinement of energy perception and understanding is developed, along with authority to teach Shoden.

In Western systems of Reiki, 'practitioners' may be at any one of these three levels and 'patients' may not necessarily be at any one of them, formally. However, unlike the Western system where a doctor or specialist treats a patient, Western Reiki practitioners incorporate the learning of Reiki into each session. The 'patient' in receiving reiki treatments is progressively learning about their own experience of 'genki'.

According to Miles and True as of 2003, the Reiki Alliance, one of several organisations of Reiki masters had more than seven hundred members in forty-five countries (Miles, True, 2003). As of today more than five hundred are now listed on their website by name (www.reikialliance.com).

Jin Shin Do ("The Way of the Compassionate Spirit") is a therapeutic massage technique developed in the 1970s by Iona Marsaa Teeguarden. Jin Shin Do is a body-mind acupressure. It integrates Reichian theories about emotions with the meridians of traditional Chinese medicine (see Appendix G). Jin Shin Do combines elements of Japanese acupressure, Chinese acupuncture, orgone of Wilhelm Reich, Chinese Qigong, principles of Ericksonian psychotherapy, and Taoist philosophy, but uses its own specialized terminology. The technique uses verbal guidance (by the practitioner), light exercise (by the patient), and fully clothed massage (touch). The major goal is to release chronic tension, referred to as "armoring", and to rebalance the flow of life-force based on the traditional Chinese concept of qi (chi). (http://www.jinshindo.org/development.htm). In Japanese language, words are expressed as images, called "calligrahs" by westerners. The Japanese character "Shin or Kokoro" is transliterated by westerners, depending on context as, heart, mind or spirit. The Shin or Kokoro is the form of Spirit or Energy (Ki) which has the intelligence of the mind or heart. Jin Shin Do recognizes that the practitioner must maintain a compassionate spirit that is listening to the energy of the patient, and that this listening is a conscious experience.

Figure 5.1 The Japanese Character for "Shin"



Source: http://japanese-calligraphy-message.blogspot.com/2011/07/kokoro-shin.html

Reiki and Jin Shin Do share a common root in traditional Japanese health teachings and both work with Spirit (energy of consciousness). Reiki has been described as an intelligent, universal or conscious energy; it is non-directed and goes where it is needed in the body. Reiki professionals recognise the therapist, the participant, and the environments in which they live in are made up of energy. The structure and flow of this energy is based on lines of information and intent that would be considered by most people to be a 'conscious energy'. The exact nature of conscious energy is that it is always contextual. There are no yardsticks to measure its length or meters to measure its intensity and it is not possible to understand how it works by applying statistical analysis of multiple participants over time. Nevertheless, the effects of working with this energy can be measured in participant outcomes.

Understanding Reiki requires an awareness of indigenous healing traditions that exist alongside, and pre-date, the Western biomedical model. In these systems, the ability to facilitate healing derives from knowledge and practices that are passed from master practitioner to student.

Reiki is practiced by people who have typically come to understand the importance of energy as the means by which Spirit speaks with the body and have trained themselves to feel the structure and flow of energy. In some cases, this ability is innate (inborn) and the choice to be a Reiki practitioner is the path used to cope with this ability. Reiki allows the recipient to have a reconnection with the restructure of the way energy moves in the body. However, the permanent effects are achieved only when the recipient develops their own new understanding of their own spirit.

This is the energy referred to by Reiki practitioners. Within the last couple of decades physiological and biophysical scientists have gathered data that supports the existence of electromagnetic radiation emanating from living organisms. The main sources of bio-electric radiation are the heart and the brain. There is now data to indicate that external electromagnetic fields can influence the body's natural field both negatively and positively, and certain frequencies of electromagnetic radiation can have healing effects on body tissues. Data also demonstrates that energy radiation from outside the living body can have profound effects on life, growth, development and health in general. There is solid evidence that all living creatures emit electromagnetic radiation that can be measured by validated scientific instruments (www.nccam.nih.gov/health/whatiscam). Jan Walleczek and Abe Liboff in the field of bio-electromagnetism offer credible scientific support for the potential role of the forces of subtle bio-electromagnetic fields in physiological processes (Liboff, 1985; Walleczek, 1995). Although this area of research is in its early stages, these connections suggest that the theoretical underpinnings of Reiki and other energy therapies may not be in direct contradiction to scientific models.

Reiki does not just work on the physical level it also helps with emotional symptoms. Reiki treatment calms the body and mind. It decreases anxiety and releases tension, leaving a person feeling relaxed and peaceful and with a general sense of well-being (P.E.M., 2002). A Reiki session can cause suppressed feelings to surface and energy blocks to be released. If a person feels tired and stressed it can revitalize them or if they are nervous and anxious it can help to soothe and relax them. Whatever emotional disturbance a person is suffering from it can help them to feel more detached, less worried and more able to deal with their problems.

To understand how energy can influence all these levels of human experience, consider a hierarchy of effects. Simple life forms already exhibit very complicated cellular structures and the theory of Reiki is that the complex molecules of life that make up cells and tissues are not only interacting on a random distribution, but are also responsive to conscious information. Conscious information does not mean mental information. What it means is that macromolecules are interfacing with energy as they carry out the tasks they are designed for. The increase in complexity in higher orders of life could be the manifestation of higher orders of energy fields that are more finely structured and hold together complex physical, emotional and mental processes familiar to humans. The highest order of energy is experienced by humans in its most adaptive and least constrained form called 'Spirit' (www.reikialliance.org).

When the human is able to recognize and work with the structured and contextual information of energy at this high order level called Spirit, then the human will or intent can be encoded into the energy patterns. When Spirit is encoded with human intent, it is then able to consciously interface with the lower order systems (mental thoughts, emotions) and those systems can affect the basic physical strata. For Example when a Reiki practitioner describes the energy as 'non-directed', this means that as a 'therapist', the Reiki practitioner is not choosing or controlling the energy. Rather the Reiki practitioner becomes an antenna that can pick up information and a conduit i.e. a conscious intermediary through which the subtle energy may bridge from the purely spiritual energy world into the physical and emotional world of the patient.

Practitioners believe Reiki has the potential to rebalance the bio-field at the deepest vibrational level, thereby removing the subtle causes of illness while enhancing overall resilience. Because Reiki is a holistic modality that supports overall healing and well-being, it is not possible to predict how quickly specific symptoms may respond. Generally, in addressing chronic conditions, a minimum of six complete treatments is advised before evaluating clinical benefit.

Evidence of the efficacy of Reiki as a therapeutic modality

Although systematic study of efficacy is limited thus far, Reiki is increasingly used as an adjunct to conventional medical care, both in and out of medical settings i.e. hospice care (Sadock, Sadock, 2003; Bullock, 1997); emergency treatment rooms (Eos,1995); psychiatric settings (Nield-Anderson, Ameling, 2001); postoperative pain (Alandydy, Alandydy, 1999; Dillard, 2002); nursing homes (Brennan, 2001); pediatric (Brill, Kashurba, 2001) and rehabilitation (Brennan, 2001).

These studies show how Reiki as a natural method of healing and relaxation can be effective when combined with other forms of treatment. Reiki is also empowering in that it is a therapy the person can learn to do as a self-treatment. Some people now use Reiki to heal many aspects of their lives (Algarin, 1995). Reiki is a supportive therapy for hospice and palliative care. Children with cancer and their families practice First degree Reiki on themselves and one another (Bullock, 1997).

Reiki not only addresses physical symptoms but also the painful feelings and stressful thoughts that contribute to illness or lack of well-being. Reiki is believed to rebalance the biofield, thus strengthening the body's ability to heal (Alandydy, Alandydy, 1999) and increase resistance to stress. It appears to reduce stress and stimulate self-healing by relaxation and perhaps by resetting the resting tone of the autonomic nervous system. Proponents of Reiki believe this might lead to enhancement of immune system function and increased endorphin production. Reiki, however, is not intended to be a substitute for conventional medical or psychological treatments; but it can enhance their effects and decrease their side effects (Nield-Anderson, Ameling, 2001).

Reiki treatment

Reiki is a vibrational or subtle energy commonly facilitated by light touch, which is believed to balance the biofield and strengthen the body's ability to heal itself. While a practitioner's ability to be a conduit for the vibrations may vary, there is ultimately no wrong technique (Haberley, 1990). Reiki's self-regulatory mechanism precludes "overdosing" - even a dry sponge only absorbs to saturation.

Reiki practitioners generally follow a series of steps outlined in the core Reiki training (www.reikialliance.com). However, the actual progression and duration of each of those steps personalised for each individual in each session in response to the conscious flow of each participant's energy i.e. each session has a plan that shifts adaptively for each recipient of the treatment. Experienced practitioners notice when the healing vibrational flow decreases, at which time they move to the next hand placement (Scales, 2001). A session can be as short or as long as needed, with full treatments typically lasting forty-five to seventy-five minutes. In practice Reiki involves the placement of the practitioners' hands a few inches above points on the body. Reiki vibration is understood to be drawn through the practitioner according to the recipient's need within the ability of the practitioner to carry the vibration (Sadock, Sadock, 2003). Recipients often sense a vibrational flow, sometimes feeling heat or coolness, or waves of relaxation throughout their body, or in specific areas that may or may not correspond to where the practitioner's hands are placed (Sadock, Sadock, 2003; Scales, 2001; Engebretson, Wardell, 2002).

A full Reiki treatment works on the major organs, the hormonal systems, the acupuncture meridians and the chakras or energy centers of the body (see Appendix E). A full treatment typically includes twelve positions on the head and on the front and back of the torso. For each step, both hands are usually placed on each side of the body (right and left) or in some cases on two linear points (above and below). The session usually starts with the head and moves towards the feet. Key steps along the way are typically: Head, throat, shoulders, heart, abdomen, pelvis, knees and feet. Most sessions incorporate a top to bottom and bottom to top series of steps. The time the practitioner spends at each step is determined by the feeling of energy i.e. its intensity, quality, pulsation or flow he/she feels (Brill, Kashurba, 2001). At times, in regions where there are underlying problems (heart, spleen, liver, kidney, reproductive organs), the conscious force controlling the Reiki energy will intensify the energy (heat or cold, strong pulsing, heavy flow) and Reiki practitioners (like the researcher) who are receptive of visual and mental imagery may also receive information of this kind (Brennan, 2001). Although such images and incoming thoughts can be shared with the participant immediately during classic Reiki sessions (to interface with participants own mental, emotional or visual experience), the Reiki sessions in this study were purposefully kept quiet. In some cases, participants themselves would make a comment on a momentary experience and this was listened to. The effect of such quiet sessions is that they usually go deeper into the pure substance of the energy and do not spend time on the emotional aspects of the treatment.

The effects of Reiki are usually to allow openings and restructurings of the energy and conscious information moving within the participant. In a similar manner to the way blood circulates in the body according to changes in the circulatory system, the energy body of the participant is changed and energy circulates along different paths and with different intensities. Since the goal of Reiki is to eventually achieve a stable or permanent change in the structure of energy, and to facilitate balance and healthy homeostasis, the effects of the Reiki session typically last for many hours or even days. The practitioner remains aware of the conscious forces during the session to allow an appropriate amount of energy change or restructuring at each step.

However, there is no agreed upon theory for how Reiki might work, and its mechanism of action is still unknown. For this reason, Reiki is a subject open to the same criticism when viewed by skeptics as other CAM modalities who would claim it cannot be efficacious because 'it lacks a known biological mechanism of action'.

Methods

Participants

Six female participants recruited directly from the North West Wales Rheumatology Department. Diagnosis confirmed by consulting rheumatologist. Two FM only participant's volunteered from the OA FM study (Chapter 2); two RA and two RAFM participants volunteered from the RAFM study (Chapter 4).

Study Design

Due to the limited time for data collection and the research programme, an experimental case study approach was applied. There were a number of dependent variables measured in the study.

Measures

Pain drawings were used for physical and emotional, images of pain. The visual analogue scale (VAS) was used to measure fatigue, physical and emotional pain. The following questionnaires were completed: participant health questionnaire (PHQ-9), arthritis self-efficacy scale (ASES), hospital anxiety and depression scale (HADS), McGill Adjective questionnaire (McGill), fibromyalgia impact questionnaire (FIQ).

Pain drawings

The participants were already familiar with pain drawings, which were identical to the drawings used in the OA/FM or RA/RAFM study. Each participant drew a new set of drawings on the day of the first Reiki session (pre-treatment) and on the day of the last session (post-treatment). The visual assessment was done only by the researcher.

Visual Analog Scale (VAS)

VAS is widely used in pain research and is proven to have good validity and reliability (Huskisson, 1983). The VAS is a system of measuring that requires a person to mark a line (100 mm) where only the endpoints are given. In this study the endpoints were 'no pain at all' and 'extreme pain'. Three VAS scales were used: fatigue, emotional pain, physical pain (see Appendix E).

Participant Health Questionnaire (PHQ-9)

This easy to use participant health questionnaire (PHQ-9) is a self-administered version of the PRIME-MD diagnostic instrument for common mental disorders (Kroenke, Spitzer, Williams, 2001). The PHQ-9 is the depression module, which scores each of the 9 DSM-IV criteria as "0" (not at all) to "3" (nearly every day). It has been validated for use in Primary Care (Dietrich, Oxman, Burns, 2003). It is not a screening tool for depression but it is used to monitor the severity of depression and response to treatment. It can be used to make a tentative diagnosis of depression. Validity has been assessed against an independent structured mental health professional (MHP) interview. PHQ-9 score ≥10 had a sensitivity of 88% and a specificity of 88% for major depression. It can even be used over the telephone (Pinto-Meza, Serrano-Blanco, Penarrubia et al, 2005). (See Appendix E)

Arthritis Self-efficacy Scale (ASES)

The Arthritis Self-Efficacy Scale (ASES) contains three subscales relating to self-efficacy in relation to controlling pain, function, and an 'other symptom scale' (Lorig, Chastain, Ung, Shoor, Holman, 1989). Each of the scales represents the answer to the question: 'How confident are you that you can…' Participants rate their responses on a 10 point Likert scale. In total there are twenty-eight items. Higher scores indicate greater efficacy for each specific subscale (See Appendix E)

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS) (Zigmond, Snaith, 1983) is a self-administered measure used to screen for the presence of depression and anxiety. The HADS was developed to provide clinicians with an acceptable, reliable, valid and easy to use practical tool for identifying and quantifying depression and anxiety. The HADS can be used in a variety of settings i.e. community, primary care, in-hospital, and psychiatry. The HADS is not intended as a complete diagnostic tool, but as a means for identifying general hospital participants who need further psychiatric evaluation and assistance (Herrmann, 1997; Bjelland, Dahl, Tangen, Haug., Neckelmann, 2002). (See Appendix E)

McGill adjective questionnaire (McGill)

The McGill adjective questionnaire is a section of the widely used self-report pain inventory (Melzack, 1975, 1987). It contains a list of 20 pre-defined groups of adjectives, participants are asked to select one adjective from each group, but only if they feel it describes their pain (each group consisted of between 2 and 6 adjectives). A score of between one and six is allocated to adjectives chosen from each group. If no adjective is chosen from a group the score is as zero. The scores of the groups are then added. Final scores range between a minimum of zero and to a maximum of seventy-seven. The McGill adjective questionnaire has proven to be a useful instrument for assessing participants' pain quality and intensity. It has been used in diverse clinical situations and shown to be a reliable and valid measure of pain for both FM and OA (Marquez, Assumpção, Matsutani, Pereira, Lage, 2008). (See Appendix E)

The Fibromyalgia Impact Questionnaire (FIQ)

The Fibromyalgia Impact Questionnaire (FIQ) was developed in the late 1980s and was first published in 1991 (Burkhardt, Clark, Bennett, 1991) with minor revisions in 1997 and 2002 (Bennett, 2005). By today, it is one of the most frequently used tools in the evaluation of FM patients (Dunkl, Taylor, McConnell, Alfano, Conaway, 2000; Bennett, 2005; Offenbacher, Cieza, Brockow, Amann, Kollerits, Stucki, 2007) being cited in over three hundred articles and translated into fourteen languages. The FIQ is an instrument designed to quantitate the overall impact of FM taking into consideration dimensions such as function, pain level, fatigue, sleep disturbance, psychological distress (Burkhardt, Clark, Bennett, 1991; Bennett, 2005). The FIQ is widely used to assess change in fibromyalgia status. It is scored from zero to one hundred with one hundred being the worst case. The average score for participants seen in tertiary care settings is about fifty. (See Appendix E)

Procedure

Interviews and treatment sessions were conducted in a Private Clinic in North West Wales. Consenting participants were enrolled in the following series of visitations:

Pre-treatment Consultation

A pre-treatment consultation lasted thirty to ninety minutes. The participant completed the pain drawings, VAS for fatigue, VAS for emotional pain, VAS for physical pain, participant health questionnaire (PHQ-9), arthritis self-efficacy (ASE), hospital anxiety and depression scale (HADS), McGill Adjective questionnaire (McGill), fibromyalgia impact questionnaire (FIQ). This pre-treatment consultation was usually combined with the first Reiki session.

Intervention - Reiki (Therapeutic Touch) Sessions

Participants attended six individual Reiki sessions at one week intervals. Each session started with a five minute discussion that addressed any issues or concerns the participant had from the previous week's session. During the session the participant was comfortably clothed and spent about one hour on a massage table, mainly on their back. Calm music was played throughout the session; once the session was completed, the participant was allowed to lie quietly for about five to ten minutes. The structure of each session and the course of each treatment were determined by the needs of each participant. Participants were advised to be accompanied to each session by someone who could drive them home. This allowed the participants to remain relaxed within the energy of the Reiki as long as possible.

Post-treatment Consultation

After the sixth Reiki treatment session, each participant returned one week later for a post-treatment consultation in which the identical questionnaires used in the pre-treatment consultation were completed, followed directly by a seventh Reiki session. Patients were also encouraged to contact the Reiki therapist at any time, during or after the study if needed.

Consent

The participants were individually interviewed. The nature of Reiki work was explained and they were given a schedule for the proposed visits. Each participant then signed a consent form.

Data Analysis

Since there are only six participants, in 3 groups of 2 patients each, the data analysis is not done statistically, but is presented for each participant.

Results

Pain Drawings

The set of pre-treatment and post-treatment drawings from each participant are shown in Appendix C. A visual assessment of the six sets of drawings confirms that the depiction of physical and emotional pain showed improvement in all participants. It is particularly noticeable in the choice of colour. Pre-treatment drawings tend to use strong colours like black, red and orange while post-treatment drawings use softer colours like grey, blue, yellow, green.

The following is a summary of points made by participants about the image drawn:

Case Study 1 (FM Participant)

Description of image pre- treatment:

> *Blob on the floor with sticks going up – witch on the stake being burnt. I'm a shape, heap, no form. Burnt at the stake... I don't think I deserve to be burnt at the stake but it is the only thing I can see.*
>
> *The reason it doesn't look like me is because I am it is like I am a lump of jelly – sticks bundle of old heaps of twigs and rubbish no fire.... It is just me falling into a bundle of sticks... the fear I am going to burn up...I am fighting to stay as a form ... I haven't gone yet, feel like I am useless, worthless, I am denying whatever I am feeling because I am a fighter.... I am fighting to say I am not going...*
>
> *I'm useless, I'm useless, I'm rubbish... then I cry... then I say I am not I am a beautiful person there is an inner beauty that is suffocated.*
>
> *After crying...I feel as if I've been searching from about my twenties for peace...Peace within myself... self- acceptance... but I haven't felt that peace for about 30 years... I am questioning myself...When I was 20ish (1970) lived in NZ & Australia... good times and good things to do... I was aware of searching and not being happy.*

Description of image post-treatment:

- *Tired heap ... blob... biding its time...its not going to stay like that... It is getting its wings ready... it is resting... A tired hanging body... resting... It seems to know just be participant...*
- *Just work it out kid!!*

Case Study 2 (FM Participant)

Description of image pre-treatment:

- *Frustrated being trapped in old an old person's body, not in control of body, pain or life feelings of ending life...just don't want to carry on anymore.. Not able to physically take own life but if I wasn't able to wake up tomorrow I wouldn't be sad it would be pure relief.*
- *I'm now a person unable to make meaningful decisions or remember names of people I work with so call everyone love to make it easier. I feel I have to depend on others so I'm impacting on their life and I', letting my work colleagues down by this uncontrollable illness that's making me so miserable and utterly depressed. I'm so tired and yet find it so difficult to sleep. I can't explain to people what it is like especially the medical profession, as they make me out to be a hypochondriac or worse... completely manic! I need help but where do I go??*
- *The images I have drawn show my frustration, however I can't say the pain stays in any one area ... It can be all over the body... But it seems to move around and settle in neck, shoulders, back and head for ages.*
- *The shaking and feeling of sickness has increased over past 4-5 months as have the panic attacks and fear of leaving my home. My social skills have gone up the wall as friends haven't stayed around me as I back out of dates supposedly at the last minute but in truth I can never remember making arrangements/ or speaking to them.*
- *It is so damn hard living this life. People just don't get me, I'm not sure anymore who or what I have become but I don't like me and need help*

before I do something that would upset my family, colleagues and close friends!

Description of image post- treatment:

- *My image depicts a person who is broken both on the inside and the out. When the pain is at its worst is almost like a dark cloud covers the person so that the true identity is hidden. It's hard to cope with the physical aspects but pain relief can be taken to ease some of the excruciating physical pain but as for emotional aspects of the illness there seems to be nothing that can be given to help ease that.*
- *People tell you to think of all the good things in your life such as your relations etc but emotionally you are unable to think of the good things.*
- *People have said that thinking positively about this illness but it's so difficult to find anything positive to say or feel. When the emotional pain overtakes the physical pain seems to increase and the hamster wheel doesn't ever begin to slow. With this comes the nervousness, the tightness in your throat and a feeling of explosiveness within your interior. What's more difficult is that other people think you look alright! You may walk slowly and try to hold everything inside but apart from that you look fine!*
- *They don't see the jousting stick penetrating through your body or the train track that has unhinged itself from its footing or the vice tightening within your stomach or the nauseating feeling working its way up your throat.*
- *All you want is a magic key to help you unlock the spirit within so that you can become normal again. I long to do things that normal people do like going out and having a laugh but this illness even takes away your laughter and sense of humour. What frightens me more is if I don't get better the illness will slowly gnaw away my soul!*

Case Study 3 (RA Participant)

Description of image pre-treatment:

- *Automatic like a robot*
- *Nothing makes me really happy!!*

Description of image post-treatment:

- *Feel like a rag doll... just want to scream!!!*

Case Study 4 (RA Participant)

Description of image pre-treatment:

- *Black lump... like a lump of despair that you cannot see your way out of*

Description of image post-treatment:

- *I feel the pain and weakness I feel as a big black blob that I can't shake off and I sometimes feel as if I will never get better.*
- *I also think people don't realise how bad the pain and stiffness is sometimes, when they say they have a bit of arthritis.*
- *I sometimes think there must be something else wrong with me for me to feel this bad!*
- *I also hate to tell the doctors this in case they think I am exaggerating.*

Case Study 5 (RAFM Participant)

Description of image pre-treatment:

- *This image means to me that the pain is like a time bomb. All I can do is sit and wait for it to go off. I do get a short warning before it happens but when it doesa go off, the pain is really bad... it hurts to even breathe at times.*

Description of image post-treatment:

- *Ladder*
- *Red – Bottom of back hurting quite a lot*
- *Blue – Trunk uncomfortable but not like it was*

- *Yellow – Shoulders because I am dealing with the emotion... I'm dealing with the physical and emotional pain ... It's getting dealt with... It is getting lighter because I can think of things logically... looking at pain in a different way... and putting it to use!*

Case Study 6 (RAFM Participant)

Description of image pre-treatment:

- *Total pain (stitch like)*
- *Sharp muscular pain*
- *Pain*
- *Back pain*
- *Swollen Hot and uncomfortable*

Description of image post-treatment:

- *How I feel with pain/present*
- *Bad RA days*
- *Painful joints or tendons/muscles*
- *Fed up*
- *Concern*

Table 5.1 - Visual Analogue Scale and McGill Adjective Questionnaire

		Fatigue[1] (0-100)	Physical Pain[2] (0-100)	Emotional Pain[3] (0-100)	McGill[4] (0-77)
Case 1	pre	72	49	100	50
diagnosis FM	post	71	68	47	38
	change	*-1 (1%)*	*+19 (39%)*	*-53 (53%)*	*-12 (24%)*
Case 2	pre	100	100	100	56
diagnosis FM	post	79	76	06	36
	change	*-21 (21%)*	*-24 (24%)*	*-94 (94%)*	*-20 (36%)*
Case 3	pre	72	46	100	62
diagnosis RA	post	74	40	100	30
	change	*+2 (3%)*	*-6 (13%)*	-	*-32 (52%)*
Case 4	pre	73	79	98	22
diagnosis RA	post	66	63	85	29
	change	*-7 (10%)*	*-16 (20%)*	*-13 (13%)*	*+7 (32%)*
Case 5	pre	71	57	78	8
diagnosis RAFM	post	63	36	24	40
	change	*-8 (11%)*	*-21 (37%)*	*-54 (69%)*	*+32 (400%)*

Case 6	pre	59	10	20	13
diagnosis RAFM	post	42	31	5	32
	change	*-17 (29%)*	*+21 (210%)*	*-15 (75%)*	*+19 (146%)*

[1] higher scores represent higher levels of perceived fatigue

[2] higher scores represent higher levels of perceived physical pain

[3] higher scores represent higher levels of perceived emotional pain

[4] higher scores represent higher levels of perceived pain

Table 5.2. Hospital Anxiety and Depression (HADS) Scores and Participant Health Questionnaire (PHQ-9) Scores.

		HADS		PHQ[3]
		Anxiety[1]	Depression[2]	
		(0-21)	(0-21)	(0-27)
Case 1	pre	18	13	26
diagnosis FM	post	12	7	12
	change	*-6 (33%)*	*-6 (46%)*	*-14 (54%)*
Case 2	pre	19	20	26
diagnosis FM	post	11	10	16
	change	*-8 (42%)*	*-10 (50%)*	*-10 (38%)*
Case 3	pre	20	17	25
diagnosis RA	post	18	18	24
	change	*-2 (10%)*	*+1 (6%)*	*-1 (4%)*
Case 4	pre	13	11	25
diagnosis RA	post	11	11	16
	change	*-2 (15%)*	-	*-9 (36%)*
Case 5	pre	12	11	18

diagnosis RAFM	post	8	6	5
	change	*-4 (33%)*	*-5 (45%)*	*-13 (72%)*
Case 6	pre	11	4	1
diagnosis RAFM	post	11	5	9
	change	-	*+1 (25%)*	*+8 (800%)*

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[1] higher scores represent higher levels of anxiety

[2] higher scores represent higher levels of depression

[3] higher scores represent higher levels of depression

Table 5.3. Arthritis Self Efficacy for Pain (SEPS), Function (SEFS) & Other Scale (SEOSS) and Fibromyalgia Impact Questionnaire (FIQ).

		SEPS[1]	SEFS[2]	SEOSS[3]	FIQ[4]
		(0-50)	(0-90)	(0-60)	(0-100)
Case 1	pre	8	22	9	78
diagnosis FM	post	35	48	50	38
	change	*+27 (337%)*	*+26 (118%)*	*+41 (456%)*	*-40 (51%)*
Case 2	pre	5	23	6	95
diagnosis FM	post	29	46	40	70
	change	*+24 (480%)*	*+23 (100%)*	*+34 (567%)*	*-25 (28%)*
Case 3	pre	43	36	23	-
diagnosis RA	post	42	37	18	-
	change	*-1 (2%)*	*+1 (3%)*	*-5 (22%)*	-
Case 4	pre	8	37	27	-
diagnosis RA	post	8	15	20	-
	change	-	*-22 (60%)*	*-7 (26%)*	-
Case 5	pre	20	48	22	85
diagnosis RAFM	post	31	61	39	68
	change	*+11 (55%)*	*+13 (27%)*	*+17 (77%)*	*-17 (20%)*

Case 6	pre	30	57	57	82
diagnosis RAFM	post	43	59	47	70
	change	*+13 (43%)*	*+2 (4%)*	*-10 (18%)*	*-12 (15%)*

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[1] higher scores represent greater belief for controlling pain

[2] higher scores represent greater belief in completing tasks of daily activities

[3] higher scores represent greater belief in controlling symptoms associated with arthritis

[4] higher scores represent higher negative impact of fibromyalgia

Participants diagnosed with FM and RAFM reported an increased belief in their ability to control their pain following the intervention of Reiki. However, participants diagnosed with RA did not report similar increases. Similar results were also reported for participants' beliefs in their ability to complete tasks of daily activities. Only participants diagnosed with FM reported increased ability to manage other symptoms associated with their disease

Participants diagnosed with FM and RAFM reported a decrease in the impact of their disease following the intervention. Participants with RA were not given the FIQ questionnaire as it relates specifically to FM.

Discussion

The main question asked in this study was whether Reiki over a six week treatment period could improve the quality of life of the pain suffering participants. Because both RA and FM are chronic conditions that slowly become worse over years and recovery to normal health can take many months or even years. Also because there are only six participants, divided into 3 groups, it is not valid to discuss average results. Therefore, discussion of the results will look at each participant individually.

Participant 1 (diagnosed with FM)

The visual assessment of pain drawings (Appendix C) shows this participant to have less physical pain in the head; otherwise, bodily physical pain may be similar. From the drawing it appears that the participant has an underlying joint pain, despite not having been identified as having RA. The participant appears to have significant change in her emotional experience of pain. The free image of the pain looks much lighter. Her own description of the drawn image (see results) goes from having very heavy feelings to enjoying feelings of hope. The choice of colours ranges from black and yellow (heavy and hot) to lighter grey, and pink implying alignment of correctly moving Ki energy.

The VAS scores and McGill Scores (see Table 5.1) show that this participant still has feelings of fatigue, but experiences a modest improvement in reported physical pain (combination of VAS and McGill), and a very clear reduction in the sense of emotional pain.

The HADS and PHQ-9 scores (see Table 5.2) show that the participant reports good reductions in anxiety levels and strong reductions in the two measures of depression.

The three scores from the 'Arthritis Self-Efficacy for Pain Test' (SEPS, SEFS, and SEOSS) (see Table 5.3) show very strong improvements in the participant's sense of controlling pains and in her symptoms and her ability to do daily tasks. There is also a significant improvement in the FIQ, indicating a reduction in the symptoms of fibromyalgia.

This participant appears to have responded well to the use of Reiki.

Participant 2 (diagnosed with FM)

The visual assessment based on the pain drawings for this participant (Appendix C) identified that there was (generally) less pain, particularly in the participants' head. The post-treatment image for physical pain still reflects strong pain. However, it appears that 'energy movement' has not reduced in intensity but has reduced in its quality – a factor reflected in the participants' choice of colour. The emotional pain reflected in the drawing is altered dramatically. It changes from being represented by images of being stuck/pierced/stabbed by 'exploding painful energy' to a drawing where the solar-plexus – the bio-energy generating chakra; the heart- the emotional/spiritual energy generating chakra; are very active. The drawing also shows the top of the head – the crown chakra which is the link to the 'higher-self' is surrounded by constant movement – reflected in the drawing of a spinning wheel.

Therefore, the drawings depict someone who has escaped from an emotional trap and emerged into a period of positive emotional change. In the free image drawing, this participant chose to recreate a body outline. Whilst, her verbal description of the image continued to show high levels of concern about the pain, the post-treatment discussion showing increased hope, and greater concern about returning to normal. A belief that it was possible to be 'normal' again was firmly installed. The written descriptions of accompanying images show the participant feeling less like a robot, an automaton moving on auto pilot and more like a rag doll. Nevertheless, whilst moving in a more fluid manner there remained a feeling of being controlled by others.

The VAS scores and McGill Scores (see Table 5.1) show a good reduction in fatigue and physical pain but dramatic reductions in the sense of emotional pain.

The HADS and PHQ-9 scores (see Table 5.2) show very good reductions in anxiety and depression.

The three scores from the Arthritis Self-Efficacy for Pain Test (SEPS, SEFS, and SEOSS) (see Table 5.3) show very strong improvements in the participant's sense of controlling pains and symptoms and good improvement in doing daily tasks. There is also a good improvement in the FIQ, indicating a reduction in the symptoms of fibromyalgia.

This participant appears to have responded well to the use of Reiki.

Participant 3 (diagnosed with RA)

The visual assessment of pain drawings (Appendix C) shows reduction in physical pain, and a change in the type of pain with emotions. The emotional pain prior to treatment appears to be clouded; the participant did not even identify the emotional pain as being at any specific point in the body. However, the emotional pain after treatment is shown as being located in the solar plexus - bio-energy generating chakra; the heart - emotional/spiritual energy generating chakra, and head - third eye or crown chakra – which represents discernment in the world or contact with higher self).

The VAS scores and McGill Scores (see Table 5.1) show that this participant is still locked into an emotional cage which prevents her from having a general perception of improvement in the level and quality of her physical pain (VAS). However, the McGill score does seem to indicate an improvement in the level of physical pain.

The HADS and PHQ-9 scores (see Table 5.2) show that there has not been an improvement in the experience of anxiety or depression suffered by this participant.

The three scores from the Arthritis Self-Efficacy for Pain Test (SEPS, SEFS, and SEOSS) (see Table 5.3) show this participant has not made an improvement in her feeling able to control or deal with her symptoms and to complete tasks.

This participant does not appear to have responded well to the use of Reiki. However, she does appear to have shifted from having the limited sense of a small person enduring pain to the belief of a more expanded, larger, more rounded person to deal with what are very real problems.

Participant 4 (diagnosed with RA)

The visual assessment of pain drawings (Appendix C) shows a slight increase in physical pain, particularly in some joints. The emotional pain at pre-treatment seems to have been mostly centered in the liver, heart - emotional and spiritual energy generating chakra- and top of the head – the crown chakra. It seems synonymous with the physical pain which perhaps shows a convergence of self-image or holistic understanding. This could mean that the participant has shifted from feeling spiritual pain to feeling the physical pain or that their emotional perception is coming closer to working with the physical pain. It is possible that in post-treatment the participant did not understand the instructions for drawing shape and feeling of pain. The choice of a black cloud turning to a grey cloud shows a slight decrease in depression. Written description of images drawn indicates a limited sense of improvement.

The VAS scores and McGill Scores (see Table 5.1) show that this participant has shown a modest improvement in her levels of fatigue, physical pain and emotional pain. It is possible that this improvement is masked by an emotional cloud, since all three of the DAS scores showed a similar modest improvement, while the more detailed McGill questionnaire gave a good improvement in perceived pain.

The HADS and PHQ-9 scores (see Table 5.2) show this participant has made no or very limited improvement in her ability to deal with her experience of anxiety or depression.

The three scores from the Arthritis Self-Efficacy for Pain Test (SEPS, SEFS, and SEOSS) (see Table 5.3) show this participant has made no improvement in her perception of her ability to control or deal with her symptoms but a strong improvement in her ability to complete tasks.

This participant has responded well to Reiki. Physical pain eased and activity increased, now her emotional pain was not lessened. It seems this participant has organic pain (RA) and emotional problems that are not closely linked to the cause of her pain. It would appear that for her life in general is a big struggle and her pain is just a part of her problem. It is plausible that taking this participant through the process of feeling pain will continue to open up the emotional life, and the convergence of self-image.

Participant 5 (diagnosed with RAFM)

The visual assessment of this participant's pain drawings (Appendix C) shows that she did not discriminate well between her emotional pain and her physical pain at the time of the pre-treatment drawing/interview. However, her pain in particular its emotional content, had significantly reduced by the time of the post-treatment drawing/interview. This change in her physical pain seems to involve a shift in the location of the pain. It appears to move from the neck – where it was perhaps/ possibly, the result of an energy blockage – to the head – the location of the crown chakra. This shift indicates that this participant is processing the pains and emotions of the energetic opening to her higher self. This dramatic change is also reflected in the written descriptions accompanying the drawings. The written descriptions on the pre-treatment drawings of pain describe a bomb waiting to explode. This indicates that the dominant pain experience for this participant is the activation of surging energy – such as a kundalini awakening – without an outlet for its release. However, the written descriptions on the post treatment drawings refer to a system (of chakras) where the lower chakras are still hot (source of Kundalini energy) but the central and higher chakras are opening and working with the energy and allowing it to release.

The VAS scores and McGill Scores (see Table 5.1) show that this participant shows modest improvement in her levels of fatigue. The VAS score for physical pain shows a good improvement while the McGill score for perception of pain shows a significantly dramatic improvement. This participant also shows a dramatic improvement in emotional pain.

The HADS and PHQ-9 scores (see Table 5.2) for this participant shows a small improvement and depression, but not nearly as strong as the emotional scores in VAS and McGill.

The three scores from the Arthritis Self-Efficacy for Pain Test (SEPS, SEFS, and SEOSS) (see Table 5.3) show this participant has made notable improvement in her belief and her ability to control or deal with her symptoms and also some improvement in her ability to complete tasks. FM symptoms also improved.

This participant has responded well to the use of Reiki. It appears that she was confronting issues underlying her low levels of confidence and her victimized personality. She was starting to believe she could be cured and that she deserved more in life. Overcoming these issues was part of her spiritual growth process.

Participant 6 (diagnosed with RAFM)

The visual assessment of this patient's pain drawing (Appendix C) shows that she experienced improvements in her levels of physical pain but this could be because during the treatment she adapted to a more emotional perception of her pain. While the free image of pain in pre-treatment drawing is centered on the physical pain; the image in her post-treatment drawing is centered on emotional aspects.

The VAS scores and McGill Scores (see Table 5.1) show that this participant has good improvement in her levels of fatigue – notably the best in the group of six participants. The VAS and McGill scores for physical pain show excellent improvement and the VAS for emotional pain also shows a high level of improvement.

The HADS and PHQ-9 scores (see Table 5.2) show that this participant did not feel less anxiety between pre-treatment and post-treatment interviews. The pre-treatment tests for depression showed very low scores - the lowest in the group of six participants. This indicates limited feelings of depression. Particularly notable is that the PHQ-9 moved up dramatically from its initial very low level.

The three scores from the Arthritis Self-Efficacy for Pain Test (SEPS, SEFS, and SEOSS) (see Table 5.3) show that this participant has made some improvement in her belief in her ability to deal with her symptoms, as well as limited improvement in her ability to complete tasks. Her FM symptoms were reduced (notably).

This participant appears to have responded well to Reiki. It appears that she was repressing or suppressing much emotional experience. The Reiki work appears not only to have reduced her experience of pain, but also to have increased her perception of her emotions.

General Overview

It is shown in a number of measured outcomes how all participants in this limited study responded well to the Reiki sessions. The participants with FM gave more dramatic responses than participants with RAFM. RA participants appear to have responded only partially. Both the FM and RAFM participants' responses were markedly bolder than those of the RA participants whose engagement in the study was more partial.

The measurements help to show how the participants respond individually to Reiki. It is plausible that this type of survey system, over a given period of time, could help counselors or doctors, who prescribe Reiki treatments, to determine how well their patients are progressing. The results could also be used to help patients determine whether other forms of therapy and self-help could be of benefit to them. Whilst this type of study could be expanded to give a more statistical understanding of how Reiki can be used in FM, it should be kept in mind that a large element of the effectiveness of the therapy is dependent on each individual patient's personal willingness to engage.

Spirituality, Personality and Health

There are many perspectives on and approaches to dealing with disease and health disorders. The real challenge however is to understand its underlying causes (Wachholz, Pearce, Koenig, 2007). What causes disease? Is there a spiritual purpose for its existence and is it connected to a person's essence or his/her personality? What if anything predisposes one person to be susceptible to a particular disorder? Is it simply a matter of genetics or is there something much more exciting, much more human, and much more manageable involved? Women with FM often have a sensitive personality and show an excessive concern for others (Van Houdenhove, Neerinckx, Ohghena, Lysens, Vertommen, 2001A; Van Houdenhove, 2003; Van Houdenhove et al, 2002,) which often causes them pain, sadness, anxiety and fear. Holistic (wholistic) medicine, if it is to be truly comprehensive, requires full awareness of the whole body in order that it can heal the existing disease on all levels. This means relating to or being concerned with complete (whole) systems rather than with the analysis of, treatment of, or dissection into parts; holistic medicine attempts to treat both the mind and the body.

From a holistic perspective disease begins on a spiritual level; it then moves to the emotional level and if not dealt with fully on that level, develops symptoms which are ultimately expressed on the physical level. Examining their spiritual and emotional beliefs allows a person to understand how their body is responding to views, perspectives, and illusions that often govern their life and most certainly impact upon it. Understanding this process leads to growth in self-awareness and the development of new options of behaviour and new styles of responding positively to rather than reacting negatively against life and all the challenges and opportunities it presents.

It is not necessarily the experience that correlates or causes a given disease but an individual's perception of the occurrence. For example, for one person, losing a long-term job can be a relief and being given permission to quit a secure position can be an opportunity to re-energise/re-direct a life in a very positive way. For another person such changes are a cause of self-hatred, rage and illusions of victimization. Perception defines the energetic response, which defines the physical experience of ease or disease. In the holistic treatment of illness, it may be important for the participant to become aware of their own personality style and then to recognize that the personality alone is not the whole person. Personality should be viewed as a mask that is developed to aid a person to feel safe and loved. Knowing this and knowing that certain aspects of the personality can sometimes block a person from being who they want to be and possibly need to be to achieve good health is a key. In order to heal from physical disease or emotional disease, the patient needs to recognise and acknowledge the patterns of beliefs that prompt reacting in a personality style to make room for beliefs that support responding from a person's essence (inner being) to facilitate deep healing. Learning to acknowledge their responses on all levels, and simultaneously to receive specifically directed energy medicine, can have a huge impact on a person's life and most importantly on their health.

Whether the treatment modality of disease and illness uses mainstream medical approaches such as drugs, surgery, psychotherapy, physical therapy, exercise and diet; or whether it incorporates alternative methods such as Chinese medicine (acupuncture and herbals), energy medicine, or homeopathy (where there are still treatments as the basis), real healing ultimately is achieved by the efforts of the individual participant. Most drugs and therapies are aimed at reducing symptoms or eliminating problems (cancer, infections, etc.). The success of these treatments requires a general improvement in the health of the participant, such as strong immune system, calm nerves, good digestion, ability to exercise, clear mental states, balanced emotional life. A major factor in complementary and alternative therapies being underestimated by mainstream medical professionals is that they deal with the underlying aspects of the participants' health i.e. emotions.

The impressive improvement as a result to Reiki shown by FM patients fits into the following theoretical psycho-spiritual framework:

The human being is designed and functions based on spiritual information. This means that their actions and desires derive from Spirit. Therefore, energy underlying the actions and desires that lead to growth is first and foremost a spiritual energy. The most intense and best structured spiritual energy flows in a life that is most highly aligned with a divine spiritual intention which can be viewed as a contract between a power higher than the self (God, etc.) and the higher aspect of each self (soul or higher self). The challenge for humanity (collectively and individually) is to balance the alignment of spiritual will – the closest alignment between spiritual intention and final action.

When an individual is out of balance or out of alignment with his/her own individual spiritual intention; or when an individual is balanced but in a social (family, work, community) environment which is not in alignment i.e. not creating higher order goodwill in collective form, the individual's higher self sends signals to his/her body to direct it and remind the individual of its spiritual intention. These signals manifest as pain/illness if they are ignored or misunderstood and incorrectly perceived.

Unfortunately, modern society has forgotten this link and its medical conventional systems do not accept or understand this and medicate the pain. For FM sufferers, pain is primarily sourced in the spiritual energy that governs the body and is experienced as non-organic pain. Their organic pain develops with time. Once medical systems understand and accept that pain is giving spiritual messages, children can be taught to understand that avoidance of certain pain is possible through an honest understanding of their spiritual will and via open communication in relation to their spirit and emotion, there will be less people suffering from FM.

Future research

The line between what is "alternative," "complementary," or "integrative" is often blurred when it comes to biofield therapies. These modalities including Reiki, are generally accepted as low-risk interventions. The widespread use of these therapies, coupled with anecdotal evidence of efficacy, indicate a need for further study of this important category of complementary and alternative medicine (CAM). Because of their foundation in subtle energies that as yet lie beyond technology's ability to consistently measure, biofield therapies present a special research challenge.

This experimental and limited study has shown significant beneficial effects in the short term use of Reiki as a therapeutic intervention for the sufferers of FM, RA and RAFM. Future research using a larger population of these patient groups in addition to other patient groups is recommended.

CHAPTER SIX

GENERAL DISCUSSION

Overview

The objective of this research programme was to explore an innovative method of using the simple body outline (pain drawing) within a rheumatology clinic. Specifically it sought to establish whether the drawn images and written expressions of pain symptoms and sensations drawn by patients could be used to differentiate between the rheumatologic conditions of Fibromyalgia (FM), Osteoarthritis (OA), Rheumatoid Arthritis (RA), and Rheumatoid Arthritis co-morbid with Fibromyalgia (RAFM).

The data reported in this thesis was collected from the interviews of 118 women who had been diagnosed with one of the above-mentioned rheumatic conditions. The primary question addressed was whether women with FM draw their pain/distress in a manner that is useful when diagnosing their condition i.e. in identifying women who have FM. The secondary, intimately related, questions were whether the simple body outline could be used as (i) a therapeutic tool and (ii) as an outcome measure following a series of six sessions of Reiki (CAM) treatments.

Despite the condition being extensively studied, the exact aetiology of FM has yet to be resolved or fully understood. In brief, the symptoms of FM develop gradually and are painful and diverse; they include fatigue, sleep disturbances and cognitive difficulties. Recent research into the chemistry of the central nervous system supports the hypothesis that FM is associated with a process called central sensitization (CS). This process is an augmented response to sensory processing through what is primarily believed to be centrally enhanced hypersensitivity (Arendt-Nielson, Graven-Nielsen, 2003). The numerous symptoms reported often overlap with a number of chronic pain conditions such as IBS, CFS (Abeles, Solitar, Pillinger, Abeles, 2008) referred to as Central Sensitivity Syndrome (CSS) by Yunus (Yunus, 2007, 2008). This makes FM complex and difficult to diagnose, and often leads to confusion when doctors are presented with suspected FM sufferers.

This complexity in diagnosing FM is rooted in the patient having to present a condition causing 'non-organic pain': i.e. pain not showing an anatomical process such as inflammation, swelling and joint deterioration. Patients who have this illness commonly experience deep emotional and psychological pain. The problem is compounded in that the variation of the pain sensations experienced makes it very difficult for the patient to explain clearly and effectively to their doctor exactly what hurts and what they are feeling; it is equally difficult for the doctor to understand and help the patient in order to help her/him. Within the British National Health Service (NHS), where these studies were researched, patients primarily consult with their general practitioner (GP) about basic health issues. Therefore the extent and rate of referral for screening of FM is dependent on the knowledge/discretion of the doctor in question and his/her ability to deal with the needs of each patient. It was hoped that this new approach would prove to be an aid to the medical profession by providing a method that would facilitate a more comprehensive understanding of the symptoms and concerns of each individual patient. This is of particular importance for FM sufferers who will most often have blood test results or x-rays that show no physical evidence for their pain.

Once or if the GP either identifies FM or refers the patient to a rheumatologist for consultation and confirmation of diagnosis, the patient will most likely be prescribed anti-depressants and sleeping aids in addition to analgesics where deemed appropriate. However, the patient and their GP will generally agree it is appropriate to first try the milder analgesics to manage their pain as there is an extensive range of pain medications available 'over-the-counter', or as prescriptions for the same purpose.

In this work the simple body outline was explored as a tool to help patients with chronic pain to communicate and express their pain and distress to their doctors (GP's and health providers). This is ultimately crucial in order for the doctor to know how best to treat the presenting condition, and to attend to the individual needs of each patient (Rothman, Wagner, 2003; Haugli, Strand, Finset, 2004).

In discussion of the relevance of this work, it is useful to consider the following questions?

(1) Does the method of pain drawing used in this work hold a diagnostic value that may be useful in identifying FM by differentiating it from other pain diseases?

(2) Does this method of pain drawing hold a therapeutic value i.e. can it help to treat the causes or symptoms of FM?

(3) Can the process of drawing the pain, and the drawings themselves, be used to improve the level of communication and understanding between patients and doctors so that they can better manage the disease outcome?

(4) Can the pain drawing method be used over time to measure the success of therapeutic interventions?

Summary

The first chapter of this thesis provides an overview of the historical background to FM; it considers current medical status and the methods of treatment used within the conventional medical system. Chapter one also reports extensively on the history, development and current use of the standard pain drawing (simple body outline) typically used in contemporary rheumatology and pain clinics. It also discusses the philosophy of complementary and alternative medicine (CAM) and explains the holistic view and approach of its practitioners to healthcare.

Chapter two and chapter three present the results from a first study that compares sixteen patients with OA to sixteen patients with FM (The FM/OA Study). In chapter two, the patients were viewed as a group and assessments and measurements were used to create numerical and statistical comparisons between the FM and OA groups. Chapter three presented the results of individual patient outcomes based on the qualitative analysis of semi-structured interviews of each FM participant.

The FM/OA Study preceded the study on FM within RA (RAFM) presented in chapter four, and is different from it in that:

- All of the sixteen FM patients knew they had been diagnosed with FM and were offered the opportunity to participate in the study by the researcher of how FM patients drew pain.
- The researcher and independent assessor (who assisted in the visual assessments) had a very limited number of pre-existing examples of such drawings by FM patients. These examples were created in a small pilot study that tested the use of the actual drawing method itself.

- Having already been enrolled for some period of time in the FM clinic, there were typically no recent Tender Points (TP) counted for the FM participants and the OA participants would not have been tested for tender points as they were simply attending a pre-operative clinic appointment.
- The FM/OA Study used the McGill Adjective Questionnaire (Melzack, 1987) that was completed as part of the semi-structured interview, whereas the McGill questionnaire was not used in the second study.
- Pain drawings in the FM/OA Study were analyzed using two established scoring methods, namely, the Margolis Scoring System (Margolis, et al, 1986, 1988) and a modified-Ransford Scoring System (Ransford, et al, 1976). Neither of these scoring systems were used in the second study.
- DAS28 Score was not used, as this scoring system is typically used with RA patients.

The findings of chapter two are consistent with those of Palmer who conducted studies on pain charts in 1949 and pain mapping in 1960. He identified that many patients who drew simple features such as lines or basic symbols could have their pain originate as functional pain from organic causes. Palmer further postulated that drawings which deviated from this simplicity probably had more psychological content (Palmer, 1949, 1960). To date there has been no proven hypothesis that explains underlying physical causes in FM i.e. an agreed upon physical mechanism to support aetiology. Studies since the 1990 publication of the ACR Criteria (Wolfe, et al, 1990) indicate that psychosocial variables contribute to the progression and severity of FM (VanHoudenhove , 2003; VanHoudenhove, Egle, Luyten, 2005). Using the McGill Adjective Questionnaire, the Margolis Scoring System (Margolis, Tait, Krause, 1986, 1988) and the Ransford Scoring System (Ransford, Cairns, Mooney, 1976) as outcome measurements in the first portion of the FM/OA study presented in chapter two, the results show that these quantitative outcomes differentiate between the FM patients and OA patients.

In chapter two it was established through the use of the simple body outline that women patients with FM and women patients with OA express their pain through the medium of drawing in very distinctive and different ways from each other. Visual assessment alone provided compelling evidence that women with FM drew more creative and dramatic representations than women with OA, their drawings being rich in information (images and annotations). Furthermore, women with FM consistently drew representations outside the simple body outline (non-organic) while none of the women with OA adopted this method of communicating their pain and distress; all of their markings were inside of the body outline (organic).

The method of the FM/OA study presented in chapters two and three was as follows: Firstly patients completed the pain drawings, before undergoing a semi-structured interview. To counter the concern that in a structured interview, questions often invite yes/no answers - or alternatively anticipate specific types of answers with participants not allowed to provide answers beyond the question - the questions used in this semi-structured interview (see Appendix F) and the intimate setting in which the interview was conducted (private discussion with a person trained in the listening skills of the counselling profession) facilitated answers that were varied and difficult to quantify using a system of scoring. Further, reflecting upon the striking simplicity of the typical drawing from OA patients, most of the questions in the accompanying semi-structured interview failed to elicit extensive responses from the OA patients. Whilst the original intention was to compare the results of the OA group with the results of the FM group based on their answers in the semi-structured interview, it was obvious by the end of these interviews that, in line with the much more information-rich and vivid drawings by FM participants, the interviews with FM patients yielded completely different, very diverse and extensive transcripts containing emotional and biographical content. Accordingly, the qualitative analysis presented of semi-structured interviews was limited to the FM group, with this analysis presented in chapter three.

In the semi-structured interview participants were also asked to report the emotions they experienced during the drawing process. They were also asked to explain the choice of images used, the meaning of these images used to confirm whether or not the drawing process helped them. Interestingly, by incorporating a semi-structured interview and asking participants about their experience of completing the simple body outline it was observed by some patients that the process of expressing their pain in drawings made it easier to then verbalise their emotional distress. Indeed, many of the participants were surprised that they were able to make associations between what they had drawn and how this related to how they were feeling and their thoughts of how the FM affected their daily life. Furthermore, analysis of the interview transcripts revealed active processing of their emotional distress during the interview. This indicated the potential of using the simple body outline pain drawing as a therapeutic tool to facilitate communication of FM sufferers' pain to counsellors or psychologists or therapists. It is important to note that in such a setting, the line between diagnosis, therapy and patient-doctor (therapist) communication is not rigid. Whether pain is being treated by a rheumatologist who may not have the training or time to deal with emotional therapy or whether it is being treated by psychologists or therapists using the emotional content of the interview as a primary observation point, it is crucial that the doctor (therapist) is able to understand what the patient is trying to say about their experience of pain. This is crucial as it will have implications on how the doctor will manage the patient's condition. In cases where FM is co-morbid with another rheumatologic condition such as RA this takes on a greater significance.

The second study presented in chapter four (The RAFM Study) explored the use of the simple body outline pain drawing method as a way of identifying RA patients with co-morbid FM. Chapter four presents the results from the RAFM Study involving eighty participants all of whom were being treated for Rheumatoid Arthritis (RA). All of the patients in were screened by a consulting rheumatologist specialising in Fibromyalgia to determine which of them would be diagnosed with FM in accordance with the TP count of the 1990 ACR Criteria (Wolfe, 1990). The purpose of this RAFM Study was to determine if the differences seen between the drawings of the OA and the drawings of the FM patients would be reflected in the differences between the drawings of women with RA and the drawings of women who have RA with co-morbid FM. The study also aimed to establish whether the differences would be distinctive enough to differentiate the drawings and to identify the presence or the possible development of FM within a population of RA patients. In summary, the RAFM Study was different from the FM/OA Study in the following ways:

- None of the eighty RA participants were aware they were being screened for FM.

- The researcher and the independent assessor (who assisted in the visual assessments) had the pre-existing examples of drawings done by FM/OA patients.
- Tender Points (TP) and Disease Activity Scores (DAS28) were assessed by one consulting rheumatologist and these results were blinded to the researcher and independent assessor.
- Measurements used for numerical comparison of RA vs. RAFM were the Regional Pain Scale (Wolfe, 2003), and the DAS28 as total score and the individual scores for its 4 sub-components.
- A semi-structured interview was performed using different questions. Not all of the interviews could be taped (permission of participants was a pre-requisite of taped interviews). In such cases no transcripts were produced. The results of such interviews were not summarized or reported in this work.

Statistical analysis revealed significant differences in the number of patients diagnosed with co-morbid FM as a result of using the simple body outline pain drawing as a measurement compared to the number of patients diagnosed using the well established 1990 ACR Criteria method that relies on TP counts. Whilst the TP count method identified 20% of the RA population as co-morbid with FM, the visual assessment of pain drawings identified 39%. Significantly the Regional Pain Scale, which has been widely accepted as an additional diagnostic criterion for FM, even identified 47% of the RA population in this study as co-morbid with FM. When all three of these outcome measurements were compared to the DAS28 (used in RA diagnosis) and its sub-components, the pain drawing had the highest correlation. This has important clinical implications. If patients presenting at rheumatology clinics are treated for RA and not diagnosed with FM, their medication levels may be increased unnecessarily if the rheumatologist believes from his her analysis of high composite DAS28 scores, that the patient is experiencing a flare-up in their RA.

Given that the previous two studies, presented in chapters 2, 3 and 4 had demonstrated a use for the simple body outline/pain drawing analysis in the diagnosis of FM (FM/OA Study), or co-morbid FM (RAFM Study), a third study (The Reiki Study) explored whether the simple body outline could also be used as a before-and-after outcome measure in complementary therapy. Using a case study approach, six patients - two with FM (who volunteered from the OA/FM Study); two with RA; and two with RAFM (who volunteered from the RAFM Study) - were treated with Reiki a complementary therapy.

The Reiki Study was different from the FM/OA Study and RAFM in the following ways:

- All six participants had participated in earlier studies, and were familiar with the pain drawing method. They had also expressed an interest to the researcher in having her work with them.
- All six participants knew their diagnosis.
- All patients agreed to attend seven meetings, once per week, with the first and the last meeting including extra time to fill out all the questionnaires and to complete the simple body outline pain drawings.
- The data is presented in the form of individual case studies, so no independent assessment of pain drawings was performed.
- In addition to or instead of pain drawings, the following measurements - all of which were based on patient questionnaire were made: Visual Analogue Scale (VAS); Participant Health Questionnaire (PHQ-9); Arthritis Self-Efficacy Scale (ASES); Hospital Anxiety and Depression Scale (HADS); McGill Adjective Questionnaire, Fibromyalgia Impact Questionnaire (FIQ). (See pages 161-163).

Comparison of the results of VAS, PHQ-9, ASES, (as SEPS 'pain', SEFS 'function', and SEOSS), HADS, McGill, and FIQ outcomes before and after the six treatments revealed that all six participants benefited from the Reiki session series. The researcher, who is experienced in the analysis of pain drawings, identified significant changes in the drawings of the patients indicating a marked/distinct improvement in their state of health.

Interestingly, the use of Reiki showed very significant changes in the outcome measurements of the various questionnaires, particularly for patients with FM. The purpose of the Reiki Study was not to prove if Reiki is a reasonable treatment for FM. However, if the results from this study, using already established outcome measurements, would be confirmed in a larger study of any type of treatment for FM, they would be considered important.

Although this work has used a standard method in order to identify a type of person called an 'FM patient' or 'FM sufferer' in order to compare them with sufferers of other rheumatologic diseases such as OA and RA, it is reasonable to ask if FM as a condition or disease exists at all. For example, is a headache a disease or a condition, or is it merely a symptom? Perhaps FM would be better understood as a collection of symptoms which might have different causes, the chase to find the miracle drugs acting upon neuromuscular system may be elusive, if the cause of FM is not in the body. Just like one form of headache accompanies either a head cold or flu, while another form of headache accompanies muscular tension in the upper spine, while another form of headache results from an injury.

The Simple body outline drawing as a Diagnostic Tool for Fibromyalgia

Does the method of pain drawing used in the work have a diagnostic value that could be useful in identifying FM by differentiating it from other pain diseases?

The results of this work clearly show that patients with FM are able to draw representations of their pain and that these representations are predominantly vivid and often contain dramatic imagery that can have meaning. If one of the diagnostic criteria for recognition of FM is that patients have extensive and anatomically distributed pain that is often dynamic in location and intensity, then many patients will depict this in their choice of image and in the accompanying description. This suggests that pain drawings might be useful as a screening method to identify those people displaying the early signs of Fibromyalgia.

The FM/OA Study explored the differences in how women with FM and women with OA of the hip/knee express their pain using images and drawings primarily within a simple body outline diagram. It was hypothesized that women with FM would respond to this opportunity to express their pain and distress differently to women who suffer from OA. The results confirm the hypothesis. There were significant differences in how the two patient groups used images and drawings to express their pain. It was clearly illustrated that women with FM created more expressive drawings in contrast to the simple markings in the drawings of the women with OA. All three methods used to assess the pain drawings - Visual Assessment, Margolis scores and Ransford scores - identified and separated the two patient groups from each other. In addition to being 100% accurate in identifying FM sufferers from OA sufferers, the visual assessment of pain drawings on the simple body outline provided the most comprehensive information regarding the patients' pain experience. The outcome supports the possibility of using pain drawings to assist in the differential diagnosis of FM.

The RAFM Study extended the research in simple body outline pain drawings to women patients with rheumatoid arthritis (RA). It researched the use of simple body outline pain drawings of women with rheumatoid arthritis (RA). A proportion of the patients also had FM and this may have influenced how they presented to their doctors and therefore, how their doctors reacted to their pain and distress. This study set out to see if pain drawings can differentiate between patients with RA and no FM (RA) and patients with both RA and FM (RAFM). It also compared the efficiency of this method to the primary and currently accepted clinical method of diagnosing FM, using the Tender Point count as stated by the ACR criteria of 1990 (Wolfe 1990). The TP count method is subjective and varies from day to day. Frederick Wolfe suggested that FM patients can be defined and differentiated from those with RA by using the regional pain scale questionnaire (RPS) (Wolfe, 2003). If it were possible to differentiate patients with RAFM from those with RA alone by a simple test like a pain drawing it would be extremely helpful to the health professionals and very beneficial to the patients. Since FM treatment does not require the prescription of drugs, the use of this pain drawing system by medical professionals who are not medical doctors offers an interesting possibility for the various treatments and therapies for FM.

It was hypothesized that the RAFM Study would show a striking difference between the pain drawings of the rheumatoid arthritis/fibromyalgia (RAFM) patients, and those of patients who had rheumatoid arthritis alone (RA). It was also hypothesized that the pain drawing exercise would prove to be a useful clinical tool in identifying a subgroup of rheumatoid arthritis sufferers who also had FM.

The percentage of participants in the RA group who were shown by the ACR criteria to have FM (20%) corresponds closely to expectations from larger studies of FM co-morbidity within an RA population. In contrast, the RPS questionnaire method and the visual assessment of pain drawing method identified 47% and 39% of these participants to be within the RAFM group, respectively. Analysis of the scores of the individual components of the DAS28 showed compelling evidence that the pain drawing method is an effective way of differentiating women with RA from women with RA co-morbid FM. This method of diagnosing FM co-morbid with RA is an interesting approach, which could easily be made available to the medical profession as well as family and community members to support the understanding of pain in RAFM. This could be studied further in larger studies of RA and FM patients.

The results of the RAFM Study showed a striking difference between the pain drawings of the rheumatoid arthritis/fibromyalgia (RAFM) and the rheumatoid arthritis alone (RA). It also showed that the pain drawing proved to be a useful clinical tool in identifying the subgroup of rheumatoid arthritis sufferers. The pain drawing could enable clinicians to identify RA patients with superimposed FM. This could help them reinterpret the subjectively high DAS28 in the light of this knowledge and rather than prescribe more drugs or different drugs, the symptoms could be managed on a more appropriate bio-psycho-social basis. This would reduce the patient's exposure to potentially toxic drugs, reduce the cost of treatment and also provide treatment which is more likely to be beneficial to the patient. The results suggested the use of this method as an outcome measure for the bio-psycho-social effects of rheumatoid arthritis could also provide a starting point for a psycho-social-spiritual intervention for people living with rheumatoid arthritis/fibromyalgia.

The Simple body outline drawing as a Therapeutic Tool for Fibromyalgia

The researcher asks the question: Does this method of pain drawing hold a therapeutic value i.e. can it help to treat the causes or symptoms of FM? A brief review of the etymology of the words diagnosis, therapy and prognosis (Appendix E) shows that the word diagnosis might be understood to mean 'thoroughly know'. The word therapy might be understood to mean 'a cure or treatment administered'. The word prognosis might be understood to mean 'foreknowing'. Combining the earliest origin of meaning of these important medical words within the framework of the modern medical system, we might say that a thorough knowledge about the patient (diagnosis), with an appropriate treatment administered to the patient (therapy), within a framework for predicting/expecting outcomes (prognosis) is the process of medicine.

The challenge facing a GP in the British National Health Service (NHS) is that he/she has a limited amount of time in which to thoroughly get to know the patient and his/her needs. The GP must work from a diagnostic framework which requires information about the patient to be derived from laboratory tests; the results of which are interpreted within a prognostic framework based primarily on 'organic causes' of symptoms/diseases, and prescribed action is based mainly on treatment options that are restricted to statistically proven methods. Unfortunately for the typical FM patient he/she presents to his/her GP with a set of symptoms that confound diagnosis. To compound the dilemma, the prognostic framework is strong in respect to a long term outcome, but weak in respect to the effect of known treatments. In short, symptoms are only likely to get worse with time, the causes are not well understood, and so the treatment is simply palliative, not curative.

Another way to ask whether or not this method of pain drawing can have a direct therapeutic effect is to put the question that whether if a patient is diagnosed with FM, can this method be prescribed as a treatment with the expectation of a positive result? The results of the semi-structured interviews that followed the pain drawing exercise did show that patients experienced emotions, and in some cases, realisations about their pain from the drawing process (chapter three). If psychological variables contribute to the progression and severity of FM (VanHoudenhove, 2003; VanHoudenhove, Egle, Luyten, 2005) then psychological treatment modalities (bio-psycho-social) could uncover and rectify emotional and inter-relational problems affecting the FM patient. They might also slow progression of the symptoms and reduce their severity as well as improve the daily life of FM sufferers (Mehl, 1988; Rosenblum, 1997; Epstein, Kay, Clauw, Heaton, Klein, Krupp, 1999; Wentz, Lindberg, Hallberg, 2004; Meeus, Jijs, 2007; Wachholz, Pearce, Koenig, 2007). From this perspective, it is questionable if many FM sufferers would derive significant benefit from the emotions experienced in the drawing process, without incorporating the drawing process within the framework of a psychological treatment modality. Any benefits derived from the pain drawing process alone, without supportive emotional therapy, might be short lived.

The simple body outline as a tool for Patient-Doctor communication

Can the process of drawing the pain, and the drawings themselves, be used to improve the level of communication and understanding between patients and doctors so that they can better manage the disease outcome for Fibromyalgia? The answer to this question requires the acceptance, a priori, that the level of communication and understanding between patients and doctors is not adequate; and that improvement in the level of communication might result in better management of the disease outcome. Since good communication and clear understanding between parties is typically valuable in any human endeavour, it is helpful to consider the way patients engage with doctors and see where in this process the issues of improvement in communication might be identified.

In the British National Health Service, patients must first consult their GP in order to receive specialized consultation and treatment. Although many types of symptoms may be a primary reason for the patient to seek advice (i.e. nausea, dizziness, depression, fatigue, etc.), pain is a primary factor in most GP visitations. Accordingly, the GP considers the pain(s) as a sign(s) or an indication of potential causes. Tests are used to determine causes of pain, with tests being centred on the search for organic causes. In many cases, organic causes are found, and with correct treatments, patients are relieved of their painful symptoms. However, in the case of conditions with complex symptoms such as FM, or other related syndromes as discussed by Yunus (Yunus, 2010), the current inability to identify organic causes that can be measured can result in patients presenting themselves to their GP a multiple of times. Since cause cannot be established, treatment options remain limited to palliatives (pain killers, anti-depressants, sleeping aids). In some cases, this situation simply continues until the patient becomes incapacitated and unable to function. One form of misunderstanding can be that patients expect their doctor to provide a clear diagnosis and offer an effective treatment, which is not easy for FM. Misunderstanding may derive from an inability to recognize mutual frustration, where the doctor becomes frustrated in not finding the basis for helping the patient recover and improve, and the patient becomes frustrated in the ineffectiveness in the system, be it the doctor or the usefulness of the treatment options he is allowed to advise. Unless both doctor and patient fully understand and accept a diagnosis of FM together, they may not agree on the importance of addressing the underlying emotional aspects. In some cases, patients themselves are not willing to consider emotional aspects as important, and may expect the doctor to offer treatments that allow them to reduce/remove their pain without addressing the need for emotional based therapies.

A breakthrough is possible when both doctor and patient accept the limits in understanding of FM that may exist and the limited options available. The shift towards this acceptance may be enhanced by a change in focus to a 'person-centred' (patient-centred) approach, which has been used since the early 1970s in the psychiatric, psychological, and counselling traditions (Rogers, 1978. 1980).

Considerations for Patient-Centered Management of FM

The person-centered approach or Person-centered Therapy (PCT), also known as Rogerian Psychotherapy, has been used and refined over 40 years, mainly by the Humanistic School of Psychotherapy (Rogers, 1978, 1980). Since Fibromyalgia is considered as a medical condition of pain in the body, adapting the Rogerian approach can be called 'Patient'-centered. In Rogerian methods, the therapist:

- Creates a non-judgmental and comforting environment.
- Approaches the patient with genuineness (Congruence).
- Validates that the patient's viewpoint/feeling is important (Empathy).
- Remains optimistic and kind at all times (Unconditional Positive Regard).
- Allows the patient to lead at times (Non-Directed Approach).

These methods can be considered alongside the growing clinical understanding of FM and the increased awareness of the importance of patient-based diagnosis. In working with GPs to better manage FM, it is important to consider the subjective experience of the patient; the importance of the patient's history; identifying the needs of the patient; the importance of underlying emotional causes; and identification of responsibilities of doctor and patient.

Pain experience in FM may start out as pain that has an objectively clear cause such as injury, trauma, irritation, and over-exertion. However, by the time the patient is diagnosable with FM, it is quite common that their pain experience no longer correlates exactly with clear causes, but seems to have been magnified, intensified, distributed throughout the body and no longer responds to simple palliatives like resting, relaxing, sleeping, light exercise. Patients who have a limited understanding of the medical viewpoint of their body may develop explanations to help understand their pain which go beyond objectively observable causes. Even if some of the causes are emotional, an objective analysis of the emotions and emotional experiences leading to pain is a rational approach. Yet, the subjectivity of the patient becomes an interlocking aspect of the experience. The simple body outline pain drawing method used in this work appears to work well for FM sufferers because it allows complex and confusing pain experiences to be depicted as images and colors, allowing an objective assessment. It should also be kept in mind that the Rogerian principles listed above were followed during the pain drawing exercise and the semi-structured interview. It seems clear that if a patient is already finding the medical system they are in to be inhospitable, they are less likely to provide rich and vivid information about their pain in the form of a drawing. Accordingly, a system which expects to use the simple body outline pain drawing to generate objective information about the patient's subjective experience of pain may benefit from a patient-centered approach.

One important benefit of the GP based system used in Britain (and commonly found throughout the world) is that the GP has experience/records of the patient's medical history. With FM, the history of the patient's experience of pain is not fully captured in the patient's medical records and important details of that history are even commonly locked up inside the patient's own subconscious memory. GPs are not trained in unlocking those memories with the patient, but that does not reduce the importance of integrating those memories and the facts they bring to the table. If the patient showing a multitude of symptoms of FM were the final chapter in a book, it is doubtful that a doctor could know the full story without having access to the previous chapters. Images are a common language of the human mind and they appear into the conscious mind as a means to activate memory; they are part of the vocabulary of those previous chapters. It must be considered, however, that the images and words chosen by patients to represent their pain, when derived by introspection, are even more private to the patient than the results of laboratory tests. In order to imagine ways in which doctors or therapists can shut down this type of information access to images from the patient's history, one need only look at the above-mentioned principles of the Rogerian approach and imagine the effects of doing the direct opposite of one or more of them.

In addressing the needs of the FM patient one must look beyond the idea that they want to be free of pain. Nearly 60 years ago, Abraham Maslow presented a new theory on the needs of humans and how they may be understood by showing the needs as structured into a hierarchical pyramid with the lowest level (physiological survival) called 'deficiency needs', and the highest level called 'self-actualization'. A core aspect of Maslow's analysis was that in order to have motivation, humans needed to have their needs met from lower to higher levels, with significant breakdowns in lower levels causing lack of function through motivational loss. Maslow also developed the concept of "meta-motivation" to describe individuals who seemed highly motivated to continuously improve, meaning strive for constant betterment. In a rough summary of Maslow's theory, as long as very basic (physiological) needs are met, the person naturally develops through further layers of needs for safety, love, and esteem, masters these needs, and within their own framework of interest, actualizes their highest potential in their own chosen endeavor, and that motivation is required (Maslow, 1943). Maslow and followers since have also described how the limited energy and resources of each individual and social system (family, community, and nation) can only be applied to a limited set of needs, and so, when there is stress and breakdown in the system, the energy is applied to lower level needs.

Many FM sufferers are from social situations and have life histories where they have already been very successful in satisfying higher needs, but with the experience of increasing pain, and with increasing hopelessness about a way out of the pain, they lose motivation. It might even be considered that being free of pain (or feeling in control of pain) is one of the basic physiological needs, or that one of the main experiences of FM sufferers is the deep desire to be free of pain in order to resume a life they knew before. Interestingly, even within the very limited numbers of patients who drew more than one time (The Reiki Study), where there is a before and after comparison, there is evidence that patients use of color and imagery shifts, with physical improvement of pain experience, towards kind-hearted images and lighter colors. Hypothetically, an FM sufferer who became accustomed to using the pain drawing exercise to show their current pain and feelings, could move towards depicting the positive aspects of their experience in images that express beauty or happiness. For example, most people can draw pictographic images of a raincloud or a shining sun.

Consider the experience of the FM patient in Britain or other European and American cultures, where the modern economic system provides for basic needs, and where self-esteem derives from social integration in career, family, church (or charity), politics. With the rapid changes in the way people communicate, such as shift away from limited phone calling over landlines from home to extensive calling over mobile phones, along with the changes in communication styles that come with new technologies such as email, text messaging, social networking, low cost videoconferencing, mobile internet access, the older members of these societies, if not 'meta-motivated' will become separated from the young people in their communities in a way that has never happened in human history. Also, even though the new communication technologies are picked up equally well by young boys and young girls, for the older generation, women are more likely to remain in the older patterns (mailing cards, calling from home). A very open-ended question, but one worth considering is: If young people are no longer in direct communication with their elders in a visible social context, how do they develop emotional experience which would normally have been available from those elders?

The older 'pre-internet' generation is the 'Baby Boomer' generation and because FM occurs with higher frequency in older people, it is predictable that the number of FM sufferers will increase. If the current medical system is unable to work with FM patients in a way that supports an understanding of the importance of the underlying emotional causes of FM, how are they going to handle the following generation? The use of simple body outline pain drawing within a patient-centered management system, to access emotional information from FM patients looks like a compelling possibility. Since it creates images, and the new technologies of communication are image based, there are even prospects that it could be used to help people who have never met the patient develop an individualized understanding. If those images are discussed in therapeutic sessions (such as shown in the semi-structured interview), those interviews could even be conducted from the patient's home using video-teleconferencing. Along the way, it is important to be cautious not to circumvent the need for emotional understanding.

Finally, it is important to consider who is responsible for the FM patient's treatment and to create a clear understanding of this. The traditional role of the GP has been to manage decisions regarding conventional treatments for the patient. In the case of FM, knowledge about the treatment options for FM is scattered and controversial and it becomes easier for the meta-motivated patient to learn far more about their options from support groups and internet sites. Also, since FM is not well managed by drugs, patients turn more often to non-conventional methods, including CAM therapies. The access to such methods and therapies is made easy within the modern digital information world. The methods studied in this work may also be done outside of the formal medical system, by practitioners who are certified in systems that are not recognized by the medical payment system (not covered by insurance or social health systems). If FM becomes a greater drain on a medical system already overburdened with costs, it is likely that responsibility for managing FM will shift onto the patient and away from the GP/doctor.

This begs the question whether the pain drawing method can be used over time to measure the success of therapeutic interventions? The aim of the Reiki Study reported in chapter five was to explore the use of the simple body outline as an outcome measure to help evaluate if the pain experience of participants changed after six treatments Reiki. In order to assure objective measurements for each patient before and after treatment, a group of validated questionnaires were used from which it is was shown that all six participants experienced improvement in pain, fatigue and emotional well-being. The simple body outline pain drawings were visually assessed and all participants produced different drawings which do appear to show less negative heavy images. The results appear to support the interpretation that the improvement measureable in the validated questionnaires is also identifiable in the pain drawing by visual assessment. However, the data set is limited.

Limitations of Research

The scientific method requires a person designing a study to create a structure that will distance the researcher from the outcome, thus limiting the influence the researcher may have on the study, in addition to using controls, comparisons and outcome measures by a statistically valid means.

The results of the studies highlight a number of important issues that could have an impact on the diagnosis and clinical management of FM; there are limitations which should be noted. For example, even though the researcher's influence on the data gathered in these studies is minimal, it could be argued that the personal life experience of the researcher may have influenced the content of some of the data gathered during interviews and this could be considered a weakness.

The visual assessments were conducted by both the researcher and an independent assessor who had no prior knowledge of the patients or their conditions. All of the participants in these studies were interviewed by the same researcher and used the same format. By standardizing the format of the assessment it was hoped that some of the experimenter influences were reduced. It could be argued that the researcher's natural empathy towards this patient group influenced the response of the FM participants, in that the researcher's ability to be an empathic listener played a role in their willingness to communicate their pain experience openly and effectively, although this could also be considered a strength.

Recommendations for future research

The research presented here shows that it is possible to use a guided drawing process to facilitate the expression of pain symptoms and pain experience in support of the diagnosis of FM. It is also reasonable to assume that, with appropriate emotional based therapies, pain drawing exercises can be integrated into therapeutically valuable treatments that should offer help to FM sufferers, and to improve their quality of life by either reducing pain or coping with it better.

Future studies within the framework of the Rheumatology practice

Recommendations for future work can be made along the lines of different themes presented here.

- Repeating of the RAFM study in a larger cohort using more than one clinic in more than one country incorporating women and men and matching for age.
- Collaborations between rheumatologists specialised in RA and FM and psychologists familiar with person-centred therapy to develop semi-structured interview questions and procedures to standardise a system based on non-directed simple body outline pain drawing as a tool for psychologists, counsellors and therapists working with FM patients.
- Adapt simple body outline pain drawing methods to web based interfacing to allow patients at a distance to be evaluated by persons other than their attending health professionals. Design the interface to be acceptable with health payment administrators so that the analysis of the patient's drawings and the resulting diagnosis can become integrated into the treatment options for FM within mainstream medical systems.
- Working with professionals such as Art therapists, teachers, Gestalt and emotional based therapists to explore if there is common meaning in the imagery of pain.

Fibromyalgia (FM) continues to be an illness that is difficult to define, difficult to diagnose (differentially and progressively), difficult to understand and difficult to treat. Even with better diagnostic methods to differentiate FM or FM-like symptoms within the broader patient base of rheumatology patients (co-morbid with RA, OA, etc.), there are no classic treatments (drugs or surgery) to offer patients who receive the FM diagnosis. The stress for FM sufferers is compounded by ineffective communication about their problems with administrators, co-workers, family members and others.

FM will be more commonly treated using CAM therapies, and it is important for CAM therapists to work to integrate their various organisations approaches to FM treatment within a common framework understood by CAM and conventional modalities.

CAM therapists close to the conventional medical system who are willing to integrate new methods are one of the most important assets to the GPs of the future.

The work presented here, using simple body outline (pain drawings) and comparing the results from the completed simple body outlines to surveys completed by patients (subjective) and tests done by clinics (objective), contributes to an increasing body of evidence that the diagnosis of presence and severity of FM symptoms and the assessments of the effects of those symptoms on the quality of life of patients with FM is more accurate when we rely on the ‘opinion’ or ‘feelings’ of the patient.

The symptoms of FM are real and non-productive. Whilst they go unrecognized and untreated, their gradual but consistent effects have significantly high social costs hidden within the work sector, the private home sector and the medical sector. The typical FM patient is not only experiencing pain, but living a life that is marginalized, in which they are often unable to participate normally in society. Given the expectations for the increasing prevalence of FM, there is much opportunity for innovative systems with effective and cost efficient treatment of FM to support the livelihoods of plenty of health professionals.

The world health community has spent many billions on studying FM over the last twenty years and much information is available from a large number of studies and peer reviewed publications. This information has brought very little to help the FM patient. Nonetheless, this vast reservoir of information represents a legacy of many hardworking scientists and clinicians who have earnestly tried to improve the lives of FM sufferers. They should not be held accountable for the fact that their work has been done inside of a medical system that now must undergo a paradigm shift in order to harmonise with the emergent realities of humanity.

FM will be better understood and managed more efficiently by adding the ‘spiritual’ to the bio-psycho-social model. From this perspective there would be a shift in treatment modality of mainstream medicine to include more spiritual and psychological aspects. The patient would be focusing their efforts towards restructuring (healing) the social interactions they are in; while the community outside of the patient provides spiritual support (since spiritual support is not typically paid for in medical systems).

Techniques such as energy healing (Reiki), sound healing or chanting, meditation and prayer are not typically funded by insurance companies or socialized medicine. However, they can be used to achieve better quality of life (less severe symptoms) in FM. Studies which direct attention to the 'indwelling Spirit' should be considered.

The secondary objective of the research programme was to provide training in methods of research. The funding for this research project was organized by the researcher as was the design of the research that incorporated a number of different research methodologies. The researcher was responsible for most of the patient recruitment and data collection. Through this research programme she also learned the skills to plan and conduct research. These skills included the analysis of data, writing research proposals for ethics; funding and disseminating results at conferences - via poster and verbal presentations - and preparing manuscripts for peer review journals. The researcher believes both of the research programme objectives were achieved.

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APPENDICES

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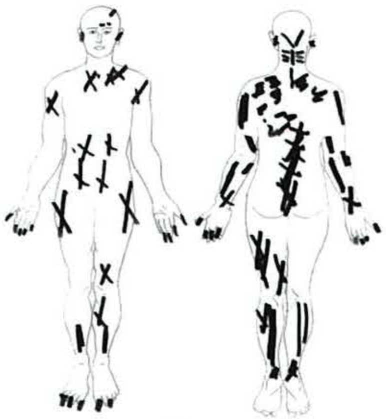

I A
Fibromyalgia

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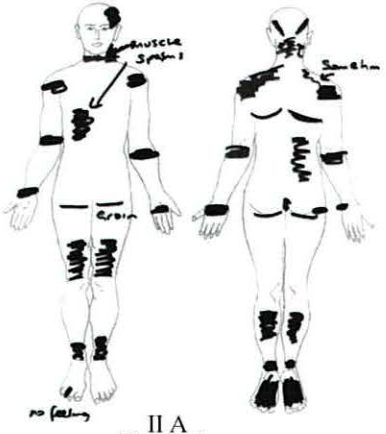

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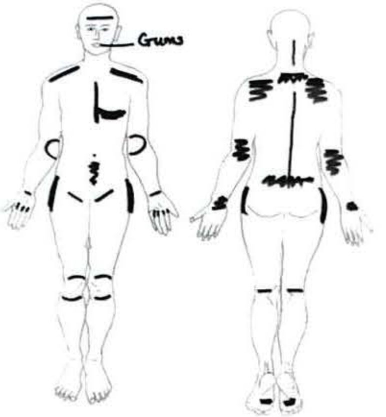

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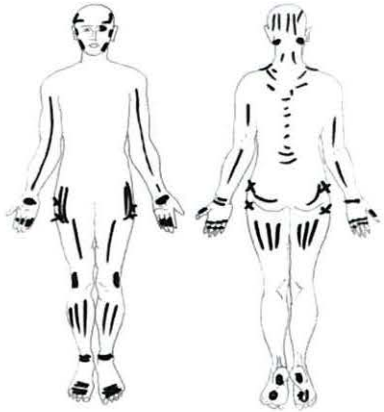

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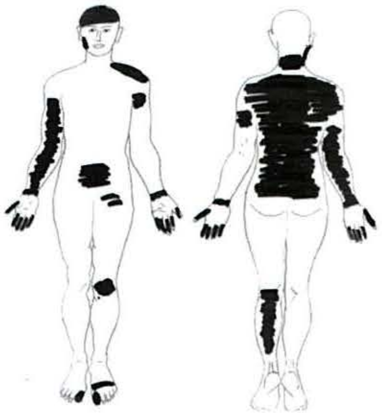

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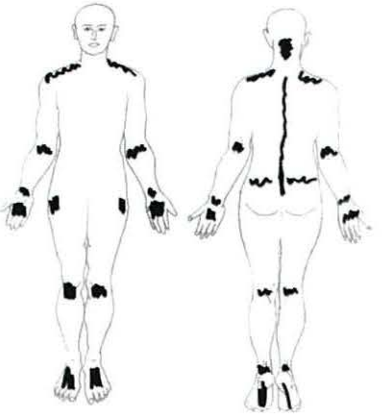

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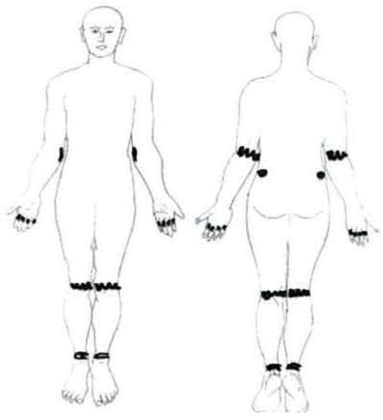

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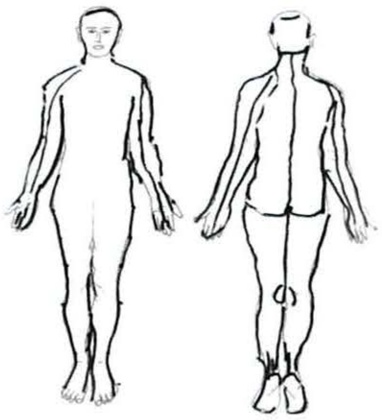

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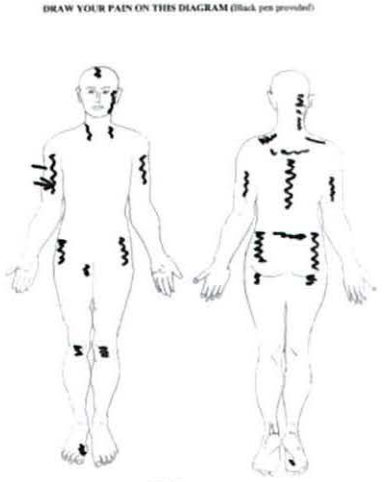

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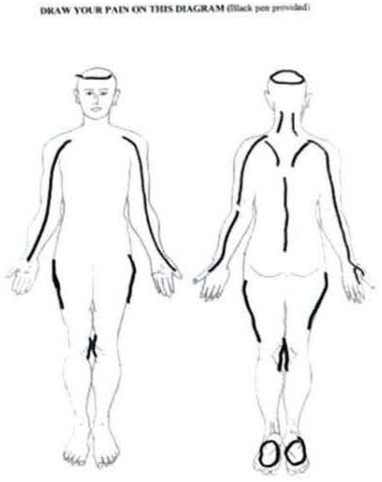

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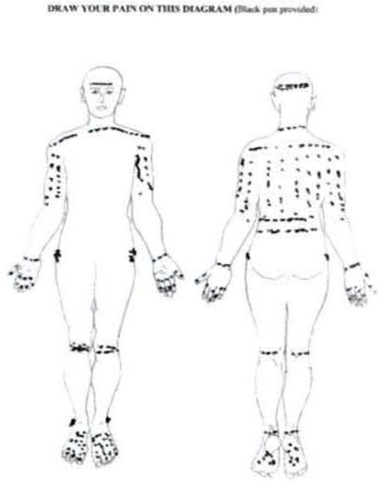

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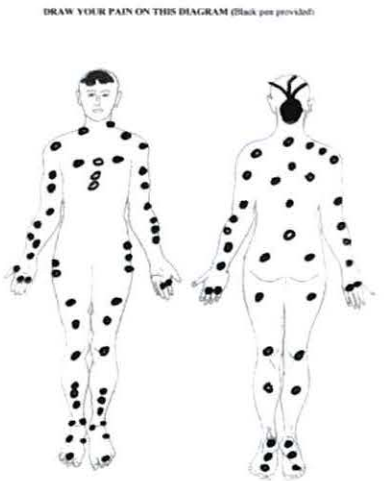

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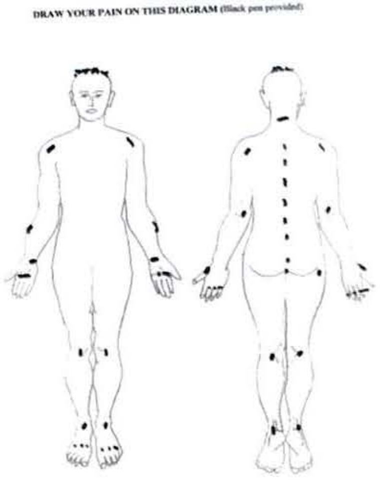

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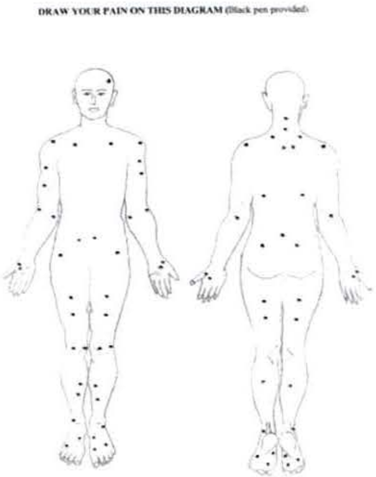

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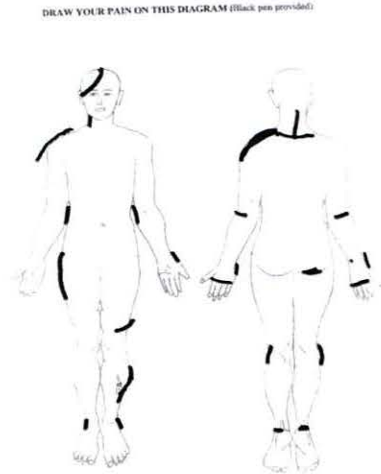

XV A
Fibromyalgia

XVI A
Fibromyalgia

2

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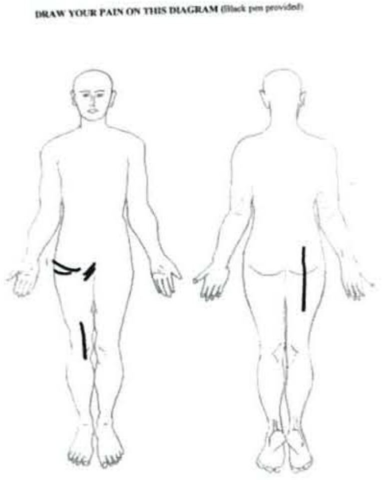

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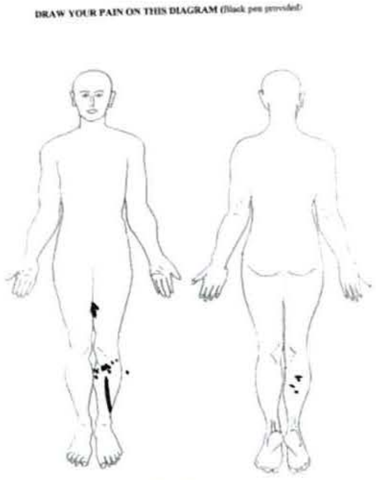
Osteoarthritis



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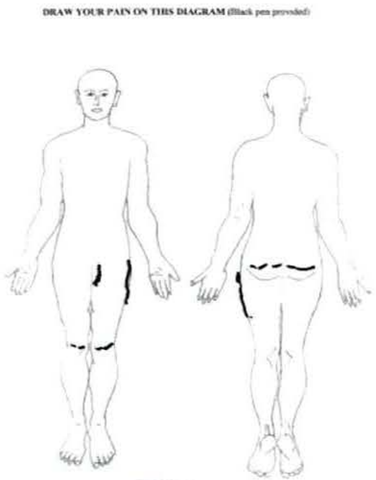

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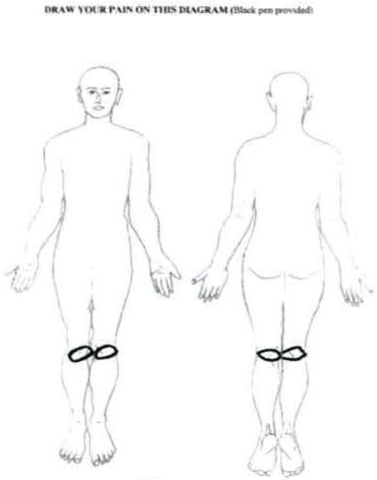
Osteoarthritis



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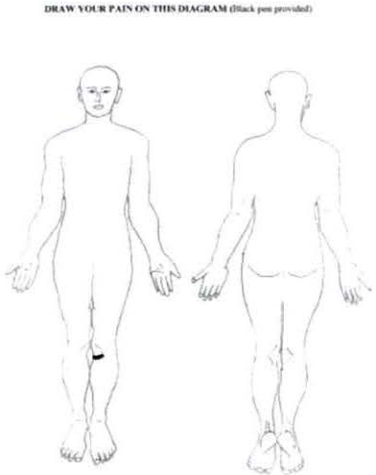
Osteoarthritis



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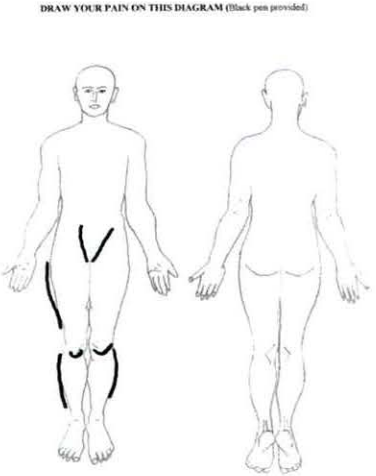

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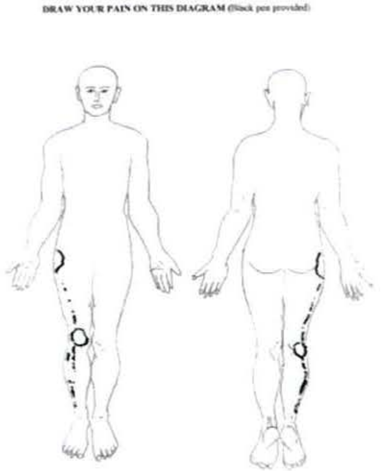

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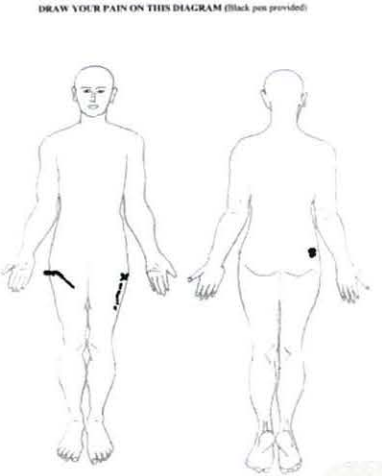

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Osteoarthritis

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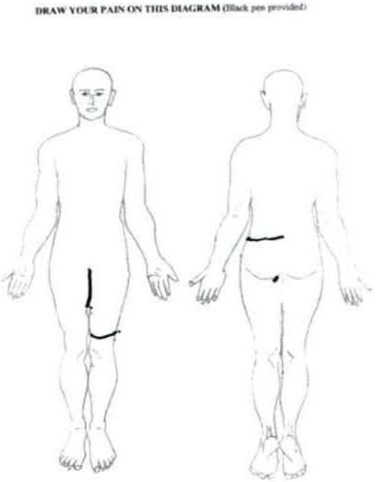

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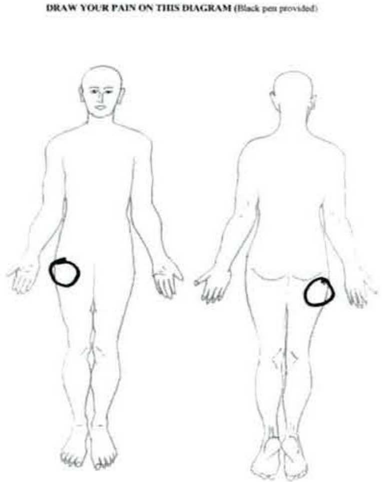
Osteoarthritis



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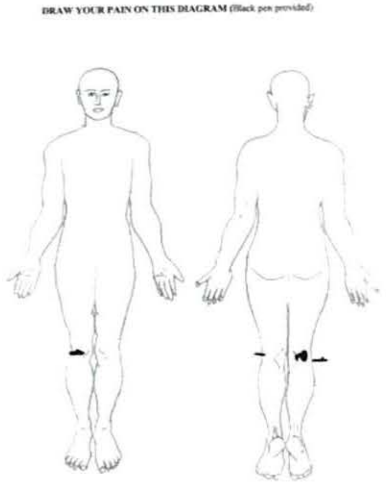

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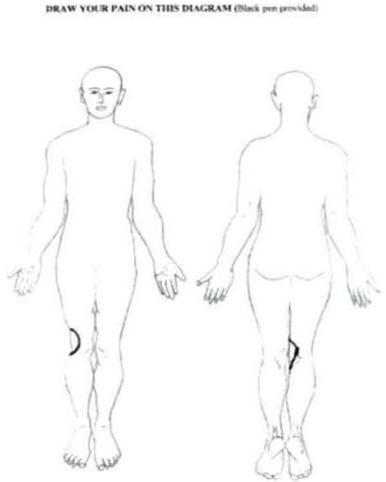
Osteoarthritis



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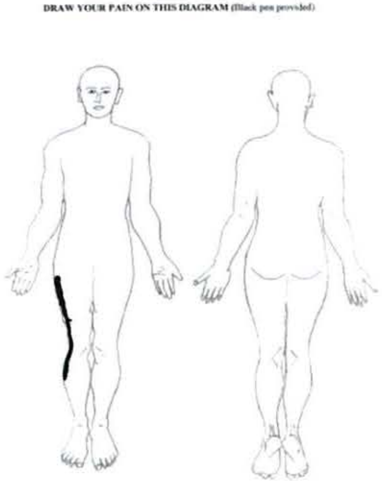
Osteoarthritis



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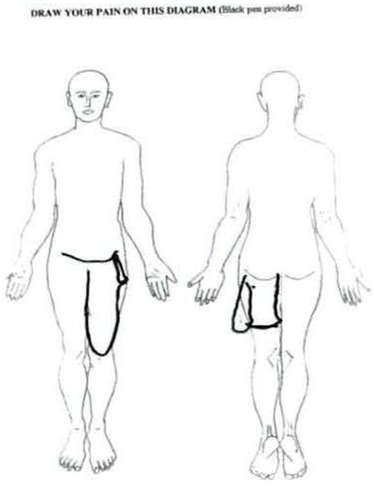

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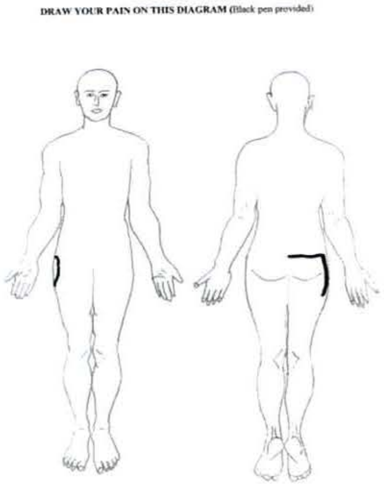
Osteoarthritis



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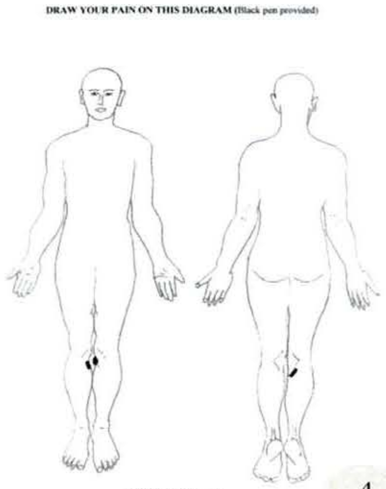
Osteoarthritis



XXXII A
Osteoarthritis

4

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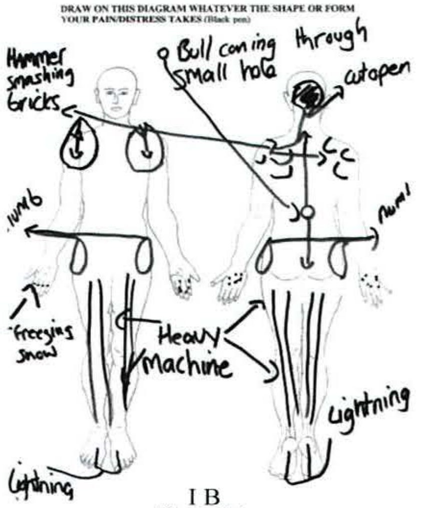

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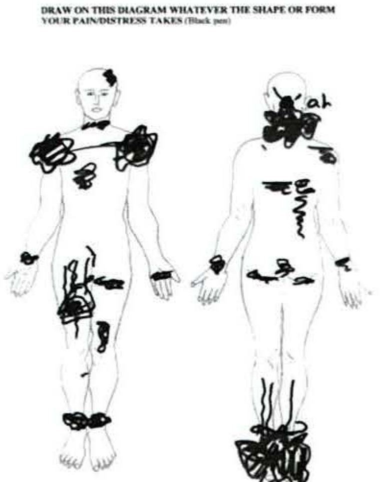
Fibromyalgia



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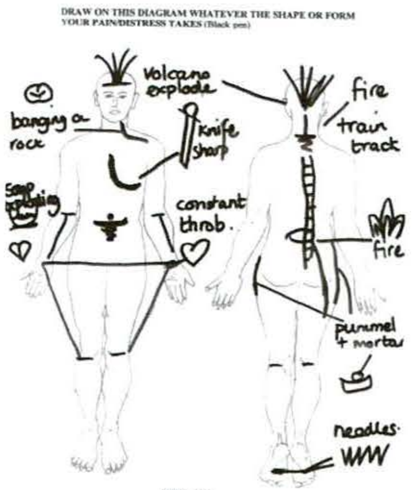

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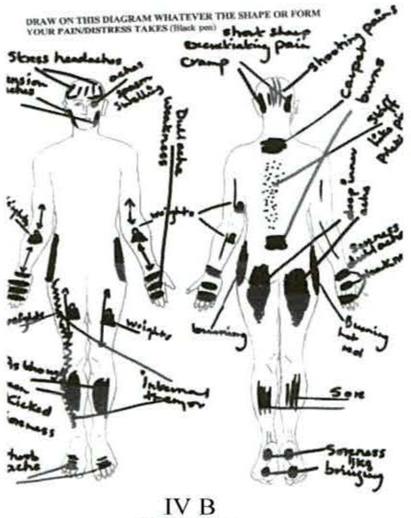

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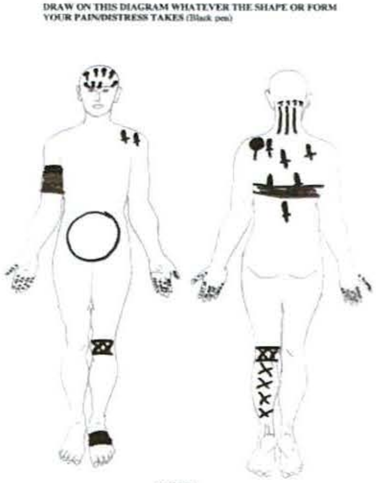
Fibromyalgia



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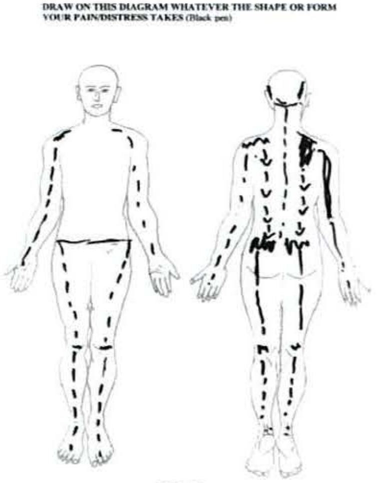
Fibromyalgia



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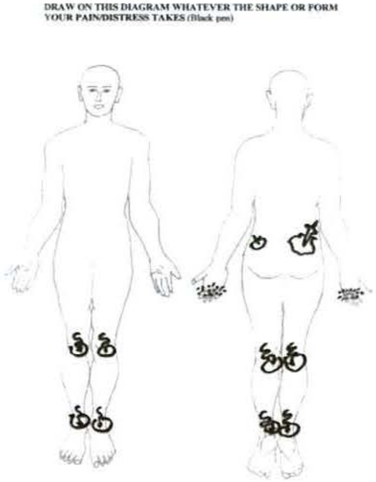

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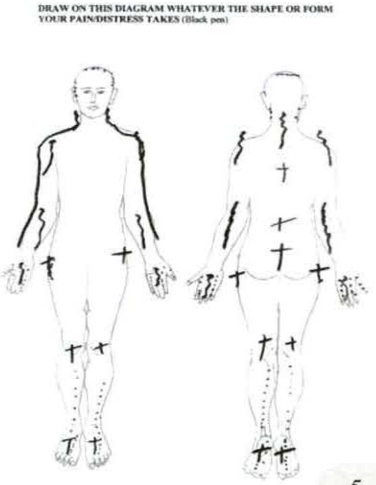

VIII B
Fibromyalgia

5

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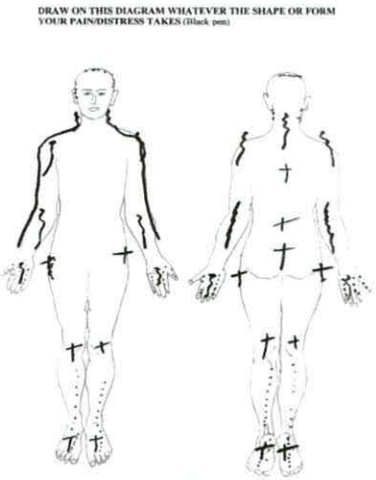

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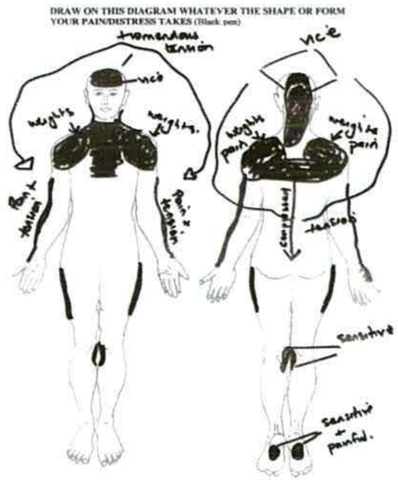
Fibromyalgia



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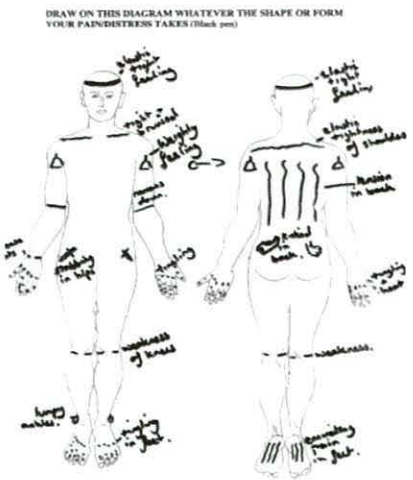
Fibromyalgia



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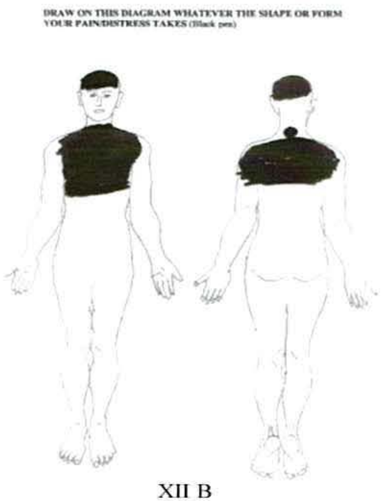

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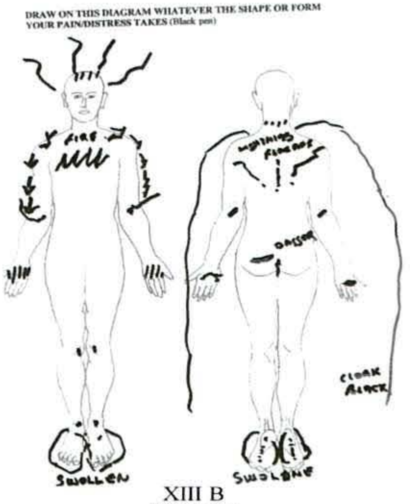

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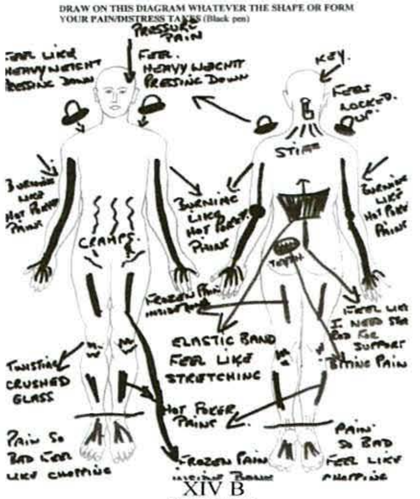


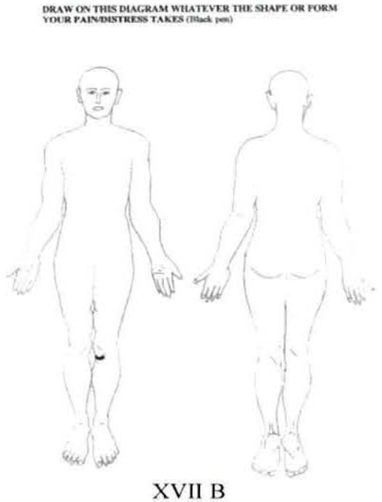
XIV B
Fibromyalgia

XV B
Fibromyalgia

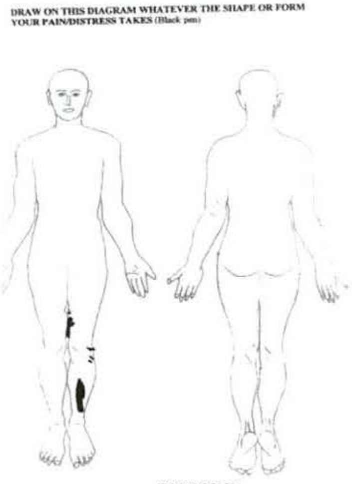
XVI B
Fibromyalgia

6

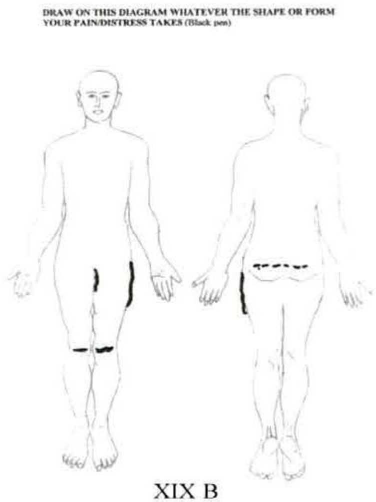
"DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black Pen)



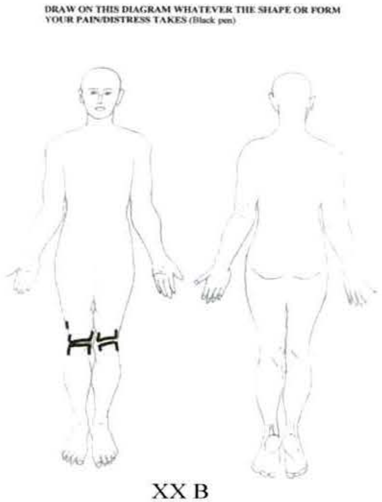
XVII B
Osteoarthritis



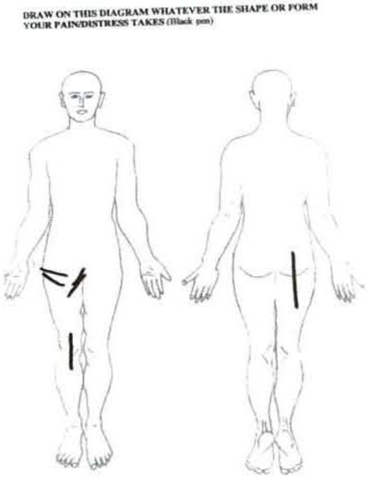
XVIII B
Osteoarthritis



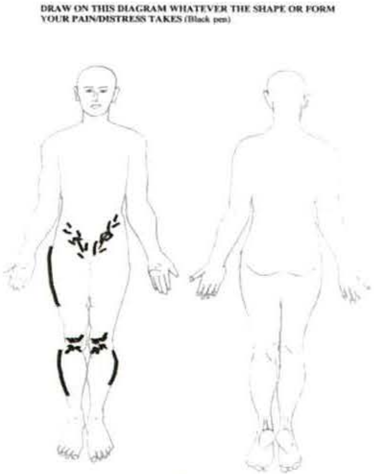
XIX B
Osteoarthritis



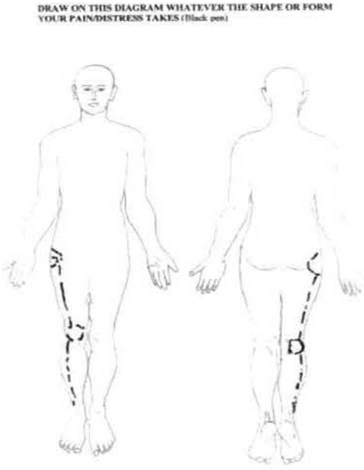
XX B
Osteoarthritis



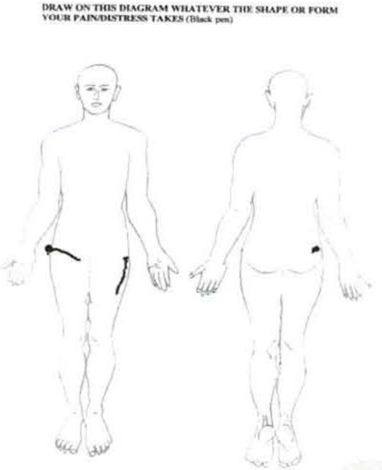
XXI B
Osteoarthritis



XXII B
Osteoarthritis

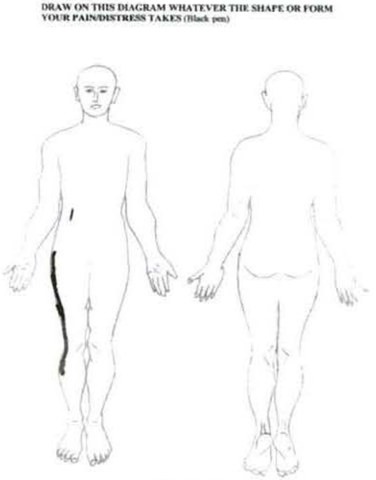


XXIII B
Osteoarthritis

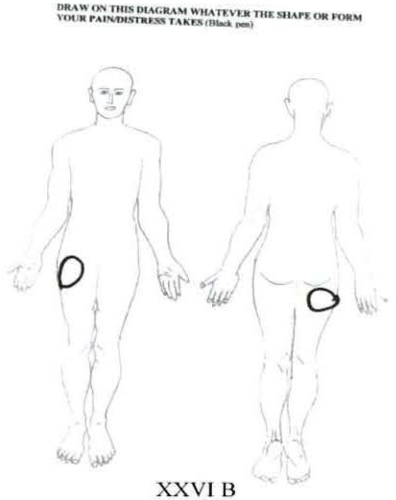


XXIV B
Osteoarthritis

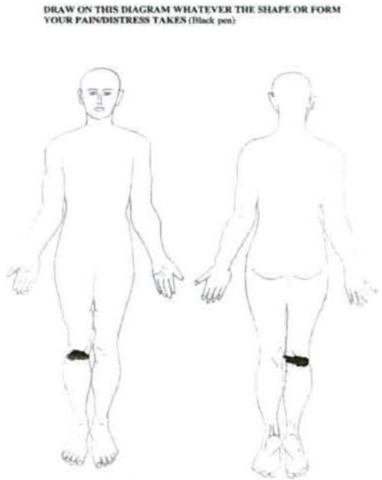
"DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black Pen)



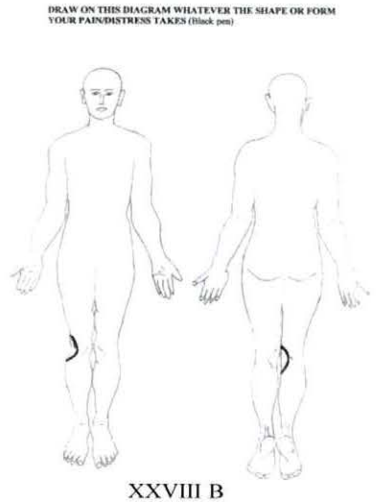
XXV B
Osteoarthritis



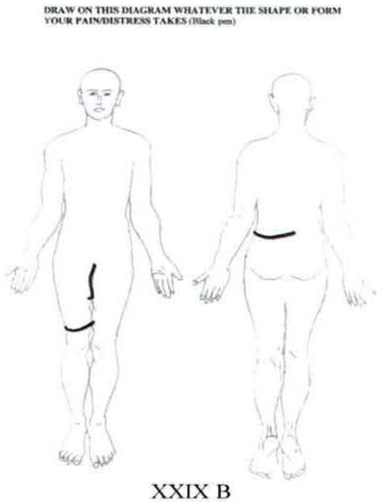
XXVI B
Osteoarthritis



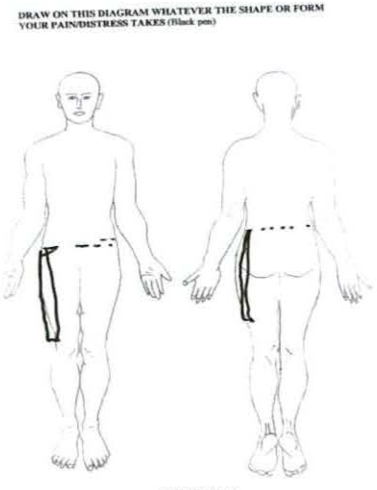
XXVII B
Osteoarthritis



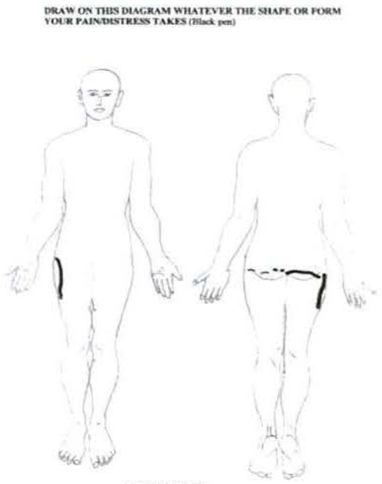
XXVIII B
Osteoarthritis



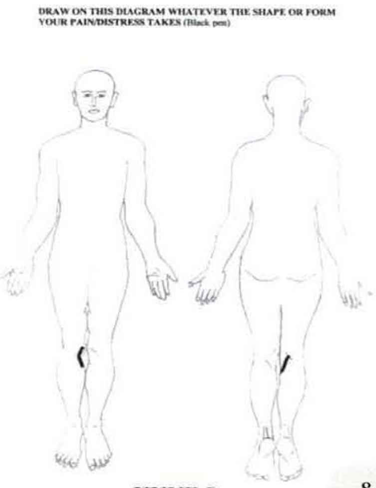
XXIX B
Osteoarthritis



XXX B
Osteoarthritis

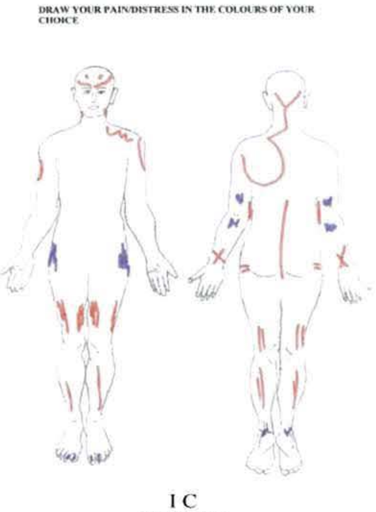


XXXI B
Osteoarthritis

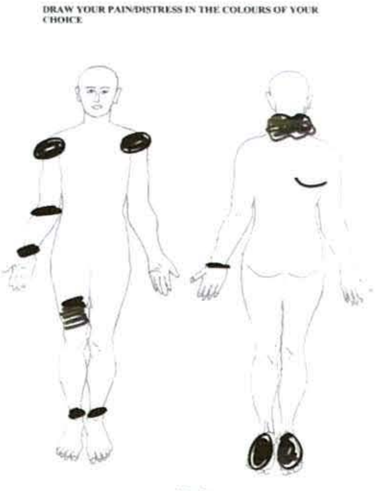


XXXII B
Osteoarthritis

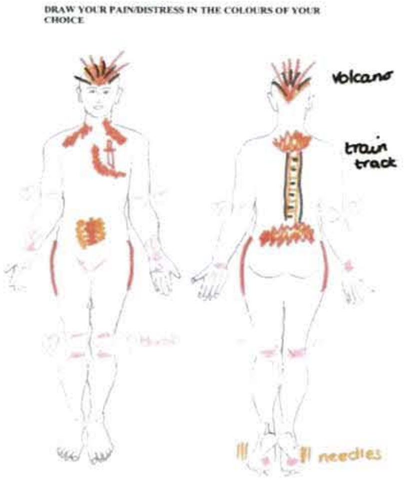
"DRAW YOUR PAIN/DISTRESS IN THE COLOUR(S) OF YOUR CHOICE"



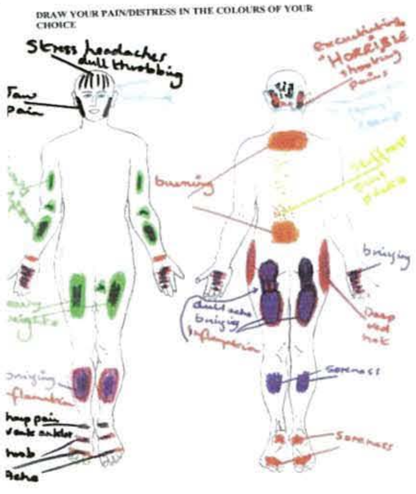
I C
Fibromyalgia



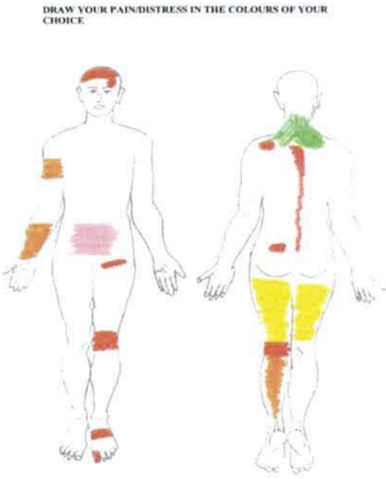
II C
Fibromyalgia



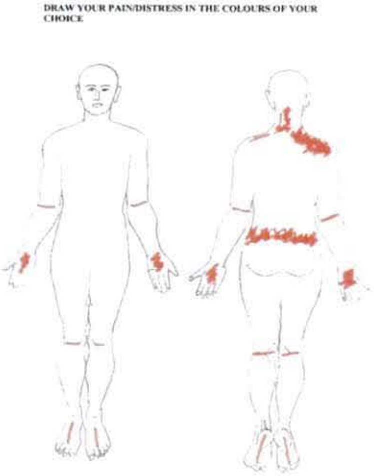
III C
Fibromyalgia



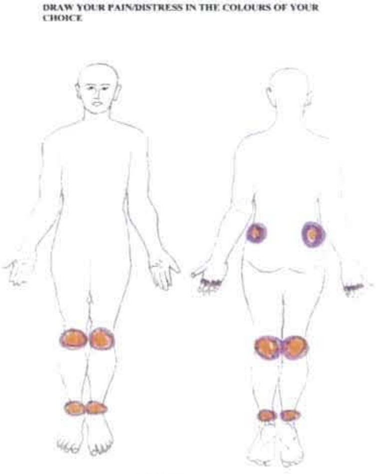
IV C
Fibromyalgia



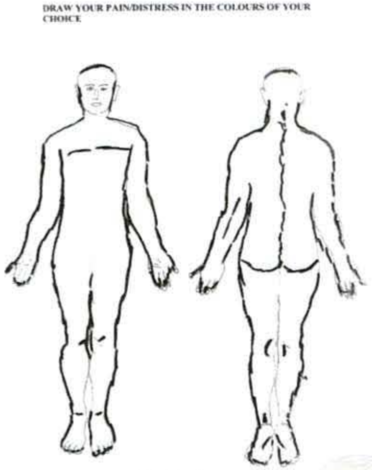
V C
Fibromyalgia



VI C
Fibromyalgia



VII C
Fibromyalgia

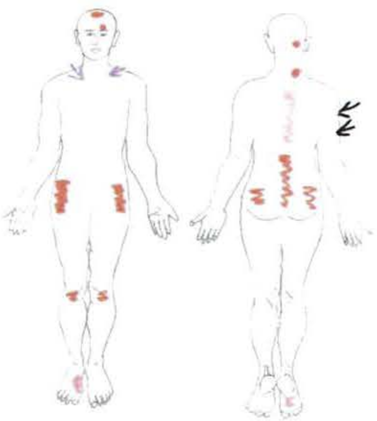


VIII C
Fibromyalgia

9

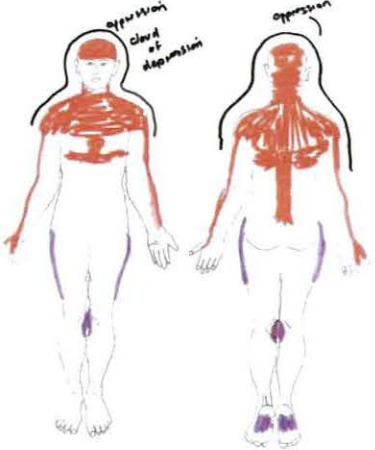
"DRAW YOUR PAIN/DISTRESS IN THE COLOUR(S) OF YOUR CHOICE"

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



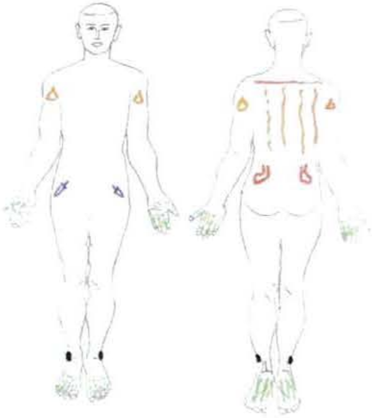
IX C
Fibromyalgia

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



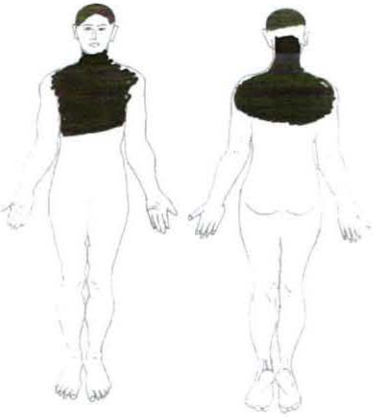
X C
Fibromyalgia

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



XI C
Fibromyalgia

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

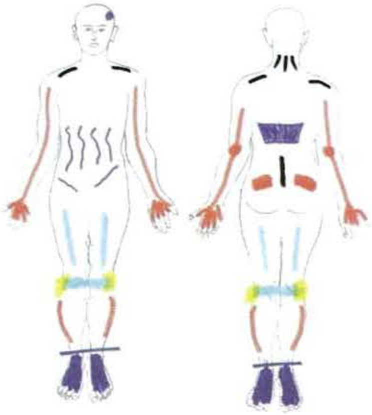


XII C
Fibromyalgia

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

XIII C
Fibromyalgia

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



XIV C
Fibromyalgia

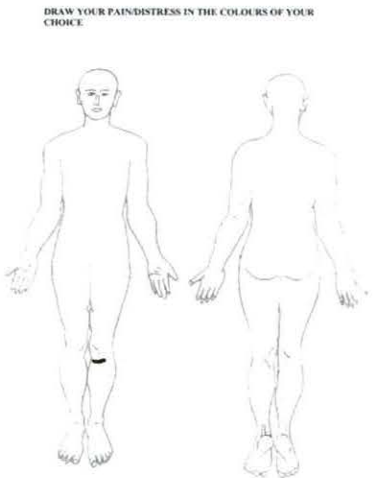
DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

XV C
Fibromyalgia

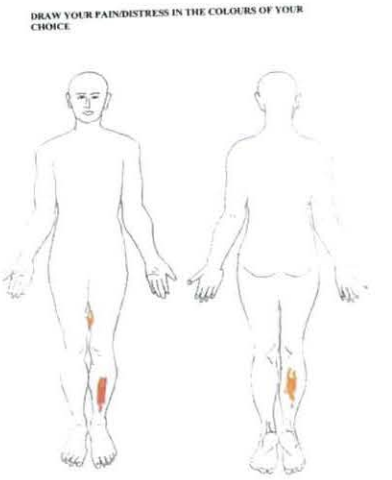
DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

XVI C
Fibromyalgia

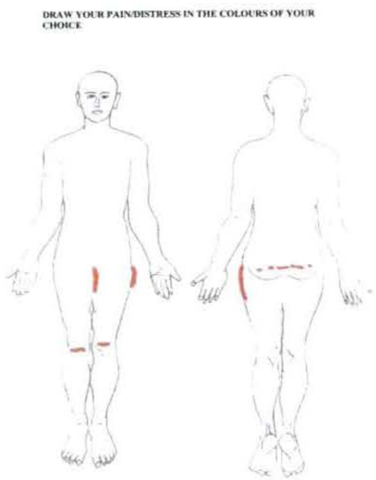
"DRAW YOUR PAIN/DISTRESS IN THE COLOUR(S) OF YOUR CHOICE"



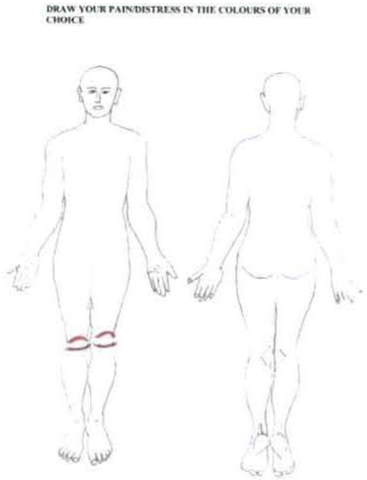
XVII C
Osteoarthritis



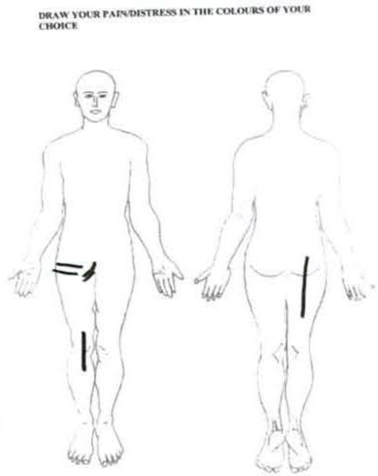
XVIII C
Osteoarthritis



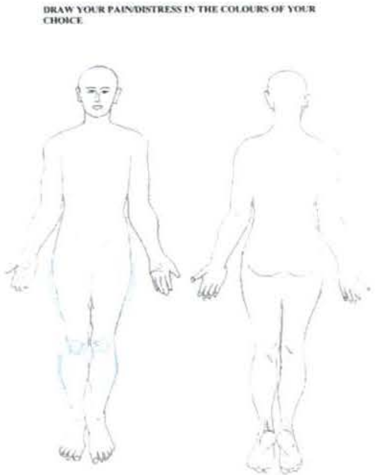
XIX C
Osteoarthritis



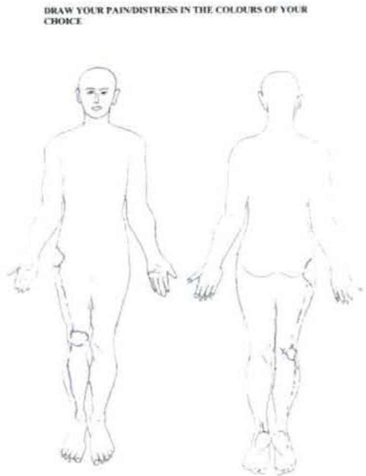
XX C
Osteoarthritis



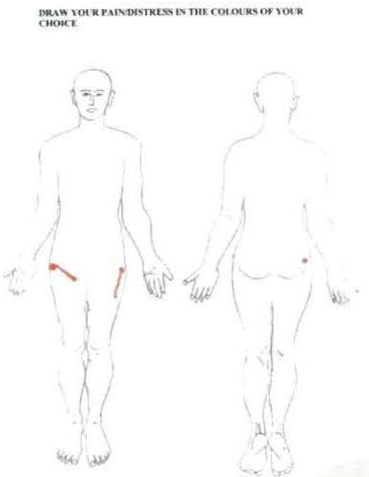
XXI C
Osteoarthritis



XXII C
Osteoarthritis



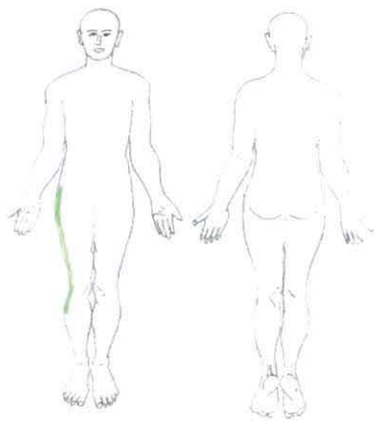
XXIII C
Osteoarthritis



XXIV C
Osteoarthritis

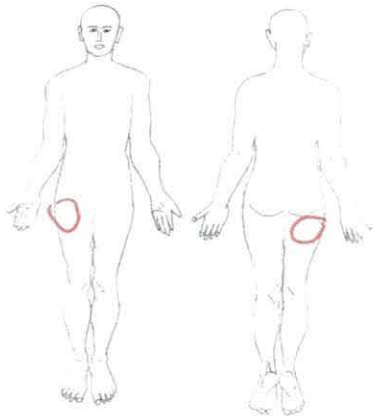
"DRAW YOUR PAIN/DISTRESS IN THE COLOUR(S) OF YOUR CHOICE"

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



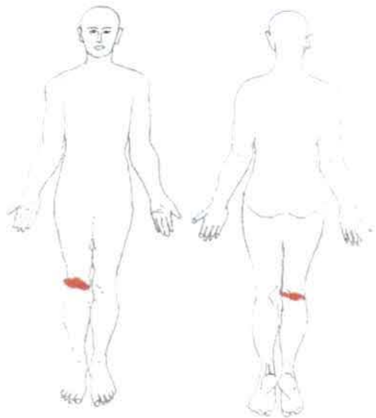
XXV C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



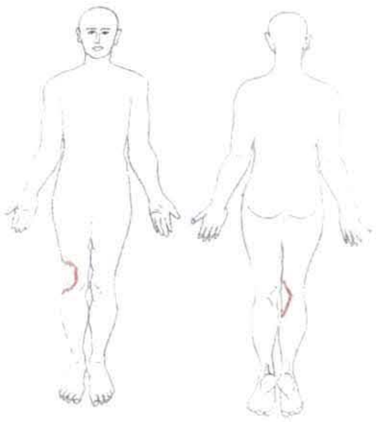
XXVI C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



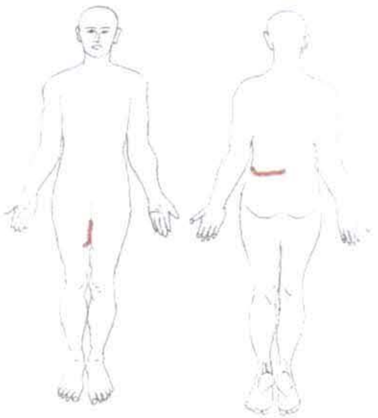
XXVII C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



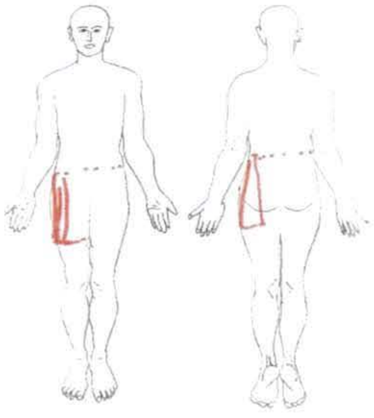
XXVIII C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



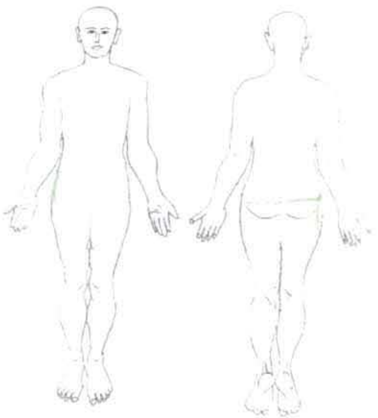
XXIX C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



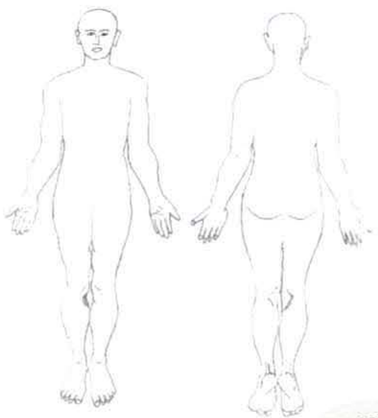
XXX C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



XXXI C
Osteoarthritis

DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



XXXII C
Osteoarthritis

"DRAW THE IMAGE/SHAPE/FORM OF YOUR PAIN/DISTRESS USING THE COLOURS(S) OF YOUR CHOICE"

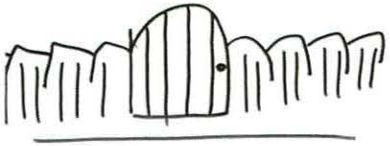
DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

I D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

II D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE



III D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

IV D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

V D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

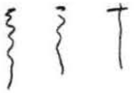
No image comes to mind
The pain is like a constant very severe
toothache

VI D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

VII D
Fibromyalgia

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

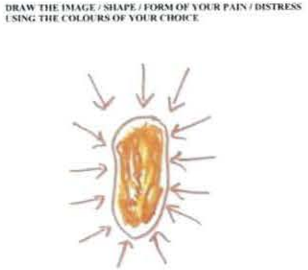


VIII D
Fibromyalgia

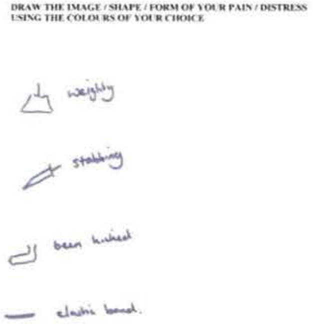
“DRAW THE IMAGE/SHAPE/FORM OF YOUR PAIN/DISTRESS USING THE COLOUR(S) OF YOUR CHOICE"


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

IX D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

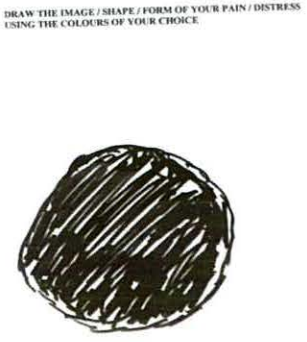
X D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

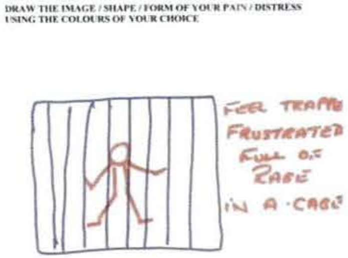
XI D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

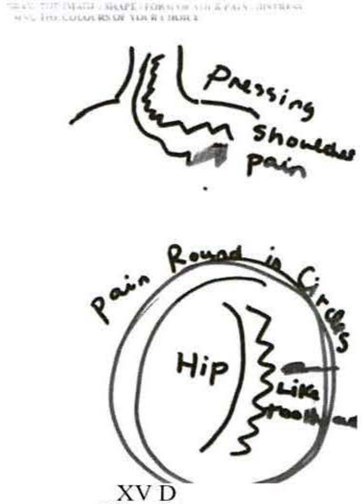
XII D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

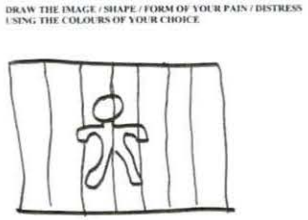
XIII D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XIV D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XV D
Fibromyalgia


DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XVI D
Fibromyalgia

"DRAW THE IMAGE/SHAPE/FORM OF YOUR PAIN/DISTRESS USING THE COLOUR(S) OF YOUR CHOICE"

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XVII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XVIII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XIX D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XX D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XXI D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XXII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XXIII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

XXIV D
Osteoarthritis

“DRAW THE IMAGE/SHAPE/FORM OF YOUR PAIN/DISTRESS USING THE COLOUR(S) OF YOUR CHOICE"

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XVII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XVIII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XIX D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XX D
Osteoarthritis

DESCRIBE YOUR IMAGE EXPLAINING WHAT IT MEANS TO YOU

XXI D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

XXII D
Osteoarthritis

DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

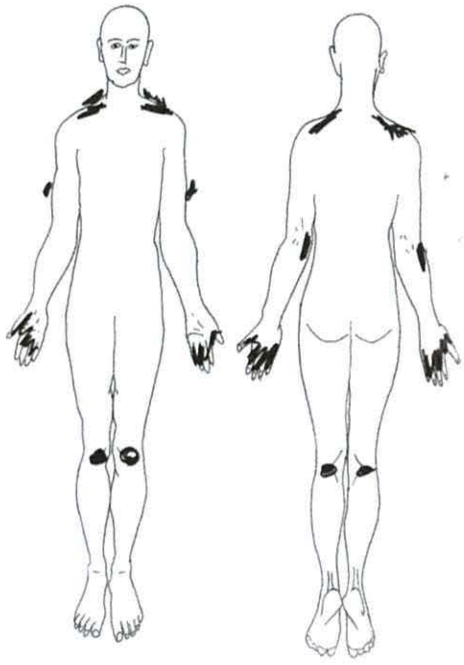
XXIII D
Osteoarthritis

DESCRIBE YOUR IMAGE EXPLAINING WHAT IT MEANS TO YOU

XXIV D
Osteoarthritis

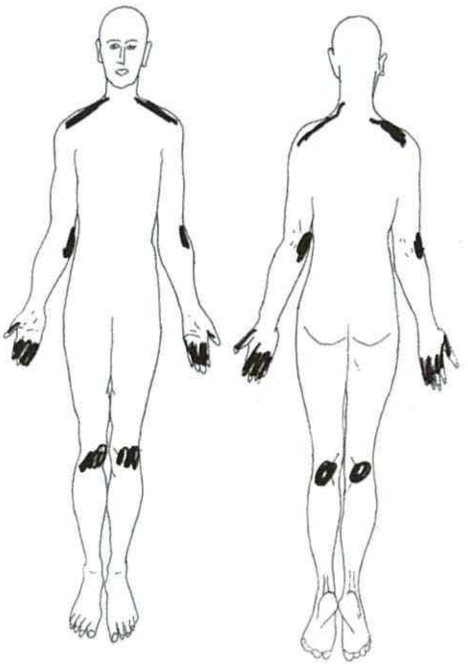
16

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



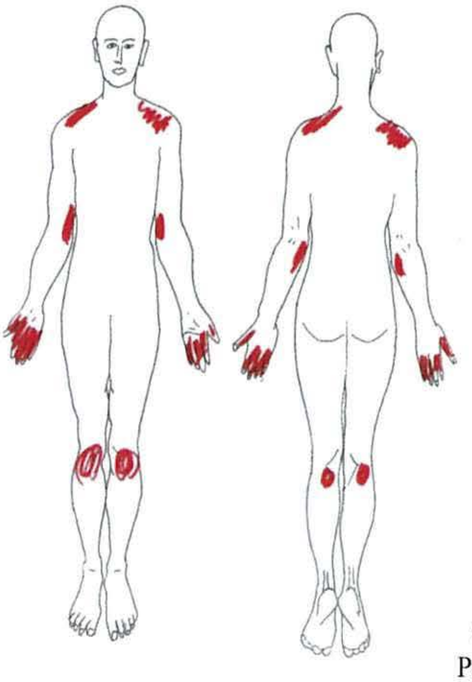
02/01

2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/01

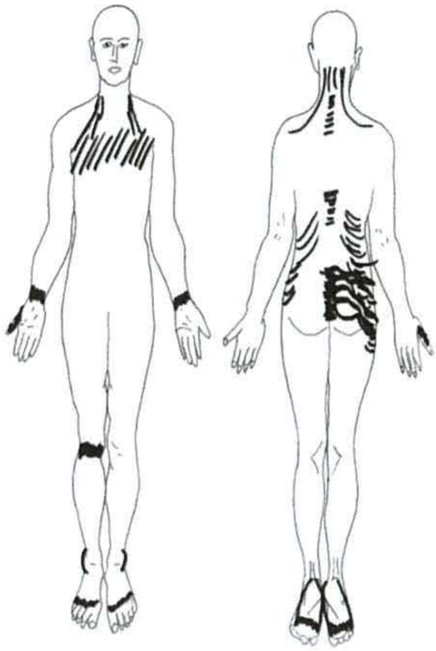
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



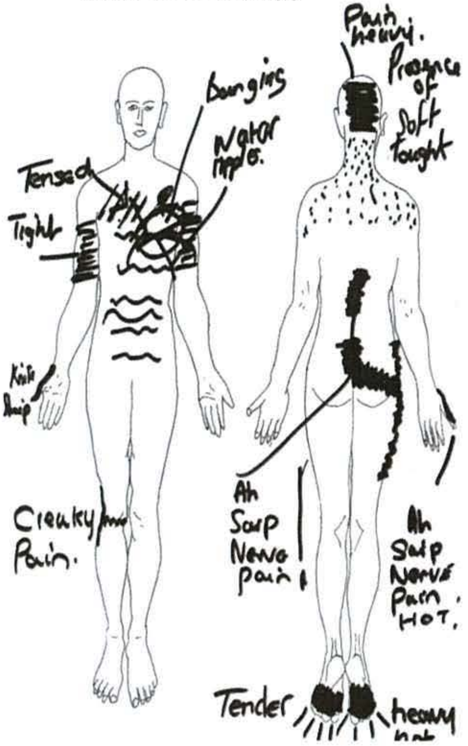
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
01

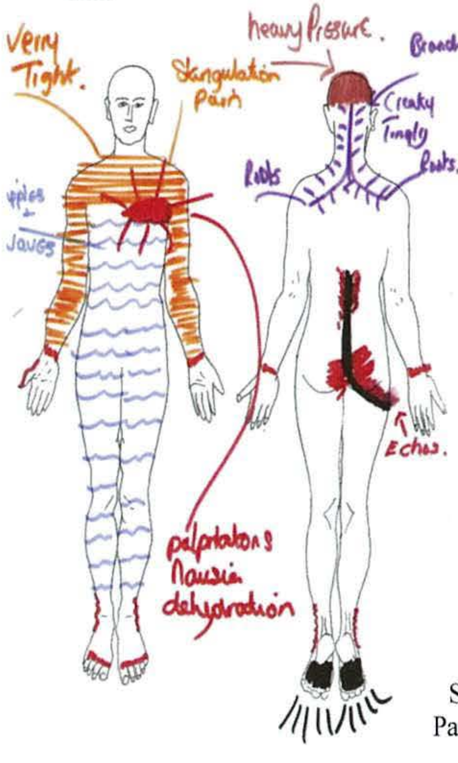
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



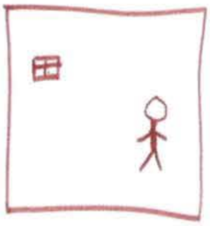
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

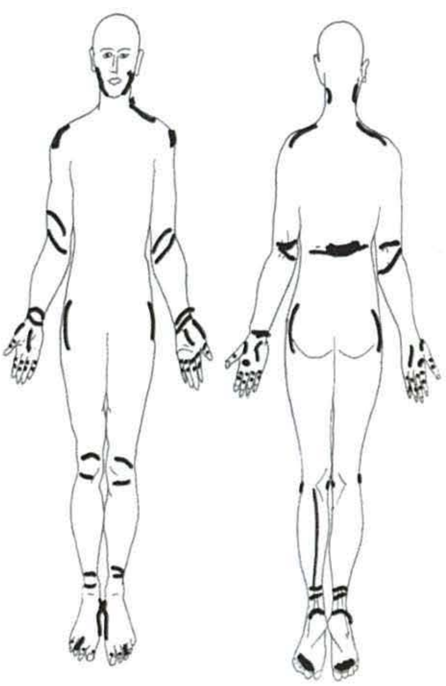


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

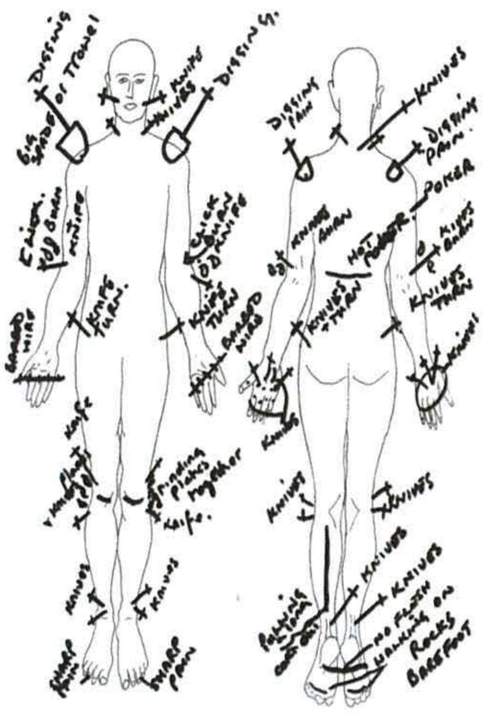


Study 2
Participant
02

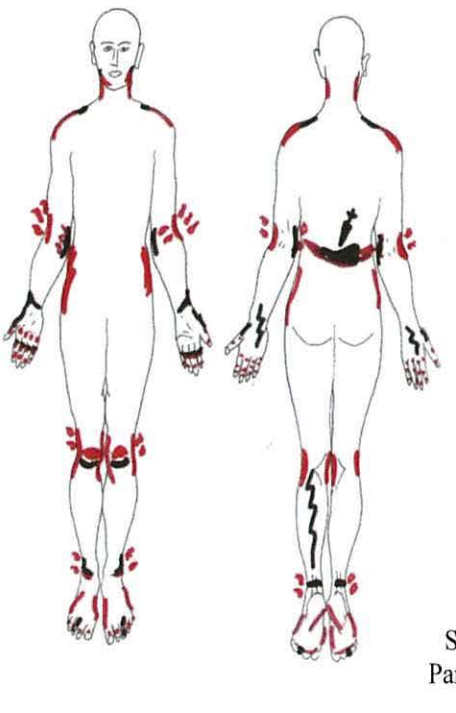
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



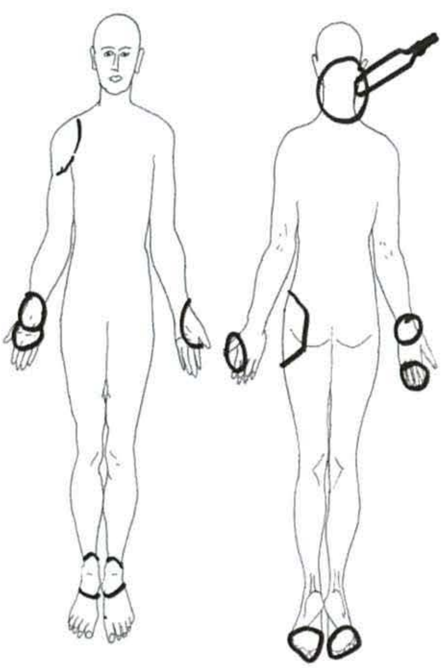
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



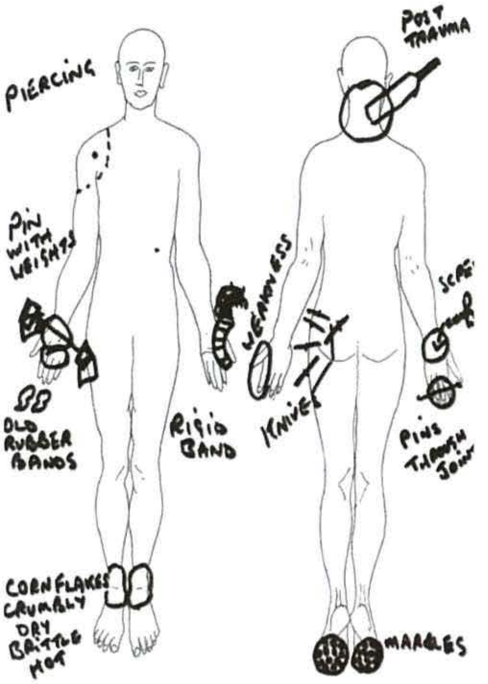
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
03

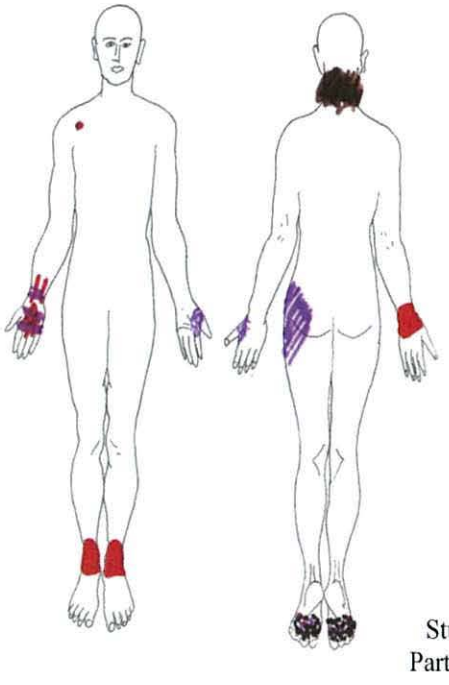
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



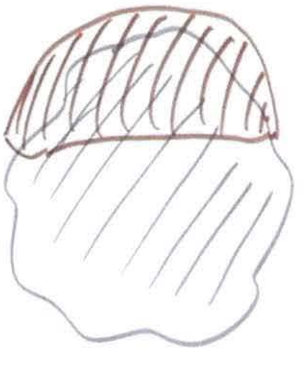
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



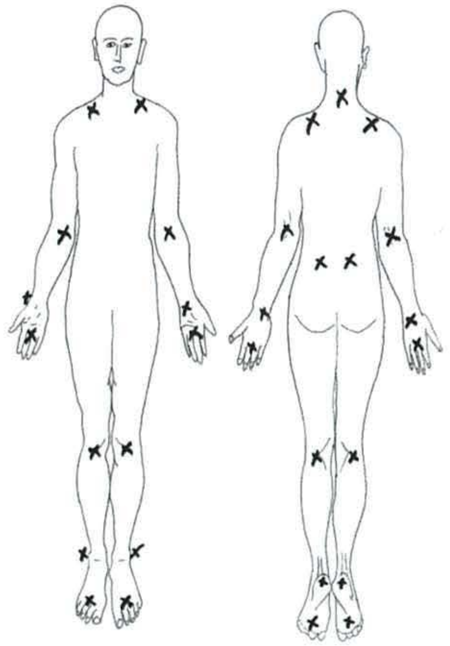
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE



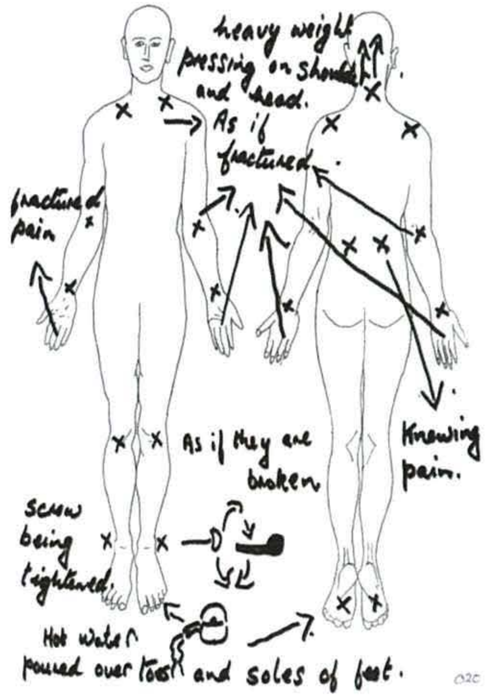
Study 2
Participant
04

0204

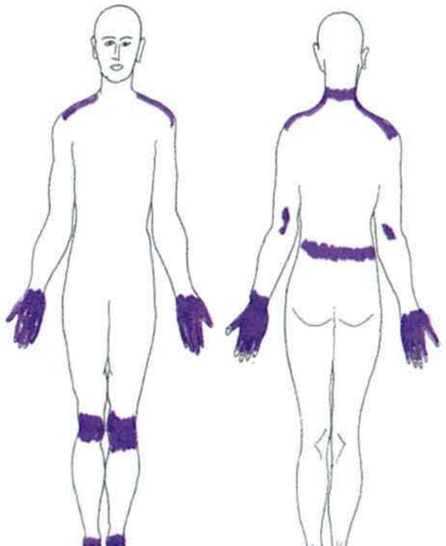
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



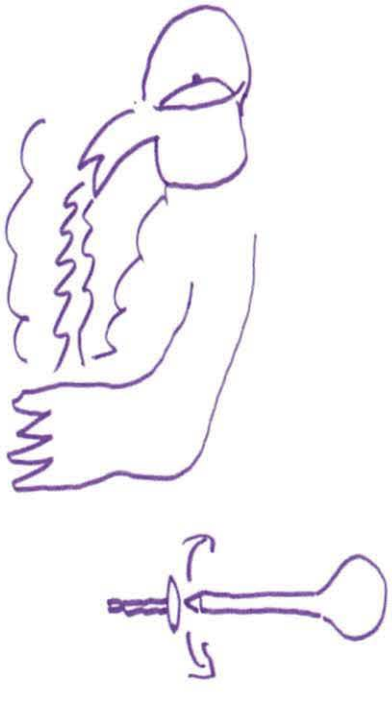
2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

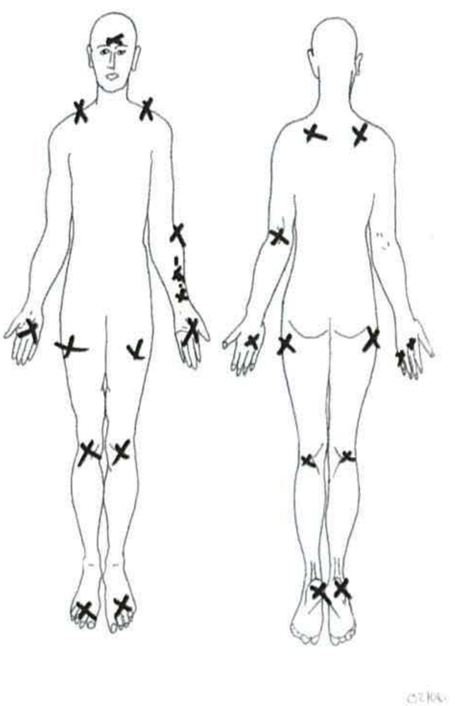


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

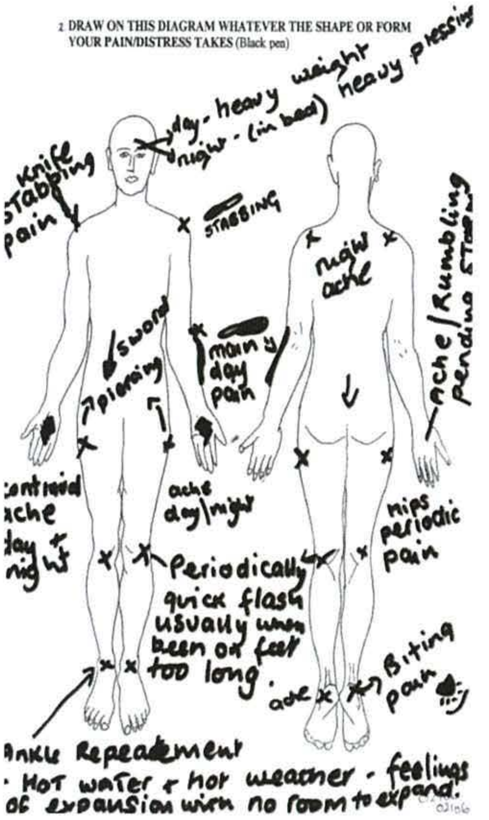


Study 2
Participant
05

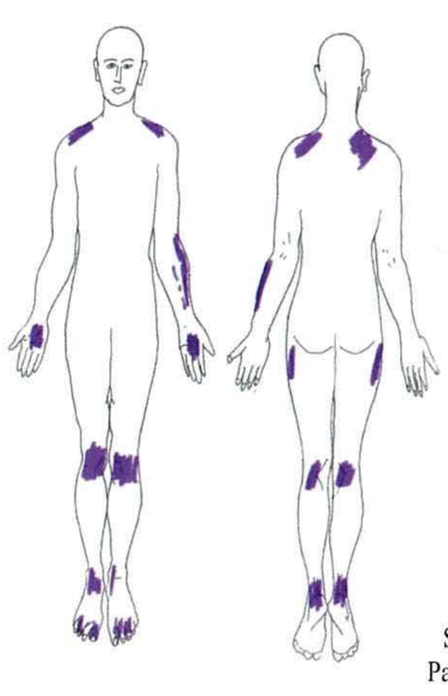
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



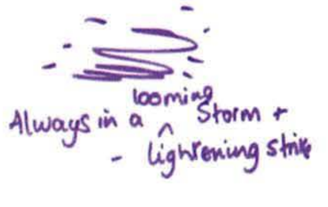
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

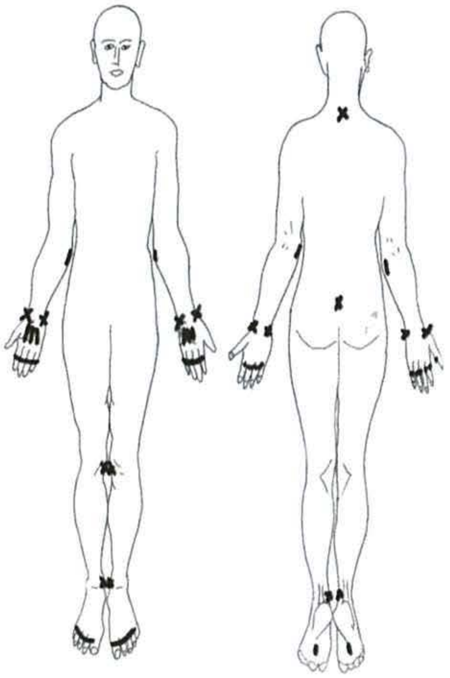


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

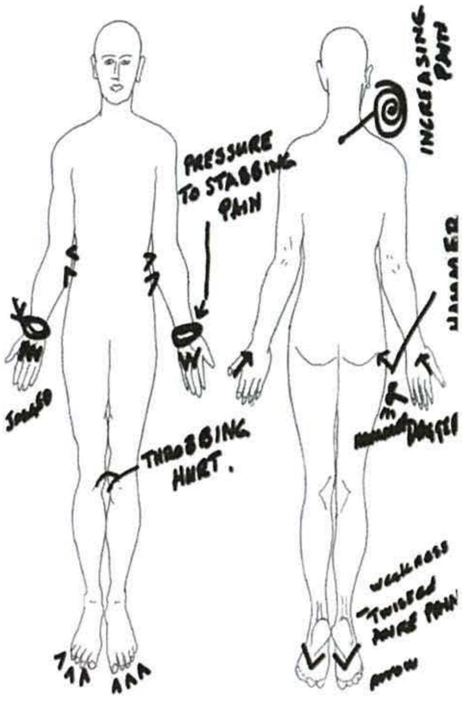


Study 2
Participant
06

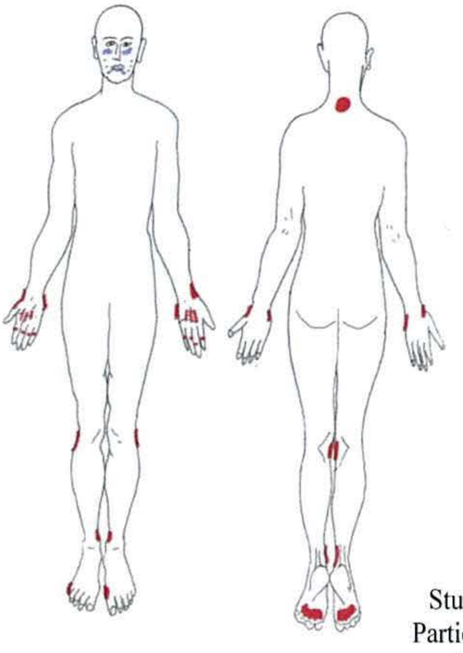
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



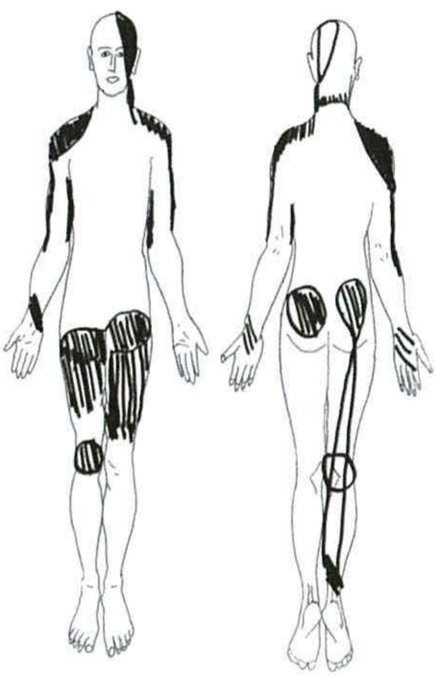
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



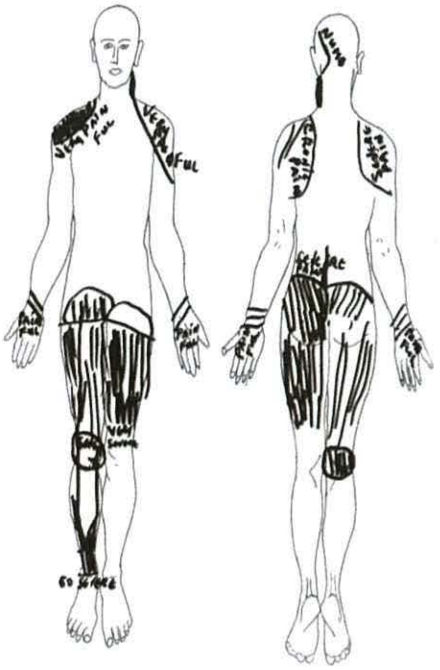
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
07

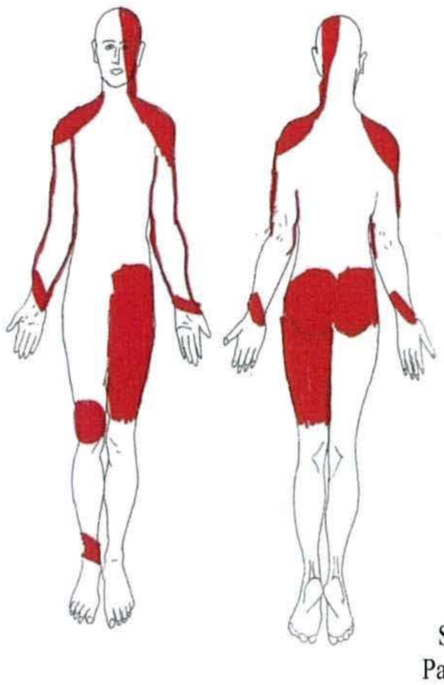
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

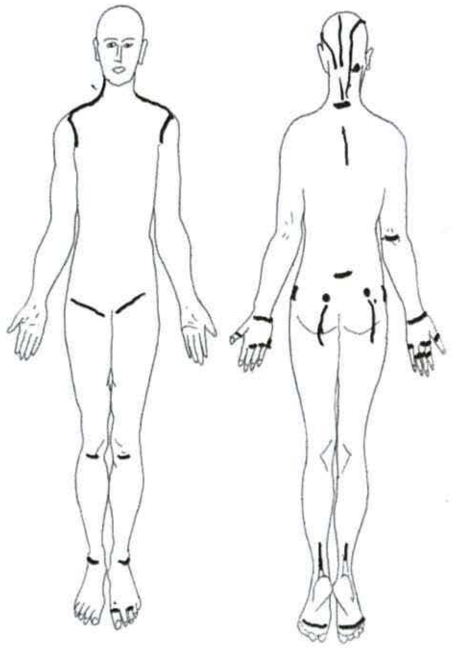


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

None

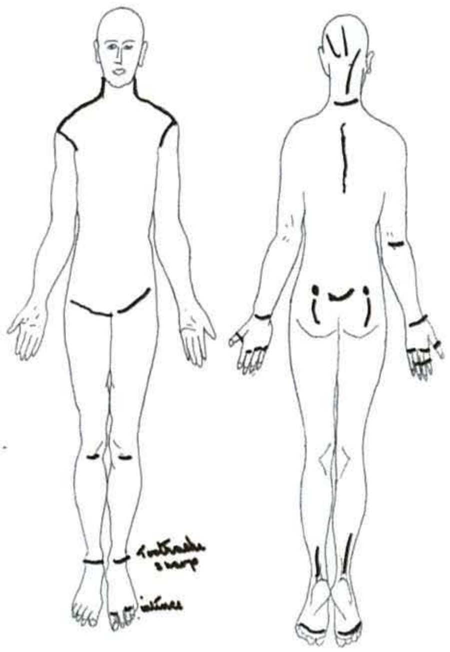
Study 2
Participant
08

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



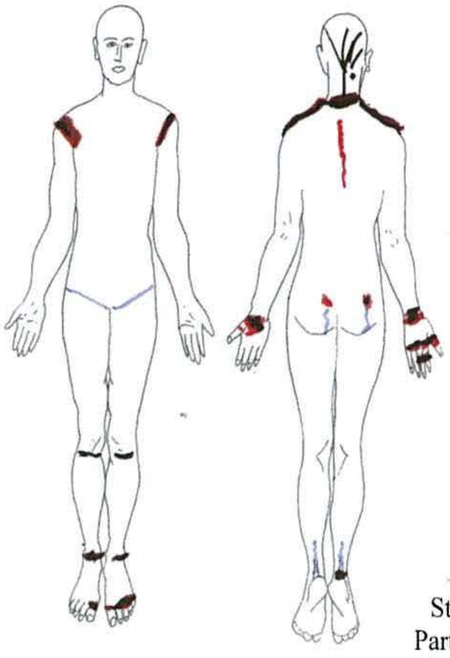
02109

2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02109

3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

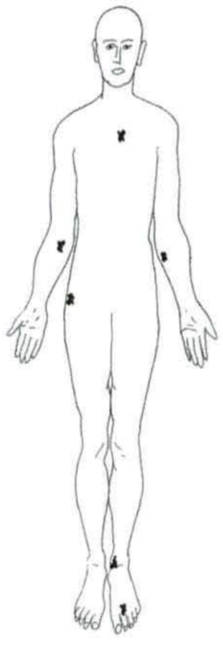


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
09

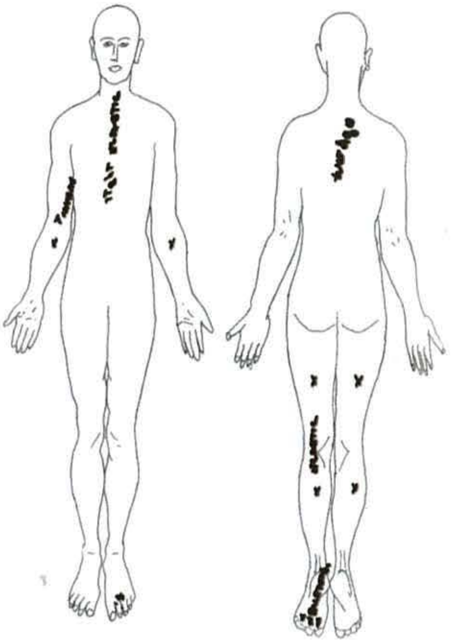
02109

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



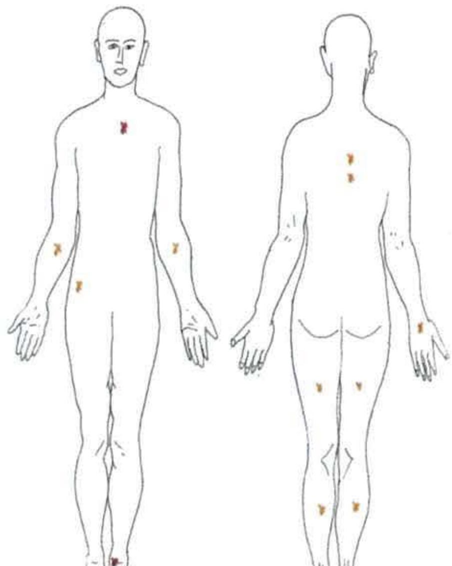
021

2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/10

3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

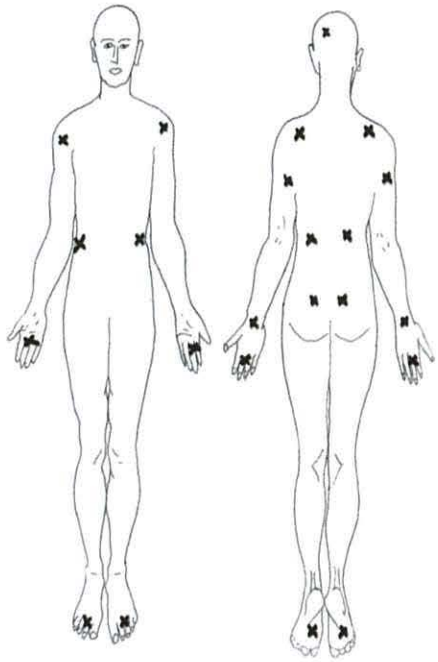


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

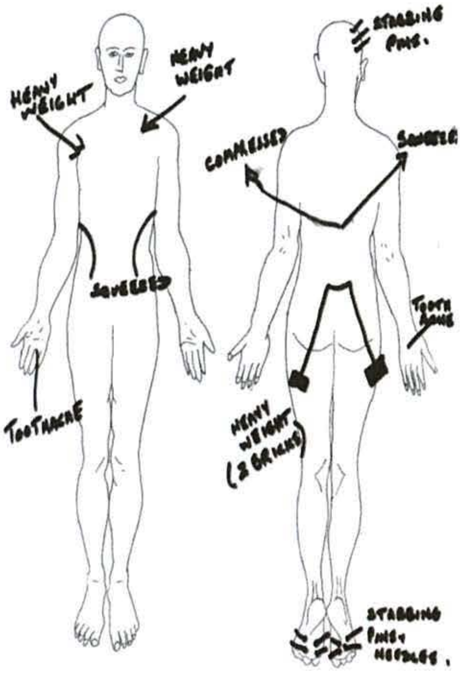
Study 2
Participant
10

02/10

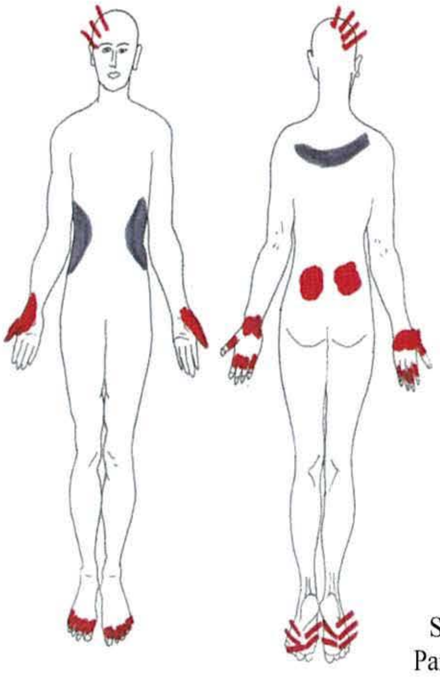
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



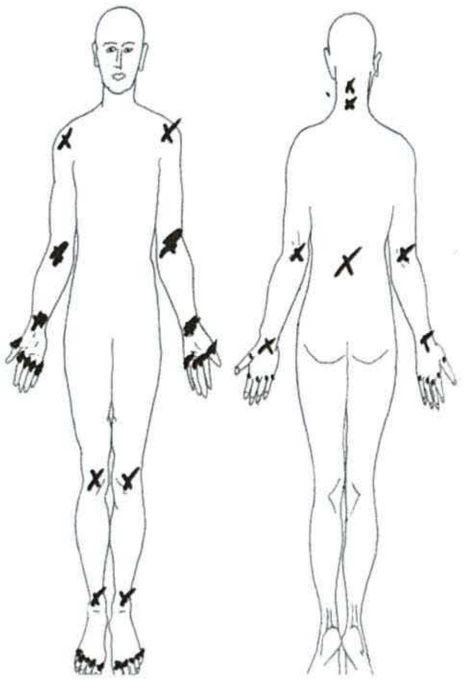
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



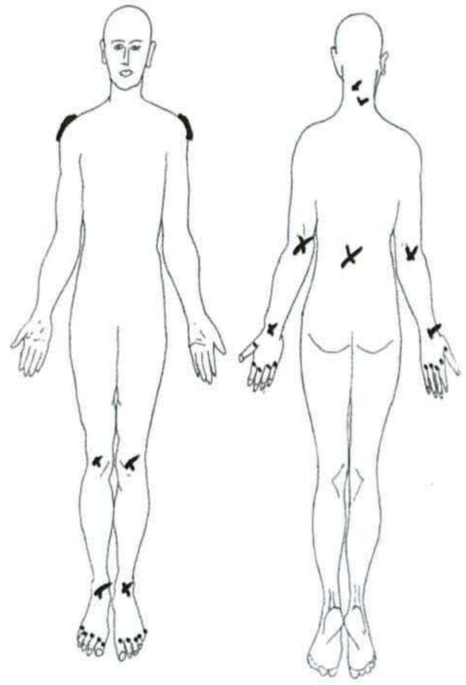
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
11

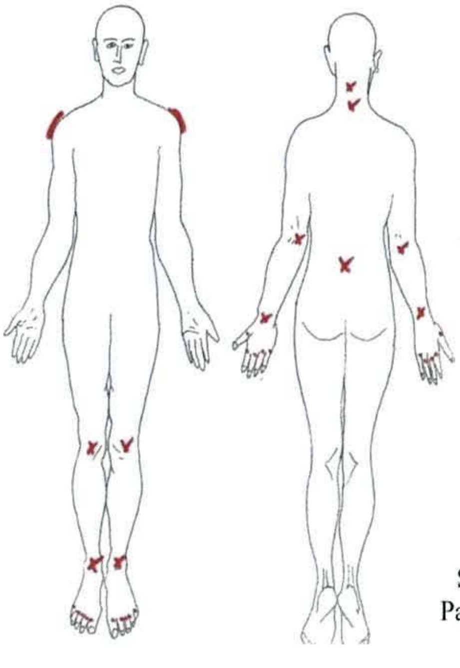
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



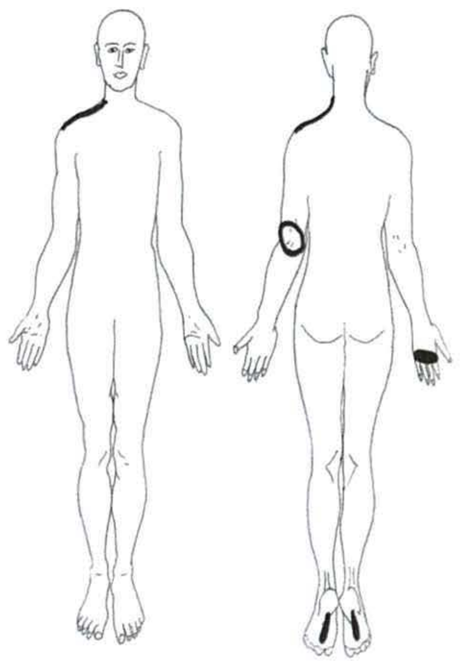
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

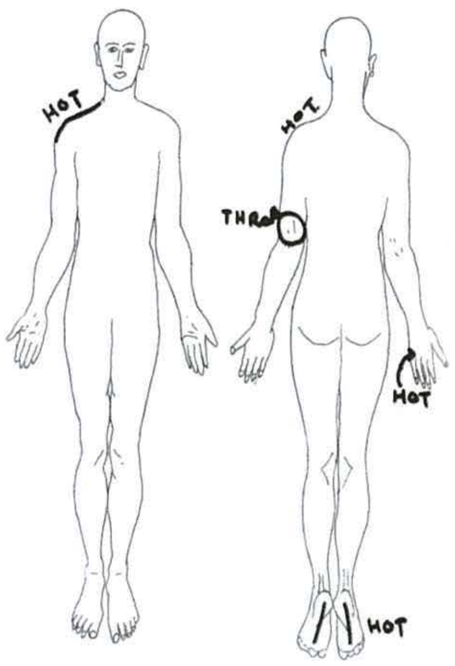
Study 2
Participant
12

1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



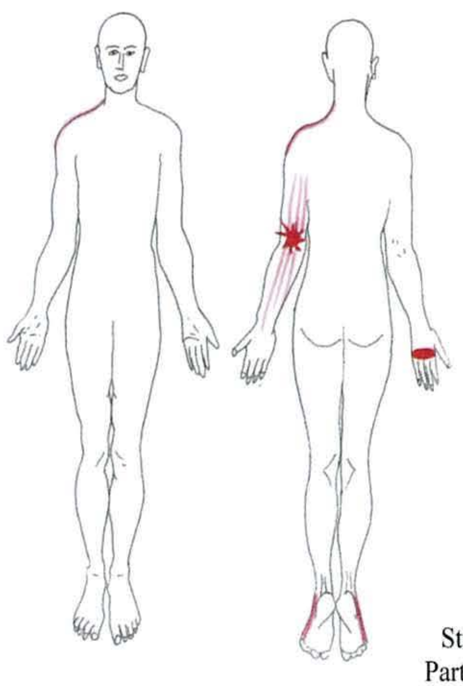
02/13

2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/13

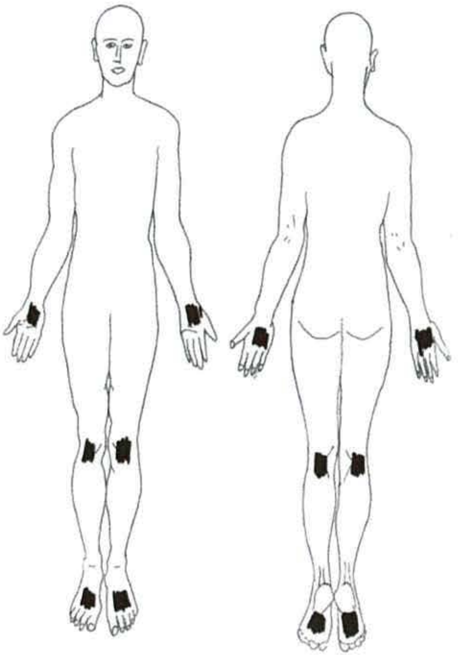
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

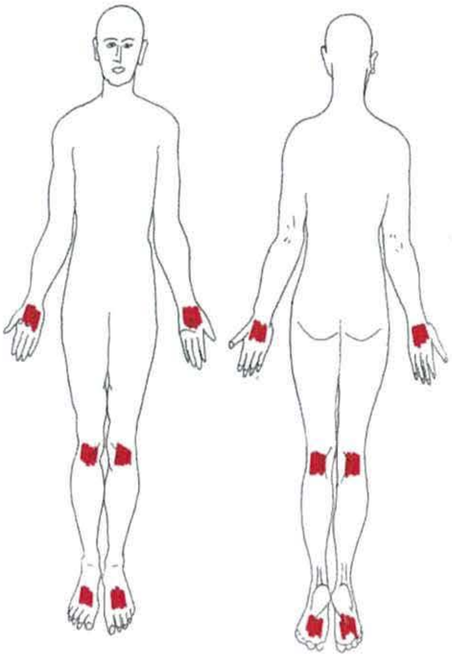
Study 2
Participant
13

2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



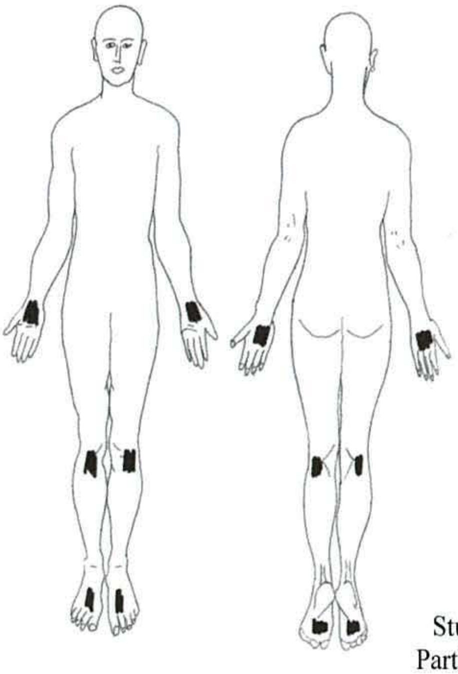
02/14

3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



02/14

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

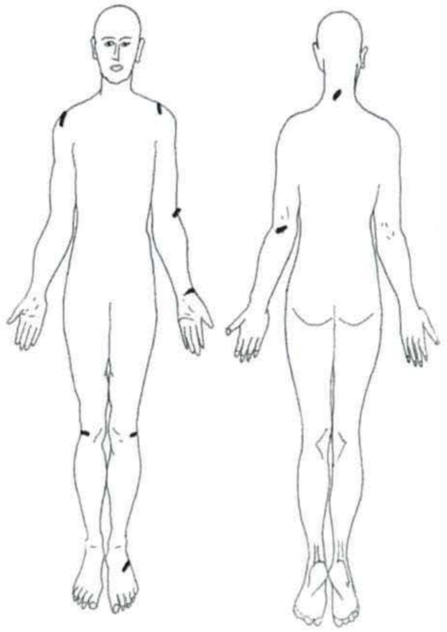


5 DESCRIBE YOUR IMAGE EXPLAINING WHAT IT MEANS TO YOU

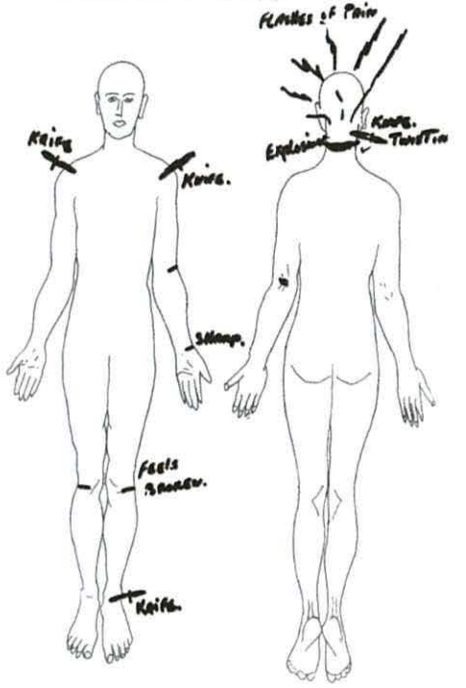
Study 2
Participant
14

I

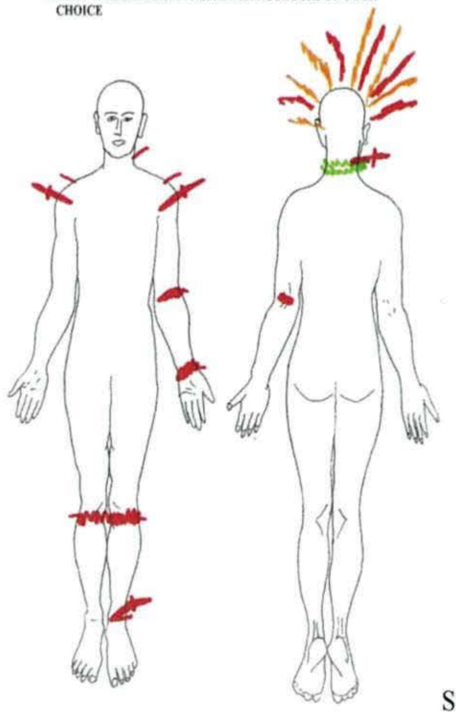
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



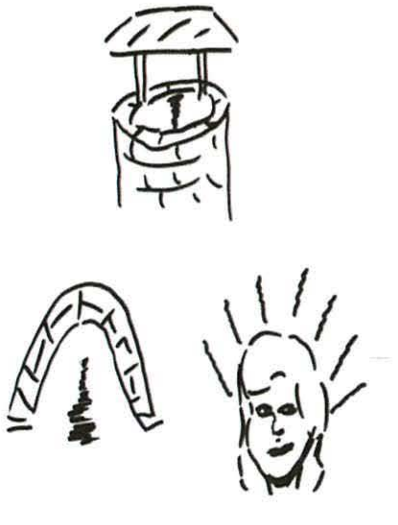
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

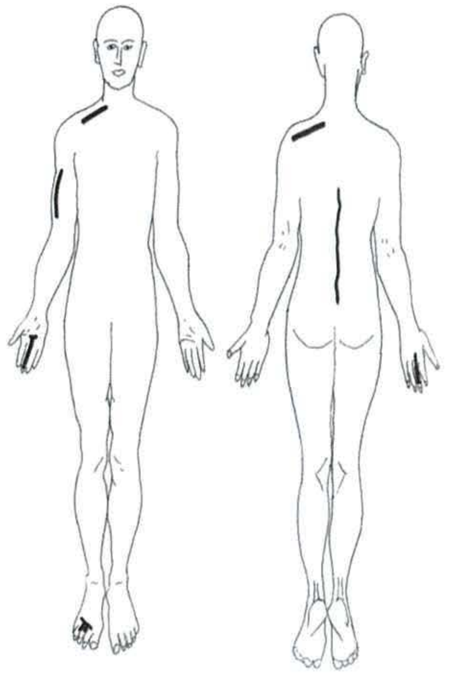


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

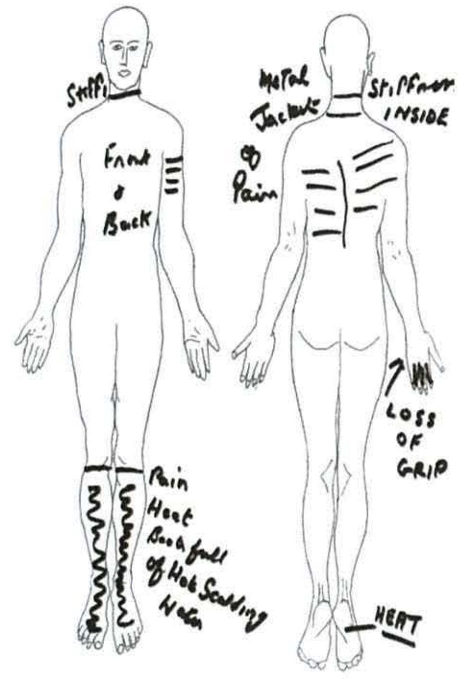


Study 2
Participant
15

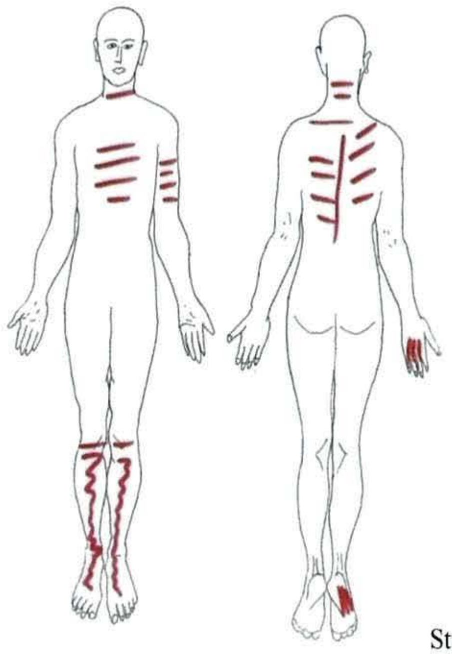
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



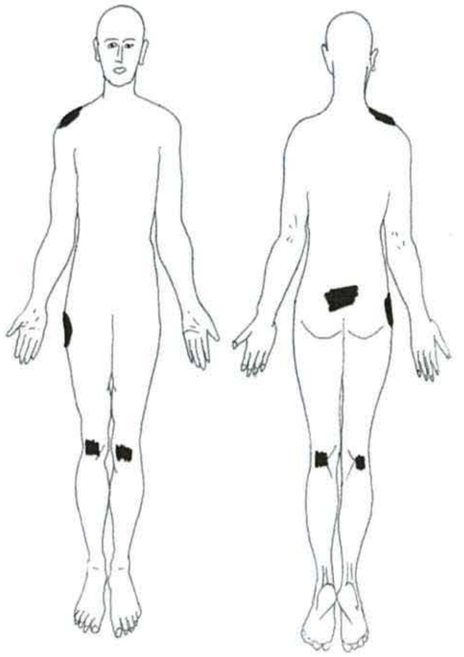
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



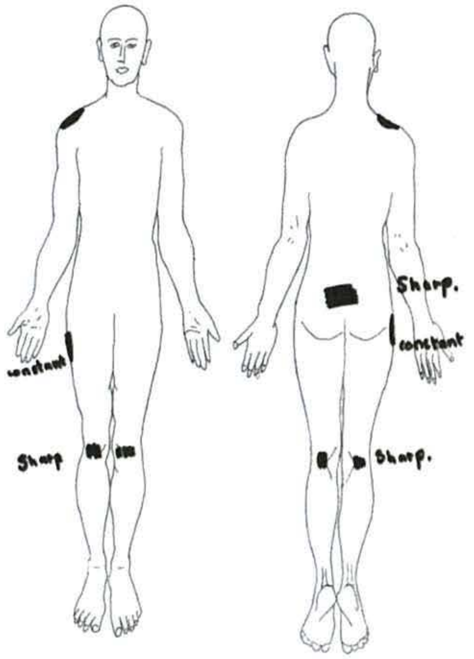
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
16

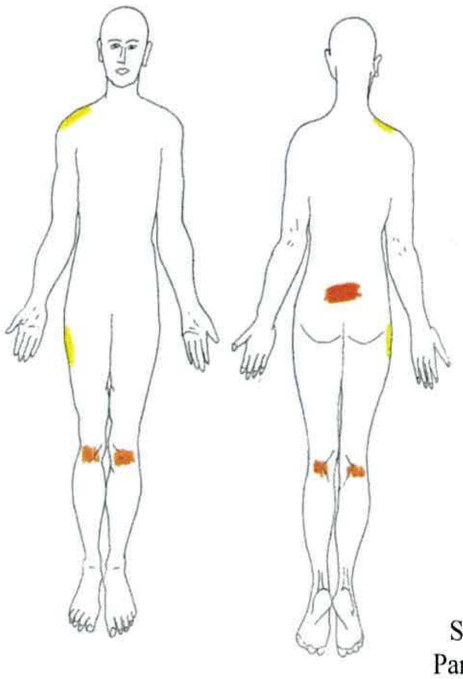
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



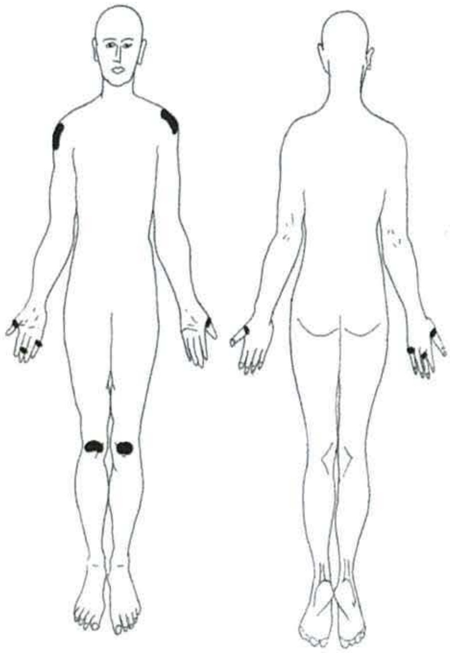
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



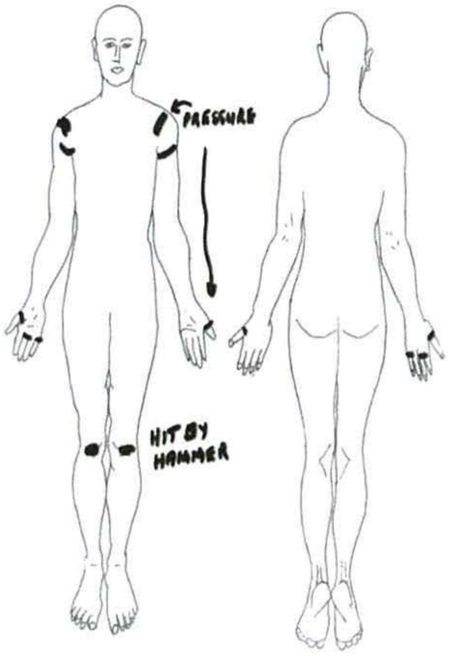
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
17

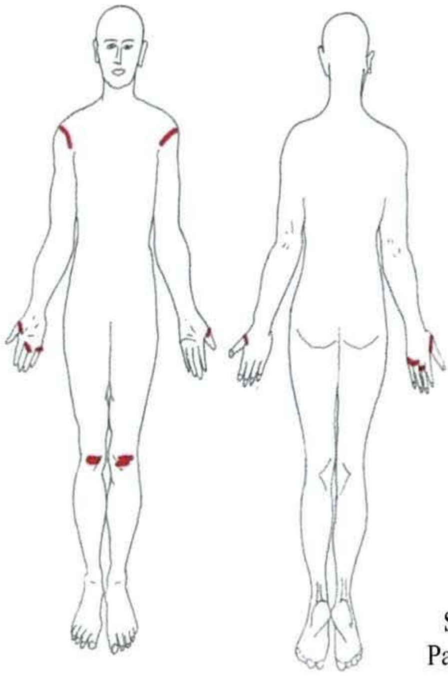
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



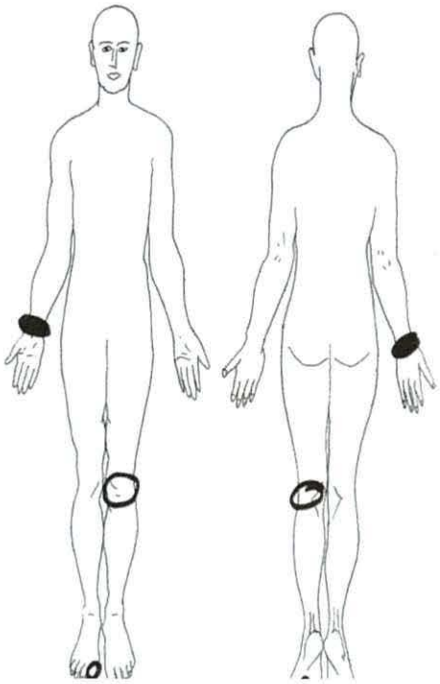
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



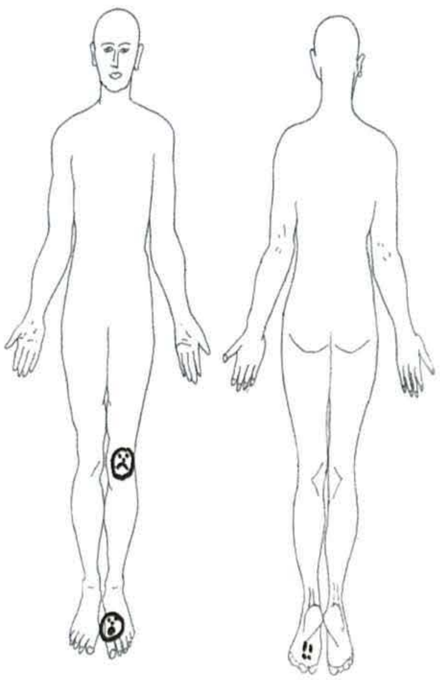
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
18

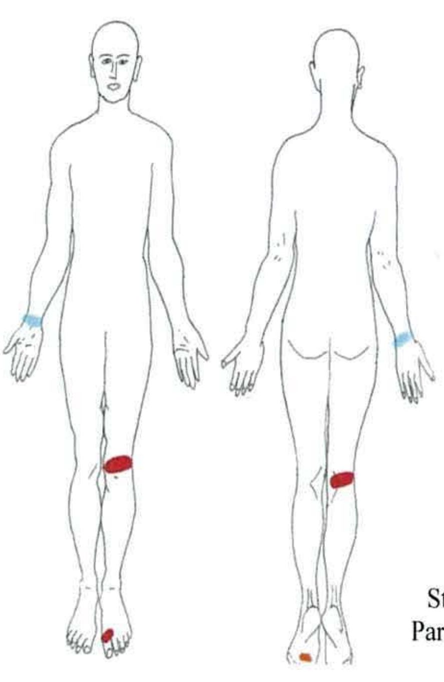
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



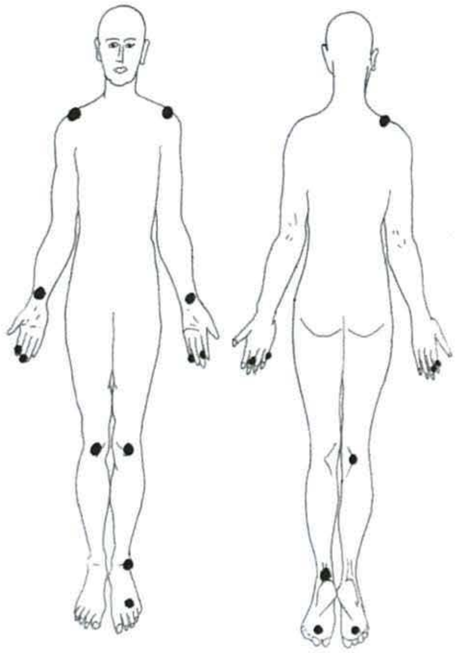
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



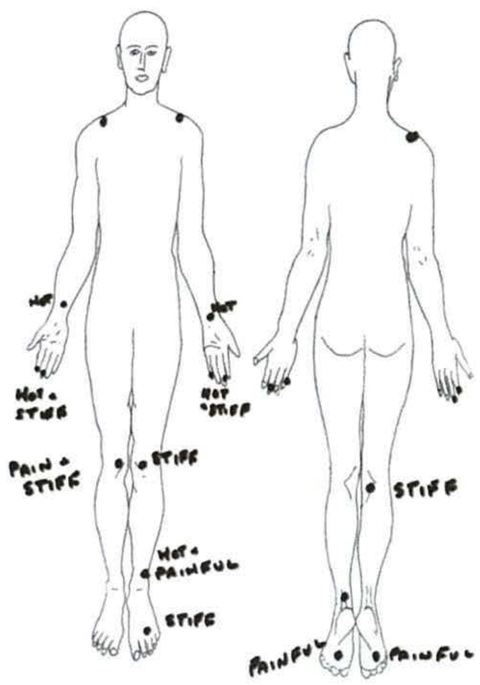
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
19

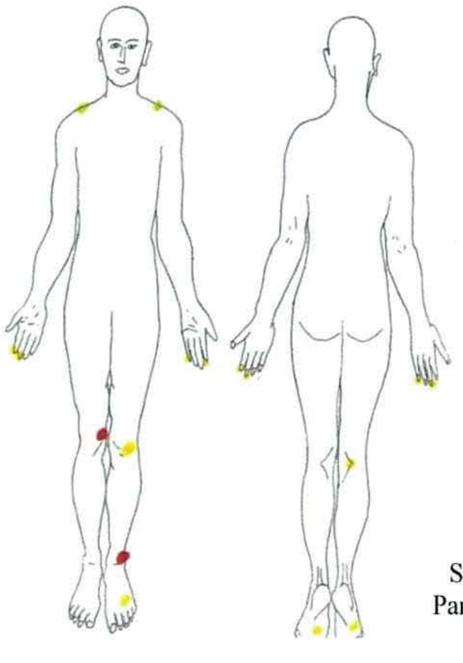
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



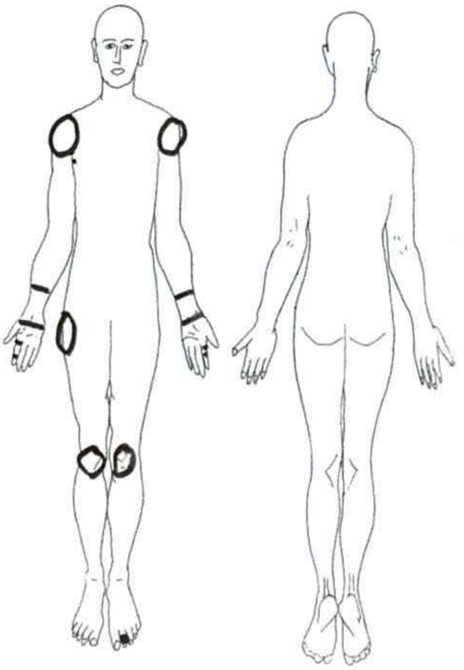
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



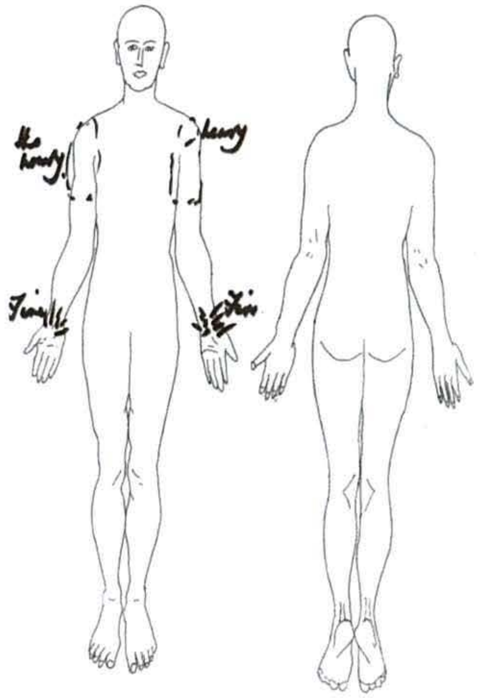
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
20

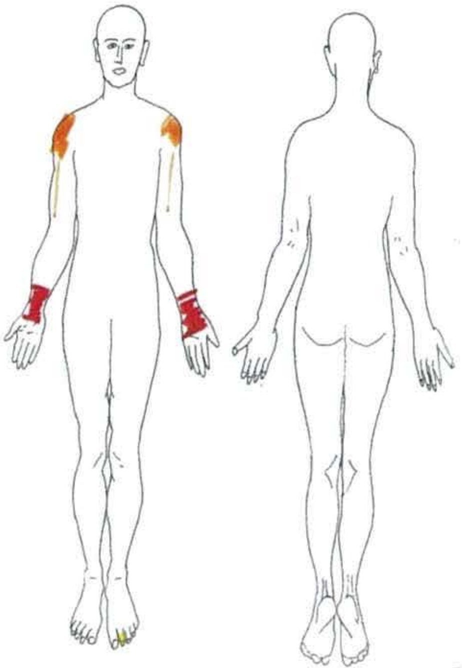
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



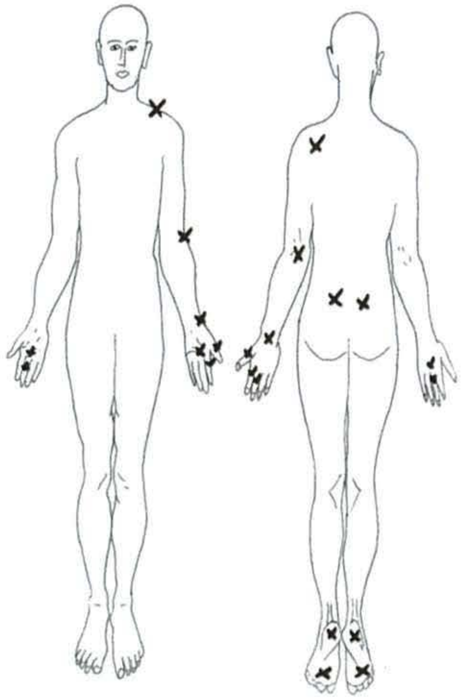
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



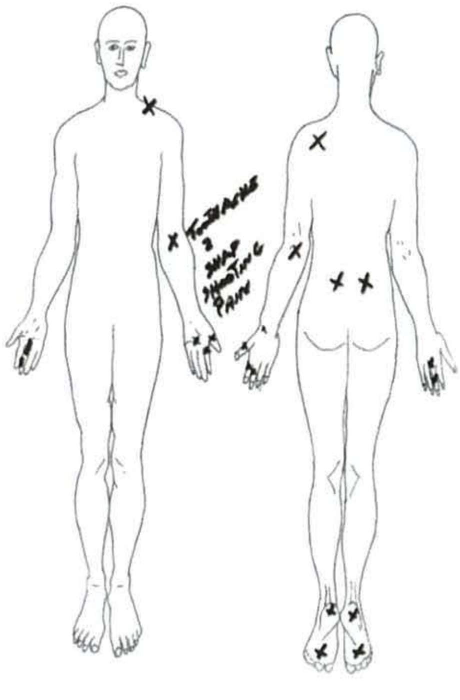
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
21

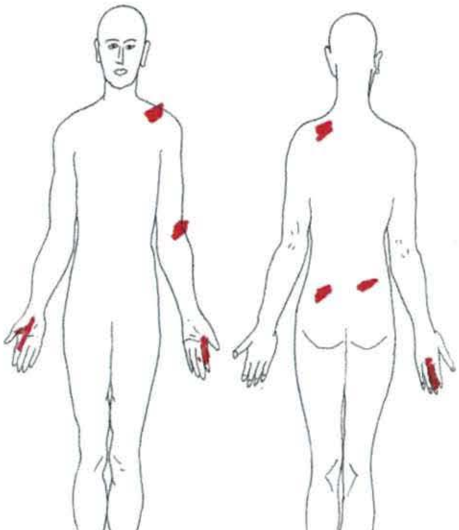
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



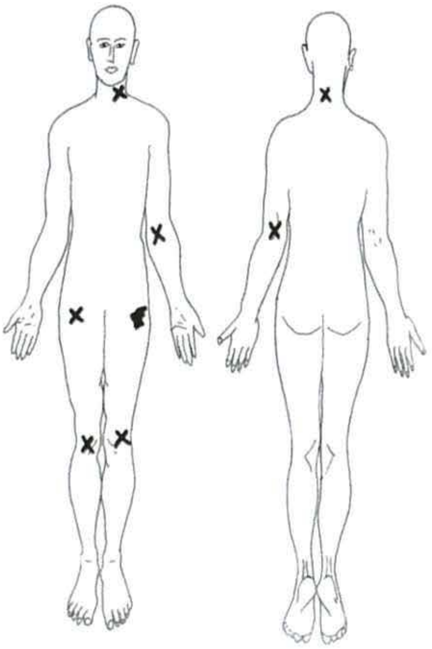
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



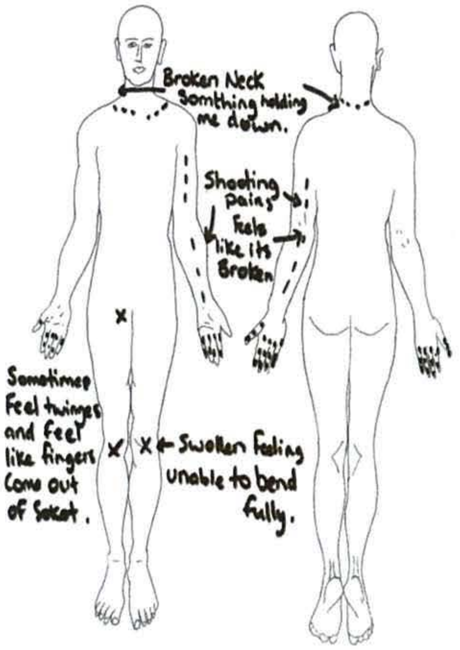
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
22

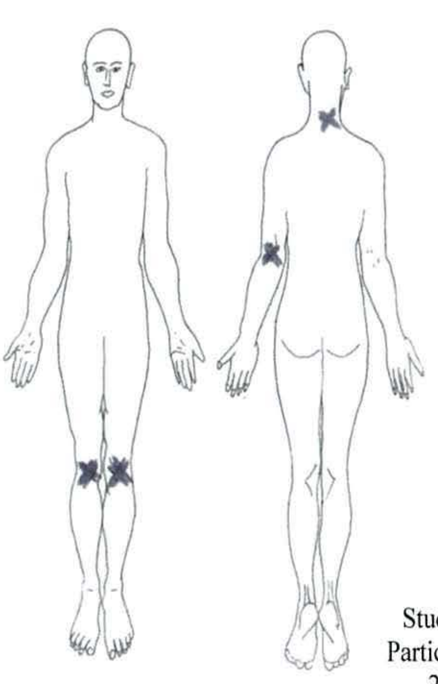
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



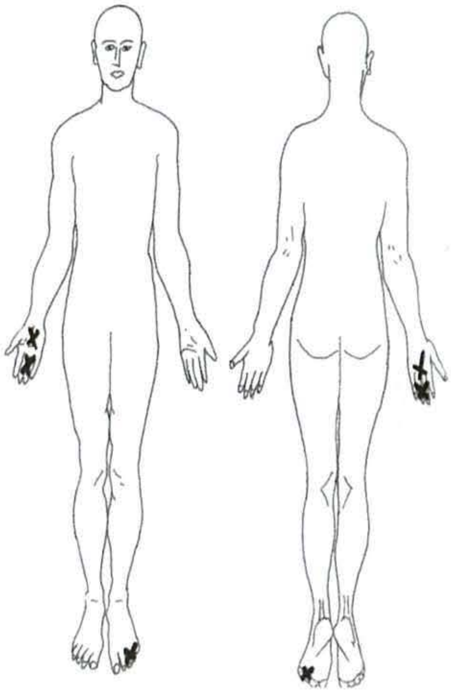
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



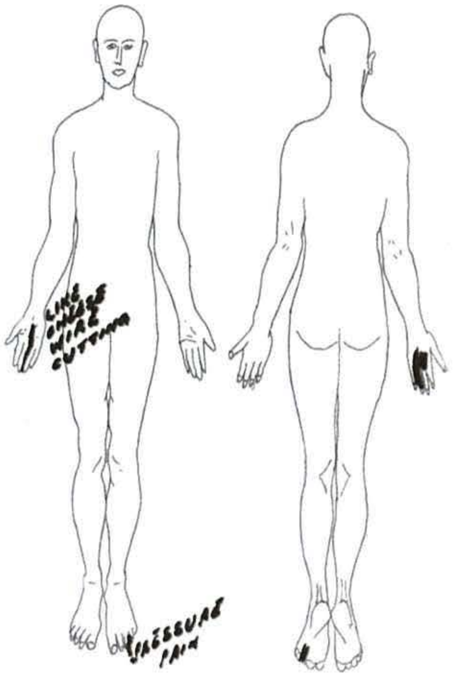
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
23

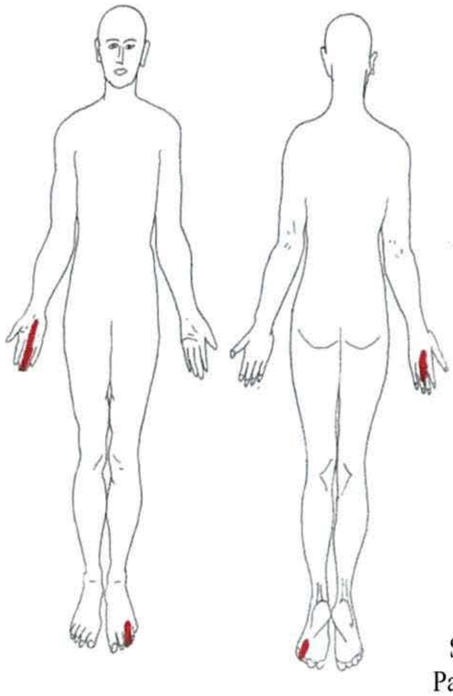
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



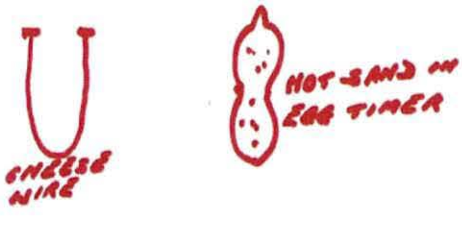
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

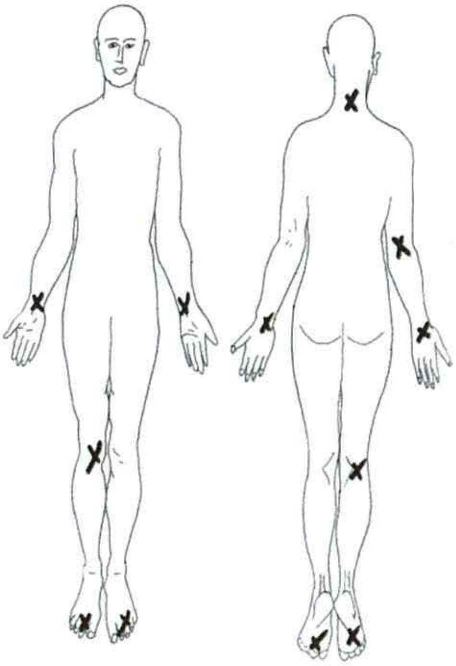


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

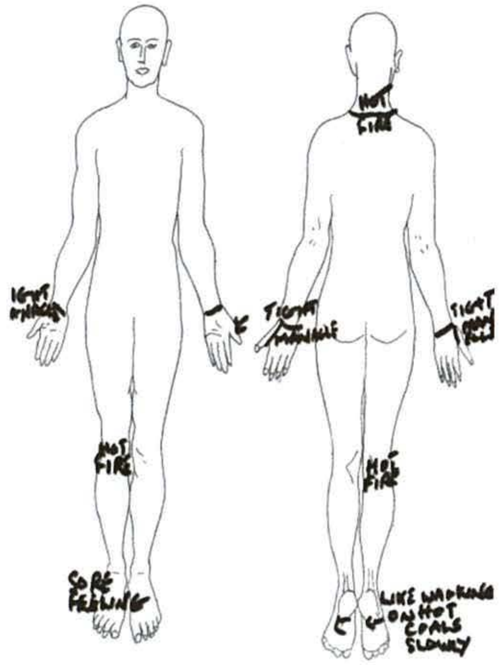


Study 2
Participant
24

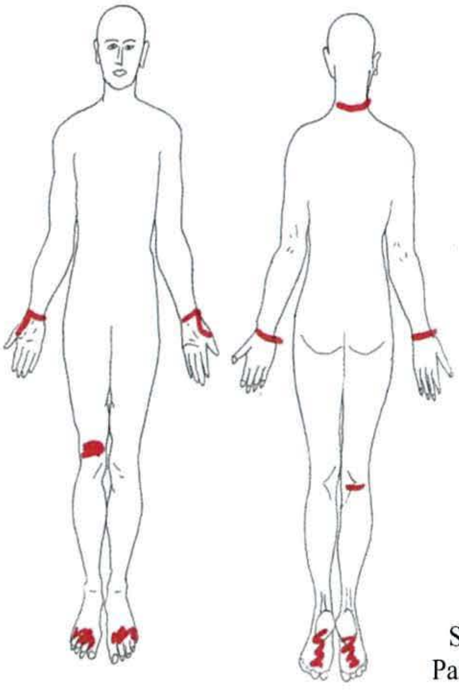
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



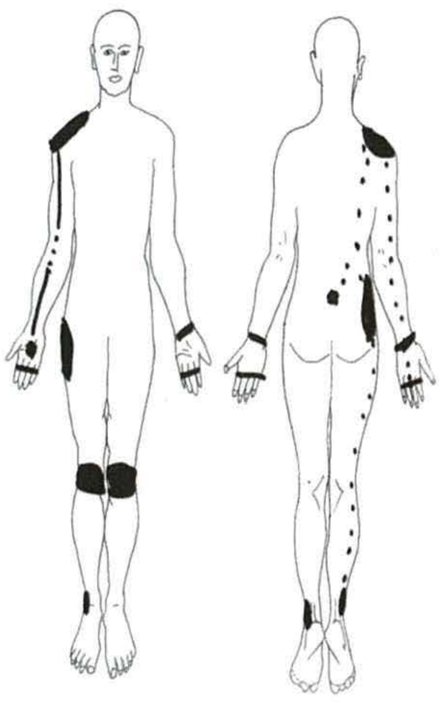
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



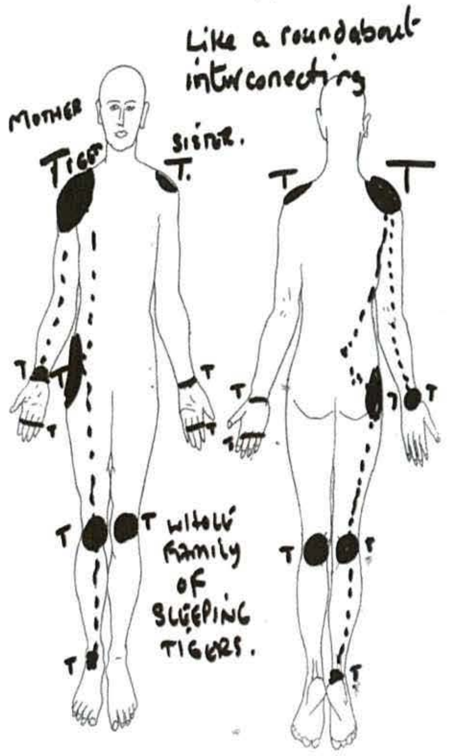
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
25

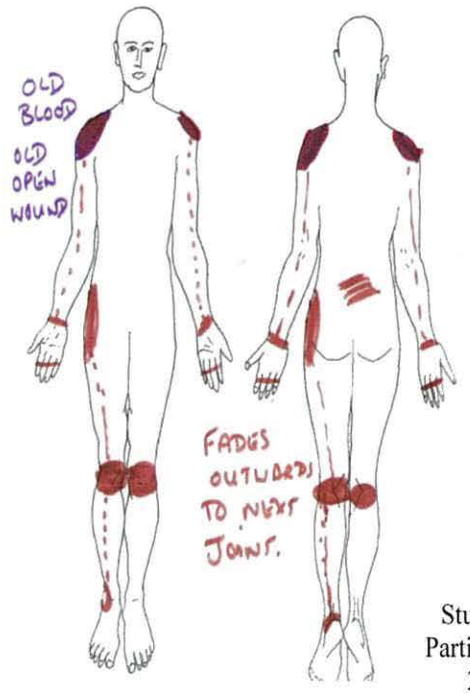
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



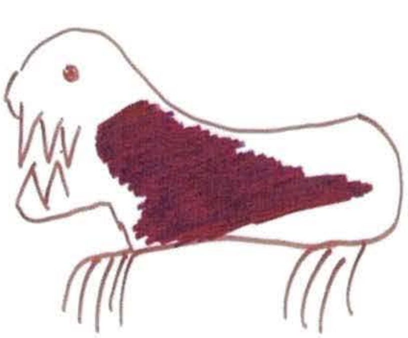
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



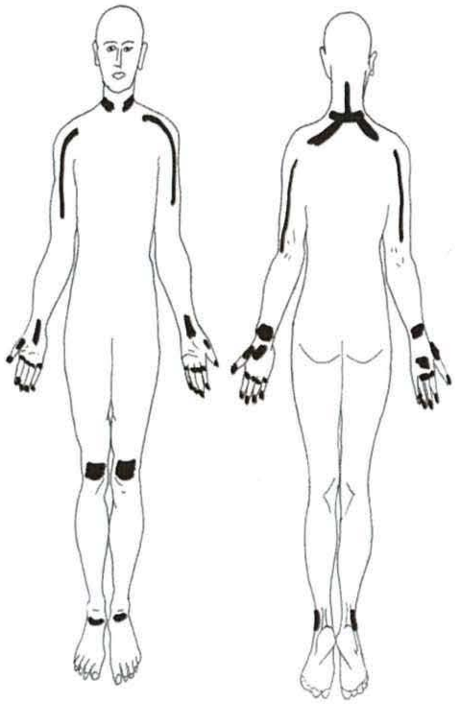
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE



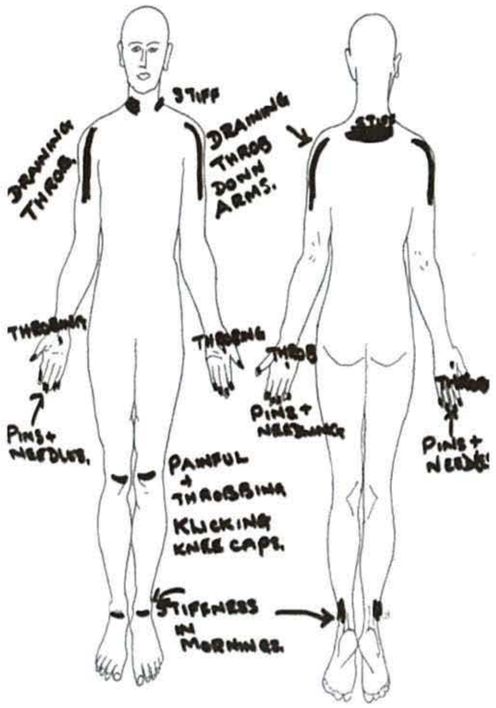
Study 2
Participant
26

02/26 02/26

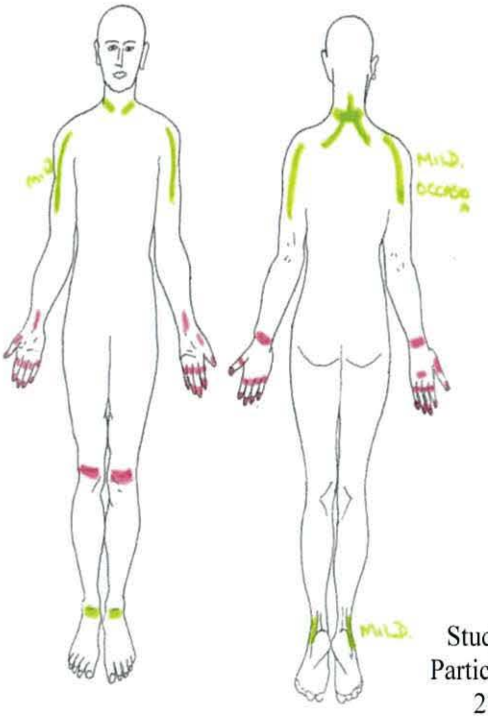
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



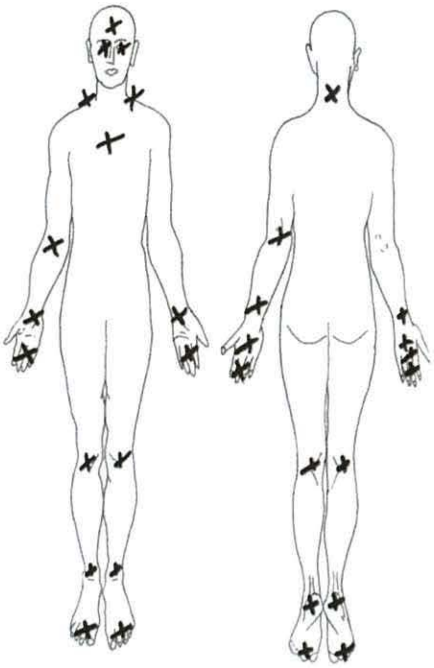
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



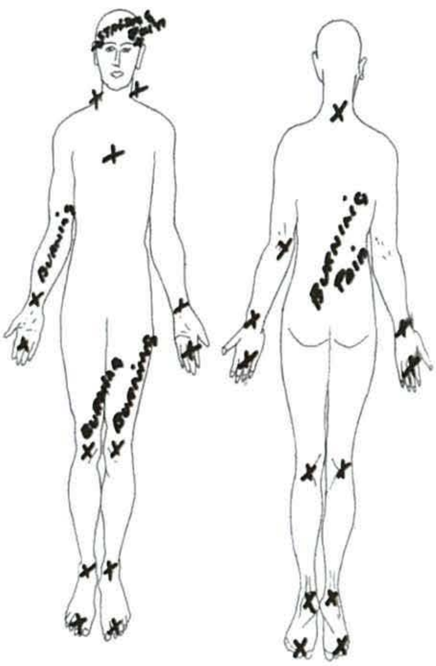
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
27

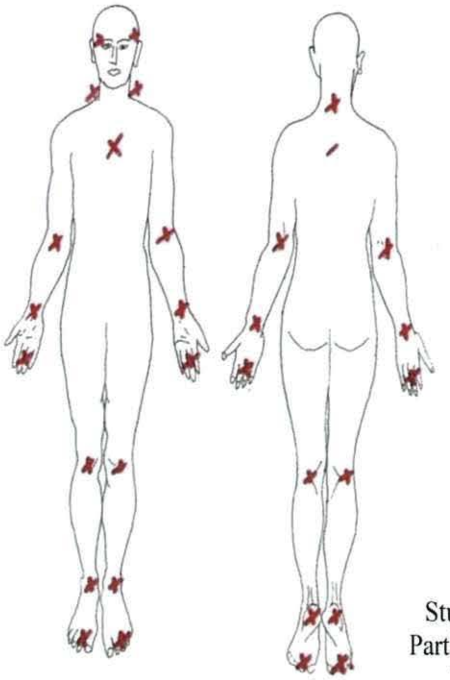
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



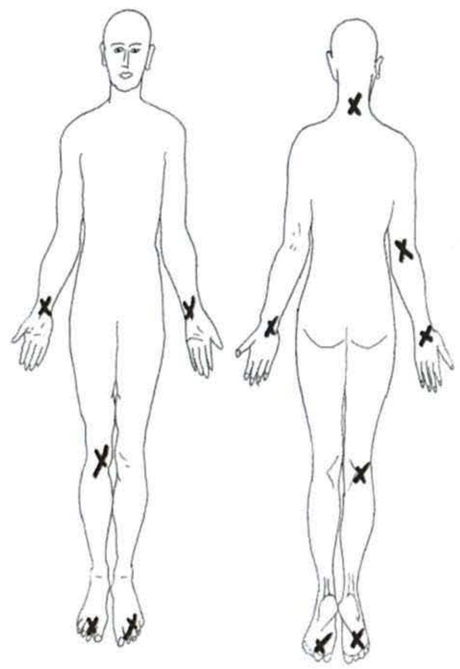
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



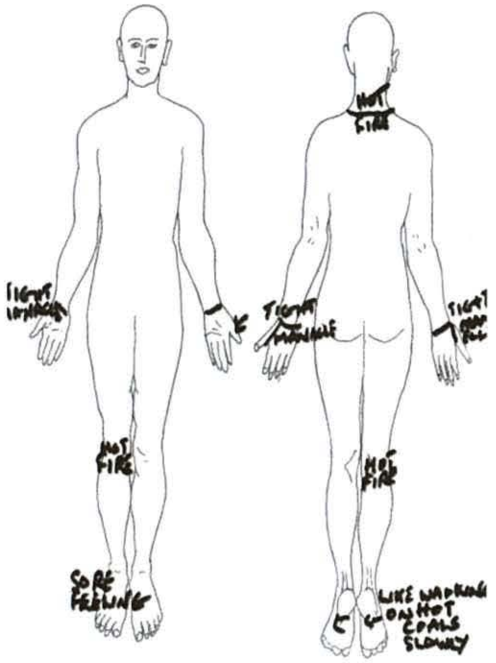
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
28

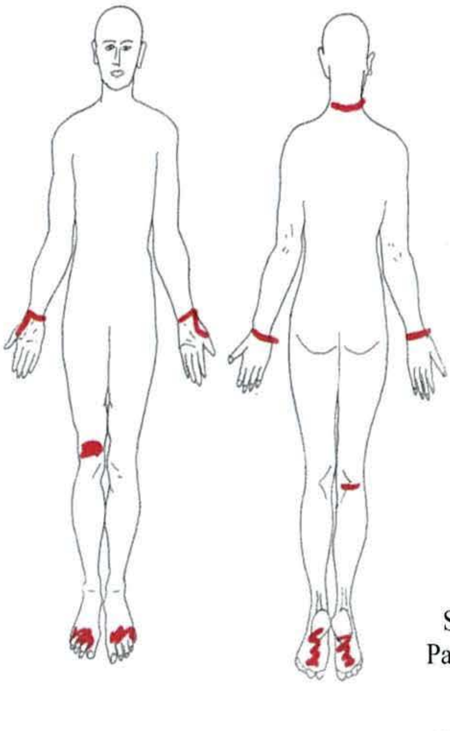
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



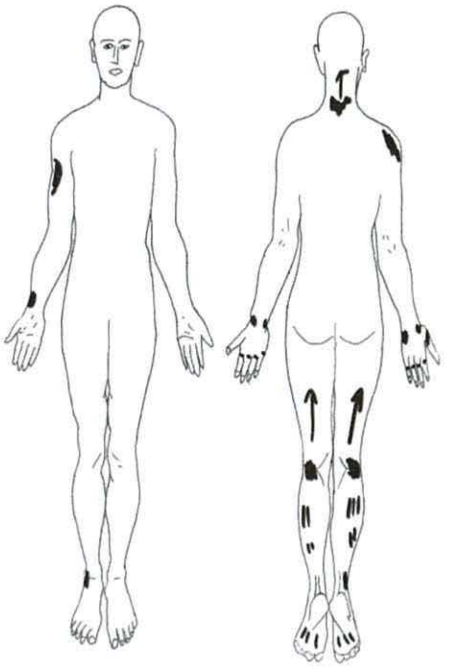
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



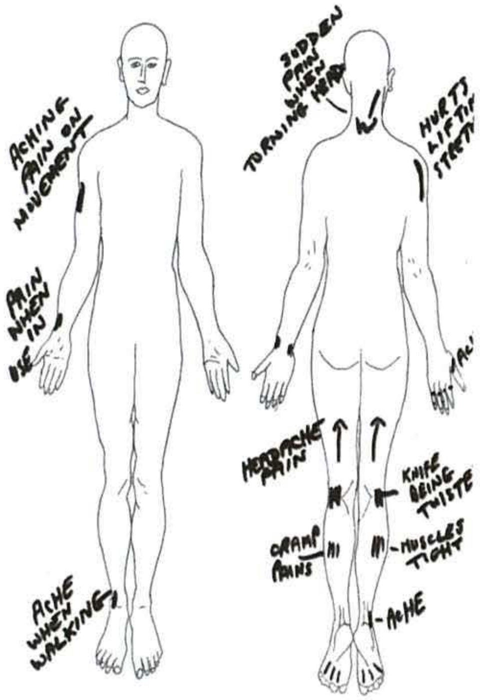
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
29

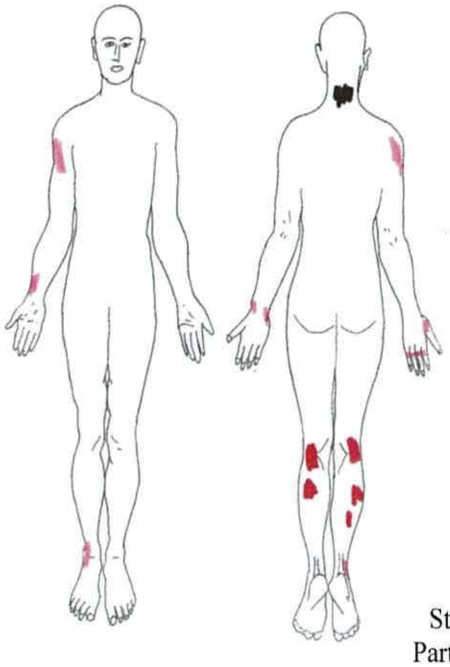
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



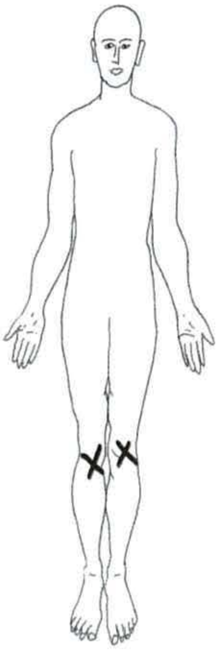
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



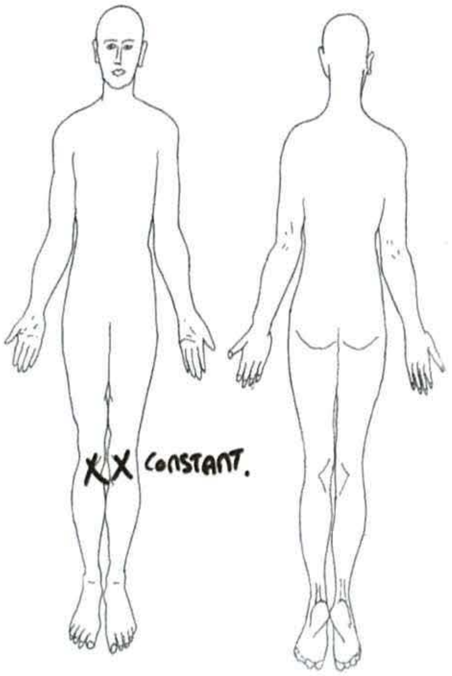
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
30

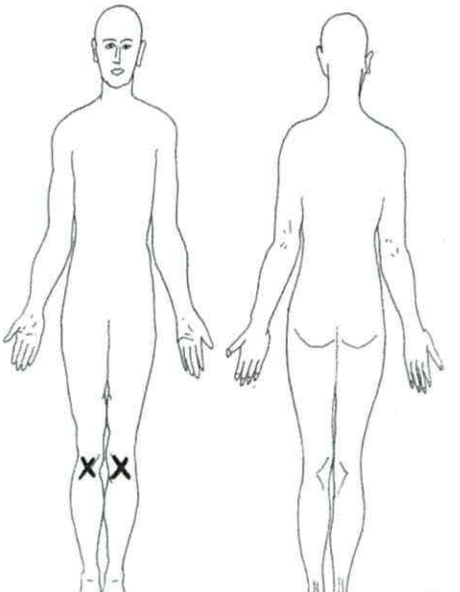
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



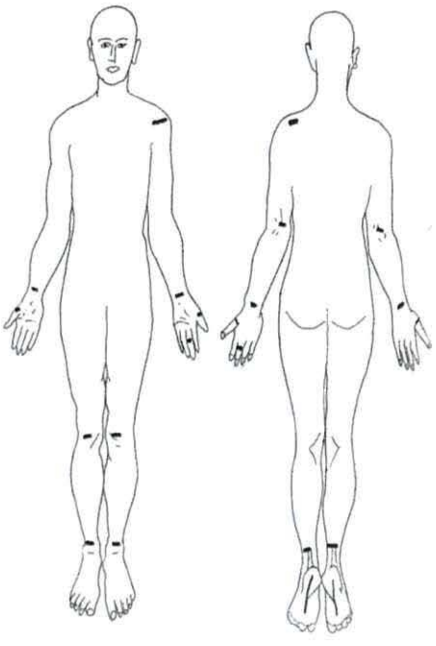
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



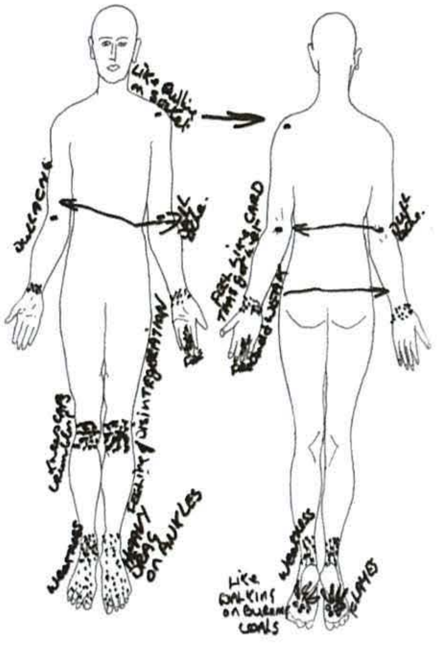
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
31

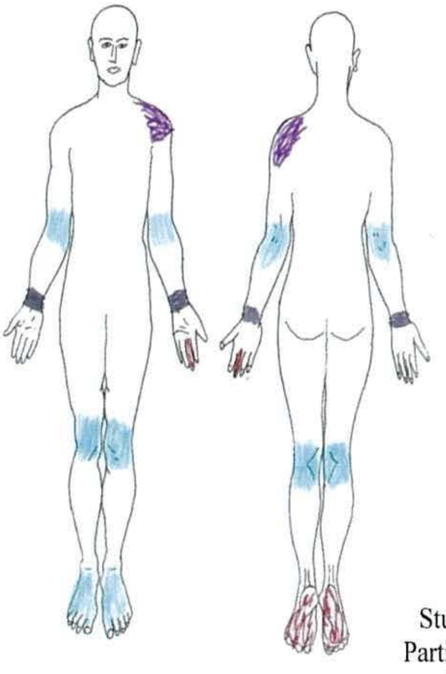
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



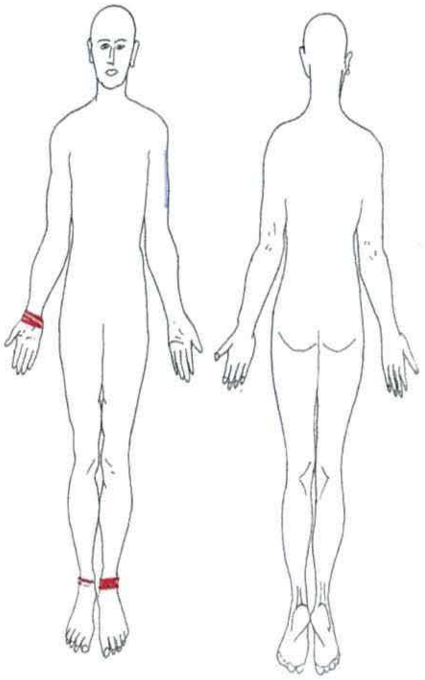
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
32

3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



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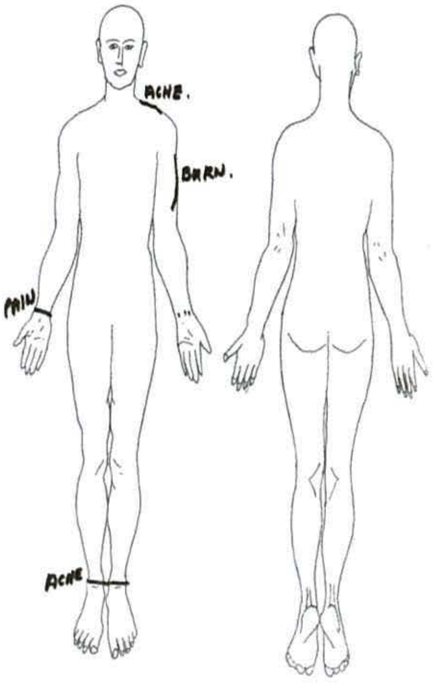
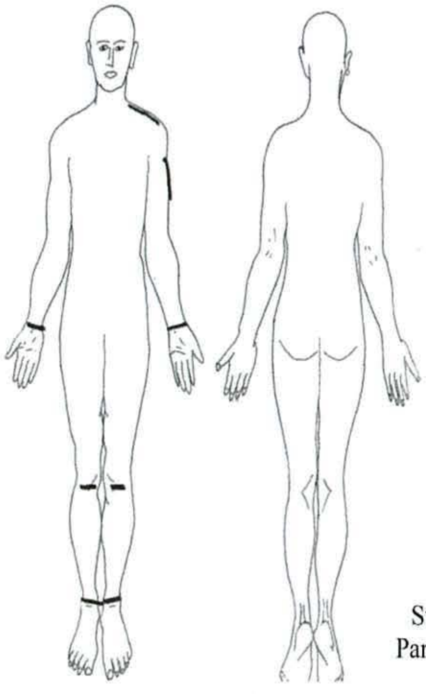


1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

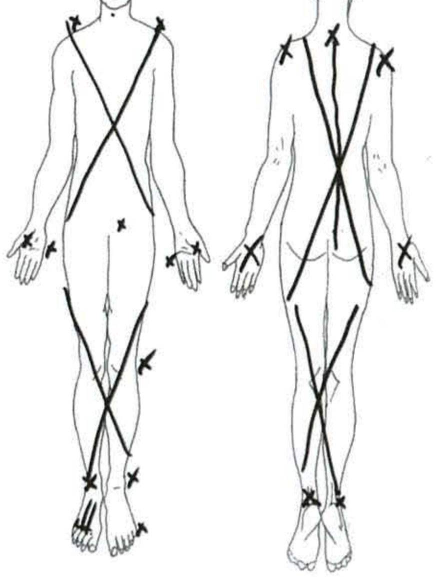


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
33

02/33

1. DRAW YOUR PAIN ON THIS DIAGRAM (black pen provided)



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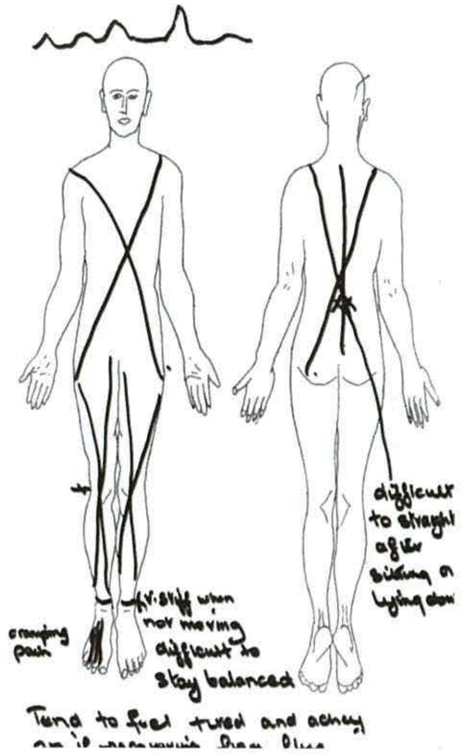
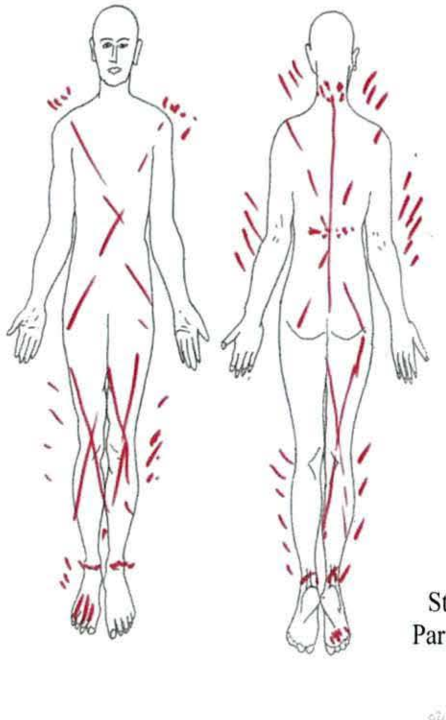


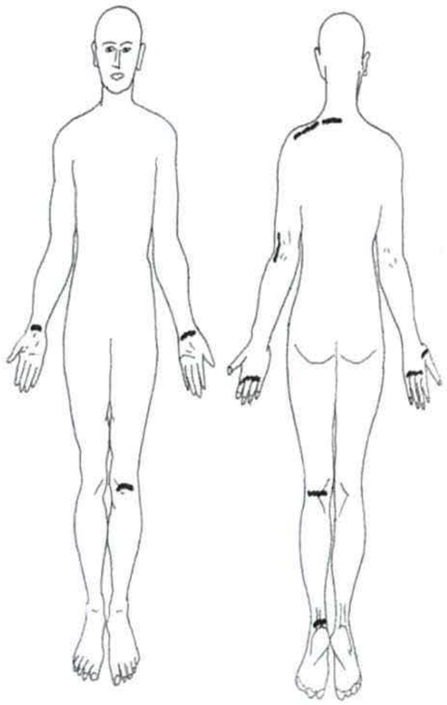
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



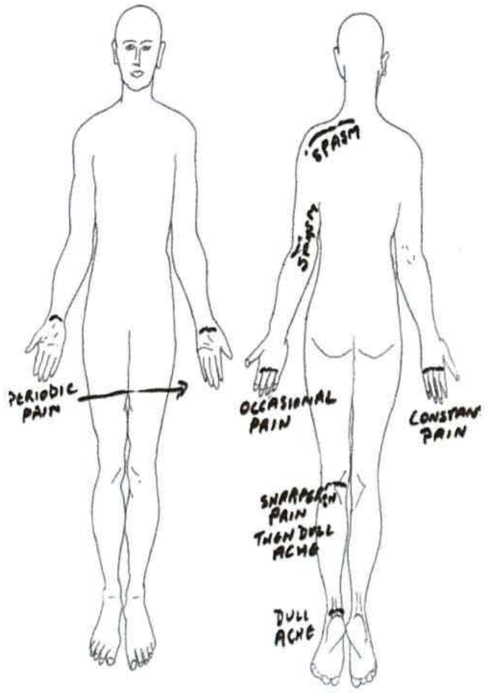
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
34

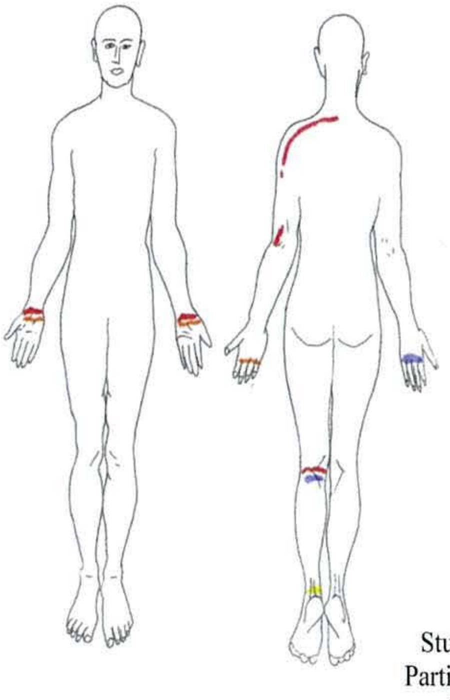
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



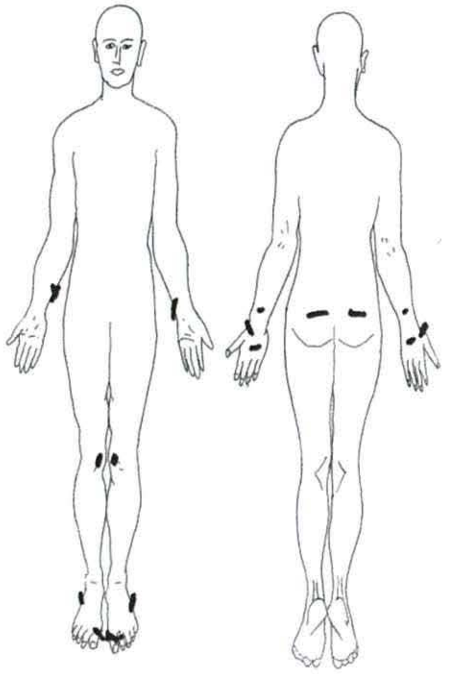
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



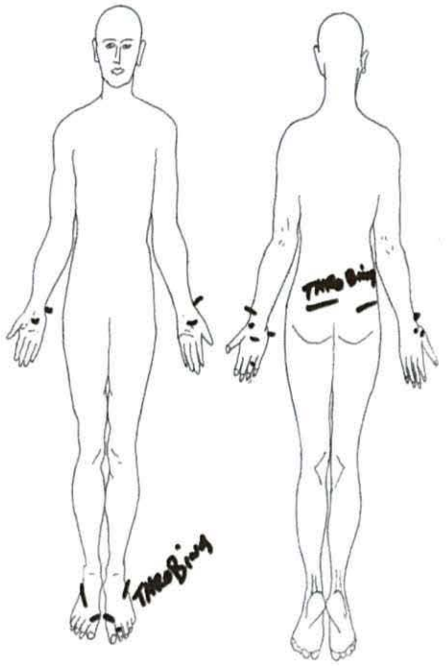
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
35

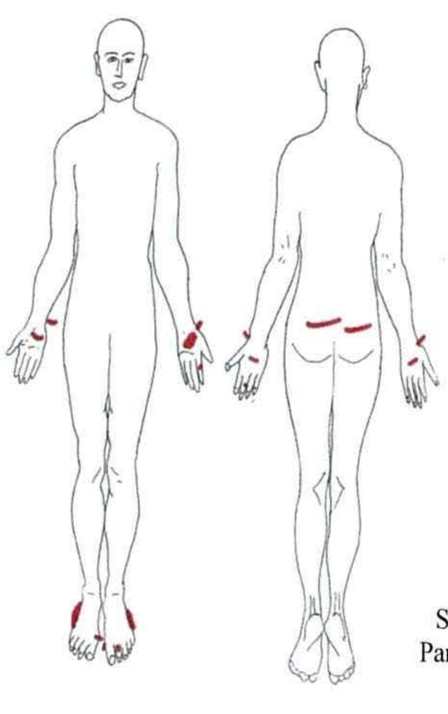
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

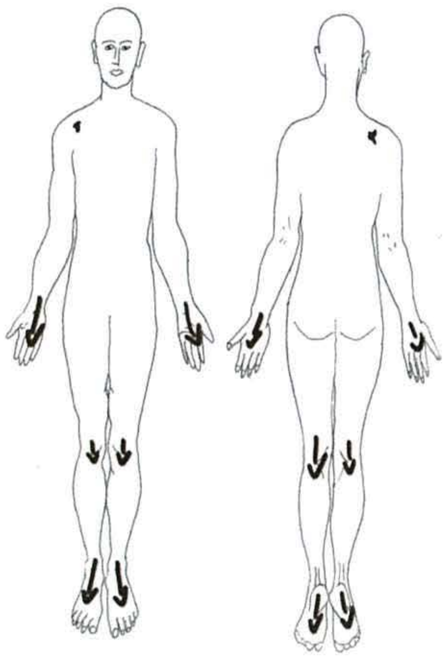


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
36

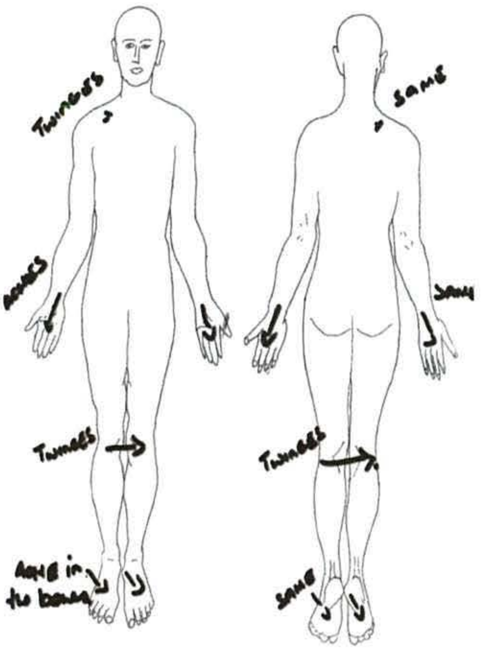
02/36

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



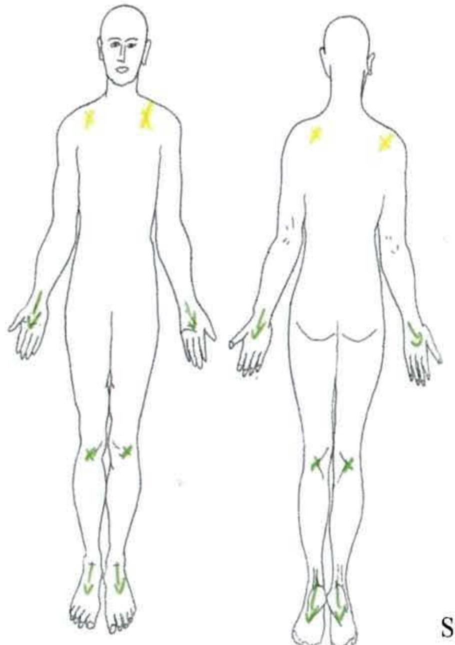
02/37

2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/37

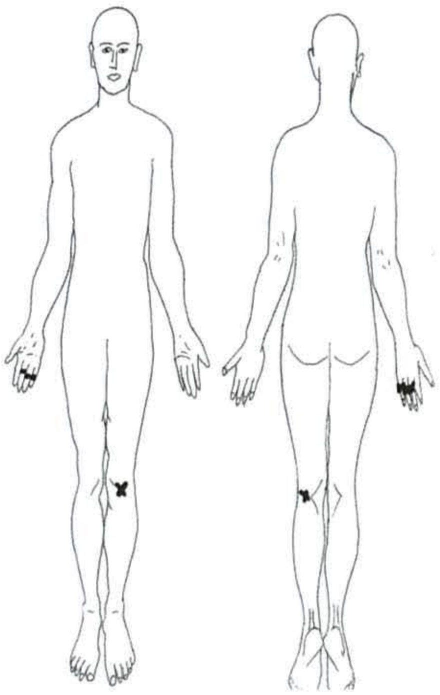
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



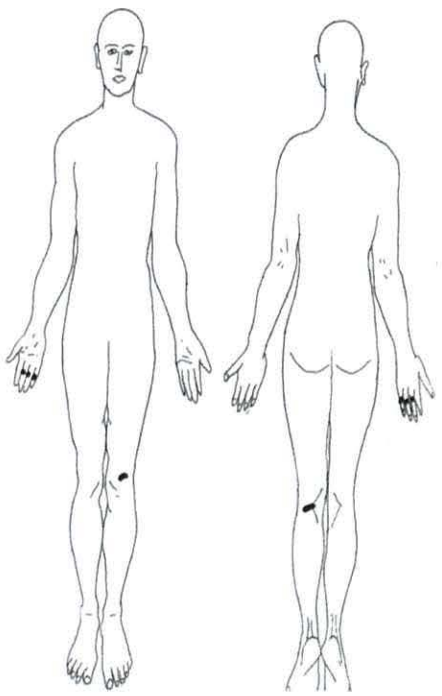
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
37

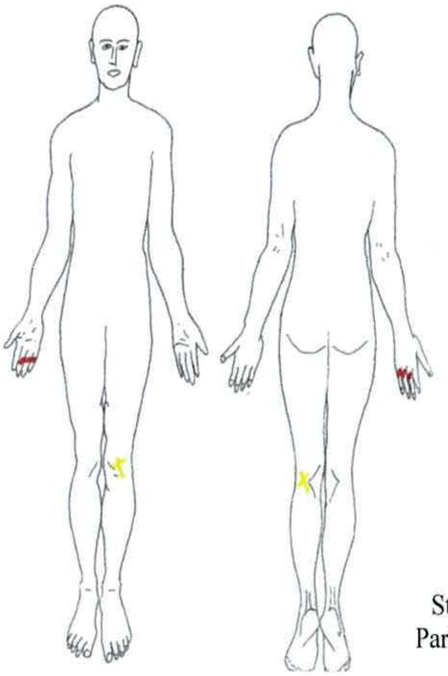
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



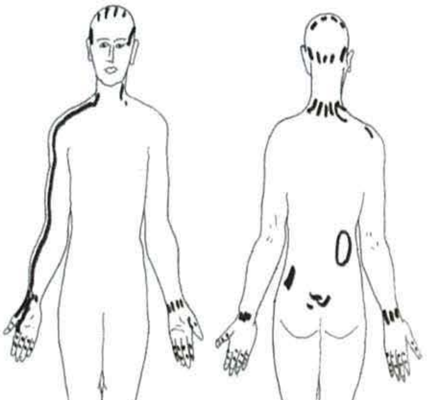
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



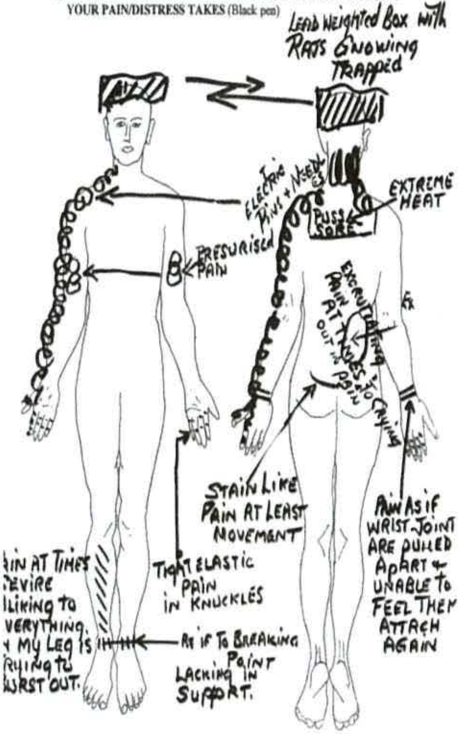
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
38

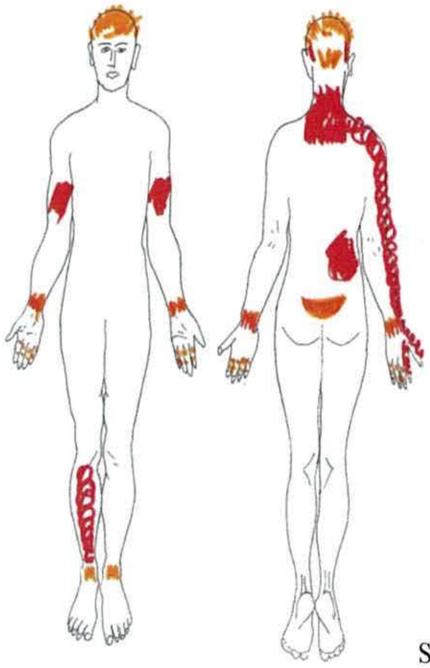
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



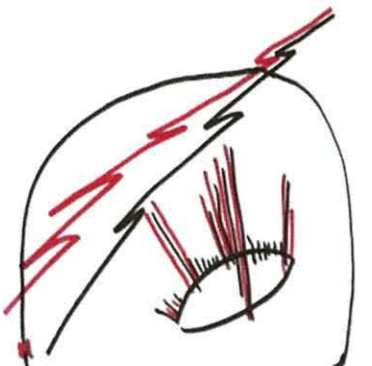
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

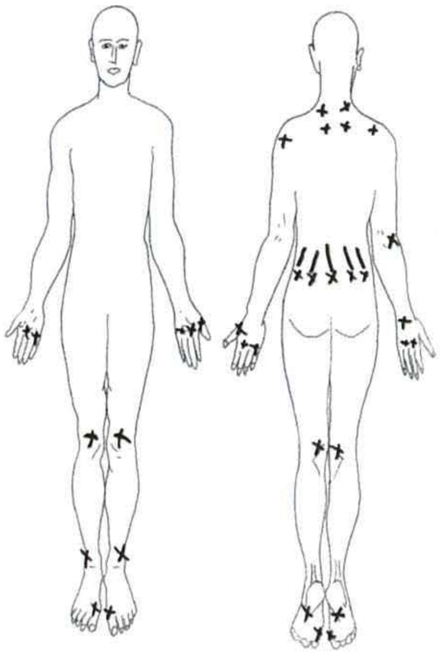


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

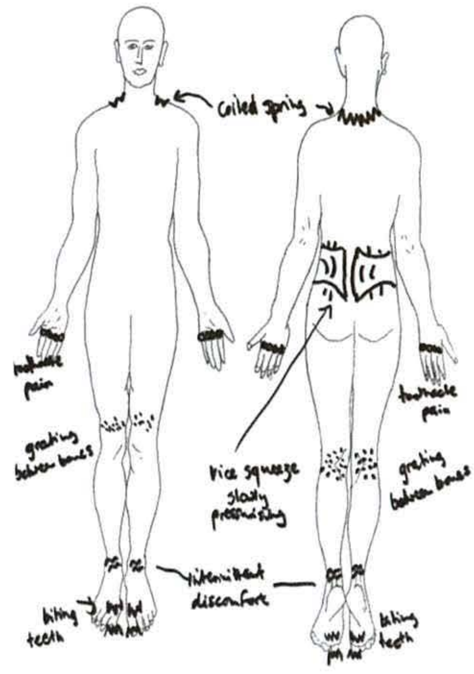


Study 2
Participant
39

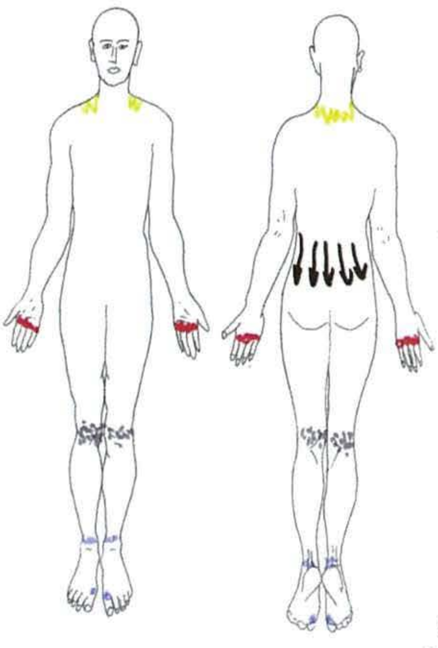
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

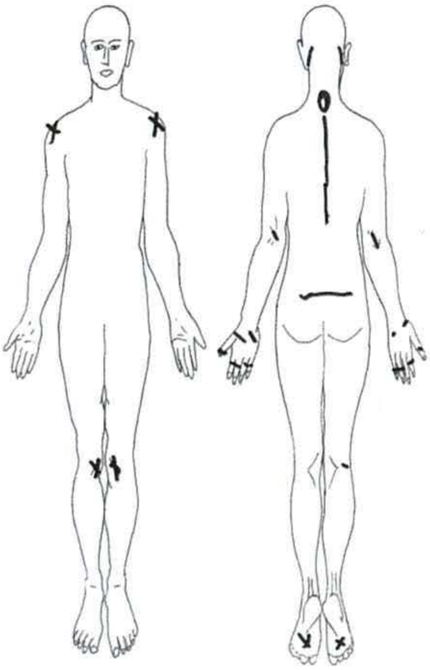


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

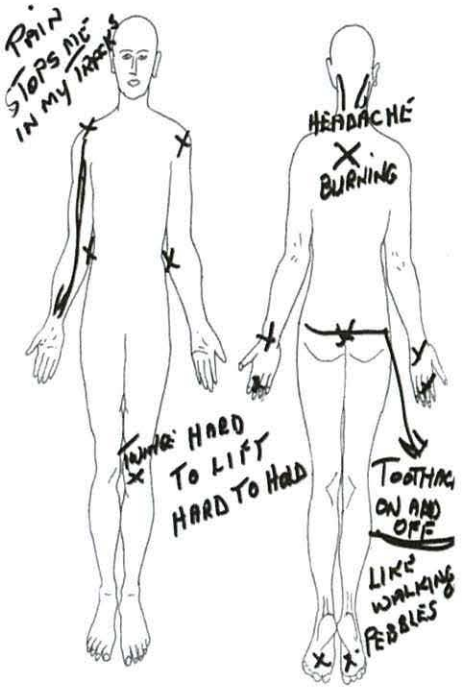
Study 2
Participant
40

02/40

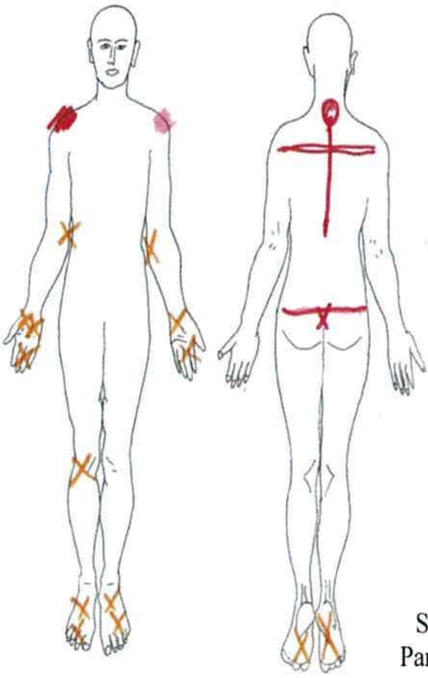
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



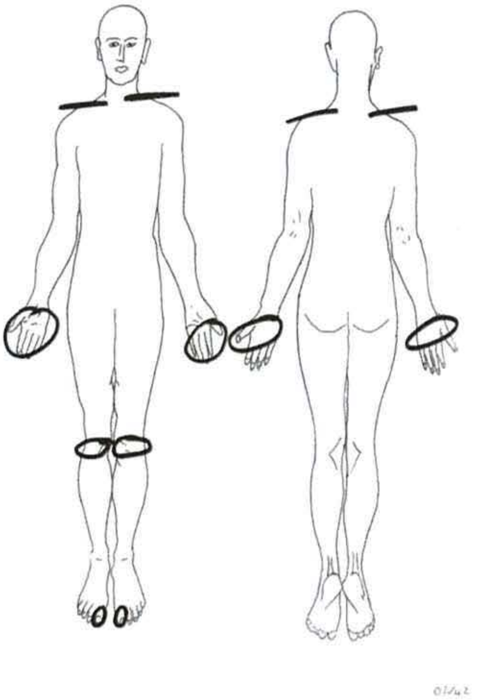
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



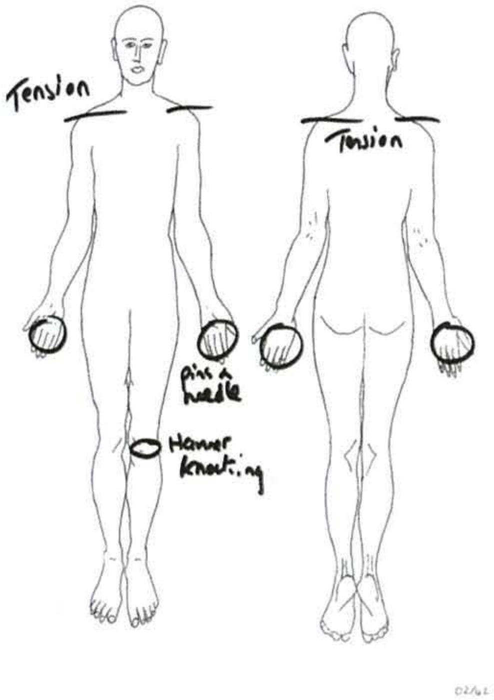
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
41

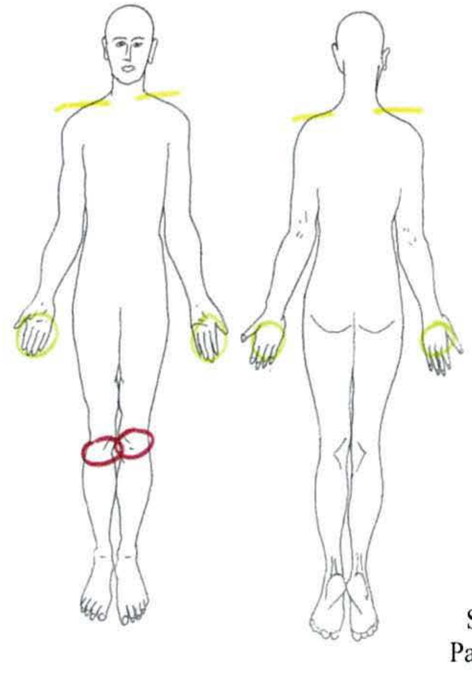
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



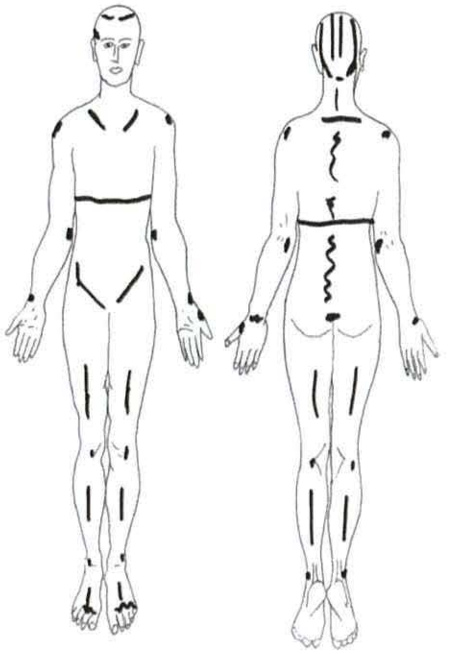
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



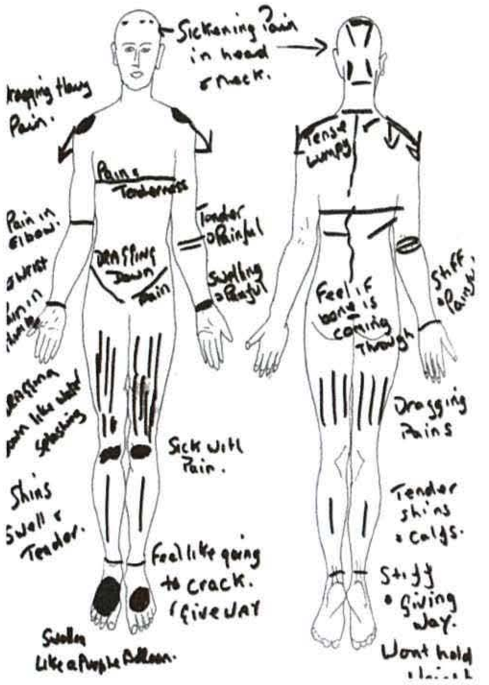
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
42

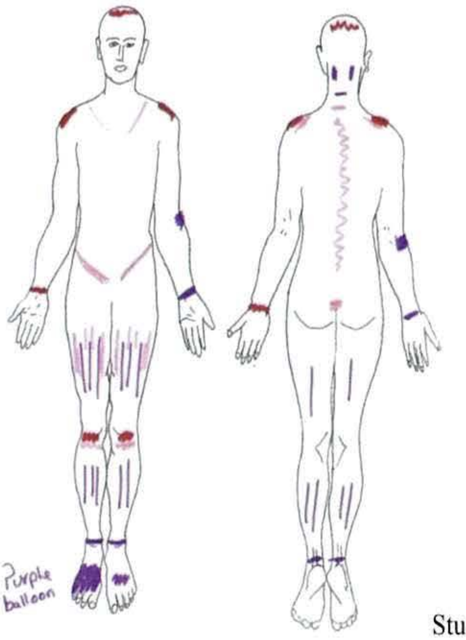
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



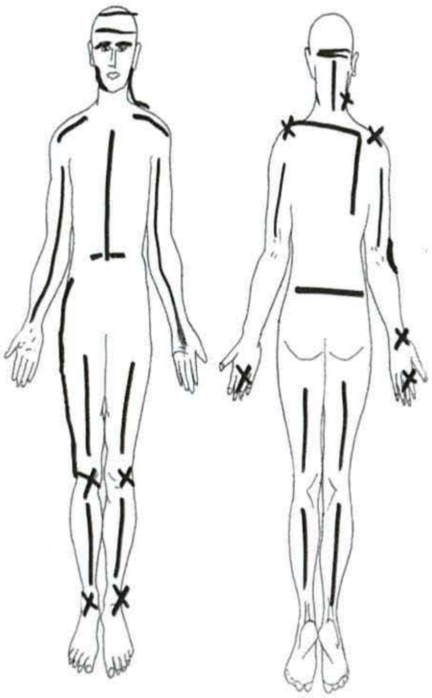
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



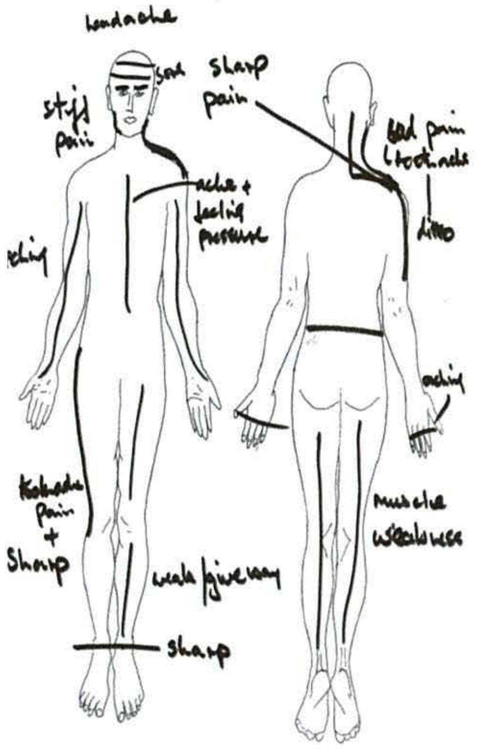
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
43

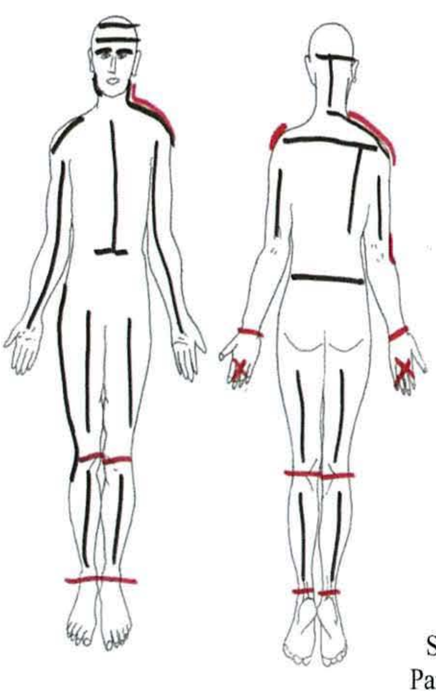
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



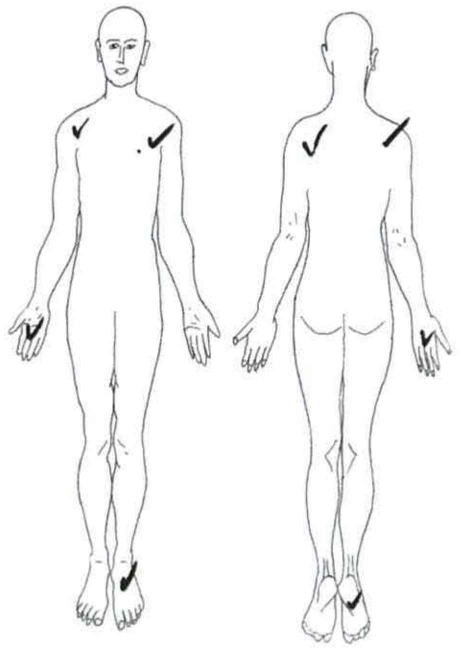
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



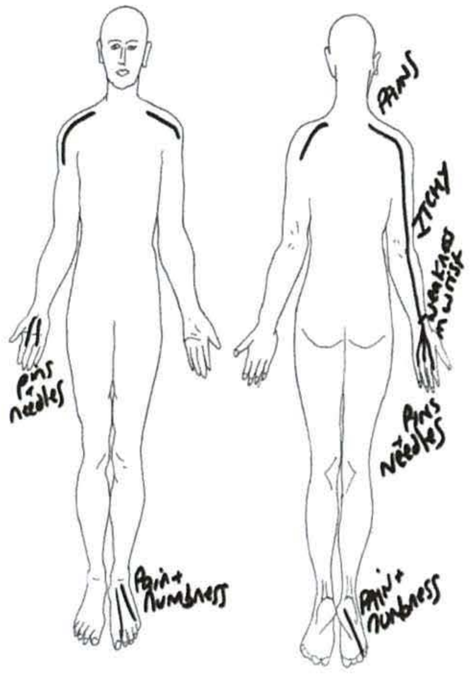
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
44

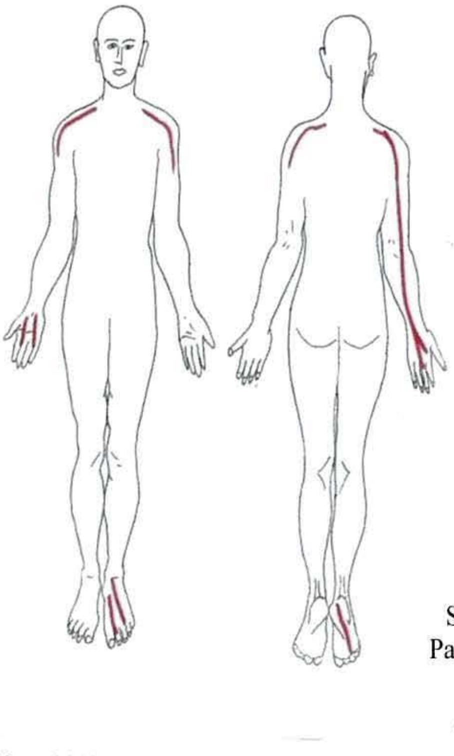
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



YOUR PAIN/DISTRESS TAKES (Black pen)



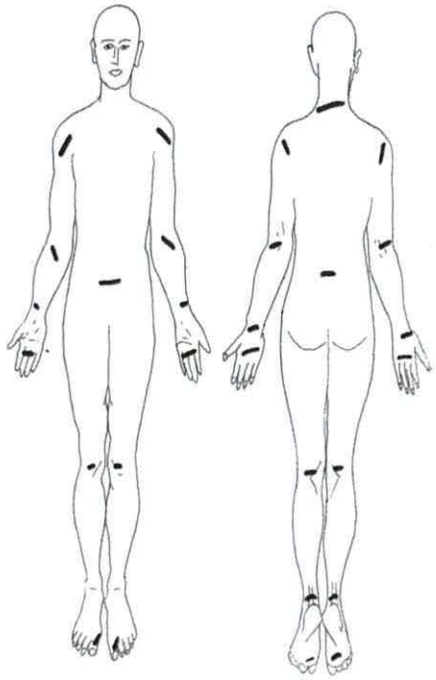
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



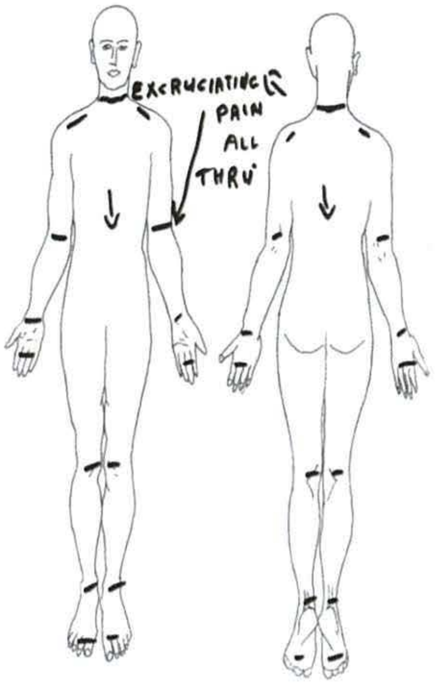
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
45

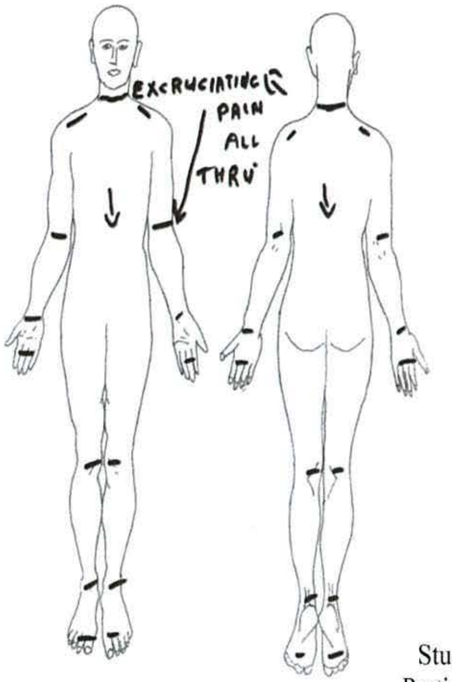
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



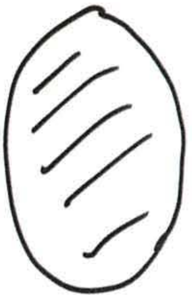
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM
YOUR PAIN/DISTRESS TAKES (Black pen)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM
YOUR PAIN/DISTRESS TAKES (Black pen)

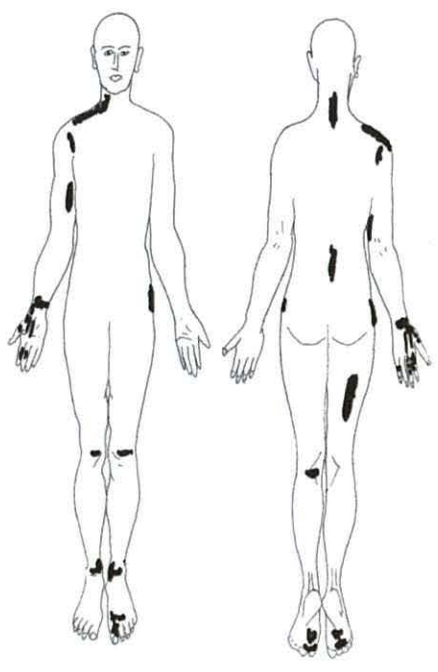


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS
USING THE COLOURS OF YOUR CHOICE

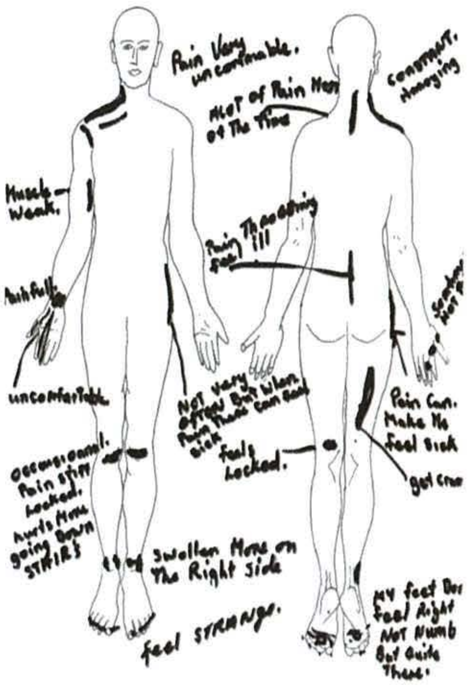


Study 2
Participant
46

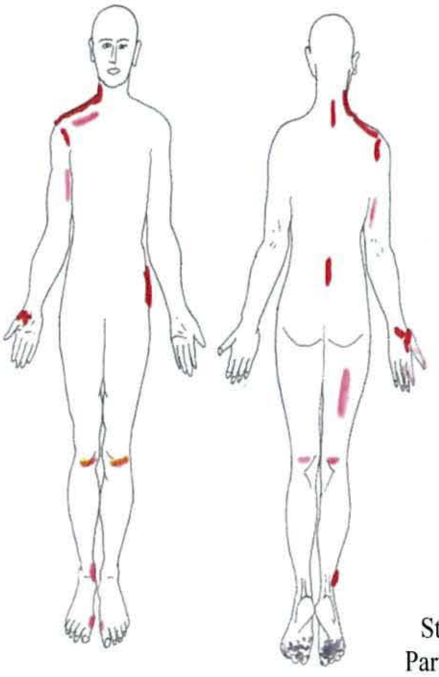
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



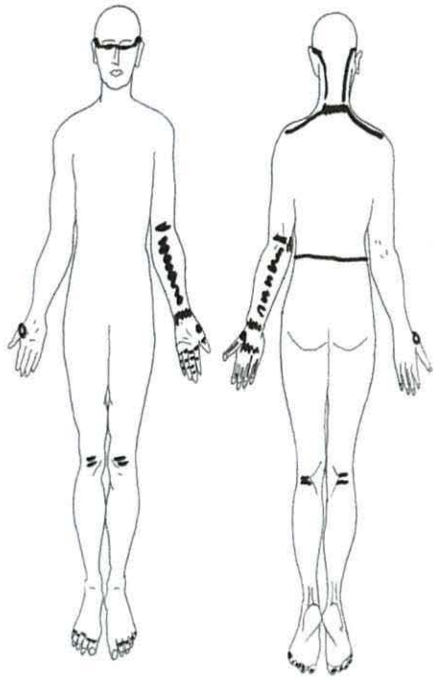
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



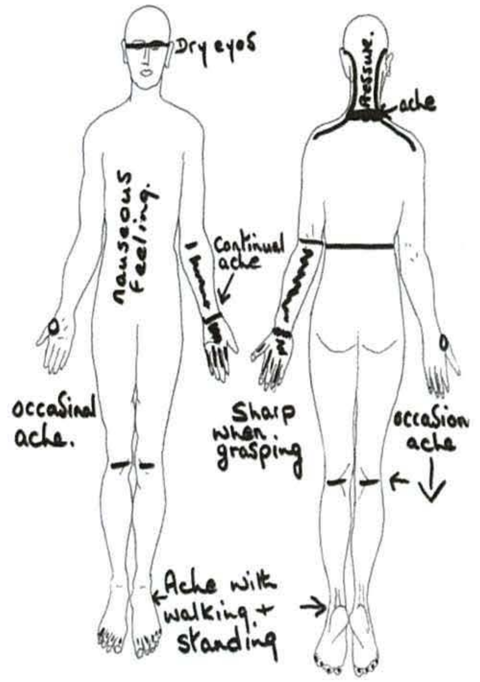
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
47

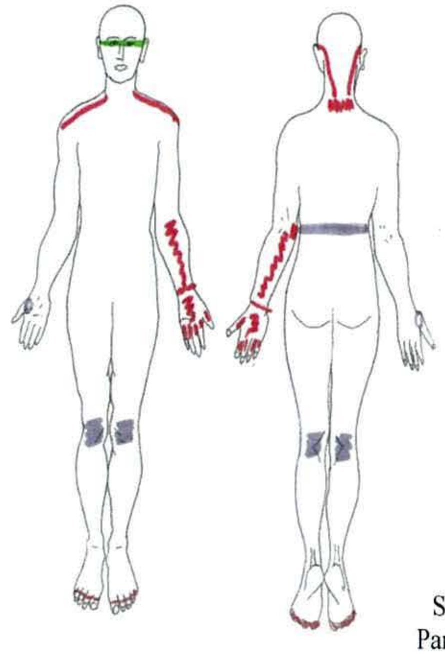
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



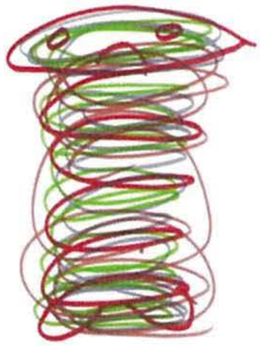
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

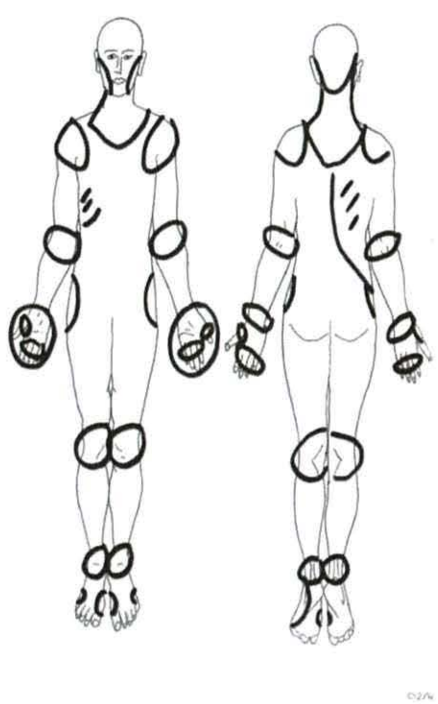


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

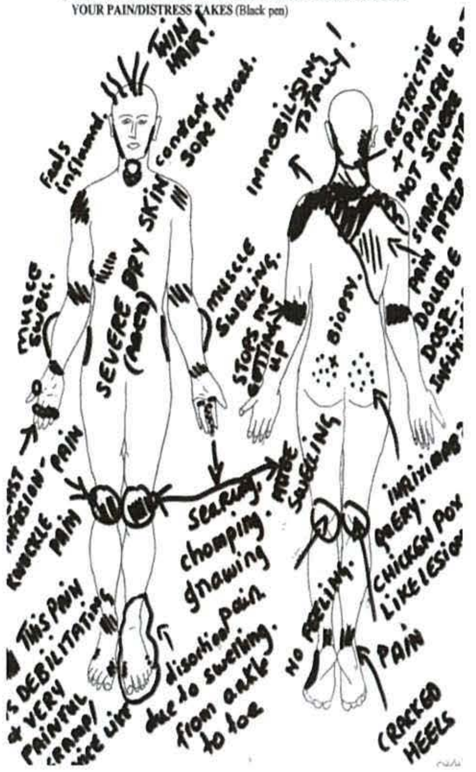


Study 2
Participant
48

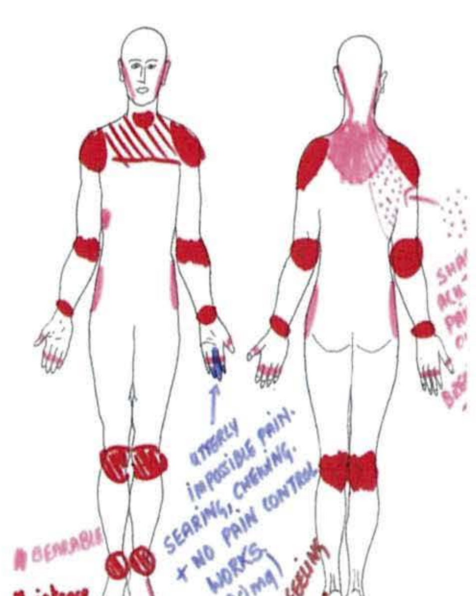
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



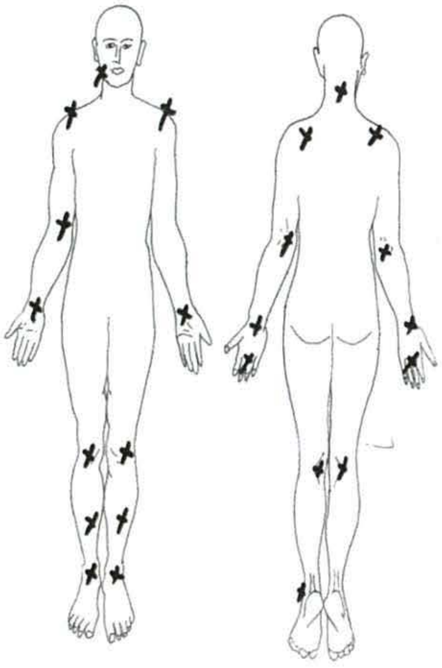
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



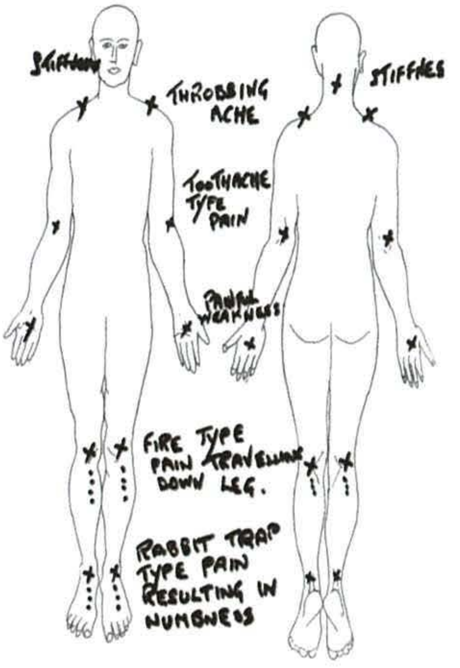
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
49

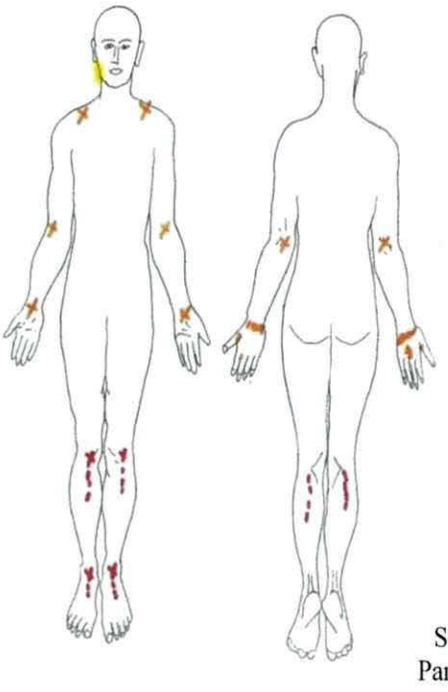
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



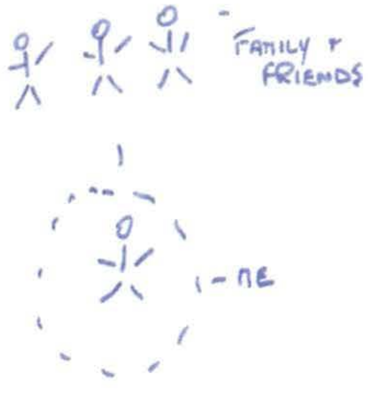
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

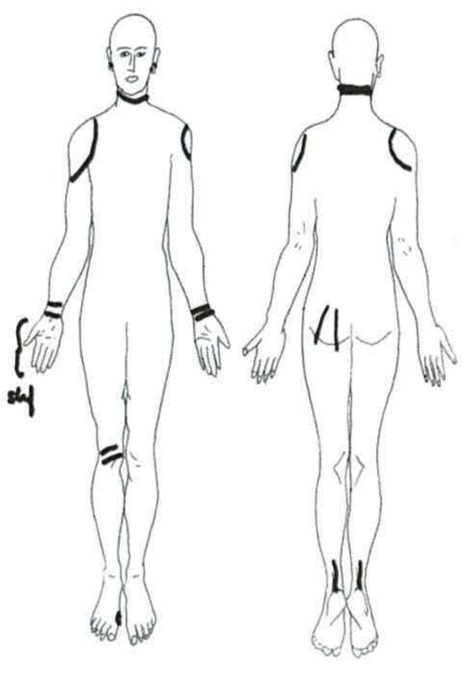


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

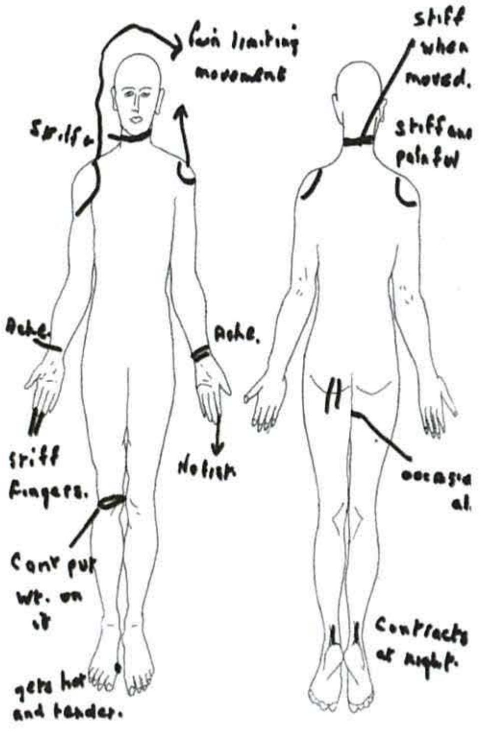


Study 2
Participant
50

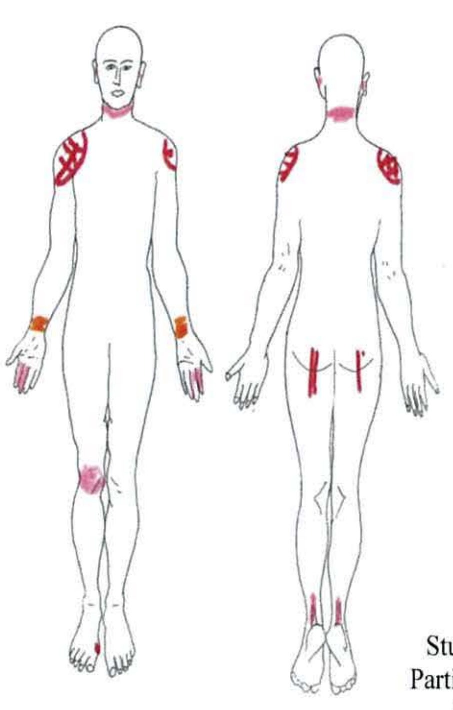
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



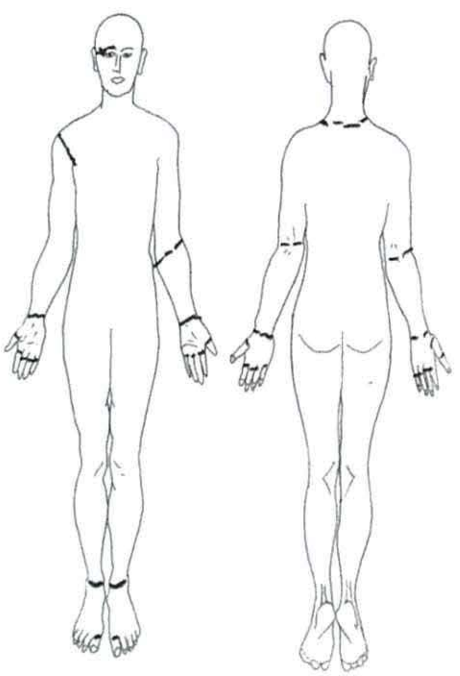
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



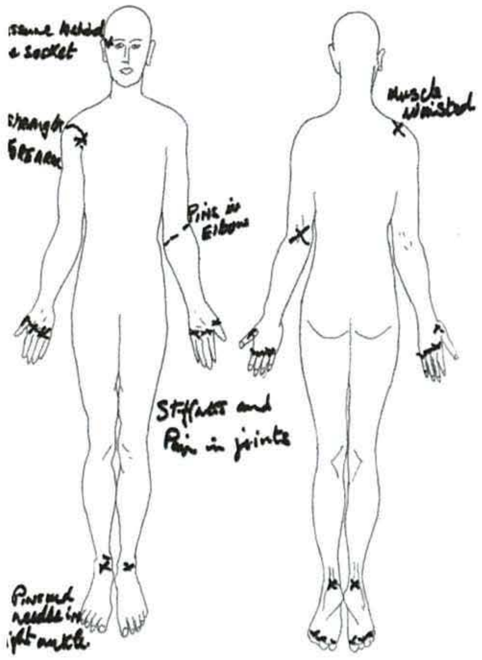
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
51

1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

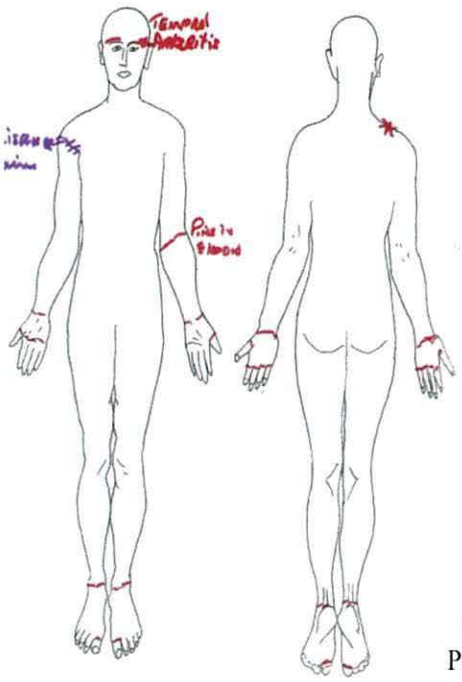


2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/52

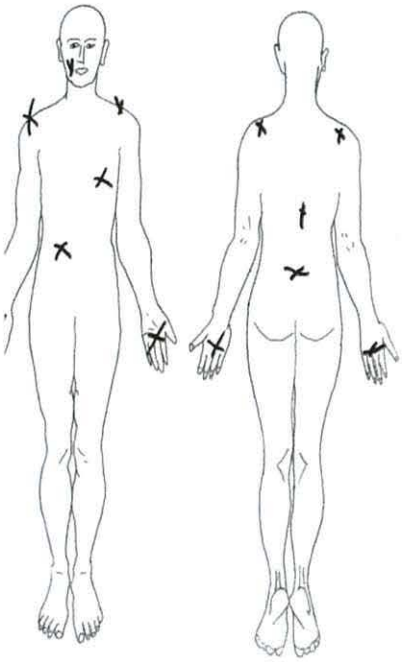
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



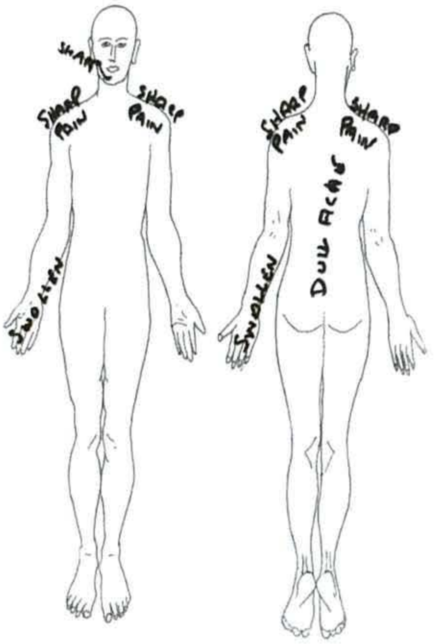
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
52

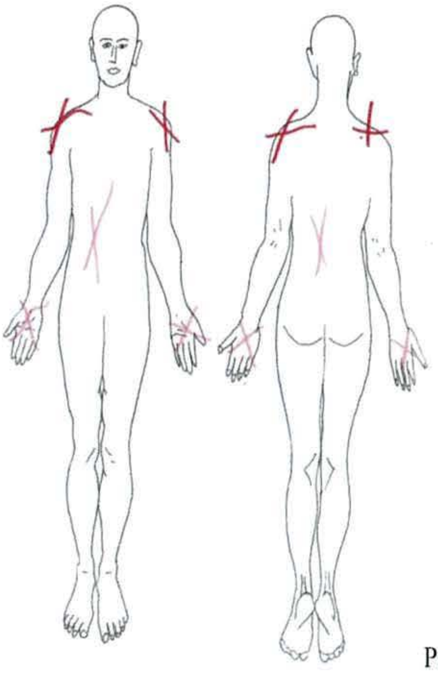
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



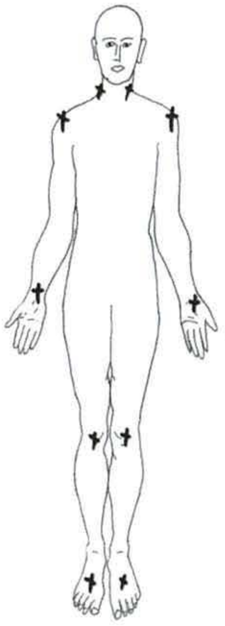
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



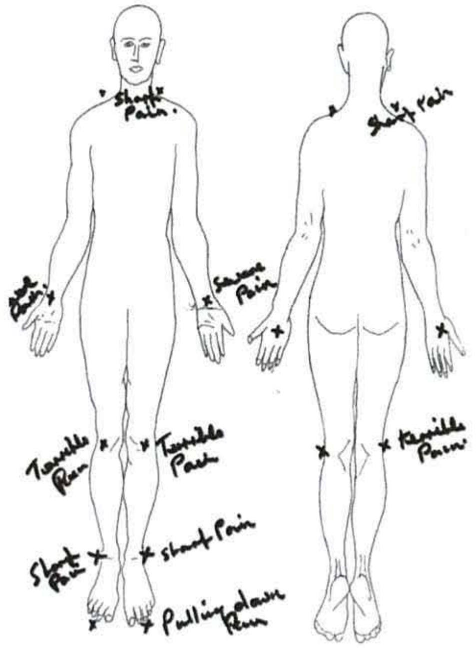
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
53

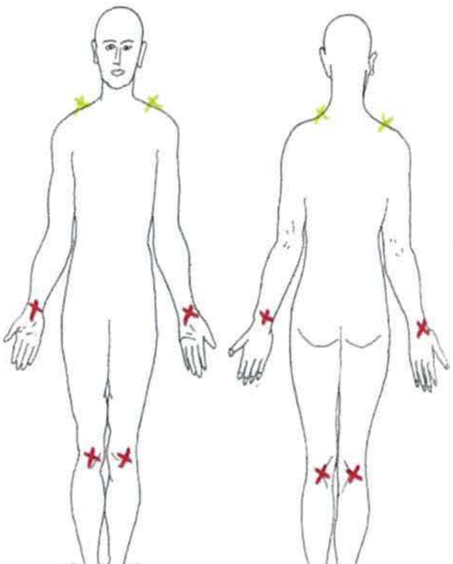
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

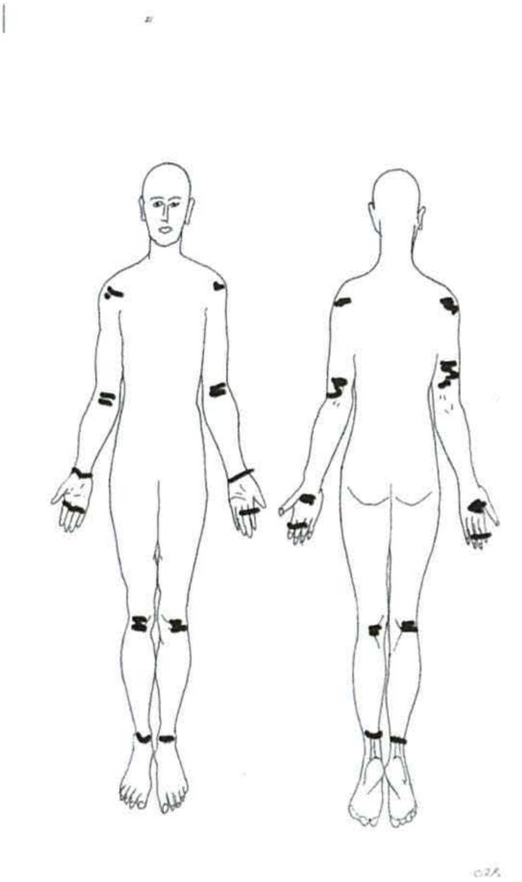


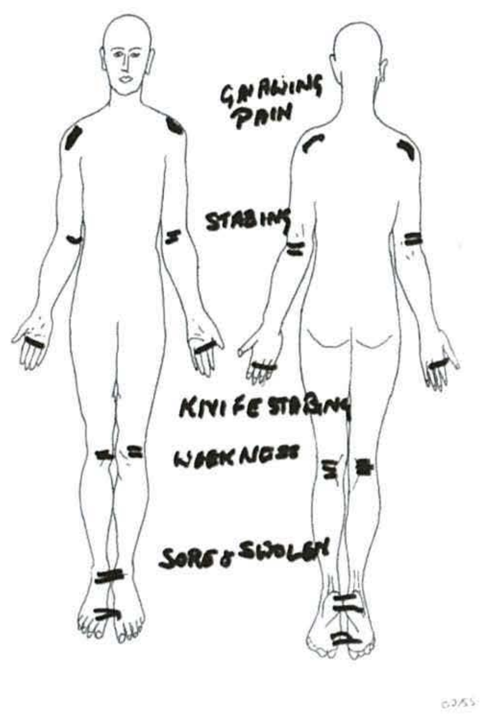
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



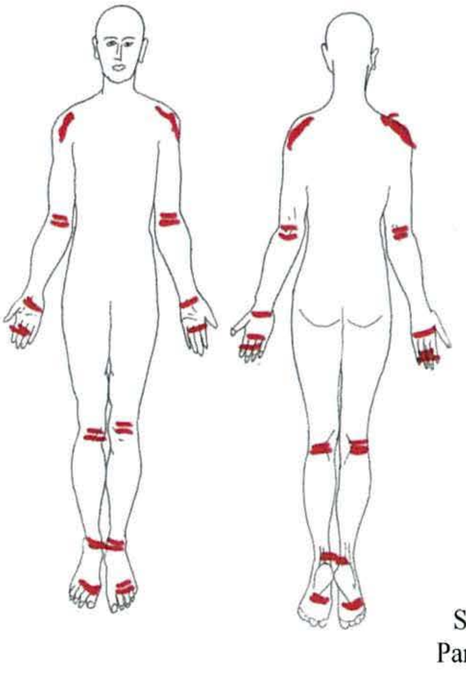
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
54





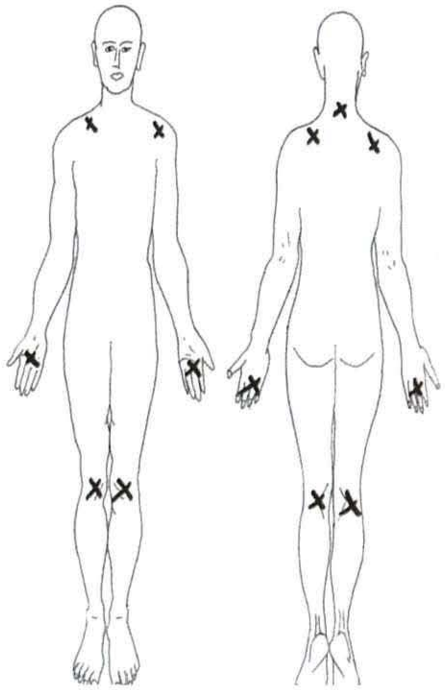
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



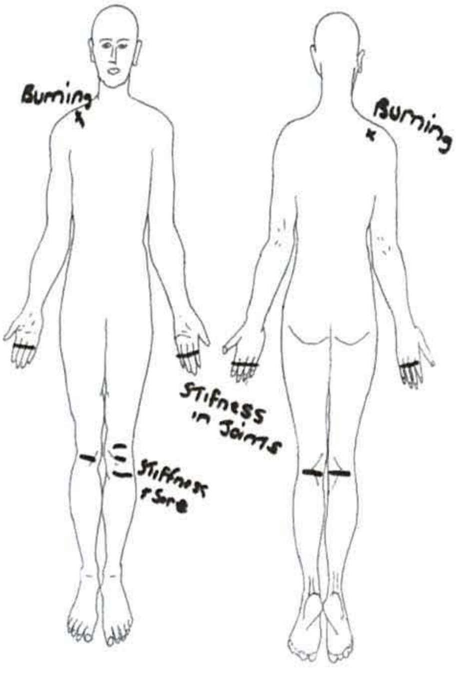
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
55

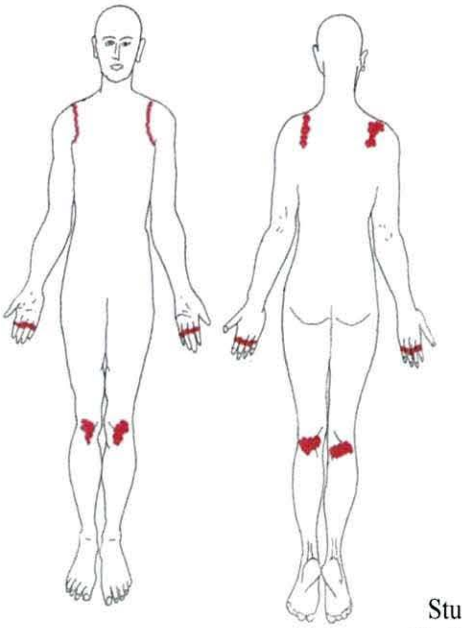
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

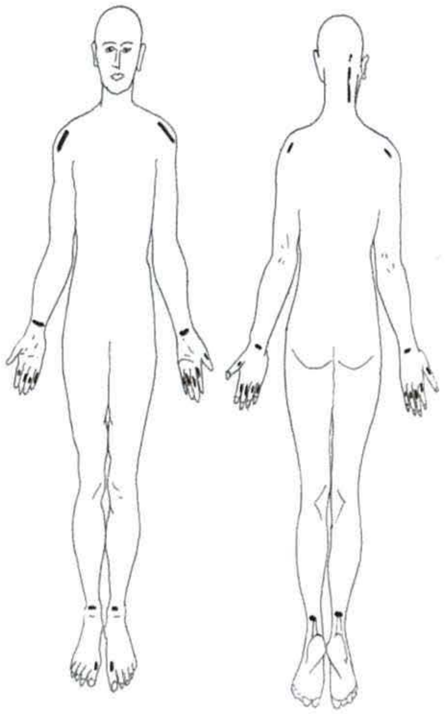


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

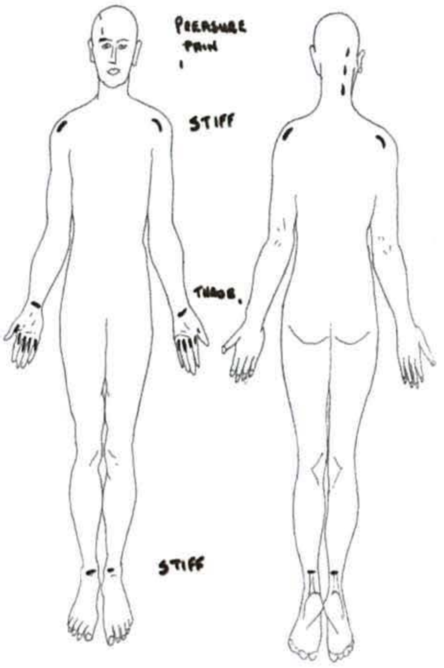
Study 2
Participant
56

02/56

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

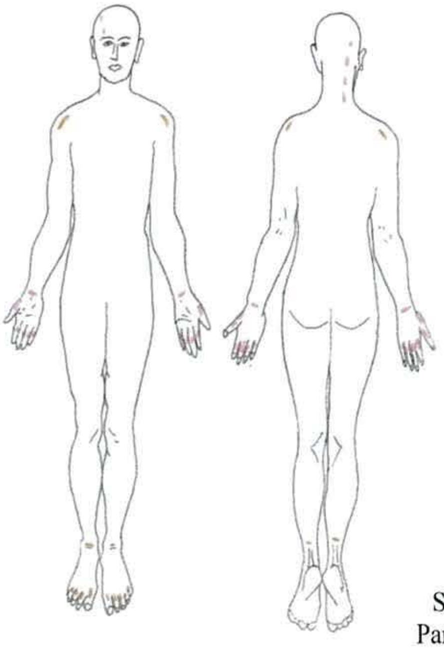


2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



02/57

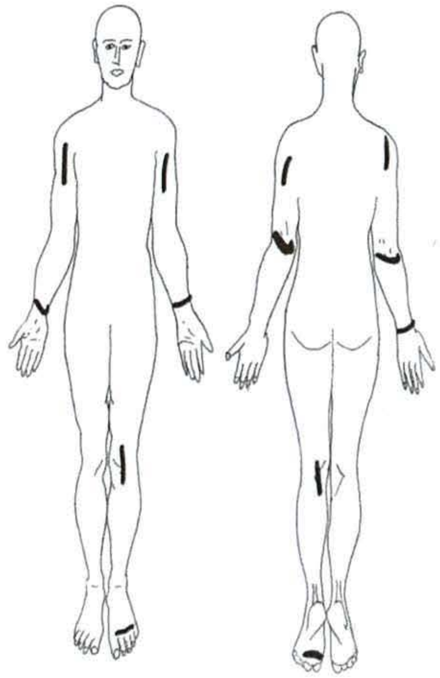
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



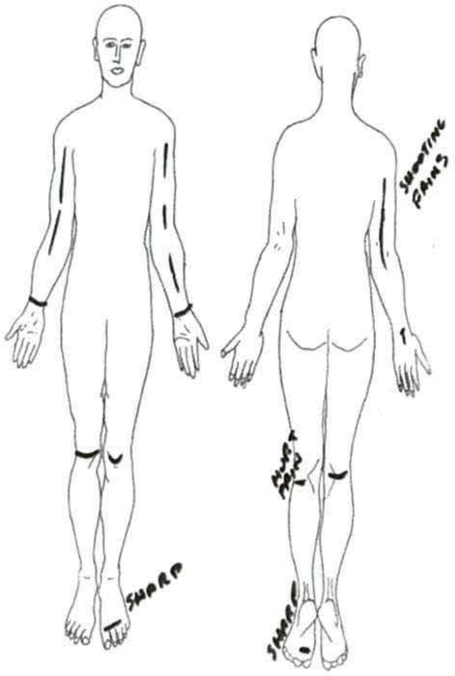
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
57

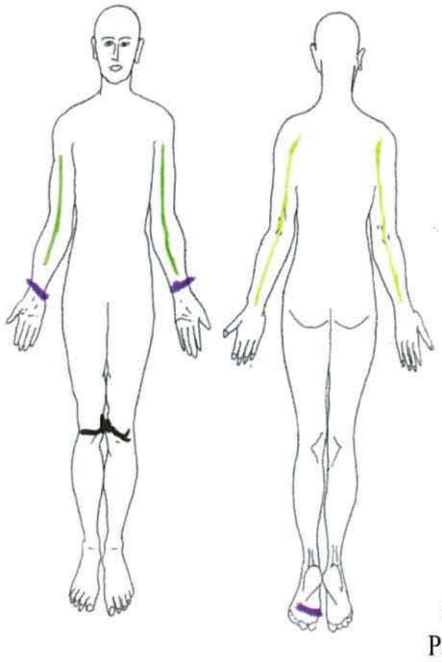
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



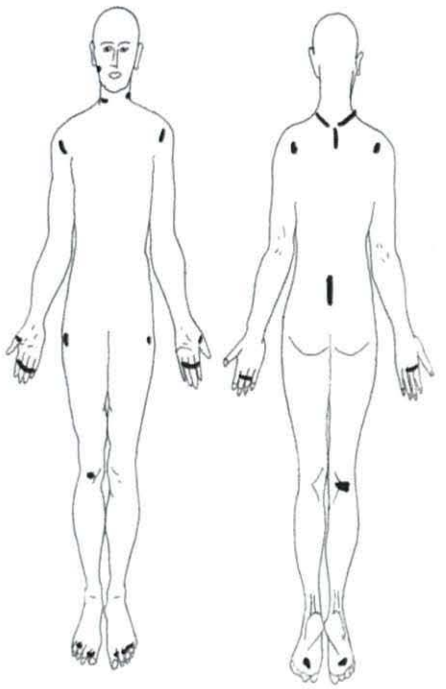
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



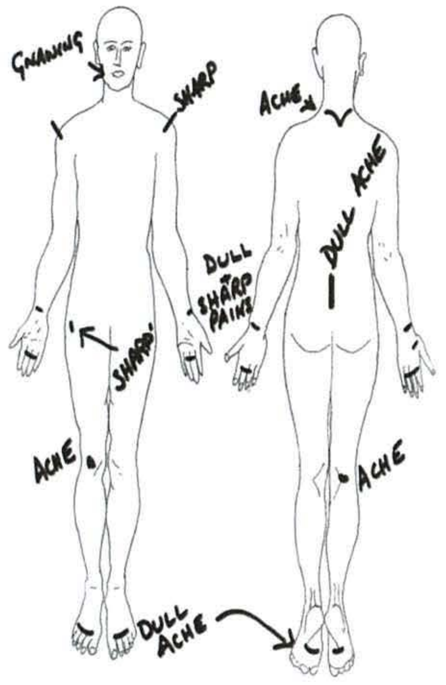
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
58

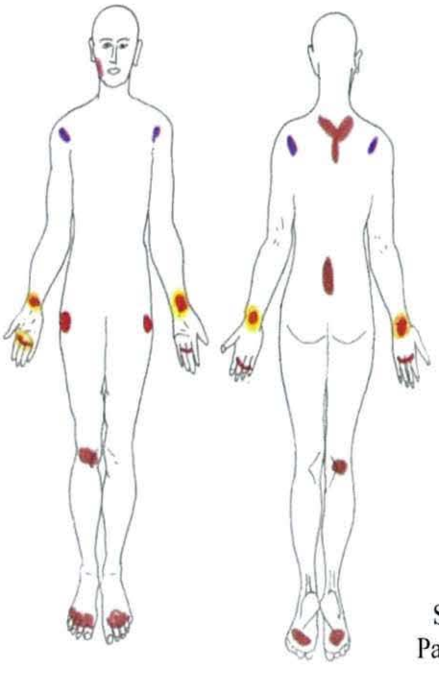
02/58



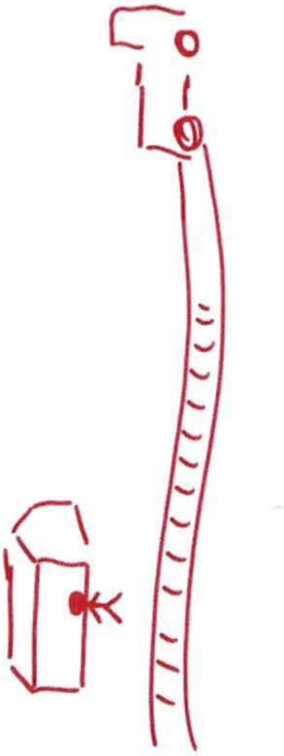
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



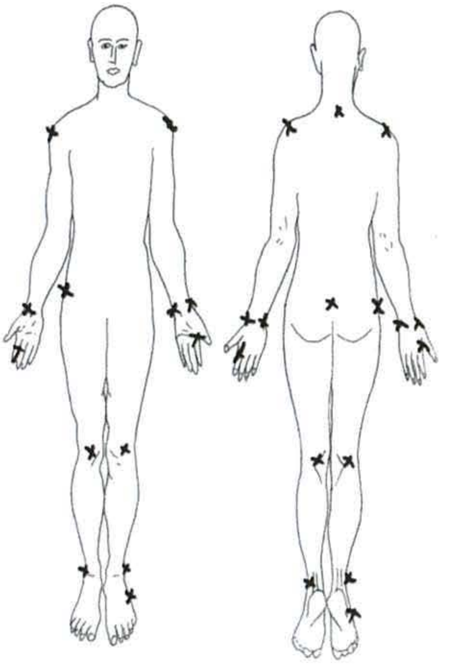
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



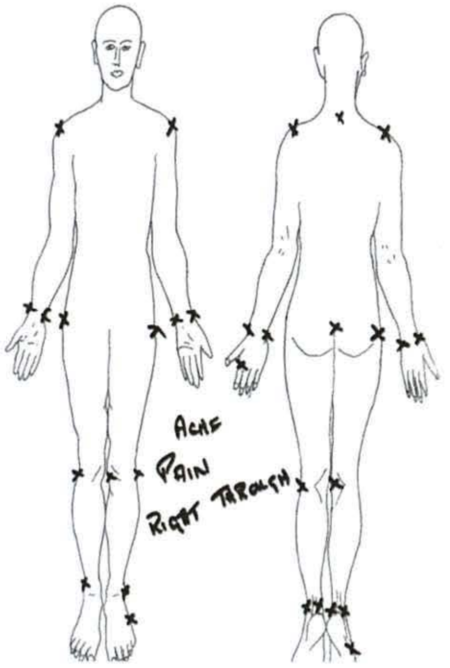
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
59

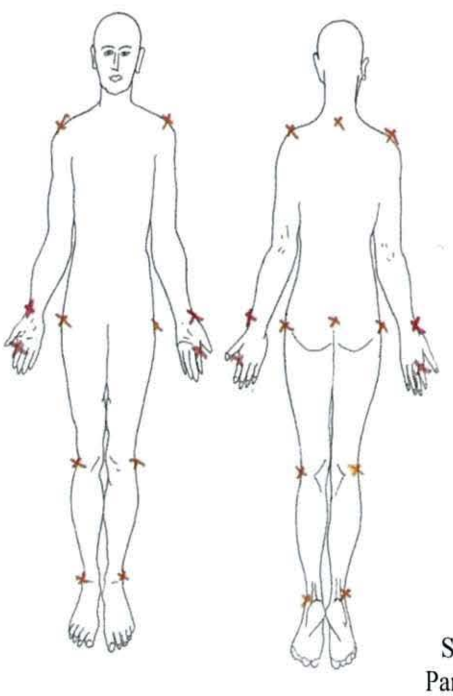
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



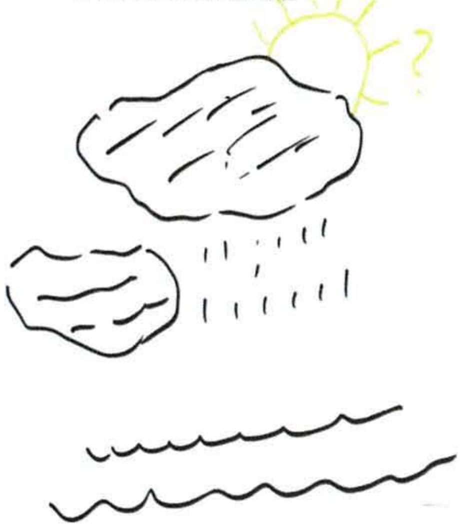
2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

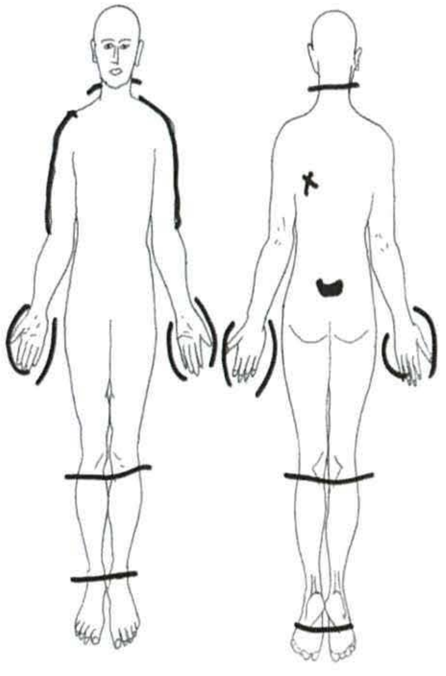


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

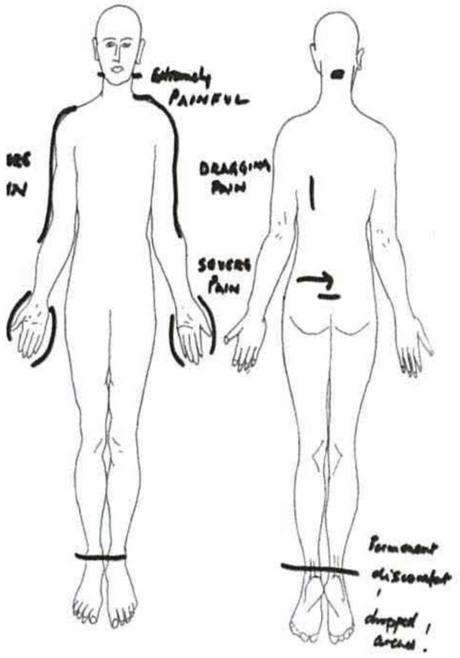


Study 2
Participant
60

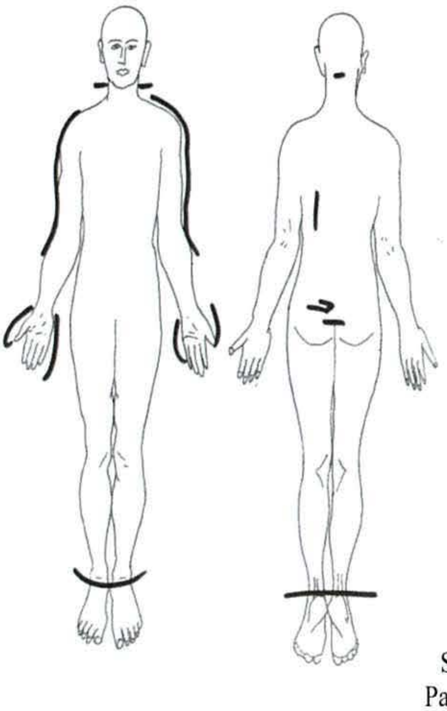
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

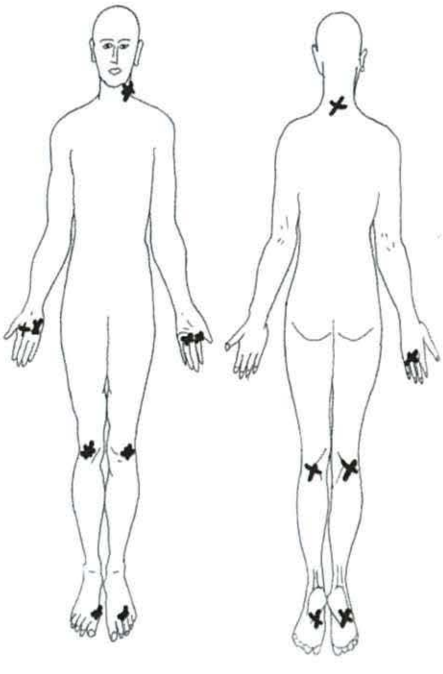


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

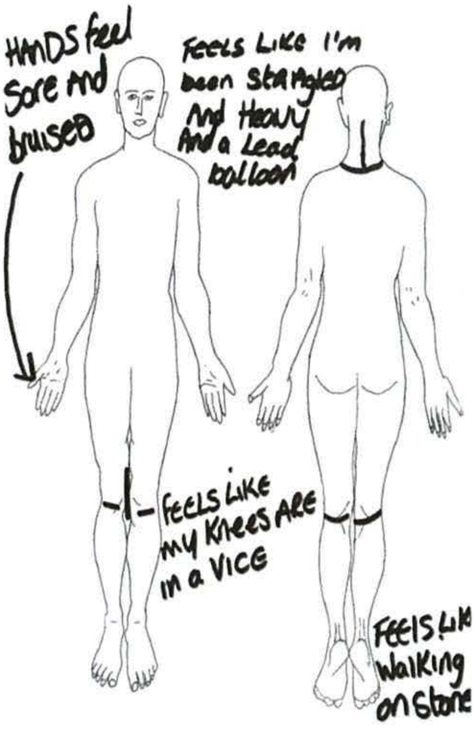
Study 2
Participant
61

02/61

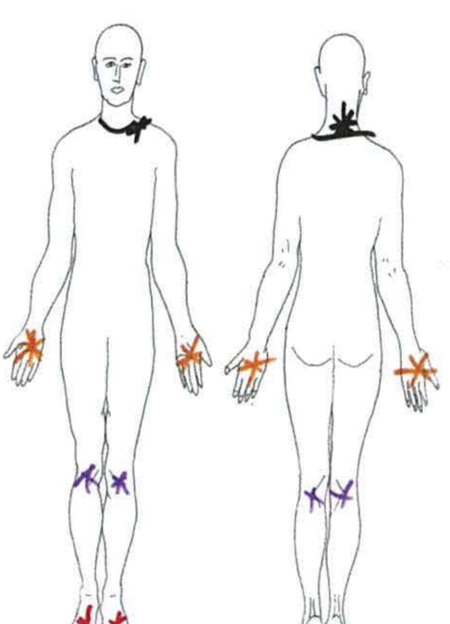
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



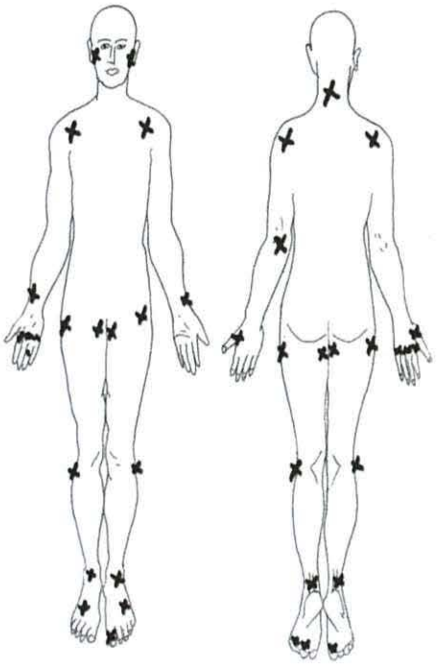
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



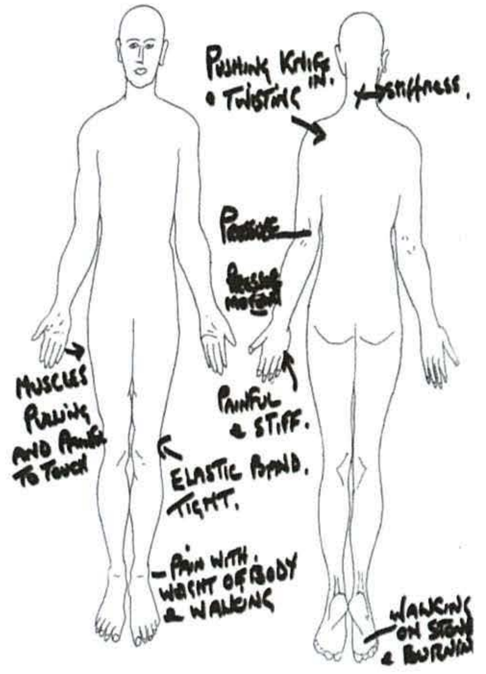
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
62

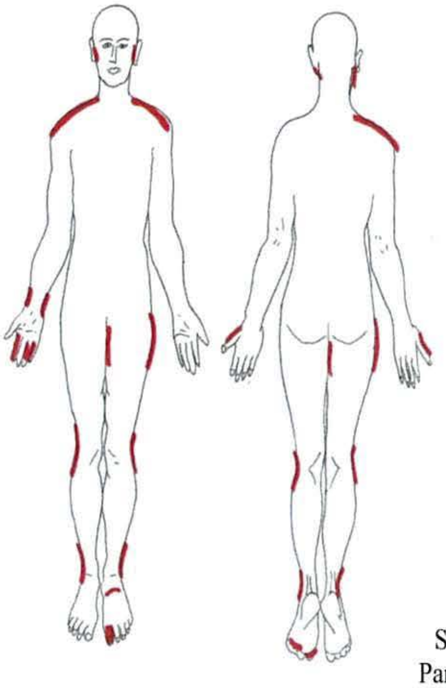
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



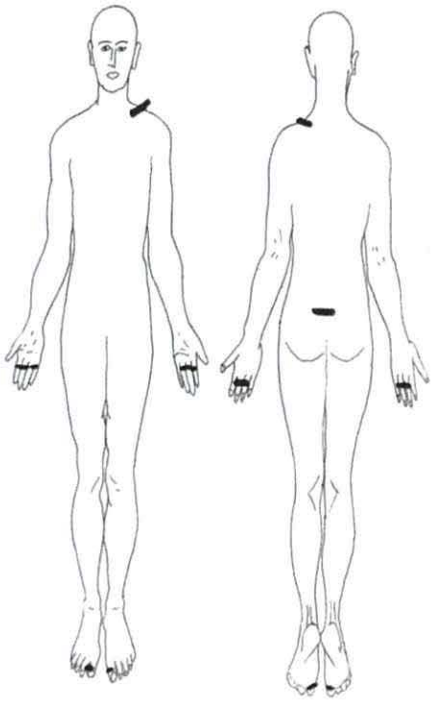
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



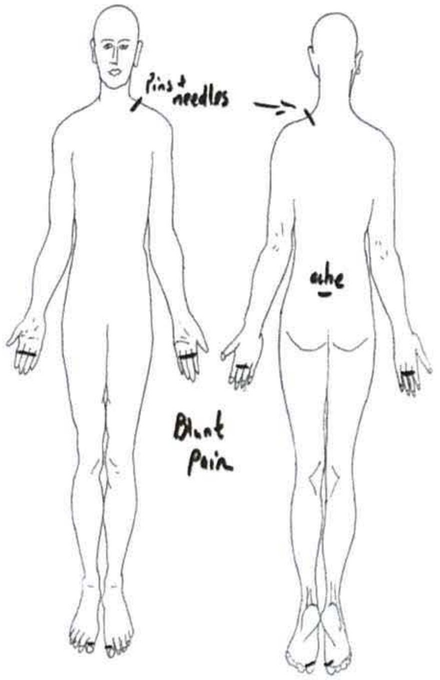
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
63

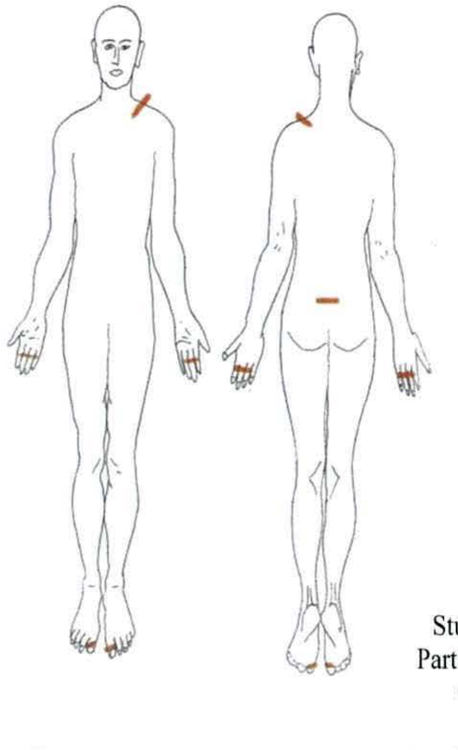
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



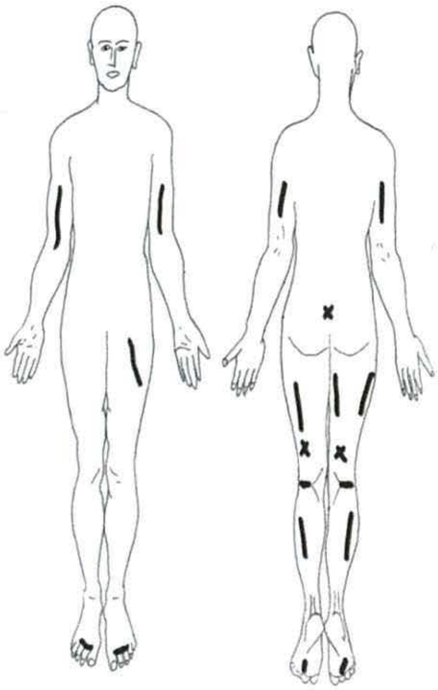
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



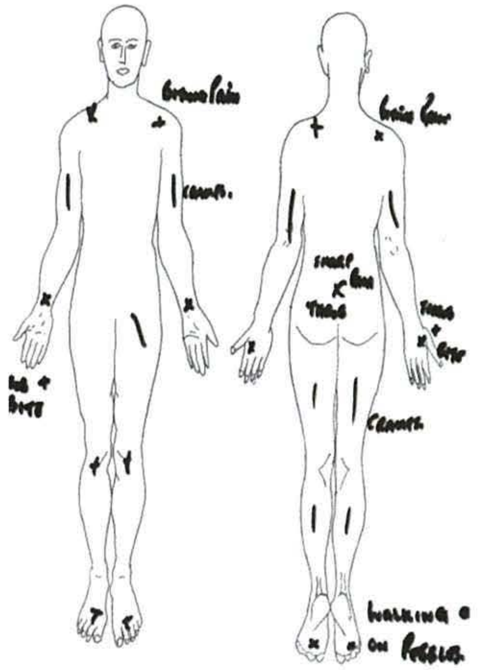
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
64

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

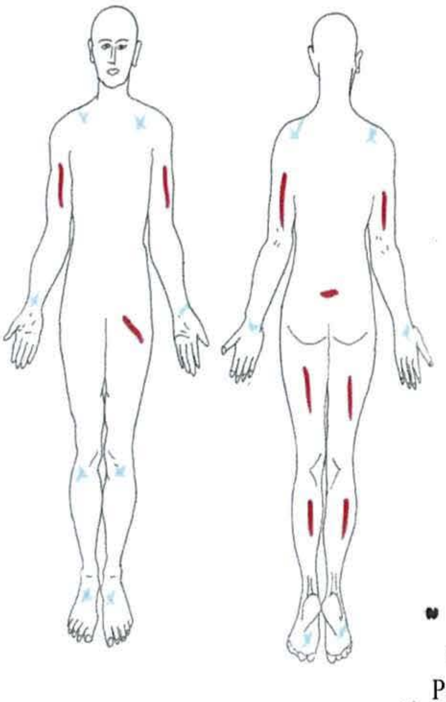


2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

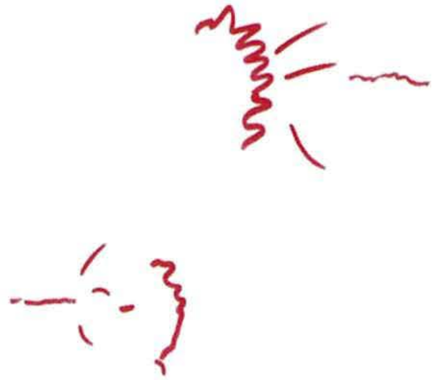


02/65

3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



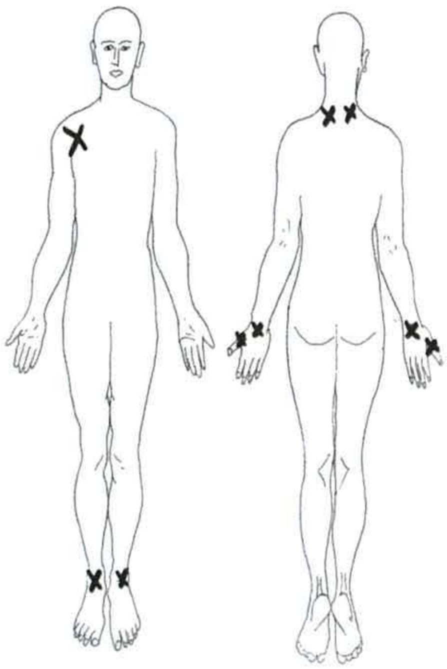
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE



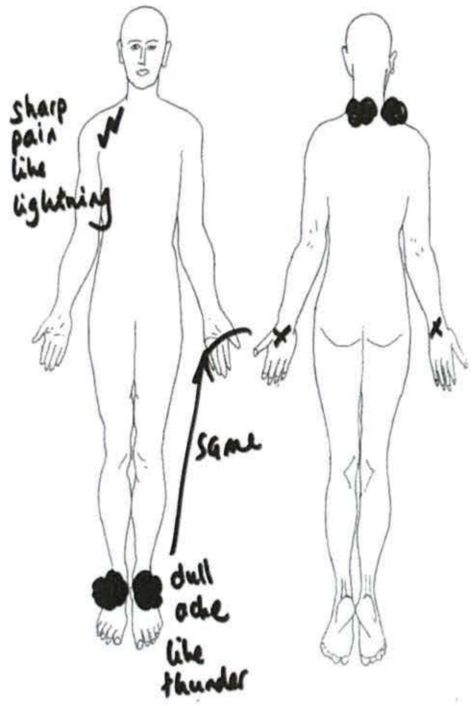
Study 2
Participant
65

02/65

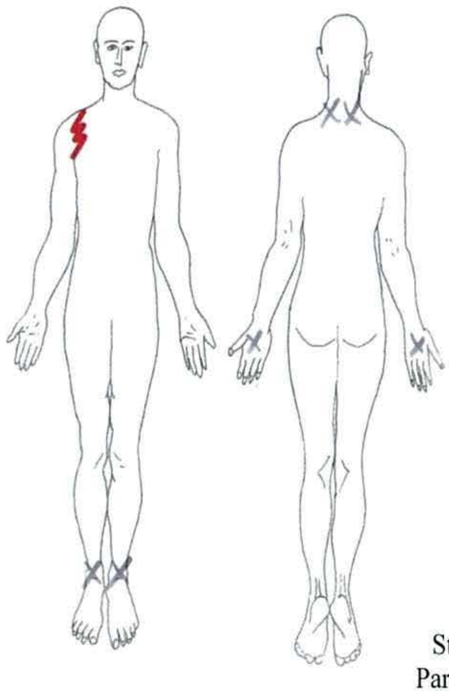
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



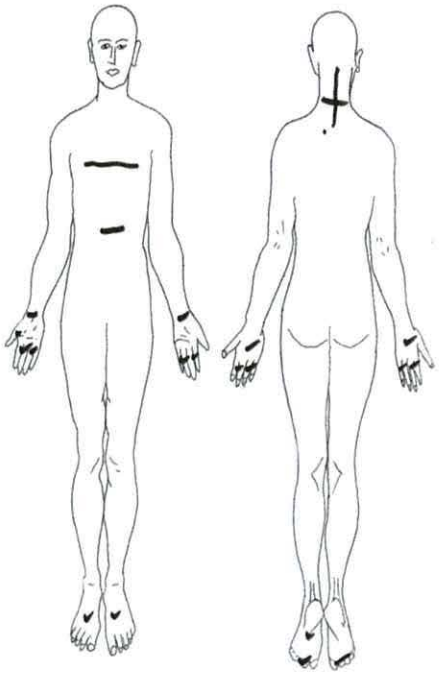
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



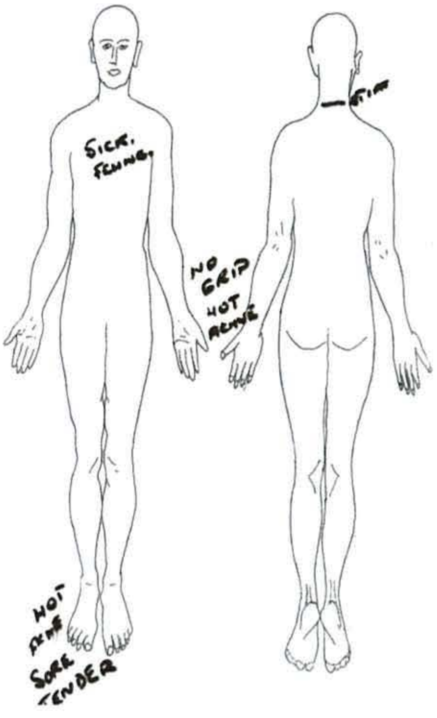
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
66

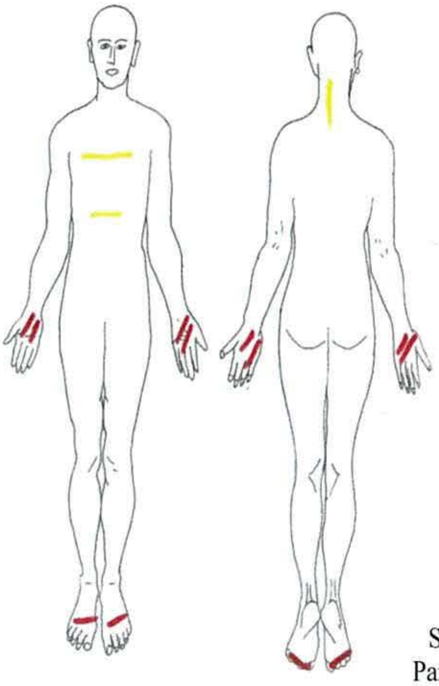
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



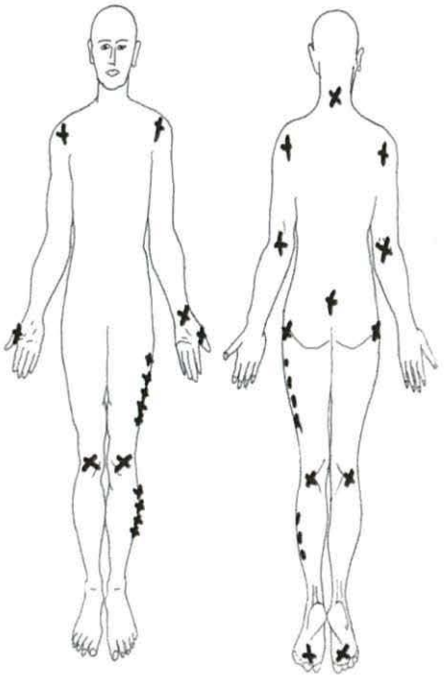
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



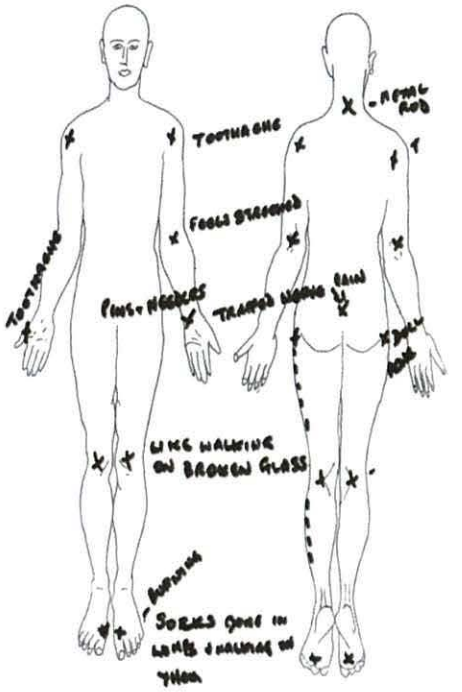
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
67

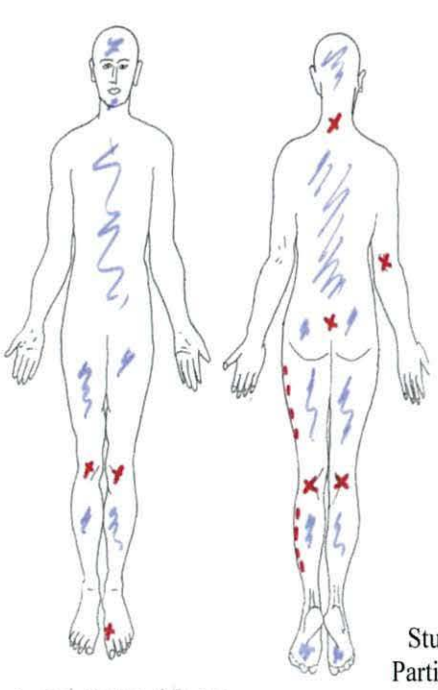
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



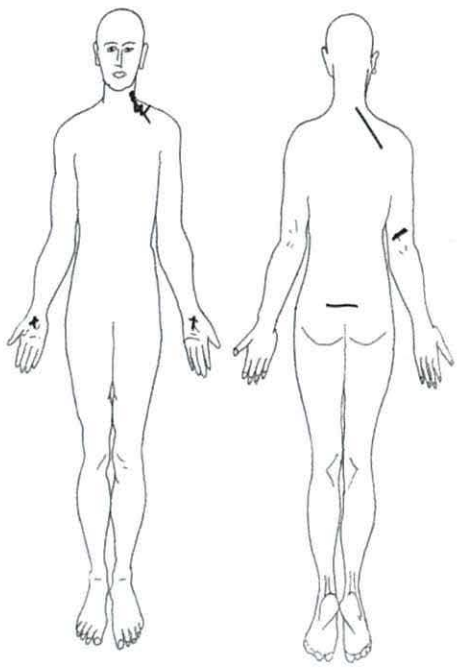
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



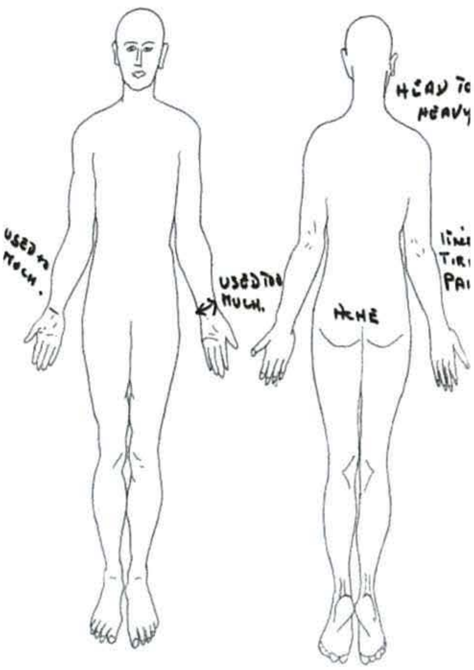
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
68

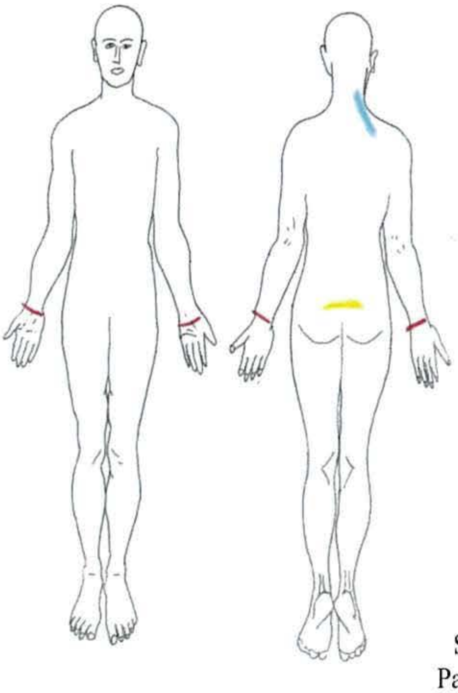
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



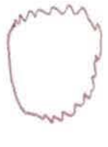
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

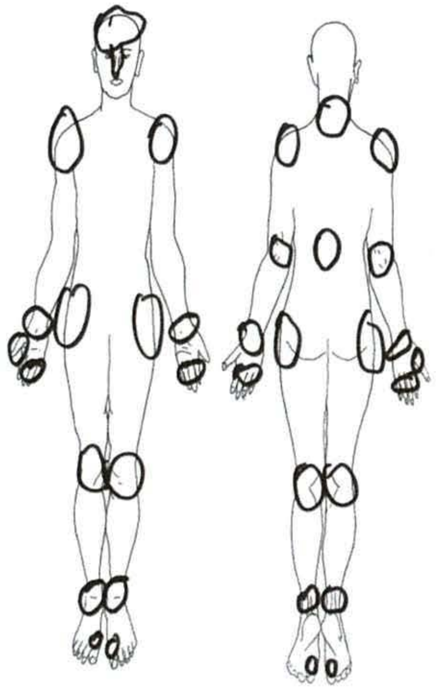


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

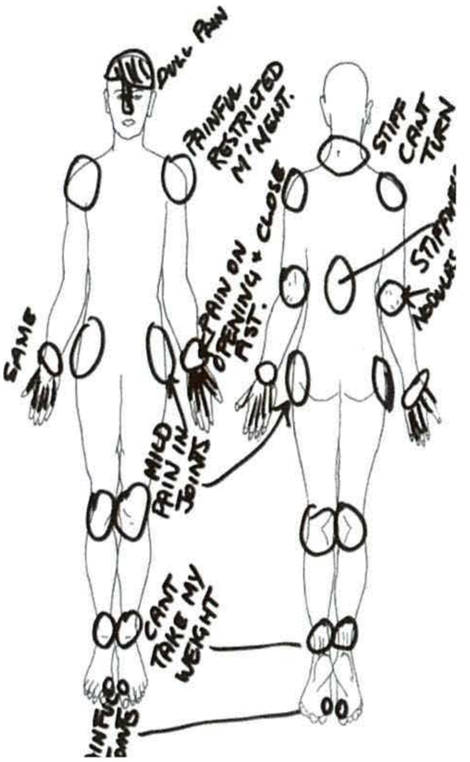


Study 2
Participant
69

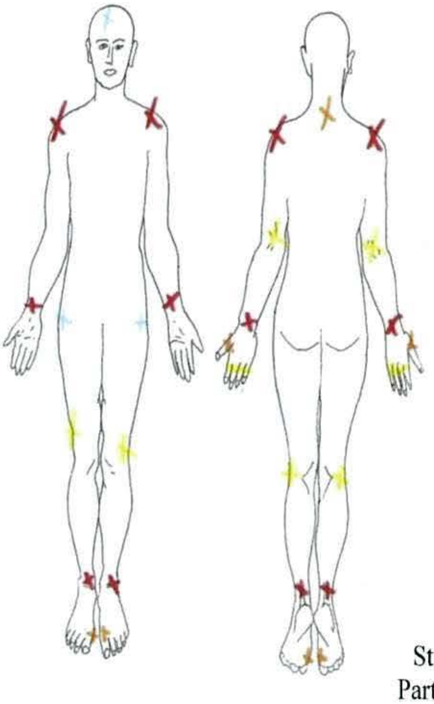
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



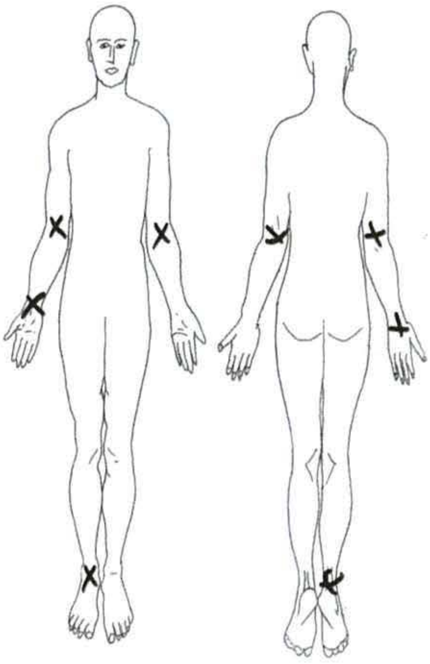
3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



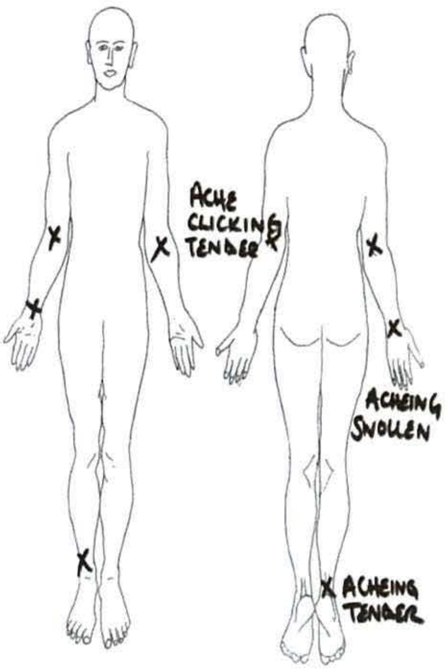
4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
70

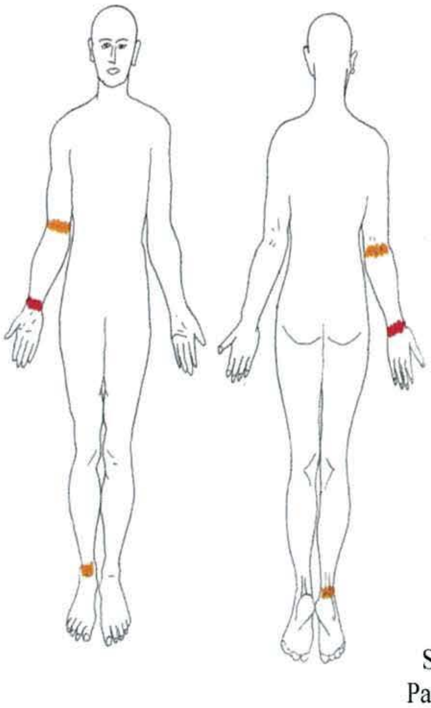
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

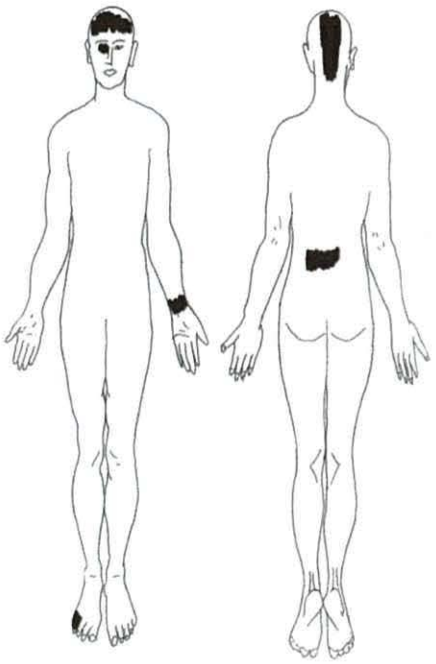


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

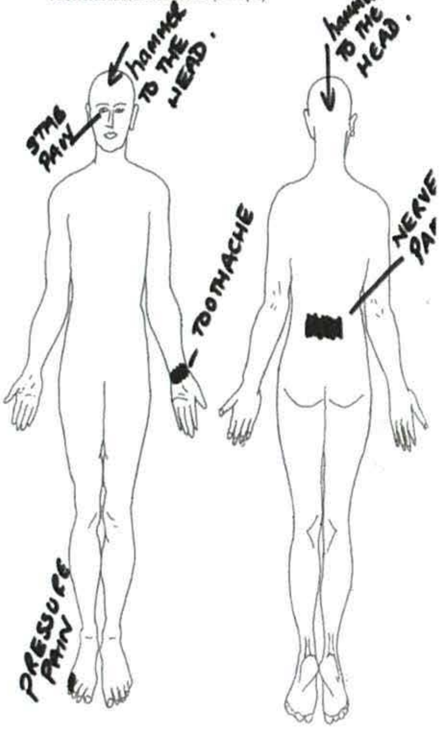
Study 2
Participant
71

02/71

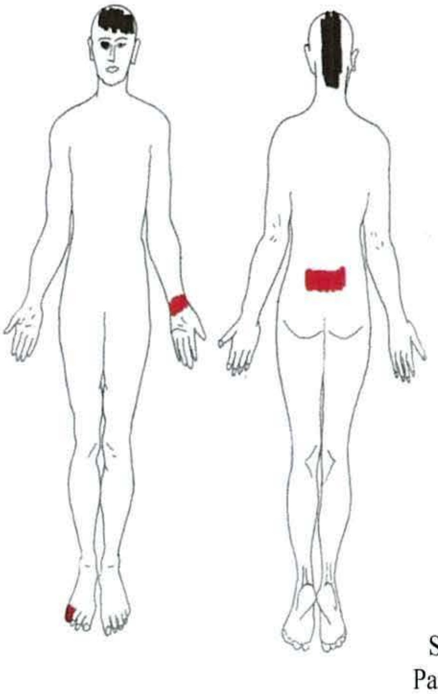
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



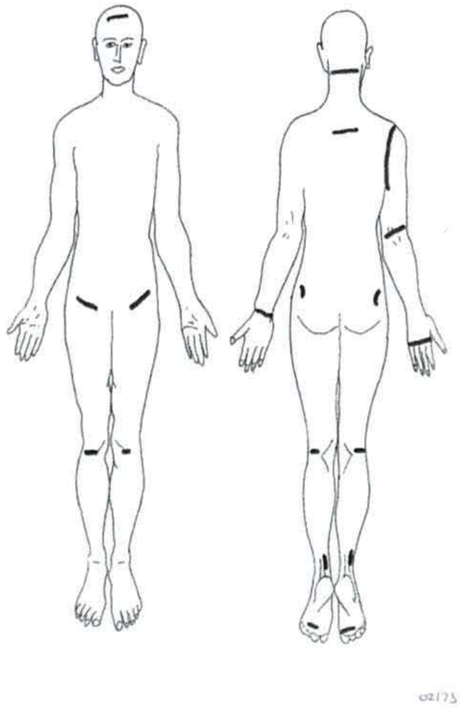
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

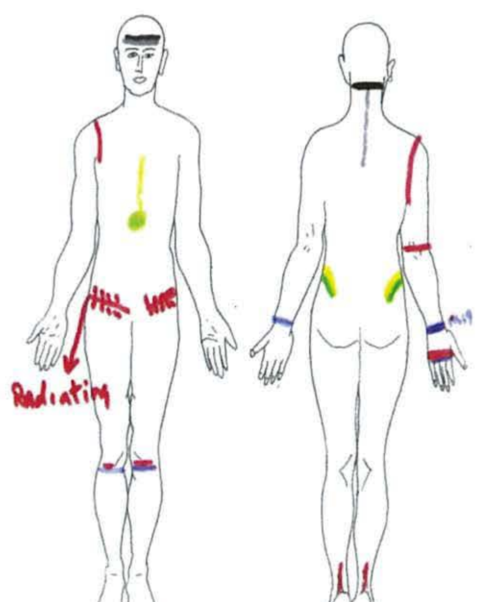
Study 2
Participant
72

1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)

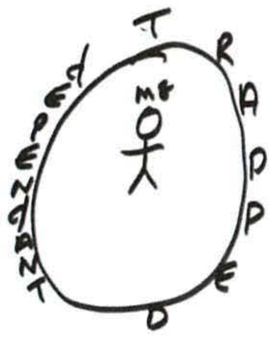


2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)

3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

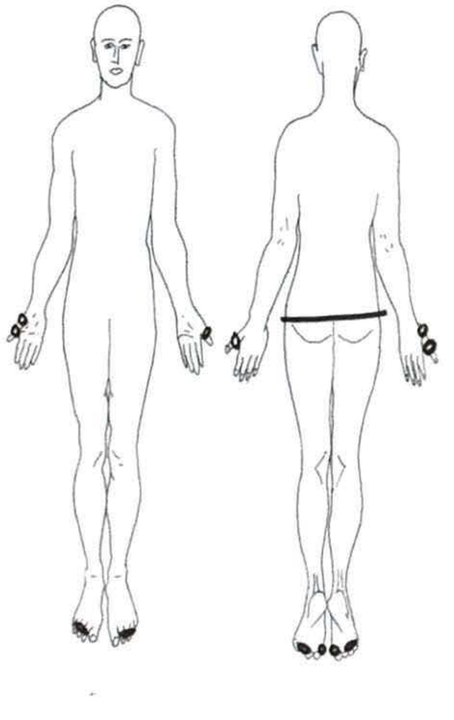


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

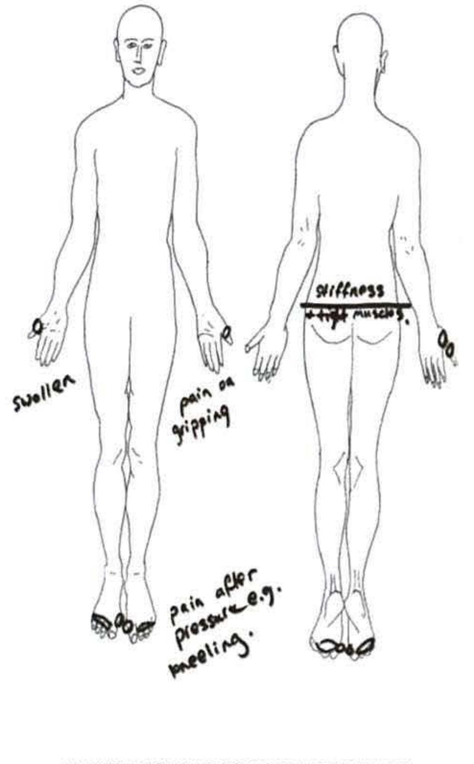


Study 2
Participant
73

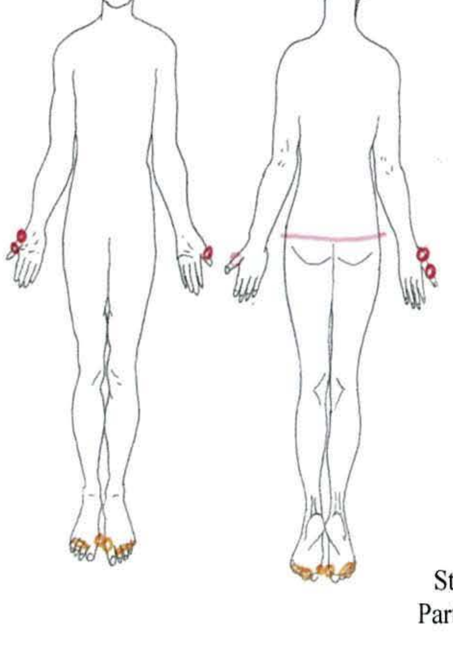
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

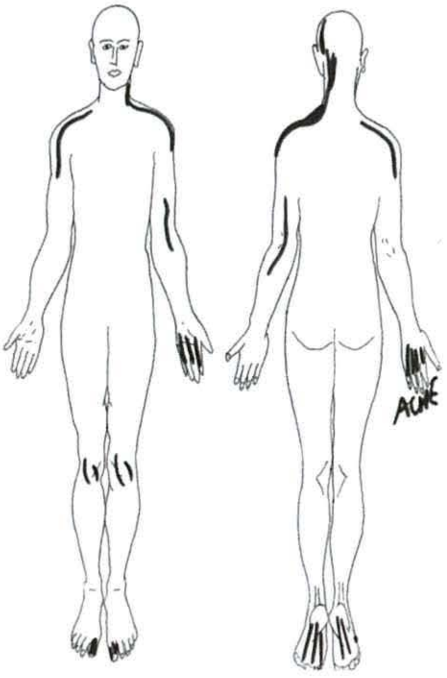


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

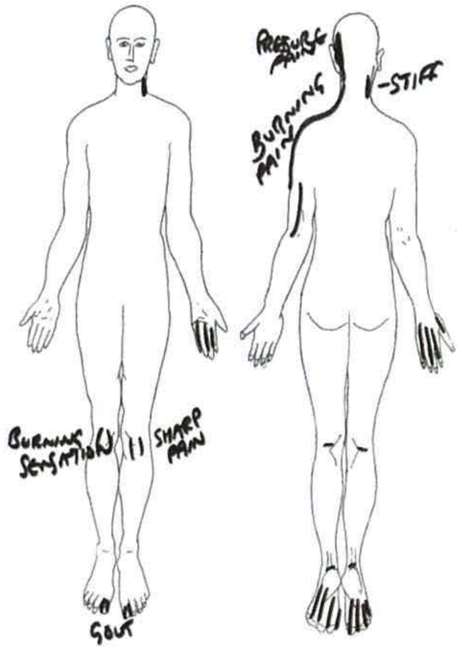
Study 2
Participant
74

0274

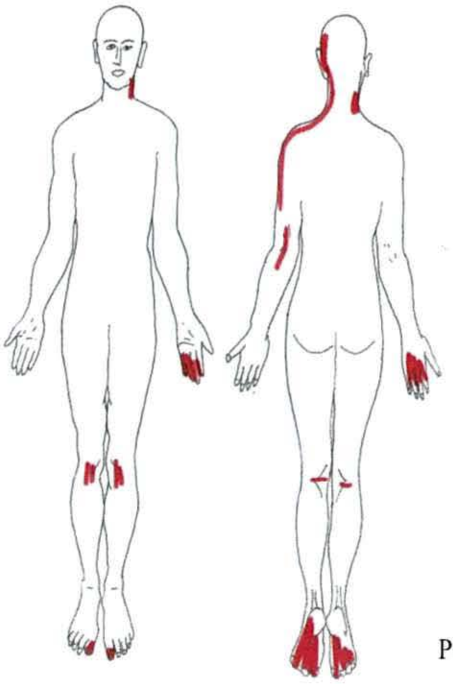
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

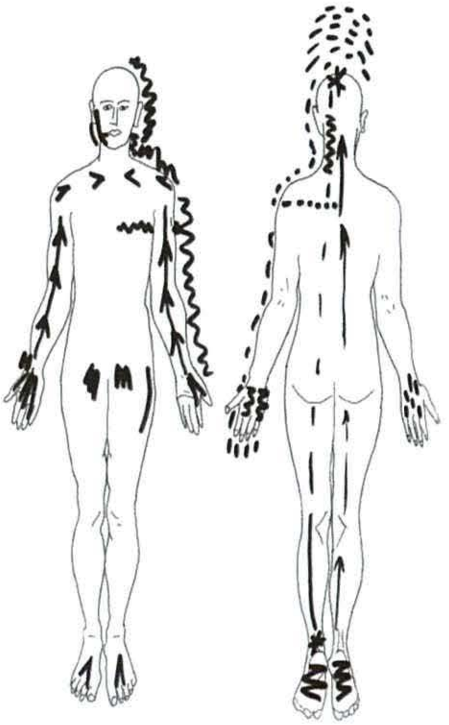


4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

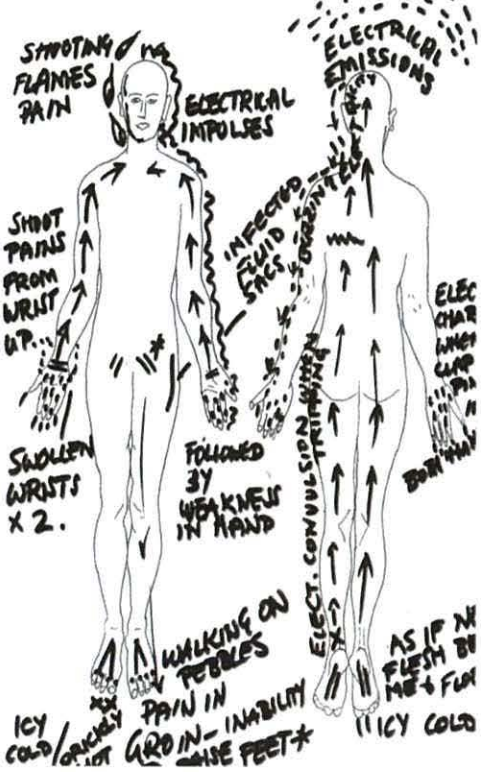
Study 2
Participant
75

02/75

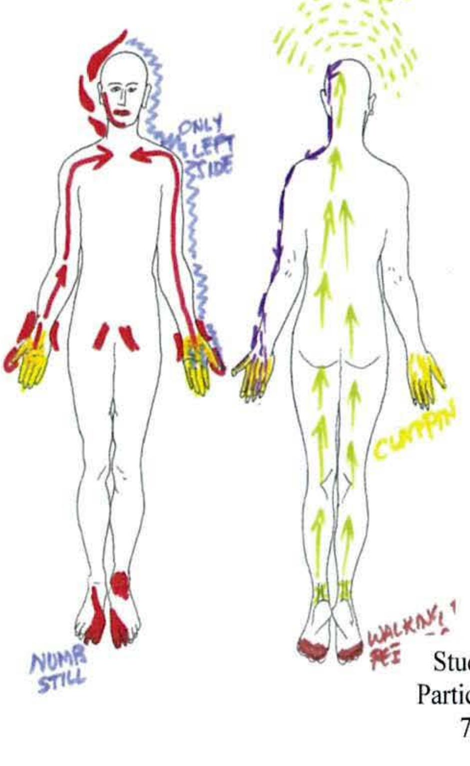
02/75



YOUR PAIN/DISTRESS TAKES (Black pen)



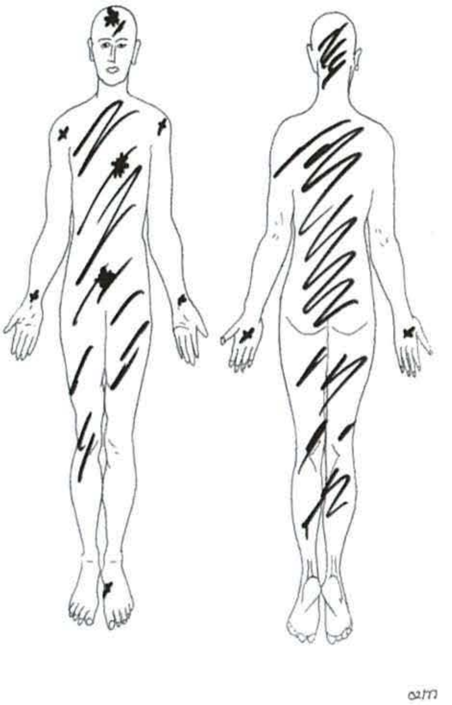
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



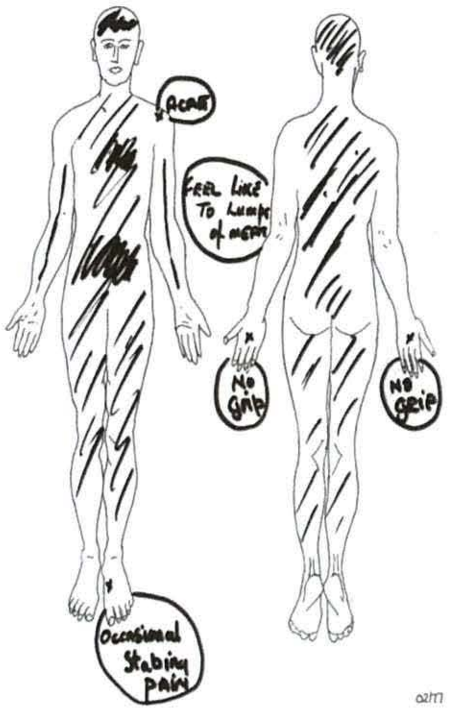
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
76

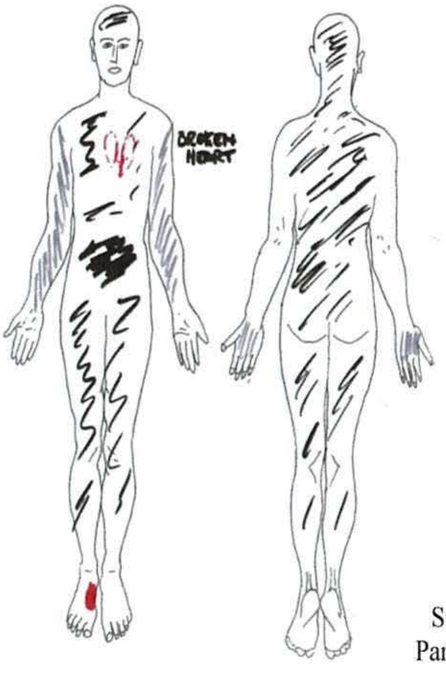
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



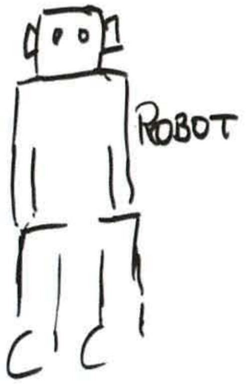
2. DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3. DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE

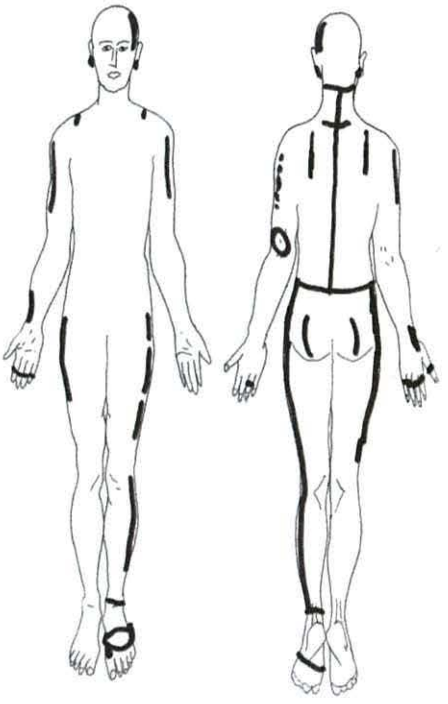


4. DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

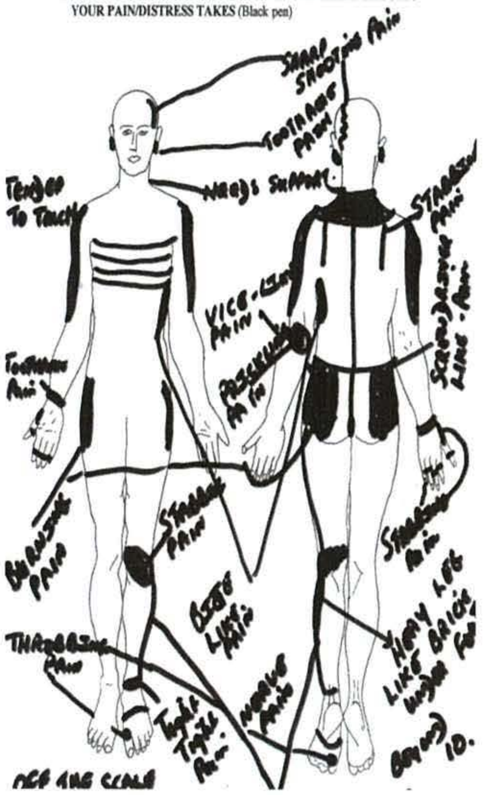


Study 2
Participant
77

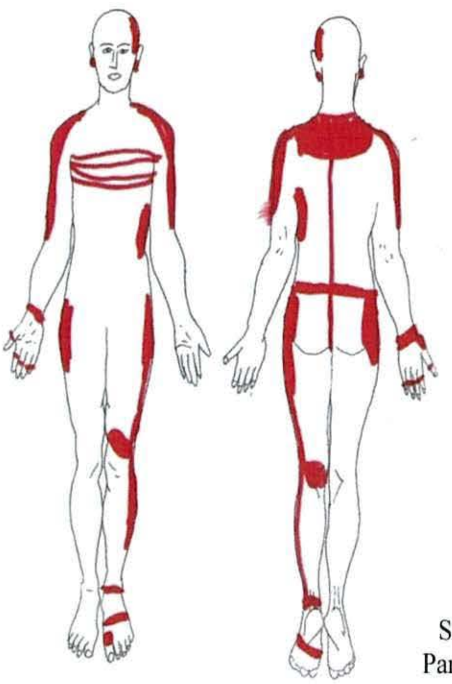
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



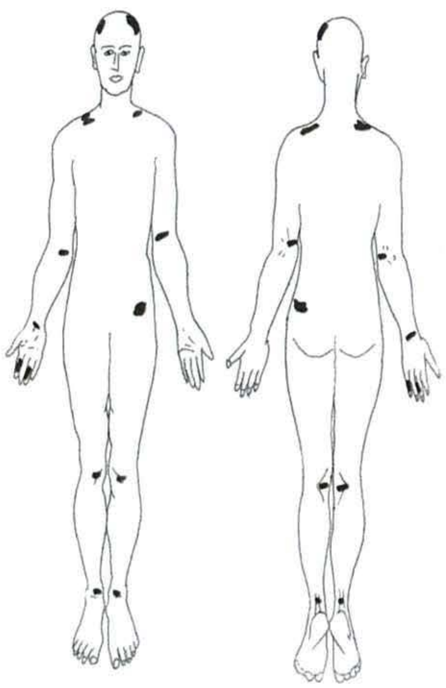
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



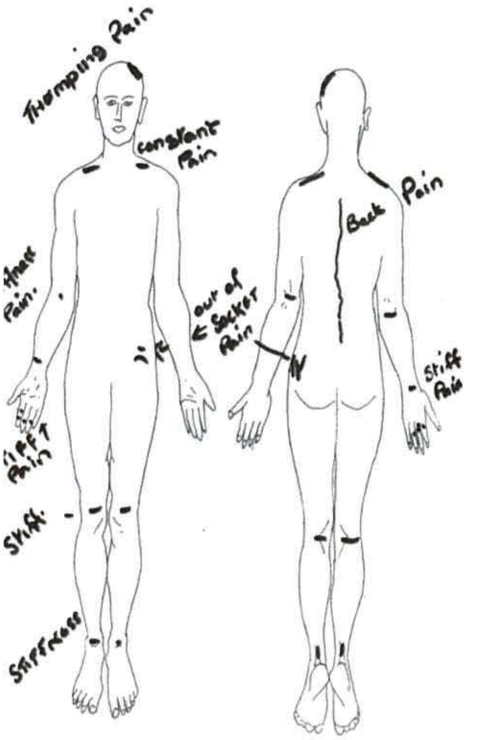
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
78

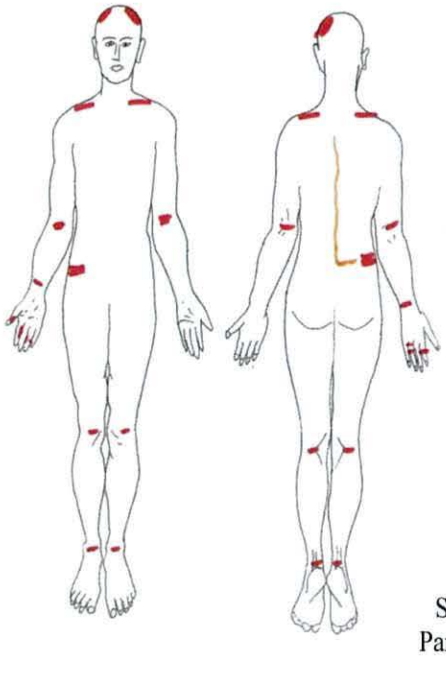
1 DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



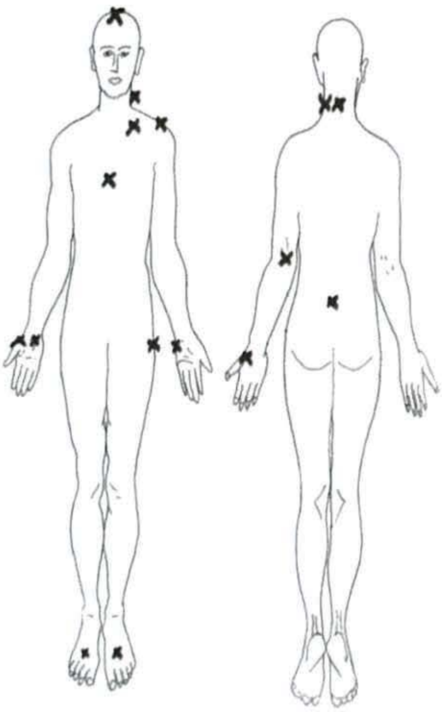
3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



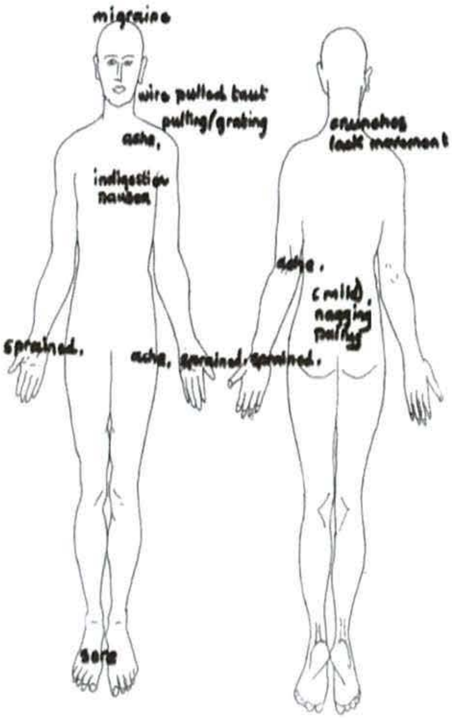
4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE

Study 2
Participant
79

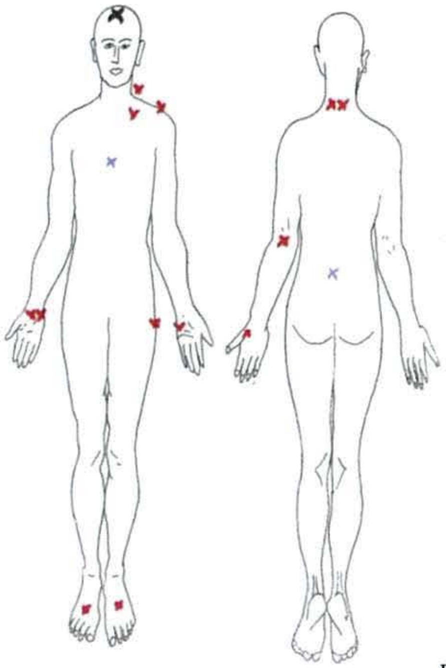
1. DRAW YOUR PAIN ON THIS DIAGRAM (Black pen provided)



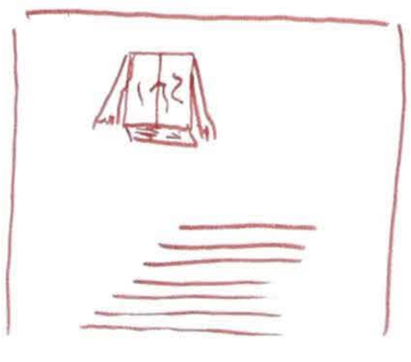
2 DRAW ON THIS DIAGRAM WHATEVER THE SHAPE OR FORM YOUR PAIN/DISTRESS TAKES (Black pen)



3 DRAW YOUR PAIN/DISTRESS IN THE COLOURS OF YOUR CHOICE



4 DRAW THE IMAGE / SHAPE / FORM OF YOUR PAIN / DISTRESS USING THE COLOURS OF YOUR CHOICE



Study 2
Participant
80

Participants	Groups			
	A	B	C	D
1	X			
2			X	
3			X	
4			X	
5			X	
6			X	
7				X
8				X
9	X			
10	X			
11				X
12		X		
13	X			
14	X			
15			X	
16				X
17	X			
18	X			
19		X		
20		X		
21		X		
22		X		
23				X
24		X		
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26			X	
27		X		
28	X			
29		X		
30				X
31	X			
32				X
33		X		
34				X
35		X		
36	X			
37	X			
38		X		
39			X	
40			X	
41				X
42	X			
43			X	
44				X
45	X			
46			X	
47				X
48				X
49			X	
50				X
51	X			
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58		X		
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60		X		
61	X			
62				X
63				X
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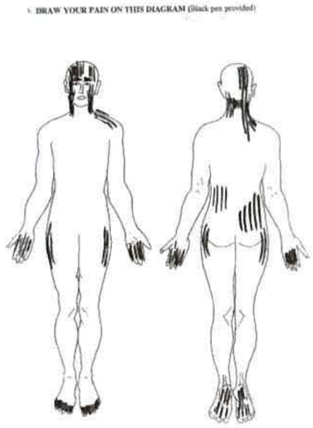
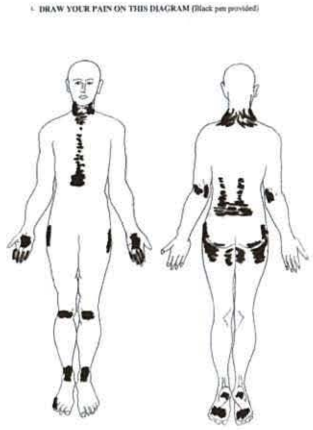
65		X		
66				X
67		X		
68				X
69		X		
70		X		
71		X		
72		X		
73			X	
74		X		
75		X		
76			X	
77			X	
78			X	
79				X
80		X		

CASE STUDY 1 - FM

PHYSICAL PAIN

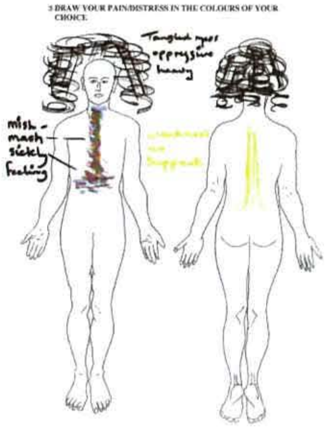


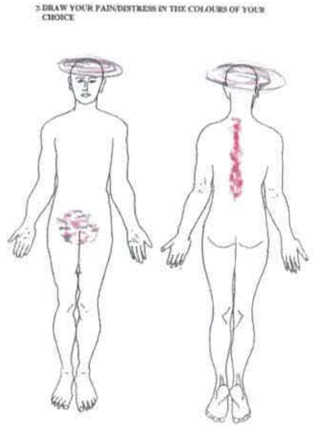


PRE TREATMENT

POST TREATMENT

EMOTIONAL PAIN





PRE TREATMENT

POST TREATMENT

IMAGE OF PAIN

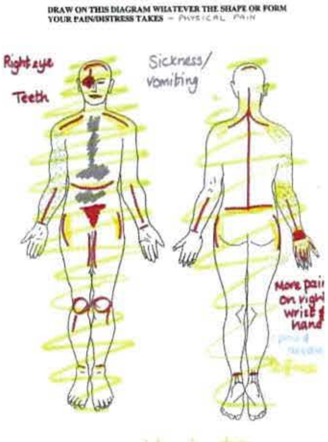
PRE TREATMENT

POST TREATMENT

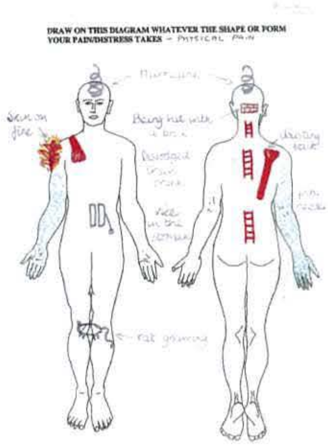
Enlargements of these images may be found in Appendix C

CASE STUDY 2 - FM

PHYSICAL PAIN

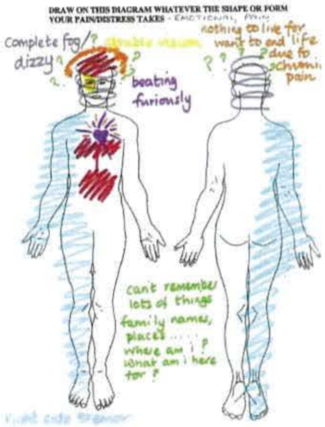


PRE TREATMENT

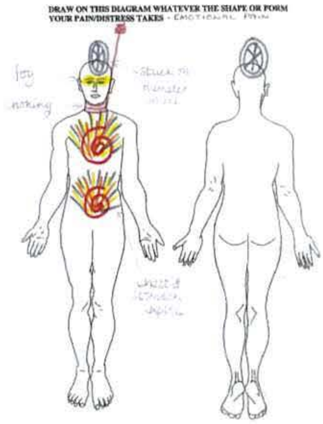


POST TREATMENT

EMOTIONAL PAIN



PRE TREATMENT



POST TREATMENT

IMAGE OF PAIN

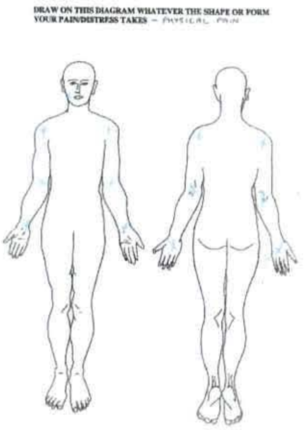
PRE TREATMENT

POST TREATMENT

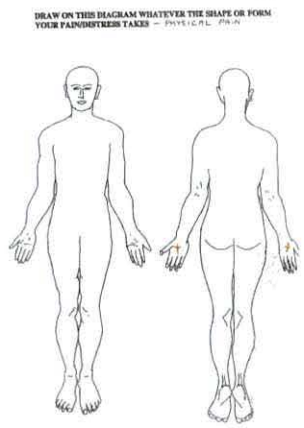
Enlargements of these images may be found in Appendix C

CASE STUDY 3 - RA

PHYSICAL PAIN

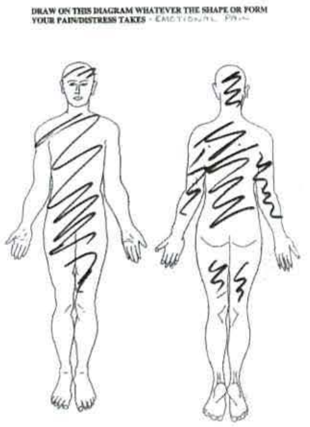


PRE TREATMENT

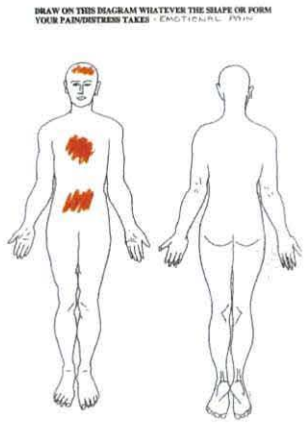


POST TREATMENT

EMOTIONAL PAIN

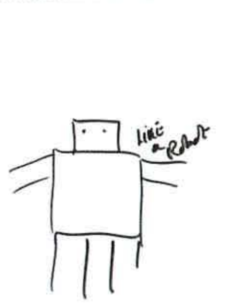


PRE TREATMENT



POST TREATMENT

IMAGE OF PAIN



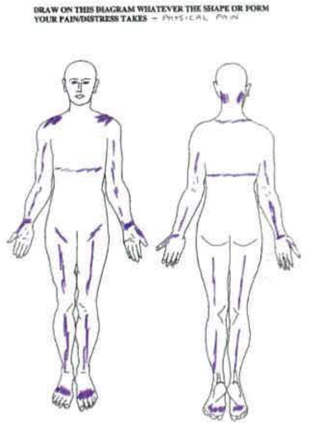
PRE TREATMENT

POST TREATMENT

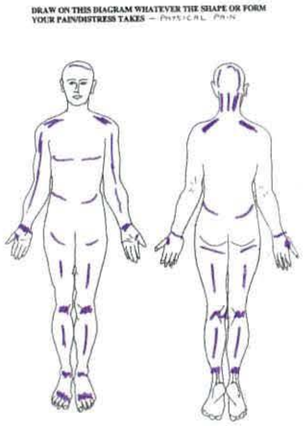
Enlargements of these images may be found in Appendix C

CASE STUDY 4 - RA

PHYSICAL PAIN

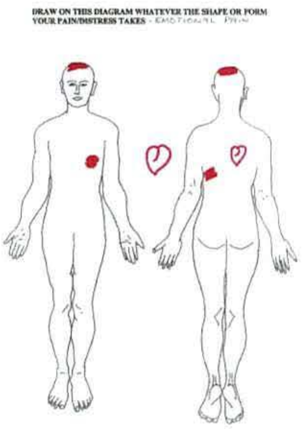


PRE TREATMENT

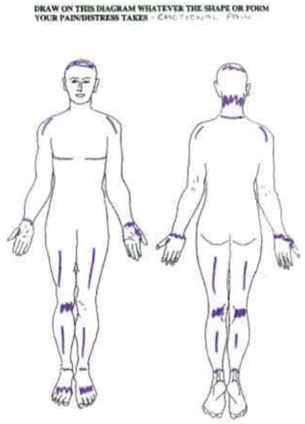


POST TREATMENT

EMOTIONAL PAIN



PRE TREATMENT



POST TREATMENT

IMAGE OF PAIN

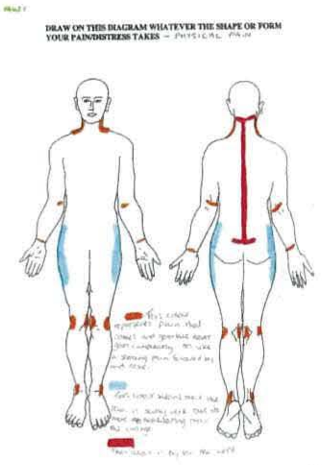
PRE TREATMENT

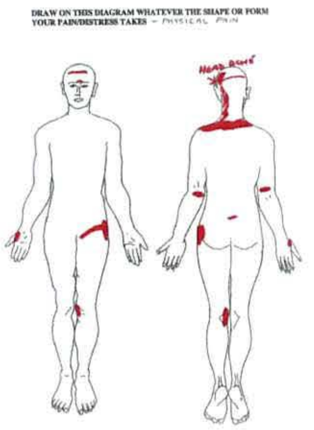
POST TREATMENT

Enlargements of these images may be found in Appendix C

CASE STUDY 5 - RAFM

PHYSICAL PAIN

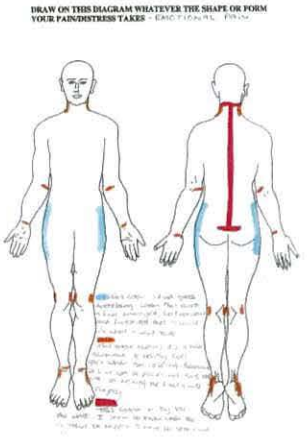


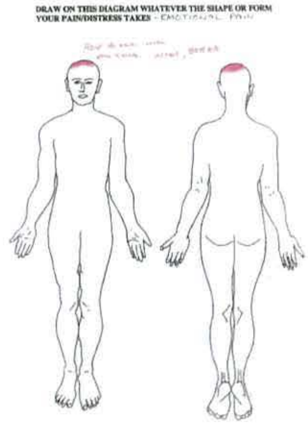


PRE TREATMENT

POST TREATMENT

EMOTIONAL PAIN

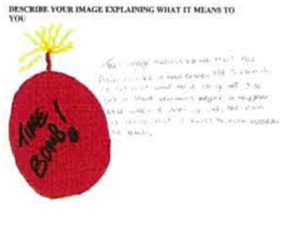




PRE TREATMENT

POST TREATMENT

IMAGE OF PAIN



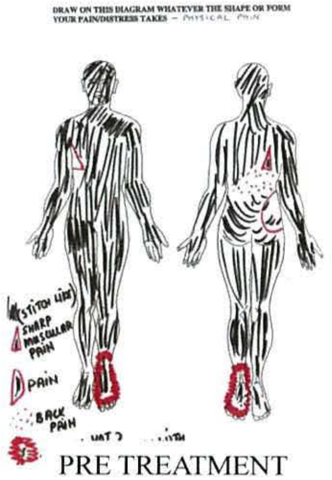
PRE TREATMENT

POST TREATMENT

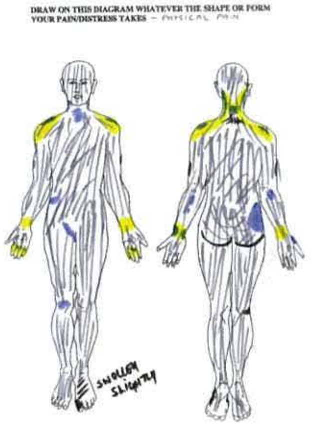
Enlargements of these images may be found in Appendix C

CASE STUDY 6 - RAFM

PHYSICAL PAIN

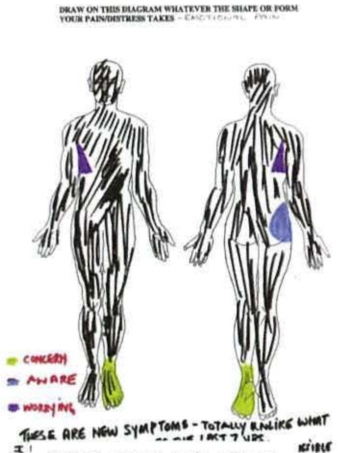


PRE TREATMENT

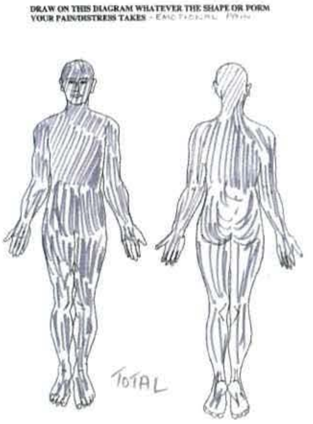


POST TREATMENT

EMOTIONAL PAIN



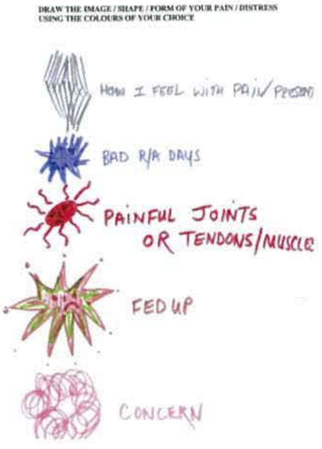
I ! BRI… PRE TREATMENT …IBLE !!



POST TREATMENT

IMAGE OF PAIN

PRE TREATMENT



POST TREATMENT

Enlargements of these images may be found in Appendix C

http://sci.rutgers.edu/forum/showthread.php?t=101755

Understanding Chronic Pain and Fibromyalgia:

A Review of Recent Discoveries

by Robert M. Bennett MD, FRCP

Professor of Medicine, Oregon Health Sciences University

Fibromyalgia tends to be treated rather dismissively, sometimes with cynical overtones. When I trained in London some 30 years ago, this diagnosis was never mentioned, even though I trained with one of the foremost rheumatologists in the world at the time. In the United States fibromyalgia has become a semi-respectable diagnosis within the last 10 years, but even so it has some critics. The problem for doctors is that fibromyalgia is not a problem that can be understood according to the classic medical model. This is the model that is used in all medical training. It is based on the correlation of specific tissue pathology with distinctive symptoms (e.g. tuberculosis of the lung causing a chronic cough). Elimination of the causative agent (e.g. the tubercule bacillus) cures the disease. This model has led to the most major advances in medicine that we benefit from today.

I have seen over 5,000 fibromyalgia patients over the past 20 years; most want to be reassured that their symptoms are the product of a "real disease" rather than figments of a fertile imagination--commonly ascribed to the psychological diagnosis such as somatization, hypochondriasis, or depression. The good news is that contemporary research is hot on the track of unraveling the changes that occur within the nervous system of fibromyalgia patients. The basic message is that fibromyalgia cannot be considered a primarily psychological disorder, but as in many chronic conditions, psychological factors may play a role in who becomes disabled and may even up-regulate the central nervous system changes that are the root cause of the problem.

What is the problem?

The problem is: disordered sensory processing.

I will try to convey to you what we mean by "disordered sensory processing." Even a superficial understanding of this topic will change the way you think about the fibromyalgia problem. Furthermore, recent advances that have been made at the molecular level hold out the promise of more effective treatment for fibromyalgia pain.

What is Fibromyalgia?

Fibromyalgia is a chronic pain state in which the nerve stimuli causing pain originates mainly in the muscle. Hence the increased pain on movement and the aggravation of fibromyalgia by strenuous exertion.

Pain is a universal experience that serves the vital function of triggering avoidance. A few unfortunate individuals have a congenital absence of pain sensation; they do not fare well due to repeated bodily insults that go unnoticed. As a physician I see patients with an acquired deficiency in the pain sensation (e.g. diabetic neuropathy or neurosyphilis) who develop a severe destructive arthritis--a result of repeated minor joint injuries that are overlooked. Thus pain sensation is a necessary part of being human. Pain sensation is a fact of life. Even the primitive amoeba takes avoiding action in the face of adverse events. In such primitive life forms, pain avoidance is purely reflex action, as they do not have the complexity of a highly developed brain to feel pain in the sense that humans do: (1)The unconscious reflex avoidance reaction that is so rapid that it occurs before the actual awareness of the pain sensation (as in all life forms), (2) the actual experience of the pain sensation (that can only occur in highly complex organisms). This is an important point, as it implies that different parts of the brain are involved in these two consequences of the pain reaction.

Over the last few years a number of important research discoveries have started to clarify the enigma of chronic pain. Many of these new findings have a special relevance to the chronic pain of fibromyalgia. The cardinal symptom of FM is widespread body pain. The cardinal finding is the presence of focal areas of hyperalgesia, the tender points. Tender points imply that the patient has a local area of reduced pain threshold, suggesting a peripheral pathology. In general, tender points occur at muscle tendon junctions, a site where mechanical forces are most likely to cause micro-injuries. Many--but not all--FM patients have tender skin and an overall reduction in pain threshold. These latter observations suggest that some FM patients have a generalized pain amplification state. There has been a recent plethora of experimental studies apposite to the pathophysiological basis of both the peripheral and central aspects of pain.

The Pathophysiological Basis for Chronic Pain

The International Association For the Study of Pain (ASP) defines pain as follows: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." This definition explicitly affirms that pain has both a sensory and an affective-evaluative component, and furthermore acknowledges that it may occur in the absence of obvious visceral or peripheral pathology. To fully understand chronic pain, one must integrate the sensory and affective/evaluative elements of the pain experience. It is equally misguided to focus on the psychological aspects of pain, as it is to address only the sensory component and ignore the affective dimensions. However, for the sake of clarity, each of these two constitutive elements will be considered separately.

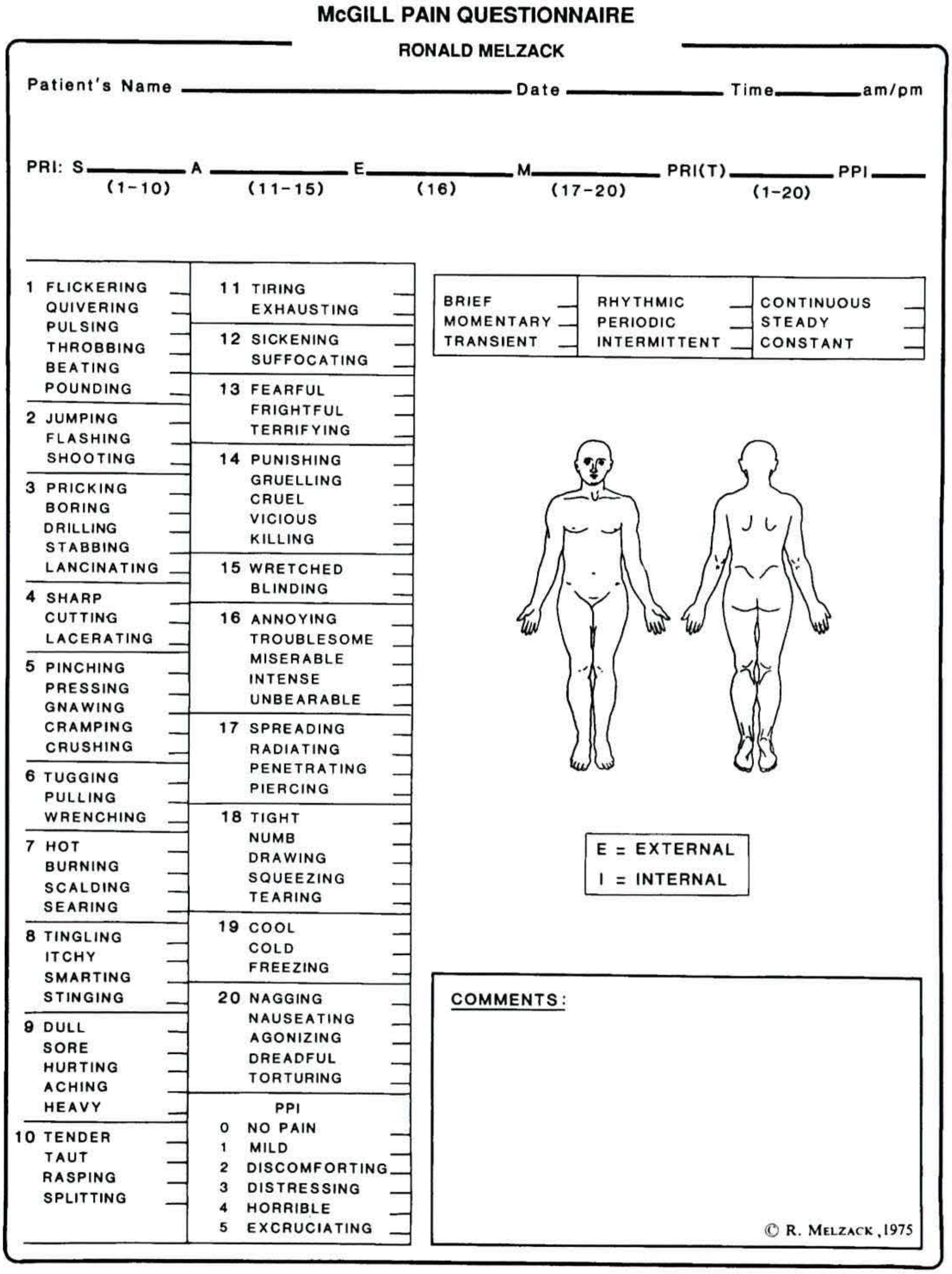
The Sensory Component

Pain is generally envisaged as a cascade of impulses that originates from nocioceptors in somatic or visceral tissues. The impulses travel in peripheral nerves with a first synapse in the dorsal horn and a second synapse in the thalamus, and end up in the cerebral cortex and other supraspinal structures.

This results in an experience of pain and the activation of reflex and later reflective behaviors. These reflex and reflective behaviors are aimed at eliminating further pain. The expectation is that this nocioceptor driven pain will be successfully abolished, allowing healing and a return to a pain-free state. The problem with chronic pain is that the linear relationship between nocioception and pain experience is inappropriate or even absent, and the expected recovery does not occur.

It is a common misconception to view the nervous system as being "hard-wired"; that is, stimulation of a nerve ending (say a needle prick) always produces the same behavioral and affective response. This concept implies that the same intensity of pain stimulus will always elicit the same degree of nerve stimulation and hence the same subjective experience of pain. It is now understood that the concept is wrong. Some 30 years ago, Melzeck and Wall proposed that pain is a complex integration of noxious stimuli, affective traits, and cognitive factors. In other words, the emotional aspects of having a chronic pain state and one's rationalization of the problem may both influence the final experience of pain. Mendell and Wall provided the first experimental evidence that the nervous system was not hard-wired in 1965. They noted that a repetitive stimulation of a peripheral nerve, at sufficient intensity to activate C-fibers, resulted a progressive build-up of the amplitude of the electrical response recorded in the second order dorsal horn neurons. If the system had been hard-wired, each stimulus would have elicited the same response in the second order neuron. They termed this phenomenon "wind-up." It is now appreciated that the phenomenon of wind-up is crucial to understanding the problem of chronic pain via the mechanism of "central sensitization."

The McGill Pain Questionnaire (Adjective Section)



McGILL PAIN QUESTIONNAIRE

RONALD MELZACK

Patient's Name ________________ Date __________ Time ________ am/pm

PRI: S ______ (1-10) A ______ (11-15) E ______ (16) M ______ (17-20) PRI(T) ______ (1-20) PPI ______

1 FLICKERING __
QUIVERING __
PULSING __
THROBBING __
BEATING __
POUNDING __

2 JUMPING __
FLASHING __
SHOOTING __

3 PRICKING __
BORING __
DRILLING __
STABBING __
LANCINATING __

4 SHARP __
CUTTING __
LACERATING __

5 PINCHING __
PRESSING __
GNAWING __
CRAMPING __
CRUSHING __

6 TUGGING __
PULLING __
WRENCHING __

7 HOT __
BURNING __
SCALDING __
SEARING __

8 TINGLING __
ITCHY __
SMARTING __
STINGING __

9 DULL __
SORE __
HURTING __
ACHING __
HEAVY __

10 TENDER __
TAUT __
RASPING __
SPLITTING __

11 TIRING __
EXHAUSTING __

12 SICKENING __
SUFFOCATING __

13 FEARFUL __
FRIGHTFUL __
TERRIFYING __

14 PUNISHING __
GRUELLING __
CRUEL __
VICIOUS __
KILLING __

15 WRETCHED __
BLINDING __

16 ANNOYING __
TROUBLESOME __
MISERABLE __
INTENSE __
UNBEARABLE __

17 SPREADING __
RADIATING __
PENETRATING __
PIERCING __

18 TIGHT __
NUMB __
DRAWING __
SQUEEZING __
TEARING __

19 COOL __
COLD __
FREEZING __

20 NAGGING __
NAUSEATING __
AGONIZING __
DREADFUL __
TORTURING __

PPI
0 NO PAIN __
1 MILD __
2 DISCOMFORTING __
3 DISTRESSING __
4 HORRIBLE __
5 EXCRUCIATING __

BRIEF __	RHYTHMIC __	CONTINUOUS __
MOMENTARY __	PERIODIC __	STEADY __
TRANSIENT __	INTERMITTENT __	CONSTANT __

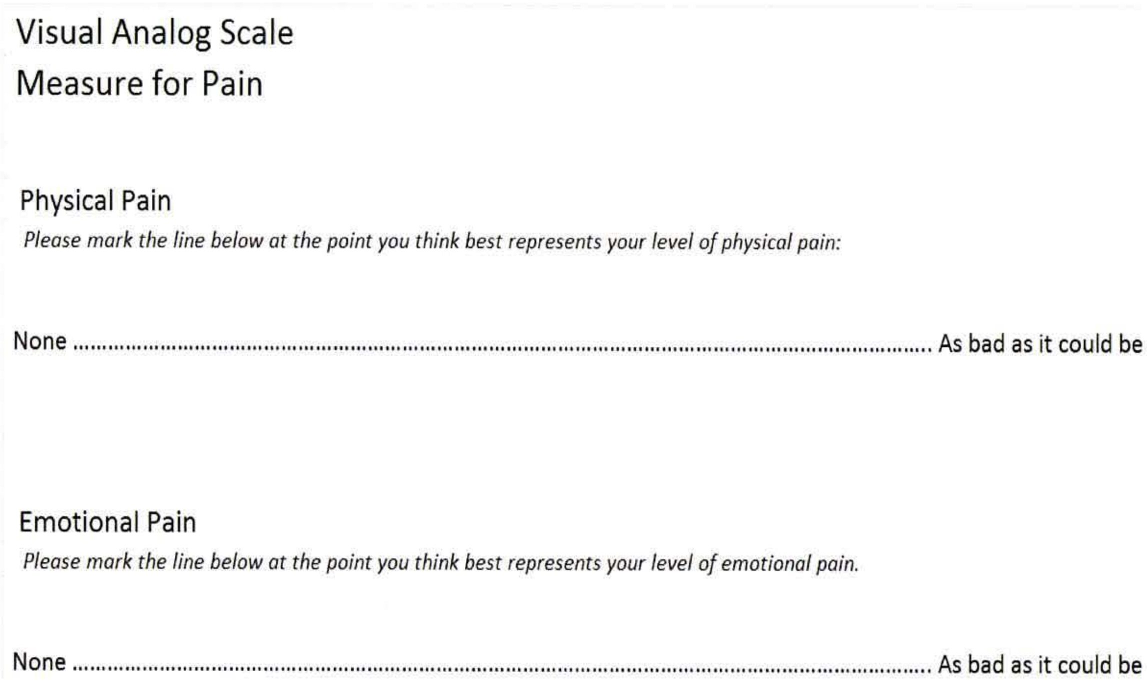
E = EXTERNAL
I = INTERNAL

COMMENTS:

© R. MELZACK, 1975

Melzack, R., The McGill Pain Questionnaire: Major Properties and Scoring Methods. *Pain* 1975; 1:277-299

Visual Analog Scale used in FM OA Study (Reported in Chapter 2)



Visual Analog Scale
Measure for Pain

Physical Pain

Please mark the line below at the point you think best represents your level of physical pain:

None .... As bad as it could be

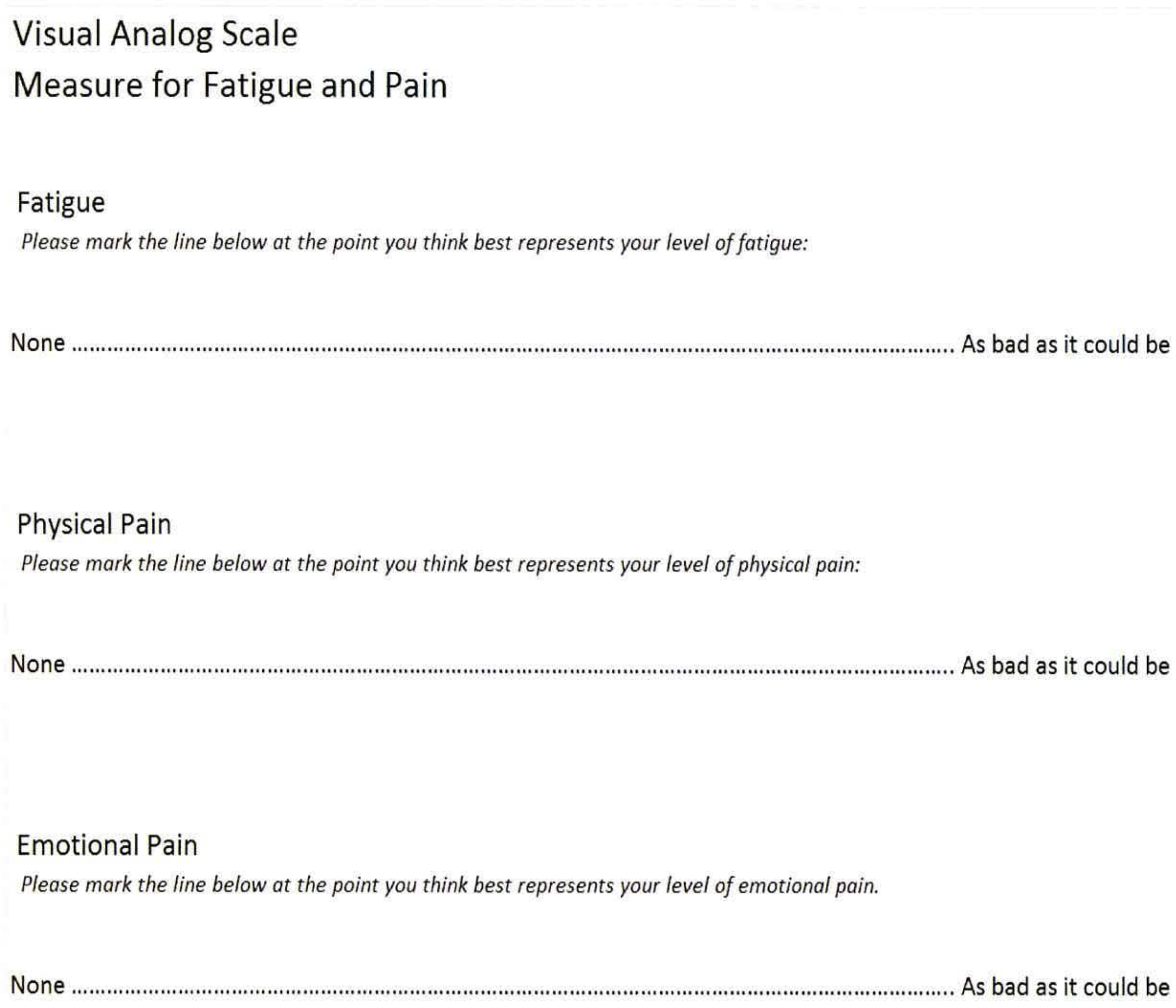
Emotional Pain

Please mark the line below at the point you think best represents your level of emotional pain.

None .... As bad as it could be

Huskisson, E. C. (1983) Visual Analog Scales in R. Melzack (Ed), Pain Management and Assessment. (33-37). New York: Raven Press

Visual Analog Scale used in RAFM Study (Reported in Chapter 4)



Visual Analog Scale
Measure for Fatigue and Pain

Fatigue

Please mark the line below at the point you think best represents your level of fatigue:

None .... As bad as it could be

Physical Pain

Please mark the line below at the point you think best represents your level of physical pain:

None .... As bad as it could be

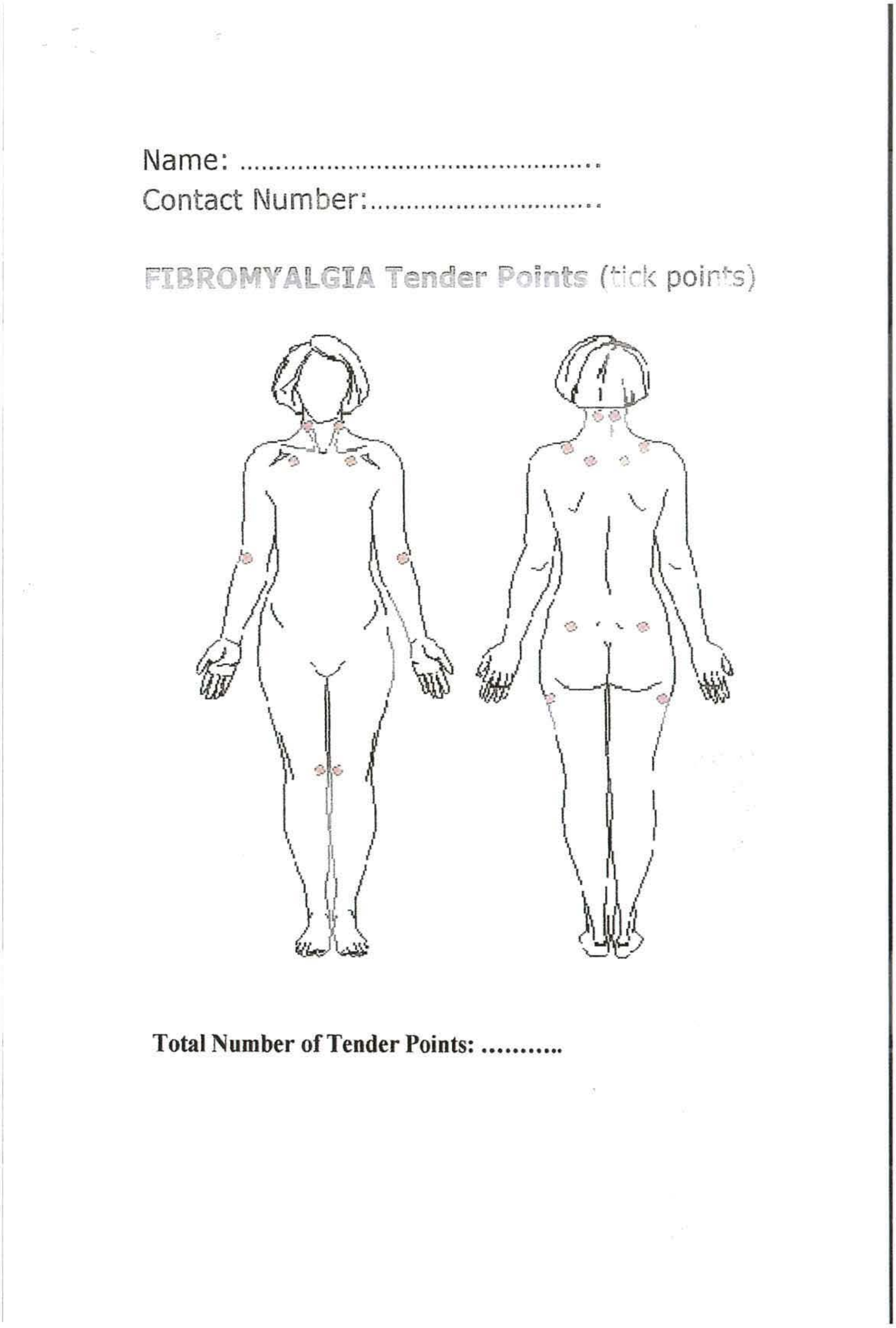
Emotional Pain

Please mark the line below at the point you think best represents your level of emotional pain.

None .... As bad as it could be

Huskisson, E. C. (1983) Visual Analog Scales in R. Melzack (Ed), Pain Management and Assessment. (33-37). New York: Raven Press

Examination Sheet for Fibromyalgia Tender Points



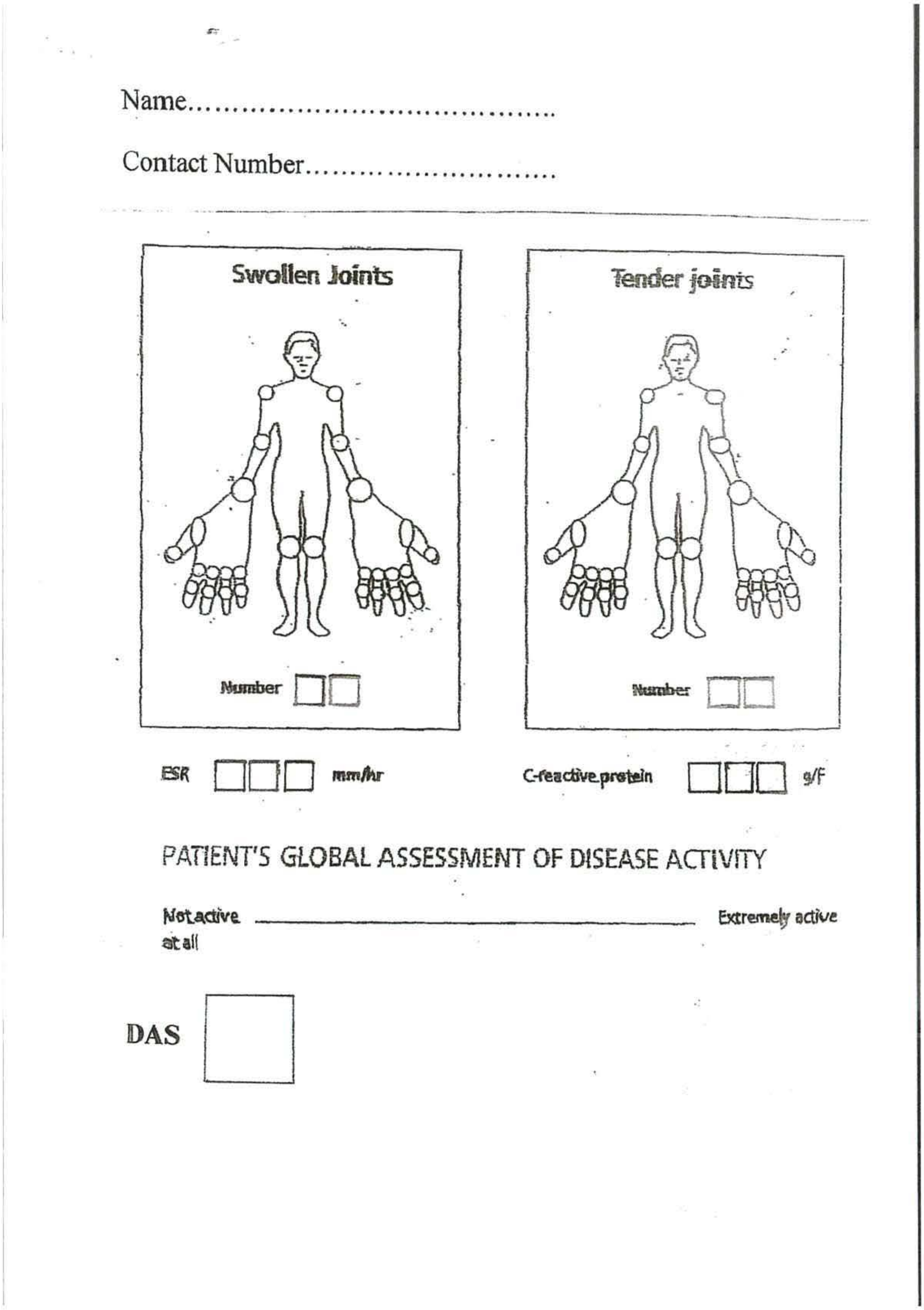
Name: ....

Contact Number:..............................

FIBROMYALGIA Tender Points (tick points)

Total Number of Tender Points: ....

DAS28 Examination and Scoring Sheet



Name.......................................

Contact Number............................

Swollen Joints

Number ☐☐

Tender joints

Number ☐☐

ESR ☐☐☐ mm/hr

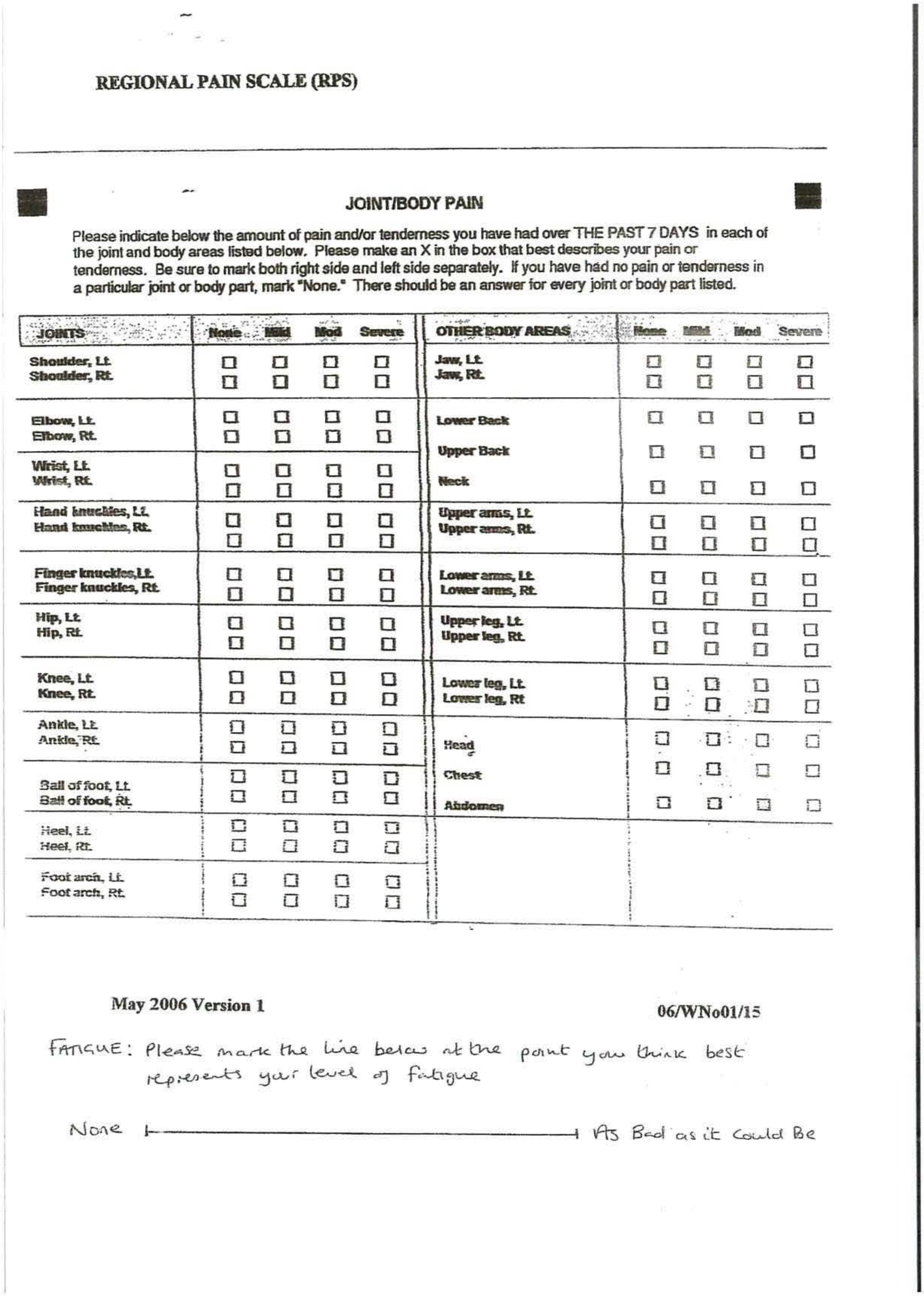
C-reactive protein ☐☐☐ g/F

PATIENT'S GLOBAL ASSESSMENT OF DISEASE ACTIVITY

Not active at all ________________________________ Extremely active

DAS ☐

Regional Pain Scale



REGIONAL PAIN SCALE (RPS)

JOINT/BODY PAIN

Please indicate below the amount of pain and/or tenderness you have had over THE PAST 7 DAYS in each of the joint and body areas listed below. Please make an X in the box that best describes your pain or tenderness. Be sure to mark both right side and left side separately. If you have had no pain or tenderness in a particular joint or body part, mark "None." There should be an answer for every joint or body part listed.

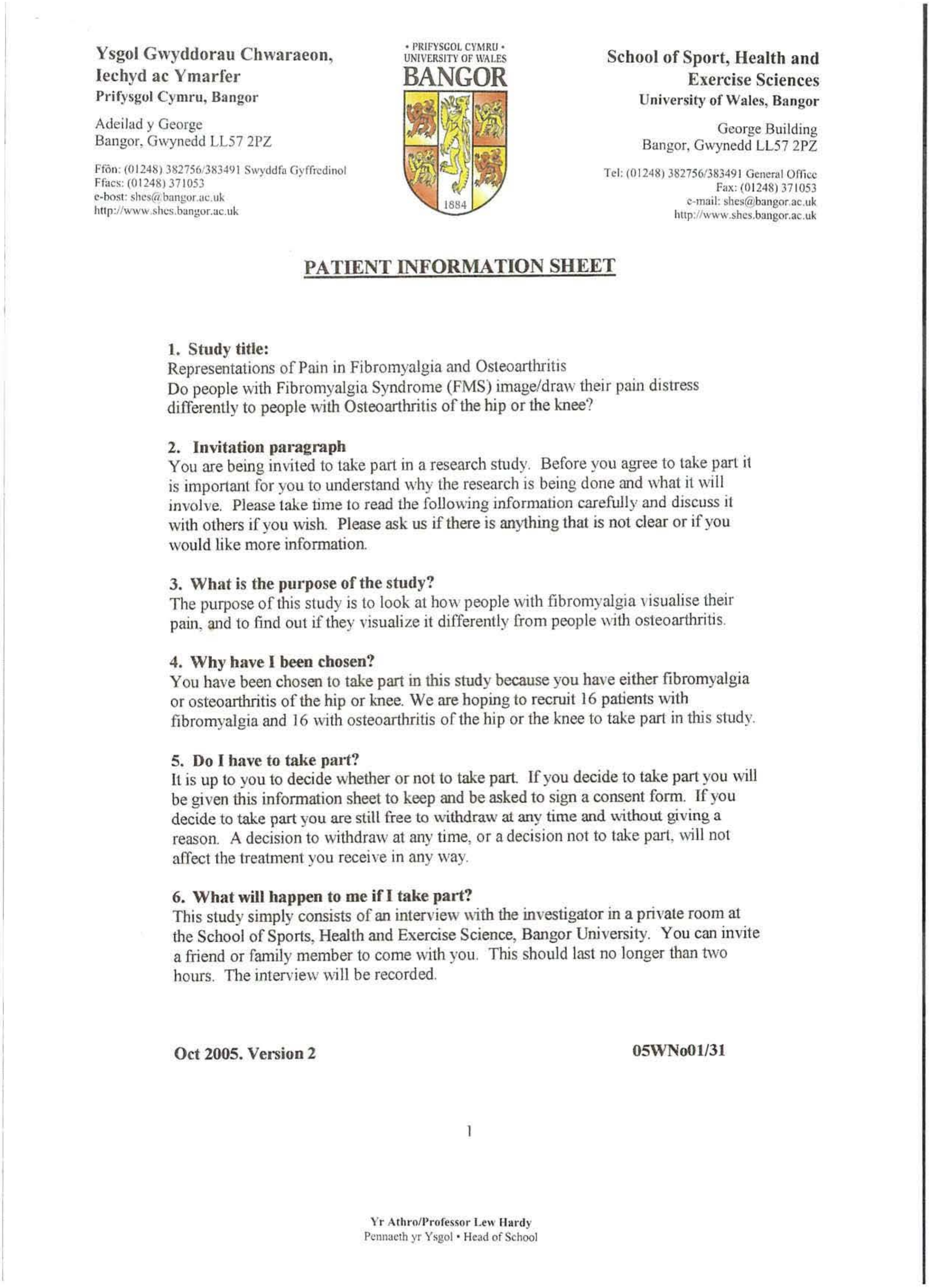
JOINTS	None	Mild	Mod	Severe	OTHER BODY AREAS	None	Mild	Mod	Severe
Shoulder, Lt.	☐	☐	☐	☐	Jaw, Lt.	☐	☐	☐	☐
Shoulder, Rt.	☐	☐	☐	☐	Jaw, Rt.	☐	☐	☐	☐
Elbow, Lt.	☐	☐	☐	☐	Lower Back	☐	☐	☐	☐
Elbow, Rt.	☐	☐	☐	☐	Upper Back	☐	☐	☐	☐
Wrist, Lt.	☐	☐	☐	☐					
Wrist, Rt.	☐	☐	☐	☐	Neck	☐	☐	☐	☐
Hand knuckles, Lt.	☐	☐	☐	☐	Upper arms, Lt.	☐	☐	☐	☐
Hand knuckles, Rt.	☐	☐	☐	☐	Upper arms, Rt.	☐	☐	☐	☐
Finger knuckles,Lt.	☐	☐	☐	☐	Lower arms, Lt.	☐	☐	☐	☐
Finger knuckles, Rt.	☐	☐	☐	☐	Lower arms, Rt.	☐	☐	☐	☐
Hip, Lt.	☐	☐	☐	☐	Upper leg, Lt.	☐	☐	☐	☐
Hip, Rt.	☐	☐	☐	☐	Upper leg, Rt.	☐	☐	☐	☐
Knee, Lt.	☐	☐	☐	☐	Lower leg, Lt.	☐	☐	☐	☐
Knee, Rt.	☐	☐	☐	☐	Lower leg, Rt	☐	☐	☐	☐
Ankle, Lt.	☐	☐	☐	☐					
Ankle, Rt.	☐	☐	☐	☐	Head	☐	☐	☐	☐
Ball of foot, Lt.	☐	☐	☐	☐	Chest	☐	☐	☐	☐
Ball of foot, Rt.	☐	☐	☐	☐	Abdomen	☐	☐	☐	☐
Heel, Lt.	☐	☐	☐	☐					
Heel, Rt.	☐	☐	☐	☐					
Foot arch, Lt.	☐	☐	☐	☐					
Foot arch, Rt.	☐	☐	☐	☐					

May 2006 Version 1 **06/WNo01/15**

FATIGUE: Please mark the line below at the point you think best represents your level of fatigue

None |———————————————| As Bad as it Could Be

Patient Information Sheet for Study One. OA and FM (Chapter 2 and 3) – Page 1



Ysgol Gwyddorau Chwaraeon,
Iechyd ac Ymarfer
Prifysgol Cymru, Bangor

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PATIENT INFORMATION SHEET

1. Study title:
Representations of Pain in Fibromyalgia and Osteoarthritis
Do people with Fibromyalgia Syndrome (FMS) image/draw their pain distress differently to people with Osteoarthritis of the hip or the knee?

2. Invitation paragraph
You are being invited to take part in a research study. Before you agree to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

3. What is the purpose of the study?
The purpose of this study is to look at how people with fibromyalgia visualise their pain, and to find out if they visualize it differently from people with osteoarthritis.

4. Why have I been chosen?
You have been chosen to take part in this study because you have either fibromyalgia or osteoarthritis of the hip or knee. We are hoping to recruit 16 patients with fibromyalgia and 16 with osteoarthritis of the hip or the knee to take part in this study.

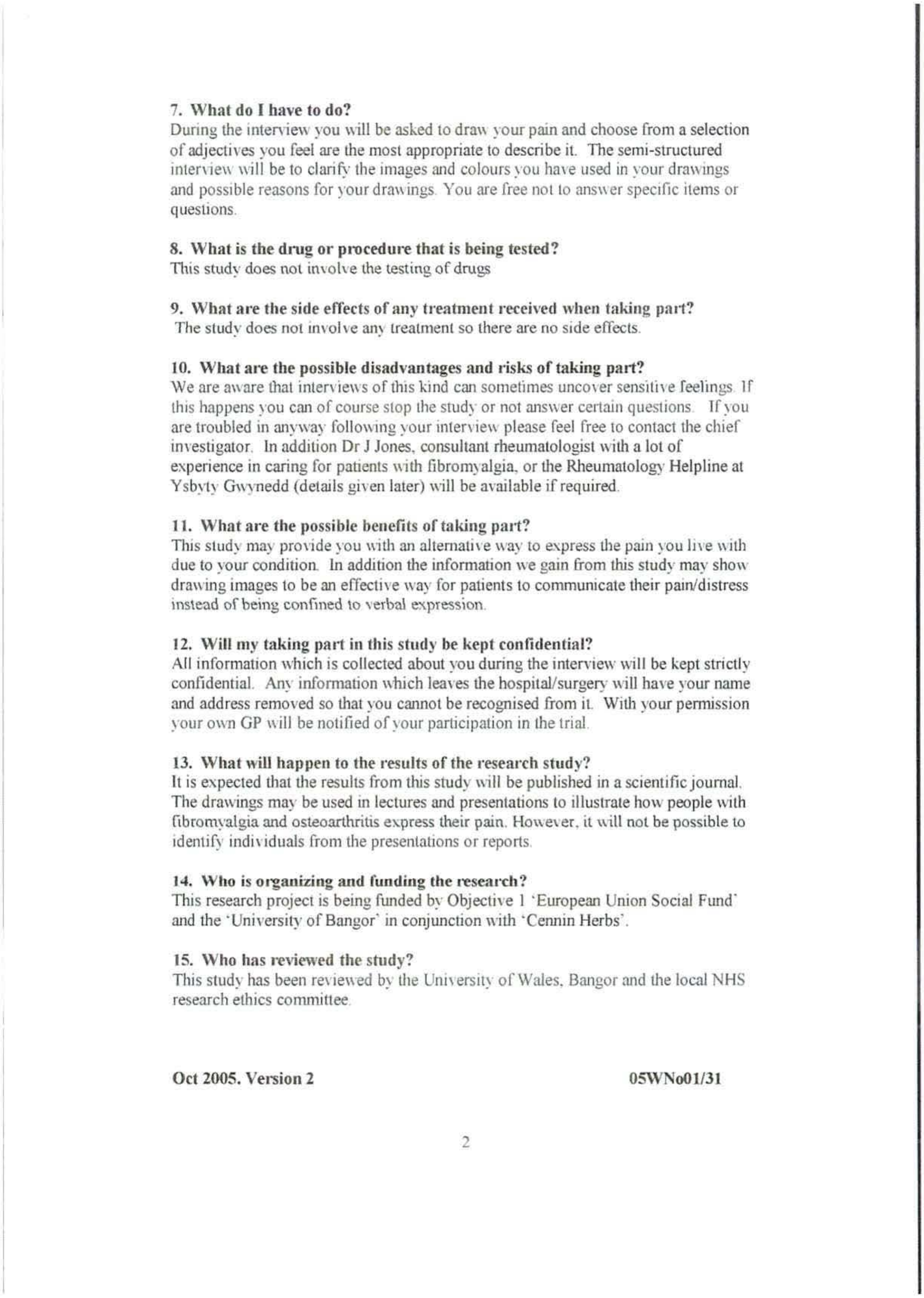
5. Do I have to take part?
It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the treatment you receive in any way.

6. What will happen to me if I take part?
This study simply consists of an interview with the investigator in a private room at the School of Sports, Health and Exercise Science, Bangor University. You can invite a friend or family member to come with you. This should last no longer than two hours. The interview will be recorded.

Oct 2005. Version 2 **05WNo01/31**

Yr Athro/Professor Lew Hardy
Pennaeth yr Ysgol • Head of School

Patient Information Sheet for Study One. OA and FM (Chapter 2 and 3) – Page 2



7. What do I have to do?
During the interview you will be asked to draw your pain and choose from a selection of adjectives you feel are the most appropriate to describe it. The semi-structured interview will be to clarify the images and colours you have used in your drawings and possible reasons for your drawings. You are free not to answer specific items or questions.

8. What is the drug or procedure that is being tested?
This study does not involve the testing of drugs

9. What are the side effects of any treatment received when taking part?
The study does not involve any treatment so there are no side effects.

10. What are the possible disadvantages and risks of taking part?
We are aware that interviews of this kind can sometimes uncover sensitive feelings. If this happens you can of course stop the study or not answer certain questions. If you are troubled in anyway following your interview please feel free to contact the chief investigator. In addition Dr J Jones, consultant rheumatologist with a lot of experience in caring for patients with fibromyalgia, or the Rheumatology Helpline at Ysbyty Gwynedd (details given later) will be available if required.

11. What are the possible benefits of taking part?
This study may provide you with an alternative way to express the pain you live with due to your condition. In addition the information we gain from this study may show drawing images to be an effective way for patients to communicate their pain/distress instead of being confined to verbal expression.

12. Will my taking part in this study be kept confidential?
All information which is collected about you during the interview will be kept strictly confidential. Any information which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it. With your permission your own GP will be notified of your participation in the trial.

13. What will happen to the results of the research study?
It is expected that the results from this study will be published in a scientific journal. The drawings may be used in lectures and presentations to illustrate how people with fibromyalgia and osteoarthritis express their pain. However, it will not be possible to identify individuals from the presentations or reports.

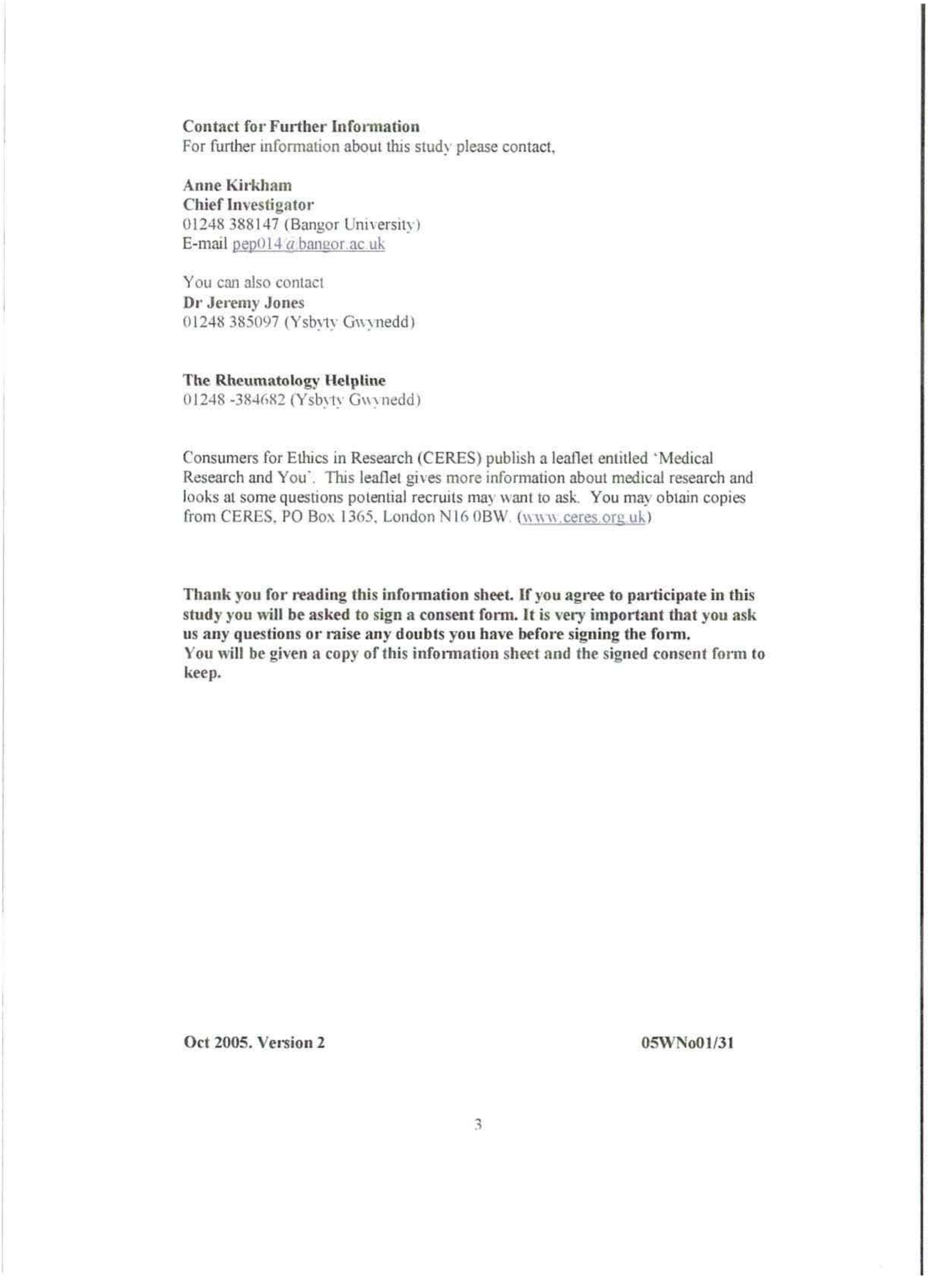
14. Who is organizing and funding the research?
This research project is being funded by Objective 1 'European Union Social Fund' and the 'University of Bangor' in conjunction with 'Cennin Herbs'.

15. Who has reviewed the study?
This study has been reviewed by the University of Wales, Bangor and the local NHS research ethics committee.

Oct 2005. Version 2 **05WNo01/31**

2

Patient Information Sheet for Study One. OA and FM (Chapter 2 and 3) – Page 3



Contact for Further Information
For further information about this study please contact,

Anne Kirkham
Chief Investigator
01248 388147 (Bangor University)
E-mail pep014@bangor.ac.uk

You can also contact
Dr Jeremy Jones
01248 385097 (Ysbyty Gwynedd)

The Rheumatology Helpline
01248 -384682 (Ysbyty Gwynedd)

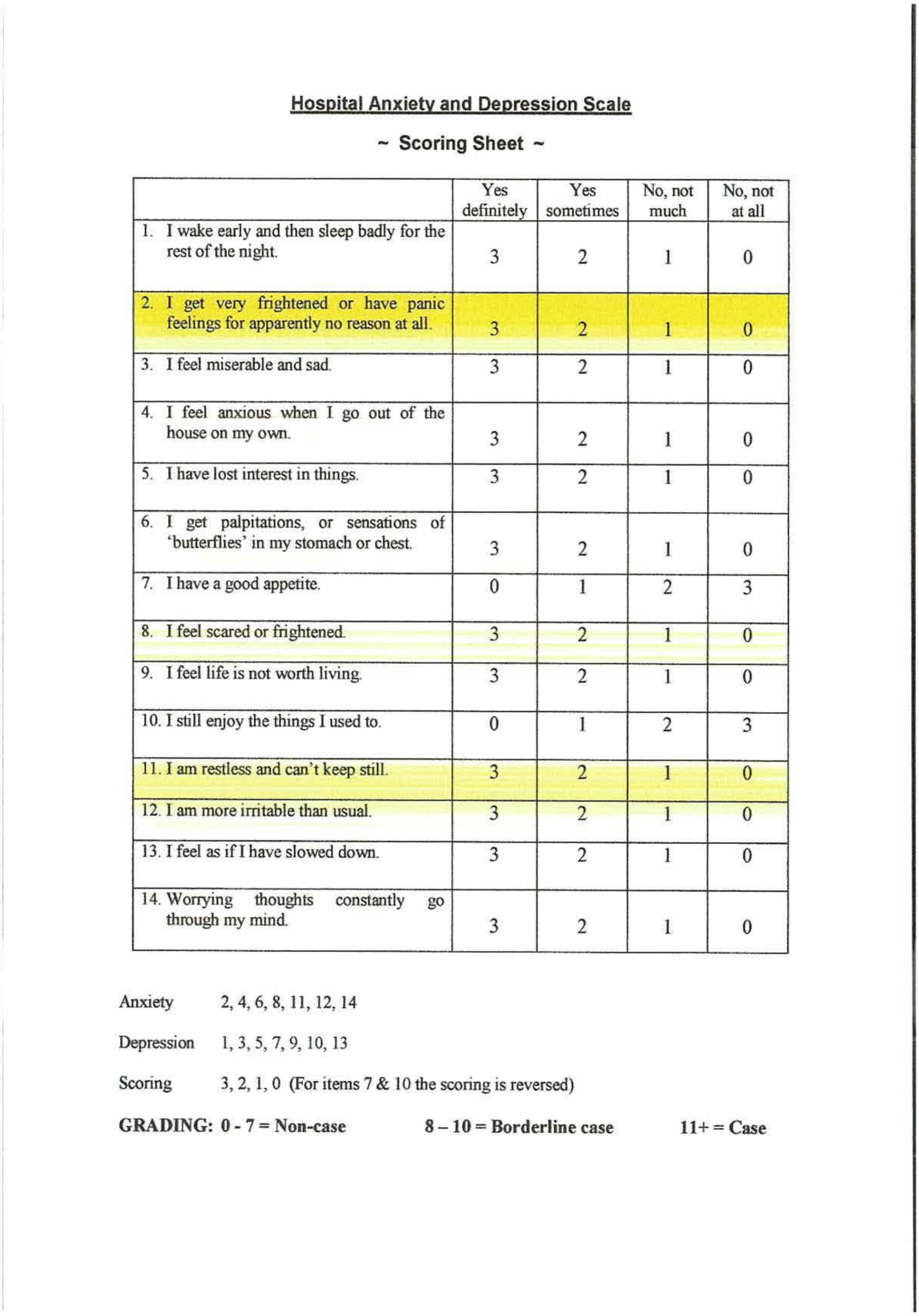
Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions potential recruits may want to ask. You may obtain copies from CERES, PO Box 1365, London N16 0BW. (www.ceres.org.uk)

Thank you for reading this information sheet. If you agree to participate in this study you will be asked to sign a consent form. It is very important that you ask us any questions or raise any doubts you have before signing the form.
You will be given a copy of this information sheet and the signed consent form to keep.

Oct 2005. Version 2 **05WNo01/31**

3

Hospital Anxiety and Depression Scale



Hospital Anxiety and Depression Scale

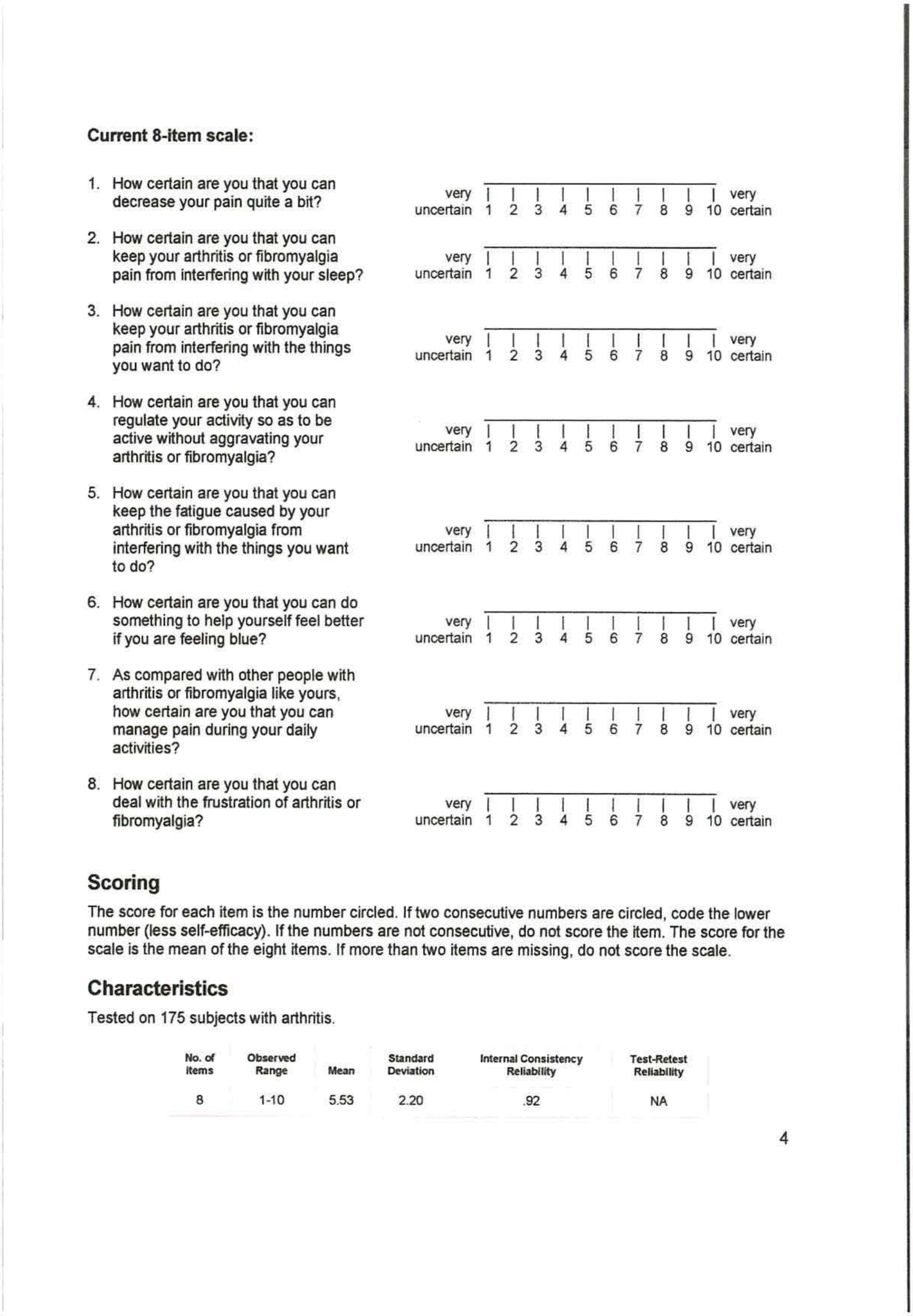
~ Scoring Sheet ~

	Yes definitely	Yes sometimes	No, not much	No, not at all
1. I wake early and then sleep badly for the rest of the night.	3	2	1	0
2. I get very frightened or have panic feelings for apparently no reason at all.	3	2	1	0
3. I feel miserable and sad.	3	2	1	0
4. I feel anxious when I go out of the house on my own.	3	2	1	0
5. I have lost interest in things.	3	2	1	0
6. I get palpitations, or sensations of 'butterflies' in my stomach or chest.	3	2	1	0
7. I have a good appetite.	0	1	2	3
8. I feel scared or frightened.	3	2	1	0
9. I feel life is not worth living.	3	2	1	0
10. I still enjoy the things I used to.	0	1	2	3
11. I am restless and can't keep still.	3	2	1	0
12. I am more irritable than usual.	3	2	1	0
13. I feel as if I have slowed down.	3	2	1	0
14. Worrying thoughts constantly go through my mind.	3	2	1	0

Anxiety	2, 4, 6, 8, 11, 12, 14
Depression	1, 3, 5, 7, 9, 10, 13
Scoring	3, 2, 1, 0 (For items 7 & 10 the scoring is reversed)

GRADING: 0 - 7 = Non-case 8 – 10 = Borderline case 11+ = Case

Arthritis Self-Efficacy



Current 8-item scale:

1. How certain are you that you can decrease your pain quite a bit?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
2. How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with your sleep?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
3. How certain are you that you can keep your arthritis or fibromyalgia pain from interfering with the things you want to do?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
4. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis or fibromyalgia?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
5. How certain are you that you can keep the fatigue caused by your arthritis or fibromyalgia from interfering with the things you want to do?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
6. How certain are you that you can do something to help yourself feel better if you are feeling blue?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
7. As compared with other people with arthritis or fibromyalgia like yours, how certain are you that you can manage pain during your daily activities?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain
8. How certain are you that you can deal with the frustration of arthritis or fibromyalgia?	very uncertain 1 2 3 4 5 6 7 8 9 10 very certain

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the eight items. If more than two items are missing, do not score the scale.

Characteristics

Tested on 175 subjects with arthritis.

No. of Items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
8	1-10	5.53	2.20	.92	NA

RAFM Study – 80 Participants (Used for Chapter 4)

Semi-structured Interview – List of Questions

1. How easy did you find it to express your pain/distress using colours/images? Scale of 1 to 10.
2. How easy did you find it to choose the words to describe your pain/distress? Scale of 1 to 10.
3. Which would you cay allowed you to express your emotion/feelings most accurately?

   a.) drawing b.) words.
4. Which of the two methods did you enjoy the most?
   a.) drawing b.) words.
5. Would you say this exercise helped you in any way? If so, how?
6. Would you say today is a good day for you?
7. How long have you lived with this condition?
8. When were you diagnosed?
9. Would you say the onset was gradual?
10. Did it develop following a particularly stressful event or illness?
11. Would you describe yourself as an optimist or a pessimist?
12. Would you have described yourself as the same before the onset of your condition?
13. What was happening in your life immediately prior to the onset of your condition?
14. Have you ever suffered from what you consider to be a major loss or trauma in your life?
15. Would you describe yourself as a sensitive person? If yes, can you describe in what way?

Consent Form: RAFM (Chapter 4)

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Representations of Pain in Rheumatoid Arthritis

Name of Researcher: M A Kirkham

1) I confirm that I have read and understand the information sheet dated Jan 2007 (Version 1) for the above study and I have had the opportunity to ask questions.

2) I understand that my participation is voluntary and that I am free To withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3) I understand that sections of any medical notes may be looked at by responsible individuals from regulatory authorities.

4) If this study turns up some new information which may influence the way your pain and arthritis is treated we shall with your

permission inform your rheumatology team and GP.

5) I agree to take part in the above study.

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Name of Patient	Date	Signature
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Name of person taking consent	Date	Signature
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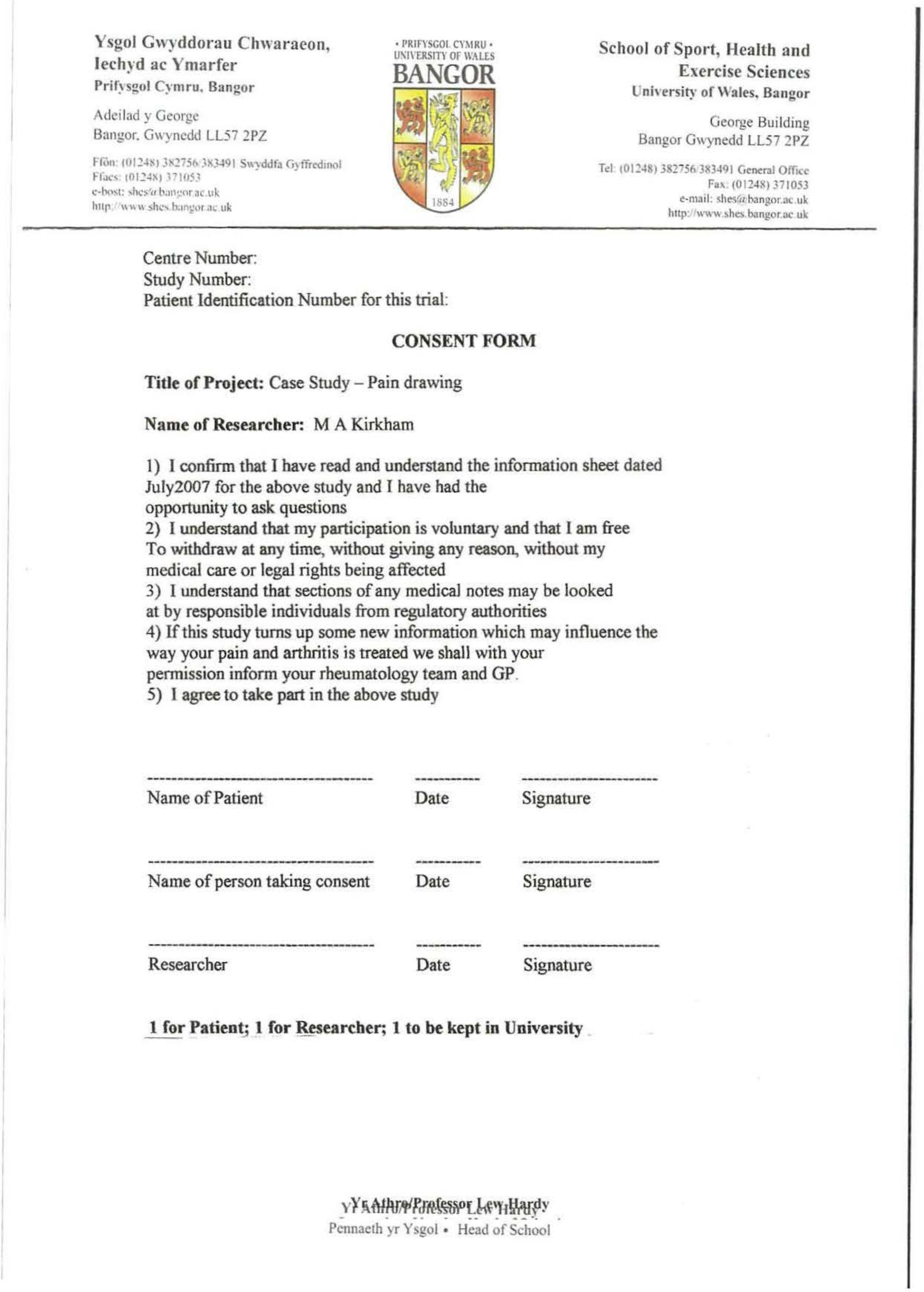
Researcher	Date	Signature

1 for Patient; 1 for Researcher; 1 to be kept in University

Jan 2007 Version 1 06/WNo01/15(a)

Consent Form: Case Studies in RA, FM and RAFM (Chapter 5)



Ysgol Gwyddorau Chwaraeon,
Iechyd ac Ymarfer
Prifysgol Cymru, Bangor

Adeilad y George
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Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Case Study – Pain drawing

Name of Researcher: M A Kirkham

1) I confirm that I have read and understand the information sheet dated July2007 for the above study and I have had the opportunity to ask questions
2) I understand that my participation is voluntary and that I am free To withdraw at any time, without giving any reason, without my medical care or legal rights being affected
3) I understand that sections of any medical notes may be looked at by responsible individuals from regulatory authorities
4) If this study turns up some new information which may influence the way your pain and arthritis is treated we shall with your permission inform your rheumatology team and GP.
5) I agree to take part in the above study

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Name of Patient	Date	Signature
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Name of person taking consent	Date	Signature
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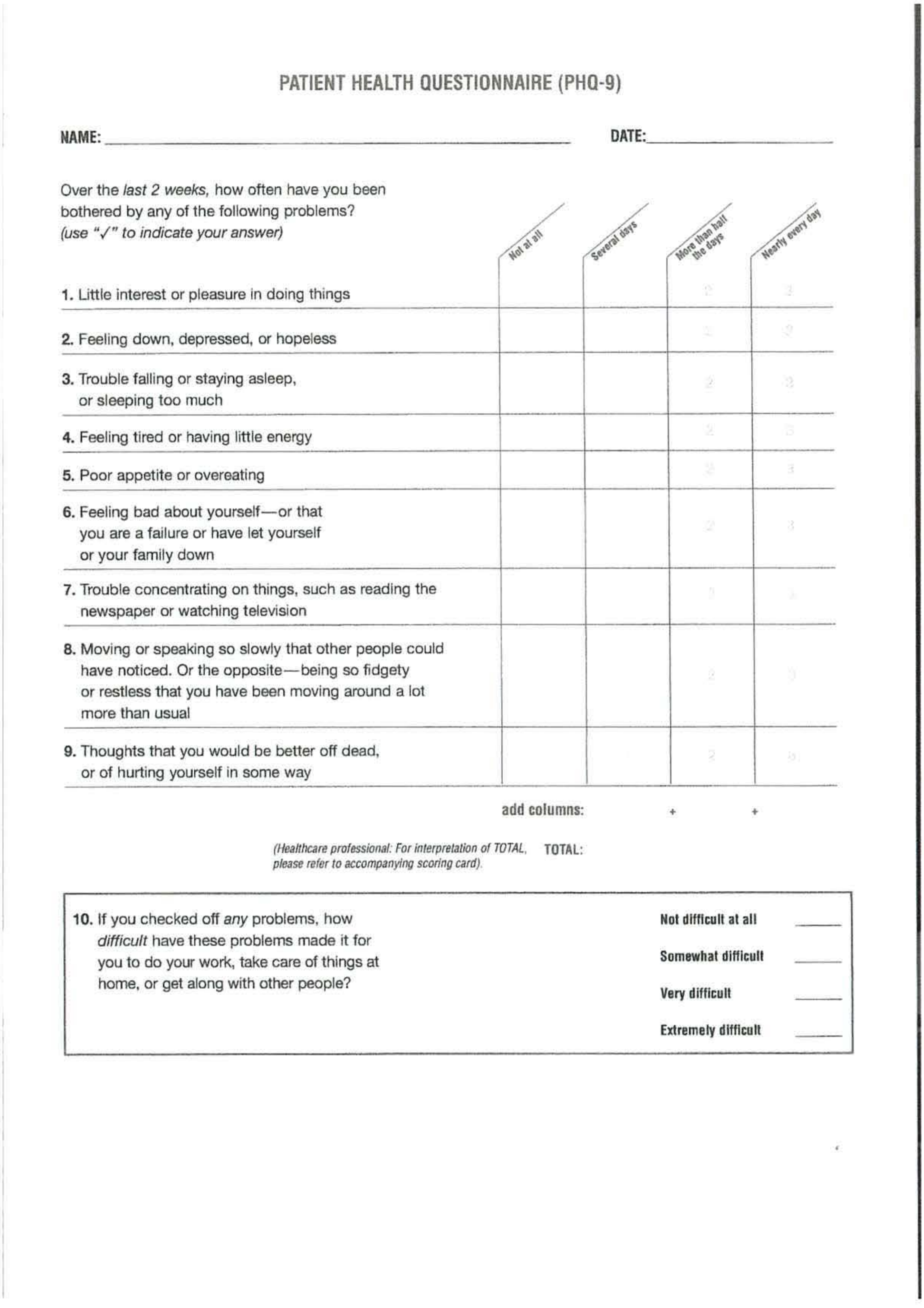
Researcher	Date	Signature

1 for Patient; 1 for Researcher; 1 to be kept in University

Yr Athro/Professor Lew Hardy
Pennaeth yr Ysgol • Head of School

Patient Health Questionnaire – Case Study (Chapter 5)



PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: ______________________ **DATE:** ______________

Over the *last 2 weeks,* how often have you been bothered by any of the following problems? *(use "✓" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things			2	3
2. Feeling down, depressed, or hopeless			2	3
3. Trouble falling or staying asleep, or sleeping too much			2	3
4. Feeling tired or having little energy			2	3
5. Poor appetite or overeating			2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down			2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television			2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual			2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way			2	3
	add columns:		+	+

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card). **TOTAL:**

10. If you checked off *any* problems, how *difficult* have these problems made it for you to do your work, take care of things at home, or get along with other people?	**Not difficult at all** ____ **Somewhat difficult** ____ **Very difficult** ____ **Extremely difficult** ____

Patient Information Sheet for Study One. RAFM (Chapter 4) – Page 1

PATIENT INFORMATION SHEET

1. Study title: Representations of Pain in Rheumatoid Arthritis

How do people with Rheumatoid Arthritis (RA) draw/image their pain?

2. Invitation paragraph

You are being invited to take part in a research study. Before you agree to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information.

3. What is the purpose of the study?

The purpose of this study is to look at how people with Rheumatoid Arthritis visualise their pain.

4. Why have I been chosen?

You have been chosen to take part in this study because you have Rheumatoid Arthritis. We are hoping to recruit 80 patients with Rheumatoid Arthritis to take part in this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the treatment you receive in any way.

6. What will happen to me if I take part?

A Rheumatologist will confirm the diagnosis of Rheumatoid Arthritis and examine your muscles. As a rule this will take place in a room in the Rheumatology Department at Ysbyty Gwynedd or in the outpatient department at one of the Trust's other hospitals. However if it is more convenient for you we could arrange a private room at the School of Sport, Health and Exercise Sciences, Bangor University.

Once this has been done you will have a single interview with Anne Kirkham, the chief investigator this should last no longer than 90 minutes. You can invite a friend or family member to come with you.

Four weeks after the initial interview ten participants will be randomly selected and asked to take part in a single follow up interview. This interview will also be with Anne Kirkham and will last for no longer than one hour.

7. What do I have to do?

During the interview you will be asked to draw your pain and choose from a selection of adjectives you feel are the most appropriate to describe your pain. In addition you will be asked to complete a brief questionnaire about which areas of your body are painful. You are free not to answer specific items or questions.

8. What is the drug or procedure that is being tested?

This study does not involve the testing of drugs or you having any procedures done to you.

9. What are the side effects of any treatment received when taking part?

The study does not involve any treatment so there are no side effects.

10. What are the possible disadvantages and risks of taking part?

We are aware that interviews can occasionally uncover sensitive feelings. If this happens you can of course stop the study or not answer certain questions. If you are troubled in anyway following your interview please feel free to contact the chief investigator. In addition Dr J Jones, consultant rheumatologist with a lot of experience in caring for patients with Rheumatoid Arthritis, or the Rheumatology Helpline at Ysbyty Gwynedd (details given later) will be available if required.

11. What are the possible benefits of taking part?

We are performing this study to try to improve our understanding about the sorts of pain which affect people with rheumatoid arthritis. We are hoping that our findings will help us identify different sorts of pain in rheumatoid arthritis which will respond to different sorts of treatment There is a chance that this will lead to improvement in the way pain in rheumatoid arthritis is managed.

This study may provide you with an alternative way to express the pain you live with due to your condition. In addition the information we gain from this study may show drawing images to be an effective way for patients to communicate their pain/distress instead of being confined to verbal expression.

It is possible that we may turn up some new information which could influence the way your pain and arthritis is treated. If this happens we will with your permission inform your rheumatology team and GP.

12. Will my taking part in this study be kept confidential?

All information which is collected about you during the interview will be kept strictly confidential. Any information which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it. With your permission your own GP will be notified of your participation in the trial.

13. What will happen to the results of the research study?

It is expected that the results from this study will be published in a scientific journal. The drawings may be used in lectures and presentations to illustrate how people with Rheumatoid Arthritis express their pain. However, it will not be possible to identify individuals from the presentations or reports.

14. Who is organizing and funding the research?

This research project is being funded by Objective 1 'European Union Social Fund' and the 'University of Bangor' in conjunction with 'Cennin Herbs'.

Patient Information Sheet for Study One. RAFM (Chapter 4) – Page 3

15. Who has reviewed the study?

This study has been reviewed by the University of Wales, Bangor and the local NHS research ethics committee.

Contact for Further Information

For further information about this study please contact,

Anne Kirkham

Chief Investigator

01248 388147 (Bangor University)

E-mail pep014@bangor.ac.uk

You can also contact

Dr Jeremy Jones

01248 385097 (Ysbyty Gwynedd)

The Rheumatology Helpline

01248 -384682 (Ysbyty Gwynedd)

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Medical Research and You'. This leaflet gives more information about medical research and looks at some questions potential recruits may want to ask. You may obtain copies from CERES, PO Box 1365, London N16 0BW. (www.ceres.org.uk)

Thank you for reading this information sheet. If you agree to participate in this study you will be asked to sign a consent form. It is very important that you ask us any questions or raise any doubts you have before signing the form.

You will be given a copy of this information sheet and the signed consent form to keep.

January 2007. Version 3 **06/WNo01/15**

Etimology List

Dia - before vowels, di-, prefix meaning "through, thoroughly, entirely," from Gk. dia-, from dia "through, throughout," probably from the root of duo "two" (see two) with a base sense of "twice."

Diagnosis -1680s, medical L. application of Gk. diagnosis "a discerning, distinguishing," from stem of diagignoskein "discern, distinguish," lit. "to know thoroughly," from dia- "apart" (see dia-) + gignoskein "to learn" (see gnostic).

Diameter - late 14c., from O.Fr. diametre, from L. diametrus, from Gk. diametros (gramme) "diagonal of a circle," from dia- "across, through" (see dia-) + metron "a measure" (see meter (2)).

Diaspora - 1876, from Gk. diaspora "dispersion," from diaspeirein "to scatter about, disperse," from dia- "about, across" (see dia-) + speirein "to scatter" (see sprout). The Greek word was used in Septuagint in Deut. xxviii.25. A Hebrew word for it is galuth "exile." Related: Diasporic

Diagram - 1610s, from Fr. diagramme, from L. diagramma, from Gk. diagramma "geometric figure, that which is marked out by lines," from diagraphein "mark out by lines, delineate," from dia- "across, out" (see dia-) + graphein "write, mark, draw" (see -graphy). The verb is 1840, from the noun.

Diaphragm - late 14c., from L.L. diaphragma, from Gk. diaphragma "partition, barrier, muscle which divides the thorax from the abdomen," from diaphrassein "to barricade," from dia- "across" (see dia-) + phrassein "to fence or hedge in." The native word is midriff. Meaning "contraceptive cap" is from 1933.

Agnostic - 1870, "one who professes that the existence of a First Cause and the essential nature of things are not and cannot be known" [Klein]; coined by T.H. Huxley (1825-1895) from Gk. agnostos "unknown, unknowable," from a- "not" + gnostos "(to be) known" (see gnostic). Sometimes said to be a reference to Paul's mention of the altar to "the Unknown God," but according to Huxley it was coined with reference to the early Church movement known as Gnosticism (see Gnostic). I ... invented what I conceived to be the appropriate title of 'agnostic,' ... antithetic to the 'Gnostic' of Church history who professed to know so much about the very things of which I was ignorant. [T.H. Huxley, "Science and Christian Tradition," 1889]

Gnostic - 1580s, "believer in a mystical religious doctrine of spiritual knowledge," from L.L. Gnosticus, from Late Gk. Gnostikos, noun use of adj. gnostikos "knowing, able to discern," from gnostos "knowable," from gignoskein "to learn, to come to know" (see know). Applied to various early Christian sects that claimed direct personal knowledge beyond the Gospel or the Church hierarchy. The adj. meaning "relating to knowledge" (with lower-case g-) is from 1650s.

Prognostic - c.1600, from M.L. prognosticus, from Gk. prognostikos "foreknowing," from progignoskein (see prognosis).

Therapeutic - pertaining to the healing of disease, 1640s, probably shortened from therapeutical (c.1600), from Mod.L. therapeuticus "curing, healing," from Gk. therapeutikos, from therapeutes "one ministering," from therapeutein "to cure, treat," of unknown origin, related to therapon (gen. therapontos) "attendant." Therapeutic was used from 1540s as a noun meaning "the branch of medicine concerned with treatment of disease."

CHAPTER THREE

SEMI STRUCTURED INTERVIEW QUESTIONS AND EXTRACTS

QUESTIONS

1. **WHAT DO THE IMAGES YOU HAVE USED REPRESENT TO YOU?**
2. **WHAT ARE THE MOST IMPORTANT EMOTIONS FEELINGS THAT YOUR DRAWINGS/COLOUR REPRESENT FOR YOU?**
3. **WHAT IS YOUR THOUGHTS AS YOU LOOK AT YOUR DRAWING?**
4. **HOW DO YOU FEEL AS YOU LOOK AT YOUR DRAWINGS?**
5. **WHAT EMOTIONS DID YOU EXPERIENCE WHILST YOU WERE DRAWING?**
6. **WHAT WOULD YOU SAY YOUR DRAWINGS ARE TELLING ME ABOUT HOW YOU FEEL ABOUT YOUR LIFE AT THIS MOMENT IN TIME?**
7. **HAVE YOU EVER EXPRESSED YOUR PAIN/EMOTIONS IN THIS WAY BEFORE?**
8. **HOW DID IT FEEL TO BE ABLE TO USE COLOURS AND DRAWINGS TO CONVEY THE PAIN/DISTRESS OF YOUR CONDITION?**
9. **HAS TAKING PART IN THIS EXERCISE MADE YOU THINK ABOUT YOUR PAIN/DISTRESS IN A DIFFERENT WAY?**
10. **WHAT INSIGHTTS IF ANY HAVE YOU GAINED ABOUT YOURSELF BY COMPLETING THIS EXERCISE?**
11. **DID YOU FIND IT THERAPEUTIC TO EXPRESS YOUR PAIN/DISTRESS EMOTIONS USING THIS METHOD?**
12. **DID YOUR RESPONSE TO THIS EXERCISE SURPRISE YOU?**
13. **WOULD YOU SAY THIS EXERCISE HAS HELPED YOU IN ANYWAY? IF SO HOW?**

1 WHAT DO THE IMAGES YOU HAVE USED REPRESENT TO YOU?

01 - Hammer smashing bricks, fingers freezing snow, toes like lightning pain, back of neck being cut open with a knife. Heavy machine rolling up leg

05 – Spiky pain, not smooth or smooth running. There are no smooth lines – it is just chaotic – just chaos!

07- Fire in the head like a volcano ready to erupt, literally like a sharp knife around the left breast and the constant throb in the wrists, elbows and the same in the knees. At the back it is like a train track, it is moving all of the time, it doesn't feel very safe and at the bottom just feels like it is on fire all of the time the same at the top. The hips are painful just feels like they are being grinded. Feet feel like sharp needles.

10 – Bowl of spaghetti tangled up, muddled pain, it all intermingles, it doesn't start or join anywhere really, It doesn't start or finish anywhere- it is just a whole body experience

14- Evil

18- No image

21 –Feeling of a sharp pain like its being cushioned it should be sharp but it isn't because it is cushioned and sometimes in different parts it actually feels twisty – the image of a dagger in a cushion

23 – Thunder, lightning and shooting pains

24 – No images

26 -Trapped, compressed, always angry frustrated with myself..almost like being forced into a smaller space, compression. No escape from the pain..you hate your body..you want to control it and it controls you…the lack of control is what I hate most

27 – Elastic band around head, weighty feeling in arms, feet kicked in back, stabbing knives in hips

28 – Black cloud heavy

29 – Cloak pain don't want to know anybody – lightning strikes, dark cloak pain shooting through

30 – Feel trapped because of so much pain cannot do the things I want to. Trapped in a cage – my body and doesn't allow me to do the things I want – not just the pain but the fatigue

31 - Mind goes blank – frightening pain...Knife- stabbing…numbness in hip…swollen joints

32 – Me in prison…no way out constant…My body is a prison...my mind doesn't work…everything looks black…the sun is shining out there but I don't see it because I haven't got the strength

2 WHAT ARE THE MOST IMPORTANT EMOTIONS FEELINGS THAT YOUR DRAWINGS/COLOUR REPRESENT FOR YOU?

01 - Like inside of an operation, horrid sensation

05 - Black, just darkness. There is no light, no glimmer there is no light. I feel as if I am fighting all of the time but i cannot see what i am fighting. Dark/black means there is no way out of the pain. I can't see it. I would love a couple of week's holiday away from the pain.

07- Pain – not knowing how to deal with it. Emotions – very tearful – I don't think any of the day is normal from one minute to the next – you can be very low one minute and then laugh and be very happy the next for no reason. It is like all of the time – there isn't anything that actually triggers it off – you can't explain it

10 - I really feel quite sad actually – emotional- really quite emotional- I feel upset. They really do make me feel sad to think those things have gone on in my body and are going on and haven't changed for a long time – it is not what a normal body should look like – I just feel that the body should be quite clear

14 – Hate for the pain

18 – Red is a real strong pain; blue is cold; white is frozen

21 - Fear – I mean it obviously restricts me from doing things I might be able to do and the fear is it will get worse to the point where I won't be able to do things that I want to do. I kind of have an image of me at 55 or something just not being able to take the dog out for

a walk and being immobile and confined…and when you realise those things in your head just goes…marches away with you …totally irrationally a lot of the time… so by the time I've finished that process I am in a wheelchair kind of thing. It is fear and also frustration!

23 – Depression

24 – Frustration...Fed up... Annoyed with it all and yet I get very depressed but basically frustration and the feeling it will never go away

26 – Anger, definitely frustration, depression...Ultra sensitivity... anxiety...Tearfulness…and the feelings of being so limited.

27 – Red as most powerful, green is constant orange is heavy burning dark blue knives associated with being the miserable one that really does get me down, light blue miserable colour- blue always makes me feel miserable Black miserable colour

28 – Black depression

29 – Pain very sad very very dark shades of grey, black…as if I am in a cloak...Don't want to come out of that cloak..Stay in there away from it..And then it's like flashes..lightning pain and attacks parts of my body…when I am like this don't come near me- leave me alone – in other words I want to bloody die!

30 – How can anyone live with so much pain and carry on

31 – Frightened of pain… frightened of falling and people watching

32 – I feel tearful because I am like this – I feel like giving up...not on life… but on trying to take away my life

3 WHAT IS YOUR THOUGHTS AS YOU LOOK AT YOUR DRAWING?

01 - Horror – all of it – if it was just one place

05 - I don't know – just darkness

07 – see somebody that is in pain – there's nothing positive about it, it affects every part of the body. There's not one area that isn't covered – it applies to every part of the anatomy.

10 – When I started to colour them they started to make more sense to me… I don't think of it as a whole I think of it as a pain in the body. Never really thought of it as a whole just individual pain as they are not all evident at the same time

14 – Want them all to go away – surprised at the extent

18 – The pain is horrible/ because I am a diabetic asthmatic OA FMS

21 - Interest in a way as I haven't ever given it that amount of thought… I mean initially when I first had the diagnosis I was worried because of the exhaustion that comes with that…

23 – horrible – want to scream

24 – I suppose I realise how littered I am with pain.. I suppose I'd never connected them up before…they've just been different... that must be that and that must be well you know...Arthritis

26 – I look a mess…looking at them makes me realise it has almost taken over my whole body and turned me from a positive person to negative and pessimistic

27 – Feel sorry for myself

28 – Depressed

29 – How much pain I am in, depression… I just think it is me

30 - Sadness

31- Normally I just say I have pain in my hip or something…doesn't tell people all the pain I am really in. Looking at the drawings brings it home to me… If I wasn't on pain killers the whole thing would be coloured.

32 – Sad...Very sad…that is how I have made my drawings

4 HOW DO YOU FEEL AS YOU LOOK AT YOUR DRAWINGS?

01 - Horrible upset because I don't want to feel like it

05 - That is the intensity of it. I don't know whether I am accepting of it. No man's land. I feel like I am in no man's land!

07 – Sad really

10 – You look at that and think that must be an unhappy person… that is what it is like in my body…surprised really… I know its there but tend to not dwell on it and just believing that one day the pains will go away

14 – Very cross

18 - no comment

21 – Slightly embarrassed... um...it feels a bit strange sitting down and talking to you about it in these terms… I have to think about it on a completely different plane

23 – Want to be ill

24 – depressed – I kind of keep hoping if I keep mobile and keep doing all of my physiotherapy and all this kind of thing it might just all go away.

26 – I feel I have got to find a cure…something I can do about it or alternatively learn to live with it and adapt... but that makes me depressed because I am a doer I am afraid..the word I always use to describe it is a 'burden' a heavy burden that you carry around every day

27 - Sad

28 – Black no hope depressed

29 – Sad the emotional pain is more than the physical

30 – Frustrated, angry...Sad

31 – Frustrated and sad… I want to do things for myself but cannot do things like cleaning…shopping…ironing because pain is so bad

32 – Sad...Depressed…it pulls me down because I feel like this

5 WHAT EMOTIONS DID YOU EXPERIENCE WHILST YOU WERE DRAWING?

01 – Upset (crying), I cry all of the time. I felt in control as I was drawing a good feeling with a little bit of frustration and anger behind it.

05 – I didn't experience any emotion at all – that is just how it is- I'm matter of fact about it

07 - Trying to put it into pictures is hard – the pictures are there but it's applying it. It is hard to identify which bit is the volcano and which bit is the train track and things like that because at some point during the day all of it applies to every bit of you and it is trying to link that picture with that pain – the actual area. But knowing the image is no problem- I know the image

10 – The colours were there straight away… the image would just say to me what the colours were... Before I'd even looked at what colours you had I could see the colours coming in.

14 – Anger

18- The pain is always there

21 - I was initially diagnosed with chronic fatigue and did a 6 week course which was very good… I think I was very lucky that my GP took it seriously… actually referred me to people that did not allow me to wallow in it… and I am really grateful for that because I think it would have been very easy for me to think 'oh my god' but there are times when I think that maybe I am making this up…sometimes worse than others I think sometimes may be I am a fraud

23 – Lowness, depression

24 – Depressed

27 - Sadness

26 – I was concentrating too hard on what I was doing but I don't think until I actually drew it that I accepted it –– Red-burning partly the emotional anger and the intensity – Black – cloud of depression that comes with the pain it is like a feeling of imprisonment – Purple – areas of pain less intense I can live with those

27 - Sadness

28 – Depression

29 – Sadness, depression

30 – Frustration, full of rage trapped in a cage…my body

31 – Just thinking about what I was drawing

32 – fed up and tired of being like this

6. WHAT WOULD YOU SAY YOUR DRAWINGS ARE TELLING ME ABOUT HOW YOU FEEL ABOUT YOUR LIFE AT THIS MOMENT IN TIME?

01- I feel like I am stuck in a time warp and stuck in a black cloud like people describe for depression except its not depression it's a pain thing.

05 - I am not happy I suppose – I am and I am not it's a bit weird. I am not happy with me if you like so dark represents me – dark I suppose!

07 – I think they will be colours of pain, negative although there are some vibrant colours there you know it is just pain. Colours of heat rather than brightness. So although I've used colours black is more representative of how I am feeling

10 - Angry – is that a wrong emotion to use – angry that… not that I would wish it on anybody else but angry you know I am not really one of those "why me" people but just angry that i have had it such a long time. I AM JUST ANGRY THAT IT MANIFESTED ITSELF AND THAT I AM IN PAIN, DISCOMFORT. Getting emotional now – I think I am angry at myself the way I take it all on board – the way I perceived things that have happened in my life and why havn't I been able to deal with things in a better way. Frustration! No one else knows – no one else can feel it. So angry with myself for making this happen to me; if I had dealt with things in a different way I would have been a stronger person. The body wouldn't have resulted in this mess.

14 - nice to be able to tell someone I've got all of the pain in all of these places

18 - That I am feeling down

21 – That I experience pain and that sometimes it is worse than others and causes me to have some difficulty in some areas of my life

23 – Depressed

24- I suppose I am trying to tell you something I had not thought of before in terms of words or images

26 – I feel as though I have still got my physical mind and body but I can't go forward in anyway

27 - Feeling sadness… very sorry for myself

28 – Depressed

29 – I have a lot of depression which doesn't help…an emotional upset or stress will start it off

30 – Sad trapped angry frustrated

31 – Frustration and sadness

32 – My life is sad because I am like this all the time black is pain and tired...Don't see colours since a few years life seems black for me... I used to see colours

7. HAVE YOU EVER EXPRESSED YOUR PAIN/EMOTIONS IN THIS WAY BEFORE?

01 – Not in this way

05- No

07 - No

10 - No

14 - No

18 – No

21 – No

23 – No

24 – No

26 – No

27- No

28 – No

29 – No

30 – No

31 – No but have used pain drawings before in pain clinic

32 – No...only to point out pain in clinic

8. HOW DID IT FEEL TO BE ABLE TO USE COLOURS AND DRAWINGS TO CONVEY THE PAIN/DISTRESS OF YOUR CONDITION?

01 - A little bit therapeutic really

05 - What I would really like to do is colour the whole body shape in black. I didn't consider other colours – only black

07 - It's good

10 – It was good – quite cleansing quite nice – good

14 - I suppose it was actually quite good to put it down on paper

18 – Words are simple enough to describe how you are feeling

21 - Well it felt difficult

23 – Found it difficult… cannot see anything but black at the moment

24 – I think it could grow on me... when you think more about it..I had never really thought about it like that...when you think about it there can be various shades of colour and various shades of grey I suppose

26 – I think it was good really – it enabled me to see the extent of it on paper

27- I suppose it is helpful because it makes you think about how you do feel about it

28 – Therapeutic

29 – It has made me feel better… it makes me feel as if I am not on my own in the wilderness screaming out and nobody listening.. I feel like I have gained a friend, I feel people like you who have suffered understand … feel you understand… someone who hasn't experienced the pain listens but they don't really understand…

30 – good

31 – Drawing the pain was helpful… don't really see colour with it at the moment…black is pain

32 – I felt I could explain easier to you

9. HAS TAKING PART IN THIS EXERCISE MADE YOU THINK ABOUT YOUR PAIN/DISTRESS IN A DIFFERENT WAY?

01 – When I do movements I've beaten the pain by doing stronger movements even if it is only for seconds

05 – May be to focus more to where the pain actually is rather than just saying all over. To say where it is otherwise I would just colour the whole thing. I really felt like colouring the whole thing – that is how it feels

07 – Yes I think it has, it is linking it to everyday life – just different to things you see and know about

10 – Yes, now I will visualise the whole whereas before I would just visualise an area, never dwell on it for very long.

14 – No – it still won't go away

18 - Not really

21- Yes it has… because I would never have thought about it in those ways

23 – Not really

24 – Yes it has...made it clearer by identifying it more than anything…because I have had it for such a long time it has just been I have that...That hurts…and that hurts…I just kind of assumed that other people hurt like that too…you don't tend to think that other people are quite normal without it…that's odd

26 – It has made me realise that it is more extensive than I thought

27 – Different approach to pain…think of colour/lights to release

28 – Yes – blocked off pain – not thought about it like this before

29 – Not really

30 – Not really

31 – Not really

32 – Not really…but it is good to speak to someone who understands

10. WHAT INSIGHTTS IF ANY HAVE YOU GAINED ABOUT YOURSELF BY COMPLETING THIS EXERCISE?

01 – Self awareness and self management

05 - Well I don't see colour where pain is concerned – I don't really see anything apart from the pain. May be I am absorbed with myself because of the pain and I don't see anything else because of the pain.

07- It makes you think about the pain as in different areas rather than as a whole. Separating every one of them as every part is hurting

10 - If I was healing and visualising now that is what I would use whereas before I haven't. I have never given myself enough time to do it always been distracted by something

14 – Don't know

18 - None really

21 – I suppose going back to the health aspect when I was in Eryri Hospital I really did a lot of thinking about it then… it was the recurrence of the pain rather than the exhaustion … I am now able to manage it

23 – None really

24 – I suppose it makes you think there is a lot more to it than what you imagine really…there are a lot more people going through these things but probably they have a lot worse than I have. I know I cope with it…there are a lot of people who are housebound…it worries me that will happen to me.. and I keep on thinking 'oh my god what am ia going to be like in five years from now…as long as I can live with it …and not think am I going to get worse

26 – I have got to take control and stop letting it control me

27 – Helped me to look at my pain in a different way

28 – I was going to say none but that is not quite true

29 - It has been good to talk to someone who understands

30 – None really

31 – None really

32 – None really

11. DID YOU FIND IT THERAPEUTIC TO EXPRESS YOUR PAIN/DISTRESS EMOTIONS USING THIS METHOD?

01 – Yes

05 – No, I wouldn't say therapeutic another way of experiencing it may be, but not therapeutic- I am not relieved so that is not therapeutic to me

07 - Yes

10 – Yes

14 - No comment

18 – No, expressing yourself

21 - It was interesting to think about it in a different way… the insight came when you asked me the question was it easy to describe it using colours, drawings or words – it actually made me realise how reliant I am on words but I am not very good at using other methods to describe things

23 - No

24 – Yes it did…it was good to talk about them and trying to put feelings and colour down where I had never done that before

24 – yes – I it did… I guess it was good to talk about them and trying to put feelings and colour down where I had never done before

27 – Yes – helped me to talk about my sadness

28 – Yes

29 – Yes

30 – Yes

31 – Yes

32 – I found it therapeutic to be able to discuss it rather than just being given tablets

12. DID YOUR RESPONSE TO THIS EXERCISE SURPRISE YOU?

01 - Yes

05- No, I am a bit of a cold fish really; I suppose I am not easily impressed. I am quite cynical and I shouldn't be really. I am very emotional in other ways as well. People have to earn it – I am just not impressed that easily

07 - How easily I could access images to describe the pain

10 - I surprised myself being able to do it because I am not very demonstrative about myself. I do feel a little bit greedy taking this time to talk about myself

14 – Yes I suppose so

18 - some of the questions

21 – No – I mean I haven't ever used it before and when I first spoke to you I thought I can never possibly do it and that I can actually visualise it in image rather than thinking about it in words… yes

23 – Found it helpful

24 – yes- I think it did really

26 – Never used drawings before – didn't have any expectations

27 – Yes

28 – Yes

29- Only the way I have talked about everything

30 – Yes.. I was worried about the picture...How do you explain pain

31 – Yes

32 – I am surprised that someone is interested in this form of suffering

13. WOULD YOU SAY THIS EXERCISE HAS HELPED YOU IN ANYWAY? IF SO HOW?

01 - Momentarily

05 - I will go away now and think about it – my thoughts and feelings- I will go away and try to analyze it a bit later.

07 - Identifying them – what is hurting the most and least rather than amalgamating them all into one

10 - Very much – it has been very therapeutic to be able to talk about it

14 – Yes because you know someone else has got it and you are not going mad

18 - No comment

21 – Well yes because it has made me think about it in different terms so… sometimes things like this don't become immediately apparent…and you kind of store them away and you mull them over and they can make a difference down the line sometimes

23 – Yes…it has made me think about pain in a different way

24 – It helps in realising where all those bits are, kind of joining them all up

26 – Yes – I think so; because it is the first time I have discussed the pain with anyone else other than the consultant, and not in the same way

27 – Helped me to look at my pain in a different way

28 – Yes – therapeutic

29 – Not feeling so alone in the pain

30 – Therapeutic

31 – Drawing the pain was helpful

32 – Yes... I feel that someone is willing to help and that I am not a nuisance…because when I go to surgeries most Doctors don't want to know!

Chinese Meridians

In traditional Eastern medicines such as Chinese healing and Indian Ayurveda it is accepted that health is based on the continuous harmonious flow of energies. It is believed that an intricate realm of subtle energy flows permeates the universe and that the physical, material world is a gross manifestation of these energies. This energy has distinct and established pathways, a definite direction of flow, and characteristic behavior which is well defined.

Illness or pain occurs when a pathway becomes blocked, and the energy flow is disrupted and the body's harmony is broken. The meridians are pathways via which the energy of the universe circulates through the body's organs and keeps the body and the universe in harmony.

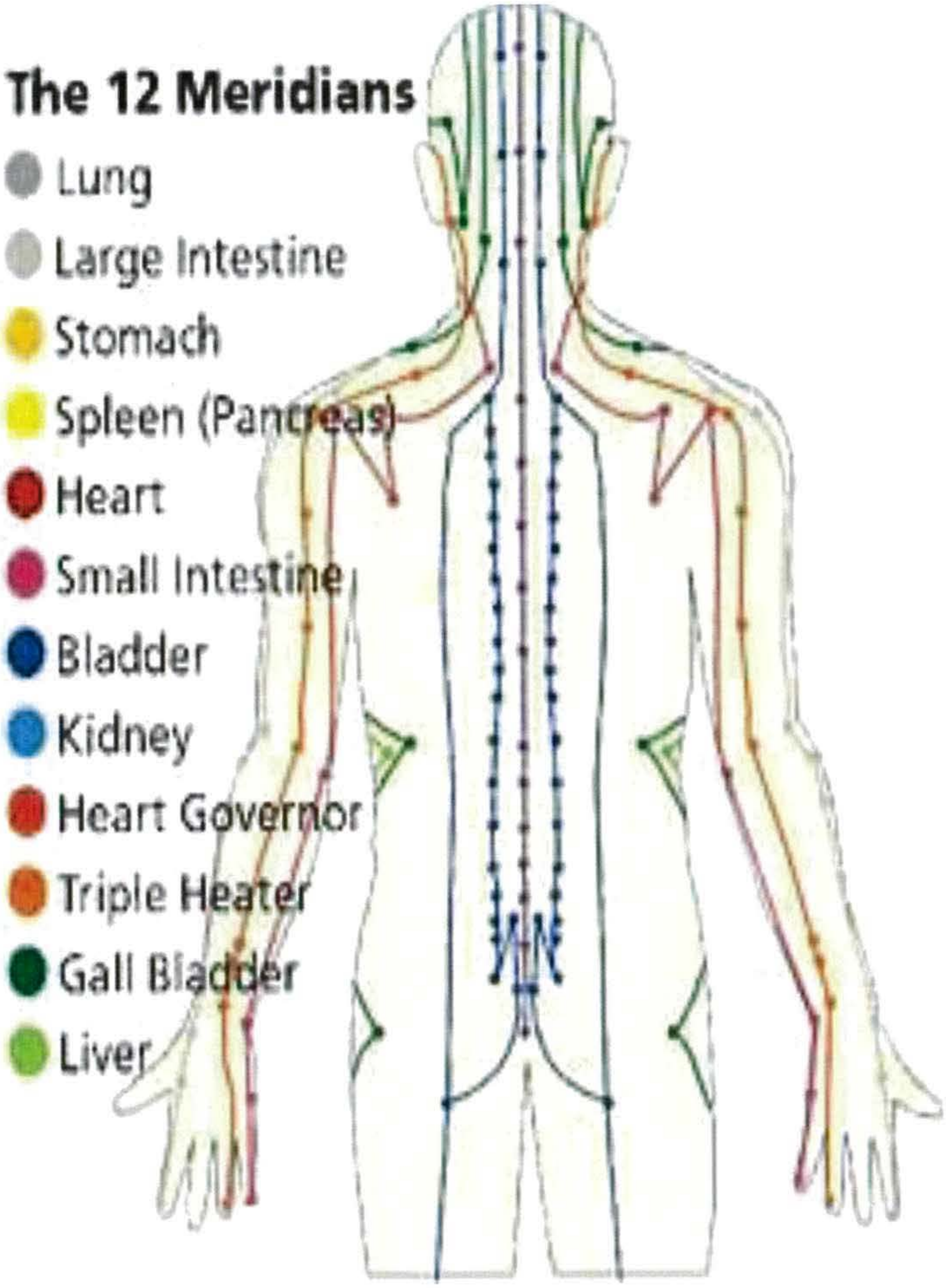
The ancient Chinese Meridian Theory, upon which acupuncture is based, refers to a system of energy that flows throughout the body. It consists of twelve pairs of main meridians that flow each side of the body, and two specific meridians or vessels all of which are connected to a network of smaller meridians. Together these constitute the body's energy system that works to maintain health.

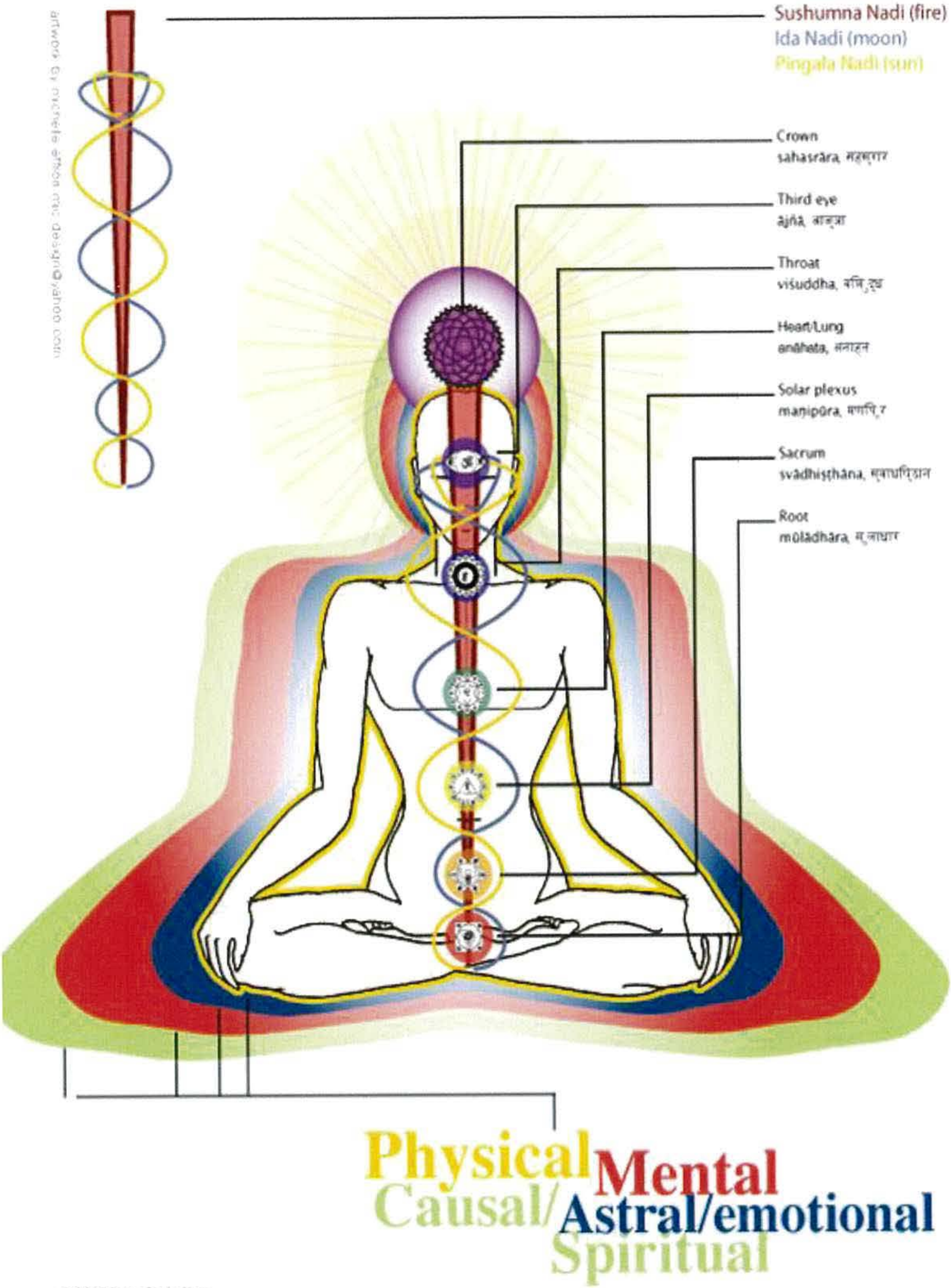
The Chinese developed a system of healing known as acupuncture that involves placing needles along these meridians or energy pathways in order to unblock them and balance the body and thereby restore and maintain health.

The following table cites the clinical relevance of some of acupuncture's modes of action.

Physiological action of acupuncture	Probable clinical relevance
Local release of calcitonin gene-related peptide(CGRP)	Powerful vasodilator
Stimulation of A delta nerve fibers	Analgesia. Acupuncture ineffective unless nerve supply is intact
Local action on dorsal horn	'Closing the gate' to incoming pain signal
Stimulation on ascending and descending pain inhibitory pathways	Produces heterosegmental pain relief, i.e. throughout the body
Endogenous opioid release: b-endorphin, met-enkephalin, dynorphins	Some effects can be blocked by naloxone(but not at kappa opioid sites)
Opioid gene up-regulation, e.g. preprometenkephalin, preprodynorphin	May explain sustained beneficial effects of treatment
Releases cholecystokinin(CCK)	Endogenous opioid antagonist, can contribute to acupuncture tolerance Anti-epileptic
Releases ACTH	Anti-inflammatory
Releases oxytocin	Analgesic and sedative
Releases serotonin	Analgesic and mood enhancing
Releases nerve growth factor(NGF)	Has a trophic effect on sensory and autonomic nerves
Widespread autonomic effects	Normalizes blood flow, BP, gastric motility etc. Contributes to pain relief

(Filshie ,White 1998; Ernst, White, 1999)


The 12 Meridians
● Lung
● Large Intestine
● Stomach
● Spleen (Pancreas)
● Heart
● Small Intestine
● Bladder
● Kidney
● Heart Governor
● Triple Heater
● Gall Bladder
● Liver



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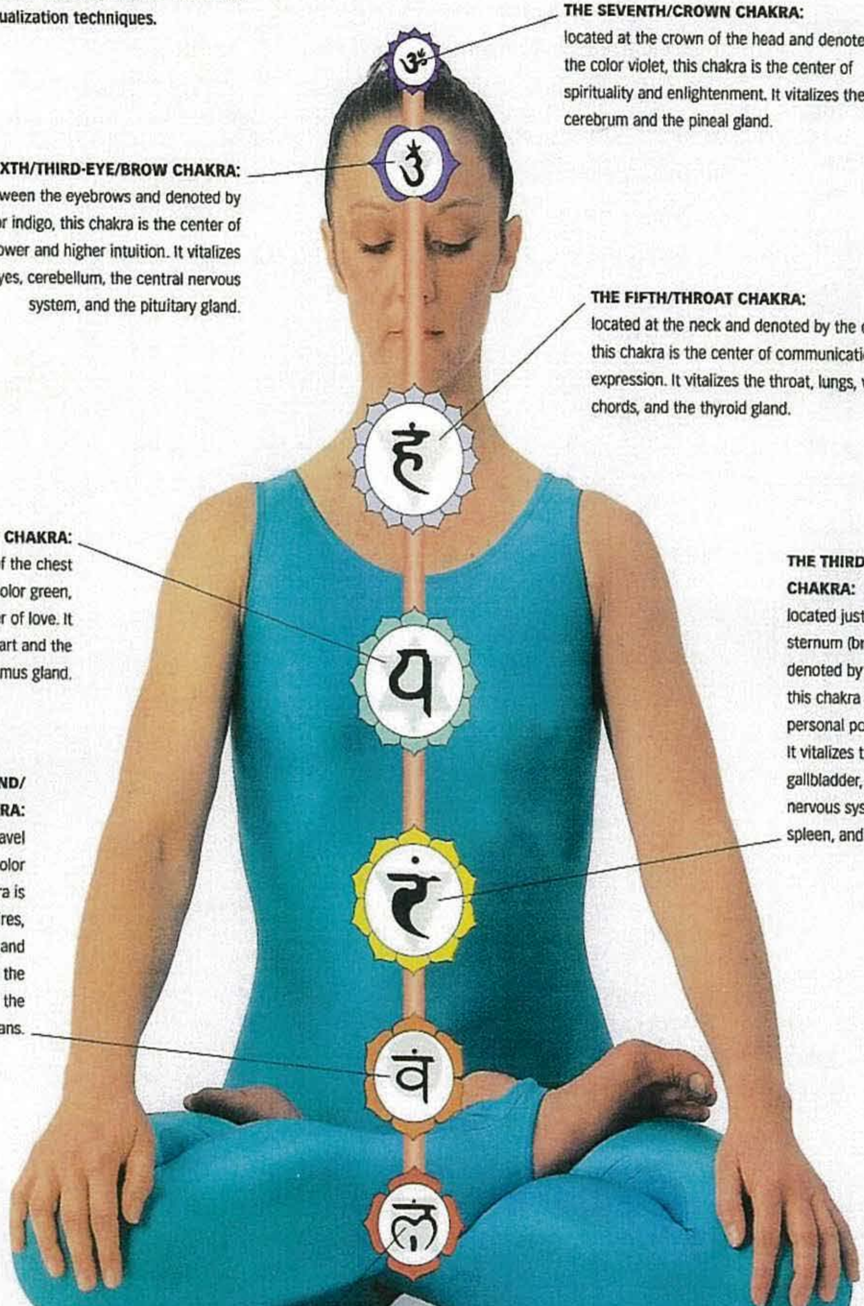
The seven chakras are acknowledged by many complementary therapies, and their imbalances can be diagnosed or treated using crystals, dowsing, flower essences, polarity therapy, or visualization techniques.



THE SEVENTH/CROWN CHAKRA: located at the crown of the head and denoted by the color violet, this chakra is the center of spirituality and enlightenment. It vitalizes the cerebrum and the pineal gland.

THE SIXTH/THIRD-EYE/BROW CHAKRA: located between the eyebrows and denoted by the color indigo, this chakra is the center of psychic power and higher intuition. It vitalizes the eyes, cerebellum, the central nervous system, and the pituitary gland.

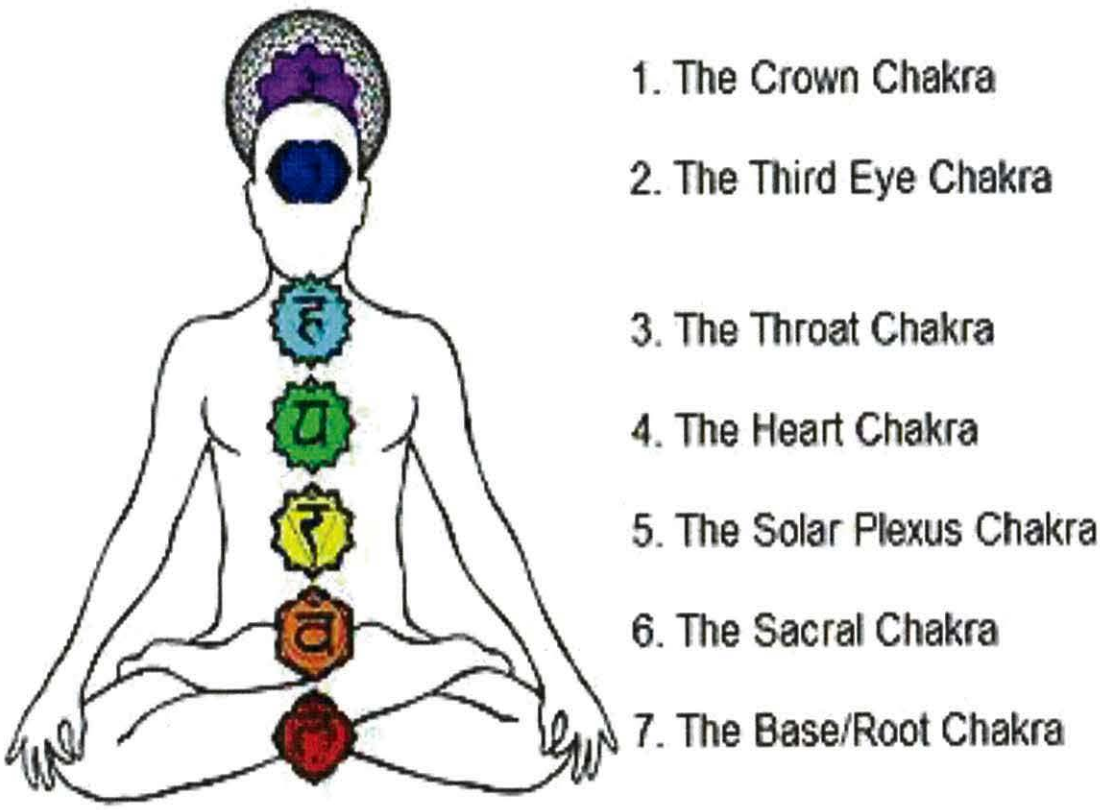
THE FIFTH/THROAT CHAKRA: located at the neck and denoted by the color blue, this chakra is the center of communication and expression. It vitalizes the throat, lungs, vocal chords, and the thyroid gland.

THE FOURTH/HEART CHAKRA: located in the center of the chest and denoted by the color green, this chakra is the center of love. It vitalizes the heart and the thymus gland.

THE THIRD/SOLAR PLEXUS CHAKRA: located just below the sternum (breast bone) and denoted by the color yellow, this chakra is the center of personal power and ambition. It vitalizes the stomach, liver, gallbladder, sympathetic nervous system, pancreas, spleen, and adrenal glands.

THE SECOND/ SACRAL CHAKRA: located just below the navel and denoted by the color orange, this chakra is connected to our desires, emotions, creativity, and sexuality. It vitalizes the digestive system and the sexual organs.

THE ROOT/BASE CHAKRA: located at the base of the spine and denoted by the color red, this chakra is connected to physical strength, determination and courage. It vitalizes the kidneys, the suprarenal glands and the spinal column.



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What are the 'molecules of emotion'? (Pert, 1997, 2000) Source: Master's Thesis 'Integrated Medicine in a Healthcare System' (2003) M .A. Kirkham.

In the Western world science has been regarded as the only source of valid truth. Therefore when science 'discovers' something that healing traditions have taught for thousands of years, suddenly it is given credence! The new paradigm of healing explores what makes people into 'holders of disease'. Contrary to ancient healing traditions which acknowledge the mind's influence on the body; the dominant worldview of medicine still does not consider that consciousness is an important causative factor of illness, but rather that it is a by-product of the neurochemical and electrical reactions in a person's brain (Pert, 1997).

However, recent scientific research by Dr. Candace Pert and her colleagues has uncovered information that proves it is time for the long held western belief to be reviewed by the orthodox medical community. There is a process of communication that in effect proves the body and mind to be one unit. Most of this activity takes place in the sub-conscious mind; which according to Pert's findings is the body itself, reporting chemical processes that enter the conscious mind as emotions. Her work has demonstrated there to be a flow of information moving throughout the whole organism providing evidence that the body is the actual outward manifestation in physical space of the mind. In the light of Dr Pert's discoveries the phrase "the power of the mind over the body" does not describe accurately what is happening. The mind does not dominate the body, it becomes the body.

This not only answers the question of how the mind manifests itself in various parts of the body, but also how the process can be brought into conscious awareness. Before her work, the emotions had not been scientifically investigated; her discoveries illustrate how the emotions are in fact the link between the spiritual world and the physical realm. By showing how all the systems are interconnected and that the body itself is in fact the sub-conscious mind, reporting back to the frontal cortex of the brain where the information is brought into conscious awareness via the emotions. Her work substantiates the theory that rather than being unscientific, consciousness is real. The central principle being that consciousness creates reality i.e. that consciousness and emotions are not to be ignored if complete health is to be achieved, and that they are in fact intertwined. This is a revelation with groundbreaking implications that will force the reductionist model to re-appraise its tunnel vision.

Dr. Pert's work centered on identifying and mapping 'receptor molecules on the surface of cells. Dr. Pert and her partner Dr. Michael Ruff established that the brain is densely populated with receptors designed to attract neuropeptides, and, crucially, discovered that these same receptors are found in every part of the body with neuropeptides attached to them. The molecules act like sense organs, in that they recognize and attract a specific type of stimulus. The particular stimuli associated with states of mind are called neuropeptides and bind to the receptor molecule, transmitting very specific instructions to the cell. For example, the peptide endorphin triggers the cell to generate feelings of well being. It is part of a larger group of chemicals known as neuropeptides, substances capable of altering moods at a cellular level. (They are naturally occurring molecules produced inside the cells then released into surrounding fluids; they are in effect messengers that seek out the right addresses to deliver the specific information that they carry).

The endorphin molecules are only attracted to opiate receptors equally other neuropeptide molecules are designed to bind with a particular type of receptor. For example neuropeptides associated with anxiety will only bind with receptors capable of receiving that information; similarly neuropeptides carrying messengers of excitement are attracted exclusively to 'excitement receptors' and so forth.

The body produces more than eighty peptides- including neuropeptides- which have been implicated in the body's digestion, breathing and many other bodily functions. For example the peptide insulin signals the cells to store sugar; and prolactin stimulates the production of breast milk. These peptides have been called "informational substances" because of their crucial role in guiding the body's responses to both inner and outer cues. Each cell in the body is studded with thousands of receptor molecules each one programmed to attract and bind with a particular peptide. They discovered that emotions trigger waves of messenger chemicals, called neuropeptides, which receive messages from all parts of the body, prompting changes that disturb or support homeostasis. In identifying the chemicals and molecules responsible for activating the body's complex responses to emotional arousal, she describes another pathway for the physiological effect of emotion on the body. This electrochemical pathway travels by way of the limbic system, which is the brain's emotional interpreter of incoming information, and down into the body by way of the adrenal glands and the autonomic nervous system. In this process, specific brain cells are activated to produce complex formulas of amino acid and peptide and neuropeptide chains, which find built-in receptor sites throughout the body that control physical processes that are involved in emotion and behaviour. Dr. Pert calls these "molecules of emotion" .i.e. they enable different body systems to communicate with each other. This information can be put there as a result of mental trauma or by a constant flow of negative thought forms being transmitted by the sub conscious; showing that the molecules of emotion are present throughout the body and that in effect the body is in fact the subconscious mind.

> "The molecules of emotion that we've been mapping for the last 25 years can be found identically in every part of our body. The idea that our mind is in our head is really an outmoded concept, its really peculiar to Western thought…it's not accurate to think that the mind is in the brain. There's just too much myopic focus on the brain."(Pert, 2000)

This means that a person communicates with their immune system and the immune system communicates equally with the body on a conscious and unconscious level. Results of groundbreaking studies of neuropeptide molecules illustrate how the exploration of the role that emotions play in the body is a key to the understanding of disease. In fact all the cells are linked by an intricate network of communications, of emotions; thus emotions were found to influence the immune system; equally the immune system influences emotions.

> "We know that the immune system like the central nervous system has memory and the capacity to learn. Thus it could be said that intelligence is located not only in the brain but in the cells that are distributed throughout the body, and the traditional separation of mental processes, including emotions from the body are no longer valid." (Pert, 1997: p.187).

Personal Statement

Until the age of twenty eight years I enjoyed a full, healthy and happy life, and rarely had cause to visit my doctor. After having my inoculations as a child to protect me from contracting polio, TB, whooping cough, measles etc., I only needed them to help me combat the occasional throat infection at which times antibiotics were prescribed. Nevertheless, I grew up in the common belief that should I need it, my doctor had a cure for all illnesses if indeed a cure was possible. Fortunately, like most people, I was healthy and active.

Then in 1988 my life changed dramatically when, after a bout of influenza, I fell seriously ill. Often too dizzy to get up from a chair, too weak to climb a flight of stairs, too tired to talk or even to listen, I suffered constant fevers, muscle aches, exhaustion and memory lapses. My life unravelled in a matter of months; but it was a long time before I was told that I was suffering from Myalgic Encephalomyelitis or chronic fatigue syndrome [M.E/CFS]. The illness was not officially recognized by the medical community despite all the debilitating symptoms; and because there was no standard medical test available so that doctors could prove its existence it was dismissed as being a psychosomatic disorder. Neither answers nor practical help were forthcoming.

My faith in doctors' ability and will to restore my health was rudely shattered. When I needed them most the only relief they offered me was a prescription for pain suppressing drugs and anti-depressants. I refused these prescriptions. I knew something was wrong and wanted to find the cause of my symptoms. I needed a reason to fight the pain, to survive the trauma and for the medical system to recognise that my illness was real and not imagined.

ME/CFS is a debilitating illness which took me to the depths of despair, and forced me to question the purpose of my existence. My health deteriorated dramatically to such an extent that I was bed-bound and unable to do most things for myself. For me even lying in bed in complete silence and darkness was painful. The illness continued until days became weeks and months and years until it became crucial that I find a cause for all of my suffering. I desperately needed to find a reason to keep fighting through the pain, and to survive the trauma. A trauma compounded by a medical system that bluntly refused to recognise that my illness was real and not imagined. In fact the medical establishment remained reluctant to acknowledge the existence of ME/CFS which was scathingly labelled 'yuppie flu' or a 'psychosomatic' problem until 2001.

Fortunately my family and close friends provided physical and emotional support through the painfully slow and arduous process of trying to find a treatment that might alleviate my condition and restore my good health. Gradually, I was introduced to complementary and alternative medicines (CAM). In my case, given that ME/CFS is such a complex illness I had to experiment with a diverse range of treatments. Some proved more effective than others; but each therapy seemed to bring me closer to regaining my health. As a result I have been inspired to study many of these therapies further with a view to helping others who face similar distressing and negative responses to their conditions from the conventional medical system.

The various healing modalities I tried whilst seeking some respite from my symptoms led to many profound spiritual experiences. Part of my learning was the clear connection between the physical pain and unresolved personal issues. Through my personal experience I have learnt how to listen to the messages of the body. Instead of perceiving pain as something bad that needs to be suppressed, I treat it as a friend that is simply trying to give me a message that something in my life needs to be adjusted. Each of the therapies provided keys which played a role in bringing me back to living a life relatively free of continuous physical and emotional pain.

Today I am qualified in Reflexology, Aromatherapy, Colour and Crystal therapy, Hypnotherapy and Indian head massage. In addition I am a 'Master 'of Reiki Healing and have a Diploma and MA with distinction in counselling and therapy. Through my counselling training I became a volunteer worker with the Benzodiazepine Service, an organization which helps people with 'prescription drug addictions'. As a result of the experience of working with addictions and their consequential problems I became aware of the dangers and potential downfall for people who become reliant on pain-killers and anti-depressants over long periods of time. It was, therefore, a culmination of my various personal experiences of the conventional medical system that led to Integrated Medicine being the focus of my MA thesis.

I wanted to explore the potential benefits of the conventional medical system evolving into an integrated healthcare system which would incorporate more CAM therapies into its treatment options for patients. It was the result of my own experiences and my belief in the need for the medical model to progress from a bio-psycho-social model to a more comprehensive bio-psycho-social–spiritual model that birthed the original concept for this PhD research .