'A Mindful Act' - Developing a brief ACT-based intervention for people receiving Osteopathy treatment and living with persistent pain



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Submitted to Swansea University in fulfilment of the requirements for the degree of Doctor of Philosophy

Swansea University 2019

Abstract

Background: Persistent pain represents a significant burden for individuals and society, exerting a profound effect on quality of life and posing a significant strain on healthcare resources. Novel interventions are needed to reduce the impact of psychological comorbidities on people who live with pain but also to improve pain self-management, enhance people's quality of life, and help them live a fulfilling life in the presence of pain.

Aims: The aim of this research was to develop a novel psychosocial intervention to accompany osteopathic treatment for people from Southwest Wales who live with persistent pain and psychological comorbidities. The MRC framework for developing complex health interventions (Craig et al. 2000, 2008) guided the development of this intervention.

Methods: A pragmatic approach that included a mixture of methods and procedures was chosen. The first phase consisted of conducting two qualitative studies to determine the needs and experiences of people living with persistent pain as well as the perspectives of osteopaths who treat them. A systematic review was conducted alongside to investigate the effects of osteopathic treatment on psychosocial factors in people living with persistent pain. The second phase consisted of utilizing the data from the first phase to inform the development of the novel intervention based on Acceptance and Commitment Therapy (ACT) principles. Focus groups and one-to-one interviews were the preferred data collection methods while data analysis was carried out using Thematic Analysis (TA) and Framework Analysis (FA).

Findings: The intervention appeared to be feasible with the support of the osteopaths. The intervention was found acceptable and no barriers to participation were reported. Program attendance was 82.5% and the participants engaged well with the exercises and with the ACT model in general. At one-month follow up, the participants reported that they continued to practice mindfulness, and continued to apply their knowledge of ACT to their personal circumstances.

Conclusion: Delivering a brief ACT-based intervention for people living with persistent pain was feasible and acceptable. All of the nine participants reported positive experiences. The collaboration between osteopaths and psychologists in supporting people who live with persistent pain demonstrates both innovation and potential and should be further explored in the future.

DECLARATION

Deci	laration

This work has	not previous	ly been ac	cepted in	substance	for any	degree	and
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Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Declaration:

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Located in Chapter 4

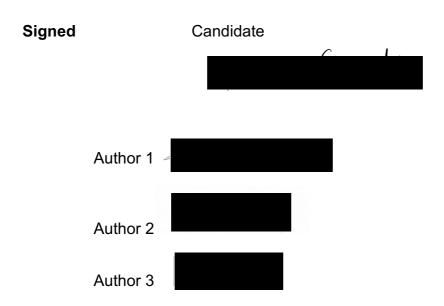
Maria Madalina Saracutu designed and operationalized the majority of the systematic review, wrote the majority of the paper, as well as edited the final draft. Dr. Darren J. Edwards supported Maria Madalina Saracutu in the conception phase as well as helping with the critical appraisal of the trials included in the review and making revisions to the manuscript. Professor Jaynie Rance and Dr. Helen Davies contributed to the conception and design of the study, and also helped revise the manuscript.

Paper 2: Protocol for a feasibility and acceptability study using a brief ACT-based intervention for people from Southwest Wales who live with persistent pain

Located in Chapter 6

Maria Madalina Saracutu designed and operationalized the majority of the protocol, wrote the majority of the paper, as well as edited the final draft. Professor Jaynie Rance, Dr. Darren J. Edwards and Dr. Helen Davies all contributed in helping MS with the design of the protocol as well as drafting the paper.

We the undersigned agree with the above-stated "proportion of work undertaken" for each of the above published peer-reviewed manuscripts contributing to this thesis:



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Acknowledgments

'Be grateful. That's one of the most important lessons in life, I think, is to just be grateful for every minute, every moment.' - Stephanie McMahon

Doing a PhD has been one of the most worthwhile and rewarding experiences in my life, one that has impacted my existence in a profound way, helping me develop as a researcher and also on a personal level. I would like to express my deep felt gratefulness to all of those who supported me throughout this journey.

First of all, I would like to thank my supervisor, Professor Jaynie Rance, who guided, inspired and motivated me throughout this PhD. I am deeply grateful for her excellent support, constant encouragement and valuable advice. I could not have wished for a better mentor and advisor. Without her help and guidance, this PhD project would not have materialized.

I would also like to express my gratitude to Dr. Darren Edwards and Dr. Helen Davies, who played an important role particularly in the initial stages of my PhD, providing instrumental support and advice in the development and publication of my research.

I gratefully acknowledge the support that I received from Dr. Julia Terry, who joined our supervision team in the fourth year of my PhD and provided helpful contributions for my thesis. I wish she had joined our team earlier.

I owe a sincere thank you to Julia Pridmore, Craig Toutt, Emma Oliver and the staff at the Health and Wellbeing Academy for their valuable contributions to several aspects of my research work including recruiting participants, engaging Osteopathy students and facilitating the intervention.

I am also grateful for their fantastic help with organising the Pain Toolkit workshops.

I would like to extend thanks to Nicholas Brace, clinical psychologist working within the Chronic Pain Assessment Team (CPAT) whose valuable insights helped me gain a better understanding of people living with persistent pain. I am also thankful for being given the opportunity to observe some of the work of the Chronic Pain Assessment Team (CPAT).

Carrying out this research would not have been possible without the efforts of the osteopathy students practicing at Swansea University Osteopathy clinic. They were instrumental in the recruitment process and were also involved in observing the intervention, showing great interest and involvement. I am also grateful to the Osteopathy students and tutors who took the time to participate in my focus groups and shared their experiences and insights. A special mention goes to Tom Johnson, from whom I learned a great deal about Osteopathy.

A special thank you is reserved for the wonderful participants in my intervention ('A Mindful Act') for their efforts and continued dedication. They were a source of inspiration and made my work worthwhile. Delivering the intervention was one of the most fulfilling experiences that I have ever had in my life.

I am deeply grateful to my colleagues from the College of Human and Health Sciences (CHHS) particularly to Emma Davies, Nick Weaver and Kerry Dare, who were a source of positivity and intellectual stimulation.

I would also like to acknowledge the fantastic support and practical suggestions provided all through my PhD by Maria Davies and Katie Retallick.

I am forever thankful to all my friends for their fantastic moral support and understanding. Thank you for sharing joyful moments but also helping me deal with difficult times.

I owe a huge debt of gratitude to my family for theri immense support, love, and patience. They might not have completely understood what my PhD was about, but they surely encouraged me every step of the way.

Last but not least, I would like to express my gratitude to Benjamin Jäger for putting up with me for the last four years. His unconditional love and support were paramount in this PhD journey.

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Abbreviations

ACT Acceptance and Commitment Therapy

MRC Medical Research Council

CAM Complimentary and alternative medicine

IASP International Association for the study of Pain

WHO World Health Organization

ICD-11 International Classification of the Diseases

MUS Medically unexplained symptoms

NCHS National Center for Health Statistics

YLDs Years lived with disability

DALYs Disability adjusted life years

COPCs Chronic overlapping pain conditions

CBT Cognitive Behvioural Therapy

MBCT Mindfulness-based cognitive Therapy

DBT Dialectical behavior therapy

MBSR Mindfulness-based stress reduction

RFT Relational Frame Theory

PACT Physiotherapy informed by Acceptance and Commitment Therapy

OMT Osteopathic Manipulative Therapy

GOsC General Osteopathic Council

CASP Critical Appraisal Skills Program

RCT Randomized Controlled Trial

QALY Quality-adjusted life year

TA Thematic analysis

FA Framework Analysis

IPA Interpretative Phenomenological Analysis

CHHS College of Human and Health Sciences

NSAIDS Non-steroidal anti-inflammatory drugs

ME Myalgic Encephalopathy

NLP Neurolinguistic Programming

HWBA Health and Wellbeing Academy

IMMPACT Pain Assessment in Clinical Trials

MMICS Multinational Musculoskeletal Inception Cohort Study

HADS Hospital Anxiety and Depression Scale

CPAQ-R Chronic Pain Acceptance Questionnaire

MAAS Mindfulness Attention and Awareness Scale

FABQ Fear-Avoidance Beliefs Questionnaire

ARCH A regional collaboration for health

CLBP Chronic low-back pain

CMWR Centre for Mindfulness-based Work & Research

1 Introduction

1.1 Introduction to the thesis

This thesis describes the process of developing a psychosocial intervention based on Acceptance and Commitment Therapy (ACT) designed to accompany osteopathic treatment for people experiencing persistent pain and psychological comorbidities. The Medical Research Council (MRC) framework (Craig et al., 2000, 2008) has guided the development of the intervention, whose steps will be explored in detail. The thesis will also present empirical evidence regarding the effectiveness of ACT for long-term pain as well as the effects of Osteopathy on psychosocial factors relevant in the development and maintenance of persistent pain.

1.2 Organization of the thesis

This thesis is structured to reflect the steps followed in the intervention development process. Consequently, Chapter 1 will outline the rationale for developing the intervention by referring to the integration of Osteopathy and ACT, as well as presenting the overall aim and the objectives corresponding to each stage of the development process.

Chapter 2 will lay the groundwork for the thesis, by addressing the complex nature of persistent pain and the burden that it exerts on people and societies, as well as outlining the most up to date approach to understanding and managing pain (the biopsychosocial model).

Chapter 3 will outline the research methodology adopted, including an account of the underlying paradigm, as well as the methods of data collection and analysis employed and the accompanying rationale. The chapter will include a discussion around pragmatism and mixed-methods, and will also address issues of validity and reliability and ethical principles.

Chapter 4 will then describe the process of identifying and appraising the existing evidence that was done by conducting a systematic review. Given that the new intervention was designed to accompany Osteopathy, and also considering the established role of psychosocial factors in the onset and maintenance of long-term pain, the systematic review focused on identifying and synthesizing relevant primary research evidence on the effects of osteopathic interventions on psychosocial factors in patients living with different pain conditions. The findings of the review played an important role in informing the development of the novel intervention.

Chapter 5 is concerned with the first phase of developing the novel intervention and consists of a preliminary qualitative study aiming to explore the needs, perceptions and experiences of people experiencing long-term pain and low to moderate depression, anxiety and/or fear avoidance as well as the experiences of osteopaths who treat them. Together with the findings of the systematic review, this qualitative study set the foundation for the novel intervention, by providing useful insights into the ways persistent pain affects people's lives as well as their preferences, capacities, and needs.

Chapter 6 will describe the second phase of the intervention development and will include an account of incorporating the results from the qualitative study with the results of the systematic review and existing theory and research literature to inform the novel intervention. This chapter will also describe the intervention protocol and procedures relevant in piloting 'A Mindful Act'.

Chapter 7 will present the findings and data analysis. The first part will include the results of the framework analysis employed to analyze the one-to-one interviews with the participants in the intervention as well as the results of the thematic analysis applied to the focus group data collected from osteopaths. The second part will include a quantitative analysis based on several measures of feasibility and acceptability.

Finally, Chapter 8 will provide a discussion around the key findings of this study, as well as presenting its strengths and limitations, its implications in terms of research, education and practice, future directions, and a reflexive account and concluding remarks.

1.3 Purpose of the thesis

1.3.1 Problem statement

Given that persistent pain represents a significant burden for individuals and society, exerting a profound effect on quality of life and posing a significant strain on healthcare resources, it is essential to improve the current understanding of pain and its management. With the recognition of the usefulness of the biopsychosocial model and the growing evidence on the impact of persistent pain on psychological and social functioning, novel interventions are needed not only to reduce the impact of psychological comorbidities on people who live with pain but also to improve pain self-management, enhance people's quality of life and help them reconcile acceptance of the condition with moving forward and living a fulfilling life in the presence of pain. Novel psychosocial interventions that integrate physical and psychological modalities are needed to address the complexity of pain and provide a more effective and acceptable alternative to the standard approach to pain management.

1.3.2 Rationale for a novel intervention combining Osteopathy and ACT

Developing a novel intervention combining Osteopathy and ACT can be justified in several ways. First of all, there is evidence supporting the effectiveness of ACT for people with persistent pain (see section 2.5.9), as well as a significant body of evidence emphasizing the effects of osteopathic treatment in managing persistent pain (please see Chapter 4, section 3.2). Integrating concepts and principles from third wave therapies like ACT may lead to an increase in the effectiveness of osteopathic care, and moderate the impact of psychological comorbidities. This type of pairing might have a strong synergistic effect, compared to standard care alone. In fact, there are recommendations to combine different types of treatment (physical, psychological, rehabilitative) to match patients' characteristics and individual needs (Turk et al., 2011). It is known that psychological processes influence the experience of pain and also the treatment outcomes; therefore there is a chance that integrating psychological approaches into physical therapy could enhance outcomes (Linton and Shaw, 2011).

Furthermore, the integration of complimentary and alternative medicine (CAM) and holistic modalities with conventional healthcare has the potential to yield significant health improvements. Osteopathy is increasingly provided in primary care settings; however, more research is needed to explore the potential benefits and cost-effectiveness of this type of provision. The economic burden of pain and the overwhelming impact of pain on individuals' physical, psychological and social wellbeing make research in this domain a priority. Including and reporting this type of evidence is needed to inform and facilitate evidence-based decision making among policymakers but also health practitioners and patients (Phillips, 2006). In addition, combination approaches offer the potential to encourage behaviour change and enhance self-management for healthier lifestyles and improved quality of life without the side effects often experienced with

pharmacological therapy (McCracken and Vowles, 2014; Foster and Delitto, 2011).

There is research suggesting that non-primary care health practitioners (such as osteopaths, chiropractors, and physiotherapists) may be ideally positioned to provide self-management and psychological support for people with persistent pain (Saracutu et al., 2018). Osteopaths can be trained to deliver an ACT-based intervention, leading to minimizing the costs related to training specialist staff or accessing psychological therapy. Given that ACT is almost exclusively delivered by psychologists or within multidisciplinary teams, psychology is a limited resource. Osteopaths and physiotherapists have increased contact with people who live with pain and are well placed to deliver brief psychological programs provided that they receive appropriate training and supervision.

Finally, Osteopathy and ACT are compatible at a conceptual level (see Table 1.1). While ACT aims to enhance psychological flexibility, osteopaths work to improve physical flexibility. Also, ACT focuses on increasing people's willingness to engage in meaningful activities in the presence of pain, which is similar to osteopaths' efforts to improve people's ability to perform more activities.

Osteopathy	ACT
Physical flexibility	Psychological flexibility
What causes the patient's pain?	How do patients react to their pain?
Ability to do more (with less pain)	Willingness to do more (with the same pain)

Table 1.1: Congruence of Osteopathy and ACT (reproduced with permission, The Osteopathy, Mindfulness and Acceptance Programme for persistent pain conference, 2016)

1.3.3 Thesis aim and objectives

The overarching aim of this research was to develop a novel psychosocial intervention to accompany osteopathic treatment for people from Southwest Wales who live with persistent pain and psychological comorbidities. The development of this intervention was guided by the Medical Research Council (MRC) framework for developing complex health interventions (Craig et al. 2000, 2008) and consisted of several steps: systematically identifying the evidence base, identifying relevant theory, determining the needs, and modelling process and outcomes.

Objectives of the first stage (Preliminary qualitative inquiry, see Chapter 5)

- increasing the current knowledge regarding persistent pain by conducting a preliminary qualitative study with people who experience persistent pain
- informing the development of an intervention by providing new understandings regarding people's experiences of living with pain.
- determining people's perceptions and readiness to take part in a novel intervention.
- exploring the views of osteopaths on their profession and their experiences treating people with pain

Objectives of the second stage (Comprehensive identification and appraisal of the evidence, Chapters 2, 4, 6)

• conducting a systematic review of the literature to synthesize relevant primary research evidence on the effects of osteopathic interventions on psychosocial factors in patients living with different pain conditions

- incorporating the results from the first study with the results of the systematic review and existing theory and research literature to inform the development of a novel intervention
- developing an intervention protocol

Objectives of the third stage (Feasibility and acceptability findings, Chapter 7)

- determining the feasibility and acceptability of the novel, ACT-based psychosocial intervention by conducting individual interviews and focus groups with the intervention participants and osteopaths.
- testing the procedures, estimating recruitment and retention and investigating changes in depression, anxiety, fear-avoidance, acceptance of pain, mindfulness, and health-related quality of life.

1.3.4 Publications

Parts of this work have already appeared in the following publications:

- Saracutu, M., Rance, J., Davies, H., & Edwards, D. J. (2017). "The
 effects of osteopathic treatment on psychosocial factors in people
 with persistent pain: A systematic review." International Journal of
 Osteopathic Medicine.
- Saracutu, M., Rance, J., Edwards, D. J. & Davies, H. (2018) "A Mindful Act: Protocol for a brief ACT-based psychosocial intervention for people with persistent pain and psychological comorbidities", BMJ Open

This chapter outlined the purpose of this thesis and its structure, as well as presenting the rationale for developing a novel intervention. The overall aims

of the study, as well as the objectives of each stage, have been delineated. The next chapter will present an overview of the current approach to persistent pain and its management as well as emphasizing the need for a novel pathway.

2 Background

2.1 Overview of the chapter

This chapter will outline the rationale for developing the intervention by addressing the complex nature of persistent pain and the significant burden that it exerts on people and the current challenges faced in providing effective pain management. The chapter will include an outline of the definition and classification of pain, as well as an overview of the current approaches to pain management from a biopsychosocial perspective, highlighting issues that need further improvement. The role of complementary and alternative medicine will also be explored. The need for establishing an alternative pathway combining Osteopathy and brief psychosocial interventions will be discussed with reference to the congruence between the two and the advantages that this new pairing may offer. Finally, the rationale for developing a novel intervention as well as the overall aim of the thesis will also be presented.

2.2 The complex nature of persistent pain

This section will provide an introduction to several different ways pain has been conceptualized throughout history. It will also present several definitions of persistent pain and a brief discussion around their usefulness. Finally, this section will include an overview of persistent pain from a biopsychosocial perspective and an introduction to the most prevalent comorbidities of pain.

2.2.1 A brief history of pain

Pain is an intrinsic part of the human condition. Life is marked by painful experiences (e.g. we are born into pain), however, over time people learned how to live with pain by extending their knowledge and finding tools to manage it while reflecting on its meaning. Throughout history, there have been numerous attempts to conceptualize pain and determine its nature. Claudius Galenus considered pain the lowest form of sensation and accepted the Greek theory of humours, associating painful diseases with an influx of black or yellow bile (Finger, 1994 in Raza & Khan, 2015). The Greek philosopher Epicurus viewed supreme pleasure as the absence of every type of pain while Plato suggested that there is nothing more pleasant for a person who is in pain than eliminating that pain (Nash, 2005). Similarly, Sir Thomas More labelled pain as the direct opposite of pleasure. The French philosopher Rene Descartes perceived pain as a physical sensation, attributing its cause to the nerve impulses produced by an injury and directly transmitted to the brain (Hall, 1972). In 1965, Melzack and Wall proposed one of the most influential theories of pain (the Gate Control Theory) according to which pain signals did not reach the brain once they were generated, but had to pass certain neurological gates present at the level of the spinal cord which determined if the signal would reach the brain (Raza and Khan, 2015). This theory also acknowledged that thoughts and emotions are an integral part of the pain experience and thus utterly rejecting Cartesian Dualism¹, an approach that had largely dominated the previous 300 years. Pain has also been regarded as an early physiological protective system that plays an adaptive role, for example, Paul Wilson Brand, a renowned orthopaedic surgeon stated: 'If I had the power to eliminate human pain, I would not exercise that right. Pain's value is too great.' (Brand in Raza and Khan, 2015, p. 120). This highlighted the fact that pain is essential for survival, with the inability

¹ The view that mind and body are two separate entities; the self is as it happens associated with a particular body, but is self-subsistent, and capable of independent existence (Oxford Dictionary of Philosophy)

to experience pain posing significant health risks (Sternbach, 1963). Pain is essentially an alarm system, warning us of a potential danger of injury; however, for people living with long- term pain, this is a weekly or daily occurrence that has a significant impact on their psychological wellbeing and quality of life. The burden of pain also has wide ramifications that affect physical, psychological, socioeconomic and occupational status (Belsey, 2002; Blyth et al., 2004).

Definition and classification of persistent pain

Chronic pain² or persistent pain has been defined as pain persisting beyond normal healing time (Bonica, 1953), or pain lasting or recurring for more than three to six months (Merskey and Bogduk, 1994). This definition is useful because it adds a temporal dimension, helping to differentiate between acute pain and persistent pain, however it is incomplete, as it does not provide any information regarding the experience of pain. The International Association for the study of Pain (IASP) referred to persistent pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage' (IASP, 1994, p. 209-214). Although this definition has been widely used, it also faced some criticism. First of all, it acknowledged the subjective nature of pain and also suggested that pain is multidimensional including both sensory and emotional features. Furthermore, this definition recognized that pain might occur in the absence of a pathology, which is consistent with the biopsychosocial model of pain (this model will be discussed in the next subsection) (Gatchel et al., 2007), suggesting that there might be different causal factors beyond tissue damage. Nevertheless, the IASP definition was criticized on the grounds that it failed to acknowledge the role of cognitive and social components, and it described the experience of pain as simply

² the terms "persistent pain" and "chronic pain" are often used interchangeably, but the newer term, "persistent pain," is preferred, because it is not associated with the negative attitudes and stereotypes that clinician

unpleasant by doing so potentially trivializing severe pain (Williams and Craig, 2016). More recently, Williams and Craig (2016) proposed an alternative definition stating that 'Pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components.' (Williams and Craig, 2016, p. 2420). First of all, their definition acknowledges the importance of subjective experience, thoughts, sensations and emotions as well as social considerations, providing a more complete understanding of persistent pain. In addition, by including the word 'distressing', they emphasized the aversive nature of pain experience. The authors also suggested that psychological issues might occur both in the presence or absence of tissue damage (Williams and Craig, 2016).

Another important acknowledgement is that pain can be a disease on its own but also a symptom of an underlying condition. The World Health Organization (WHO) adopted the new version of the International Classification of the Diseases (ICD-11) that was developed by the International Association for the Study of Pain (IASP). The new diagnostic categories distinguish between chronic primary pain (a disease on its own), and chronic secondary pain (a symptom of another condition) (Treede et al., 2019). This distinction is an improvement, as it allows for dual coding, improved classification and the development of targeted policies. The IASP task force brought together pain experts from around the world in an attempt to develop a pragmatic, research-based classification of pain to be included in the revised edition of the ICD (ICD11). The seven pain categories recognized were identified based on perceived location (e.g. headache), aetiology (e.g. cancer pain), or the main anatomical system affected (e.g. neuropathic pain).

Chronic primary pain (e.g. irritable bowel syndrome, 'non-specific' chronic low back pain, fibromyalgia)

Chronic cancer-related pain (e.g. chronic cancer pain, chronic postchemotherapy pain)

Chronic postsurgical and posttraumatic pain (e.g. chronic pain after amputation, chronic pain after burns injury)

Chronic neuropathic pain (e.g. chronic painful polyneuropathy, chronic central post-stroke pain)

Chronic secondary headache or orofacial pain (e.g. chronic orofacial muscle pain)

Chronic secondary visceral pain (e.g. chronic visceral pain from persistent inflammation or from vascular mechanisms)

Chronic secondary musculoskeletal pain (e.g. chronic musculoskeletal pain from persistent inflammation, chronic musculoskeletal pain associated with osteoarthritis)

Table 2.1: The seven categories of chronic pain conditions included in ICD- 11 (extracted from Barke et al., 2018)

2.2.3 Pain from a biopsychosocial perspective

For more than a century, the biomedical model has been dominant in Western medicine (Bennett, 2016). This approach postulated that pain originates through the physiological mechanisms in the human body (Bendelow, 2013). By seeking to explain all disease in biological terms, this model is reductionist³. This approach is currently the most commonly used in medical science, determining disease prevention, diagnosis and treatment (Glass and Hall, 2008). Physicians are typically treating disease by identifying a single abnormality in isolation, similar to the way mechanics locate the faulty part of a broken car (Ahn et al., 2006). While reductionism focuses on a treat-the-symptom process, holism⁴ takes into account cultural and existential dimensions and everything that affects health by focusing on

³ Reductionism is an approach to understanding the nature of complex things by reducing them to the interactions of their parts, or to simpler or more fundamental things (Retrieved from https://www.philosophybasics.com/branch_reductionism.html)

⁴ According to holism the universe and especially living nature is seen in terms of interacting wholes (as of living organisms) that are more than the mere sum of elementary particles (Retrieved from https://www.merriam-webster.com/dictionary/holism)

finding and treating the causes, rather than the symptoms (Federoff and Gostin, 2009). One good example is idiopathic pain, which is under the label of medically unexplained symptoms (MUS). These symptoms or diseases cannot be explained in terms of organic pathology, which contributes to the patients being subject to stigma and marginalization (Freeman, 2005). This is closely related to the Biopsychosocial model proposed by Engel that provides a holistic view of the human being, by the different hierarchically defining organized systems interdependently constitute an individual (Bendelow, 2009). For example, this model regards pain as an interactive psychophysiological phenomenon that cannot be separated into isolated, independent psychosocial and physical components (Turk and Monarch, 2002). The biopsychosocial model is phenomenological, as it recognizes that lived experience is filled with meaning and values. Bendelow suggested that the biomedical approach to pain is simplistic and unsophisticated, and it often results in physicians being frustrated due to the intractable nature of pain which then leads to doubting patients' reports of pain and labelling them as 'frequent fliers" or "heart sink" patients (Bendelow, 2013). Not only does the biopsychosocial model provide a better account of the underlying dynamics of persistent pain, but it also provides healthcare professionals a set of alternative tools to address not only the biological but also the psychosocial variables associated with this condition. Pain cannot be evaluated without an understanding of the person who perceives it (Anchin, 2015).

2.2.4 Comorbidities associated with persistent pain

Pain can have a highly destructive impact on the psychological and social wellbeing of individuals, who commonly experience high levels of stress and struggle to self-manage (Craig, 1994). Pain is known to affect the individuals' activity, social interactions and consequently their wellbeing (Michaelis et al., 2015). Furthermore, there is a high rate of comorbidity in the occurrence

of pain and mental health (Currie and Wang, 2004). The average percentage of people living with persistent pain who also display symptoms of anxiety and depression is reported to be between 50% and 75% (Banks and Kerns, 1996; Sigtermans et al., 2009; Rayner et al., 2016). There is evidence revealing that the burden of persistent pain and its prevalence are underestimated and in addition, treatment is not always adequate (Kress et al., 2015).

Anxiety and depression play an important role in the persistence of pain and in the decrease in quality of life (Dahan et al., 2014). Previous literature acknowledged the co-existence of pain and depression, however, it is not yet known whether pain causes depression or depression amplifies pain (Fasick et al., 2015). It is known that people suffering injuries who result in pain lasting for more than six months are likely to develop depressive symptoms and on the other hand, people with a long history of depression are often diagnosed with unclassified pain syndromes (Blair et al., 2003). It has also been suggested that the severity of pain or depression might lead to an amplification of the association between the two (Blair et al., 2003). This is consistent with the finding that people experiencing pain and comorbid depression reported worse pain and functioning compared to those without depression (Holzberg, 1996).

There is a vast literature documenting the severity and the impact of depression in people living with long-term pain and emphasizing the need to take action. Rayner et al. (2016) conducted a cross-sectional study based on a standard self-report measure and revealed that 60.8% of people living with persistent pain in the UK also experience depression, with 55.6% meeting the criteria for severe symptoms. They also found that people living with pain and depression reported a greater absence from work, more generalized pain, increased pain interference as well as lower pain acceptance and greater healthcare utilization and costs compared to those without depression (Rayner et al., 2016). In addition, there is evidence supporting the fact that individuals living with physical as well as mental health conditions often face stigma, which has a negative effect on functioning, treatment-seeking and emotional health (Naushad et al., 2018).

People living with persistent pain often experience anxiety (Blair et al., 2008, Bushnell et al., 2013) and in turn, anxiety may increase the probability to develop long-term pain (Dimova et al., 2013; Grupe and Nitschke, 2013). Research has shown that state anxiety affects pain perception, leading to increased self-reported pain intensity, a reduction in pain tolerance and a decrease in pain threshold (Carter et al., 2002; Jones et al., 2003). In addition, studies have shown an association between decreased pain-related anxiety and decreased pain severity, as well as decreased depression and affective distress in people living with persistent pain (McCracken and Gross, 1998; Adler and Gattaz, 1993). There is increasing evidence to support the co-occurrence of persistent pain and anxiety disorders such as generalized anxiety disorder, panic attacks, social anxiety or posttraumatic stress disorder (Sareen et al., 2005; Kroenke et al., 2013). Past literature revealed that anxiety significantly impacted on people's experience of pain, leading to anger and sadness (van Middendorp, 2010) and enhancing people's suffering (Hubbard et al., 2015). A study examining the association between anxiety, health-related quality of life and functional impairment in a sample of 250 people living with musculoskeletal pain revealed that nearly a half of the participants screened positive for one or more anxiety disorders, and reported worse health-related quality of life compared to those without anxiety (Kroenke et al., 2013). Similarly, a study of 500 people living with persistent pain found that comorbid depression and anxiety is strongly related with more severe pain, greater disability and poorer health-related quality of life (Bair et al., 2008). Conversely, some studies have also documented the prevalence of pain in people living with anxiety disorders such as panic disorder or post-traumatic stress disorder (Asmundson and Katz, 2009).

Persistent pain affects people's quality of life significantly, making everyday activities (such as doing household chores) difficult. People living with pain are also less able or unable to sleep and report that pain has a significant effect on their social relationships (Breivik et al., 2006). Another significant issue that affects this population is pain-related fear of movement (kinesiophobia), which then leads to hypervigilance and avoidance behaviours. Similarly, people with persistent pain often catastrophise. This is seen as having exaggerated negative thoughts and feelings in response to actual or anticipated pain (Quartana et al., 2009).

Burden and costs of persistent pain 2.3

Persistent pain has been recognized as a significant health concern, with negative consequences on individuals and society as a whole (Duenas et al. 2016). This section will illustrate the burden and impact of persistent pain by presenting recent data regarding the prevalence, incidence and costs of pain. Estimating the prevalence of persistent pain and its impact is crucial in helping differentiate people with limitations in major life domains (such as work or engaging in self-care activities) from those who maintain normal life activities despite living with pain and thus gaining a better understanding of this population's needs (Dahlhamer, 2018). In addition, determining the prevalence of persistent pain also has implications in terms of targeting pain management interventions. According to a cross-sectional survey conducted by the National Center for Health Statistics (NCHS) in 2016 an estimated 20.4% (50 million) US adults experienced persistent pain with 8% (19.6 million) reporting high impact pain (Dalhamer, 2018). Higher prevalence was reported among women, older adults, unemployed adults or adults living in poverty or rural areas. Similarly, a UK based study conducted by Fayaz et al. (2016) revealed that nearly 28 million adults (43% of the general population) are experiencing persistent pain, and this number is likely to

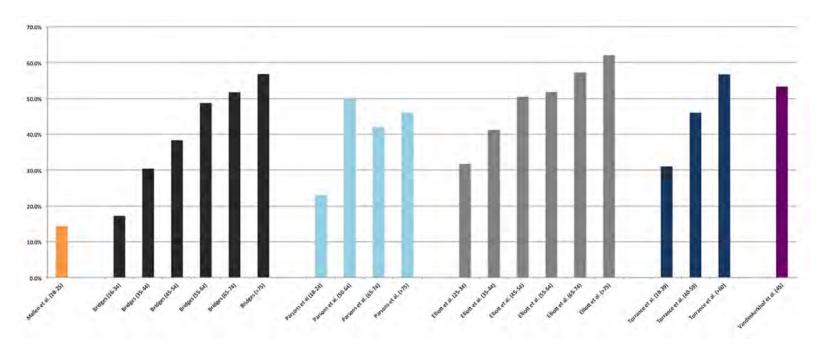
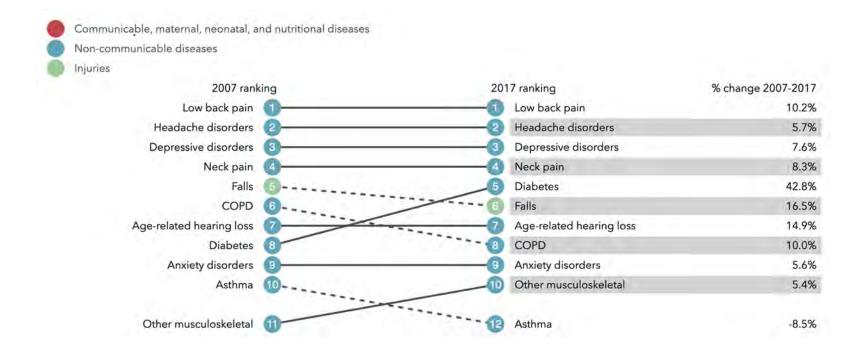


Figure 2.1: The prevalence of persistent pain stratified by age (Fayaz et al.,2016)

increase in the future. They demonstrated that prevalence of pain increased with age, ranging from 14.3% in 18-25-year-old group to 30% in 18-39 old and 62% in those over 75 (see figure 2.1) (Fayaz et al., 2016). The study also showed that persistent pain was more common in women than men. In Wales, an estimated 600,000 people are living with long-term pain (All Wales Medicines Strategy Group, 2016). The next decades are likely to witness a considerable rise in the prevalence of persistent pain in the U.K., as a result of the ageing population.

According to the Institute for Health Metrics and Evaluation, the health problems causing the most disability in the UK between 2007-2017 were low back pain, headache disorders, depressive disorders and neck pain respectively (Institute for Health Metrics and Evaluation, 2017) (see figure 2.2). The data pointed towards a 10.2% increase in low back pain as well as a 5.7% increase in headache disorders and a 7.6% increase in depressive disorders in the 10-year period.

Musculoskeletal problems continue to be a major cause of years lived with disability (YLDs) and one of the leading causes of disability-adjusted life years (DALYs) in the UK (Global Burden of Disease Collaborative Network, 2017). Musculoskeletal conditions include a range of health issues affecting the bones, joints, muscles and the spine, but also autoimmune conditions such as lupus (State of musculoskeletal health, 2018). There are three groups of musculoskeletal conditions: inflammatory (such as rheumatoid arthritis or ankylosing spondylitis), conditions of musculoskeletal pain (e.g. back pain, osteoarthritis) and osteoporosis and fragility fractures (Arthritis Research UK, 2016). These conditions contribute to a substantial loss of quality of life by limiting people's normal functioning. They affect relationships and work and also have repercussions on the society, through the costs related to treatment and loss of productivity (State of musculoskeletal health, 2018). Moreover, they account for the third largest area of NHS spending (£4.7 billion in 2013-2014) (NHS England, 2014). Although there is research



Top 10 causes of years lived with disability (YLDs) in 2017 and percent change, 2007-2017, all ages, number

Figure 2.2: Top 10 causes of disability in the UK between 2007-2017 (Institute for Health Metrics and Evaluation, 2017)

acknowledging the high prevalence of musculoskeletal conditions and their negative impact, the people affected by them are experiencing a lack of recognition and support.

There is increasing evidence suggesting the presence of a significant overlap among a range of poorly understood pain disorders, previously labelled as central sensitivity syndromes or complex persistent pain conditions. These conditions have been recently termed 'chronic overlapping pain conditions' (COPCs) (Veasley et al., 2015) (see figure 2.3). Pain may be accounted to a pathophysiological process in the affected tissues (e.g. inflammation or lesions), however this only accounts for a percentage of people experiencing COPCs. For another significant percentage no organ pathology is found, however, people often demonstrate neural, immune or endocrine abnormalities (Veasley et al., 2015). An increasing number of studies suggested that there are variable rates of overlap among COPCs, as well as acknowledging the increased likelihood of developing a new COPC as the number of pain conditions augments (Sinaii et al., 2002; Lim et al., 2010; Aaron and Buchwald, 2001; Aaron et al., 2001; Yunus, 2012). In addition, the delays that this population experiences in obtaining an accurate diagnosis and effective treatment can result in a worsening of symptoms, poorer health outcomes, a decrease in quality of life and increased disability (Yong et al., 2015; Krieger et al., 2014). The effects of these stigmatizing conditions are profound, impacting not only individuals and their families but the society as a whole (Nguyen et al., 2013; Snelgrove and Liossi, 2013; Meeus et al., 2014).

The healthcare system is fragmented which means people living with COPCs usually seek care from different specialists (e.g. urology, rheumatology, gynaecology) receiving multiple treatments and recommendations. There is a lack of coordinated care that contributes to stigma and invalidation, poor outcomes, decreased quality of life and increased disability (Donaldson and Meana, 2011) (see figure 2.4).

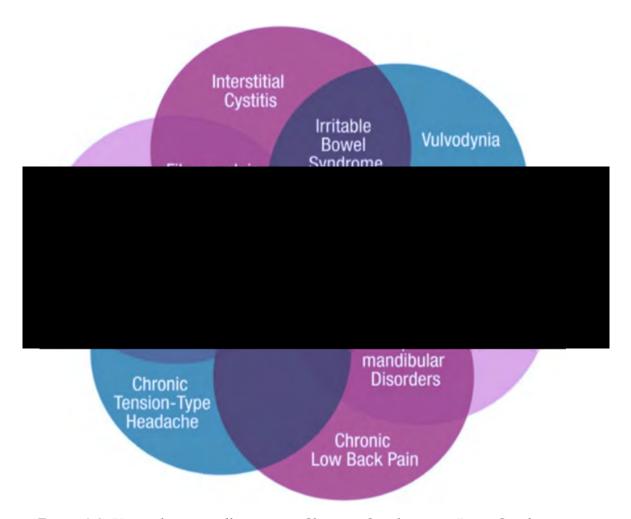


Figure 2.3: Venn diagram illustrating Chronic Overlapping Pain Conditions (Veasley et al., 2015)

Persistent pain represents a significant burden for individuals, health systems and societies and poses a considerable strain on limited healthcare resources across all countries (Dagenais et al., 2008). Pain has been recognized as a major clinical, social and economic problem that has a profound effect on people's quality of life (Phillips, 2009). Persistent pain affects nearly 100 million Americans, with costs amounting to an estimated \$560-635 billion (Institute of Medicine, 2011). Treatment was found to be often inadequate and not effective, with both patients and clinicians lacking the knowledge about effective pain management. The Committee on Advancing Pain Research, Care and Education (Institute of Medicine, 2011) identified several shortfalls (e.g. gaps in policy, treatment, and education) to

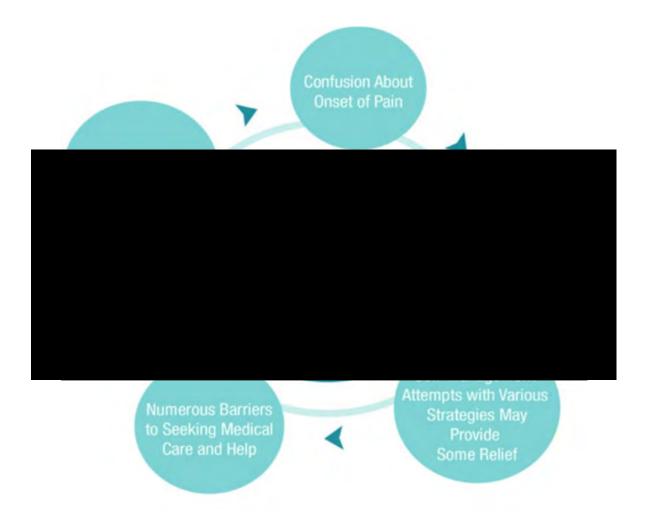


Figure 2.4: Typical patterns experienced by people living with COPCs (Veasley et al., 2015)

be addressed in order to improve the understanding and management of pain.

Similarly, Breivik et al. (2013) suggested that the personal and socioeconomic impact of persistent pain in Europe is as great or greater than other established health conditions and argued that pain should be prioritized alongside these other conditions. Previous data revealed that in Europe, the cost of conditions associated with persistent pain amount to billions of euros annually, and represent 3-10% of the gross domestic product (Raftery et al., 2012; Christensen et al., 2011; Gustavsson et al., 2012). Hospitalization was found to account for half of the total direct costs, while social benefits was the largest contributor to indirect costs (Raftery et al., 2012).

Persistent pain exerts a significant burden also in the U.K. Donaldson (2008) found that £584 is spent on painkillers and long-term pain revealing to be the second most common reason for claiming welfare benefit. In addition, according to the National Pain Audit (2012), 41% of patients expressed that pain prevented them from working, and people living with pain were hospitalized approximately three times more often than the general population. People experiencing persistent pain were found to consult their GP five times more frequently than other patients, translating to 4.6 million appointments per year and estimated costs of £69 million (Belsey et al. 2002). Despite the fact that persistent pain represents a substantial burden on the healthcare resources and on the people who live with pain and their families, nevertheless, it is an area low on the political priority list (McQuay, 2008). 'People who through no fault of their own have their lives demolished by pain deserve our help.' (McQuay, 2008, p.954).

State of pain management in the U.K. 2.4

Pain may become an area easy to ignore in the current political climate, as some regard it as a non-threatening condition whose consequences are not immediately visible. It is essential, therefore, to highlight the importance of pain management in reducing some of the suffering and the personal and societal costs associated with this condition.

In the U.K., persistent pain is usually managed at a primary care level and in the community, however, when symptom control is not reached in a timely manner, patients need to access secondary and tertiary pain centres, where they can access higher intensity and more complex treatments (Faculty of Pain Medicine, 2015) (see figure 2.5). The management of pain in

primary care should be holistic and evidence-based, including both pharmacological and non-pharmacological approaches as well as self-management, psychology, physiotherapy, complimentary therapies and pain management programs (Mills et al., 2016). These treatment approaches may be based entirely in primary care or supported by referral to a specialist. The Faculty of Pain Medicine (2015) launched the 'Right Patient Right Professionals Right Time' initiative, suggesting that pain should not be left untreated and that it is imperative that patients see the right professionals at the right time with minimal delay between healthcare systems. Nevertheless, there are challenges associated with the assessment and management of persistent pain in general practice. The complex nature of pain (including physical, psychological and social factors) together with the limited time and resources available are within the most prominent issues (Smith and Torrance, 2011).

Setting realistic evidence-based standards that will guide the delivery of pain services across the UK is equally important. According to the Core standards for pain management services in the UK (published in 2015), NHS England adopted a 'House of Care' model in managing patients with persistent pain (Core standards for pain management services in the UK, 2015).

In Wales, the NHS embraced the prudent healthcare principles (Aylward et al., 2013). Informed by the work of the Bevan Commission, these principles emphasize the establishment of an early biopsychosocial assessment within the community and making sure that self-management is available early to the patients with long-term pain conditions. The guidance also recommends fully exploiting the resources that are already available as well as identifying interventions and initiatives that are cost-effective and promoting healthcare that fits the needs of the patients. In recent years, chronic pain services in Wales have shown improvement; however, there is still some variation in provision and delays in accessing appropriate treatment (Khot and Lewis,

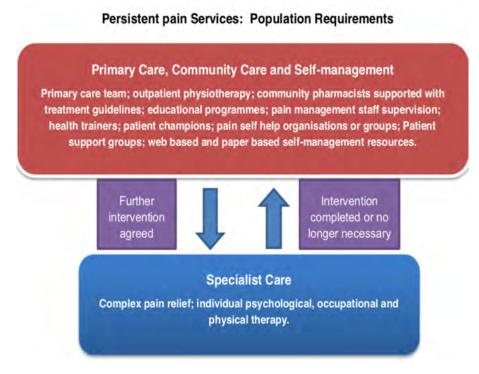


Figure 2.5: Figure illustrating different levels of care services required by people living with persistent pain (Welsh Government, Living with Persistent Pain in Wales, 2018)

2014). Further work is necessary to improve access to pain management programs and specialized interventions.

The National Pain Audit (2012) argued that pain management services in England and Wales did not meet national standards and faced issues such as insufficient staffing. The report suggested that recruiting and retaining specialist staff is essential in addressing the complex biopsychosocial nature of pain. Similarly, the Faculty of Pain Medicine (2018) identified several problem areas that need further improvement: pain services are poorly represented within current commissioning frameworks, there are shortfalls in specialist pain workforce training and an inadequate undergraduate teaching of pain management in the UK (Faculty of Pain Medicine, 2018). In addition, it has been argued that the complexity of pain can influence the interaction between patients and healthcare professionals. People's expectations include a clear diagnosis and effective treatment while GPs find persistent pain difficult to manage and generally have a negative perception of people living with pain (NICE guideline: Chronic pain: final scope, 2018).

The National Institute for Health and Care Excellence (NICE) provides national guidance and advice meant to improve health and social care in England. NICE guidelines make evidence-based recommendations on a wide range of health topics, including long-term pain. A new guideline is currently under development and expected to be released in January 2020. The new guidance aims to complement the existing NICE guidance for specific pain conditions (e.g. low back pain, sciatica, rheumatoid arthritis) and recommend pharmacological and non-pharmacological interventions for chronic primary pain conditions that were not addressed before (NICE guideline: Chronic pain: final scope, 2018). The scope for the new guidance identified some key issues including the assessment of biological, psychological and social factors that may cause or perpetuate the experience of pain and establishing the effectiveness of strategies employed to improve

quality of life of people experiencing persistent pain (e.g. pain management programs, peer-led programs, pharmacological and non-pharmacological interventions for chronic primary pain) (NICE guideline: Chronic pain: final scope, 2018). The main outcomes that will be considered when searching for and assessing the evidence will include pain reduction, physical function, depression, anxiety, health-related quality of life and adverse events (NICE guideline: Chronic pain: final scope, 2018).

Overview of the current treatment approaches for pain 2.5 management

Medical advances have contributed to a better understanding of the underlying mechanisms of persistent pain nevertheless the management and treatment of pain remains a challenge both for clinicians and patients (Scascighini and Sprott, 2008). The last decades have witnessed a shift from the traditional biomedical model that emphasizes structural and biomechanical anomalies to a biopsychosocial model that focuses on the role of psychosocial factors in the development and maintenance of symptoms (Stanos and Houle, 2006). Following this paradigm, treatments for long-term pain include a mixture of medical, physical and psychological components. The biopsychosocial approach provides a wider breadth of inquiry and intervention and also changes the focus from pain relief to devising strategies to increase functional ability and wellbeing in spite of the pain (Hylands-White et al., 2017).

This section will provide a synopsis of the treatment approaches currently available for managing persistent pain, including biomedical approaches and biopsychosocial treatments.

2.5.1 Biomedical approach

This approach mainly comprises of pharmaceutical, surgical and electrical treatments (see figure 2.6). Pharmaceutical management of persistent pain includes the use of non-opioid analgesics in the first instance, followed by weak opioids and strong opioids (Verassi et al., 2010). Adjuvant drugs (such as co-analgesics, anticonvulsants, tricyclic antidepressants) are also prescribed where needed. This approach is based on the World Health Organization pain ladder (WHO, 1996) that was originally developed for treating cancer pain. A large-scale survey exploring the prevalence, treatment and impact of persistent pain in fifteen European countries found that 55% of the people living with pain who participated were taking non-prescription analgesics (non-steroidal anti-inflammatory drugs (NSAIDs), paracetamol and weak opioids), while two-thirds were taking prescription medicines (Breivik et al., 2006). This study also highlighted that 40% of the respondents had inadequate management of their pain. As it is unlikely for a single medication to result in satisfactory pain relief, combination pharmacological treatment has been recommended as an important part of pain management (Hylands-White et al., 2017). The rationale for combination therapy consists in the need to target different pain mechanisms that contribute to the overall pain syndrome (e.g. chronic neck pain may have both a neuropathic and inflammatory component) (Dale and Stacey, 2016). However, there is a lack of research aiming to identify combination drug therapies for specific pain conditions.

Another key issue in this approach is finding the balance between effective treatment and acceptable side effects (Dale and Stacey, 2016). Inadequate pain relief, as well as unacceptable side effects, contributes to the discontinuation of treatment (Varassi et al., 2010). In particular opioid-related side effects (such as gastrointestinal and central nervous system issues) remain a major clinical challenge. Also, as opioid prescriptions have increased, issues related to overdose, abuse and

addiction escalated (Sullivan et al., 2008; Boudreau et al., 2009; Olsen et al., 2006). According to a large-scale observational study looking at opioid prescribing in primary care practices in Wales, there was a large increase in strong opioid prescribing between 2005 and 2015, particularly among people living with pain as well as depression or anxiety and also in areas of greatest deprivation (Davies et al., 2018). The authors have emphasized the need for national guidance to facilitate safe and rational opioid prescribing in persistent pain.

An additional issue to be addressed in the future is improving the communication between patients and practitioners. Inadequate communication often leads to patients and doctors having different expectations of treatment and also to a failure in understanding the patients' situations fully (Varassi et al., 2010). This may also be the result of the training received in medical schools that failed to equip the future practitioners with an understanding of the mechanisms that contribute to persistent pain and with an awareness of the role of psychosocial factors in the development of long-term pain (Glajchen, 2001).

Finally, invasive procedures for persistent pain are known to pose major risks and to be costly (Hylands-White et al., 2017). Surgery is suitable only in a minority of patients and recommended only after careful consideration, mainly due to its invasive and irreversible nature and also due to the risk of complications (Hylands-White et al., 2017).

To sum up, pharmacological treatment plays an important role in pain management, however, it needs to be placed in a broader framework including nondrug strategies. Educating medical students about persistent pain and improving the communication between patients and practitioners are also important areas for further development.

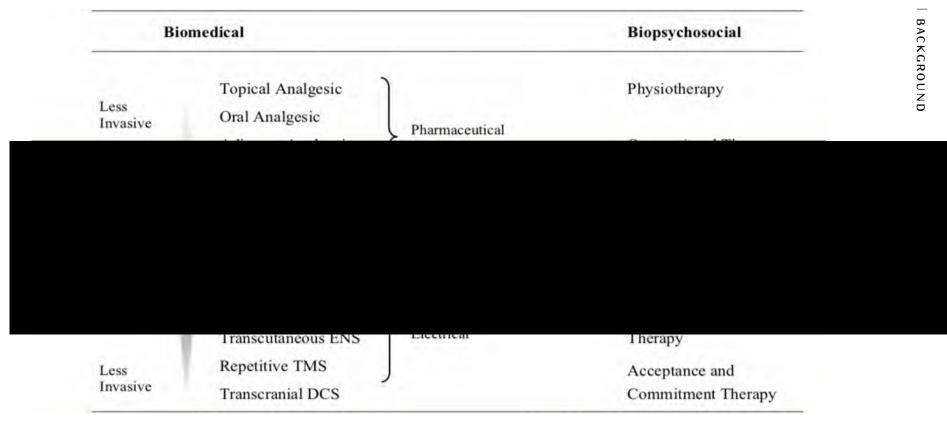


Figure 2.6: A classification of treatment approaches for pain management (Hylands-White et al., 2017)

2.5.2 Biopsychosocial approach

Persistent pain is currently seen as a complex biopsychosocial disorder, therefore, the interventions required for managing it must also have biological, psychological and social dimensions (Disorbio et al., 2006). Successful long-term management of pain requires a range of treatments administered by different specialists and tailored to meet individual patient needs (Fields, 2011). This multidisciplinary approach includes disciplines such as physiotherapy, nursing, occupational therapy and psychology (see figure 2.6).

Physiotherapy 2.5.3

Physiotherapists are an essential part of the multidisciplinary pain management team (Core Standards for Pain Management Services in the U.K., 2015). Physiotherapy aims to maintain and maximize patients' functional ability, along with providing pain education and encouraging self-management (Sabers, 2003). Patients are taught that pain may not be necessarily related to tissue damage and that avoiding activity may worsen pain long term. Physiotherapists are involved in a range of interventions and activities such as patient education, exercise therapy, graded exposure to activity, but also research and evaluation. Evidence supports the benefits of physical activity in populations living with persistent pain (Meeus et al., 2016; O'Connor et al., 2015). Several systematic reviews revealed that aerobic and resistance exercise were more effective than no intervention in improving physical function and pain in fibromyalgia and knee osteoarthritis (Bidonde et al., 2014; Busch et al., 2013; Fransen et al., 2015). Similarly, findings suggested that exercise might yield better pain and disability outcomes when combined with pain education (Moseley, 2002; Pires, Cruz, & Caeiro, 2015). In fact, the most recent NICE guidelines for managing low back pain and sciatica recommended providing people with

advice and information tailored to their needs and abilities in order to support self-management (NICE, 2019). The guidelines also recommend considering a group exercise program (biomechanical, mind-body or a combination) provided that people's preferences, needs and capabilities are taken into account (NICE, 2019). However, a major challenge associated with taking part in exercise programs is low adherence rates, for example, people living with fibromyalgia have demonstrated poor exercise tolerance which constitutes an important barrier to engaging in exercise (De Gier et al., 2003; Culos-Reed and Brawley, 2000). Poor adherence to exercise and physical activity has been shown to compromise effectiveness in usual care (Hayden et al., 2005; van Gool et al., 2005) while supervised or tailored exercise seemed to enhance adherence. Moreover, strategies such as positive reinforcement, goal setting, feedback, development of problem-solving skills and self-monitoring were found to positively impact adherence (Aitken et al., 2015). The role of a physiotherapist also involves changing behavioural patterns around painful physical sensations and supporting patients in setting short-term and long-term goals based on people's individual values. A biopsychosocial physiotherapeutic approach informed by a psychological paradigm (such as CBT, ACT or motivational interviewing) has been recommended for use when interacting with patients (Core Standards for Pain Management Services in the U.K., 2015).

2.5.4 Occupational therapy

The belief underlying occupational therapy is that performing daily activities is essential to people's physical and psychological health and wellbeing. The role of occupational therapists is to enable people to perform everyday activities (College of Occupational therapists, 2013).

Given the impact of persistent pain on self-care, work, family and social roles, physical activity, leisure and sexual activity, occupational therapists

are ideally placed to assess the consequences of pain in all these areas and help people reengage in meaningful activities (Core standards for Pain Management in the UK, 2015). Previous literature acknowledged that performing meaningful activities is a crucial factor in persistent pain, as it has the potential to mediate the pain experience by altering biological and psychosocial factors that influence pain (Skjutar et al., 2010; Robinson et al., 2011; American Occupational Therapy Association, 2014). Occupational therapists often work as part of multidisciplinary teams and are well placed to intervene early and to prevent the development of chronicity (American Occupational Therapy Association, 2014). They teach people living with persistent pain early on that rest is not a good way to deal with pain and that performing a baseline level of activity is key to recovery (Hylands-White et al., 2017). Occupational therapists also teach people the importance of planning things in advance and pacing (taking regular breaks for rest). Some of the techniques and interventions used by occupational therapists include graded activity, communication skills training, coping skills training, stress management, ergonomics, self-care and leisure activities and facilitating return to work.

2.5.5 Psychological interventions

The biopsychosocial perspective views persistent pain as an illness rather than a disease, recognizing its subjective nature and emphasizing that treatment approaches are aimed at managing rather than curing pain (Roditi and Robinson, 2011). In this context, psychological based interventions have witnessed increased popularity and recognition as adjunctive treatments. Some of the most recent psychological approaches to pain management aim to increase self-management and target cognitive, emotional and behavioural components of pain rather than trying to eliminate pain itself. Psychologists are well suited to address the comorbidities that are frequently encountered in populations living with

persistent pain and thus improving pain treatment outcomes. Psychologists can also help people experiencing long-term pain navigate role transitions (e.g. job loss), interpersonal difficulties (isolation) and emotional suffering (e.g stress, anxiety, sadness) (Roditi and Robinson, 2011). However, there are differences in the scope, duration and goals of psychological therapies for pain. According to the framework proposed by Sturgeon (2014), therapies belong to four major categories: operant-behavioural therapy, cognitive-behavioural therapy, mindfulness-based therapy and acceptance and commitment therapy (see table 2.2).

2.5.6 Operant therapy

Operant therapy for persistent pain focuses on supporting people to reduce pain-related behaviours and adopt more adaptive behaviours. Some of the techniques utilized include graded activity, pacing and medication management (Gatzounis et al., 2012). Evidence showed that behavioural therapy has positive effects on pain experience, mood, negative cognitive appraisals and social functioning (Williams et al., 2012).

Cognitive Behvioural Therapy (CBT) 2.5.7

Cognitive Behavioural Therapy (CBT) is considered the current 'gold standard' for psychological management of persistent pain and has been widely implemented (Day et al., 2012). CBT is part of the 'second wave' of psychological approaches and is based on the assumption that emotions and behaviour are largely determined by cognitive perceptions of the world (Turk et al., 1983). In line with this theory, treatment targets beliefs as well as cognitive processes (such as automatic thoughts) and behaviours (Turk et al., 1983). CBT interventions for pain generally include basic education about pain, coping skills training, problem-solving approaches, and cognitive restructuring (Roditi and Robinson, 2011). The aim of coping skills

Therapeutic modality	Description of treatment
Operant-behavioural therapy	Treatment focuses on extinguishing maladaptive behavioural responses and fostering of adaptive behavioural responses to pain. Behavioural responses are altered through reinforcement and punishment contingencies and extinction of associations between the threat value of pain and physical behaviour.
Cognitive-behavioural therapy (CBT)	Treatment applies a biopsychosocial approach to pain that targets behavioural and cognitive responses to pain. CBT protocols involve psychoeducation about pain, behaviour, and mood, strategies for relaxation, behavioural pacing, behavioural activation, positive event scheduling, effective communication, and cognitive restructuring for distorted and maladaptive thoughts about pain.
Mindfulness-based stress reduction	Treatment promotes a nonjudgmental approach to pain and uncoupling of physical and psychological aspects of pain; teaches "nonstriving" responses to pain through experiential meditations and daily mindfulness practice intended to increase awareness of the body and proprioceptive signals, awareness of the breath, and development of mindful activities.
Acceptance and commitment therapy	Based on psychological flexibility model, treatment focuses on development of acceptance of mental events and pain and ceasing of maladaptive attempts to eliminate and control pain through avoidance and other problematic behaviours; emphasizes awareness, defusion, and acceptance of thoughts and emotions as well as behavioural engagement in pursuit of personal goals.

Table 2.2: Current psychological therapies for persistent pain (reproduced from Sturgeon, 2014)

training is to identify current maladaptive coping strategies (e.g. catastrophyzing) and support patients in replacing them with more adaptive coping strategies (use of positive statements, social support).

Problem-solving techniques aim to help patients adhere to their efforts while cognitive restructuring focuses on challenging negative cognitions and aid patients in reformulating thoughts to make them more balanced and adaptive (Roditi and Robinson, 2011). There is a large body of evidence acknowledging the efficacy of CBT for different pain conditions across a variety of pain-related outcomes (Astin et al., 2002; Astin et al., 2002; Eccleston et al., 2009; Keefe et al., 2005; Turner et al., 2006). CBT has been shown to reduce pain intensity and interference, work absenteeism, medication use and disability-related behaviour; these effects have been maintained both short term and long term (Johansson et al., 1998; Linton and Ryberg, 2001; Turner et al., 2006). However, some issues related to the effectiveness of CBT for the management of persistent pain have been identified. These include lack of uniform treatment components, issues of effective delivery, differences in delivery across populations and clinicians and variability in outcomes across different trials (McCracken and Turk, 2002).

2.5.8 Mindfulness-based therapies

Mindfulness-based approaches have been labelled 'the third wave' of psychological therapy (Hayes et al., 2006). Originally stemming from Buddhism and more recently integrated into Western psychology, mindfulness meditation is a method of cultivating moment-to-moment awareness and acceptance of inner experiences (thoughts, emotions, sensations). Mindfulness-based therapies include: mindfulness-based stress reduction (MBSR) (Kabat-Zinn, 1982), mindfulness-based cognitive therapy (MBCT) (Segal et al., 2002), dialectical behavior therapy (DBT) (Linehan, 1993), and acceptance and commitment therapy (ACT) (Hayes et al., 1999) as well as variations of these approaches. Mindfulness techniques promote nonjudgmental awareness and acceptance of the present moment without changing it. Unlike CBT, which posits that negative, maladaptive thoughts

need to be changed, mindfulness therapists adopt a non-judgmental approach to thoughts and encouraging emotional distance from thoughts instead (Day et al., 2012). Previous research has shown that mindfulness-based interventions improved pain symptoms across different pain-related disorders such as fibromyalgia (Davis and Zautra, 2013), migraine (Wells et al., 2014), chronic pelvic pain (Fox et al., 2011) and irritable bowel syndrome (Garland et al., 2011). Moreover, mindfulness-based stress reduction (MBSR) has demonstrated efficacy in different pain populations, for example, people living with neck pain, migraine, fibromyalgia and musculoskeletal pain (Wallace, 2006; Garland et al., 2014; de Boer et al., 2014). The health-promoting effects of mindfulness are most evident for pain and pain-related comorbidities, such as opioid misuse and addiction, stress, depression and anxiety (Garland et al., 2013; Creswell et al., 2016, Williams et al., 2014; Goldin et al., 2013). A recent systematic review and meta-analysis synthesizing evidence on the efficacy and safety of mindfulness meditation interventions for the treatment of persistent pain concluded that mindfulness did improve pain and depression symptoms and quality of life, however, additional rigorous, and large-scale trials are needed to provide better estimates of the efficacy of mindfulness meditation (Hilton et al., 2016).

2.5.9 Acceptance and Commitment Therapy (ACT)

Acceptance and Commitment Therapy (ACT) is a therapy emerging from cognitive-behavioural therapies, built upon both the first and second wave of behaviour therapy but nevertheless different from these (Hayes, 2004). ACT advances a treatment model consisting of awareness and non-judgmental acceptance of both positive and negative experiences and also the identification of meaningful values and appropriate actions towards goals that are consistent with those values (Hayes, Stroshal and Wilson, 1999). ACT interventions include a combination of mindfulness and

acceptance along with activation and behaviour change methods (Hayes, 1999).

The theoretical underpinning of ACT is Relational Frame Theory (RFT: Hayes et al., 2001), a theory according to which human language and cognition are dependent on relational frames (relationships among words or events that people derive). Hayes et al. (2001) suggested that relational frames describe different patterns of derived relational responding that emerge such as equivalence, comparison, distinction, opposition and hierarchy. One example is: if you are told that 'A is opposite of B and B is the opposite of C' then you will derive an opposition between A and B and between B and C but a relation of sameness between A and C (Barnes-Holmes et al., 2004). Transformation of function is one of the most important features of RFT and it plays a crucial role in understanding human psychopathology. One example illustrating this concept is as follows: a young boy is told that he is going to the 'doctor' and is thereafter exposed to an uncomfortable medical examination (the word 'doctor' triggers aversiveness through classical conditioning), after which the boy is told that 'dentists are doctors who look after your teeth' (equivalence is established between doctor and dentist). When required to go to the dentist after a while, the boy will likely show signs of anxiety although he has never had an aversive experience at the dentist. This demonstrates that the aversive functions of 'doctor' have been transferred to 'dentist' (Barnes-Holmes et al., 2004).

ACT is rooted in the psychological flexibility model, a framework according to which the content, form and intensity of experiences (such as thoughts and feelings) alone are not sufficient to explain behaviour, instead behaviour is determined by the function of these experiences in a particular context (Hayes et al., 2013; McCracken and Morley, 2014). Psychological flexibility comprises a set of six processes: acceptance, cognitive defusion, awareness of the present moment, self-as-context, values and committed action (for a

detailed description of these processes see Chapter 6, section 6.2.5) (Hayes et al., 1999). These terms are not technical descriptions of psychological processes, but rather mid-level terms (Hayes et al., 2012). The opposite of psychological flexibility is psychological rigidity (or inflexibility) whose two central mechanisms are experiential avoidance and cognitive fusion (Hayes et al., 2006). Experiential avoidance has been conceptualized as attempting to avoid negative thoughts and feelings despite the harmful consequences that they produce long-term (Hayes et al., 1999). Some examples of avoidance can be: postponing important tasks due to the discomfort they evoke or avoiding social gatherings due to the anxiety it leads to. Cognitive fusion, on the other hand, refers to becoming entangled with thoughts, feelings and memories and focusing all the attention on these rather than on direct experience.

Unlike traditional CBT, that focuses on replacing maladaptive thoughts with more adaptive ones, ACT targets the process of thinking, by reducing its behavioural influence (Hayes et al., 2006). Moreover, ACT regards many forms of distress as inherent to being human (e.g. self-doubt, fear, uncertainty, negative thinking) and thus it does not explicitly aim to reduce distress, its focus being on enhancing people's ability to engage in meaningful activities in the presence of distress. For example, in the context of persistent pain, the ACT model centres on the idea that attempting to change aversive internal experiences are futile and may lead to increased distress (McCracken et al., 2002; McCracken and Eccleston, 2005). Rather than focusing on controlling or minimizing pain and distress, ACT promotes pain acceptance and aims to increase functioning while decreasing the interference of pain with value-driven behaviour (Wetherell, 2011). Although traditional CBT has been a successful treatment for longterm pain, demonstrating reductions in pain and improvements in functioning, new approaches like ACT can offer an important avenue for many patients living with pain (Hayes, Strosahl and Wilson, 1999). ACT helps people clarify what is truly important, then uses that knowledge to

guide, inspire and motivate change for the individual to live a more full and meaningful life.

The past two decades have witnessed an increased interest in the utility of applying ACT to persistent pain. This approach proposes that pain is an inevitable part of life and that struggling to avoid it contributes to more suffering (Vowles and Thompson, 2011). In fact, the struggle with pain is regarded as a form of non-acceptance or resistance. The focus of ACT in this context is to support people who experience long-term pain to engage in values-driven behaviour while being in contact with pain and discomfort (McCracken, 2005). Treatment efforts revolve around assisting people who live with pain to live a more meaningful and rewarding life while developing more acceptance of pain (McCracken, 2005). ACT makes use of experiential and exposure-based methods, metaphors and mindfulness- related exercise (Dahl et al., 2005).

The effectiveness of ACT for persistent pain is supported by empirical research (Association for contextual behavioural science, 2019). Over the last ten years, ACT has attracted a lot of interest, in fact, there has been a substantial increase in the number of randomized controlled trials examining the effectiveness of ACT-based interventions as well as systematic reviews and meta-analyses. To date, five systematic reviews and meta-analyses investigated the effectiveness of ACT for persistent pain and generally, they provided support for the use of this approach, indicating that it can effectively improve health outcomes.

Veehof et al. (2011) conducted a systematic review and meta-analysis of thirty studies (both controlled and non-controlled) reviewing the evidence of the effects of acceptance-based interventions (such as MBSR and ACT) on a sample of 1235 people who lived with persistent pain. They revealed an effect size of 0.37 on pain and 0.32 on depression in controlled studies. The authors suggested that although MBSR and ACT were not superior to CBT, they were considered good alternatives and recommended that more high-quality

studies were needed to focus on therapies integrating mindfulness and behaviour therapy (Veehof et al., 2011). Mindful of the increase in the number of acceptance and mindfulness-based interventions for pain in the years that followed, Veehof and his colleagues updated their systematic review in 2016. The updated review included twenty-five randomized controlled trials (RCTs) totalling a pool of 1285 people living with persistent pain. They compared acceptance and mindfulness-based interventions to the waiting list, treatment as usual and education or support groups, and found ACT to have significantly higher effects on depression and anxiety than mindfulnessbased interventions (MBSR and MBCT). In addition, effect sizes ranged from small (on all outcomes except anxiety and pain interference) to moderate (on anxiety and pain interference) at post-treatment and from small (on pain intensity and disability) to large (on pain interference) at follow-up (Veehof et al., 2016). The authors concluded that individuals generally respond well to acceptance and mindfulness interventions with benefits persisting after treatment. They reiterated that these interventions are not superior to CBT but nevertheless valid alternatives (Veehof et al., 2016).

Öst (2014) reviewed sixty RCTs (4234 participants) looking at the effectiveness of ACT on psychiatric disorders, somatic disorders, and stress at work. The author concluded that ACT did not lead to statistically significant higher effect sizes than CBT in RCTs with direct comparisons, and also suggested that ACT is probably efficacious for persistent pain (Ost, 2014). Ost also stated that: 'ACT is not yet well-established for any disorder ' (Ost, 2014, p.105). Atkins et al. (2017) conducted a thorough evaluation of the methods, the approach and the data used by Ost and concluded that there were ninety-one factual or interpretative errors committed (unreliable quality ratings, factual errors). The authors also suggested that Ost's data were dominantly more negative toward ACT (Atkins et al., 2017) recommending that Öst's review should be set aside when considering the evidence base for ACT.

In 2014, Hann and McCracken conducted a systematic review focusing on primary and secondary process variables in ACT-based pain trials, and also reviewed the evidence for efficacy. The search identified 1034 articles out of which ten studies were selected as eligible. All the trials included a measure of an aspect of psychological flexibility, with pain and emotional functioning being the most commonly measured outcomes. The review concluded that ACT was mostly efficacious for improving general functioning and decreasing distress when compared to inactive treatments. Hann and McCracken recommended that future ACT trials should define outcomes as primary, secondary and process variables and they should include not only measures of pain and emotional functioning but also measures of physical and social functioning (Hann and McCracken, 2014). Other suggestions were: addressing the risk of bias and including variables such as cognitive delusion and self-related variables.

Hughes and her colleagues published the most recent systematic review and meta-analysis of ACT in 2017. Eleven trials were reviewed and the results revealed that ACT was favoured compared to controls. There were significant medium to large effect sizes for pain acceptance and psychological flexibility as well as significant small to medium effect sizes for anxiety, depression and measures of functioning (Hughes et al., 2017). The authors suggested that due to several methodological limitations of the studies included, the effects found may have been overestimated and thus further methodologically robust trials are needed (Hughes et al., 2017). Overall, the evidence base indicates a similar effectiveness of ACT compared to CBT as well as a significantly greater effectiveness compared to inactive treatments for persistent pain. Although there is growing evidence to support the effectiveness of ACT, there are currently only a small number of high-quality studies and more RCTs are needed, particularly comparing ACT with active treatment comparisons (Hann and McCracken, 2014).

A recently emerging area of interest is treatment utility, and particularly drop out rates. Interventions cannot be effective if participants do not engage in them. Although research in this area is still in its infancy, a meta-analysis conducted by Ong et al. (2018) set out to determine the collective drop out rate for ACT in RCTs and to compare it with other interventions, identifying potential moderators of drop-out. The meta-analysis revealed a 15. 8% dropout rate in RCTs of ACT (12.1% in chronic pain and fibromyalgia), which is slightly better than the drop out in CBT trials (25.3%). Drop out rates did not differ by participant characteristics or study methodological quality, however, master's level therapists were associated with higher drop out than psychologists.

Finally, there has been an increasing interest from health professionals and policymakers in the cost-effectiveness of interventions, particularly due to the limited funds allocated to public healthcare services. A recent systematic literature review assessing the economic impact of third-wave therapies (MBCT, MBSR, ACT, DBT and eBA) revealed an acceptable cost-effectiveness and cost-utility (Feliu-Soler et al., 2018). The authors suggested that thirdwave therapies are efficient from a societal or a third-party payer point of view and that more economic evaluations are needed. Likewise, Luciano et al. (2017) analyzed the cost-utility of a group-based ACT program for 156 people living with fibromyalgia who were randomized in three groups (eight 2.5 hour ACT sessions, recommended pharmacological treatment and a waiting list control). ACT was found to be more cost-effective compared to recommended pharmacological treatment in people with fibromyalgia. Feliu-Soler et al. (2018) advised that there is a valid need for well-designed economic evaluations of ACT for persistent pain and recommended that cost-cost-effectiveness analyses should be embedded in future RCTs.

2.5.10 Multidisciplinary pain management

Due to the complex nature of long-term pain, medical treatment or singular approaches might not be effective and multidisciplinary treatment might be necessary (Gatchel et al., 1994).

Given that the current understanding of persistent pain is based on a biopsychosocial paradigm, interdisciplinary pain management programmes have been developed to target all of the aspects (biological, psychological and social) and address the complex needs of people living with pain (Dale and Stacey, 2016). Multidisciplinary teams are usually composed of physicians, psychologists, physical therapists and nurses in an outpatient setting. However, interdisciplinary pain management is usually introduced very late in the treatment, often as a last resort when all other interventions have failed (Olason, 2004). The majority of multidisciplinary interventions focus on restoring function but they also teach cognitive behavioural skills aimed to improve pain management from the patient's perspective (Scascighini and Sprott, 2007). Nevertheless, multidisciplinary evaluation and treatment is not necessary for all the people with persistent pain and it is not possible for all this population to be managed in a multidisciplinary way due to the high numbers and limited healthcare resources. Therefore, it is crucial for practitioners to identify the patients who need and would benefit from this approach, for example patients with an uncertain diagnosis despite a thorough medical evaluation who do not respond to initial therapy or patients presenting with an elevated level of physical, psychological and social dysfunction who may profit from an early referral to a multidisciplinary team (Chen, 1996).

There is a considerable amount of evidence suggesting that a multidisciplinary approach to pain management is beneficial to patients, healthcare providers and to the society as a whole. The integration of different treatment modalities and strategies has resulted in improvements

for people with persistent pain in terms of a reduction of the use of medication, improved functional abilities, improved patient care and satisfaction and a reduction of healthcare utilization (Cassisi et al. 1989; Deardorff et al. 1991; Kames et al. 1990; Flor et al. 1992; Chen 1996; Luk et al. 2010). Moreover, pain management programs have proven more beneficial compared to standard medical care (Gatchel & Okifuji, 2006; Guzman et al., 2001).

Furthermore, multidisciplinary management of persistent pain was shown to be effective and cost-efficient a when compared with non-multidisciplinary treatment or usual care (Turk 2002; Scascighini et al. 2008; Cunningham et al. 2009; Dysvik et al. 2010). However, a report of the National Pain Audit and a workforce planning analysis undertaken by the Faculty of Pain Medicine indicated that there were still shortfalls in the provision of pain specialists and pain services across the UK (National Pain Audit, 2012; Workforce Update, 2014). The National Pain Audit suggested that only 40% of the pain clinics in England were multidisciplinary. Existing resources for pain-management are outstretched and the increase in workload is not likely to be absorbed within these services (McGhie and Grady, 2016). Clinical commissioning groups in England and health boards in Scotland and Wales should acknowledge the issues surrounding pain services and work collaboratively to address this challenge.

2.6 The role of complementary and alternative approaches in pain management

A considerable number of people around the world access healthcare approaches outside mainstream medicine (Bove et al., 2018). In the UK, survey data showed that nearly a quarter of the population use Complimentary and alternative medicine (CAM) each year (Ernst and

White, 2000; Tomas et al., 2001; Hunt et al., 2010). Complimentary and alternative medicine (CAM) has been defined as a group of diverse healthcare practices and products not currently considered being part of conventional medicine (National Center for Complementary and Integrative Health, 2018). Complementary health approaches have been classified into two subgroups: natural products (herbs, dietary supplements) and mind and body practices (a diverse group of procedures administered by a trained practitioner, including yoga, Chiropractic, Osteopathy, massage therapy, meditation, acupuncture, tai chi, qi gong and movement therapies) (The National Center for Complementary and Integrative Health, 2018).

Persistent pain (particularly musculoskeletal pain) is one of the most common reasons for people to use CAM, with more than 40% of individuals living with musculoskeletal pain in the US having tried some form of complementary therapy (Clarke et al., 2015). Similarly, a national survey of CAM use in England in 2005, including 4862 adults showed that 16% of the sample had seen a CAM practitioner (Sharp et al., 2018). The study also revealed that people used CAM mostly for manual therapies (massage, Osteopathy, Chiropractic) as well as acupuncture, yoga, Pilates, reflexology and meditation and that women, people with a higher socioeconomic status and those in South England were more likely to access CAM. Musculoskeletal conditions accounted for 68% of use while mental health 12%. The survey also showed that most people self-referred and self-self-financed.

A systematic review and narrative synthesis investigating people's reasons for choosing or avoiding CAM for musculoskeletal conditions revealed that people provided similar rationales for using and also for avoiding CAM (Corp et al., 2018). People with musculoskeletal conditions perceived CAM to fill in existing gaps in their care (practitioner time or quality of the therapeutic relationship) and also emphasized that CAM aligned well with their philosophy about illness and healthcare suggesting that CAM has the

ability to give them control over managing their condition (Corp et al., 2018). Moreover, a study examining the CAM services accessed from UK primary care identified twenty sites that provided data on service history, features, integration, success and sustainability. The results showed that acupuncture and homeopathy were the most common, followed by massage, Osteopathy and mindfulness (Sharp et al., 2018). The authors suggested that attitudes towards CAM from NHS staff, lobby groups and the public are crucial in the success of existing integrated CAM services together with a better communication and understanding between general practitioners and CAM therapists (Sharp et al., 2018). The main challenges for integrating CAM were the lack of funding and negative perceptions. In addition, the study emphasized the need for more robust and high-quality empirical data, particularly focusing on cost-effectiveness of CAM.

Manual therapies may be the most common CAM treatment type for people living with pain (Bove et al., 2018). However, a series of issues have been identified: there is a lack of homogenous manual therapy training across countries and disciplines as well as a lack of research on effectiveness and difficulties distinguishing treatment effects from the non-specific effects of therapeutic touch (Bove et al., 2018). Manual therapies are also present in several pain guidelines. According to a recently published report synthesizing eleven evidence-based guidelines for pain in the US, Canada and the UK, manual therapies were mentioned in the ICSI (2016) guidelines for pain as well as the SIGN guidelines (2013) and were recommended mainly for low-back pain and also for neck pain (in combination with exercise) (Canadian Agency for Drugs and Technologies in Health, 2016). For persistent pain generally, the guidelines supported the use of physical therapy, exercise therapy, manual therapy, and massage as part of an integrated treatment approach.

2.7 A novel pathway integrating physical modalities and psychological approaches

Over the past few years, there has been increasing interest in integrating physical and psychological approaches and modalities in order to improve outcomes for people living with pain and establish a novel pathway congruent with the biopsychosocial paradigm. One of these initiatives is the ExACT trial, a study investigating whether a combined exercise and ACT-group based intervention is more effective than a stand-alone supervised exercise program in reducing pain interference at 12-week follow-up (Casey et al., 2018). A similar trial is Physiotherapy informed by Acceptance and Commitment Therapy (PACT), a study based on a brief physiotherapist-delivered treatment guided by ACT principles designed to improve pain self-management (Godfrey et al., 2016). The program consists of two face-to-face sessions and a follow-up phone call and was considered feasible and acceptable for patients. The only intervention to date combining Osteopathy and ACT is OsteoMap, an initiative funded by the Department of Health conducted at the University College of Osteopathy (formerly known as the British School of Osteopathy) (Carnes et al., 2017). This innovative intervention was piloted over a period of three years and was based on integrating psychological interventions based on ACT with osteopathic treatment. A total of 256 patients with long-term musculoskeletal conditions took part in a program consisting of six one hour sessions of osteopathic treatment combined with acceptance-based exercises and home practices aiming to develop mindfulness and self-care skills. OsteoMap aimed to enhance patients' resilience and wellbeing and their ability to live a more active and fulfilling life in spite of ongoing pain. Preliminary findings from the OsteoMap program have revealed a significant improvement in psychological flexibility but also in levels of pain, mood and coping at six-month follow up (Carnes et al., 2017). A randomized controlled trial to compare the effects of OsteoMap with

standard osteopathic or medical care is envisaged to follow in the future. The OsteoMap team suggested that it is possible to integrate Osteopathy and other manual therapies with ACT for the benefit of people living with persistent pain and recommended that further research should focus on establishing the effectiveness of this type of intervention.

Summary of Chapter 2 2.8

This chapter provided an exploration of the complexity of pain, by referring to the different ways it has been conceptualized and classified, as well as discussing the current approaches to pain management (biomedical and biopsychosocial) and their usefulness. The rationale for establishing an alternative pathway integrating Osteopathy and brief psychosocial interventions was also outlined, with reference to the potential advantages that this new pairing might offer.

$3\mid$ Methodology

3.1 Overview of the chapter

This chapter will describe the research methodology adopted for this study, including an account of the underlying paradigm as well as the methods of data collection and analysis employed and the accompanying rationale. The intervention development will be placed within pragmatism, one of the four paradigms informing research practice as well as in functional contextualism. A discussion around mixed-methods design will also be presented. The present chapter will also include a description of the data collection and data analysis methods employed as part of developing and piloting the intervention, as well as ethical considerations. The chapter will present a rationale for the suitability of the methods to address the research questions (outlined in Chapter 1, section 1.3.3), by citing relevant methodological literature. Issues of validity and reliability will be addressed as well as the advantages and disadvantages of the methods adopted. The MRC framework for developing complex health interventions¹ guided the choice of methodology adopted for this study (Craig et al., 2000; Craig et al., 2008). The framework influenced the chosen methodology.

3.2 Research paradigm

A research paradigm represents a 'philosophy or set of beliefs, worldviews or values used to justify and put forth research priorities and choices' (Cibangu, 2010,

¹ An overview of the MRC framework and the steps involved in developing complex interventions can be found at the beginning of Chapter 5

p. 177). Bates (1999) recommended that researchers should be aware of the paradigm underlying their research approach.

Creswell (2003) also stressed the importance of identifying the 'worldview' (another term for paradigm, epistemology and ontology or research methodology) underlying the research that one is planning to conduct. He suggested that authors should provide information addressing the philosophical worldview assumptions that they bring to the study, as well as the strategies of inquiry related to the chosen worldview and the specific methods that translate the approach into practice (Creswell, 2003). According to Creswell, there are four worldviews: postpositivism, constructivism, advocacy / participatory and pragmatism (see table 3.1).

Four worldviews		
Postpositivism	Constructivism	
 Determination Reductionism Empirical observation and measurement Theory verification 	 Understanding Multiple participant meanings Social and historical construction Theory generation 	
Advocacy/Participatory	Pragmatism	
 Political Empowerment/ Issue oriented Collaborative Change-oriented 	 Consequences of actions Problem-centered Pluralistic Real-world practice oriented 	

Table 3.1: Four worldviews (adapted from Creswell, 2003

Postpositivists hold a deterministic and reductionist view based on cause and effect and focus on testing theories believing that evidence and rational assumptions shape knowledge. Constructivists assume that individuals assign subjective meanings to their experiences and thus the goal of the researcher is to explore the participants' views of the topic being studied as in-depth as possible (Creswell, 2003). The advocacy worldview arose in the 1980s and 1990s to address issues related to social justice and prosed that research should be interwoven with politics to tackle social issues, empowerment or inequality.

Pragmatism is a paradigm concerned with applications (what works) and searching for solutions to problems (Patton, 1990). This approach is known to emphasize the research problem instead of the methods employed aiming to derive knowledge about the problem (Rossman and Wilson, 1985). Pragmatism is advocating the idea that the researcher is free to choose the methods, techniques and procedures that best fit the aims of their research (often both qualitative and quantitative methods are employed). This paradigm is rather flexible, as it allows exploring multiple methods and assumptions, as well as different methods of data collections and analysis (Creswell, 2003).

Creswell (2003) suggested that philosophical worldviews influence the practice of research and proposed a framework illustrating the interconnection of worldviews, strategies of inquiry and research methods (see figure 3.1).

From an ontological point of view, postpositivists view reality as singular and independent from the researcher while constructivists believe that reality is multiple and the researcher's scope is to actively explore the multiple perspectives from participants (Creswell, 2018). Pragmatism advocates the existence of both singular and multiple realities and researchers often test hypotheses but they also provide multiple perspectives. Creswell (2013) suggested that pragmatism is characterized by



Figure 3.1: A framework illustrating the interconnectedness between worldviews, strategies and research methods (from Creswell, 2003)

practicality, meaning that researchers who chose this paradigm often employ the most suitable methods in order to address the research questions (e.g. a researcher might chose to use both qualitative and quantitative methods if that fits well with the research aim).

Functional contextualism 3.2.1

Functional contextualism (FC) is a modern philosophy of science rooted in philosophical pragmatism and contextualism proposing that all behaviour occurs in context and has purpose (ACBS). FC seeks to understand people within their environments, before turning to reductive explanations of human problems (e.g. that depression is caused by a 'chemical imbalance'). This philosophy is a contemporary update of radical behaviourism. Its core tenets include focus on the whole event, sensitivity to the role of context in understanding the nature and function of an event, emphasis on a pragmatic truth criterion, and specific scientific goals against which to apply that truth criterion (Hayes, 2004).

Pragmatic truth criterion is based on the idea that 'there is no right behaviour, no truth, only what will work for an individual' (Hayes et al., 2004). In functional contextualism, truth is contextual and pragmatic rather than absolute. This philosophical stance considers no thought, feeling or memory as fundamentally problematic, dysfunctional or faulty, it all depends on the context. The target of change is not the thoughts themselves but their function. For example, the thought 'I am not good enough' can emerge and not influence a person, who would continue to engage in valued actions or they can get tangled in this thought and stop doing what they care about. The thought is the same, but the function has changed.

FC provides a starting point for the development of effective interventions that incorporate a person-in-environment perspective (Boone et al. 2015). In other words, FC seeks to develop theories and interventions that are useful

tools for researchers, health professionals, and clients to produce change. Functional contextual concepts such as 'acceptance' and 'psychological flexibility' are descriptions of behaviors or qualities of behavior that can be observed and described. Behaviour includes not just public or overt actions, but also internal events such as thoughts, feelings, memories and physical sensations— behaviors that only the individual experiencing them can observe. For example, a person who is depressed might engage both in overt behaviors such as staying in bed all day and internal behaviors such as ruminating on hopeless thoughts. In a clinical context, a functional contextualist would not ask a client to challenge a negative thought they identified but rather to examine whether it the thought is useful in the service of some goal (learning a new skills or pursuing a new job). Similarly, researchers adopting a functional contextualist approach do not seek to determine whether a model or theory is a true representation of how health or suffering occur in the world, instead they focus on the utility of the model in service of outcomes being targeted (e.g. increasing quality of life).

Functional Contextualism is the philosophy underlying Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999). ACT emphasizes the context and function of psychological processes as opposed to their form, incorporating contextual and experiential change strategies in addition to traditional strategies (Hayes, 2004). ACT conceptualizes psychological problems as rooted in six core processes that describe both the interplay between human language and cognition and the control of behaviour by direct experience (Hayes et al., 2006). ACT utilizes interventions that are less verbal and more experiential (e.g. metaphors, mindfulness and experiential exercises) to help people simply notice their experiences (thoughts, feelings, memories) rather than trying to change them.

The main goal of ACT is to increase psychologically flexibility, by helping people respond with willingness to whatever they encounter, whether thoughts and feelings or external circumstances, when doing so serves building a rich and meaningful life. Psychological flexibility has been broken down into six interrelated processes: values, committed action, defusion, self-as-context, acceptance, and contact with the present moment. ACT teaches people to bring these processes foreword, both in therapy and in life.

Psychotherapies have traditionally focused on symptom reduction (Batten, 2011). Functional contextualism offers a good alternative, shifting the focus to outcomes important to the individual. Future paradigms should explore clients' contextual needs, rather than trying to reduce the symptoms of psychological disorders.

A mixed-methods approach to intervention development 3.3

Methodology can be described as a strategy of enquiry that informs adopting a certain set of procedures (Creswell, 2009). Two major methodologies used in research stem from two different paradigms (positivism and constructivism respectively): quantitative and qualitative research (Teddlie and Tashakkori, 2009). However, more recently, a mixed-methods approach has become increasingly applied in a variety of social, behavioural and health disciplines (Creswell and Clark, 2018).

Mixed method research has been conceptualized in different ways since its emergence, however Johnson et al. (2007) provided a comprehensive definition by drawing upon nineteen different explanations: 'Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the breadth and depth of understanding and corroboration' (Johnson et al., 2007, p. 123). This definition proposes that mixing different strategies, inferences and

viewpoints belonging to both the quantitative and qualitative paradigms serve a purpose: achieving a superior understanding of the research problem, providing more breadth and depth.

The researchers who employ mixed methods are advised to establish a rationale for mixing quantitative and qualitative methods and state the intended consequences of employing this approach. Given that the overall aim of this PhD project was the development of a novel intervention, adopting a mixed-method approach based on pragmatism was an appropriate choice. Developing a novel intervention is a solid rationale for the pragmatic approach adopted, as it was justified by the need to 'develop, implement and evaluate a program' (Creswell, 2018, p. 11). A pragmatic paradigm perfectly suits multicomponent projects where a series of studies are needed to reach an objective (in this case developing an intervention). An example of this is the multiphase evaluation study carried out by Peterson et al., (2013) in Creswell and Clark (2018) based on the development and implementation of an intervention to motivate behaviour change for individuals living with chronic illness. The authors justified that by integrating both qualitative and quantitative methods and findings the researchers may gain a better understanding of participants' stance and thus tailor the intervention approaches more effectively (Peterson et al., (2013) in Creswell and Clark (2018)).

A mixed-method approach to health research begins with the assumption that the nature of the evidence collected by investigators depends on the type of health-related issue as well as the social, behavioural and biomedical theoretical underpinnings of the project (NIH Office of Behavioral and Social Sciences, 2018). In line with this, quantitative methods are deductive and ideal for measuring known phenomena and establishing patterns of association or making causal inferences while qualitative methods are mainly inductive and allow for the identification of new phenomena or explanations in regards to why phenomena occur and the range of their effects (Pasick et al., 2009; Pollock, 2012; Peter, 2015). The mixed-methods approach goes beyond merely collecting different types of quantitative and qualitative data and enables a more comprehensive understanding of health problems and strategies to alleviate them (Lewin et al., 2008; Fetters et al., 2013).

The present research employed a mixture of methods and procedures that were chosen because they fit well with the research aims and best met the purpose of the overall project. This pragmatic approach combined qualitative and quantitative methods in a unique way that is different from the typical mixed-method designs commonly used in research (e.g. triangulation, explanatory mixed-method design).

In line with the guidance proposed by the Medical Research Council (MRC) framework for developing and evaluating complex health interventions (Craig et al. 2000, 2008) an iterative approach has been adopted to the intervention development comprising of two preliminary qualitative studies investigating the needs and perspectives of people living with pain as well as the views and experiences of osteopaths who treat people experiencing long-term pain, a systematic review of randomized controlled trials looking at the effects of Osteopathy on psychosocial factors relevant in persistent pain and a mixed-method feasibility and acceptability study (see table 3.2).

It is important to mention that, although the development process was placed within a mixed-methods approach underlying a pragmatic worldview, the qualitative component was predominant throughout the project (studies 1 and 2 and 4 were entirely qualitative while study 3 included quantitative measures in addition to the qualitative interviews). This is mainly due to the need to involve participants in designing and piloting of the novel program, through determining their needs and exploring the meanings they assigned to pain and the way pain impacted on their lives. A quantitative paradigm was considered unsuitable for achieving this goal, as it could not yield the same breadth of data as a qualitative approach. However, collecting quantitative data will play a more

important role later on, when evaluating the intervention. A future randomized controlled trial will be essential in testing the effectiveness of the intervention. Conducting a trial was not feasible within the timeline of this PhD and given the available resources. Moreover, training the osteopaths to deliver the program would have required additional funding, time and resources. However, the preliminary research that is reported in this thesis is valuable in setting a solid groundwork for future studies that will evaluate and improve the intervention as well as gain a better understanding of the underlying processes and mechanisms. Also, researching within the field of Osteopathy contributed to the fairly limited body of qualitative literature in this area. Thomson et al. (2011) suggested that qualitative research provides a unique opportunity to explore the different perspectives of Osteopathy and thus adding a contextual dimension to the existing evidence-based approach. Petty et al. (2012) also proposed that more qualitative research is needed to develop a more robust and comprehensive knowledge base in manual therapy.

Methods of data collection 3.4

This section will include a description of the two methods of data collection utilized in the intervention development process: focus groups and individual interviews. In addition, this section will address feasibility and acceptability and the way these concepts have been applied to modelling the process and outcomes.

3.4.1 Focus groups

A focus group consists of a group discussion with a particular topic organized for the purpose of research, and moderated and recorded by a

Stages in the development of 'A Mindful Act' (2016-2019)			
Systematically identifying the evidence	Identifying the theory	Determine the needs	Modelling process and outcomes
A systematic review investigating the effects of osteopathic treatment on psychosocial factors in people living with persistent pain	Reviewed the existing theory and evidence base regarding the effectiveness of ACT-based interventions for long-term pain	Conducted two qualitative studies to determine the needs and experiences of people living with persistent pain as well as the perspectives of osteopaths who treat them	Utilized the data resulting from previous stages to inform the development of the novel intervention. Then, I progressed to develop an intervention protocol and assess the feasibility and acceptability of the intervention.
Systematic review of 16 RCTs looking at whether osteopathy has an influence on depression, anxiety, fear-avoidance or pain catastrophyzing	An account of the ACT model and the effectiveness of ACT interventions for people who experience persistent pain can be found in Chapter 1.	Study 1 - 'A qualitative study exploring the experiences of living with persistent pain of people from South Wales and their views on the development of a novel psychosocial intervention'	the feasibility and

Stages in the development of 'A Mindful Act' (2016-2019)			
Systematically identifying the evidence	Identifying the theory	Determine the needs	Modelling process and outcomes
The systematic review was updated in 2019, and four new RCTs were included and assessed for quality (see chapter 3).	The research literature focusing on the effectiveness of ACT for persistent pain was updated in 2019 (see chapter 2)	Study 2 - 'A qualitative inquiry into osteopaths' perspectives on their professional identity and their personal views on treating people with persistent pain'	group study exploring Osteopathy students' views on a novel psychosocial intervention
Original systematic review: 2016-2017 Updated: 2019	Literature review 2016- 2017 Updated: 2019	Studies 1,2 were conducted in 2016 and 2017 respectively	'A Mindful Act' was developed and piloted in 2018. Studies 3,4 were carried out in 2018 as well.

Table 3.2: Table illustrating the development of 'A Mindful Act' informed by the steps proposed by the MRC framework (Craig et al. 2000, 2008)

researcher (Kitzinger, 1994). Focus groups were first used in the 1940s in the context of market research, however, the success of this method contributed to an extended use beyond the private sector (Morgan, 1996). Focus groups were adopted for application in qualitative research in social sciences and more recently they have been used extensively in health research to explore the perspectives of patients and healthcare providers (Tausch and Menold, 2016). A few examples of health research fields where focus groups were employed include: specific illnesses (rheumatoid arthritis, Feldthusen et al., 2013; cancer, Gerber et al., 2012), community health research (Daley et al., 2010), devising new diagnostic or therapeutic methods (Vincent et al., 2006).

The purpose of conducting focus groups is to generate information on collective views, and the meanings underlying those views. Focus group methodology is particularly useful in gaining a rich understanding of participants' experiences and beliefs (Morgan, 1998). Focus groups can be used as a standalone method but also in multi-method designs; to explain or extend findings collected through other methods or to feedback results to participants (Bloor et al., 2001). A common use of focus groups is to bring together a group of individuals who experienced the same problem (e.g. a group of residents of a deteriorating neighbourhood) (Rubin and Rubin, 1995). The discussion between the participants is usually audio-recorded, transcribed, and analysed later with the help of conventional qualitative analysis techniques (usually content analysis or thematic analysis) (Wilkinson, 1998). Rich data is obtained when focus group participants share common experiences and individual perspectives are enhanced by the dynamics of the group; in this sense, the focus group is more than a technique but a social process (Douglas et al., 2008).

In the context of healthcare research, focus groups are particularly advantageous as they help advance our understanding of illness, by identifying people's perceptions of health-risk behaviours or their views

regarding the causes of disease (Wong, 2008). Furthermore, focus groups are effective in addressing sensitive issues that are difficult to assess (e.g. mental health) (Naish et al., 1994) and they often help researchers gain an insight into people's experiences of ill health and health services or the attitudes and views of healthcare providers (Denning, 1993). An extensive range of health topics has been explored by using focus groups (experiences of living with chronic illness or disability, reproductive issues, healthcare practices and procedures, health-related behaviours) (Wilkinson et al., 1998). Given its advantages, researchers are increasingly employing focus groups to investigate the experience of living with persistent pain (e.g. Borkan et al., 1995; Henwood and Ellis, 2004; Douglas et al., 2008). There is a growing body of literature consisting of focus group research trying to explore perspectives and experiences of different chronic pain conditions from both patients' and carers' viewpoint (Jordan et al., 2007, Shaw and Huang, 2005). Petty et al. (2012) suggested that conducting more qualitative research is needed to develop a more robust and comprehensive knowledge base in manual therapy. Thomson et al. (2011) reinforced this idea and proposed that qualitative research provides a unique opportunity to explore the different perspectives of Osteopathy and thus adding a contextual dimension to the existing evidence-based approach.

Focus group studies with patients and osteopaths²

The first step of this research project focused on enhancing our current understanding of people's experiences of living with persistent pain and their psychosocial needs, to then utilize the resulting research knowledge in the intervention development. Equally, it was crucial to explore the experiences of osteopaths who supported people in managing their condition. These aims were addressed with the help of a focus group methodology, which contributed to a depth of data as a result of the interaction between participants, who shared their experiences and

² For information about participants and recruitment see Chapters 5, 7; Ethical principles are outlined in Section 4.6

perspectives openly. It has been suggested that individuals are more likely to provide sincere responses in this type of setting. Participants built on each other's' ideas, which was very useful in terms of identifying their needs. Moreover, by employing a focus group methodology, participants were at the centre of their own care and their views were used to develop the novel intervention.

Two focus groups were conducted in 2016 and 2017 respectively, involving nine people experiencing long-term pain recruited from the Osteopathy Clinic and ten osteopaths who were staff members in the same clinic (see chapter 5 for aims, design, participants, recruitment). Another focus group was conducted in 2018 with six Osteopathy students who were involved in recruiting participants for the intervention (see chapter 7). Although these focus groups involved different categories of participants (people living with persistent pain, Osteopathy tutors, Osteopathy students) they all followed the same protocol. Ethical approval was granted by the CHHS Ethics Committee for both of the studies.

The focus group discussions took place in a noise-free conference room within the College of Human and Health Sciences and lasted little over one hour. The venue was appropriate, as it was easily reachable by participants and also convenient in terms of parking and access to public transport. The time of the day when the focus groups were scheduled was decided depending on the availability of participants. Light refreshments were offered before the focus group, and this provided the main facilitator with the opportunity to greet the participants and build a rapport. Comfortable chairs were provided and movement breaks were allowed, as long as they did not interfere with the discussion. The focus group started with the facilitator introducing themselves and the assistant, followed by information regarding the location of toilets, safety procedures, the duration of the discussion and an overview of the project and its purpose. Following that, all participants signed a written consent form before the focus group

discussion began (see appendix A.3). It was important to set out the ground rules (see appendix A.4), a group agreement including the principles of participation (e.g. be respectful, speak one at a time, focus on the topic). The discussion followed a semi-structured format; the facilitator encouraged interaction among participants by using prompts and probes, also by rephrasing and summarizing (e.g. 'can you tell me more about that?' 'What do you mean exactly?'). The aim was to achieve a balance between enabling the exploration of each topic and keeping the discussion focused. Another researcher assisted the facilitator by recording observations (e.g. verbal and non-verbal cues, the general feel of the discussion). The assistant also made notes about the major topics raised and the key points made by participants in response to questions. The last part of the focus group was structured in a way that allowed the participants to add anything they have not mentioned before and to ask any questions they might have had. Participants were reassured that the discussion has been confidential and the information anonymized. They were thanked for their contribution in person and also by email after the focus group.

Focus groups are considered a 'useful method for learning about the vocabulary and thinking patterns of a population within its social context' (Hoppe et al., 1994, p.118). This method of data collection is naturalistic, as it enables spontaneous interaction between people, therefore increasing the chance of gaining deeper insights than might be elicited with the help of individual interviews or questionnaires (Ritchie et al., 1994). Focus groups differ from other data collection techniques used in social research by two aspects: firstly, the source of information is a group; secondly, the heuristic value of focus groups lie in the interaction emerging during the discussion (Acocella, 2012). Although focus groups are an excellent data collection method, that allows participants to build upon each other's ideas stimulating thinking and discussion and generating high-quality data, there are also several limitations to this method.

First of all, focus groups require very good planning: the participants, facilitator, and assistant have to be available at the same time. This is particularly challenging when the participants are people who live with persistent pain. They might experience fatigue, mobility issues, fear of pain, or have limited availability, factors that make participation difficult. Moreover, in order to facilitate a successful group interaction, it is essential to create a comfortable environment where participants can feel safe to express their opinions. In addition, according to the principle of 'homogeneity', the group participants should not be too different (too distant cultural levels or social status) or have widely different perspectives as this may lead to inhibitions and unpleasant situations causing a level of conflict that may deter the focus group discussion (Bloor et al., 2001).

A focus group is considered more a group discussion rather than a group interview (Krueger, 1994). Two main interactions occur during a focus group: the facilitator-participant interaction, where the facilitator proposes a topic and participants reply to it and the interaction among participants (Acocella, 2012). The interaction between participants is more important, as it constitutes the informative source of the focus group (Puchta, 2005). However, an intrinsic limitation of focus groups is that the information that is likely to emerge will reflect the experiences that the participants have in common and share (Acocella, 2012). A skilled facilitator should encourage both cohesion and confrontation of opinions within the group. Another limitation of focus groups is the susceptibility to bias because individual and group opinions can be influenced by dominant participants or by the facilitator (Kitzinger, 1994). Furthermore, the discussion often digresses from the original topic, contributing to 'messy data' (Wong, 2008). In this case, the facilitator needs to overcome this setback by guiding the participants through the discussion and ensuring that all the participants have a chance to join in (Smithson, 2000). Last but not least, focus group data can take considerably longer to analyse than data resulting from surveys.

Taking into consideration both the advantages and disadvantages of employing focus groups, this method fitted well with the aims of the research project and yielded a wealth of qualitative data, that proved to be very useful in developing the intervention.

Focus Groups		
Advantages	Disadvantages	
Rich source of data	Data analysis can be time consuming	
Allows building up on other's ideas to express own views	Facilitators need to be trained and able to lead the group	
Able to reach many participants at once	One dominant group member can sway the tone of the entire group	
Participants can share and compare their experiences	Planning can be difficult	

Table 3.3: The advantages and disadvantages of conducting focus groups

3.4.2 Individual interviews

Interviews are one of the most widely used data collection techniques in qualitative research (Sandelowski, 2002). This method is employed in order to collect detailed accounts of participants' thoughts, beliefs and attitudes towards a given phenomenon (Loiselle et al., 2007). This approach is based on the assumption that if questions are correctly formulated, participants will share their experiences that reflect their reality (Macdonald, 2006). Interviews are most appropriate in situations where little is known about a particular phenomenon or detailed insights are necessary from individual participants (Silverman, 2000). This method is also suitable for exploring sensitive topics, where participants may not want to talk about such issues in a group environment.

There are three main types of interviews: structured, semi-structured and unstructured. While structured interviews are based on a list of predetermined questions with little or no variation or follow-up to responses, unstructured interviews do not reflect any preconceived ideas or theories and are usually employed when nothing is known about a particular topic and significant 'depth ' is required (Gill et al., 2008). Semi-structured interviews, on the other hand, are a mixture of the previous two: they involve several key questions that help define the subject area while allowing the interviewer or interviewee to pursue an idea or response in more depth (Britten, 1999). This approach is frequently used in healthcare due to its flexibility, as it allows for the emergence and elaboration of information that is of particular importance to participants. Designing an interview schedule that will yield as much information about the study phenomenon as possible and also address the aims of the research is essential (Britten, 1999). The questions should be straightforward, open-ended and neutral. It is imperative to put participants at ease by starting with easy questions and then continue with the more sensitive topics. It must be pointed out that a participant's responses are based on their account of the world and not a direct representation of reality (Silverman, 1998).

Before the start of the interview, participants should be provided with information about the study and assured about ethical principles (e.g. confidentiality, anonymity, right to withdraw). This will give them a good idea of what to expect and increase the likelihood that they will provide honest answers. Also, establishing rapport prior to the interview can have a positive effect on the subsequent development of the interview (Kvale, 1996). Moreover, the interviewer should possess good listening skills, and adopt an open and neutral body language, nodding, smiling and allowing the participants to recount their experiences as fully as possible without interrupting them unnecessarily (Stewart et al., 2008).

Individual interviews have been employed in the current project on two occasions. Firstly, interviews were used in 2016, as part of Study 1 (see table 3.2) at the request of three participants who either did not feel comfortable sharing their experiences of living with persistent pain with a group or were not available on the date chosen for the focus group. Combining data from focus groups and interviews is not uncommon (Lambert and Loiselle, 2007). Although these are two independent data collection strategies their combination can be advantageous as complementary views on phenomena might be generated. This is an example of mixing different methods in order to meet specific research needs. Some researchers prefer to combine these methods for pragmatic reasons (as in this case) when participants are unable or unwilling to attend a focus group (Rees et al., 2003). Secondly, individual interviews were conducted in 2018 as part of assessing the feasibility and acceptability of the intervention (Study 3). The nine participants who took part in 'A Mindful Act' were interviewed in regards to their experiences of taking part in the program. It is important to note that the main facilitator of the intervention was also the one to interview the participants about the acceptability and feasibility of the program. This might have been beneficial, as there was a strong rapport between the facilitator and the participants built over the six weeks of 'A Mindful Act'. This might have led the participants to feel comfortable with sharing their honest opinions about the program. On the other hand, there is a possibility that this was a source of bias, since the participants may have consciously or unconsciously chosen to share only positive feedback about the intervention. This will be discussed further later on, as part of the section about Ethical principles (see section 4.5).

Conducting individual interviews has several advantages over other data collection methods: it helps gain detailed information about individual experiences while also capturing non-verbal cues (e.g. body language), it is useful for exploring sensitive topics, data can be easier to analyse as there is a single perspective on a phenomenon (e.g. compared to focus groups)

Individual interviews		
Advantages	Disadvantages	
Gaining in-depth and detailed information about an individual's experience	It may take longer to collect the data	
Useful for sensitive topics	Limited to one participant's view, no peer comparison	
Data can be easier to analyze	Interviewers need to posses very good one-to-one communication skills	
Planning can be easier	May be more costly (e.g. time, travel)	

Table 3.4: Advantages and disadvantages of individual interviews

and planning can be easier (see table 3.4). However, there are also several disadvantages: interviewing one participant at a time may take longer and consequently it may be more costly in terms of time and travel, the data is limited to one participant's view and therefore there is no peer comparison (as in focus groups), interviewers need to possess excellent communication skills and be a good active listener.

Assessing the feasibility and acceptability of the 3.5 intervention

The second stage of the development and evaluation process outlined by the MRC guidance (feasibility/piloting) includes testing procedures, estimating recruitment/retention and determining sample size (Craig et al., 2008). The guidance emphasizes the importance of assessing feasibility and acceptability. An early evaluation of the acceptability of a complex intervention can highlight aspects of the interventions that can be modified before a definitive trial (McCracken et al., 2014; Cramer et al., 2011). According to the MRC guidance, this stage is very useful in providing

insights regarding the appropriateness of the procedures, the recruitment process, participant retention and how acceptable the participants find the program (Craig et al., 2008). The MRC guidance also suggests using a mixture of quantitative and qualitative methods to better understand barriers to participation and estimate response rates and recommends carrying out a series of studies meant to refine the design, before progressing to a full-scale evaluation (Craig et al., 2008). However, neither the original MRC guidance nor the updated versions provide an operational definition of acceptability and feasibility or guidance on how to assess them. Despite this, the two concepts were defined with the help of previous research literature and similar studies assessing the acceptability and feasibility of health interventions.

Acceptability 3.5.1

Acceptability has been conceptualized as a 'multifaceted construct that reflects the extent to which people delivering and receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention' (Sekhon et al., 2017, p. 88) (see figure 3.3). Acceptability plays a key role in the design, evaluation and implementation of healthcare interventions (Sekhon et al., 2017). Although acceptability is not a sufficient condition to guarantee the effectiveness of an intervention, it is a key factor in the successful implementation of interventions to both intervention deliverers and recipients (Diepeveen et al., 2013).

Based on the theoretical framework provided by Sekhhon et al. (2017), acceptability was divided into three categories: prospective acceptability (how an individual feels about the intervention prior to participating), intervention coherence and adherence (the extent to which a participant understands the intervention and how it works and also the engagement

with the program) and experiences of taking part (including perceptions of the intervention, barriers, satisfaction) (see figure 3.2). Barriers to taking part were assessed with the help of one to one interviews, while burden (the perceived effort needed to take part in the program) was explored during the initial meeting with the prospective participants. Assessing intervention coherence and adherence involved collecting data on program attendance, homework completion and a short quiz testing participants' knowledge of ACT (see chapter 7).

Acceptability and feasibility	How would you describe your experience of taking part in 'A Mindful Act' programme?
Process of change	What did you learn from this programme?
Acceptability	What was the aspect of the programme that you liked the most? What was your favourite activity (or session)?
Suggestions for further improvement	What did you least like about the programme? What do you think could be improved about 'A Mindful Act'?
Barriers	Were there any difficulties to taking part?
Process of change	Are there any changes in your perspective of living with pain? If the answer is 'Yes', what are they?
Implementing change	Do you practice Mindfulness? How often?
Process of change	Have you noticed any differences in your life as a result of taking part in 'A Mindful Act'? If 'yes', what are these differences?
Acceptability	Would you recommend this intervention to someone you care about?

Figure 3.2: Table illustrating the assessment of feasibility and acceptability through one-to-one interviews (Saracutu et al., 2018)

Acceptability

A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experiential cognitive and emotional responses to the intervention.

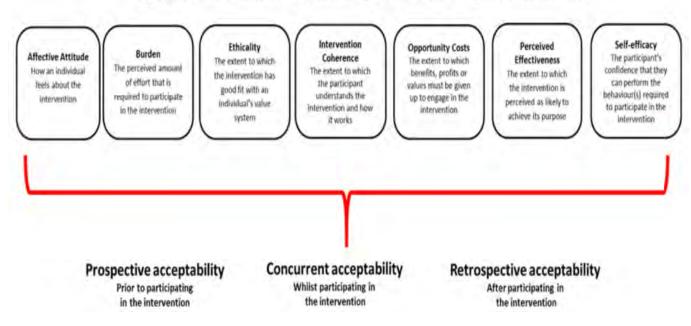


Figure 3.3: Theoretical framework of acceptability (reproduced from Sekhon et al., 2017)

3.5.2 Feasibility

Feasibility studies have been defined as studies estimating important parameters that are needed to design the main study standard deviation of the outcome measure, willingness of patients to be randomized, willingness of clinicians to recruit participants, number of people eligible, follow-up rates, response rates and adherence/ compliance rates (NIHR, 2015). Although some authors use the terms 'feasibility' and 'pilot' interchangeably, others suggest that there are several features that distinguish the two (e.g. the pilot is a small-scale version of the main study aiming to determine whether the components of the main study can work well together while feasibility studies focus on assessing whether it is possible to perform a full-scale study).

The purpose of conducting feasibility studies is to decide whether an intervention is appropriate for further testing, therefore enabling researchers to determine whether or not the intervention can be relevant and sustainable, by identifying if the methods and protocols employed need modification but also by elucidating the process of change (Bowen et al., 2009). Furthermore, feasibility studies are particularly useful in testing the suitability of interventions in real-world settings (Bowen et al., 2009). In the first stages of developing an intervention, the main question that researchers ask is: Can it work? This is the question underlying feasibility studies, usually followed by two other important questions (Does it work? and Under what conditions does it work?) that are addressed by efficacy and effectiveness trials. The MRC framework recommended that the investigators should be confident that the intervention can be delivered as intended, and be able to make safe assumptions related to the recruitment and retention rates, effect size and variability to help design a full-scale trial (Craig et al., 2008). For example, McCracken et al., (2014) conducted a study to assess the feasibility of a brief group-based ACT intervention for people who live with pain designed to be delivered in general practice. The methods used in examining feasibility were: analysis of recruitment and attendance, self-report treatment evaluation and follow-up interviews (McCracken et al., 2014). The authors suggested that although these methods were partly exploratory, they predicted high feasibility (successful recruitment of 60 participants over nine months, more than 75% endorsement of 5 or higher on a scale assessing treatment evaluation and a majority of 'acceptable' ratings for each of the 12 features of the treatment) (McCracken et al., 2014).

Based on the guidance set out by the MRC framework, the feasibility of 'A Mindful Act' was determined by assessing the recruitment³ process (number of participants referred, number of people attending an interview with the researcher) and also the measurement tools (by recording the time taken by participants to fill in the questionnaires, the number of items missing and the follow-up rates) (Saracutu et al., 2018) (see figure 3.4).

Feasibility

Recruitment process

- Number of people referred from Osteopaths and eligible for screening.
- Number of people attending interview with researcher.

Feasibility of measurement tools

- Time taken to fill in questionnaires.
- Missing data from questionnaires.
- ▶ Follow-up response rates (1 month and 3 months follow-ups).

Figure 3.4: Assessing the feasibility of 'A Mindful Act' intervention (extracted from Saracutu et al., 2018)

The results of feasibility study provided valuable information that will be useful in carrying out a full-scale trial and conducting a process evaluation to clarify the causal mechanisms of the intervention and to better understand the process of change. However, it is worth mentioning that the study involved a small number of participants and lacked a control group. Running

³ A detailed description of the recruitment process is included in Chapter 5 (Intervention protocol).

more than one group, or including a control would have been a better test of feasibility; nevertheless, this was not possible due to time and resource requirements. This will be further discussed in Chapter 8 (Discussion), as part of the limitations.

Ethical principles 3.6

Ethical reflexivity is a core feature of research as many ethical questions may emerge throughout the whole research process (von Unger, 2016). Researchers often ask themselves: Will this project be worthwhile? What are the potential risks to participants? What is my role as a researcher? While these questions might not always have an easy answer, it is crucial to clarify them and follow ethical guidelines.

The question of ethics is pervasive in qualitative research, mainly due to the 'emergent, dynamic and interactional, nature of qualitative research' (Iphofen and Tolich, 2018, p.1) that entails complex ethical responsibilities. Commonly, qualitative researchers are involved in all the stages of the research process from designing the study, interviewing the participants, transcribing and analyzing the data, reporting the themes, therefore, it has been argued that the researchers are an integral part of the process (Fink, 2000). Given this involvement, the researcher-participant relationship must be carefully considered. In addition, carrying out research involving vulnerable groups⁴ may raise a series of particular risks (e.g. anxiety and distress, confusion of the research process with a therapeutic encounter) that need to be addressed. Some important ethical concerns to be taken into account while carrying out a research study are informed consent, confidentiality, anonymity, and risk of harm.

⁴ People who live with persistent pain are seen as a vulnerable group (Pincus et al., 2000)

The College of Human and Health Sciences (CHHS) Ethics Committee granted approval for all four studies. Swansea University Osteopathy Clinic also granted permission to carry out the studies: in fact, the osteopaths collaborated with the research team throughout the whole research project. The first two studies were approved in February 2016 while the last two were granted permission in December 2017. This section will address all the above-mentioned ethical principles and the way they have been applied throughout the research project.

Informed consent 3.6.1

For qualitative researchers, it is of utmost importance to specify in advance what data will be collected and how it will be used (Marzano, 2007). This principle emphasizes the researcher's responsibility to inform the participants about different aspects of the study in a comprehensible language. In line with this principle, all the participants were provided with an information pack containing information about the nature of the study and its objectives, the role of the participants, the identity of the researchers involved in the project and the financing body and how the results will be used. In addition, they had the opportunity to ask additional questions either in person or via phone or email. All the participants gave their verbal and written consent to take part in the research. They were allowed two weeks to consider their participation and to ask questions. Participants were informed of their right to withdraw at any point during the study, without any consequences. This was stated in the information pack as well as in the consent form. Participants were also informed that they did not have to answer any questions they did not wish to. The participants were also made aware that the analysis of the data collected during the research was likely to be disseminated in academic journals or presented at different conferences. They were made aware that this data might include direct quotations, however, the data will be unidentifiable. Consent was granted

from all participants for the use of verbatim quotations within the report and subsequent publications.

3.6.2 Confidentiality and anonymity

The confidentiality of the participants is very important. All the participants received a unique code, only known by the researcher. This code was attached to all the files that relate to the individual. Any identifiable information was removed in the transcription process and replaced by pseudonyms. Participants' consent forms were kept in a cabinet locked at all times, within a secure building within Swansea University, as well as on a password-protected computer. Only the researcher had access to this cabinet. All data was anonymised to ensure confidentiality. Participants were advised not to disclose information that they came across during the focus groups discussions or the six- week program. It is important to note that the research team did not have access to the participants' medical history or records kept by the Osteopathy clinic. This was reserved to the osteopaths, who acted as gatekeepers. Audio-recordings of the focus groups and interviews were uploaded to a secure computer, but not deleted immediately after transcription as they were considered an important source of data. They will be kept until the completion of the study and for a further five years, after which they will be destroyed (consistent with Swansea University Ethics policies).

Risk or harm, anxiety or distress 3.6.3

Qualitative research aims to gain an in-depth understanding of an issue, including participants' beliefs and experiences, some of which might bring to surface sensitive topics (Richard and Schwartz, 2002). This might provoke anxiety or distress in participants. Discussing personal experiences of living with pain might be distressing for some, and bring up painful thoughts and

feelings. The researcher was aware that this was something likely to happen and was observing signs of potential distress during the focus groups and interviews. A few of the participants did show some mild signs of distress (e.g. a change in tone of voice) and they were offered a small break. They were asked whether they wanted to continue with or to withdraw from the interview or focus group discussion. In addition, all the participants were provided the contact details of different free support groups should they need additional support. A clinical psychologist was also available in case there was a realistic need for additional immediate support.

When the researchers in a study are health professionals, this might lead to a power imbalance. The participant might be feeling pressured to participate in a study because they believe they are dependent on their carers (Holloway and Wheeler, 1996). This issue was addressed by having the osteopaths reinforce to patients that they did not need to take part in the focus groups or the intervention and that they will receive osteopathic treatment as usual regardless of their involvement in the research.

In addition, given the openness of the interview questions, allowing the participants to speak on their own terms might have been perceived as therapeutic. It was essential to emphasize the distinction between an interview and a therapeutic encounter. Moreover, the main researcher clarified her role and boundaries to the participants in the intervention (e.g. emphasizing her duties as a researcher and facilitator) to avoid any related confusions (being perceived as someone providing psychological therapy).

3.6.4 Inconvenience and burden

In addition to the risks mentioned above, the inconvenience and costs involved in participating in research studies need to be taken into consideration. Interviews and focus groups normally last approximately

one hour and require the participants to travel. This might be difficult for people who experience pain or have mobility issues.

The researcher made sure that all the research activities took place in an easily accessible room within the University, where there was plenty of space, enough natural light and comfortable chairs. Yoga mats were also provided for the mindfulness practice (during 'A Mindful Act'). The travel costs could not be covered, however, the participants in the first study were offered a 50% discount to be used towards an Osteopathy session, and the six-week program was provided for free. In addition, light refreshments were offered to all the participants in all four studies. Moreover, it was important to ensure good timekeeping and allow participants to take movement breaks should they feel uncomfortable or in pain (provided they did not disturb the other participants).

3.6.5 Researcher-participant relationship

The relationship between the researchers and participants in qualitative studies can raise ethical concerns. Given that throughout this research project the main researcher was involved in interviewing the participants, data transcription and data analysis as well as facilitating the intervention, it is important to acknowledge that the researcher developed a good familiarity with the participants. Despite making efforts to delegate some of the research activities (e.g. interviewing participants), this was not possible. However, a co-facilitator helped with the delivery of the intervention and offered a more neutral perspective. The familiarity between the researcher and the participants in 'A Mindful Act' might be a source of bias. The interviewees were asked to share their honest views on the program and might have felt compelled to provide positive feedback. This will be further discussed in the Reflexivity section (see chapter 8).

Data analysis methods 3.7

This section⁵ illustrates the data analysis methods employed in the development of the intervention and the rationale for employing them. Thematic analysis and framework analysis will be discussed in relation to the aims of the project and their fit with the research questions. A detailed account of the process of applying these analysis methods and their advantages and disadvantages are detailed below.

Thematic analysis 3.7.1

Emerging in the late 1960s and early 1970s within the context of qualitative research, thematic analysis (TA) has been defined as 'a method for identifying, analysing and interpreting patterned meanings or themes in qualitative data' (Braun and Clarke, 2006, p.79). What distinguishes thematic analysis from other qualitative methods is flexibility; in fact, Braun and Clarke (2006, 2013) suggested that thematic analysis is not bound to a particular epistemological or theoretical perspective, which makes it a useful research tool able to provide a detailed and complex account of the data. This also means that there are many ways to approach TA (Javadi & Zarea, 2016); furthermore, this method has been widely used in a range of different contexts (e.g. social, behavioural, clinical, health, education sciences) (Braun and Clarke, 2013). However, flexibility may also lead to inconsistency and lack of coherence when developing the themes from the data (Holloway and Todres, 2003). TA aims to identify themes (patterns in the data that are important or interesting) and use these themes to address the research question, however, this method goes beyond merely summarising the data, it also involves a good level of interpretation and making sense of the data (Maguire and Delahunt, 2017). Moreover, an advantage of this method consists in its

⁵ Please see chapters 5 and 7 for a detailed description of the participants, recruitment and outcome measures employed in the four studies conducted

accessibility, particularly to researchers who might be more inexperienced or unfamiliar with qualitative methods (Braun and Clarke, 2006; King, 2004). However, one disadvantage of TA is the lack of substantial literature to guide novice researchers on how to conduct it rigorously (Nowell et al., 2017). Rohleder and Lyons (2015) suggested that thematic analysis is an excellent tool for clinical and health research due to its flexibility and fit with various types of research questions (concerned with individual views and experiences or social construction of meaning) (see table 3.5). In their editorial published in 2014, Braun and Clarke suggested that qualitative research provides important insights into the experiences and perspectives of patients and healthcare professionals in ways that may complement the knowledge obtained through quantitative methods (Braun and Clarke, 2014). The authors argued that thematic analysis is perfectly suited for applied health research, particularly when conducting research linked to practice and policy and offering researchers a toolkit for carrying out sophisticated qualitative data analysis that can be presented in an accessible way to those outside academia (Braun and Clarke, 2014). Finally, Braun and Clarke recommended the use of thematic analysis for health and wellbeing research. However, they also advised researchers to employ this method wisely and to consider several factors such as the topic, the researchers conducting the research and their level of experience, the intended audience, the theoretical framework of the research and the context (Braun and Clarke, 2014).

In the context of the current project, thematic analysis has been adopted to facilitate an in-depth exploration of the individual experiences and needs of people living with pain as well as investigating the experiences and views of osteopaths (see table 3.2). This aligns well with the research aims suitable with TA, by focusing on individuals' lived experiences of a health condition and also on the way a specific group of patients and health professionals view a certain health issue (in this case persistent pain). The first step in developing the intervention consisted in conducting a preliminary study to enhance our understanding of people's experiences of living with persistent

Type of research question

Experiences - research questions focused on individual lived experiences of particular health/ clinical conditions, interventions and so on.

Understanding and perceptions - research questions focused on how particular groups (of patients or professionals) view a particular health/clinical condition and so on

Influencing factors - research questions that explore the individual and social factors that underpin particular health/clinical phenomena

Practice/accounts of practices - research questions that explore the things people do in the world/or how people make sense of the things they do in the world

Construction - research questions focused on the role of language (or 'discourse') in constituting particular versions of 'reality'

Table 3.5: Research questions suitable for Thematic Analysis (adapted from Rohleder and Lyons, 2015)

pain and to explore their willingness to engage in a novel ACT-based program. Data was also collected from osteopaths to achieve a greater understanding of their experiences supporting this population. The patients' reported needs; barriers and preferences have been useful in deciding the structure, content and the mode of delivery of the intervention.

After considering several qualitative methodologies (e.g. IPA, content analysis), (see figure 3.5), thematic analysis was considered the most suitable method for several reasons. First of all, the aim of the study and the research questions were highly compatible with TA (e.g. 'What are people's experiences of living with long-term pain?'). In addition, an approach with the right balance between description and interpretation was needed. There is a vast literature focusing on the experiences of people living with pain, however, very few studies explored the experiences and views of osteopaths in regards to treating people living with pain. The rationale for conducting studies 1 and 2 were not only to investigate people's needs and experiences but also to use the emerging results to inform the novel intervention. Furthermore, given that the researcher was familiar with this approach, this was another solid rationale. The structured step-by-step approach of TA

was convenient and relatively easy to employ. There was an interest in the key themes emerging from the data without assuming either a phenomenological or narrative approach.

Due to the nature of the research questions (see paragraph above), neither IPA nor content analysis were considered suitable. IPA has a phenomenological underpinning and focuses on the way participants make sense of their world and the meanings they assign to experiences and events (Smith and Osborn, 2007). IPA differs from TA through its emphasis on sense-making by both participants and researcher, therefore having cognition as a central analytic concern (Smith and Osborn, 2007). Regarding content analysis, despite its similarities with thematic analysis (both aim to identify meanings that are valid across a group of participants and both use coding) there are also marked differences. These two methods produce different types of conclusions, with thematic analysis typically resulting in qualitative, inductive conclusions while content analysis providing quantitative, objective measures about messages (data) (Neuendorf, 2019).

The epistemological framework underlying the methodology employed in this research is critical realism (Robson, 2002). According to this approach, knowledge or 'truth' can exist and be shared by several individuals, however, each individual's experience will be influenced by their own subjective constructions (Robson, 2002).

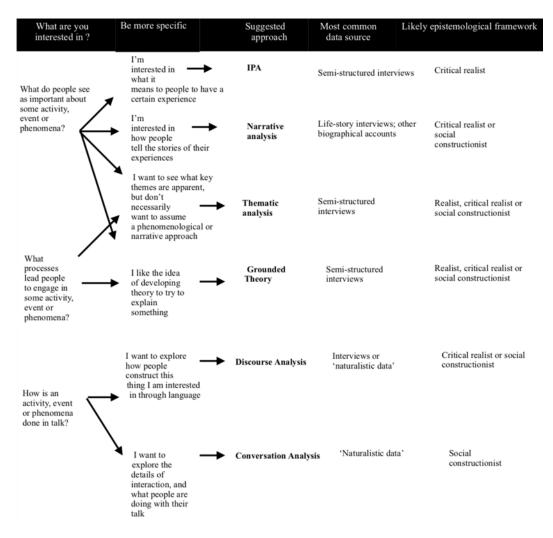


Figure 3.5: Methodologies in qualitative research and underlying epistemological frameworks (adapted from Sullivan et al., 2012)

Critical realists suggest that despite the existence of an objective reality, it is impossible to access it in its true form due to the lens of the participant and the lens of the researcher analysing the participant's account (Howitt, 2010). Each of these lenses may represent a further distortion of the reality. It is acknowledged that the researcher influences the way data will be interpreted. The goal of the first study was to gain an understanding of people's lived experiences of persistent pain as well as determining their needs and views on a novel intervention. There is an objective reality that the participants experience, however pain is a subjective and personal phenomenon, and the meanings assigned to it differ from individual to individual. Participants' meanings and views are conveyed through the conversation with the researcher, who interprets the data from their own perspective. Braun and Clarke, (2006) also acknowledged the impact of the researcher on the research, by implying that analysis does not emerge but is instead constructed by both the researcher and the participant. Therefore, the researcher needs to acknowledge their position in relation to the study (see chapter 8).

The process of analysing the data has followed the six steps outlined in Braun and Clarke (2006). It is important to note that the same process was followed in carrying out the analysis as part of studies 1, 2 and 4.

To ensure rigour in the analysis three researchers each coded a portion of the data and came together to compare and review the codes, and also to discuss where there were inconsistencies. A number of codes were more carefully described and operationalized until the team of researchers reached a consensus regarding each individual theme.

Following that, the themes were reviewed more in detail. A decision was made to also include themes representing unique perspectives or experiences (e.g. pain as a growth experience) as well as beliefs or opinions that do not necessarily represent the majority of participants' point of view. The team also explored the relationships between themes. A series of questions were

addressed during the process of reviewing the themes (e.g. Do the themes make sense? Does the data support the themes? Is there any overlap between the themes?)

After a debriefing session, the team reached a consensus in regards to the final version of the themes and subthemes. A report was produced that contained a coherent account of the data and also supporting quotes from participants (see chapters 5 and 7).

Nowell et al. (2017) provided guidance for researchers using thematic analysis and explored several issues linked to rigour and trustworthiness (concepts similar to validity and reliability). Lincoln and Guba (1985) introduced several criteria that studies must fulfil as part of demonstrating trustworthiness: credibility, transferability, dependability, and confirmability.

Credibility is concerned with the consistency between respondents' views and the researcher's representation of these views (Tobin and Begley, 2004). In the present study, a number of techniques such as prolonged engagement with the data and researcher triangulation were employed to meet the credibility criteria. The criterion for dependability includes ensuring that the research process is logical, transparent and clearly presented (Tobin and Begley, 2004). To demonstrate dependability, the research team made sure that the analysis process was traceable and clearly outlined (see the section above and worked examples). In addition, emphasis was placed on establishing a clear and logical link between researchers' interpretations and the original data. This is referred to in the literature as confirmability and is based on demonstrating how conclusions and interpretations have been reached (Tobin and Begley, 2004). Each theme was described in detail and quotes were provided to highlight salient themes and illustrate the link between the data collected from the participants and the interpretations of the data proposed by the researchers. Moreover, the observations recorded during the focus group and interviews were also explored and utilized in the

analysis process. Finally, it was recommended that researchers reflect and evaluate their involvement in the research process including the interaction with the participants, the methodological choices and the influence on the data analysis. This has been conceptualized as 'reflexivity' and it involves a critical and self-reflective account of the researcher's background and assumptions and the way these might have impacted on the research process (Tobin and Begley, 2004). Research bias is impossible to eliminate, however, it is essential to develop an awareness of the most likely sources of bias and openly acknowledge them. A detailed reflexive statement has been included in Chapter 8.

3.7.2 Framework analysis

Developed in the 1980s by applied qualitative researchers, framework analysis (Ritchie and Spencer, 1994) has been increasingly used within social and health sciences and more recently in psychology, demonstrating to be a useful analytic approach with multidisciplinary significance (Srivastava and Johnson, 2009). Some of the advantages of this method consist in that it is highly driven by the accounts of participants, it is flexible and dynamic allowing amendments throughout the process, systematic, transparent, enabling associations and comparisons between and within cases (Bryman and Burgess, 1994).

In the early stages of developing the feasibility and acceptability study, the decision about the qualitative approach to employ was taken after exploring different possibilities. The key issues that determined this choice were: type of research question, the nature of the data collected (individual interviews) and the experience of the main researcher. Ritchie and Spencer (1994) proposed four types of research questions suitable for framework analysis (see table 3.6).

Category	Aim	Sample questions
Contextual	Identifying the form and nature of what exists	What are the dimensions of attitudes or perceptions that are held? What is the nature of people's experiences? What needs does the population have? What elements operate within a system?
Diagnostic	Examining the reasons for or causes of what exists	What factors underlie particular attitudes perceptions? Why are decisions or actions taken, or not taken? Why do particular needs arise? Why are services or programs and not been used?
Evaluative	Appraising the effectiveness of what exists	What are the dimensions of attitudes or perceptions that are held? What is the nature of people's experiences? What needs does the population have? What elements operate within a system?
Strategic	Identifying new theories, policies, plans or actions	What types of services are required to meet the needs? What actions are needed to make programs or services more effective? How can systems be improved? What strategies are required to overcome the identified problems?

Table 3.6: Qualitative data analysis for applied policy research (reproduced from Srivastava and Thomson, 2009, p.74)

The interviews conducted with the participants in the intervention addressed some 'a priori' concepts ('what were participants' experiences of relating to and applying the ACT model?'); therefore it was decided that this 'a priori' model would be guiding the thematic framework. This fitted well within the contextual and evaluative categories. The study aimed to explore people's experiences of taking part in the program (contextual, identifying the form and nature of what exists) but also to understand the ways in which they made sense of and implemented ACT (evaluative, appraising the effectiveness of what exists). This was different from the approach taken to analysing the data collected from M. Ost students, where thematic analysis was a better fit, given there was no 'a priori' framework and the only aim was to gain an insight into their experiences of supporting people who live with persistent pain. Regarding the nature of the data collected, one-to-one interviews are compatible with framework analysis (Ritchie and Spencer, 1994). In addition, framework analysis is not tied to any epistemological paradigm (Gale et al., 2013) and it offers novice researchers and those in collaborating in multidisciplinary teams a good entry point (Ward et al., 2013).

Framework analysis is very similar to thematic analysis, particularly in the initial stages when recurrent themes are identified from the data. However, central to the framework approach is a series of interlinked stages that allow the researcher to move back and forth across the data until a coherent account emerges, leading to the development of a conceptual framework (Ritchie and Lewis, 2003). On the other hand, one of the limitations of framework analysis is the risk that researchers might treat the five stages of the analysis as mechanical steps to follow (Parkinson et al., 2016). This might occur particularly when managing large data sets, with coding being done mechanically, whilst shifting away from the research question. Parkinson et al. (2016) advised that the researchers must focus on the research question and have an awareness of how the framework will help in answering it.

The analysis followed the five stages outlined by Ritchie and Spencer (1994): familiarization, identifying a framework, indexing, charting and mapping and interpretation (see chapter 7). NVIVO was the chosen software package to assist with data management and analysis. The search and coding retrieval tools, as well as the possibility to generate a coding matrix, played an important role in this decision.

Summary of chapter 3 3.8

This chapter provided an account of the methodology adopted for this study, which was guided by the MRC framework (Craig et al., 2000; Craig et al., 2008). The intervention development was placed within a pragmatic research paradigm, employing a mixture of methods that are in line with the aim of the overall study. The chapter included a discussion around the methods of data collection and data analysis that were employed throughout the study, justifying the rationale for their use and describing the steps involved in the process. Ethical principles and trustworthiness were also discussed in detail. The next chapter will present the process of identifying and appraising existing evidence in relation to the effects of Osteopathy on psychosocial factors in people experiencing persistent pain.

The effects of osteopathic treatment on psychosocial factors in people with persistent pain: A systematic review

4.1 Overview of the chapter

This chapter will illustrate the process of systematically identifying the current evidence base as well as identifying relevant theory, as outlined by the MRC framework (Craig et al., 2008). This step in the intervention development consisted of a comprehensive identification and appraisal of the existing evidence, through conducting a systematic review of the literature. Given that the new intervention was designed to accompany Osteopathy, and also considering the established role of psychosocial factors in the onset and maintenance of long-term pain, (Burton et al., 2004; Pincus et al., 2006) a systematic review was conducted centred on identifying and synthesizing relevant primary research evidence of the effects of osteopathic interventions on psychosocial factors in patients living with different pain conditions. The review was published in the International Journal of Osteopathic Medicine and can be found in Appendix A.1 (Saracutu et al., 2018)¹. An updated version of the review written in 2019 is included in the first part of this chapter. Parts of the original review have been reproduced in this chapter.

Following that, the results from the previous phase (determining the needs and experiences of people living with persistent pain and the osteopaths

¹ Saracutu M, Rance J, Davies H, Edwards D.J. The effects of osteopathic treatment on psychosocial factors in people with persistent pain: a systematic review. International Journal of Osteopathic Medicine 2018;27:23–33.

who treat people experiencing pain) were incorporated with the results from the systematic review and existing research literature to inform the development of the novel intervention.

The effects of osteopathic treatment on psychosocial 4.2 factors in people with persistent pain: A systematic review

Introduction and background 4.2.1

Pain can have a highly destructive impact on the psychological and social wellbeing of individuals, who commonly experience high levels of stress and often struggle to self-manage (Craig cited in Wall and Melzack, 1994). There is a high rate of comorbidity in the occurrence of pain and mental health (Currie and Wang, 2004). The average percentage of patients living with persistent pain who also display symptoms of anxiety and depression was reported to be between 50% and 75% (Sigtermans et al., 2009; Rayner et al., 2019). Previous literature revealed that emotional distress contributes to an increase in pain intensity, pain-related disability and poorer response to treatment (Sherman et al., 2000; Blair et al., 2003). Furthermore, people who live with persistent pain are known to experience significant psychological problems including depression and anxiety as well as somatization, anger, decreased self-esteem and self-efficacy and poor emotional functioning (Burke et al., 2015). Another robust predictor of pain and disability in this population is pain catastrophyzing (Quartana et al., 2009), which has been defined as the tendency to respond to pain with negative interpretations and negatively anticipating outcomes (Jensen et al., 2009). There is evidence revealing that the burden of persistent pain and its prevalence are underestimated and in addition, treatment is not always adequate (Kress et al., 2015). Given the costs to the individuals with pain and society, new

research is needed to address the complex nature of pain and its management.

The current understanding of pain is based on the biopsychosocial model, emphasizing that pain is an interactive psychophysiological phenomenon that cannot be separated into isolated physical and psychosocial components (Turk and Monarch, 2002). This model is phenomenological, as it recognizes that the lived experience is filled with meaning and values. Morris (1991) suggested that pain cannot be understood merely in terms of anatomy and physiology: 'Pain is never the sole creation of our anatomy and physiology. It emerges only at the intersection of bodies, minds and cultures '(Morris 1991, p.3).

Not only does the biopsychosocial model provide a better account of the underlying dynamics of persistent pain than the traditional biomedical approach, but it also provides healthcare professionals a set of alternative tools to address the biological and psychosocial variables associated with persistent pain. Pain cannot be evaluated without an understanding of the person who perceives it (Anchin, 2015). One relevant example is fibromyalgia, a pain disorder that primarily affects women and is distinguished by widespread musculoskeletal pain and abnormal pain processing as well as fatigue; sleep problems, cognitive difficulties and psychological distress (Coghill and Eisenach, 2003). In addition, people living with this condition report that fibromyalgia has a negative impact on their relationships, often leading to separation or divorce (Steiner et al., 2010). Fibromyalgia is known to impair all aspects of health status through its effect on financial, physical, psychological, cognitive and social status (Bergman, 2005). The evidence-based guidelines for management of fibromyalgia emphasize the adoption of a biopsychosocial approach based on a multi-component intervention including pharmacotherapy, education, exercise, sleep hygiene counselling and cognitive behaviour therapy (Turk and Adams, 2016).

Osteopathy has been defined as a patient-centred healthcare discipline, based on the principles of interrelatedness between the structure and the function of the body, the innate ability of the body for self-healing and on adopting a whole-person approach to health mainly by practising manual treatment (New European Standard for Osteopathy services, 2017). Osteopathic care is uniquely integrated into patient management. The choice of technique, duration and frequency is also tailored for each individual patient and their needs (World Health Organization, 2010). Osteopathic philosophy and practice is congruent with the biopsychosocial model, by adopting a whole person approach to illness and by acknowledging that psychological factors may have a profound effect on physiology and homeostasis² (Paulus, 2013). Knowledge from a biomedical standpoint is essential in understanding pain, however, it cannot be separated from knowledge of perception and pain from a psychosocial perspective. The osteopathic approach is consistent with the biopsychosocial model through acknowledging the interplay between biological (neurophysiology, physiological dysfunction), psychological (illness beliefs and behaviour, emotions, coping strategies) and social (culture, social interaction) factors in the onset and maintenance of pain. Nonetheless, despite the alignment of osteopathic principles with the biopsychosocial model (see figure 4.1), at a practical level, there are still several challenges to overcome. For example, research suggests that osteopaths were more prone to explain pain by using pathological and biomechanical terms rather than psychosocial terms (DiGiovanna et al., 2005). Moreover, a recent cross-sectional survey involving 216 UK registered osteopaths concluded that osteopaths are still strongly biomedical in their approach to the treatment and management of pain (MacDonald et al., 2018). The authors acknowledged that osteopaths are ideally situated to provide overarching biopsychosocial care to people living with pain, however, they need to develop a better understanding of pain and demonstrate an increased

² The concept of "homeostasis" is seen as a balanced and effective integration of the physical, chemical and mental components of the body (Stone, 1999).

ability to engage with psychosocial factors to help people experiencing long-term pain make sense of their pain and improve their lives.

There is a significant body of evidence emphasizing the effects of osteopathic treatment in managing persistent pain. A meta-analysis of osteopathic manipulative treatment for low back pain showed that Osteopathic Manipulative Therapy (OMT) significantly reduced back pain compared to placebo and the effect persisted at least for three months (American Osteopathic Association Guidelines for Osteopathic Manipulative Treatment (OMT) Back Pain, 2016). In addition, a recent randomized double-blind controlled trial aiming to assess recovery from chronic low back pain revealed that a regimen based on six OMT sessions over 8 weeks was associated with significant and clinically relevant measures for recovery from chronic low back pain (VAS for LBP intensity and the Roland-Morris Disability Questionnaire) (American Osteopathic Association Guidelines for Osteopathic Manipulative Treatment (OMT) Pack Pain, 2016). The authors recommended that a course of osteopathic treatment might be appropriate before progressing to more invasive and costly interventions for low back pain.

Furthermore, a randomized controlled trial funded by the Medical Research Council (UK BEAM trial) concluded that the combination program of spinal manipulation and exercise was more beneficial than either of the treatments alone and when compared with "best care" (UK Beam trial team, 2004). A health economic analysis conducted alongside the trial concluded that using spinal manipulation in addition to 'best care' is cost-effective in GP practices. Similar results were reported by Williams, who undertook a pragmatic trial for patients with neck or back pain in North Wales (Williams, 2003). They reported that an osteopathy primary care clinic improved short-term pain-related outcomes and long-term psychological outcomes. A cost-utility analysis performed for this trial suggested that a primary care osteopathy

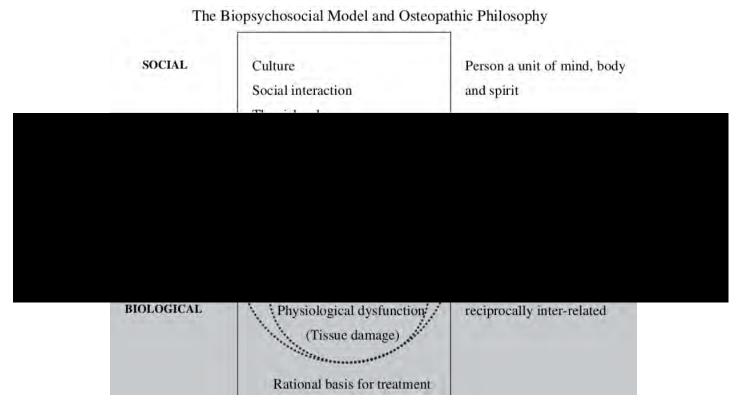


Figure 4.1: The biopsychosocial model and osteopathic philosophy (Retrieved from Penney, 2010; A model adapted from Waddell G & Burton AK: Concepts of rehabilitation for the management of common health problems. London, The Stationery Office, 2004)

clinic added to usual general practice might be cost-effective (Williams, 2004).

Osteopathy demonstrates good outcomes when compared to other treatments for persistent pain. Chown and his colleagues investigated differences between group exercise, physiotherapy and osteopathy for people with back pain recruited from a hospital setting and collected data at baseline, six weeks and twelve months after discharge (Chown et al., 2008). There was a smaller dropout rate among the Osteopathy group than in the other groups due to participants' preference for hands-on treatment, a more flexible appointment schedule or past experience with private practice. Furthermore, research by Orrock et al. (2016) explored the experiences of people receiving osteopathic healthcare by conducting a quantitative survey of patients with persistent non-specific low back pain followed by qualitative semi-structured interviews. The results indicated that common outcomes of Osteopathy were: a reduction in pain, increased flexibility, and improvements in posture and in the ability to complete daily tasks. The participants commonly engaged in autonomous decision-making, and regarded Osteopathy as being holistic while emphasizing the individualization of the interventions and the collaborative relationship with the osteopaths, who heard their stories and consulted them in regards to treatment and outcome planning. Finally, the results of a study commissioned by the General Osteopathic Council in 2014 showed that participants receiving osteopathic treatment reported positive experiences (GOsC, 2014). Osteopaths were shown to discuss the treatment options thoroughly and provide clear information about the costs of the sessions. Participants also highly valued being provided information regarding the remit of Osteopathy as well as details about the treatment (including treatment risks). The study conducted by GOsC concluded that Osteopathy provides patients with a therapeutic option characterized by a low risk-to-benefit ratio and with an increasingly growing evidence base.

Despite the existent evidence, more health economic data is needed to investigate the cost-effectiveness and cost-utility of Osteopathy. A systematic review and critical appraisal of the available health economic evidence for Osteopathy only resulted in sixteen studies of which the majority demonstrated a high risk of bias. The authors of the review concluded that published comparative health economic studies of Osteopathy cannot inform policy and practice due to their inadequate quality and quantity (Steel et al., 2017). This is consistent with the recommendations made by the Bevan Commission in Wales regarding prudent healthcare a concept denoting the need to identify interventions and initiatives that are cost-effective and promoting healthcare that fits the needs and circumstances of the citizens by making most effective use of available resources (Bevan Commission, 2013). Further health economic analyses are needed to establish the cost-effectiveness and cost-utility of Osteopathy and other holistic modalities employed in persistent pain management. There is a gap in the literature when it comes to comparisons with standard practise or the best-available alternative (Gold et al., 2003).

Massive efforts have been made to establish the role of psychosocial factors in persistent pain. Several authors emphasized the need for awareness of the psychosocial factors and the way they influence persistent pain outcomes (Burton et al., 2004; Pincus et al., 2006). A psychosocial factor strongly associated with disability and work loss is fear avoidance. Waddell and his colleagues suggested that 'fear of pain and what we do about it is more disabling than the pain itself' (Waddell et al., 1993, p157). Another relevant psychosocial factor is 'pain catastrophyzing', defined as a set of exaggerated and maladaptive cognitive and emotional responses during actual or anticipated painful stimulation (Quartana et al., 2009). The literature also points to robust associations between pain catastrophyzing and an array of pain-related outcomes such as clinical pain severity, pain-related activity interference, disability and depression (Sullivan et al., 2001; Edwards et al., 2006). There is also evidence linking psychosocial

factors with the transition from acute to persistent pain (Von Korff et al., 1993; Linton et al., 2000; Pincus et al., 2002). Psychosocial factors are significantly related to the onset of back pain and they also play a role in the development of persistent pain (Hasenbring et al., 2001). Of these, pain-related cognitions, catastrophyzing and fear-avoidance yielded the most empirical support. Moreover, psychosocial factors were shown to be more predictive than biomedical or biomechanical factors. More efforts are needed to elucidate the specific relevance and role of psychosocial factors in the aetiology and progression of different types of persistent pain. Equally, conducting more randomized controlled trials of osteopathic treatment reporting not only measures of pain and physical functioning but also psychosocial outcome measures is paramount.

Despite the advancements in osteopathic research, there is a gap in understanding the underlying mechanisms through which osteopathic manipulation affects psychosocial factors of persistent pain. The dynamics of this process are yet to be understood. The effects of osteopathic treatment might be due to a reduction in fear followed by an improvement in pain beliefs. They might also be due to the collaborative nature of the patient-practitioner relationship or to placebo. Fryer (2017) discussed potential biological and psychological mechanisms that might account for the therapeutic effect of Osteopathy. He advanced the hypothesis that osteopathic treatment may improve movement and function and reduce pain through a 'bottom-up' influence on tissue and a 'top-down' impact on cognitive and psychological factors (see figure 4.2). However, high-quality evidence is needed to support these mechanisms. Further research is needed to elucidate and establish potential models of change.

One of the most influential models trying to account for the role of psychological factors was adapted from Acceptance and Commitment Therapy and utilized specifically for persistent pain (Hayes et al., 1999). This model posits that individuals should reduce their attempts to avoid or

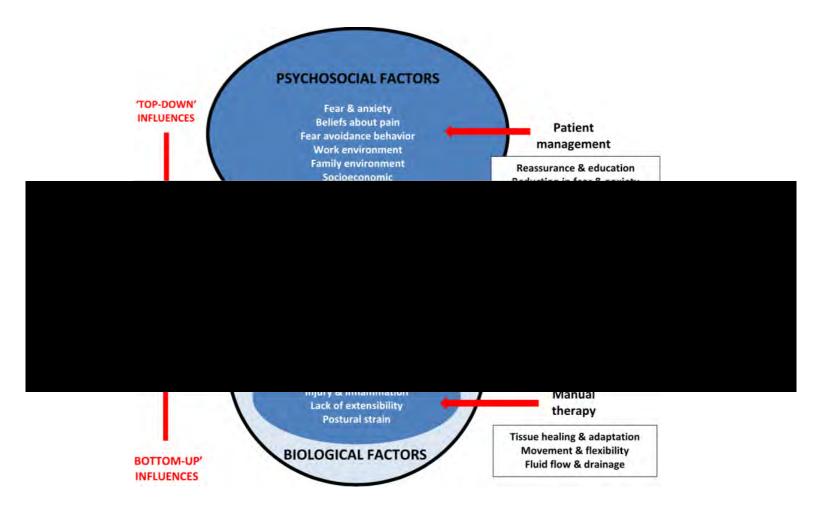


Figure 4.2: Psychosocial and biological factors in somatic pain and aims of osteopathic management (Retrieved from Fryer, 2017)

control pain and instead focus on pursuing their personal goals and engaging in valued activities through acceptance (McCracken et al., 2004). Research has also shown that pain-related acceptance is associated with higher physical functioning and less emotional distress (McCracken et al., 2003). Similarly, preliminary findings from the OsteoMap program, an initiative conducted at the University College of Osteopathy (UCO) have revealed a significant improvement in psychological flexibility (CI 95%, 4. 48:10.87, p<. 0001) but also in levels of pain, mood and coping (CI 95%, 11.54: 20.53, p<. 0001) in a cohort of patients living with persistent pain (Carnes et al., 2017). This was as a result of a six weeks intervention based on osteopathic treatment, mindfulness and acceptance-based pain management exercises ('ACT made simple', Harris, 2009).

4.2.2 Review aims

Given the evidence regarding the role of psychosocial factors in the progression and maintenance of long-term pain and the research emphasizing the positive effects of Osteopathy on people living with different pain conditions, this review will aim to identify and synthesize primary research focusing on the effects of Osteopathy on psychosocial factors. The emphasis of the review will be on proving an answer to a specific question ("What are the effects of Osteopathy on psychosocial factors of persistent pain?"). There is a limited amount of evidence in this area: the trials of osteopathic treatment reporting effects on psychosocial factors are very scarce. This review will include an analysis of the identified evidence as well as a quality appraisal conducted by using the Critical Appraisal Skills Program (CASP).

4.2.3 Systematic review method (as outlined in Saracutu et al., 2018)

Inclusion criteria

- Type of study: Peer reviewed RCTs and controlled clinical trials published in academic journals.
- Type of participants: Adults reporting persistent pain (back pain, lower back pain, neck pain, shoulder pain, chronic headache, pelvic pain, fibromyalgia, arthritis, CRPS)
- **Type of intervention:** Studies using different Osteopathic modalities: Osteopathic manual therapy (OMT), Osteopathic Manipulation (OM), Mobilization, Manipulation, Spinal manipulation, high-velocity low amplitude manipulation, (HVLA), Myofascial release, Manual Therapy, Massage, Soft tissue treatment.
- Type of outcome: psychological outcomes including at least one of the following: depression, anxiety, fear-avoidance, catastrophyzing, acceptance and self-efficacy (generic outcome measures with a psychological component e.g. generic health status, quality of life were also included)
- Language: English.

Exclusion criteria

Trials published in a language different than English; no peer review; research other than RCTs or controlled clinical trials, studies that did not involve adults; reports of healthy or asymptomatic participants; trials of post-partum pain or pain associated with cancer, chronic fatigue; IBS, gout or other conditions; trials of physiotherapy or other interventions different from Osteopathy and manual therapy; research studies that did not include

psychosocial outcomes or generic outcomes with a psychological subcomponent.

Search strategy for study identification

8 electronic databases (Medline Complete, CINAHL Complete, Cochrane Library, Psychinfo, Psycharticles, Web of Science, Scopus) have been searched from 1980 to 2019, using a search strategy that used a combination of keywords (Search terms). Reference lists were also screened, in addition to citation tracking and hand searching of key Osteopathy journals (such as the International Journal of Osteopathic Medicine).

Search terms

Chronic pain, persistent pain, long-term pain, musculoskeletal pain, nociceptive pain, neuropathic pain, chronic headache, back pain, fibromyalgia, neck pain, pelvic pain, arthritis, CRPS

Additional keywords related to Osteopathy: osteopath* n/3 manipulat* or osteopathic intervention or manipulative treatment or OMT or Spinal Manipulative Therapy or myofascial release or HVLA or Soft Tissue Mobilization or Muscle energy technique or Manual therapy

Further key words: psychosocial factors, psychosocial outcomes, psychosocial health, coping, acceptance, catastrophyzing, avoidance, social support, depression, anxiety", self-efficacy

Proximity operator

Proximity searching has been used to help refine the search. Proximity operators allow searching for two or more words that occur within a specific number of words from each other (e.g. osteopath* n/3 manipulat*). Databases have different proximity operators (Medline Complete, CINAHL Complete, Psychinfo, Psycharticles use n/; Web of Science & Cochrane Reviews employ NEAR/and Scopus uses w/).

Data selection

Original systematic review (1980-2017) as in Saracutu et al. (2018)

The search strategy identified 886 potentially relevant titles and abstracts that were screened for potential inclusion (see figure 4.3) After removing duplicates, 862 abstracts were reviewed. The inclusion and exclusion criteria were applied. Trials reporting outcomes from samples with pain resulting from other conditions, trials reporting interventions different than osteopathy, trials of asymptomatic, acute or sub-acute samples and or trials published in a language different than English were excluded. 24 articles were retrieved and after full-text screening 8 were excluded for not fully meeting the inclusion criteria. 16 trials were included in the synthesis. Two researchers performed the search independently, and after applying the exclusion and inclusion criteria, they reached an agreement in regards to the trials to be selected. A third reviewer validated the results.

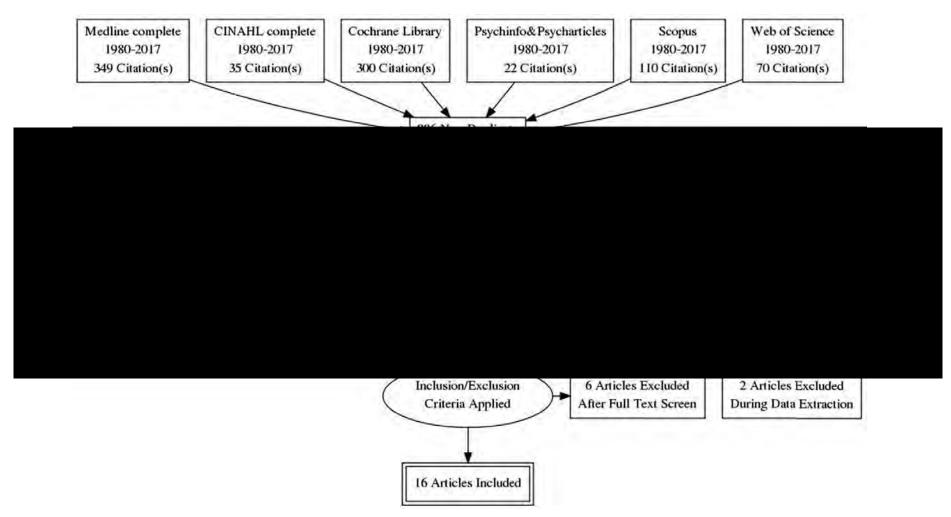


Figure 4.3: Flow diagram of the selection process in the original review (Saracutu et al., 2018)

Updated systematic review (2016-2019)

In the first instance, 2149 articles were identified. After applying the inclusion and exclusion criteria 1788 records were removed. 361 articles were retrieved for further selection. After a full-text screening 347 studies were excluded for a variety of reasons, most common being: failure to report psychosocial or quality of life outcomes or investigating interventions other than Osteopathy (e.g. Craniosacral therapy). Finally, 4 studies were selected to be included in the update (see figure 4.4). This process involved one researcher performing the search and an additional researcher validating the results.

Study characteristics

Original review

The sixteen selected studies employed participants living with lower back pain (6), neck pain (5), fibromyalgia (2), back pain non-specific (2) and chronic migraine (1). The control groups received one of the following: standard care, placebo (e.g. sham OMT, sham Manual therapy, OMT with sham ultrasound physical therapy), specific manipulation or exercises (e.g. sling Neurac exercise, non-thrust manipulation, sustain appophyseal natural glide), nonspecific exercises or a multimodal program (consisting of CBT, education e 'The Back book' and exercise). Study characteristics including sample size and type of pain condition, type of intervention and control group, outcome measures employed and results were extracted and presented in Appendix A.1 (Appendix 1 in the systematic review article).

Update

The four studies selected for the review update included people living with chronic low-back pain (non-specific low back pain-3, low back pain -1). The interventions consisted of various osteopathic treatment packages: OMT with specific diaphragm techniques, Spinal manipulation (HVLAT) on lumbar region paired with postural and ergonomic advice, visceral OMT and manual therapy. The control groups received: a sham-diaphragm

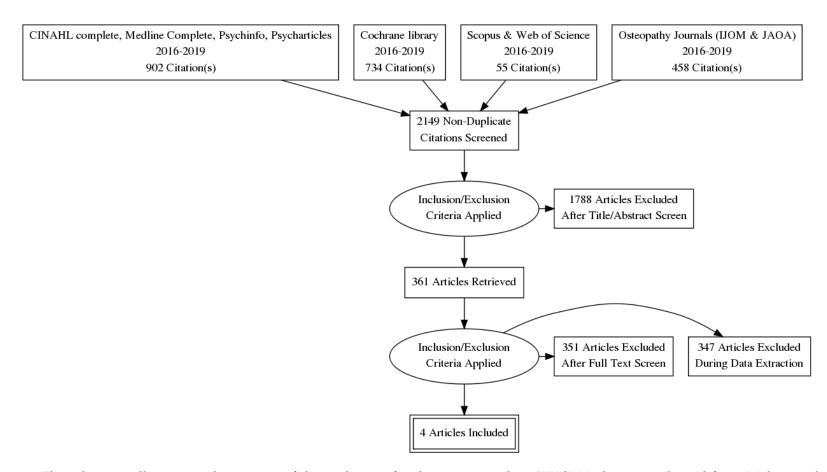


Figure 4.4: Flow diagram illustrating the process of data selection for the review update (PRISMA diagram adapted from Moher et al., 2009).

intervention with manual contact, core stability exercises combined with postural and ergonomic advice, standard OMT and a spinal stabilization exercise program respectively. The majority of the studies reported changes in quality of life (3 out of 4) while only one study focused on psychosocial outcomes (anxiety, depression, fear avoidance and catastrophyzing). A more detailed description of the 4 RCTs can be found in Appendix A.2.

Quality assessment

CASP (Critical Skills Appraisal Program) for Randomized Controlled Trials was preferred for quality appraisal. This tool is widely used in health research, valid, user-friendly, accessible and appropriate to the topic of this review. CASP was designed to address the trials' validity, results and the relevance to practice. The tool comprised eleven different questions and assessed criteria related to the internal and external validity of the trials (Did the trial address a clearly focused issue? Were patients, health workers and study personnel blinded; was the assignment of patients to treatments randomized?) but also evaluating the results (How large was the treatment effect?) and the applicability and relevance of the studies (Can the results be applied in your context or to the local population?) (Critical Appraisal Skills Program, 2017). Scores ranging from 0 to 2 were assigned to each question (e.g. were patients, health workers and study personnel blinded? o-no blinding, 1-single blinded/partially blinded, 2- double-blinded). The 16 trials have been ranked according to their total score (ranging from 14 to 22) and divided into quartiles (Table 4.1).

The first quartile (lower quartile) contains the 25th percentile of the data-in this case the trial with the lowest score. The majority of the trials included in this review (eleven) fell into the second quartile. They all obtained a total score of 15 or 16 and were considered to have a medium quality. The third quartile also called upper quartile (the 75th percentile of the data) was comprised of the four trials with the highest quality (scored 19, 20 or 22). The reviewers agreed that the trial in the lower quartile (considered to have

a low quality due to insufficient randomization, selection bias and a high attrition rate) should be excluded from the final analysis.

In regards to the four studies included in the review update, the quality assessment followed the same process as in the original review. The RCTs fell into the medium quality category since they scored either 15 or 17. None of the 4 studies reported effect sizes, two had limited external validity and two had no blinding. However, all of the studies were randomized, all the participants were accounted for, the groups were similar at the beginning of the trials and there were no attrition issues.

Original review			
Quartiles	CASP ratings	Trial name	
First quartile (Lower quartile) Low quality	14	Hough et al.	
Second quartile (Median) Medium quality	15-16	Sung et al.; Williams et al Voigt et al.; van Dongen et al UK BEAM trial; Chown et al Cleland et al.; Castro-Sanchez e al.; Cheung-Lau et al.; Gamber e al.; Niemisto et al.	
Third quartile (Upper quartile) High quality	17-22	Bialowski et al.; Licciardone et a Lopez-Lopez et al.; Moustafa an Diab	
Updated version			
Quartiles	CASP ratings	Trial name	
Second quartile (Medium quality)	15	Sarker et al.; Tamer et al.	
	17	Marti-Salvador et al.; Ulger et al.	

Table 4.1: Table illustrating the merged results of the quality assessment

4.2.4 Results of the review (overall)

There were sixteen RCTs selected for full analysis in the original version and four additional RCTs analyzed in the review update. Psychological and generic health outcomes were extracted and are discussed below.

Depression and anxiety (see table 4.2)

Six trials assessed changes in depression. Of these, three found significant differences. Moustafa and Diab reported significant differences between the experimental and control groups on BDI scores (p < 0.0005) at 1-year follow-up. Licciardone et al. reported a significant interaction between OMT and comorbid depression (p = 0.02) indicating that patients with comorbid depression did not respond favourably to OMT in their study. Marti-Salvador et al. found a significant decrease in depression and anxiety as measured by HADS at 4 and 12 weeks in the intervention group (OMT) compared to control (4 weeks- mean difference=-5.2, p< .001; 12 weeks- mean difference=-6.3, p< .001). Three other reports found no significant effects of Osteopathy on depression (Castro-Sanchez et al., Lopez-Lopez et al. and Gamber et al.). Although the RCT conducted by Gamber and his colleagues did not report significant effects, the authors reported that the two OMT groups were less frequently depressed, had less frequent losses of energy were less often lonely.

Four trials reported anxiety as one of the outcomes. Bialowski et al. found that state anxiety³ was significantly associated with changes in pain sensitivity in participants who received spinal Manipulative Therapy (r =0.62, p =0.04). Similarly, Castro-Sanchez et al. reported that a 20-week massage-myofascial release program significantly improved anxiety but also quality of sleep and quality of life in patients with fibromyalgia. The experimental group experienced an improvement in regards to anxiety

³ State anxiety has been defined as a transitory emotional state involving feelings of apprehension nervousness and physiological responses such as an increased heart rate (Spielberg, 1979)

compared to baseline and also against placebo (p<. 041). Lopez- Lopez et al. reported that only trait anxiety interacted with manual therapy while Moustafa and Diab revealed a statistically significant change favouring the experimental group in terms of all the outcome variables including anxiety (F = 2560.6 p < 0.0005).

Trial name	Depression	Anxiety	
Castro-Sanchez et al.	No significant effect	Sig. increase in trait anxiety (p< 041) compared to baseline and placebo; Sig. improvement in trait anxiety (p < 0.043) at 1 month follow-up	
Gamber et al.	No significant main effect		
Lopez-Lopez et al.	No significant effect	Sig. three-way treatment x anxiety x time interaction, with respect to VAS F (2, 24)=6.65, p=0.005, ηp2=0.36; High anxiety interacts with mobilization and SNAG effects	
Moustafa and Diab	Sig. group x time effect BDI $F = 872.9$ (p < 0.0005)	Sig. group x time effects BAI (F = 2560.6, p < 0.0005)	
Licciardone et al.	OMT x comorbid depression Interaction effects (p =. 02)		
Bialowsky et al.		State anxiety (r=. 62, p= .04) significantly associated with changes in A fiber mediated pain sensitivity (SMT group)	
Marti-Salvador et al.		Sig. decrease in depression and anxiety, at 4 and 12 weeks in the intervention group compared to sham (HADS 4 weeks- mean difference=-5.2, p< .001); HADS 12 weeks- mean difference=-6.3, p< .001)	

Table 4.2: Depression and anxiety outcome results

Fear avoidance and pain catastrophyzing (see table 4.3)

Four RCTs were reporting fear-avoidance outcomes, three of which found significant effects. The UK Beam trial found that the manipulation package alone did not produce significant changes while manipulation followed by exercise produced significant improvements in fear-avoidance beliefs both at three and twelve months. Equally, Sung et al. found a significant decrease in fear-avoidance in the thoracic manipulation group. Marti-Salvador reported a significant decrease in fear-avoidance in the OMT group at both 4weeks and 12 weeks compared to sham control. Finally, Cleland et al. found no significant differences in fear-avoidance scores.

In relation to pain catastrophyzing, Bialowski et al. reported a significant association with pain sensitivity in patients who received Spinal Manual Therapy (r=-. 67, p<. 02). The authors suggested that the changes in temporal summation related to SMT were only minimally influenced by psychological factors. In the Marti-Salvador trial, the between-group analysis showed a significant decrease in PCS scores at 4 and 12 weeks in the OMT with diaphragm techniques intervention group compared to the sham diaphragm control group.

Quality of life and generic health status (see table 4.4)

There were ten trials investigating changes in health-related quality of life (seven in the original review), eight of these reporting significant improvements in the intervention groups. Findings reported by Castro-Sanchez et al. indicated that there were significant post-intervention improvements in the experimental group (massage myofascial release therapy) in several dimensions of the SF-36: physical function (p < 0.007), physical role (p < 0.039), body pain (p < 0.043) and social function (p < 0.48) compared to baseline. Similarly, Cheung-Lau et al. reported a significantly greater improvement in the physical component of the SF-36 (PCS) post-intervention and at 6 months follow-up for the Thoracic Manipulation group compared to control. Findings reported by Niemistö et al. also

Trial name	Fear avoidance	Pain catastrophyzing
Cleland et al.	No differences in fear avoidance	
UK BEAM trial	Manipulation followed by exercise at 3 & 12 months 2.40 (1.41-3.39) p < 0.001; 1.24 (0.07-2.41) p < 0.5)	
Sung et al.	Significant change in FABQ only in manipulation group (pre-test 73.6 ± 7.3 , post-test 87.9 ± 4.2)	
Marti-Salvador et al.	Significant decrease in fear avoidance in the intervention group, mean differences after 4 weeks: FABQ =-25.9, 95% CI, p<.001; 12 weeks FABQ=-23.1, p<.001)	Significant decrease in pain catastrophyzing at 4 and 12 weeks (PCS -6.9, p< .001; PCS -6.5, p< .001)
Bialowski et al.	Pain catastrophyzing (r = -0.67, p = 0.02) associated with changes in A fiber mediated pain sensitivity in lower extremity in SMT participants	

Table 4.3: Fear avoidance and catastrophyzing results

pointed to an improvement in health-related quality of post-intervention, however, this was true for both the Manipulative treatment and Consultation groups; there were no significant differences found at 12 months follow-up. For patients living with chronic lower back pain, both a manipulative treatment program with exercises and a physician's examination with information and advice enhanced health-related quality of life and reduced healthcare utilization and costs. Furthermore, Tamer et al. observed significant improvements in all SF-36 scores in the visceral OMT group after the treatment, with greater changes in physical function (p=0.028), energy (p=0.034), and total physical score (p= 0.025). The UK BEAM trial also found significant improvements for the participants receiving spinal manipulation in what concerns pain, back beliefs and general physical health, paired with an improved mental health at three months post-intervention and less disability at 12 months. In addition, Ulger et al. showed that both spinal stabilization exercises and manual therapy have significant positive effects on quality of life (p<0.001), however manual therapy was found to be more effective on pain and functional parameters (bodily pain, p< 0.05). Voigt et al. investigated the effects of OMT on pain and quality of life in a sample of participants living with migraine and reported significant improvements in the intervention group in regards to days lost due to migraine but also in four out of eight parameters of SF-36 (physical role functioning, mental health, vitality and body pain). Finally, there were improvements reported in the ROMANS trial (Williams, 2003). At two months post-intervention, the osteopathic treatment group showed greater improvement than the usual care group on SF-12 mental score. After 6 months, the improvements remained significantly greater for the mental health score of the SF-12 for the Osteopathy group.

Two trials reported that there were no significant differences in quality of life between the intervention and control group. Licciardone and his colleagues found medium effect sizes for OMT in improving general health, decreasing healthcare utilization and work disability in a population of people experiencing lower back pain, however, none of these results reached statistical significance. Similarly, Van Dongen et al. suggested that the

healthcare costs were found to be significantly lower in the manual therapy group compared to physiotherapy, however, there were no significant differences in quality of life.

Five trials investigated the effects of Osteopathy on quality of life. A study conducted by Chown et al. found a significant increase in EQ-5D scores for all the three interventions (exercise, Physiotherapy and Osteopathy) at six weeks follow up. Nevertheless, the authors suggested that the participants in the exercise group had a significantly lower attendance and that those in the one-to-one therapies expressed greater satisfaction. Findings from Sarker et al. revealed a similar pattern in that both the intervention and control group showed an increase in EQ-5D scores, however, there was a significantly better improvement in quality of life in the spinal manipulation group compared to the core stability exercises group. Furthermore, the UK BEAM trial also conveyed that all three packages (spinal manipulation, exercises and manipulation followed by exercise) increased participants' QALYs when compared with standard care. The authors also suggested that adding spinal manipulation to the 'best care' available for back pain is cost-effective and that manipulation on its own gives better value for money than the combined package. Moreover, Williams et al. reached similar conclusions, showing that people living with spinal pain who received physical interventions (manipulation, exercise, combined treatment) experienced a significant improvement in quality of life (EQ-5D) both at 2 months and 6 months post-intervention, compared to standard care. The authors added that a primary care osteopathic clinic yielded long-term psychological improvements at little additional cost.

Finally, there were two trials reporting that there were no significant differences in quality of life. Van Dongen et al. suggested that the manual therapy and the physical therapy groups had similar results in relation to functional status and QALYs. In addition, findings from the ROMANS trial showed that there were no significant differences in EQ-5D scores at both 2 and 6 months follow-up in the Osteopathy group (Williams, 2003).

Trial	Health related Quality of Life	Trial	Generic health status
Castro- Sanchez et al.	Sig. improvements post-intervention SF36: physical function (p < 0.007), physical role (p < 0.039), body pain (p < 0.043) and social function (p < 0.48) compared to baseline.	Chown et al.	Increase in EQ-5D scores of 0.1 for all groups at 6 weeks follow- up (Osteopathy -0.11 (0.02-0.19), p < 0.5)
Cheung- Lau et al.	Intervention group showed a significantly greater improvement in the Physical Component (PCS) of the SF36 (41.24, 8.40, p 1= 0.002) immediately post-intervention and at 6 months follow-up.	Sarker et al.	Both the intervention and control group showed an increase in quality of life (EQ-5D-3L); the mean difference between groups was 4.78 (95% CI, p< .001). A significantly better improvement was noticed in quality of life of the spinal manipulation group compared to core stability exercises group.
Licciardone et al.	Medium effect sizes for OMT in improving general health, decreasing healthcare utilization and work disability, but not statistically significant.	UK BEAM Trial	Physical interventions improved EQ-5D scores more than best care. Relative to best care, manipulation generated a mean of 0.041 (95% credibility interval 0.016 to 0.066) QALYs per participant, combined treatment generated 0.033 (-0.001 to 0.067), and exercise generated 0.017 (-0.017 to 0.051).

Trial	Health related Quality of Life	Trial	Generic health status
Niemistö et al.	Both Manipulative treatment and Consultation groups had a significant improvement in health related QoL (p < 0.001, ANOVA). No differences at 12 months follow up (p= 0.93, ANOVA).	Van Dongen et al.	No sig. dif. between the MTU and PT group in QALYs ($\beta = -0.01$; 95% CI: -0.04)
Tamer et al.	Improvements were observed in all SF36 scores in the vOMT group after the treatment (p < 0.05). Improvements in the physical function (p = 0.028), energy (p = 0.034) and total physical score (p = 0.025) parameters in the intervention group were better compared to the other variables.	Williams et al. (ROMANS trial)	No significant differences in EQ-5D scores at 2 months and 6 months follow-up for the Osteopathy group.
UK BEAM trial	Manipulation group had a sig. improvement in SF36 physical score at both 3 and 12 months		
Ulger et al.	There were significant improvements in quality of life according to SF36 after treatment (p < 0.001), with no significant difference among groups except the "bodily pain" subgroup of SF36 (p < 0.05)		

Trial	Health related Quality of Life	Trial	Generic health status
Van Dogen et al.	No significant dif. between the MTU and PT group in functional status ($\beta = -1.03$; 95% CI: -2.55-0.48),		
Voigt et al.	4 out of 8 domains of SF36 in the OMT group showed a significant improvement (vitality, p < 0.01; mental health, p = 0.05; bodily pain, p= 0.05 and physical role functioning, p < 0.01)		
Williams et al. (ROMANS trial)	U		

Table 4.4: Results outlining findings reporting health related quality of life and generic health status outcomes

4.2.5 Review discussion

The current evidence base looking at the effects of Osteopathy on psychosocial factors associated with persistent pain is limited. This review was one of the few to investigate whether osteopathic interventions affect psychosocial factors relevant to persistent pain. The studies considered for this review revealed that Osteopathy does affect psychosocial outcomes to some extent. Participants undergoing osteopathic manipulation were found to have decreased anxiety and fear avoidance. In addition, several studies (eight out of ten) showed significant improvements in health-related quality of life. Despite that, more research studies are needed to further investigate these findings.

The results of this review are consistent with those obtained by Williams et al. (2003), authors of the first review of spinal manipulation examining psychosocial outcomes. Their review included twelve studies reporting psychological outcomes, six of which had a verbal comparator. The findings revealed a small benefit of spinal manipulation compared to verbal interventions (mean benefit of spinal manipulation equivalent to 0.34% of the population standard deviation [95% confidence interval (CI) 0.23-0.45] at 1-5 months; 0.27 of the SD [95% CI 0.14-0.40] at 6-12 months). Additionally, there was a small benefit of spinal manipulation compared to physical interventions (exercise). It is important to note that it is unclear whether the improvements were due to the distinct characteristics of the compared interventions or due to incidental placebo effects. The authors acknowledged that the psychological effects resulted from certain characteristics of the treatment (reducing distressing symptoms such as pain and fear). Our review revealed similar effects, for example, the UK BEAM trial found a significant improvement in fear-avoidance beliefs as a result of manipulation and exercise.

Significance and implications

It is essential to acknowledge that psychosocial factors play a role in the onset and maintenance of different pain conditions (Rahman et al., 2008; Jacobs, 2013). However, more efforts need to establish the relevance and role of each of these factors in the aetiology and progression of pain and also to modify these factors with the help of psychological interventions. In the future, it would be beneficial for trials to report not only measures of pain and physical function but also psychosocial outcome measures.

It is also paramount to elucidate the underlying mechanisms through which osteopathic treatment affects psychosocial factors in persistent pain populations. The dynamics of this process are yet to be understood. One hypothesis could involve a reduction of fear accompanied by an improvement in pain beliefs. The collaborative nature of the patient-Osteopath relationship might also play a role. More research is needed to address this question and establish potential models of change. Process studies are needed to deconstruct the individual components of the osteopathic care and shed light on their effects on patient outcomes.

Osteopathy itself is not a psychosocial intervention, however, it might be worth combining Osteopathic treatment with brief psychological packages. Integrating concepts and principles from third wave therapies like Acceptance and Commitment Therapy (ACT) could lead to an increase in the effectiveness of osteopathic care, and moderate the impact of comorbidities. This type of pairing might have a strong synergistic effect, compared to standard care alone. In fact, there are recommendations to combine different types of treatment (physical, psychological, rehabilitative) in order to match patients' characteristics and individual needs (Turk et al., 2011). It is already known that psychological processes influence the experience of pain and also the treatment outcomes; therefore there is a chance that integrating psychological approaches into physical therapy could potentially enhance outcomes (Linton and Shaw, 2011). In addition, health economic evidence could be valuable in determining the cost-effectiveness of such combined packages.

In the future, osteopaths might benefit from a better awareness of the way their intervention influences psychosocial outcomes. Certain aspects of the care they provide such as the rapport with the patient, the provision of relevant information and encouraging self-management or showing empathy may all play a role in enhancing patient outcomes. A study conducted at the University College of Osteopathy exploring the students' attitudes and beliefs towards psychosocial factors when treating people with non-specific low-back pain concluded that the main barriers encountered by the student when treating this population were lack of experience but also lack of training on the management of psychosocial factors (Delion and Draper-Rodi, 2018). Osteopaths are ideally positioned to educate patients in regards to how certain factors as depression, anxiety or fear avoidance contribute to the onset and maintenance of persistent pain. Being aware of psychosocial factors might also signify a better understanding of the pain experience and the context in which persistent pain occurs. Additional training could be made available to provide Osteopaths with an extra set of skills and knowledge that will not only help their professional development but also enable them to support patients with persistent pain more effectively.

Osteopathy is a type of complementary therapy. The integration of complimentary and alternative medicine (CAM) and holistic modalities with conventional healthcare has the potential to yield significant health improvements. Osteopathy is increasingly provided in primary care settings; however, more research is needed to explore the potential benefits and cost-effectiveness of this type of provision. The economic burden of pain and the overwhelming impact of pain on individuals' physical, psychological and social wellbeing make research in this domain a priority. Including and reporting this type of evidence is needed to inform and

facilitate evidence-based decision making among policymakers but also health practitioners and patients (Phillips, 2006).

Limitations

It is important to acknowledge some limitations of this review. First of all, the samples investigated in the selected studies were heterogeneous (patients with different persistent pain conditions such as lower back pain, neck pain, fibromyalgia etc.). Pain is a very complex and subjective experience and there are marked differences in regards to causes and contributing from time to time and then subside, only to come back again subsequently (Coghill, 2010). For example, in fibromyalgia, the pain is widespread and flares are associated with prolonged activity, soft tissue injuries, poor sleep, and exposure to cold and psychological stressors (Coghill and Eisenach, 2003). Patients with chronic migraine experience headache episodes daily or neardaily; there is also a tendency for these episodes to increase in frequency over time (Häuser and Kopp, 2013). As a result, the findings of this review cannot be generalizable across specific types of persistent pain. However, this review is insightful because it emphasizes some particular effects that could potentially be valid across different persistent pain conditions.

In addition, there were a variety of manipulation techniques delivered by different health practitioners. There is often an overlap of techniques with other practitioners like chiropractors or physiotherapists, who use manipulative techniques similar to those of Osteopaths. Despite the differences, it is important to point out that all these practitioners employ manual, hands-on techniques and a similar approach to delivering treatment (Carnes and Fawkes, 2013). The similarities between these approaches might prove useful in undertaking collaborative research (e.g. UK BEAM trial).

Furthermore, many of the trials included in the review were not blinded (nine out of twenty) or only partially blinded (eight). There were only three double-blinded trials. However, it is important to emphasize that, while blinding or 'masking' is the cornerstone of treatment evaluation, it is difficult to obtain in trials assessing non-pharmacological intervention (Boutron Guittet et al., 2007). Blinding both the participants and the treatment provider is very challenging. It is more feasible to blind the researchers involved in the data collection and analysis.

Another common limitation in trials of this type concerns high drop out rates. It is known that high attrition may produce bias. The results might not be due to the effects of the intervention but to a loss of participants who were unresponsive or more or less symptomatic than the others (Zweben et al., 2009). It is also possible that some participants might fear adverse events or have concerns regarding being assigned to a placebo group. One of the trials initially selected for this review was excluded from the final analysis due to high attrition (23.5%) and insufficient randomization. Hough et al. reported that younger, unemployed people with lower back pain who had higher psychosocial risk scores tended to 'drop-out' of treatment (Hough et al., 2007). They also indicated that there might have been potential selection bias.

Other possible sources of bias of the analysed trials include long-term follow-up periods, selection bias (differences in baseline characteristics) and the possibility that the therapist was also the principal investigator (which might have resulted in more favourable responses). In addition, more often than not participants who volunteered to take part were recruited from private practice, which limits the external validity of the results.

The findings of this review are encouraging, suggesting that osteopathic treatment may have some effects on psychological factors such as anxiety and fear-avoidance but also particularly on the quality of life of people living with persistent pain. Further research is needed to further investigate these effects and to evaluate the effectiveness of integrating psychological principles and interventions into Osteopathic practice. Only then will a fuller understanding of the role of Osteopathy in persistent pain management be achieved.

Conclusions of the review

The findings of this review are encouraging, suggesting that osteopathic treatment may have some effects on psychological factors such as anxiety and fear-avoidance but also particularly on the quality of life of people living with persistent pain. Further research is needed to further investigate these effects and to evaluate the effectiveness of integrating psychological principles and interventions into Osteopathic practice. Only then will a fuller understanding of the role of Osteopathy in persistent pain management be achieved.

This systematic review contributes to the advancement of knowledge in regards to the role of Osteopathy in the management of persistent pain and it is one of the few to explore the effects of osteopathic interventions on psychosocial factors. There are important implications in terms of improving pain management by using a holistic approach, and also there is scope for pairing Osteopathic treatment with psychological interventions to enhance the health and wellbeing of people with persistent pain.

Summary of Chapter 4 4.3

This chapter illustrated the second stage of the intervention development and consisted of a comprehensive identification and appraisal of the evidence concerning the effects of Osteopathy on psychosocial factors in people with persistent pain. The results indicated that osteopathic treatment might have an effect on anxiety, fear avoidance and quality of life.

The evidence resulting from the systematic review supported the inclusion of Osteopathy as a component of the novel intervention. Given its positive effects on psychosocial factors that play a role in persistent pain, there was scope to pair Osteopathy it with a brief psychological package. The logic behind this pairing was that the effectiveness of Osteopathy could be enhanced by the additional psychological package, potentially leading to a reduction in comorbidities and an increase in the quality of life of people living with persistent pain. This initial evidence resulting from the systematic review contributed to forming a base for the novel intervention.

The next chapter will present results from a preliminary qualitative inquiry comprising two studies investigating the experiences of people living with persistent pain and the perspectives of osteopaths who treat them. The results of these studies consolidated the basis for the novel intervention.

5 Preliminary Qualitative Inquiry

5.1 Overview of the chapter

This chapter contains the results from the first phase of developing a novel psychosocial intervention for people living with persistent pain and psychological comorbidities. Following the recommendations of the MRC framework (Craig et al., 2008), a qualitative study was conducted to explore the needs, perceptions and experiences of people experiencing long-term pain and low to moderate depression, anxiety and/or fear avoidance as well as the experiences of osteopaths who are involved in treating them. This study provided useful insights into the ways in which persistent pain affects people's lives as well as their experiences of navigating the healthcare system and their preferences, capacities and needs in relation to a novel intervention.

In addition, a second study involving a focus group was conducted aiming to explore the perspectives of osteopaths on their role in supporting people with pain as well as assessing their views on being involved in delivering a novel intervention. This first phase of the overall study explored the potential of integrating osteopathic treatment with a brief psychosocial program and thus establishing a novel pathway for people experiencing persistent pain. This phase aimed to inform the novel intervention, by providing useful insights into the ways in which persistent pain affects people's lives as well as their needs and preferences.

A framework for developing complex interventions

Complex interventions have been defined as interventions containing several interacting elements (Craig et al., 2008). Widely used in healthcare, public health and social policy, complex interventions have important consequences and also pose a series of methodological challenges. The complexity of health interventions may be related to several dimensions such as the number of components and their interactions, the number and variability of outcomes, or the number of groups or levels targeted by the interventions. Due to the fact that much biomedical and public health research has been regarded as wasteful (presenting weaknesses in design, conduct and analysis) (Ioannidis, 2014; Ioannidis et al., 2016), a framework was needed in order to aid the researchers; funders and policymakers develop and evaluate complex interventions. The first Medical Research Council (MRC) framework was published in 2000 and proved to be very useful in guiding the decision-making process (e.g. adopting appropriate methods or making practical decisions related to the intervention).

The framework has been updated in 2008 (see figure 5.1), taking into account several recommendations from the literature including: giving greater emphasis to the development phase, adopting a less linear model of evaluation and acknowledging that interventions might work best if tailored to the context rather than standardised (Craig et al., 2008). The MRC guidance suggested that interventions should be developed systematically, built upon the best available evidence and solid theoretical rationale and tested in a phased approach.

Bleijenberg et al. (2018) proposed to enhance the developmental phase of the MRC framework, by adding new elements such as problem identification, determining the needs of recipients and providers and examining current practice and context (see figure 5.2). This was done to strengthen the internal and external validity of complex interventions and also to increase the

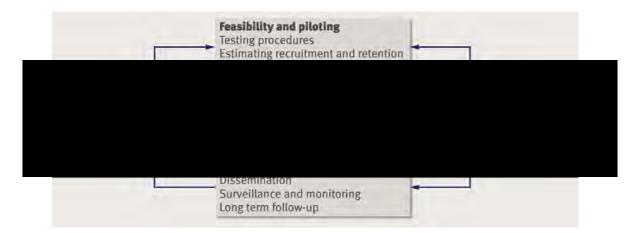


Figure 5.1: The key elements of the development and evaluation process (Craig et al., 2008)

chance of developing interventions that are fit for context, effective and well adopted.

As a result of the updated framework, the development process, an iterative approach has been recommended instead of a linear, step-wise method (Craig et al., 2008; Richards and Halberg, 2015). The relationship between the elements involved in this process is bilateral, meaning that the different elements continuously influence each other as gaps in knowledge are being filled and the intervention is being shaped. Van Meijel et al. (2004) suggested that a user-centred approach involving an interdisciplinary team of researchers as well as recipients and providers might increase the feasibility, efficacy and effectiveness of the intervention. In addition, O'Cathain et al. (2014) and Ludvigsen et al. (2013) recommended the use of qualitative methods (in-depth interviews and focus groups) to analyze the nature of the problem and determine who is affected by it, as well as exploring the problem from different perspectives. Furthermore, another crucial element is reviewing the literature as this may provide important information about the way to move forward and decide whether additional data needs to be collected (Bleijenberg et al., 2018).

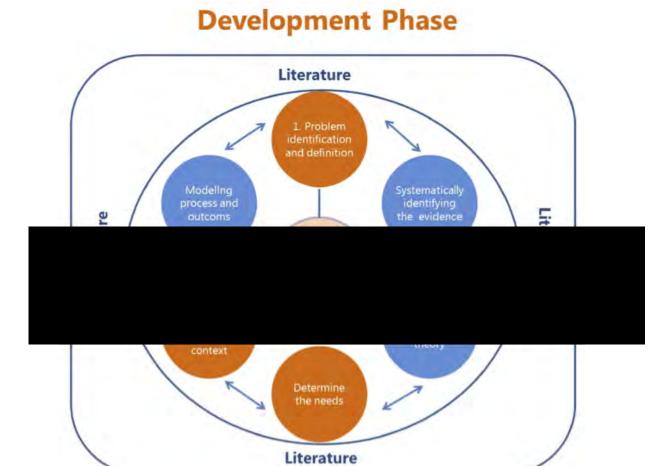


Figure 5.2: Updated MRC Framework (Bleijenberg et al., 2018). Blue elements are from the original MRC Framework (Craig et al., 2008)

Study 1 - 'A qualitative study exploring the 5.3 experiences of living with persistent pain of people from South Wales and their views on the development of a novel psychosocial intervention'

Introduction to the first qualitative study

Living with persistent pain is one of the most challenging experiences people can be confronted with. There is little doubt on the enormous burden that pain poses on both individuals and the society as a whole. The impact of long-term pain on individuals' physical, psychological and social wellbeing is well established. For example, pain is known to have adverse effects on mood, daily activities, relationships, employment status, sleep and all the aspects of wellbeing (Keefe et al., 2004; Sheehy et al 2006; Breivik et al., 2006) Recent survey data showed that 27% of people living with pain felt socially isolated because of pain while 36% expressed that pain had a negative impact on their family and friends (Pain Alliance Survey Europe, 2017).

At a societal level, the impact of pain can be illustrated by the immense economic costs, the high number of days of work lost, the decrease in work productivity, the high healthcare utilization that characterizes this population, but perhaps most importantly by the amount of suffering that it causes. According to recent statistics 20% of Europeans reported living with persistent pain (approx. 95 million people) The respondents expressed their concern about the inequalities in accessing treatment, the burden of pain itself and the substantial reduction in their quality of life (Pain Alliance Europe, 2017). The total costs of the consequences of long-term pain was estimated to be around €300 billion. In addition, according to a European report, the access to pain management appeared to be inconsistent within and across European countries, who showed marked differences in the type of healthcare services they offered for pain and a fragmented care that contributed to significant costs for their governments (Pain proposal European Consensus report, 2010).

Improving the lives of people who experience long-term pain is considered paramount. Taking this into account, more needs to be done to improve the way persistent pain is being perceived and managed and also to support people in living a better life despite the pain. To do this it is crucial to gain a better understanding of the subjective experiences of pain and untangle the complex processes involved. Gaining a better understanding of the pain experience and the psychosocial needs of people experiencing pain will lead to substantial improvements in healthcare by enabling the development of effective interventions and policies.

A systematic review of qualitative studies looking at patient's experiences of chronic non-malignant pain revealed that often people living with pain do not feel believed by health professionals and struggle to negotiate the healthcare system (Toye et al., 2013). The results of this synthesis emphasized the need for legitimization of the patient's pain experience and the recognition by practitioners of the patients as people whose lives were deeply changed by pain. Furthermore, the authors suggested that to help people move forward, healthcare professionals should sit alongside their patients and consider them collaborative partners. In addition, Vlayen et al. (2016) proposed an approach that emphasizes the interruptive function of pain, suggesting that pain interferes with peoples' on-going activities and ultimately compromises the sense of self. This process occurs when the inability to complete tasks or perform according to one's expectations results in frustration, loss of roles and a challenge of the sense of self (Harris et al., 2003).

Given the complexity and subjective nature of pain and the fact that it affects a broad range of life domains, its management should be shifted from merely reducing physical symptoms to improving people's psychological functioning and quality of life. Although Cognitive Behavior

Therapy (CBT) has been shown to be effective for people living with persistent pain, new approaches like Acceptance and Commitment Therapy (ACT) have demonstrated similar effectiveness and may offer an important avenue for many patients living with pain. This model emphasizes acceptance and engaging in behaviour in line with one's values over cognitive restructuring and symptom reduction (that are goals of CBT)(Forman et al., 2015). The ultimate goal of ACT is to improve functioning by increasing psychological flexibility and the ability to act according to personal values, even in the presence of negative experiences.

Integrating concepts and principles from third wave therapies like ACT with more physically based approaches or manual therapies could provide new opportunities in regards to moderating the impact of long-term pain and associated comorbidities on people's lives. We already know that psychological processes influence the pain experience and the treatment outcomes, therefore by integrating a psychological approach and physical therapy may enhance the outcomes (Linton and Shaw, 2011). Turk et al. (2011) recommended pairing different types of treatment (physical, psychological, rehabilitative) in order to match patients' characteristics and individual needs. Research is needed to explore this new avenue and assess the effectiveness and utility of this new pairing.

Rationale

This exploratory piece of research focused on assessing the psychosocial needs of people presenting with low to moderate depression, anxiety or fear avoidance undergoing Osteopathic treatment at Swansea University Osteopathic Clinic. The study revealed people's perspectives on living with pain and the way they reconciled acceptance of their condition with moving forward. It was equally important to explore the acceptability and willingness to engage in the new intervention (Craig et al., 2008). This is in line with the MRC framework that recommends an assessment of needs as part of the preliminary stages of developing an intervention (Bleijenberg et al., 2018).

Aims

The aims of this study were as following:

This piece of research aimed to increase our current knowledge base of persistent pain while also informing the development of a novel intervention by providing new understandings regarding people's experiences of living with pain.

In addition, the study aimed to determine people's perceptions and readiness to take part in a novel intervention will be very useful in tailoring the intervention according to people's needs while limiting the barriers to taking part.

Objectives

To increase our understanding of people's experiences of persistent pain and explore the ways in which pain impacts on people's lives while also identifying their needs and perspectives of the future living with pain

To utilize the emerging evidence base in combination with existing research knowledge to inform the development of a novel intervention

To gain an understanding of the perceptions and willingness of people who experience long-term pain to participate in a novel psychosocial intervention

Method

Design

The study aims were addressed by using a qualitative design, in an attempt to gain an understanding of the meanings, experiences and perspectives of people who live with persistent pain. The most common methods of data collection in qualitative research are interviews and focus groups (Stewart et al., 2008). These data collection methods fit well with the objectives of this study, as their purpose is to explore personal views, experiences and beliefs. In addition, interviews and focus groups provide a more profound understanding of social phenomena than would be obtained by employing quantitative methods (Silverman, 2000). Focus groups are particularly useful when it comes to generating information on collective views and the meanings underlying these views, as well as generating a rich understanding of participants' beliefs and experiences (Morgan, 1998).

Adopting a focus group methodology was particularly well suited to this study due to the very nature of persistent pain (pain is both an individual and a collectively constructed phenomenon) (Douglas et al., 2008). Consequently, focus group dynamics contribute to the generation of rich data, by enabling participants to share common experiences but also different perspectives on living with pain. Often participants build on each other's' ideas, which is very useful in terms of identifying their needs. Researchers are increasingly applying a focus group methodology to explore experiences of living with pain in different populations (Borkan et al., 1995; Henwood and Ellis, 2004; Douglas et al., 2008). There is a growing body of literature consisting of focus group research aiming to explore the perspectives and experiences of different long term pain conditions from both patients' and healthcare providers' viewpoint (Jordan et al., 2007, Shaw and Huang, 2005). A more in-depth account of the use of focus groups can be found included in Chapter 4 (Methodology).

Thematic analysis (Braun and Clarke, 2006) has been adopted for this study to facilitate an in-depth exploration of the individual experiences and perceptions of people living with pain. This approach is widely used and offers the flexibility of moving back and forth through the phases of analysis. A detailed description of the rationale for using thematic analysis is presented in Chapter 4 (Methodology).

Participants

This study involved a purposive sample of nine adults (six females and three males) recruited from the Osteopathic Clinic at Swansea University. All the names used are pseudonyms, to ensure anonymity. The inclusion criteria were as follows: (a) Aged 18 years or over (b) participant had a history of non-malignant pain¹ lasting for at least 6 months, (c) participants received/ were receiving osteopathic treatment within Swansea University Osteopathic Clinic, (d) participants experienced pain and they were willing to discuss the impact of pain on their lives, (e) participants were able to communicate effectively in English and (f) they were deemed able to give informed consent.

Recruitment

Participants were selected through Swansea University Osteopathic Clinic between September and October 2016. Permission to carry out this study was provided by the Director of the Osteopathy Clinic and the Research Ethics Committee within the CHHS granted approval. A poster was placed in the clinic waiting area advertising the study (see appendix A.5). Potential participants who expressed interest were briefed by the osteopaths and given a participant information sheet and a consent form. They were made aware of the inclusion and exclusion criteria and given two weeks to consider whether or not they wanted to take part in the study. Two weeks prior to

People living with cancer-related pain have been excluded from the study on the grounds that cancer pain is different from other types of pain. Cancer pain is also likely to progress rapidly, unlike non-malignant pain. Due to the aforementioned reasons and also due to safety concerns, the study only included people living with non-malignant pain.

the focus group all the participants who were willing to take part were sent an invitation letter, followed by a reminder before the day of the focus group. The date, time and location were chosen carefully by taking into consideration the participants' availability and preferences (e.g. time of the day, comfortable chairs, parking availability). Four participants expressed that they preferred to be interviewed individually, which lead to the main investigator accommodating their needs and conducting a focus group as well as four additional on-to-one interviews.

Focus group

A focus group was conducted on the 12th of November 2016 in a meeting room within the CHHS. The focus group lasted approximately one hour 35 minutes. The main researcher moderated the focus group discussion while an assistant provided support and participant observation (taking notes). The main investigator carried out the one-to-one interviews separately, without any assistance.

Focus group schedule

The focus group discussion involved several open-ended questions prompting people to share their personal journey of living with pain, and the different ways their life was influenced by it (see appendix A.6). In addition, the strategies used by participants to manage pain were given consideration. This was useful in exploring the views and experiences of navigating the healthcare system. Prompts and probes were used throughout the discussion (e.g. Can you please tell me more?) to encourage participants to provide additional details and examples.

The focus group also involved a brief introduction to Mindfulness and Acceptance and Commitment Therapy (ACT). This was done through a PowerPoint presentation followed by a video and a group discussion, where participants had the chance to ask questions or share their thoughts. After a 15minute break, there were some additional questions in regards to the way participants perceived their future living with pain and whether they considered a future ACT-based program acceptable. The schedule was flexible, allowing the participants to voice the aspects that were most important to them. The facilitator encouraged the participants to express different views and respect each other's perspective. The same schedule was used for the four one-to-one interviews, the only difference being that there were no group discussions.

Data analysis

The focus group and individual interviews were audio-recorded and transcribed verbatim. Subsequently, they were uploaded to NVIVO 10. The data was analyzed by using the thematic analysis, by following the six steps outlined in Braun and Clark (2006) (See table 5.1). The process involved familiarizing with the transcript, listening to the audio recordings and coding the data by using an inductive approach to identify dimensions underlying people's experiences of living with pain, their perceptions of pain management and their beliefs about the future. Having read the entire data several times, a conceptual tool was created to classify, understand and examine the data (See table 5.2). Thus a coding frame was devised to guide the thematic analysis, containing the full set of codes that were applied to the dataset. To ensure rigour in the analysis three researchers each coded a portion of the data and came together to compare and review the codes, and also to discuss where there were inconsistencies. A number of codes were more carefully described and operationalized and a consensus regarding each individual theme and the underlying codes was reached. Following that, the themes were reviewed more in detail. A decision was made to also include themes representing unique perspectives or experiences (e.g. pain as a growth experience). Finally, the themes were refined named and brief quotes were selected to illustrate their content. A report was produced of the relaying the results of the analysis.

Trustworthiness is a concept encountered within qualitative research, similar to validity and reliability. Lincoln and Guba (1985) introduced several criteria that studies must fulfil as part of demonstrating transferability, trustworthiness: credibility, dependability, and confirmability. Credibility is concerned with the consistency between respondents' views and the researcher's representation of these views (Tobin and Begley, 2004). In the present study, several techniques such as prolonged engagement with the data and researcher triangulation were employed to meet the credibility criteria. Moreover, to achieve dependability, the research team ensured that the analysis process was traceable and clearly outlined (see previous section and worked example). In addition, emphasis was placed on establishing a clear and logical link between researchers' interpretations and the original data. This is referred to in the literature as confirmability and is based on demonstrating how conclusions and interpretations have been reached (Tobin and Begley, 2004). Each theme was described in detail and quotes were provided to highlight salient themes and illustrate the link between the data collected from the participants and the interpretations of the data proposed by the researchers. Moreover, the observations recorded during the focus group and interviews were also explored and utilized in the analysis process.

Steps in conducting Thematic Analysis	Techniques used to establish trustworthiness in the process of conducting TA
1. Familiarising yourself with your data	Prolonged engagement with the data Theoretical and reflective thoughts were documented (See chapters 5 and 8) Storing raw data in organized archives and keeping field notes
2. Generating initial codes	Researcher triangulation Devising a coding framework (see table 5.2) Team meeting and debriefing
3. Searching for themes	Researcher triangulation Diagraming to make sense of theme connections
4. Reviewing themes	Team meeting to discuss themes and subthemes
5. Defining and naming themes	Team consensus on the final version of the themes
6. Producing the report	Describing the process followed in conducting TA Reporting on the theoretical, methodological and analytical choices

Table 5.1: Table illustrating the process of identifying, analysing, and reporting qualitative data using thematic analysis (Braun and Clarke, 2006) and the techniques used to demonstrate trustworthiness (adapted from Nowell et al., 2017)

Theme	Subtheme	Supporting quotes		
Pain is multidimensional This superordinate theme illustrates the different ways in which pain impacted on participants' lives, transforming them into 'chronic pain sufferers'.	Changes in self-perception This theme addresses the influence that living with pain exerted on the way people's self-perception	Loss of roles and status	Charlotte - 'How it started It started first when I was a nurse and ummm the first thing that happened to me was the first problem I had was with my ankle and the problem was so severe that it meant I had to give up being a nurse, which was very difficult for me. That was very unexpected, total career change was necessitated as a result of that. That was a big deal in my life and I was only twenty-nine.' Gabrielle - 'It was a very, very trying time, it has been a very difficult journey because obviously I've gone from, you know, I was a workaholic, my profession was very important to me. I've lost my house, I lost my car, I lost everything.' Charlotte - 'Yes. I would say my greatest hobby before was walking. Obviously, it has curtailed that.' Riley - 'I suppose I stopped doing some sports, because of it or it made it more difficult. I think it's always there, I think. So, I carry on. There's nothing particular that I don't do because of it, but it just makes things more difficult.'	

 Table 5.2: Worked example illustrating the coding framework applied to the data

Theme	Subtheme	Supporting quotes		
		Becoming vulnerable and dependent	Jane - 'Yes. It made me feel I suppose sort of disabled in a way that I never considered myself to be before, because I needed help with things, like reaching to get things from a cupboard or hanging something in my wardrobe, simple everyday things I couldn't do as easily.' Gabrielle - ' It was a very, very challenging time, because all those, the narrator in your head you cannot get away from, you know. I was in bed or in a wheelchair, and I couldn't tolerate television or noise or sensory overload. I couldn't see properly. '	

Findings

Participant characteristics

The sample was heterogeneous and included people with very diverse conditions: shoulder pain, neck back pain, back and lower back pain, spinal pain, arthritis (See table 5.3). Five participants shared that they experienced pain in multiple sites (e.g. shoulder and back pain or neck and lower back pain). One of these individuals expressed that she has been diagnosed with multiple conditions including fibromyalgia, generalized encephalopathy and neurogenic bladder. In regards to the number of years with pain, the majority of the participants reported having lived with pain for twenty years or more. This is valuable in explaining the wide array of treatments and procedures that the participants engaged in throughout the years (painkillers, occupational therapy, Physiotherapy, Osteopathy, Massage, Acupuncture, Yoga, herbal remedies, hyperbaric oxygen therapy, hydro dilatation).

Themes and subthemes

Data analysis revealed three broad conceptualizations of the participants' experience of living with pain and their acceptability of a novel intervention, which are presented in Table 5.4. These interrelated themes provide a useful insight into participants' collective understanding of the impact of persistent pain on their lives and their strategies for pain management as well as their views on a novel psychosocial intervention. A discussion of the emerging themes and subthemes, along with illustrative quotes is presented bellow

Participant	Type of pain condition	Time living with pain	Pain management
Charlotte	Ankle pain, Spinal pain	Twenty years	Physiotherapy, Osteopathy
Gabrielle	Neurogenic bladder, Encephalopathy, Fibromyalgia Generalized pain	Twenty years	Physiotherapy, occupational therapy, counselling, hyperbaric oxygen, natural remedies, Osteopathy
Jane	Shoulder and neck pain	One year	Pain killers, NSAIDs, Physiotherapy, Osteopathy, Hydro dilatation
Joanna	Neck and lower back pain	Did not specify	Yoga, massage, Acupuncture, Osteopathy
Laura	Shoulder and back pain	Eighteen years	Sports massage, herbal remedies, Physiotherapy, Osteopathy
Richard	Back pain	Twenty years	Physiotherapy, painkillers, Osteopathy

Table 5.3: Table containing participant characteristics (pain condition, time living with pain, pain management approach

1. Pain is multidimensional 'Hall of mirrors'	2. Experiences with pain management and navigating the healthcare system	3. Acceptability of novel intervention
1.1 Understanding the nature of pain	2.1 Pharmacological intervention (painkillers, NSAIDs) 'I don't think chronic pain is well understood, or all the side effects that come with the medication that they prescribe'	3.1 Willingness to engage in the intervention
1.2 Changes in self- perception Loss of roles and status Becoming a 'chronic pain sufferer'	2.2 Physiotherapy 'It was very much about giving me exercise for me to do on my own'	
1.3 Functional daily activities	2.3 Mind-body interventions Meditation Yoga Multidisciplinary program	
1.3 Pain as a growth experience 'As far as pain goes it can be a great teacher.'	2.4 Manipulative interventions Osteopathy 'The Osteopathy is probably the thing that works the best'	
1.5 Social aspects of pain 'There isn't much wrong with you, is there?' Stigma Isolation Society's perception of chronic illness	2.5 Natural products Herbal remedies, plant based products (e.g. turmeric, black pepper)	
1.6 Psychological aspects Coping strategies Mood Feeling depressed Catastrophyzing	2.6 Navigating the healthcare system Ambivalence	
1.7 Beliefs about the future		

Table 5.4: Themes and subthemes illustrating participants' experience of living with pain and the acceptability of a novel intervention

Theme 1. Pain is multidimensional -'Hall of mirrors'

This category encompasses the different facets of pain as experienced by the participants. In this sense, it is as if a person would find themselves in a 'hall of mirrors', each of them having particular characteristics (some convex, some concave, others with a ripple effect, or textured) and reflecting back a different angle of the person in the middle. This metaphor is useful in portraying a situation where pain impacts the individual in various different ways: by shifting the perspective they have of themselves ('becoming a chronic pain sufferer') and influencing their ability to perform their normal daily activities, by contributing to stigma and isolation and also affecting their mood, thoughts and emotions. This may lead to the person feeling confused and frustrated, as they do not recognize themselves in this new version (living with the pain) and focus all their efforts in understanding the nature and causes of pain as well as the ways in which it can be reduced or eliminated. However, the experience of pain can also be used to guide personal growth and encourage the person with pain to become more self-compassionate and caring.

1.1 Understanding the nature of pain

This theme illustrates people's experience of making sense of the pain by trying to understand more about its causes, its symptoms, and the ways it can be managed. Failure to understand these factors may result in confusion and frustration. This is evident in one participant's account:

'For me, I would like to know exactly what is going on. I'm still having tests; it might be this, it might be that. The health service takes so long and you have to live with it while you're waiting. I don't actually know... I know about my neck, but I don't really know what is going on with my lower back. So I find that so frustrating. In fairness, I would like something to keep me going a bit longer, so that I can do more of the things that I used to do before I had to stop. I found it very depressing.' (Samantha, focus group participant)²

Furthermore, it seems that the intensity and frequency of the pain are two of the factors that influence the participants' pain experience and dictate the

² All names used are pseudonyms, to ensure anonymity

degree to which their lives are affected by it. Two participants expressed that in their view, it is a matter of degree, with pain being manageable when low in intensity and intolerable, 'filtering everything else out' when high in intensity.

'I think it's a matter of degree, and I think it's very different or it would be very different if the intensity of the chronic pain would go up. If you put it on a scale from zero to ten where ten is something that is intolerable and zero is no pain, mine is in the bottom three. So, it's about intensity. When I think about people... my wife treats people with chronic pain and the way she would describe it, varying from eight to nine and up, I'm not at that place. I think my view may well change if *suddenly my pain went from three to eight.'* (Simon, focus group participant)

But do I think being conscious of here and now in my environment as opposed to the internal suffering associated with my spine does? Yes, it does, to a certain extent where pain gets to a particular level where it filters everything else out and you just cannot see beyond that.' (Charlotte, interview participant)

Similarly, two other participants shared that they could not pinpoint what caused the onset of the pain but that it seems to alternate in frequency and intensity ('it seems to come and go', 'sometimes is better, sometimes is worse').

'I don't know how it started; I don't know why it started. It's been on and off since then. Sometimes is better, sometimes is worse.' (Riley, focus group participant)

'I have a back problem, which probably started about twenty years ago. The first thing I remember is visiting the GP, I was quite young. Like Riley's, it seems to *come and go.'* (Richard, focus group participant)

1.2 Changes in self-perception

This theme captures the discrepancy between the 'old self' fulfilling former roles and the 'new self' having to relinquish them due to the pain. This appears to have a negative impact on people's self-regard. Pain seems to compel people to redefine their self-concept and rethink their roles and relationships with others. The impact of pain on identity is well documented in the literature (Clarke & James, 2003; Morley et al., 2005; Waters et al., 2004; Miles et al. 2005; Lin Yu et al., 2015; Vlayen et al., 2016). People living

with pain report an 'altered sense of self' and not recognizing themselves anymore. The same effect can be illustrated in the accounts of two of the participants, who report having had to renounce their professional career and status as a result of living with long-term pain:

'How it started... It started first when I was a nurse and ummm... the first thing that happened to me was ... the first problem I had was with my ankle and the problem was so severe that it meant I had to give up being a nurse, which was very difficult for me. That was very unexpected, total career change was necessitated as a result of that. That was a big deal in my life and I was only twenty-nine.' (Charlotte, interview participant)

'It was a very, very trying time, it has been a very difficult journey because, obviously I've gone from, you know, I was a workaholic, my profession was very important to me. I've lost my house, I lost my car, I lost everything. Oh, who are you?' then you say:' I'm this or that', and then to be nothing at all, you know...' (Gabriele, interview participant)

In addition, living with pain can alter the way people are perceived by others. It appears that in the eyes of others, people experiencing pain are defined by their limitations (what they can or cannot do), and that pain has become embedded in their identity.

'It alters the way people see me, the ones close to me. They see me now, first as... it's 'How's the pain?' 'How are you feeling?' they see me as a chronic pain sufferer first in some ways. It's a difficult one that. I suppose they say: 'We can't go there', 'We can't do that', 'We better not have a holiday there because that would be too much walking for you' so they also see me as defined by my limitations.' (Charlotte, interview participant)

1.3 Functional daily activities

This category captures the influence of pain on participants' ability to perform usual activities such as doing chores, gardening, carrying the shopping, opening jars or cans or getting into bed. This is mainly due to reduced mobility and decreased range of motion. The impact of pain on daily activities is well acknowledged in the literature. A survey of persistent pain in Europe found that pain severely affected sleep, the ability to exercise, walk, perform household chores, attending social activities and also reduced

the ability to drive a car (Breivik et al., 2012). Some participants shared the ways in which the pain limited them but also how they managed to adjust to and reconcile doing certain activities (for example asking for help from their loved ones).

'It's not going to go away, so it's learning to live with it, finding ways... just doing things around the house, like I can't open bottles or jars or... so unless my husband is in, I just sit there looking at it thinking: 'I wish I could open that bottle' (laughs). It's finding ways to deal with every day chores or... in a different way. Our garden has had to be reorganized, we have raised beds because you can't bend anymore, you know. You're always thinking what you need to do to make life easier, because of pain and lack of mobility.' (Samantha, focus group participant)

'I think it's about knowing your limitations as well. You know if you're bad, you can't carry that bag of shopping and you need extra help' (Laura, focus group participant)

But the other bit of it is that it did have some impact on certain functionalities. Now bear in mind that my shoulder... it was the left one and I am right handed so it wasn't impairing my ability to do things like writing or put the kettle on, those kind of things (everyday functionality things). But in terms of things were I was using my left arm or shoulder, rather than the right it would have an impact on certain things but not across the spectrum.' (Simon, focus group participant)

1.4 Pain as a growth experience

One participant shared a unique perspective on living with pain. Specific to her account was the idea that pain is the means to learning something new about herself, therefore 'a teacher' ('As far as pain goes it can be... I think it can be a great teacher.'). Gabrielle regarded pain not as a threat, but as an opportunity for self-development, an experience that lead her to becoming more compassionate with herself and others. It seems that she previously was a 'hard task-master', a very ambitious and career-oriented individual who did not focus too much on self-care as long as she reached her goals. Pain appeared to have helped shift her perspective on life.

'So, I've really designed this illness to be a growth experience rather than a victim of circumstance, you see. [...] I have much more compassion for people now, than I did when I was working. I was always compassionate but not as I am now, you



Figure 5.3: Picture retrieved from Adyashanti (2015) https://upliftconnect.com/ reality-of-enlightenment/

know. I had no compassion for myself then, I was a very hard task- master of myself. '(Gabrielle, interview participant)

This participant described pain as an embodied experience, and rather than viewing it as an unwanted phenomenon that needs to be eliminated, she 'sinks into it' going into a meditative like state where 'great learnings come out of it'. Pain in this case is depicted as a spiritual experience through which the individual surrenders instead of trying to escape and through this achieves a positive transformation.

'Sometimes pains are trying to tell you things and if you use... If go into the meditation and then into the pain, rather than removing myself from it and distancing and separating myself from it, that's the pain. So, I think if you can observe the pain to start and then you allow yourself to sink into it, it's really frightening to sink into it, but then peace is at the other side of it. I suppose it's similar to what women use in childbirth, that very thing, rather than escaping the pain, just sink into it and some times big gifts come out of that, you know I think big learnings come out of that from a spiritual perspective.' (Gabrielle, interview participant)

1.5 Social aspects of pain

The experience of pain occurs and is shaped within the social context. It has been documented that people living with persistent pain often feel misunderstood, disbelieved or unaccepted by others (Werner and Malterud, 2003; Allegretti et al., 2010). The 'invisible' and subjective nature of pain may lead individuals to feel invalidated and having to justify and defend their experience (Koool et al., 2010). Moreover, stigmatization is known to affect people living with pain by exerting a negative influence on their perceptions, self-esteem, care-seeking behaviour and engagement in rehabilitation (Holloway et al., 2007; Slade et al., 2009).

Two of the participants expressed that they felt misunderstood, disbelieved or stigmatized by others, who could not accept that although pain was not visible it was very real, or that living with pain is as difficult as living with a different chronic condition. Moreover, one of the participants also emphasized the difficulty to preserve authenticity in spite of living with long-term pain. This is illustrated in the fragments bellow:

You know, people still ask you if damp weather is going to make any difference, but it doesn't. If it's damp today, your pain is not worse than yesterday, when the sun was shining.' (Samantha, focus group participant)

'So, you know, finding the path of authenticity is very difficult, and also the judgement that if you are having a good day, and you put your make up on, and ok, you can't dress as you used to because you can't wear heels, and you put ribbon around your stick to cheer it up (smiles), but it's still a stick; I was 37 when this happened to me, which is quite young. I played squash, I played rugby, and I was very active. But if you do have a day when you do do those sorts of things, people think: 'There isn't much wrong with you, is there?' So you are really in a double bind situation with these sorts of illnesses. [...] 'And even the hierarchy of illness, there is a massive hierarchy among the disabled, you know, there is a hierarchy everywhere. [...] People would go: 'You've got that, ohhhh you ought to have what I've got.' I mean, you know, there is a hierarchy in everything, so it has been a big *lesson.'* (Gabrielle, interview participant)

The participant also talked about being isolated and reclusive. She recalled feeling grateful for having her best friend support her throughout the journey, as they were in a similar situation. Isolation is common within people with chronic illnesses, in particular those living with any form of 'invisible' symptom (Richardson, 2005). Isolation may be a result of reduced mobility but also a self-imposed strategy to avoid unfavourable reactions from the others (Radley, 1994).

'I became reclusive; it wasn't worthy even trying to go out. Completely isolated, completely isolated. I was very fortunate in one was because my best friend from when we were ten she got MS (smiles). And so we continued on the journey, we use to swap lipsticks, now we swap catheters, you know (smiles). It was a great gift, us both being in the same position and really, it was only a matter of . . . I became ill and six months later she did. That was a great gift.' (Gabrielle, interview participant)

Furthermore, the same participant discussed about what she perceived as the society's failure to understand chronic illness, and their biases and prejudice towards those who live with a chronic condition. They appear to treat it as an 'acute' problem, expecting the people who experience pain to 'get better or die' instead of ' dangling about here, feeling awful all the time'.

'People don't know how to cope with chronic illness, because we're in such a society where everything is instant, you know. And there is sort of a feeling that, you know, with a chronic illness, either you get better or you die, one or the other, dangling about here, feeling awful all the time, people don't know how to cope with that, as a general thing. They just don't know how to cope with it.' (Gabrielle, interview participant)

1.6 Psychological aspects of pain

Psychological factors have been acknowledged as being essential to the experience of pain and therefore the focus of a plethora of research. Several key emerging themes revolve around affective and cognitive psychological factors such as coping strategies, mood, depression and fear of pain.

Coping strategies

People with persistent pain need coping strategies to manage their pain and its impact. Previous studies have suggested that the most frequently used coping strategies by this population include medication, exercise, task persistence, coping self-statements, pacing, cognitive strategies (such as distraction) and religious activities (Barry et al., 2004; Ersek et al., 2006).

Two participants touched upon several coping strategies that they use to manage pain. Pacing is one of the strategies used and refers to adapting one's level of activities to the pain. Gabrielle expressed that pacing posed a challenge to her patience and that she needed to do everything gradually. This appears to be very different from how she used to perform activities before ('chronic pain has changed everything').

'But now I realised that I have to do a bit, stop. And it's a big challenge to patience; chronic pain is a big challenge to patience. Chronic pain has changed everything.' I need to do it gradually, really slowly, and I need lots of rest time, sleep time [...]' (Gabrielle, interview participant)

Another participant described the difficulties that she was facing due to feeling pain in both her spine and her leg, and not being able to sit or move for a long amount of time. There was a sense of frustration in her tone, as she used irony to express her inability to decide on the better coping strategy (rest or activity). Charlotte also mentioned using distraction and directing her attention away from the pain.

'This is the irony of it: with my spine the longer I sit down, the more pain I'm in and I have a problem with my leg and the more I move, the more pain I'm in. So I feel that I'm in a catch 22 really. [...] So what else do I do? Distraction I suppose.' (Charlotte, interview participant)

Mood and depression

It is undeniable that pain can have a negative effect on mood. This is conveyed by one of the participants, whose mood seemed to have been influenced by pain, leading to him being 'grumpy' and struggling with work.

'It can affect mood sometimes, if I have headaches. I'm rubbish with pain; it makes me feel really grumpy. So I'm more likely to be grumpy or struggle with work.' (Riley, focus group participant)

Similarly, Charlotte suggested that she struggled to think and envision the future and was focusing instead on 'getting through the day', which made her feel low. Moreover, she emphasized the negative impact of pain on her emotions, expressing that pain played a significant role on her feeling depressed.

'C: My aims have always been in regards to my career but right now, all I can do is get through the day, to be frank, so I find it really hard to think about the future. Interviewer: How does that make you feel? C: Dejected really, depressed, yes. Interviewer: How did living with chronic pain affect your emotions? C: I suppose it's significant, it made me feel quite depressed. I struggle to overcome that.' (Charlotte, interview participant)

Another participant admitted feeling depressed, in the context of futile attempts to identify the nature and causes of her pain and find effective pain relief. This is not uncommon among people living with persistent pain, in fact, the relationship between long-term pain and depression is well documented in the literature (Blair et al., 2003; Arnow et al., 2009).

'In fairness, I would like something to keep me going a bit longer, so that I can do more of the things that I used to do before I had to stop. I found it very depressing.' (Jane, focus group participant)

Catastrophyzing

Exaggerated negative thoughts occurring during actual or anticipated pain have been conceptualized as 'pain catastrophyzing' (Sullivan et al., 2001). This construct includes elements of rumination, magnification and helplessness (Rosenberg et al., 2015). One of the participants voiced her fear that pain will worsen leading to her being unable to move around or climb the stairs, leaving her isolated. Likewise, Charlotte seemed to hope that her situation would improve mainly because she could not contemplate having to cope with her health getting worse. A tendency towards avoiding difficult thoughts was also present in her account, which may be associated with decreased acceptance of pain.

'I'm hoping that it won't be as bad as it is now because it's quite scary. I live on my own and I think: "If this carries on, I have to move, the steps, I've got lots of steps", you know and so I won't be able to do it in a years' time." (Joanna, focus group participant)

'I'm hoping it will be better, either because I would have had the surgical intervention or ... because the pain has diminished for some other reason. If it doesn't get better ... I don't think I want to think about not getting better, to be frank with you because I don't think I can cope with another part of my body giving up.' (Charlotte, interview participant)

1.7 Beliefs about the future

Participants' beliefs about the future living with pain fell into three subthemes: pain and ageing, maintenance mindset and preparedness to work around the pain.

There is a common belief among the elderly that pain is a normal part of the ageing process (Jinks et al., 2007). It has also been suggested that acceptance of pain as part of ageing may be necessary for the elderly to enjoy a full and active life (Roy and Thomas, 1987; Cook and Thomas, 1994). This is illustrated in Simon's perspective: he believes that experiencing pain is inevitable in old age.

'I do but also, I am also old enough and wise enough to think that at my age, if it's not this it's going to be something else. So if it's not chronic pain in my shoulder *it's going to be somewhere else.'* (Simon, interview participant)

A similar perspective can be observed in Gabrielle's narrative when she acknowledged being prepared to face old age having already experienced chronic illness, which is similar to the effects of ageing in her view. There is a sense of acceptance in the way she talked about her outlook on ageing, expressing that 'looking 20 years younger than you are it's like trying to stick an autumn leaf back on the tree' and thus suggesting that ageing and its effects are part of the natural life cycle. Considering herself fortunate for having already faced hardship unrivalled by the ageing process, Gabrielle exhibits a unique and intriguing perspective.

'I think if you have a chronic illness naturally, later on, you're gonna have the same problems as other elderly people have on top of what you've already got. I'm certainly aware of that, but then on the other hand I feel more prepared for that than many people of my age, because I think in our culture we're in the situation where looking good means looking 20 years younger than you are, it's like trying to stick an autumn leaf back on the tree, it's the cycle of life (laughs). That's what happens, you know. I've already dealt with incontinence, I've been in a wheelchair and all that, so I feel that I'm in a very fortunate position because I've done that bit.' (Gabrielle, interview participant)

A different pattern emerged from the data in regards to participants' beliefs about the future and it revolved around a 'maintenance mindset', where people suggested that they engaged in exercise and physical activity to prevent 'degeneration' and to improve their posture and range of motion. Jane shared her belief in getting better and continuing to exercise despite the pain, by 'working around it'. She appeared determined to keep swimming, although not to the same level as before, and training for a 10k run. By this, she demonstrated an accepting and upbeat attitude and some positive beliefs in regards to the future living with pain.

'I just do the exercises that I do nearly every day. The way I understand it to be is partly about maintenance, so making sure that there is no more degeneration but it's also by continuing to do these particular exercises that will improve the posture, improve the flex, in some of these areas, which will get back to the best possible position. That's never going to go away, it's just a matter of the degree of it and the exercises to prevent it from getting worse.' (Simon, interview participant)

'Well, I perceive that it will get better. I think it is not going to stop me from doing what I want to do. That's my attitude towards it. So, even if I can't swim the way that I want to, it won't stop me from going swimming, if you get what I mean. And I might not be able to do badminton, but I signed up to do a 10k. So, that doesn't involve using all that arm movement but it is another way of keeping fit and doing it in the company of other people. So, my attitude is to work around it, if it's still there and if it's still restrictive.' (Jane, interview participant)

Theme 2. Experiences with pain management and navigating the healthcare system

This category comprises the participants' shared experiences of navigating the healthcare system and using different treatment modalities such as pharmacological interventions, physiotherapy, mind-body interventions, manipulative therapies, natural products and other procedures. This is consistent with previous literature indicating that most people living with persistent pain are treated within primary care (Mills et al., 2016), where they

have access to both pharmacological and non-pharmacological approaches, but also using Complimentary and Alternative Medicine (CIM)³.

2.1 Pharmacological Interventions

Most of the participants mentioned having taken pain medication, however, they expressed different viewpoints in regards to this. Some talked about using non- prescription analgesics (Paracetamol, Ibuprofen) or non-steroidal anti-inflammatory drugs (NSAIDs), with different results. Riley experienced some pain relief by taking painkillers, while Jane needed stronger painkillers and was prescribed anti-inflammatory medication.

'It's mainly painkillers and I take probably more than I should. It's mostly over the counter painkillers and they ease it for a bit.' (Riley, focus group participant)

'Originally painkillers, just Paracetamol, Ibuprofen, then... [...] Then I went to a GP who suggested stronger non-steroidal anti-inflammatory drugs, so I was taking a high dose Naproxen.' (Jane, interview participant)

Other participants showed their dissatisfaction with taking painkillers due to their side effects, or the inability to perform usual activities (such as driving) as before. It appears that dealing with the medication side effects may have been equally difficult for the participants as managing the pain itself.

'I've got strong painkillers, which I don't like taking because I can't drive with them.' (Laura, focus group participant)

'I won't take a lot of painkillers, I can't function. I don't know what to do about my leg, but with my spine, I've adapted, you know, I've got this (elevated computer stand) so that I can use when I work.' (Charlotte, interview participant)

'It has been quite an experience, but I don't think chronic pain is well understood, or all the side effects that come with the medication that they prescribe. Because even something like Cocodamol, if you take it often it makes you feel so ill, as well as, on top of being ill.' (Gabrielle, interview participant)

³ A category including a variety of practices including: manipulative methods, mindbody interventions, traditional medicine and naturally products (National Center for Complementary and Alternative Health, 2016)

One of the participants emphasized that she preferred using natural products for pain relief rather than pain medication. She brought to light a problem that she experienced in the past when she was taken off the pain medicine and then was unable to have it prescribed again, at a later point in time, by another doctor, who failed to acknowledge that she was living with a long-term pain condition.

I was prescribed Naproxen and Co-codamol. I try not to take these things. I take turmeric and black pepper every day and I prefer more natural remedies, despite being prescribed these things. I think a lot of patients are in this position, that if they try to do something themselves and then they say something to the doctor about it then they take the painkillers off their prescription and then you can never get them back again. There is a huge waste of money in the health service. You have no relationship with the doctor, and I was in this situation, I said: 'I don't want the Naproxen, just take it off.' And then I had a period when the pain was bad and so then I actually got to the doctors, a doctor that I didn't know so he said: 'What do you want the painkillers for?' And I go: 'Well, it's a chronic situation'. 'Well, you can't be, you're not on them now so what do you want them for?' (Gabrielle, interview participant)

Finally, two of the participants suggested that they did not make use of painkillers at all or only occasionally.

'I used painkillers occasionally, but not very often.' (Richard, focus group participant)

'I used to take a lot of painkillers but I don't do it anymore since I've retired. If I can't do something today, I'll do it tomorrow.' (Samantha, interview participant)

This is consistent with previous literature suggesting that a large proportion of people living with pain were taking NSAIDs (55%), Paracetamol (43%), and weak opioids (13%) (Breivik, 2012).

2.1 Physiotherapy

Seven out of the nine participants disclosed having tried physiotherapy among other treatment modalities. Richard suggested that initially the sessions with the physiotherapist followed by doing the exercises recommended proved to be effective, however, after a while he stopped

doing them and was not followed up afterwards. For Jane, stretching her joints was very difficult considering the increased amount of pain that she experienced whilst doing it. Charlotte had yet a different experience; she mentioned searching for physiotherapy exercises online and following them but according to her they were not effective. These experiences seem to reveal a pattern, suggesting that it is difficult for people with persistent pain to keep performing the exercises recommended by the physiotherapists on a long-term basis, particularly when there is no support or follow-up involved.

'I first had some physio with some exercises afterwards, which seemed to work but then you stop doing the exercises after a while and forget doing them. Apart from those, nothing followed up professionally since then.' (Richard, focus group participant)

'It was very much about giving me exercise for me to do on my own, rather than manipulating the joint; that for me was all right, but it's really hard to stretch your joint when it's painful and to push it beyond the limit of what pain will naturally allow you to do. So I found that really hard, to put that pressure on the joint.' (Jane, interview participant)

'I've done... Every time prior to me getting a diagnosis, I look for physiotherapy exercises online, I follow those, they don't work. ' (Charlotte, interview participant)

2.2 Mind-body interventions

This theme includes participants' experiences trying different approaches such as meditation, yoga, acupuncture and multidisciplinary programs. These modalities seem to have been used on their own or in in conjunction with conventional treatment. One of the participants recalled having been inspired by her sister to train in meditation and having practised it for managing pain for the last seventeen years.

' Well, I couldn't read at the time so my sister, my twin used to read things like Louise Hay- How to heal your life and all that sort of stuff. So, when I felt a bit better, I trained in Meditation and that's what I use at this time for pain. This was in a yoga Centre and I've done different types of Meditation. For sixteen or seventeen years I've been meditating at least once a day, usually twice a day. I did a course in Meditation and energy management. ' (Gabrielle, interview participant)

The same participant shared her experience of undergoing a variety of treatments within an MS centre, where a multidisciplinary team supported her recovery. Despite being a voluntary service and where people did not need to be referred, to her surprise the therapies offered within the centre seemed to have helped Gabrielle. She appeared to be very pleased both with the team of health professionals supporting her and the different therapies have undergone.

'I went to the MS centre and they were very good. I had physiotherapy, occupational therapy, counselling, and hyperbaric oxygen. It was a wonderful team. It was a voluntary service and I wasn't referred by anybody. I didn't think I could go because it was an MS centre but they saw me and said your symptoms are so similar that we are happy to have you here. So that was really good but I found that and I went there, and I wasn't referred by anyone. Interviewer: Did you find it helpful? Gabrielle: It was really helpful.' (Gabrielle, interview participant)

Another participant suggested trying different treatments including painkillers, physiotherapy, acupuncture and Osteopathy to manage her pain. Given that none of these therapies were effective in relieving pain, Samantha ended up having a hip replacement.

'I've had lots of different treatments over the years: from Chinese herbal remedies, physiotherapy, acupuncture, Osteopathy. When I was working, my neck used to cease up at the end of the day. Even when I was driving home I would think: 'Am I gonna make it?" I used to take a lot of painkillers but I don't do it anymore, since I've retired. If I can't do something today, I'll do it tomorrow. Interviewer: Did any of these therapies help your pain improve? Samantha: None of them helped which is why I ended up having the hip replacements.' (Samantha, focus group participant)

Finally, Joanna expressed that she practised yoga regularly, after having been recommended to stay active, and that she felt that it benefitted her.

'I did say that yoga was helping me, but then I haven't done yoga for a few days. I know they say keep active. ' (Joanna, focus group participant)

2.4 Manipulative interventions

Osteopathy

All the participants have had Osteopathy at some point in their life, most of them experiencing benefits from the treatment. Overall, the participants expressed that they noticed improvements as a result of undergoing osteopathic treatment. One of them is Gabrielle, who had Osteopathy mainly to manage her coccyx and lower back pain. She suggested that Osteopathy was effective in helping her stop slouching and also mentioned that osteopaths are within the few health professionals who practise manipulation.

'And then, I've had quite a lot to do with Osteopathy. My nephew was an osteopath. So I had had Osteopathy over the years, so I started coming here for my coccyx and then my lower back pain. They've been treating me ever since. It has been about eighteen months I suppose. [...] It has been very helpful. For the coccyx, that really got better. If I don't slouch then it's really, really good. If you think, the chiropractors and osteopaths are the only people who put your hands on you. Doctors don't do that anymore.' (Gabrielle, interview participant)

Simon reported a similar experience, finding Osteopathy convenient and easily accessible. He expressed a preference for the osteopaths' approach and felt comfortable with the treatment. He also suggested an increase in his quality of life (from 70% to 90% according to him) as a result of taking part in the sessions and although his problem was not 100% 'fixed' he declared himself satisfied.

'I didn't know anything about Osteopathy but by being engaged in the establishment and setting up, I found it very interesting and it helped me with some other minor things in the past. So, my first thinking was to go to one of the osteopaths here, partly because it's convenient, but also in terms of how they approach it and what they do... fits with what I am comfortable with. [...] And it's gone from... talking to the Osteopaths every time I see them, it's like: What's your quality of life? You know those percentages and it might have been 70% at the beginning and it's now 90 to 95%. So over that period of time, it has improved, It's not 100%, in terms of "fixing it", if that's the right expression, but it's not far off.' (Simon, interview participant)

In addition, another three participants expressed having benefited from osteopathic treatment and having their pain alleviated as a result (at least temporarily).

'When I was working, I was having Osteopathy and that used to ease the pain for a few days.' (Samantha, focus group participant)

'I've had had sports massage, which eased ... but then I found Osteopathy. I know when my shoulder is playing up, I book an appointment the soon as I can and it does alleviate the pain quite well. '(Laura, focus group participant)

'The Osteopathy is probably the thing that works the best, it certainly has recently anyway.' (Riley, focus group participant)

Osteopathic treatment seemed to have helped Jane only to a certain extent. She suggested that her shoulder was less constricted after the Osteopathy appointment, however afterwards she experienced pain and soreness in her shoulder. Her goal was to achieve a better range of movement and less pain, and it appears that despite the decrease in pain, her movement remained the same.

'Jane: I was having Osteopathy treatment here, and that had some effect. Interviewer: Can you tell me more about it? Jane: Well, it felt much less constricted immediately after the treatment but in the evening it would be very painful and sore because my shoulder joint had been stretched and manipulated. I don't fee I got a lasting benefit, it didn't really... what I wanted was to have much more freedom of movement and less pain. The pain was less, but the restriction was the same.' (Jane, interview participant)

Finally, only one participant reported that they did not benefit at all from Osteopathy. According to Charlotte, the Osteopathy sessions contributed to her pain getting worse. In addition, the osteopath conveyed that due to a structural problem in her leg, they could not be of much help to her.

'Charlotte: Ok. I've had Osteopathy and ummm it wasn't effective for me. Interviewer: May I ask for how long? I can't remember how many sessions. I may have had six for my spine and they tried to do tractions. It didn't help; in fact, it made the pain worse. With regards to my leg, I think I had four sessions and I think she said: 'I think there is something structurally wrong there'. 'The structural

problem is easing into the pain' so she couldn't do much about that. ' (Charlotte, interview participant)

2.5 Natural products

Despite the popularity and longstanding use of herbal medicine, the available data from clinical trials of the usage and effects of plant-based natural products for pain is very limited (Chen and Michaelsen, 2017). Herbal medicine is considered the foundation of traditional medical system worldwide, however, the knowledge regarding the mechanisms of different nutrients for alleviating pain is very limited.

One of the participants shared her experience with using natural remedies.

In a first instance, this participant referred to using turmeric (Curcuma) and black pepper (Piper nigrum), as a replacement for prescribed medication. It is known that turmeric has anti-inflammatory effects and therefore may help increase resistance to illness (Bengmark et al, 2009). However, clinical trials are needed to determine whether treatment with turmeric extracts can benefit people living with long-term pain by preventing or suppressing flares or alleviating pain.

In addition, Gabrielle talked about her journey to Peru, where she took part in a retreat and was taking ayahuasca (Banisteriopsis caapi), a sacred plant native to the Amazon that has been used as medicine by shamans across South America. Although she described numerous challenges to overcome in this journey (being in a wheelchair, feeling fatigued and having to stop for a couple of days to get some rest, being emotionally challenged) Gabrielle also conveyed that this experience has benefitted her greatly.

'I take turmeric and black pepper every day and I prefer more natural remedies, despite being prescribed these things. '[...] I read about it and it was an amazing healing plant, from a cactus, so I contacted someone who did the retreat in Cusco, in Peru. With the altitude and the hills and the wheelchair that was completely impossible. So I contacted someone else, and they were with ayahuasca, which is the sacred plant. And they worked with San Pedro too, so I went there. I was there for two months and it was physically, spiritually and emotionally the hardest thing

that I've ever done. And most people will say that. But it has amazing results; this medicine has been used in the jungle for centuries or millennia. So I've been three times now.' (Gabrielle, interview participant)

2.6 Navigating the healthcare system

This category describes the ambivalence of navigating the healthcare system, with one participant sharing both positive and negative experiences. This theme can be illustrated well by the account of Gabrielle. She recalled being seen by a specialist in Myalgic Encephalopathy (ME) in a clinic where she felt that the health professionals acknowledged her symptoms and were very supportive and empathetic. She seemed to be very satisfied with the care received there.

'There was a Professor who run a clinic there and he specialized in ME and not just this business of people being 'a bit tired', you know (smile). I mean it was the other symptoms as well, the neurological symptoms and everything that went with that. And it was a brilliant clinic, absolutely brilliant, they were really helpful, and they understood, and they were supportive, and they would give you things like magnesium for pain, which they'd found to be useful. I found that it helped me.' (Gabrielle, interview participant)

Gabrielle expressed that she valued being acknowledged and taken seriously, as well as being listened to by health professionals. This was particularly important in the context of being in excruciating pain, feeling vulnerable and unable to ask for help.

'He listened to me, you know and when my left-hand side got worse he examined me and he said: 'Right, ok, we need to get you into hospital. You have to have an emergency MRI, you have to have these things.' And I said I don't want to go. He said: 'You have to, you must.' He took it seriously and just being listened to was the biggest gift that he gave to me because when you are in pain and the pain sometimes is so bad that you are crying and you can't reach out and ask for help it's a very difficult situation. And I think it's the only illness where the rest of the world tries to push you into denial.' (Gabrielle, interview participant)

However, the same participant shared some disturbing experiences such as having to deal with doctors who refused to believe her, denied her the treatment she needed, and fobbed her off, claiming that her pain is imagined. Gabrielle realized that the balance of power was skewed in favour of the

health professional and yet she found the courage to confront the doctors and explain that her problems were genuine. Unfortunately for Gabrielle, not being believed also resulted in being denied the financial support she needed, and having to fight the decision for two years.

'And in this particular clinic, when I went to see him for the first time, there were some people in the waiting room, patients, and this man said to me: 'Have you seen him before?' and I said: 'No' and he said: 'Don't disagree with him, whatever he says to you don't disagree with him. If he says you are getting better, agree, you are getting better because if you don't he will make your life a misery.' And I thought 'No, that's ridiculous'. I thought that can't be right. Anyway, it turned out to be true. He basically ignored all my medical history, just ignored all of it. He said this is all psychosomatic and I said: 'But I had urodynamic testing, I have a neurogenic bladder, I had all the objective testing'. 'Ignore it all, ignore it all, you will never get better with these fixed illness beliefs'. And I said to him: 'I'm sorry but I don't understand what you are saying'. He said: 'You've got fixed illness beliefs'. And I said: 'Well, one of us has.' (laughs). And then he wrote a report to the benefits saying it was all psychosomatic, he had examined me. And he hadn't. It took me two years to actually fight that.' (Gabrielle, interview participant)

This is not a singular experience; in fact, the research literature suggests that this is a common pattern within people who live with long-term pain. There is a plethora of studies documenting that people who experience persistent pain often feel disbelieved and dismissed by healthcare providers, as well as being told that the pain is 'in their head' (Osborn and Smith, 1998; Walker, 1999; Soderberg, 1999; Gullacksen and Lidbeck, 2004; Snelgrove 2009; Madden, 2006).

What is more, Gabrielle shared another traumatic experience which lead her to fear and distrust doctors and avoid going to the hospital. After having had an operation and needing to be catheterized due to her neurogenic bladder, Gabrielle did not receive the necessary care from the nurse, which resulted into her stitches bursting and her bladder displaced. She recalled feeling disempowered, vulnerable, fearful and having her integrity threatened.

'It was a very traumatic experience. In fact I signed myself out of hospital. I thought: 'I am gonna die here.' Obviously I couldn't for a week but, then I went home and my GP was very good and he came, I was very ill. He nursed me at home; he put a drip up for me because he knew I would not go back there. I would rather have died at home then haven got back there because I felt so unsafe.' (Gabrielle, interview participant)

Theme 3. Willingness to engage in the novel intervention

All the participants in this study have been briefed about mindfulness-based interventions as well as ACT. In addition, they were also given the opportunity to ask questions and get further clarification from the main researcher. While some of them had some knowledge and practised mindfulness, no one was familiar with the ACT model. One of the participants shared that she previously trained in Meditation and supported the idea of engaging in mindfulness practice as in her view 'mindfulness is an empowering practice'.

'Mindfulness, I think, should be for everyone, because if people were mindful about what they were doing we would never be in the mess as a society that we do. But most people are wondering around unconscious of what they are actually doing. [...] I think Mindfulness is an empowering practice, not a disempowering practice. But I think it needs to be approached and suggested in a very careful way to people, as an adjunct to management.' (Gabrielle, interview participant)

Similarly, Joanna mentioned having practised mindfulness before having back pain but not recently. She also suggested that mindfulness could be useful in managing pain and that she was willing to engage in a mindfulness-based intervention should there be one available.

'I have done Mindfulness before my problems actually started, more for being more present. I haven't actually practised it since I've been having my back problems so ... hmm. I think if you have a problem in your body that is bothering you, it really does help. More emotionally I used it, not so much for physical pain but I'll give it a go.' (Joanna, focus group participant)

On the other hand, Riley expressed that he was not familiar with mindfulness and wanted to engage with it since it was something novel for him.

'The Mindfulness is one I haven't tried so I would be interested in looking at that more, but I think most other things I did try...' (Riley, focus group participant)

Similarly, Richard argued that despite being unable to fully grasp the connection between mindfulness and pain he was interested in engaging with a novel mindfulness-based intervention as an alternative to ongoing treatment.

'I think it's interesting and helpful. I can't see the immediate connection to pain discomfort but I am sure there is one. I would be interested in trying something new; if I can I would rather not continue on a long course of Osteopathy or something *like ongoing treatment.*' (Richard, focus group participant)

Simon emphasized that he would need to have more information before engaging in a novel intervention, and also that it would have to fit well within his schedule.

'Actually, the money is not the issue, it's the time. So, yes, probably but until I *know more about that.*' (Simon, interview participant)

The only participant who showed reluctance towards an intervention based on mindfulness or ACT was Charlotte. Despite her tactful answer, she wanted to get across her distrust in the intervention being effective. She also added that receiving counselling was not something she would be comfortable with due to previous experience.

'I am sure that it is effective for some people. I think it can be effective to a certain extent. I am trying to be diplomatic really, I don't think it's effective so ... I don't want to be offensive. I think it depends on the severity of your pain.' what's involved, then that's my caveat. [...] I have experienced counselling and I'm very uncomfortable with it. I'm fine delivering it but I don't like receiving it.' (Charlotte, interview participant)

This study set out to increase our understanding of persistent pain while also informing the development of a novel intervention by providing an insight into people's experiences of living with pain. The analysis resulted into three major themes that represented participants' perception of the pain's complex and multifaceted nature, their different experiences with pain management and navigating the healthcare system and also their views on a novel intervention based on mindfulness and ACT (see figure 5.3). Pain seemed to impact participants' lives in different ways, by leading to changes in self-perception, influencing their ability to perform daily

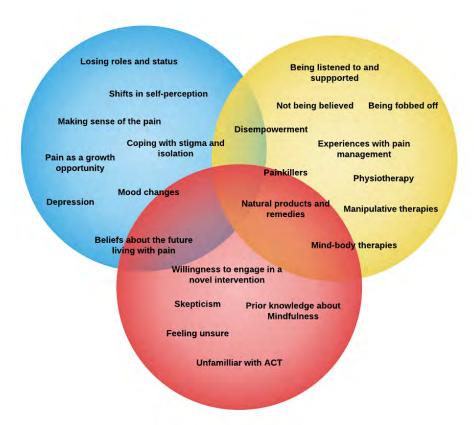


Figure 5.4: Diagram illustrating participants' experiences of living with pain and their views on a novel intervention

activities, contributing to stigma and isolation but also helping them develop more compassion towards self and others.

Study 2 - 'A qualitative inquiry into osteopaths' 5.4 perspectives on their professional identity and their personal views on treating people with persistent pain'

Introduction to the second qualitative study

The current understanding of Osteopathy comprises an approach to healthcare based on the principles of interrelatedness between the structure and the function of the body, the innate ability of the body for self-healing and on adopting a whole-person approach to health mainly by practising manual treatment (New European Standard for Osteopathy Services, 2016).

Although osteopaths' professional knowledge, beliefs and guiding values have been addressed theoretically and investigated in relation to clinical practice, there is little research on the osteopaths' views on their own profession and how these translate into their practice (Tyreman, 2008; Lucas and Moran, 2007). A recent qualitative study employing grounded theory set to explore registered osteopaths' professional identities, views and conceptions of osteopathy in the UK and revealed that the participants interviewed held different views in relation to their practice of Osteopathy (Thomson et al., 2013). This heterogeneity in professional identity might explain the differences in the osteopaths' approach and decision-making. The authors suggested that the process of identifying an epistemology of Osteopathy through research is essential to the development of the profession.

Furthermore, a study commissioned by the General Osteopathic Council (GOsC) to explore the perceptions and expectations of the general public and osteopathic patients concluded that the participants were generally positive about their experiences and treatment (GOsC, 2014). However, the study also found that many of the respondents had a vague understanding of Osteopathy and the osteopathic standard of practice. There was a sense that osteopaths sat separately from the NHS, which may have contributed to a decreased trust in the profession compared to other professions embedded within the healthcare system. Despite the usefulness of these findings, this research had a limited scope and scale.

The most commonly encountered health concerns that osteopaths are faced with in their practice are back pain, shoulder and neck pain as well as non-specific musculoskeletal issues (Johnson et al., 2002, Fawkes et al., 2014). The understanding and management of pain has shifted from the traditional biomedical model to a more inclusive and holistic biopsychosocial model that acknowledges the role of the psychological and social context in the development and management of persistent pain. Although osteopaths have moved to adopt an approach consistent to the biopsychosocial framework, there are several challenges related to the implementation of this model in clinical practice (Singla et al., 2015; Synnot et al., 2015). A qualitative study based on interviews with a sample of Italian osteopaths suggested that the osteopaths taking part in the study presented a lack of knowledge and skills to address the psychosocial factors relevant in the management of long-term pain (Formica et al., 2018). This might have important implications in terms of education and training, for osteopaths to develop a better awareness of the psychosocial factors contributing to persistent pain. This may translate into an increased understanding of the pain experience and the context in which pain occurs, as well as enabling them to support patients more effectively (Saracutu et al., 2017).

Finally, in the endeavour to advance our current understanding of persistent pain it is crucial to explore the experiences of osteopaths who support patients living with long-term pain. Ultimately, this will contribute to a better account of the underlying dynamics of pain management from an osteopathic point of view and perhaps gain a better awareness of the mechanisms behind the osteopathic approach to pain.

Rationale

In order to improve the current understanding of persistent pain, it is crucial to explore the experiences of health professionals working with people who live with this condition. The complexity and pervasiveness of persistent pain poses significant challenges, not only to health professionals working in primary care but also to manual therapists such as osteopaths who have direct contact with this population. Consequently, osteopaths are required to acknowledge and respond to the multidimensional nature of this complex biopsychosocial phenomenon. Understanding their views, experiences and interactions with individuals living with persistent pain can provide valuable insights into the role of osteopathy in the management of long-term pain and their professional development needs.

Aims

This study aimed to gain an insight into osteopaths' experiences of treating people who live with persistent pain as well as exploring their acceptability and willingness to engage in training to provide them with the necessary skills in order to deliver a brief psychosocial intervention. This is in line with the MRC framework for developing complex interventions that recommends not only an assessment of needs but also an examination of current practice and context (Craig et al., 2008). In order to develop an intervention to accompany Osteopathy, it is crucial to gain an understanding of current osteopathic practise and context while exploring osteopaths' experiences and beliefs related to treating people who live with long-term pain.

Method

Design

The study employed a qualitative methodology, with data being collected through a focus group and analyzed by using Thematic Analysis (TA). The focus group methodology was specifically well suited for this study, as it facilitated generating information on osteopaths' collective views and the meanings underlying their perspectives. Not only did this enable spontaneous ideas emerging from the interaction but it also contributed to the richness of the data. The thematic analysis followed a data-driven approach, with themes emerging directly from the data using inductive coding.

Participants

The participants recruited for this study were working as lecturers and clinical tutors within Swansea University's Osteopathic Clinic. All of the osteopaths taking part were registered with the UK statutory Register of Osteopaths and some of them were practising in their private clinics as well as within the university's Osteopathy clinic. The inclusion criterion for the participants consisted of: having practised Osteopathy for a period of minimum 6 months and being willing to discuss and give examples of treating people living with long-term pain.

The participants in this study were representative of osteopaths practising in the United Kingdom: there were almost equal numbers of females and males (five males and four females), aged between 31 and 50, coming from different backgrounds but holding professional qualifications in Osteopathy. According to General Osteopathic Practice Survey (2007), there were 5,358 osteopaths registered in the United Kingdom in 2007, of which 2,637 were male and 2,721 were female. There were 141 osteopathy practices in Wales, similar to Scotland (156) and much less than England (4,596) (General Osteopathic Council Practice Survey, 2007).

Recruitment

The osteopaths within the university's clinic were sent an invitation letter together with an information sheet and a consent form (see appendix A.7). They were also provided the necessary details in regards to the time, date and location of the focus group two weeks in advance. Nine of the osteopaths expressed interest to take part and returned the signed consent

form. Ethical approval was granted from the Research Ethics Committee within the College of Human and Health Sciences to conduct this study (more detailed information about the ethical considerations can be found in the Methodology chapter).

Focus group

A focus group was conducted in June 2016 in a noise-free meeting room within the College of Human and Health Sciences (CHHS) at Swansea University. The focus group lasted approximately one hour and fifteen minutes. The main researcher moderated the focus group discussion and another researcher assisted with technical support and took notes in regards to non-verbal cues. The focus group was audio recorded.

The focus groups discussion was be guided by means of a topic guide (see appendix A.8), containing both broad and more specific open-ended questions in relation to the osteopathic profession and the experiences of treating people living with persistent pain. When designing the questions, consideration was given to existing literature in regards to the most prevalent issues that people living with long-term pain are experiencing. Due to time constraints, it was not possible to introduce participants to ACT and Mindfulness, as in the previous study. However, several of the participants shared that they came across ACT and Mindfulness previously. Others expressed the contrary, as they have not been previously exposed to the ACT model.

Data analysis

The interaction between the moderator and the participants was recorded and then transcribed verbatim. The transcript served as the primary text and was first read several times by a team composed of the main researcher and two other researchers The researchers first familiarized with the data in order to gain theoretical sensitivity, and then went on to manually assign codes the text. This process was data-driven and followed an inductive approach.

Thematic analysis (Braun and Clarke, 2006) was the preferred method as it was considered well suited to elucidate the concept of persistent pain from an osteopaths' perspective and explore lived experiences treating people with long-term pain. The analysis has followed the same steps as the first study looking at experiences of people living with pain (see the first part of the current chapter). Following the familiarization and the coding stages, the three researchers came together to discuss the codes and check for accuracy and consistency. Related codes were then grouped together to form themes and quotes from the text were used to support the emerging themes (see figure 5.4 and table 5.5). Subsequently, the themes were refined and vetted by the team members, giving consideration to the overall narrative of the analysis. After a debriefing session, the team reached a consensus in regards to the final version of the themes and subthemes. A report was produced that contained a coherent account of the data and also supporting quotes from participants. Personal data was annonymised and the participants' names were replaced with pseudonyms.

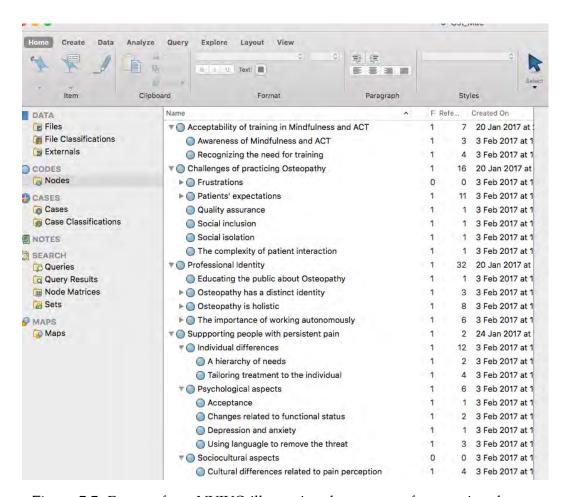


Figure 5.5: Excerpt from NVIVO illustrating the process of generating themes

Theme	Subtheme	Supporting quote
Osteopaths' attitudes towards training to deliver ACT This theme illustrates the acceptability of ACT training and osteopaths' perceptions in regards to delivering a novel intervention	Acknowledging the need for additional training	Bianca: 'Are we trained enough to deal with psychological aspects of a patient's care? I think what we tell them is going to affect many aspects of their life and are we going to influence them in a good way, in a bad way or have no influence whatsoever?'
	Working within the boundaries of Osteopathy	Sophie: 'I was going to say that in a way it's down to every individual practitioner and their experience. For myself, I am trained as an osteopath and prior to that, I had training as a Master neurolinguistic programmer. Post Osteopathy, over the last twenty years, I have added acupuncture so I've sort of increased the depth and the width of my expertise and within that expertise, there is a recognition that if it's going into somebody else's department, then the patient goes there. Ultimately I am an osteopath.'

Table 5.5: Working example illustrating the coding framework applied to the data

Findings

Out of the twelve invitations sent, nine received a positive response. The main reason for not being able to participate was lack of availability on the day selected. The osteopaths taking part in the focus group were all based within Swansea University and fulfilled both an academic and a clinical role. Some of them also worked in private practice. Although all the osteopaths in the group held qualifications in Osteopathy, they also had different backgrounds (e.g. nursing) and were applying their skills in different areas (e.g. working with athletes). One of the participants was trained in Neurolinguistic Programming (NLP) and Acupuncture.

Themes and subthemes

The study identified three main themes that illustrated the participants' narrative. They are presented in table 5.6. The first theme revolves around the osteopaths' perception of their own professional identity and their views on working as osteopaths in the UK, including dealing with patients' expectations and raising awareness within the general public and other health professionals about the remit of Osteopathy.

The subsequent theme is centred on the experiences of treating people living with persistent pain and acknowledging that pain is a complex phenomenon, comprising different dimensions and unique to each individual. Finally, the last theme captured the participants' attitudes towards taking part in training to deliver ACT. A complete account of each theme and subtheme, accompanied by supporting quotes from the transcript will be presented below.

Theme 1. Professional identity

'If you can't clearly articulate what you do, then that's an issue'

This category is concerned with the way osteopaths perceive their profession and the relationship between holism and clinical decision making, as well as osteopaths' reflections on patients' views and expectations of Osteopathy

Professional identity - 'If you can't clearly articulate what you do, then that's an issue'	Experiences of engaging people who live with persistent pain	Osteopaths' attitudes towards training to deliver ACT
An integrated holistic approach is central to Osteopathy	Psychological aspects of persistent pain 'Each patient is different' Chicken egg relationship —Is physical pain causing emotional pain or vice versa? Using language to remove perceived threat Putting pain into context—cultural differences and pain perception Pain relief vs. improved functioning	Acknowledging the need for additional training 'Any amount of training in something is better than none' Working within professional boundaries
Nebulous identity -'We're almost a jack of all trades'		
Working autonomously or working in isolation?		
Patients' expectations as perceived by osteopaths		
Educating the public and health professionals about Osteopathy		

Table 5.6: Themes and subthemes accounting for osteopaths' experiences of treating people with persistent pain

and the perceived need to educate the general public and other health professionals about their profession (see figure 5.6).

An integrated holistic approach is central to Osteopathy

Osteopaths referred to the integration between the mind and the body as one of the most fundamental tenets of their profession. This is presented almost in contrast with the dualistic view held by the biomedical profession that regards the mind and the body as two separated entities, and persistent pain as a physical ailment.

' I think medicine has fallen back into Cartesian dualism, the mind and the body separated, a magic bullet, 'the pill can fix it'. I think that perhaps, we, like physiotherapy, we have developed to the point that we are now embracing the mind and the body not being distinct in terms of a patient's pain experience.' (Ryan, focus group participant)

According to the focus group participants, the concept of 'holism' is central to Osteopathy as a profession; in fact, this is one of the main reasons why most of them chose this particular career pathway. This finding is consistent with the literature, suggesting that Osteopathy is built upon holistic assumptions: the unity of mind and body, the acknowledgement that the body is capable of self-healing (the ability to return to a state of homeostasis), the mutual relationship between structure and function and treatment being based on an understanding of all the above (Turner and Holroyd, 2016).

'The fact that you look at the mind and the body as one also fitted so I studied Osteopathy.' (Sophie, focus group participant)

'I thought that can make so much sense (Osteopathy) and I've always found it very logical, rather than just patching people up with whatever medication.' (Caroline, focus group participant)

'When you first see somebody and you start to realize that they are suffering from chronic pain, it's important not to just ask them: 'how bad is the pain?' but to get a lot of information on how it affects them on a daily basis, what they can do, what they cannot do.' (Bianca, focus group participant)

The participants suggested that the remit of Osteopathy is different from solely alleviating pain. In their view, osteopaths work to decrease people's suffering, and to restore them to a state of homeostasis. While the biomedical model is largely based on prescribing people medication ('a magic bullet', the pill can fix it'), Osteopaths spend more time with each individual patient and try to understand more about their case history, lifestyle and potential psychosocial factors that might have contributed to the onset and maintenance of pain.

' If you look at Osteopathy, this is maybe one of the advantages: the fact that you get to spend potentially an hour with the patient, you look at their case history, you look at how their lifestyle is contributing towards their complaint, you try to work out what their complaint is, you come to a working diagnosis, you form treatment plans and the majority of the osteopathic profession I would assume would integrate lifestyle suggestions not just hands-on manual therapy in their treatment. '[...] It depends on individuals, it depends on what you classify as chronic pain, it depends on the area of pain and it depends on their mindset and also whether you can look at them as a whole rather than just as pain.' (Chris, focus group participant)

'When you first see somebody and you start to realize that they are suffering from chronic pain, it's important not to just ask them: 'how bad is the pain?' but to get a lot of information on how it affects them on a daily basis, what they can do, what they cannot do. The more information you gain in the first place from these people, the more you can see whether the treatment had an impact.' (Bianca, focus group participant)

This is in line with the results of a study exploring the meaning of holism to Osteopathic professionals through in-depth interviews (Turner and Holroyd, 2016). This piece of research identified the osteopaths' views on holism and on the way holism translated in practice, within the context of the osteopathic encounter. According to this study, osteopaths regarded holism as a multidimensional concept including biomechanical, biomedical, biopsychosocial, energetic, environmental, and spiritual components and also importantly the relationships between all of these components (Turner and Holroyd, 2016).

Nebulous identity -'We're almost a jack of all trades'

Identifying Osteopathy's remit and epistemology is essential for its professional recognition and development. The majority of the participants expressed their frustration with having to justify themselves to the medical professionals, however, they also seemed discontented with their own profession, for lacking a clear identity and an established evidence base. They suggested that the medical profession sometimes discredits Osteopathy and regarded as a 'jack of all trades' or as dated ('dinosaurs') and this might be due to its nebulous identity. Another frustration seemed to stem from not being able to pinpoint the exact mechanisms of the osteopathic encounter and what are the elements that contribute to its effectiveness.

This aligns well with the results from a qualitative study suggesting that osteopaths held different views and conceptions in regards to their practice of Osteopathy (Thomson et al., 2014). They argued that this diversity of views might provide an explanation for the osteopaths' heterogeneity in clinical decision-making, and have important implications in terms of training at undergraduate and postgraduate level.

'And they found that osteopaths had such a higher autonomy relative to physiotherapists. So it's interesting where that comes from, that firm belief in themselves and the firm belief that they should be autonomous. Yet, a rather nebulous way of describing what their remit is, what they do and the efficacy in the *modern world.*' (Ryan, focus group participant)

'I will agree with you Ryan and I think it's about identity, and I'm not sure that us, as a profession have an exclusive identity, but we're willing to say, I think we say that we're almost 'a jack of all trades' rather than identifying ourselves as a clear therapeutic pathway.' (Dominic, focus group participant)

'I think if you're talking about hands-on Osteopathy in a clinical practice on a day-to-day basis, some of the frustrations, (it's a better word than the challenges) of having to justify ourselves to the medical profession and particular ideas that medical profession has on what Osteopathy is, where it is coming from, whether it is regarded as dinosaurs by some GPs, for example, as I know of.' (Benjamin, focus group participant)

'Despite trying really, really hard, I don't think I really know what is effective from all that complex interaction. I think that is one of the most frustrating things about being an osteopath, it's very hard to distil down what am I doing that it's actually helping this person from this very complicated half-hour or one-hour interaction.' (Thomas, focus group participant)

'I completely agree about identity and clearly articulating and being able to identify what an osteopath is. [...] This is an educational issue and if you can't clearly articulate what you do, without using the word "articulate" in Wales (laughter) then that's an issue.' (Chris, focus group participant)

Working autonomously or working in isolation?

For osteopaths, being able to work autonomously seemed to play a crucial role, first of all in deciding to train in this profession, but also afterwards, when drawing comparisons with other health professionals. In addition, working autonomously appeared to be advantageous, particularly for the women in the profession, who had the flexibility to decide whether to work full-time, part-time or take time off and therefore ensure a better work-life balance. Furthermore, qualifying as an osteopath also translated into being able to work in different settings (private practice, multidisciplinary clinics, academia).

'But then I found about Osteopathy and it allowed me to work in an autonomous way which I found more appealing and I thought it was exciting and kind of interesting, the idea of figuring out what was actually wrong with the person. [...] And they found that osteopaths had such a higher autonomy relative to physiotherapists. So it's interesting where that comes from, that firm belief in themselves and the firm belief that they should be autonomous.' (Ryan, focus group participant)

'I picked Osteopathy as a woman, one day when I will have kids, it would be great to be able to have, you know, the ability to gain income but not have to leave my children so much, work part-time... At the moment I work part-time in the university, and part-time in a private clinic as a part of a multidisciplinary clinic, with lots of different types of therapists. You can work with different types of people, with different ages, different backgrounds so it's exciting as well.' (Danielle, focus group participant)

Although autonomy can seem to be advantageous at a first glance, it may also present drawbacks. Most osteopaths work independently, in small practices and are often isolated from one another and from other health professionals. In these circumstances, the opportunity to reflect on their practice, share insights and feedback contributing to their professional development may be limited. In addition, this might have a negative effect on osteopaths' social abilities. Equally, this might also present challenges in

terms of quality assurance. The osteopathic profession may find it difficult to ensure that all the osteopaths maintain the same quality standards, regardless of their background, location or other factors. This is illustrated in one of the participants' narrative:

'The majority of osteopaths work privately so you have the private practice, and linking it with what Ryan said and adding to that, is also quality assurance. There are a lot of osteopaths working in private practice but to standardize their approach, that's very difficult, that's a challenge, to ensure that we're all operating at the same level and the same standards. There is good and bad in everything. I think you need clear guidelines to ensure that you if you see one osteopath you get the same care as if you see another one. And then the social aspect of being an osteopath, because working by yourself for many years is a challenge. You are expected to have social skills, to be able to interact with people, yet you don't socialize with the people you work with, because they are your patients, unless you work in multidisciplinary clinics, and I think it's a challenge for the majority of people in private practice, especially in rural areas that they go away from the profession because of literally just working by themselves.' (Chris, focus group participant)

Patients' expectations of Osteopathy as perceived by osteopaths

Existing literature suggested that individuals who seek treatment within complementary and alternative medicine have done so out of personal belief, they were frustrated with the treatment received within the mainstream or were simply looking to find the most effective approach (Furnham and Vincent, 2000; Bishop et al., 2007). The osteopaths taking part in the present study expressed several views consistent with this finding. First of all, most of the participants agreed that in their experience, patients they treated were seeking merely 'a quick fix' and getting their complaint sorted promptly. Ryan suggested that 'patients are married to the outcome' and they were not at all concerned with the osteopathic philosophy. On a similar note, Caroline argued that Welsh people were not willing to pay for healthcare and expected to receive a quick relief from pain. She also suggested that there might be different expectations depending on the geographical region, for example, people living in London might be focusing on prevention more than individuals from other parts of the country.

'I think we as a profession are quite gracious in the way we consider the expectations that patients have. We are concerned with having a good interaction and doing a good job. From my perhaps limited and meandering experience, I find that patients are pretty much married to the outcome. Someone is going to pay you one pound a minute, once a week that's really what they're concerned with... a 'quick fix'. I don't find patients concerned much about the osteopathic philosophy. I find that people are willing to pay you quite a lot of money for a short amount of time, they want to minimize the amount of time to actually come and see you and they want to get as better as possible.' (Ryan, focus group participant)

'In Wales, perhaps people don't feel as they should be spending money on their own healthcare and blame Aneurin Bevan for that (laughter). Yes, they want it sorted out as quickly as possible. [...] They come with the expectation of getting out of pain as quickly as they can. Even people who have known the practitioner for years and trust them will still wait and see if it gets better on its own very often, rather than getting it sorted out. Perhaps in London, somebody whose back is a bit bad will say: 'I'll nip this in the bud'. Certainly, it varies regionally and, you know, I do find it difficult because you get people out of pain and they come back, you don't get people out of pain and they don't come back (laughs) because they haven't got any faith in you. It's quite a difficult business model from that perspective.' (Caroline, focus group participant)

The interaction between patients and osteopaths may affect the outcomes of the treatment. According to Dominic, people place a lot of value on being listened to and also expect some physical manipulation from osteopaths. From his perspective, the fact that the people were able to share their story with someone who listened non-judgementally and being the recipient of hands-on therapy may have yielded positive outcomes. In this sense, the osteopathic encounter may have an added psychological effect. This is in line with a study exploring Australian peoples' expectations of osteopathic healthcare whose findings revealed that the practitioners' listening skills, professionalisms and knowledge were considered key aspects of the therapeutic relationship (Orrock, 2016). Moreover, the interviewees placed a high emphasis on being listened to and valued having a therapeutic relationship based on trust, hope and respect. They expressed their content with being considered partners or collaborators and feeling empowered to take an active role in managing their pain.

Patient education is known to play an important part of the osteopathic encounter. Sophie suggested that in her view, patients expected to be provided some information and explanation in regards to their condition, as well as the manual treatment. This is consistent with Orrock's (2016) study, where people undergoing osteopathic treatment expressed that they received not only manual therapy but also education about the condition, rehabilitation advice and also information concerning ergonomics and stress reduction.

'They expect something different. They expect ... they want someone to listen to them, so what Thomas was talking about, that patient interaction is very different from a GP consult which is, 5 minutes or even an NHS physio, which is now down to 20 minutes. So, they expect quite often more physical work, they expect you to come put your hands on, do something. And that's where I think the ones who get better get the relief from. We seem to do something by actually putting our hands on them and finally the pain will go. I think that this interaction has a lot of psychological effect on patients who get better, patients who find relief.' (Dominic, focus group participant)

'I would agree with that, but also I would say that it's that time that we can give the patient when you listen. So I think patients appreciate being heard, and being given the time to actually explain. Certainly in my way of practising there is interaction going on verbally whilst you are treating as well so there is a very psychological side to it as well, if you like. I don't know if that's the same with all my colleagues, there might be many who actually treat physically and silent.' (Sophie, focus group participant)

One of the respondents shared that the referral route was an important factor in what concerns peoples' expectations. In his view, those who selfreferred often had a better understanding of Osteopathy and what the treatment entailed compared to others who were referred by word of mouth and expected a 'quick fix'. Finally, another interviewee argued that people responded better if an achievable and realistic outcome was being set in the first place.

'I also think that is important and it all depends on how patients have come to Osteopathy in the first place. My experience tells me that if someone self-referred, they often have an idea of Osteopathy or some idea of where treatment can take them. If they heard from word of mouth they can be a little bit cautious, a little naive

and perhaps looking for a 'quick fix', where they can be fixed in one or two sessions when it's not always the case. I think it depends on the route into the treatment, in the first place.' (Benjamin, focus group participant)

'I think it goes back to patients' expectations. If you can manage their expectation or give them an achievable outcome, then you get a better response.' (Danielle, focus group participant)

Educating the public about Osteopathy

This theme illustrates osteopaths' views on educating the general public about Osteopathy and its remit. One of the focus group respondents argued that a large proportion of the society was unfamiliar with Osteopathy and that in his opinion people from affluent areas had better access to it than others from more disadvantaged regions. In his view, this was an issue to do with social inclusion, in that people who were in high need of musculoskeletal treatment might not necessarily have been able to afford it.

'This sticks in with trying to educate the population and change corporate opinions but accessing different areas of society that are not familiar with Osteopathy, five thousand osteopaths in the UK, there are only one hundred in Wales. [...] You need to look at social inclusion and Osteopathy is often geared towards affluent areas, probably middle-class areas. So if you want to educate people you need to look at social inclusion, so we need to look at how to get Osteopathy to people who may need musculoskeletal treatment but can't necessarily afford it. And then obviously how do you do this? How do you cover the costs? And then there is recognition, recognition for what it is that we do, but again this links into education, social inclusion, costs, so I think there are lots of different challenges.' (Chris, focus group participant)

This ties in with a study commissioned by the General Osteopathic Council (GOsC) in 2014 with members of the general public, aiming to explore people's perceptions and expectations of the profession as well as their level of knowledge and trust in Osteopathy (Report on focus group conducted for the General Osteopathic Council, 2014). This piece of research revealed that most of the interviewees who had previously visited an osteopath tended to hold positive views on the osteopathic profession and were very knowledgeable about its remit compared to those who had no contact with Osteopathy. In addition, those who never visited an osteopath tended to

be doubtful in regards to the efficacy of Osteopathy and its professional standing. In addition, there was very little awareness about the training that osteopaths were required to undergo as well as very little knowledge about its regulation. This reinforces the idea that there is a need for osteopaths to raise awareness about their profession and reach people from different geographical areas as well as people with lower income levels.

Theme 2. Experiences of engaging with people who live with persistent pain

This major theme reflects the nature of persistent pain, from the perspective of the osteopaths who took part in the focus group. They viewed pain as a subjective multifaceted experience that varied hugely between individuals. The respondents suggested that pain was appraised differently by individuals and also affected different life domains.

Psychological aspects of pain

Osteopaths shared that people often presented with signs of depression, anxiety, fear of pain or high levels of stress, alongside pain and physical symptoms. These issues have been overlooked or not been addressed within primary care, resulting into an escalation and increased anxiety. Chris expressed that people often became fearful that their situation was going to worsen and their quality of life would decrease.

'I have numerous examples; I have seen multiple people with chronic pain. I think it's the psychological and emotional element that maybe it is not dealt within the healthcare structure. I see lots of people who show signs of depression, I see lots of people who develop anxiety, become quite stressed. They become quite fearful that they are not going to improve and it affects their quality of life [...]. So, one of the most important things for people with chronic pain is how it impacts their overall life, not just their physical, but also their mental attitude.' (Chris, focus group participant)

'Each patient is different'

Osteopaths also emphasized the importance of tailoring their approach to fit different individuals' needs, while also being aware of contextual factors

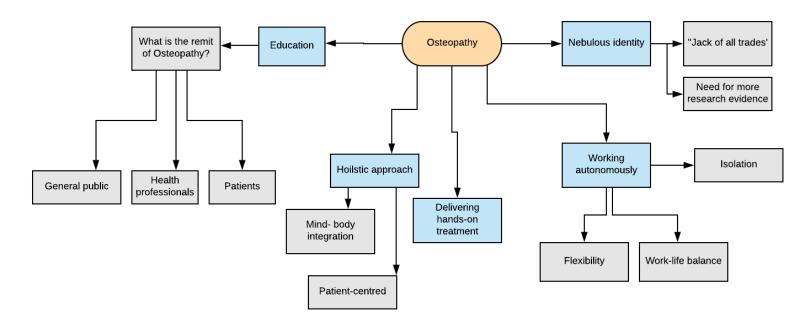


Figure 5.6: Diagram representing Osteopaths' views on their professional identity

and the way they might influence pain experience (e.g. culture, beliefs, self-efficacy). The type of pain may also play an important role in the way osteopaths treat patients (e.g. people with chronic low back pain with good self-efficacy have different needs than people experiencing neuropathic pain). In addition, the amount of support that people need varied notably: some can self-manage successfully and need minimal guidance, while others struggle and are in need of more extensive help.

'Or let's say facial pain, headaches, functional abdominal pain or the extreme of chronic low back pain. You would have to approach those very differently than your typical chronic knee osteoarthritis, especially if the patient already has good selfefficacy like Ryan already mentioned. That's very different to chronic neuropathic pain. The psychological landscape of those patients would be at two ends of the spectrum potentially.' (Thomas, focus group participant)

'That is more consistent with the chronic neuropathic pain. It is interesting that sometimes the location of chronic pain can matter, from a sort of hierarchy of needs: facial pain, someone who cannot eat is more debilitated than someone who can learn to walk or can walk ok. I always find it interesting how the low back, when it's neuropathically damaged, in some cases I've seen, has been burned with boiling oil and things like that, and the scar that forms around it, how that becomes so significant because of the context of the injury. [...] Lots of people come to you with persistent pain, which they manage quite well. They come see you for an MOT; they have dealt with it. I don't want to use fancy terms like 'self-efficacy' or 'locus of control' but if the patient at that time is dealing quite well with their pain, you are there to offer whatever support you can. Of course, like Chris says, there are other people with different substrates of fear avoidance and this sort of things.' (Ryan, focus group participant)

'Ryan also made a very valid point: it depends on what you classify as 'chronic pain' because we are looking at the extreme of chronic pain, but there are people who are in pain every day, who just have pain and don't necessarily present with other problems as well. So it depends where on the scale the individuals are with chronic pain.' (Chris, focus group participant)

Chicken egg relationship - Is physical pain causing emotional pain or vice versa?

One of the osteopaths shared a very interesting perspective on the interplay between physical pain and emotional pain:

'I think what's important as well is the 'chicken and egg'- do they develop emotional based issues with chronic pain or the fact that they have emotional problems leads to chronic pain?' (Chris, focus group participant)

The same participant acknowledged the importance of psychosocial factors and life events (such as the relationship with the partner, bereavement, moving to another place etc.) Although it is very difficult to establish the direction of causality, nevertheless it is important to recognise that these factors have an impact on people who live with persistent pain. Moreover, it is crucial to identify potential factors that could contribute to the transition from acute to persistent pain, and recognize the individuals who might be at risk.

'I don't think you can underestimate the complex relationship between pain and mental health. There was some research done about anxiety and low back pain. I can't remember the guy's name but the research was on people with chronic low back pain and it transpired that this particular individual had a long-term problem with their relationship. That problem was sorted and the low back pain went. It was presented initially as low back pain. So it's complex. I don't think we should ever forget that.' (Benjamin, focus group participant)

'I have seen plenty of people presenting with acute, six months later they find that their partner has been cheating on them and they become a chronic patient. Would they have developed that had their mental state not changed? I've seen it with bereavement, with having to move, with relationship problems. Someone can present with acute problems they can manage and once a change in their life happens, the perspective of their pain, their world changes, and then they become chronic problems. I think it's a complete spectrum and people can fall upon it, and I think different events in their lives can have a different impact on how they present with pain.' (Chris, focus group participant)

Using language to remove perceived threat

This theme illustrates the importance of the terminology used by osteopaths in their consultations and the effects that this might have on the patients. Ryan expressed that, taking time to provide appropriate explanations and using simple language that people can understand may have positive effects and remove the threat, making people less fearful of pain or their condition. In addition, he emphasized that the language used by osteopaths or other

health professionals is crucial, as it may also have negative implications and contribute to people catastrophyzing or becoming fear avoidant.

This is consistent with the results of a study conducted by Thomson and Collyer (2017), suggesting that the language used by student osteopaths influenced patients' beliefs about low back pain both positively and negatively. The results indicated that the use of metaphors and analogies, biomedical terminology, as well as evoking emotions and person-centred care all influenced the patients' perception of the language used and consequently on their level of engagement in their care.

'Fundamentally, I try to remove the threat, the perceived threat that is bothering them. You can do a lot with language and explanation, but maybe myself and people around this room are not necessary typical of the practising community because we re all working in the university and spend quite a lot of time being self-critical about what we are doing and what Osteopathy is. [...] I agree with that but I also think that we never see our failures. We seldom see people whom we made worse, and you can make people worse by suggestion, by use of language, by the terminology you *use.*' (Ryan, focus group participant)

Putting pain into context: cultural differences in pain perception

Cultural affiliation has been identified as an important factor having a significant role in the perception and response to pain. Several studies revealed that some cultures such as Hindu or Asian promote a positive acceptance of pain, as well as regarding pain as a normal inevitable phenomena (as a results of unfolding karma or the natural ageing process) (Whitman, 2007; Dickson and Kim, 2003). Similarly, research suggested that African cultural identity was bound up with a collective history of hardship and resilience, leading to a more stoic representation of pain and also a degree of scepticism and distrust towards Western biomedical interventions (Bates et al., 1993; Baker et al., 2008; Campbell et al., 2009).

The impact of culture on pain perception was mentioned by two of the osteopaths, who acknowledged that cultural affiliation and beliefs have a considerable effects on illness perception and behaviour. Sophie described an

episode involving a Kenyan woman who was a victim of street violence and who displayed a very stoic attitude to pain improvising a prosthesis made of pipe and not complaining at all about her suffering and disfigurement. Furthermore, Sophie seemed to be very surprised by the woman's attitude, portraying the woman as a very compliant and grateful patient who was also very accepting of her condition. This experience seemed to have had a powerful impact on Sophie, who became increasingly aware of the significant influence that culture has on the perception and response to pain.

'I think it's quite well established; illness behaviours are different in different societies. Limping in Australian aboriginals who have chronic low back and leg pain is almost non-existent while here it's highly common. Equally, all sorts of different illness or dysfunction, mental illness...' (Ryan, focus group participant)

'She came to see us with a prosthesis made out of a piece of pipe, and it didn't have any cup to make a gentle support, it was purely a functional appendage that she used. She wanted some help with some lower back pain. She didn't complain, she didn't talk about her pain; she didn't talk about her disfigurement if you like, and she was very accepting of anything that we could do. She was incredibly compliant as well, and the result was phenomenal. We did relatively little, in that we were able to replace that prosthesis with something much more comfortable for her. She was immensely grateful. It was interesting, that the concept and that perception of pain were very different in that society than it is here.' (Sophie, focus group participant)

Pain relief vs. improved functioning

Participants identified two patterns they encountered in their practice: one in which a patient receiving osteopathic treatment for a certain condition experienced notable improvements in their ability to perform everyday activities (such as walking or having dinner out with their family) despite the pain remaining the same and another where a person with the same condition exhibited a similar level of physical symptoms and dysfunction but experienced significantly less pain. Bianca argued that it is essential for osteopaths to gather information not just about the nature of the pain but also about the different ways pain influences peoples' quality of life and their treatment goals (whether they focus on improving functional abilities or they aim for pain reduction). Similarly, Thomas gave the example

of patients living with temporomandibular joint disorder, who despite exhibiting similar dysfunction experience varying levels of pain and different levels of functioning.

'When you first see somebody and you start to realize that they are suffering from chronic pain, it's important not to just ask them: 'how bad is the pain?' but to get a lot of information on how it affects them on a daily basis, what they can do, what they cannot do. Somebody might say that, when they go out for dinner with their family they cannot sit down for half an hour without being in agony, so you get a lot of information on those particular factors and then, over time you notice that actually they might be able to sit down for an hour now, or they might be able to walk for longer. The more information you gain in the first place from these people, the more you can see whether the treatment had an impact. Their pain might still be as bad as it was before, it might not have improved very much but perhaps what they can do has improved quite significantly, either through educating them or through hands-on treatment.' (Bianca, focus group participant)

'Outcomes can vary a lot. You can measure an outcome based on an easily measurable qualitative change, and that might improve yet their pain and function in daily activities remain very poor. I have seen many patients with temporomandibular joint disorder, which is very similar to lower back pain, except it's in the jaw. You can have some patients who have excellent improvements in the biomechanics; they've been doing exercises. They improve their range of motion, all sort of mechanical improvements, yet their pain is still severe or worse even. And there are other patients who have the same level of dysfunction qualitatively in the jaw, but then their pain is reduced massively. It's very difficult to understand what's the difference between those two types of patients. That is probably the same with musculoskeletal problems, you can see an objective improvement in a joint or whatever but the pain remains severe and vice versa, someone can have a lot of physical manifestations of problems but the pain is reduced.' (Thomas, focus group participant)

The osteopaths portrayed persistent pain as a multifaceted phenomenon influenced by the cultural context of the patient, psychological and social factors, the approach and language used by osteopaths to explain pain and remove the perceived threat and their ability to tailor the treatment (see figure 5.6). They also recognize that outcomes may vary significantly between different individuals with some focusing on improving their ability to perform valued activities while others emphasize pain relief.



Figure 5.7: The different dimensions of pain as conceptualized by osteopaths

Theme 3. Osteopaths' attitudes towards training to deliver ACT

Acknowledging the need for additional training

One of the recommendations outlined in the Osteopathic Practice Standards states that osteopaths should use their professional judgement in order to evaluate whether they have the training and competence to treat a patient or whether they need to seek advice or refer the patient further (General Osteopathic Council, 2018). One of the osteopaths taking part in the focus group suggested that 'any training in something is better than none', simultaneously acknowledging the impact that osteopaths can have on patients through the language they use. Similarly, Bianca expressed that she was unsure whether osteopaths had the necessary training to deal with the psychological aspects of patients' care. She also acknowledged that the message communicated by osteopaths had a significant influence on many aspects of people's lives, and may affect them in different ways.

'We seldom see people whom we made worse, and you can make people worse by suggestion, by use of language, by the terminology you use. You can make people decidedly worse. And I think that any amount of training in something is better than none.' (Ryan, focus group participant)

'Are we trained enough to deal with psychological aspects of a patient's care? I think what we tell them is going to affect many aspects of their life and are we going to influence them in a good way, in a bad way or have no influence whatsoever?' (Bianca, focus group participant)

Working within professional boundaries

This theme reflects some of the respondents' views in regards to working within the limits of their own profession. One of them suggested that allowing patients to share their thoughts and feelings and 'take things off their chest' is part of being an osteopath. In his view, osteopaths need to make a judgement about whether the patient might benefit more from being listened to than having the manual treatment.

'I do think it's a judgment call because you can treat patients by simply allowing them to get things off their chest and ... You can treat someone for fifteen minutes by just allowing them to speak and they feel better for it, without any hands-on treatment at all, so it's a judgment call when it comes to treating someone who has mental health issues.' (Benjamin, focus group participant)

Furthermore, another osteopath suggested that despite being familiar with different psychological approaches, he chose not to apply them, instead providing patients advice or referring them to someone more appropriate. Sophie shared a similar view by suggesting that despite having added NLP and acupuncture to her skill set, she was ultimately an osteopath. In addition, she agreed that it was down to the osteopaths to make a judgment about the most appropriate treatment, based on their professional experience. Sophie also reinforced the idea that it was best to refer patients to someone else in case a situation would have presented that was outside her area of expertise. These views are consistent with the Osteopathic Practice Standards suggesting that osteopaths should work collaboratively with colleagues and other health professionals in order to secure the most adequate care for the patients or refer them appropriately (General Osteopathic Council, 2018)

'We talk about mindfulness, NLP, CBT, ACT, Motivational Therapy. I probably have read books on all them, and probably more than one book. Do I apply them? No. Do I advise patients? If I think it's beneficial to them, yes. If I thought that their needs were greater than my ability and I was digging myself a hole, and causing patients problems then I refer them to the appropriate person. ' (Chris, focus group participant)

'I was going to say that in a way it's down to every individual practitioner and their experience. For myself, I am trained as an osteopath and prior to that, I had training as a Master neurolinguistic programmer. Post Osteopathy, over the last twenty years, I have added acupuncture so I've sort of increased the depth and the width of my expertise and within that expertise, there is a recognition that if it's going into somebody else's department, then the patient goes there. Ultimately I am an osteopath.' (Sophie, focus group participant)

To sum up, osteopaths in this study held a range of different views in relation to their experiences that were characterized by three major categories: professional identity, experiences of engaging people living with persistent pain and osteopaths' attitudes towards training to deliver ACT.

Summary of Chapter 5 5.5

This chapter provided an exploration of pain, both from patients' and Osteopaths' perspectives, which was useful in informing the development of the intervention. The patients' experiences are represented by three main themes: pain is multidimensional 'hall of mirrors', 'experiences with pain management and acceptability of novel intervention. The themes resulting from the focus group with the osteopaths revolved around professional identity and maintaining a holistic approach, but also around challenges they face in their practice treating people with different pain conditions.

The findings of this preliminary qualitative inquiry contributed to informing the novel intervention. A detailed account of how the patterns and themes emerging from the participants' accounts lead to decisions regarding the components of the novel intervention will be presented in Chapter 6 (see section 6.2 Informing the development of the novel intervention and Section 6.2.9 Basis for the novel intervention).

6.1 Overview of the chapter

This chapter will describe the process of incorporating the results from the first study (determining the needs and experiences of people experiencing long-term pain) with the results of the systematic review and existing theory and research literature to inform the development of a novel intervention. The chapter will also describe the protocol and procedures relevant in piloting 'A Mindful Act'. Following a preliminary qualitative study that explored the experiences and needs of people living with persistent pain as well as the experiences of osteopaths who treat people with pain, the next phase of the project was to develop a brief ACT-based psychosocial intervention. This was delivered to a group of people from Southwest Wales who lived with persistent pain and psychological comorbidities (e.g. depression/ anxiety) or maladaptive coping strategies (e.g. catastrophyzing). The results obtained from the focus groups and qualitative interviews (see chapter 5), together with the results of the systematic review (see chapter 3) and relevant research literature (chapters 2 & 6) have informed the development of the intervention.

This chapter will provide an account of the steps taken in shaping the intervention, as well as a description of the protocol that was followed in piloting the program and assessing its feasibility and acceptability. A paper was published in 2018 based on the protocol for 'A Mindful ACT' (see appendix A.7), parts of which will be presented in this chapter.

6.2 Informing the development of the intervention

6.2.1 Persistent pain and its impact on 'self'

Some patterns were identified in the narrative of people living with persistent pain who took part in the focus group, mostly surrounding a shift in self-concept as a result of living with pain and a constant struggle with eliminating pain that was causing a great deal of suffering, preventing them from engaging in valued activities and living a normal life (see chapter 5, section 5.3).

A person's identity is fundamental when it comes to their wellbeing (Rogers, 1961). Identity is strongly connected with personal traits, social roles and characteristics that define people and provide them meaning and orientation. People often perceive pain as a threat to their identity and try to defend or hold onto their 'real me' (Toye et al., 2013). Persistent pain often contributes to changes in one's physical and psychological integrity, therefore impacting on who a person is and who they might be in the future (Crombez et al., 2003). People make great efforts to preserve their self-image, which may explain why they engage in attempts to avoid or eliminate pain.

Participants living with persistent pain in the focus group study experienced a shift in self-perception: from being independent and strong to dependent and vulnerable individuals.

'My identity has changed, from seeing myself as a very physically strong, energetic nurse, taking care of people who are vulnerable and so forth to seeing myself as being someone who is not robust, not strong, not physically capable. I has made me feel weak and I don't like it' (Charlotte, interview participant)

Another effect of living with pain was a loss of roles and equally a decreased familiarity with their previous self.

'Oh, who are you? Then you say 'I'm this or that' and then to be nothing at all, you *know...'* (Gabrielle, interview participant)

Participants acknowledged that they became defined by pain and also by their limitations and inability to perform the tasks they used to before. They appeared to struggle with their 'new self with pain' and go to great lengths to revert to their 'old self without pain'. Furthermore, they also mentioned a lack of self-compassion and an inclination towards self-criticism

'I have much more compassion for people now than I did when I was working. I was always compassionate but not as I am now, you know. I had no compassion for myself then, I was a very hard taskmaster of myself.' (Gabrielle, interview participant)

Recent developments that include self-related processes as a therapeutic focus are based on mindfulness (Carmody et al., 2009), self-compassion (Neff, 2004) and the psychological flexibility model (Hayes et al., 1999; McCracken and Morley, 2014). These developments might represent a significant opportunity for supporting people who live with long-term pain.

The Psychological Flexibility model (Hayes et al., 2006) 6.2.2

According to this model, 'self' is conceptualized along three dimensions: self as content (identifying the self with one's psychological experiences- 'I am my thoughts and feelings'), self as process (ongoing awareness of one's thoughts, feelings, sensations) and self as context (separation or de-identification with one's psychological experiences, being more than merely a sum of one's thoughts and feelings) (McHugh, 2015). Self as context can be explained as a perspective that can be taken, one that includes a distinction between 'self' and 'experiences', a sense of self as a 'container of thoughts and feelings' or 'a place where thoughts and feelings occur'. Enabling a 'self as context' has the potential to help people shift their paradigm, from identifying with their psychological experiences ('I am disabled'. 'I am vulnerable', 'I am dependent') to taking a step back and detaching themselves from their thoughts and feelings. From a psychological flexibility point of view, becoming over-attached to 'self as

content' may lead to avoidant behaviour, while 'self as context' alongside an awareness of ongoing experience ('self as process') can facilitate more effective and engaged behaviour patterns and also a better ability to engage in behaviour guided by goals and values. The awareness that phenomena as thoughts, feelings, sensations, memories are merely content that continuously change and that does not constitute the essence of a person can help people see themselves as a 'context', a continuous and stable consciousness from which phenomena are experienced. Developing this new perspective has the potential to help people become aware that perhaps they were identifying themselves with something that was only part of their identity and experience (e.g. 'I am in pain' may be associated with 'I am pain' and become maladaptive while 'This is me thinking that I am in pain' can prove helpful in separating the person from their thoughts).

6.2.3 Self-compassion

Previous research suggests that self-blame, negative self-evaluation and self-criticism has been associated with higher levels of pain and psychological distress (Gil et al., 1990; Williams and Thorn, 1989). A solution for this can be self-compassion, defined as a strategy where unpleasant feelings are approached with mindfulness, self-kindness and common humanity (Neff et al., 2005). This strategy encapsulates being open to one's suffering rather trying to avoid it, and being willing to alleviate the suffering with kindness (Neff, 2003). The three components of self-compassion (self-kindness, mindfulness and common humanity) promote a kind and straightforward attitude towards self that may lead to a more adaptive strategy to manage difficult emotions and challenging experiences (Neff, 2003). Previous research showed that self-compassion could enable people living with persistent pain to better adjust to their condition and experience less pain catastrophyzing and disability as well as higher positive affect (Wren et al., 2012). Similarly, Costa and Pinto-Gouveia

(2011) suggested that there was an association between self-compassion and pain acceptance, where self-compassion enabling people living with pain to continue engaging in daily activities. Self-compassion was also related to lower anxiety and depression (Costa and Pinto-Gouveia, 2013).

6.2.4 The relationship with pain

The function of pain is to promote health and integrity, by distinguishing between harmful and harmless situations and prompting avoidance of dangerous stimuli that could contribute to tissue damage, thus increasing one's chance of survival (Damasio, 1994). The issue is that, when it comes to long-term pain, numerous failed attempts to avoid or eliminate the pain lead to a high amount of suffering (Hayes et al., 2012). People experiencing persistent pain often become absorbed by the struggle to eliminate or control pain and may not be aware that while caught up in this endeavour, their focus suffers a shift from pursuing their values and living a meaningful life to engaging in attempts to 'get fixed' and return to their 'previous self'.

'In fairness, I would like something to keep me going a bit longer, so that I can do more of the things that I used to do before I had to stop' (Samantha, interview participant)

Most of the participants expressed that they have been living with pain for more than ten years, and tried a variety of different therapies and modalities to eliminate pain and gain back control, with limited success. Pharmacological management (painkillers, NSAIDs, anti-inflammatory drugs) appeared to have had reduced effectiveness long-term and was accompanied by side effects. Physiotherapy also seemed to yield limited effectiveness long-term. One of the participants shared that he performed the exercises recommended by the physiotherapist for a while, then forgot to do them and had no follow-up. Similarly, other participants found it difficult to do the exercises on her own, mostly because of the pain felt when stretching her joint beyond the limit. Other treatments include

Occupational therapy, Osteopathy, Massage, Acupuncture, Yoga, herbal remedies, hyperbaric oxygen therapy, hydro dilatation. This illustrates well participants' arduous efforts to keep pain under control. The underlying message is, in this case, is to get rid of the pain at any cost and this tendency is strongly embedded in our culture (Deurzen, 2008). According to Deurzen, our whole civilization is 'being centred on the idea that we should avoid effort and pain as much as possible' (Deurze, 2008, p.73). Moreover, this idea is also present in the work of several scientists and philosophers (e.g. Denis Diderot, Julien Offray de La Mettrie, Marquis de Condorcet, Jeremy Bentham, John Stuart Mill) who stated that the fundamental origins of human activity were centred on the search for pleasure and the avoidance of pain (Sørensen, 2010). However, empirical research revealed that numerous futile attempts to identify the causes of pain and obtain pain relief might lead to depression (Blair et al., 2003, Arnow et al., 2009). One of the participants expressed that pain stopped her from doing the things she used to do before, which made her feel depressed

'In fairness, I would like something to keep me going a bit longer, so that I can do more of the things that I used to do before I had to stop. I found it very depressing' (Jane, interview participant)

Furthermore, another participant suggested that she was fearful of the future and her situation deteriorating, leaving her unable to cope ('I'm hoping that it won't be as bad as it is now because it's quite scary. I live on my own and I think: ' If this carries on, I have to move, the steps, I've got lots of steps', you know and so I won't be able to do it in a years' time', Joanna). This indicates a tendency towards catastrophyzing and avoidance. In direct contrast with this perspective is regarding pain as an opportunity to learn something new about one's own self and being more compassionate. One of the participants in the focus group shared this unique viewpoint, describing pain as an embodied experience rather than an unwanted phenomenon. Pain was depicted as a 'teacher', an experience through which the individual

surrenders instead of escaping leading to growth and positive transformation

'So, I've really designed this illness to be a growth experience rather than a victim of circumstance, you see ' (Gabrielle, interview participant)

Furthermore, this approach to pain denotes acceptance and empowerment.

6.2.5 Acceptance and Commitment Therapy (ACT)

Stemming from the functional contextualism (Biglan and Hayes, 1996; Hayes, 1993; Hayes and Brownstein, 1986; Hayes, Hayes, and Reese, 1988), ACT is supported by empirical research, demonstrating reductions in pain and improvements in functioning and offering an important avenue for people experiencing long-term pain (Hayes, Strosahl and Wilson, 1999). Instead of avoiding, denying and struggling with their emotions, people learn to accept that these responses should not prevent them from living a value-driven life. With this understanding, people begin to accept their challenges and develop willingness to develop behaviour patterns in line with their goals and values regardless of hardship.

The theory behind ACT is based on the idea that trying to control painful thoughts and feelings and suppress them is not only futile but ultimately leads to more distress and suffering. ACT proposes an alternative based on mindfulness, cognitive defusion, identifying personal values and committing to action consistent with meaningful goals to increase psychological flexibility (see figure 6.1). In this model, acceptance is seen as a moment-by-moment process of embracing experience without trying to alter either its form or frequency, particularly when doing so is harmful from a psychological point of view. Acceptance in the context of pain refers to renouncing the struggle and learning to live a meaningful life despite the pain. A study examining changes in the processes of psychological flexibility following and ACT-based interdisciplinary program for people living with persistent pain revealed that pain acceptance was the variable with the greatest significant improvement pre-post test that was also maintained at follow-up (Scott et al., 2016). Furthermore, correlational studies suggested that acceptance is linked with better physical, social and emotional functioning (McCracken, 1998; McCracken and Eccleston, 2003; Viane et al., 2003). Developing acceptance is not the end goal but considered a method of achieving greater flexibility. Also, acceptance plays a vital part in the process of adjusting to pain (McCracken and Eccleston, 2003).

Cognitive defusion is a process by which people distance themselves from their thoughts, and become unstuck by engaging in direct sensory experiences, without being dominated by the literal content of the thoughts (McCracken et al., 2014). People are taught to notice their thoughts without feeling compelled to act on them or believing they are true. Defusion is in direct opposition with fusion and it encapsulates different techniques (Thank your mind, Silly voices, Sing it out) that help people step back and watch their thoughts (e.g. 'I am never going to get better' becomes I am having the thought that 'I am never going to get better'). Defusion diminishes the literal impact of language and facilitates acceptance through a decreasing the effect of negative evaluations (they are taken less literally). In addition, it contributes to decentring by decreasing the attachment to a conceptualized self (e.g. 'I am anxious', 'I am useless').

Another central process of ACT is contact with the present moment or mindfulness. Mindfulness had been defined in multiple ways: as 'paying attention in a particular way: on purpose, in the present moment, nonjudgmentally' (Kabat-Zinn, 1994, p. 4), as being 'actively engaged in the present' (Langer, 2000, p. 220) and 'the self-regulation of attention' (Bishop et al., 2004). This concept entails focusing the attention on the 'here and now', and being in contact with internal sensations, thoughts and emotions as well as external stimuli (sounds, smells, sights and touch) as a conscious human being, distinct from the content being noticed. Previous research has identified

some mechanisms explaining the effects of mindfulness meditation on pain. One of these mechanisms is based on decreasing cognitive control and increased sensory processing in the brain leading to the attenuation of pain (Gard et al., 2012). Furthermore, functional magnetic resonance imaging studies revealed that meditation contributes to less pain activation in the contralateral primary somatocortex and also leading to a decrease in pain intensity through activating the anterior cingulate cortex, thalamus and insula, regions responsible for pain processing (Grant et al., 2011; Zeidan et al., 2012). Mindfulness meditation may also modulate pain perception, pain memory and emotional responses to pain by reducing prefrontal cortex activity as well as a leading to less activation of the hippocampus and amygdala (Grant et al., 2011). In addition, mindfulness has the potential to help people connect with their pain rather than trying to eliminate it. Through a better body awareness and self-regulation, increased selfcompassion and flexibility, mindfulness might aid people to let go of the struggle and to make space for pain in their lives while diverting their attention to living consistent with their values.

The participants in the focus group study expressed curiosity and interest in mindfulness, given that it was something novel, that they have not experienced previously. One of the participants expressed that he was unsure about the link between mindfulness and pain but that he interested in learning more.

One important ACT tenet is values. They have been defined as the basis of how people chose to live their lives by providing them with direction (Hayes et al., 1999). Although values and goals are related, they are nevertheless two distinct things. Goals are objectives of a valued life. They are attainable outcomes or stepping- stones (e.g. securing employment) towards valued directions (e.g. work). People living with long-term pain tend to occupy more and more of their time with pain management, often overlooking valued activities such as social contact, exercise, professional development,

community involvement or parenting, that normally provide life meaning. Neglecting valued activities and increasing the focus on pain may lead people to being disconnected from their values and becoming depressed, as a result of being entangled in a perennial struggle with the pain. ACT exercises may be useful in helping people identify longstanding values and barriers that prevent them from moving towards valued directions.

A concept directly connected to goals and values is committed action, which is regarded as flexible behaviour patterns in alignment with valued directions (Åkerblom et al., 2016). This includes persisting in actions that might bring physical or psychological discomfort (Hayes et al., 2006). Research has shown that engaged living (performing valued life activities) is associated with decreased distress and an improvement in health and wellbeing (Trompetter et al., 2013; Wilson et al., 2010).

The use of ACT with people living with persistent pain is supported by empirical research. A review published in 2014 suggested that increasing research supports the use of ACT with this population (McCracken and Vowles, 2014). The observed effects were positive: an increase not only in physical but also in social functioning and decreased healthcare utilization, even at 3 years follow-up. Furthermore, a recent meta-analytic review of 25 RCTs (1285 patients with persistent pain) concluded that individuals responded well to acceptance and mindfulness interventions and that the benefits persisted after the treatment (Veehof et al., 2016). Another recent review suggested that ACT was more effective than treatment as usual on several outcomes such as functioning, anxiety and depression (Hughes et al., 2017). Furthermore, results from a brief (four-session) group-based ACT intervention carried out in Southwest England with persistent pain patients revealed that the use of ACT is feasible in general practice and considered acceptable by patients (McCracken et al., 2014). One of the advantages of

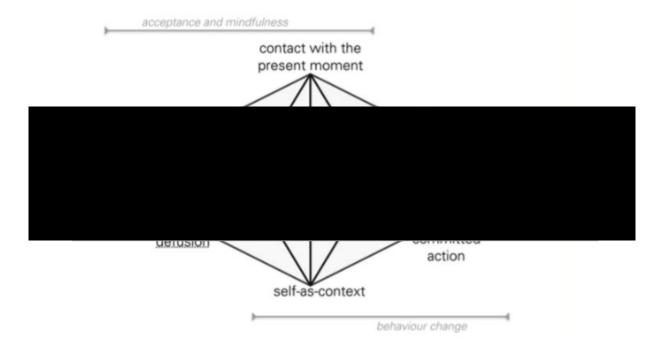


Figure 6.1: The **ACT** hexaflex mid-level diagram illustrating six constructs (retrieved from Hulbert-Williams et al., 2016)

this model consists in its transdiagnostic¹ nature and the fact that it can be adapted or integrated into different contexts and settings.

6.2.6 Relational frame theory (RFT)

From a theoretical perspective, ACT is based on Relational Frame Theory (Hayes et al., 2001). RFT is a comprehensive model of language and cognition suggesting that human language is based on people's learned capacity to arbitrarily relate events (Prevedini et al., 2011). Previous research revealed that people have the ability to learn things through relational frames (the main functions of cognition and language), without necessarily having the direct experience of an event (Dougher et al., 2007). RFT also posits that the normal verbal processes that help human beings dominate their environment may also contribute to narrow, rigid behaviour, driven by socially constructed verbal rules instead of by is direct consequences (Hayes et al., 2006). In this

¹ The ACT hexaflex diagram illustrating six mid-level constructs (retrieved from Hulbert-Williams et al., 2016)

sense, when language processes are directed towards solving problematic thoughts, feelings or memories rather than solve external problematic events or situations, psychological pain starts to inhibit these functions leading to experiential avoidance (Hayes and Smith, 2005).

The unwillingness to stay in contact with unpleasant thought, sensations, emotions and memories and the tendency to avoid contexts in which they may occur has been conceptualized as experiential avoidance (Hayes et al., 1996). People tend to experience language in a very literal way so that the thought or word denoting something (even when it does not describe an objective reality) takes the place of the actual thing and can often dominate behaviour ('If I go out I will feel pain and be a burden to the others' becomes 'I am a burden to the others' and leads to the person avoiding to go out (Hayes et al., 2001).

The aim of ACT is not to directly modify the content of cognitions but to foster actions in line with people's valued directions by changing the context of these cognitions (from literally to non literally) in a way that they are not barriers to behaviour anymore, regardless if they are true or not. In the context of long-term pain, this can translate into helping people become aware that thoughts (including thoughts about pain) are merely mental events whose content may or may not be true, and that avoiding activities (e.g. exercising, socializing) will have a negative effect on their quality of life and wellbeing long term, contributing to isolation and a worsening of their physical and psychological health. ACT may be useful in helping them engage in behaviour consistent their values although doing so might cause some discomfort (Hayes et al., 2001).

6.2.7 Self-management

Within the context of chronic conditions there has recently been an increased emphasis on self-management, which refers to being able to manage the symptoms; the treatment, the consequences and the lifestyle change necessary when living with a long-term condition (Barlow et al., 2002).

Research evidence supports the idea that effective management of persistent pain depends more on what people do than what is being done to them, therefore self-management plays a significant role in this condition (Jensen et al., 2003). There are five core self-management behaviours as identified by Lorig et al. (2001): problem-solving, decision making, resource utilization, developing a rapport with the health provider and taking action. In addition, another essential feature of self-management is self-tailoring, which refers to using the adapting the aforementioned behaviours to align with their personal needs rather than the health care professional's evaluation of their needs. Furthermore, research identified that knowledge; self-efficacy and self-regulation are internal characteristics that play an important role in self-management (Ryan and Sawin, 2009; Lorig et al., 2001; Marks et al., 2005).

However, some of the barriers to self-management most commonly reported by people who experience persistent pain are fatigue, low levels of energy, low mobility and sometimes inability to travel (Jerant et al., 2005). These limitations hinder individuals from accessing support resources and participating in therapies or programs delivered over a longer period of time. One of the solutions can be designing brief interventions as they are short, likely to be more acceptable and they simultaneously promote self-management skills. Additionally, from a cost-effectiveness point of view, brief interventions are less expensive, time-limited, structured and goal-directed. Equipping people who experience persistent pain with the knowledge and skills necessary for effective self-management, as part of a brief program delivered over a short period of time may be advantageous and lead to empowerment, increased self-efficacy and involvement in self-care activities, and less reliance on the healthcare system.

6.2.8 Social support

People who live with chronic illness are engaged in long-term management of their condition. With this management comes the need for information, emotional support and companionship, especially from people who experience similar problems and can relate to their situation (Blair, 2009). Previous literature found that social support plays an important role in mental health, through the positive emotions elicited by having close attachments with others and also due to receiving help in times of need (Cohen and Wills, 1985; Schwarzer and Leppin 1989). Furthermore, social support is also related to physical health, through its beneficial influences on cardiovascular, endocrine, and immune systems (Hobfoll et al., 2001). A recent meta-analytic review investigating the effectiveness of support groups for people living with chronic conditions revealed that support-group interventions may yield a positive influence on the management of chronic ill-health and lead to successful adaptation (Brunelli et al., 2016). Moreover, results from a study investigating perceived social support and its interaction with participation in daily activities and health-related quality of life in a sample of people living with CLBP and neck pain revealed that a sense of social and emotional support significantly interacted with the level of engagement in daily activities both in participants with and without mental health issues (Smite et al., 2012).

Developing an intervention for people living with long-term pain to be delivered in a group context may enhance social support and self-management. Participants may share information, similar experiences and management strategies and also support each other's progress. They may also help each other increase their confidence in participating in different activities and become less isolated. Creating bonds with people in a similar situation may also contribute to a decrease in anxiety and depression.

6.2.9 Basis for the novel intervention

Based on the findings from the qualitative study and the theoretical and evidence base identified, an ACT-based group intervention was designed to accompany Osteopathy sessions.

The decision to adopt ACT as a basis for the novel intervention underlies a series of considerations. Firstly, acceptance and mindfulness-based interventions are known to be as effective as CBT and considered good alternatives for people living with pain (Veehof et al., 2016). Furthermore, ACT incorporates acceptance strategies, mindfulness techniques and behavioural techniques focusing on changing people's relationship with private events (thoughts, feelings, memories, bodily reactions) while helping them identify what is truly important and live a more flexible and meaningful life. This approach is helpful for people who experience long-term pain, who are often caught up in a struggle to eliminate pain. In addition, mindfulness supports awareness of the present moment, which enables people to adopt a more flexible response to pain, as well as acceptance and self-compassion. Moreover, the principles of ACT are congruent with Osteopathic philosophy and holism (see table 1.1) ACT aims to increase psychological flexibility while osteopaths work to improve physical flexibility. Also, ACT focuses on increasing people's willingness to engage in meaningful activities in the presence of pain, which is similar to osteopaths' efforts to improve people's ability to perform more activities. All these arguments support the adoption of the ACT model as a conceptual framework for the intervention.

'A Mindful Act' (the novel intervention) consisted of six weekly sessions aiming to increase psychological flexibility and self-management. It concentrated on basic ACT tenets, mindfulness practice, holding self-stories lightly, practising self-compassion and self-care, acceptance and values identification and committed action towards a meaningful life. The six

sessions were structured to include: group activities, mindfulness exercises, reflections on the homework practice and movement breaks All the participants received a workbook containing homework exercises based on each week's topic.

6.2.10 Intervention goals and logic model

Through defusion techniques, the participants will be guided towards recognizing thoughts as mental events as opposed to absolute truths while also holding self-stories more lightly, and developing more compassion towards self (see figure 6.3). The new realization that self is different from pain and merely a context for thoughts, feelings and memories may also facilitate an increase in self-management and self-care behaviour. Acceptance is the direct counterpart of avoidance and also linked to self-care and self-compassion. Accepting to willingly experience pain and abandon fighting it may allow people to focus on their personal values instead and live a more rich and meaningful life. In addition, practising mindfulness and integrating it in one's daily life could help reduce catastrophyzing though present moment awareness and self-regulation. Being aware of thoughts, feelings and bodily sensations may contribute to participants developing increased acceptance of pain and starting to identify and pursue values. The social support provided by the group may play an important role in the maintenance of the aforementioned changes. People with pain might share similar experiences and realize that they are not alone; they may also provide each other companionship and support.

A logic model has been developed (see figure. 6.2) to illustrate the intervention structure and content, the activities involved and the outcomes. This model is useful in communicating in simple lines the relationship between intervention resources and content and intervention outcomes. 'A Mindful Act' was based on six sessions delivered in a group setting

involving: a participant handbook, information about the ACT model, hands-on activities, metaphors and videos, group discussions and mindfulness practice. The program offered the combined benefits of education about ACT and its application to pain as well as many opportunities for practice (e.g. Body scan, self-compassion meditation). The group discussions and activities enabled participants to get to know each other and share similar experiences, which contributed to increased social support. The short term outcomes of the intervention outcomes were achieving a better understanding of persistent pain and ACT as well as developing the necessary skills to apply the ACT principles to their daily lives. Long-term outcomes included an improvement in general health and quality of life, a reduction in anxiety and depression as well as less avoidant behaviours and catastrophyzing, better self-management skills, more psychological flexibility and reduced isolation.

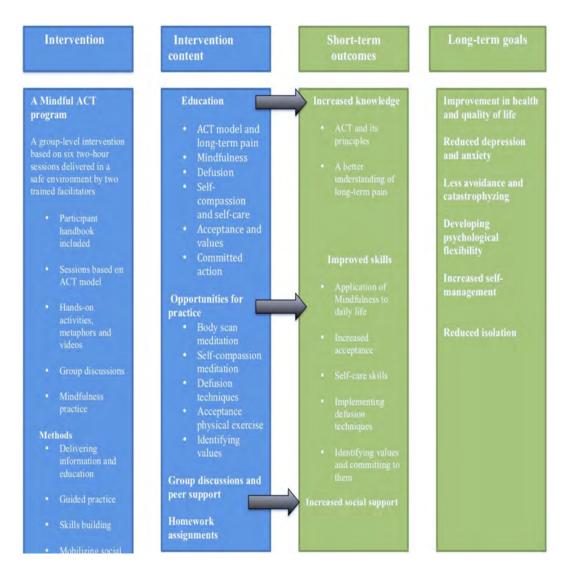


Figure 6.2: Logic model of 'A Mindful Act' program (adapted from Campbell et al., 2000)

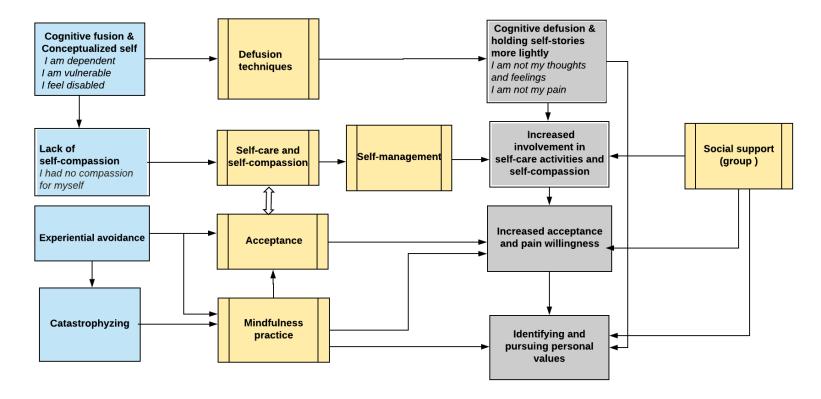


Figure 6.3: Mechanisms of change underlying the novel ACT-based intervention

6.3 Intervention protocol

6.3.1 Designing the intervention

The participants' reported needs, barriers and preferences have influenced the structure, content and the mode of delivery of the intervention (Saracutu et al., 2018). The majority of the participants from study 1 expressed curiosity and interest in trying something novel (none of them has taken part in a mindfulness or ACT program before). Some barriers identified by participants were: the amount of time necessary to take part, travel time, side effects of medication, not being able to sit for long periods of time and being in pain, short attention span and not feeling well enough to participate. They expressed a preference for group activities, the use of real-life examples, videos and hands-on activities. All of these aspects were taken into account when developing the intervention.

In an initial stage, a series of supervision team meetings took place to discuss and review the objectives, methods and procedures relevant for the intervention (See figure 6.4). Simultaneously an active collaboration with the Health and Wellbeing Academy (HWBA) was initiated, to support provision of the setting for the program and the recruitment process as well as delivery of the intervention. The osteopaths² collaborated closely with the main researcher in recruiting participants for the program and also volunteered to observe several sessions.

6.3.2 Overview of the intervention

'A Mindful Act 'is a brief program composed of six two-hour sessions that took place over six consecutive weeks. Based on ACT principles, this intervention will focus on increasing psychological flexibility. The

² Master students in Osteopathy practising under supervision in the Osteopathy clinic within the Health and Wellbeing Academy

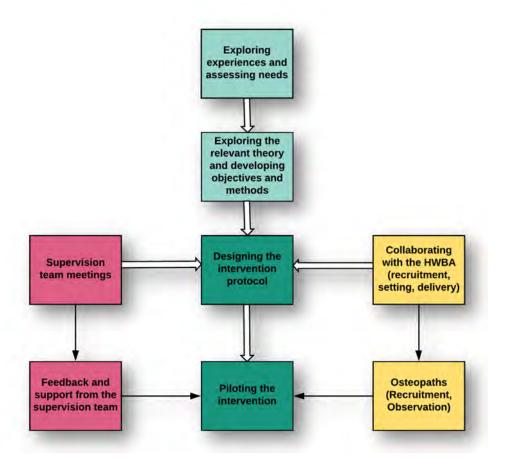


Figure 6.4: The process of designing and piloting 'A Mindful Act'

intervention centred on basic ACT tenets, mindfulness practice, holding self-stories lightly, practising self-compassion and self-care, acceptance and values identification and committed action towards a meaningful life (see table 6.1). 'A Mindful Act' was largely built up of freely accessible material³ from Russ Harris and Kelly Wilson. The sessions consisted of: education about ACT, group activities and discussions, mindfulness exercises, reflections on the homework practice. All the participants received a workbook containing homework exercises based on each week's topic. The researcher encouraged the participants to do the homework exercises; however, it was up to each participant how much they wanted to engage with it. They were able to retain the workbook after the completion of the program.

6.3.3 The structure and content of the intervention

Each of the six sessions were structured in a similar manner (see figure 6.5). The first part consisted of welcoming the participants and offering them light refreshments, allowing them to settle. Following that, the participants were asked to reflect on the previous session and share insights on what they have learned previously as well as on the homework exercises. The second part of the session involved the participants being introduced to a new ACT principle, through a presentation containing illustrations, examples and videos. Often the participants had the opportunity to explore ACT through hands-on exercises (e.g. practising defusion techniques), or group debates. Finally, the facilitator provided a summary of the session's topic, followed by guidance on the homework for the following session.

The intervention content and materials were based on available mindfulness and ACT resources that have been adapted for use with a group of people living with persistent pain (see figure. 6.6). Handouts, homework exercises

³ Permission was obtained to use these materials



Week 2- Discovering Mindfulness

Welcoming participants (tea, coffee, cake) Discussing about homework (in pairs) 10 minutes Introduction to Mindfulness (Madalina) 30 min Break 15 min Body scan instructions (Craig) Body scan meditation (20 minutes) Homework for next week (Madalina) 5 minutes

Figure 6.5: Figure illustrating the structure and content of the second session

Sessions	Content	
Week 1—Introduction	 Welcoming the participants and introducing the team A brief overview of the purpose of the programme and the content of each session Explaining basic ACT tenets The nature of persistent pain and getting caught up in the struggle Homework- Attempted solutions and their long-term effects exercise (Russ Harriss) 	
Week 2—Learning to be mindful	 Reflections on the homework, opportunity for questions What is Mindfulness and how is it useful? Embedding Mindfulness into daily activities (eating, walking, communication, acts of kindness) Group body scan exercise (20 min) Homework: Daily Mindfulness practice sheet 	
Week 3 — Defusion	 ▶ Reflecting on Mindfulness practice ▶ What is defusion and how to hold self-stories lightly ▶ Brief Observer self exercise ▶ 'Passengers on the bus' metaphor and group discussion ▶ Homework based on 'Passengers on the bus' 	
Week 4—Self-compassion and self-care	 ▶ Reflection on homework and Mindfulness practice ▶ Self-compassion explained ▶ Self-care activities ▶ Eight practices for recovery and a life well-lived (Kelly G. Wilson) ▶ Homework: Growing circle of self-care (Kelly G. Wilson) 	
Week 5—Acceptance and values	 ▶ Reflecting on self-care and self-compassion ▶ Acceptance as opposed to avoidance ▶ Acceptance physical exercise ▶ What are values and why are they important? ▶ Matrix interview exercise (Kelly G. Wilson) ▶ Homework: Values clarification exercise 	
Week 6—Committed action—a way forward	 Brief reflection on values Committed actions towards a rich, meaningful life The willingness and Action Plan exercise (Russ Harriss) How will you take this forward? Final conclusions and reminder about follow-up 	

Figure 6.6: Table illustrating the structure of the intervention (Saracutu et al., 2018)

and links were collated to form a workbook (see appendix A.19). The first session focused on introducing the participants to ACT as well as discussing the nature of persistent pain and providing an overview of the program. The second session started with an introduction to mindfulness and different ways to practice it, followed by a 20-minute body scan meditation while the following centred on explaining defusion and practising different defusion techniques. Session 3 was based on clarifying defusion by using the 'Passengers on the bus' metaphor and also demonstrating different defusion techniques.

Sessions four and five focused on learning about self-care and self-compassion and also introducing participants to acceptance and identifying values. Finally, the last session centred on committed action and identifying ways of applying the skills learned during the program to increase psychological flexibility and wellbeing.

6.3.4 Intervention facilitators and training

A qualified osteopath provided support for the main researcher in delivering the ACT-based program (see table 6.1). The researcher has a background in health psychology and is also trained in delivering ACT-based interventions, while the assistant is an experienced osteopath. In a first instance, the researcher proposed that the most suitable facilitators of the intervention were the osteopaths since they already had a rapport with the participants and the training in delivering ACT could have benefited their professional development. However, due to limited time and resources, it was not possible to train osteopaths to deliver 'A Mindful Act', however, they were involved in the recruitment process and also had the opportunity to observe the program. The two facilitators had a series of meetings prior to the intervention to discuss and plan different aspects of the program (e.g. structure and content of the sessions, roles and

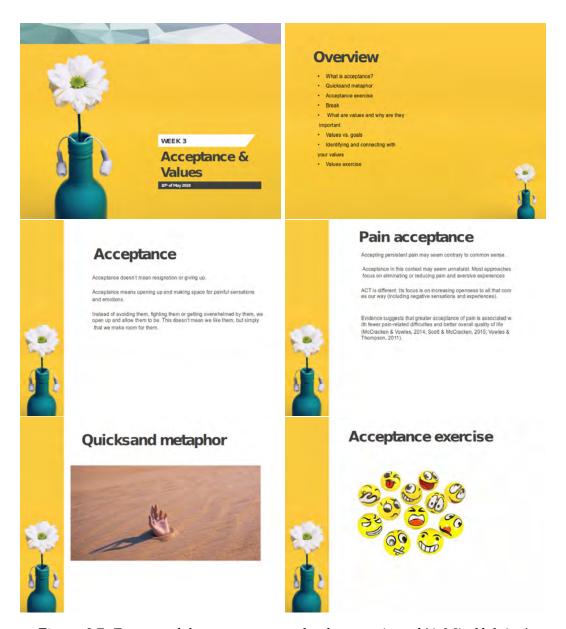


Figure 6.7: Excerpt of the acceptance and values session of 'A Mindful Act'

responsibilities) and continued to collaborate in order to ensure the successful delivery of the intervention.

6.3.5 Research governance

According to the British Association for Mindfulness-based Approaches (BAMBA), mindfulness-based teachers should embody ethical integrity as well as mindfulness. This association developed the Good Practice Guidelines for Teaching Mindfulness-Based Courses, a framework that promotes good practice in teaching mindfulness-based courses. Although the guidelines include mindfulness-based programs taught in mainstream settings (usually delivered over 8 weeks), they not limited to those courses.

A teacher of mindfulness-based approaches should have the following:

- A. Mindfulness Based Teacher Training
- B. Training or background required in addition to mindfulness-based teacher training
- C. Ongoing Good Practice Requirements

'A Mindful Act' is not a standard 8-week mindfulness-based program but an ACT-informed intervention tailored for people living with persistent pain. However, the program included a session aiming to teach participants about mindfulness and provide them some strategies to integrate it into their lives. A supervised body scan meditation complemented the session and offered the participants a chance to experience mindfulness. The homework consisted in filling in a mindfulness practice form or starting a mindfulness diary.

A. In line with the BAMBA guidelines, I demonstrated familiarity with mindfulness through personal participation in an eight-weeks Mindfulness Based Stress Reduction course provided by the Centre for Mindfulness-based

Work & Research (CMWR). The course was based on the core MBSR syllabus of Jon Kabat-Zinn and consisted of eight consecutive weekly MBSR sessions of two hours, and a four-hour guided silent practice. Guided meditations were provided on CDs to facilitate home practice.

B. The guidelines emphasize the importance of a 'professional qualification' in mental or physical health care, education or social care, or equivalent life experience, recognized by the organization or context within which the teaching will take place. My background and training in Health Psychology equipped me not only with generic psychology skills but also with the ability to plan and manage psychological interventions, research, teaching and training. These competencies were invaluable in the process of planning and facilitating 'A Mindful Act'.

C. The ongoing good practice requirements include: a commitment to a personal mindfulness practice, engagement in processes that continue to develop mindfulness-based teaching practice and regular supervision with an experienced mindfulness-based teacher.

I demonstrated commitment to personal mindfulness practice through daily formal and informal practice. This includes practicing mindfulness with the help of app, keeping a mindfulness diary, using mindful breathing to manage pain when it arises, communicating mindfully, within others. I have engaged in reflection both on my personal mindfulness practice and my teaching of mindfulness to ensure compliance with existing standards and also in order to improve. Additionally, I have kept up to date with the evidence base, particularly regarding mindfulness-based interventions for people experiencing persistent pain.

Throughout the process of developing, planning and delivering 'A Mindul Act', I participated in regular supervision sessions with an experienced health psychologist registered with HCPC (Professor Jaynie Rance) who provided feedback, support and guidance throughout the process.

Additionally, I was under the supervision of a nursing lecturer with many years of experience in mindfulness-based interventions research and teaching (Dr. Helen Davies).

According to the Association for Contextual Behaviour Science (ACBS) there is no ACT certification process⁴ therefore there is no such thing as an officially certified ACT therapist. The association aims to promote an open, self-critical and supportive community and encourage taking part in training workshops facilitated by peer-reviewed ACT trainers.

6.3.6 Recruitment process

Recruitment for 'A Mindful Act' was done in partnership with the Osteopathy clinic and consisted of two stages. The first stage involved osteopaths identifying adult patients living with persistent pain from the clinic who met the inclusion and exclusion criteria provided by the main researcher (see table 6.2). The main facilitator briefed the osteopaths in regards to the inclusion criteria for participating in the intervention (see table 6.2) and instructed them to refer people living with persistent pain presenting mild or moderate anxiety and/ depression (HADS scores ranging between 8-10 or 11-14). In addition, they were briefed to recruit people showing mild to moderate fear avoidance or pain catastrophyzing (according to their personal record). Those patients who underwent psychological therapy or were receiving treatment for depression or anxiety were excluded. The Osteopathy clinic was routinely collecting data from their patients (e.g. HADS), which aided osteopaths in identifying potential participants for the intervention. The main researcher provided ongoing support and guidance to the osteopaths throughout the recruitment, working closely with the Director of the Osteopathy clinic to ensure the smooth running of the process.

⁴ Please see https://contextualscience.org/act_certification

Following that, the main researcher asked potential participants⁵ some questions about their current state of health (to find out more about potential physical limitations that might interfere with participation see appendix A.9). The main researcher also reiterated the nature of the intervention (six sessions delivered in a group, complemented by homework and a one to one interview approximately 2 weeks after the last session). The participants had the chance to ask whatever questions they might have had regarding the intervention. This was done prior to taking part in the program. After the completion of the program, the nine participants received a certificate of appreciation to thank them for taking part. Two weeks after the end of the program, participants were invited to a one-to-one interview with the main researcher about their experiences of taking part and their views on the program.

The osteopaths who were involved in the recruitment for 'A Mindful Act' were invited to take part in a focus group after the completion of the program. Three of them also observed several sessions of the intervention. The seven osteopaths who participated in the focus group were provided with an information sheet and consent form. They were given two weeks to consider whether or not they wanted to take part and return the consent form. The focus group took place in a multipurpose room within the Wellbeing Academy in May 2018. The osteopaths were sent a thank you email to show appreciation for their time and contribution.

6.3.7 Intervention outcomes

The primary outcomes of the program included the feasibility of recruitment and measurement and the adherence to the intervention (see chapter 4, section 4.5.2). The secondary outcomes (measured at baseline, upon completing of the program, at one month and three months

⁵ This was done face to face. The potential participants were invited to the HWBA.

Main researcher	Assistant	Research team
Coordinating the whole intervention: creating all the necessary materials, delivering the intervention and making sure that all the ethical principles that apply (protecting confidentiality and anonymity, obtaining informed consent, providing the right to withdraw, minimizing the risk of harm, debriefing the participants) are adhered to. Other responsibilities: data collection (quantitative and qualitative) and the data analysis; liaising with the M. Ost. students to facilitate the recruitment process; liaising with the HWBA staff (receptionists) for room booking and other matters to do with the setting of the intervention; keeping a record of all the procedures and forms relevant for the intervention; sending participants a summary of the results and disseminating the results (papers and conferences)	The assistant fulfilled a supportive role. He worked under the supervision of the main researcher and the academic supervisory team. This role included: help setting up the room, welcoming the participants, handing out the workbooks, answering any questions participants had in regards to the intervention, helping facilitate the sessions. Other responsibilities Support with quantitative data collection at baseline and end of intervention (providing help in case participants experience difficulties using I-pads), creating some content (e.g. session 1- the nature of persistent pain and getting caught up in the struggle), reflecting on the intervention and providing feedback to the main researcher and the research team	The academic supervisory team provided supervision and support for the main researcher and the assistant throughout the whole process.

Table 6.1: Table illustrating the roles and responsibilities of the facilitators

follow-up) were intended provide some preliminary data on outcomes such as depression and anxiety, acceptance of pain, mindfulness, fear avoidance and quality of life (see figure 6.4). The properties of the psychometric tools

Inclusion criteria **Exclusion criteria** Patients living with persistent pain **Patients** with malignant pain who are able to read, write, speak (medical history); patients who and comprehend English; patients experience severe mental health able and willing to commit to six issues or addiction problems consecutive weekly sessions, to be history/self-declared); (medical interviewed about taking part and patients who are currently to fill in questionnaires at four time psychological undergoing treatment (self-declared/medical points history)

Table 6.2: Inclusion and exclusion criteria applied by osteopaths (Saracutu et al., 2018)

we employed for measuring these outcomes (HADS, MAAS, CPAQ, FABQ, EQo-5D-5L) will be discussed in this section. Selecting suitable outcomes is one of the key methodological challenges that researchers face.

The fourth point above illustrates one of the key methodological challenges in measuring outcomes in populations experiencing persistent symptoms resulting from long-term conditions: selecting suitable outcomes. Typically, these will depend on the aim of the study. Measuring patient-centred outcomes, that is, those that are meaningful, relevant and important to patients, has already been recognized in both the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) and Multinational Musculoskeletal Inception Cohort Study (MMICS) recommendations. IMMPACT and MMICS were international consensus studies that recommended a list of outcome measures for research in chronic pain and back pain populations, respectively. Both made recommendations with regard to measures for pain, psychological states, patient satisfaction, disability, global health/well-being, health-care use, symptoms and adverse events, physical functioning, work-related outcomes, tests and examinations, financial issues, lifestyle, weight and social/demographic factors. The choice of outcomes is in line with these recommendations.

evaluate and test the effectiveness and cost-effectiveness self-management support intervention for people living with chronic musculoskeletal pain (Taylor et al., 2016). The authors chose to use HADS after carefully considering criteria such as: the absence of confounding somatic items, brevity and clarity, and widespread use in research (Taylor et al., 2016).

Mindfulness Attention and Awareness Scale (MAAS)

MAAS is one of the most commonly used measures of mindfulness in research (Brown and Ryan, 2003). The 15-item scale assesses awareness of the present moment. The 15 statements refer to everyday experiences and are rated on a scale from 1-6 according to their frequency (1-almost always, 6-almost never). MAAS has good psychometric properties: internal consistency ($\alpha = 0.82$), test-retest reliability ($\alpha = 0.82$) and convergent validity with related measures (Carlson and Brown, 2005). Increases in the practice of mindfulness have been related to positive outcomes such as a better ability to handle long-term pain, fibromyalgia and physical stress (McCracken et al., 2004). According to a study analysing the cognitive and behavioural processes underlying mindfulness in a sample of one hundred and fifty patients seeking treatment for persistent pain, there was support for the internal consistency and criterion and construct validity of MAAS in patients living with pain (McCracken and Thompson, 2009).

Chronic Pain Acceptance Questionnaire (CPAQ-R)

The CPAQ-revised scale has been designed to measure acceptance of pain. Developing more acceptance is related to fewer attempts to avoid or control pain and also with more engagement in valued activities. The items on the CPAQ are rated from 0 to 6 (0 -never true and 6- always true). Higher scores indicate a higher level of acceptance. CPAQ has two factors: activity engagement and pain willingness. They significantly predicted pain-related disability and distress. The CPAQ demonstrated excellent internal consistency (.78-. 82) and validity and showed moderate to high

correlations with measures of avoidance, distress and daily functioning (Waddell et al, 1993). A study investigating the psychometric properties of CPAQ in an Internet sample of people living with pain revealed that the scale demonstrated good reliability and validity and provided evidence for the psychometric soundness of CPAQ (Fish et al., 2010). The findings suggested that higher CPAQ-8 and subscale scores were correlated with less depression and anxiety, pain severity and pain interference, and fewer medical visits for pain (Fish et al., 2010).

Fear-Avoidance Beliefs Questionnaire (FABQ)

FABQ is based on the fear-avoidance model, which explains why some patients with acute pain recover while others develop chronic pain (George et al., 2008). This questionnaire measures patients' fear of pain and avoidance of physical activity. FABQ has two subscales (Work and Physical activity) helping identify beliefs about how work and physical activity affect their pain. There is a strong relationship between elevated fear-avoidance beliefs and chronic disability. Avoidance may lead to an increase in disability, reduced activity levels and adverse physical and psychological effects (Williamson, 2006). FABQ showed good reliability (0.97) and validity. FABQ is correlated with Roland and Morris Disability Questionnaire (r = 0.455, P = 0.000) and with Tampa Scale of Kinesiophobia, another measure of fear-avoidance (0.53 for FABQ work subscale and 0.76 for the physical activity subscale) (Sekhon et al., 2017). A study conducted to explore the relationship between fear-avoidance beliefs, pain and disability index in patients with low back pain revealed that FABQ-P showed a significant correlation with FABQ-W, FABQ-total, VAS and RMDQ (Chung et al., 2013). The authors concluded that screening for fear-avoidance beliefs might be useful for identification of patients at risk of psychosocial problems as well as pain intensity and physical impairment (Chung et al., 2013).

EQ-5D-5L

The EuroQol Group introduced this measure in 2009 to improve the instrument's sensitivity and to reduce ceiling effects. EQ-5D comprises 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The patient is asked to indicate his health state by ticking the box corresponding to the most appropriate statement in each of the dimensions. The resulting digits can be combined into a five-digit number describing the patient's health status. The Visual Analogue Scale (VAS) records the patient's self-rated health on a vertical scale, where the endpoints are 'the best health you can imagine' and 'the worst health you can imagine'. EQ-5D is easy to complete and to score. In addition, the results can be used in health economic evaluations by performing QALY7 calculations (converting the 5 digit combinations into numbers that reflect overall quality of life). Vartiainen et al., 2017 assessed the validity of EQ-5D and 15D in patients living with pain and suggested that although there were considerable differences between the two instruments (e.g. EQ-5D appeared less sensitive than 15D particularly in people living with pain who had a better health status), both instruments were valid (Vartiainen et al., 2017).

Summary

This chapter provided an account of the process of developing the intervention. A group of 12 participants were recruited through the Health and Wellbeing Academy After being referred by an Osteopath, and attending a brief meeting with the researcher, the participants took part in six ACT-based sessions over six consecutive weeks. The intervention aimed to teach people how to develop more acceptance and self-compassion, be more mindful and clarify personal values to live a more rich and meaningful life. The main outcomes included the feasibility of the recruitment process and the measurement tools, the acceptability of the

⁷ QALY means quality-adjusted life year, and is a summary measure of health outcome used in economic evaluations; One QALY is equal to one year in perfect health.

intervention for both the participants and the osteopaths and the adherence to the program. The secondary outcomes were: depression, anxiety, fear-avoidance, pain acceptance, mindfulness and quality of life. It was expected that the participants who engaged with the activities, filled in the workbook and implemented what they learnt in their daily lives were going to obtain some benefits. ACT starts from the premise that by accepting and learning to live with pain, one can reduce the control it exerts over their lives. This intervention guided individuals to change their focus from trying to eliminate pain to living as well as possible with pain. Through experiential exercises and metaphors, participants learned the futility of trying to control pain and the benefits of acceptance strategies. Participants were encouraged to explore their values and set goals consistent with those values to improve their quality of life. The next chapter will present the findings of the study assessing the feasibility and acceptability of the intervention.

7.1 Overview of the chapter

This chapter will present the findings from the data analysis of studies three and four (see chapter 4, table 4.2) that aimed to assess the feasibility and acceptability of the novel intervention. The first part is qualitative and includes the framework analysis employed to analyse the one-to-one interviews with the participants as well as the thematic analysis applied to the data resulting from the focus group with osteopaths. Framework analysis is increasingly common within applied healthcare research and it presents several advantages: it is heavily driven by the accounts of the participants, it is dynamic (open to amendment), systematic, transparent and it allows comparisons and associations between and within cases (Bryman and Burgess, 1994, p. 176).

These two distinct qualitative methods were chosen as the nature of the data collection differed for each set of participants (intervention participants and osteopaths, see chapter 4, section 4.4). There were some 'a priori' concepts that were explored in interviews with participants who took part in the intervention ('what were participants' experiences of relating to and applying the ACT model?); hence this 'a priori' model would guide the thematic framework. This fits well within the contextual and also within the evaluative category (categories outlined in Bryman and Burgess, 1994, p. 174) in that we were interested not only in people's experiences of taking part in the program (contextual) but also in how they made sense of and implemented ACT (evaluative). In regards to analysing the data collected from osteopaths, thematic analysis was deemed more suitable, as there was no 'a priori'

framework and the aim was to gain an insight into their experiences of supporting people who live with persistent pain and explore their views on integrating psychosocial interventions (such as 'A Mindful Act') and Osteopathy.

The second part of the chapter consists of several measures of feasibility (time taken to fill in surveys, missing data, follow-up response rate) and acceptability (attendance, time dedicated to homework, knowledge of ACT), as well as the results of a statistical analysis investigating if there was any indication (or trend) of change between the start of the program, the completion and one-month after in regards to mindfulness, acceptance of pain, fear avoidance, depression, anxiety and generic health status.

Qualitative findings 7.2

7.2.1 Framework analysis

The process of carrying out the framework analysis

The analysis followed the five stages outlined by Ritchie and Spencer (1994): familiarization, identifying a framework, indexing, charting and mapping and interpretation.

Familiarization

Given that the researcher was the person interviewing the participants, and also the one transcribing the data, familiarity was more easily achieved, by listening to the audio recordings and reading the transcripts several times. The average length of interviews was 25 minutes, which made it possible to familiarize with each transcript in depth. A second researcher read a selection of verbatim transcriptions to gain familiarity with the data and contribute to the development and validation of the themes. The team

came together to discuss the data and agree on initial codes and subsequent themes (see table 7.1).

Initial codes	Extract from Transcript				
A change in life perspective	'But certainly after the first session, I realised how it was going to change well, change my life basically [] I found that my whole outlook on life has changed.' (Kevin)				
Living in the 'here and now'	'I've been conscious that when I've been out, we've had some really nice weather recently and I've been out really sort of taking notice, having a moment 'look at that sky, it's clear blue, look at the trees and the outline of the isn't nature beautiful? What a lovely moment this is!', really absorbing that moment and being grateful for it.' (Hannah)				
Increased confidence	'I'm more confident in the physical self which I think I mentioned to you before, that I was on a stick a lot of the time when I was first attending 6 weeks ago. I'm pretty much not on a stick at all and certainly haven't been for the last week, hardly at all.' (Sophie)				

Table 7.1: Initial codes illustrating the changes perceived by the participants (with quotations)

Identifying a framework

The starting point for developing the framework categories was the topic guide used in conducting the semi-structured interviews, which includes several questions related to the understanding and application of ACT principles (see Appendix A.10). A total of 200 initial codes have been refined and grouped into themes that were then clustered under three major themes: Engaging with the ACT model, Experiences of taking part in the intervention and Perceived changes. These were also integrated into the framework (see table 7.2).

1. Engaging with the ACT model	2. Taking part in the program	3. Perceived changes following the program			
1.1 Understanding and practicing acceptance	2.1 Expectations	3.1 A different perspective on living with pain			
1.2 'Acceptance physical exercise'	2.2 Views on content and structure	3.2 Increased confidence in own abilities			
1.3 Learning about defusion	2.3 Facilitators	3.3 Slowing down and being more mindful			
1.4 Experiences of practicing mindfulness	2.4. Practical aspects of the program	3.4 From self-criticism to self-compassion			
1.5 Developing self-care and self-compassion	2.5 'Gelling together'	3.5 Osteopathy & ACT work well together			
1.6 Understanding and identifying values	2.6 Suggestions for improvement				

 Table 7.2: Framework categories

Indexing

The final framework was developed after several iterations. The framework matrix (categories vs. cases) was constructed by using the matrix coding feature of NVIVO 12 (see table 7.3). NVIVO allowed the extraction of all the data coded to a specific category for each of the participants (e.g. Hannah's experience with Mindfulness or Naomi's experience with acceptance), facilitating the in-depth exploration which proved valuable in the next stages.

Charting

All the data indexed to the different categories was summarized for each of the participants in an Excel document (see appendix A.11). NVIVO and Excel were used simultaneously to facilitate extracting and summarizing the data. This enabled the researcher to move easier between the original coded text and the summary.

Mapping and interpretation

The next step consisted in moving beyond the data management towards understanding and interpreting it. Ritchie and Spencer (1994) suggested that key characteristics of the data should be pulled together to interpret the data as a whole. Therefore, this stage included clarifying concepts, representing phenomena and establishing relationships and explanations. At this point, it was essential to find patterns and write the narrative in light of the research questions ('How did participants relate to ACT?' 'What were people's experiences of taking part in the program?' 'Were there any changes as a result of participating?') Interpretation has taken different forms, and lead to the development of visual representations (concept maps) and a narrative presentation of the study's findings.

Framework category 1. Engaging with the ACT model

All nine participants were proactive in trying to familiarize themselves and make some changes based on the ACT model. They described their

	Emily	Hannah	Jasmine	Kevin	Noami	Sara	Simone	Sophie
Engaging with the ACT model	О	О	O	О	О	О	О	О
Acceptance	3	О	1	О	5	2	2	1
Acceptance physical exercise	4	О	3	0	О	1	1	1
Defusion	0	0	0	2	О	3	О	0
'Passenger on the bus'	1	1	0	0	О	О	1	О
Becoming aware of avoidant behaviours	1	0	0	О	О	О	О	1
Mindfullness	9	8	6	7	3	3	11	2
Managing pain with the help of mindfulness	О	0	0	О	1	О	О	0
Mindful communication	О	0	О	2	0	О	О	1
Mindful eating	0	О	0	0	0	О	О	1
Mindfulness - this 'hippie', 'new fangled'	О	1	О	О	О	О	1	0
Self-care and self-compassion	6	2	1	0	0	5	3	0
Everyone else comes first	0	1	1	0	2	О	2	0
You're in pain, take a breather	О	О	0	О	3	О	3	О

 Table 7.3: Extract from NVIVO 12 showing the matrix coding results

experiences of engaging with it as being positive. Several participants expressed that it was not always easy to understand ACT and that they needed some clarification or some additional time to think about it. One example is Hannah, who talked about some specific principles as being slightly abstract:

'When you're talking about things like defusion, it's not a concept that you use in everyday life is it? You wouldn't say to somebody 'well, I'm going through a period of defusion'. [...] Obviously, values and commitment are, and self as context as well.' (Hannah, Intervention participant)

Similarly, another participant (Diane) talked about the concept of values as being a bit more difficult to grasp. However, this was to be expected, given that the participants did not have any prior knowledge or contact with ACT.

'Interviewer: Do you feel that you have a good understanding of ACT? Diane: Yeah. I: Was it difficult to grasp? D: A little bit, at times. Interviewer: Can you give me some examples? Diane: Values and goals confused me a bit. But I'm good now. That was the only thing.' (Diane, Intervention participant)

1.1 Understanding and practising acceptance

This category describes participants' accounts of the process of achieving an understanding of and practising acceptance. A mixed picture emerged from the data with several participants indicating that they grasped this concept and started to work towards increasing their acceptance of pain (although not always easy), while others focused on reverting to their 'previous self', without the pain, showing little or no acceptance.

A good example of trying to 'let go' of things that are outside one's control and moving forward with the pain is expressed by Emily, who decided to focus on things that she can do, that are meaningful (e.g. going to the gym and doing different exercises). This is consistent with the literature, suggesting that people with higher acceptance of pain are willing to 'engage in a course of action that is meaningful and satisfying even in the presence of pain' (McCracken et al., 2004, p4).

'I know I won't recover fully, but I- I think in my head I still always search for something that would make it better. Um, but it's okay to accept it and- and actually you feel- you feel better accepting that you- you're gonna live with this. So, I now go to the gym and I do what I can do and then if it's easier next time I do a little bit more. But I've accepted that I'm not getting back on the running machine or rowing *machine or lift weights.'* (Emily, intervention participant)

Naomi shared a different perspective, refusing to accept her 'new self' with pain and struggling to get back to doing the things she used to do previously (running long distance, lifting weights) and feeling 'useless'. Naomi's attitude towards pain acceptance surfaced in the session before the last and also during the interview. She admitted feeling jealous when watching Vidyamala's video (during the intervention) about accepting pain and moving forward by using mindfulness. A sort of 'enmeshment' can be observed, where the boundaries between self and pain are blurry, and self-acceptance is directly dependent on the absence of pain and the ability to function and perform activities like before. In addition, the emphasis on the difference between 'then ' and 'now' is well documented in the literature (Snelgrove and Liossi, 2009).

'I don't think I'll ever accept it. I don't think I- It's just– Going from two years ago, being the type of person that would go on runs for fun and compete with myself constantly and strive for my personal best and-and run, not even little distances, I mean, 5K, 10K, 10 miles. I love doing it. I love going to the gym and-and lifting weights. And to go from that to physically not being able to. I feel like a useless version of my- of what I used to be. I mean, like, I put on weight, no matter what I do, I can't lose it. [...] The only thing I didn't like is that bloody woman talking about how she doesn't take painkillers anymore cause she's accepted her pain and it's her friend. I think that's probably about jealousy as well.' (Naomi, intervention participant)

Another participant described yet a different experience, with acceptance being directly influenced by the perceived pain intensity. As her pain gets worse and negative affects functioning, she is struggling to accept it.

"...I knew it was about acceptance and I suppose I hoped that it would help me accept my situation better...um...it has to a degree but I think it will be...I don't think I've reached full acceptance yet I think I'm part of the way. I've only just started and I think it's because um things are so recent with me, it's only recently

that my condition got worse...quite significantly worse...' (Sara, intervention participant)

1.2 'Acceptance physical exercise'

The 'Acceptance physical exercise' was adapted from Dr. Sonja Batten's "ACT in Context podcast' and aimed to help the participants understand three different ways to respond to pain: using avoidance and batting it away, ignoring it and refusing to be in touch with it, and lastly adopting an open and accepting stance while focusing on one's values. At first, the participants described feeling a bit puzzled, after which they had a sort of 'a-ha' moment they fully understood its meaning. However, this 'unconventional exercise' that was used to physically illustrate 'acceptance' had a strong impact on the participants. Although Sara, who volunteered for this exercise was not aware of its meaning in the beginning, after a while she understood its purpose. For Jasmine, it was one of the most memorable activities, where she recognized her own coping mechanisms in the part of the exercise illustrating avoidance.

'I knew what you were trying to get at it was like that yeah if you accept something you open your arms out to it and its better to like hold your hands out and say yeah okay I know I need to change and it's easier to accept something than sort of hideaway from it because I've sort of done it in the past and it's never worked for me so it it was something that really triggered in my mind like yeah I do do that.' (Jasmine, intervention participant)

She also expressed that to accept something; one needs to have an open stance (as in opening your arms up and letting the softballs touch you). Simone had a similar experience expressing that this activity was put across very well, in a way that was easy for people to understand, despite the complexity of the message.

'Interviewer: Do you remember the acceptance physical exercise? Simone: The one with the balls? Interviewer: Yes. Was that straightforward? Simone: Yes, it took a while to understand what was going on and then the penny dropped then, I was like ' oh yeah, I get it'. (Simone, intervention participant)

One of the participants went a step further and demonstrated it in her workplace, in front of her colleagues. 'Um, at first they were, like, 'You're gonna throw balls at me? [laughs] How is that gonna- How's this gonna help? But it just it- I think for some people to see something physically is easier for them to understand it. And everyone was, like, well, that's really... Actually, that's great. And you can use it for every sort of situation.' (Emily, intervention participant)

1.3 Experiences of learning about defusion

This category includes comprehending defusion and experiences of using defusion techniques. The meaning of this concept was conveyed through the 'Passengers on the bus metaphor', that was perceived by the participants as being useful and easy to relate to. In addition, they were practising various defusion techniques in class, which helped them understand that thoughts are simply thoughts and not binding realities.

'Interviewer: Did you like the metaphor about the passengers on the bus? Emily: Yeah. Yeah, I did like passengers on the bus. Yeah, and I think it makes it easy to relate- it's relatable in that way.' (Emily, intervention participant)

'We were given good examples, with the typical runs of the people in the bus ('Passengers on the bus' metaphor)' (Hannah, intervention participant)

It makes you more aware of your thoughts, like before I would never have thought, you know, like you said, about the man on the bus. I would never have thought about that, you know all all these thoughts coming at me...' (Simone, intervention participant)

Defusion had a stronger impact on some. Kevin recalled starting to understand defusion better when he became aware of thoughts occurring when he stepped out of his comfort zone (such as exploring a new place on his own, while on a cruise trip). He learned some useful techniques, such as thanking the mind and then going sightseeing on his own, despite the fear of getting lost or not making it back on time. For him, this was a revelation, as he was more aware of the impact his thoughts had on his behaviour and decision-making.

'Now I sit there and I hear these comments going on and I remember from one of the sessions saying 'well, thank you very much for that, but I'm not gonna go for that one at the moment' and we went round town quite happily and didn't order any coffee (smile) because the trouble is we didn't have time. We were looking at so many other things. It was quite a revelation. [...] I realise now that these little comments sort of pop in and because they are there, I then don't do it.' (Kevin, intervention participant)

Sara had a similar experience. She described defusion as the thing that made the biggest difference in the way she now relates to her thoughts. Acknowledging that she is often ruminating, getting stuck in the same thoughts and feeling upset, she learned to detach from her thoughts and look at them 'almost scientifically'. Sara now regards defusion as a switch, allowing her to step back and challenge her thoughts instead of getting caught up in them.

'Yeah, well I think the defusion exercise um, that was probably the thing that made quite a difference in my um thought processes 'cause I have a problem with ruminating and my mind almost stuck like, like it's in a loop, the same thing going round and round, stuck on repeat and it's quite upsetting and I found that the diffusion exercise taught me about how you can maybe detach from the emotion and *um look at it almost scientifically.'* (Sara, intervention participant)

1.4 Experiences of practising mindfulness

A strong emerging category consisted of participants' account of engaging in mindfulness practice. In the first instance, some participants talked about a sense of scepticism towards mindfulness ('this new, fangled thing' (Hannah), 'stuff for hippies' (Emily), '... before I didn't believe it in. I did use to think oh, it's not really for me. I didn't really believe in it to be honest.' (Diane) or having heard about it but not fully understood what it entails.

Taking part in the session dedicated to mindfulness and having first-hand experience of practising the Body Scan lead to a different understanding and perception of it.

'I think the course has made me more committed to do it, because of the positive *effect that it has'* (Emily, intervention participant)

'I think again that will take some practice, I think it does help you to enjoy the moment more and to be more grateful for the moment but it will take practice.' (Sara, intervention participant)

The encouragement and constant feedback received from the other participants and the facilitators served as reinforcement for practising mindfulness and embedding it in everyday life. There was a common perception of mindfulness as something that needs practice and is done intentionally.

'I think once you get a habit of practising, you do keep doing it but is- is almost making yourself do it in the first place.' (Emily, intervention participant)

This is consistent with the definition of mindfulness as being 'the awareness that emerges through paying attention on purpose, in the present moment, and non-judgmentally to the unfolding of experience moment by moment' (Jon Kabat Zinn, 2003, p. 145) and suggests that the participants reached a good level of understanding of the essence of mindfulness.

All nine participants expressed that they started practising mindfulness, and provided examples of how they incorporated it into different activities of daily living such as

eating

'I've switched from my sort of lunches, I've switched from my winter soups to my summer salads, but I'm putting different things, different textures in as I'm eating it, I'm really enjoying it and I'm thinking to myself this is nice' (Sophie, intervention participant)

communication

'I don't actually sit there thinking ' Oh, what can I say next' rather than listening to what they're saying to me. So it's just calmed me down I think, more than anything, *it slowed my mind down'* (Kevin, intervention participant)

spending time in nature

'It's simple things like being in the park with the kids, and they notice what on the trees, that's mindfulness, noticing their surroundings and hearing the birds tweeting' (Diane, intervention participant)

sleeping

'I try to do one in the morning, one in the middle of the day, and to like split my day up and one before I go to bed because I have big problems like going to sleep so I found it really big, it made a tremendous impact on my sleep' (Jasmine, intervention participant)

'Having that focus and that, you know sometimes even if you cannot absolutely hear it it's just background music, background sound and description, it's surprising how it helps me get off to sleep, prevents me getting up so many times in the night, *which I was always getting up a lot'* (Sophie, intervention participant)

and responding to stressful situations

'Yeah, I think in the past I when I have a stressful situation I would be emotional about it and - and not really be very constructive, whereas now, um when I'm faced with a situation- I think the more you try to, um, introduce mindfulness, um it becomes a habit.' (Emily, intervention participant)

The participants reported beneficial effects of using mindfulness to manage pain. It seems that mindfulness practice lead Hannah to achieve a greater awareness of her body and a better ability to relax. She describes breathing through pain, letting go and managing without needing painkillers.

'I think it's helping me to just relax more, to be more aware of myself and it's definitely helped with my pain because I'm more body aware, I'm trying to be more aware of my posture and my breathing and I think that it has generally helped. This morning I had a bit of pain, but then you breathe and think about yourself, put yourself in a good place and this is going to pass over, you don't need painkillers you don't need anything else, just you know go with it.' (Hannah, intervention participant)

Other participants, who adopted mindfulness to help with the pain and also with the stress, anxiety and panic accompanying pain, reported similar experiences.

'And the more you cry, the more upset you get, the more it hurts, 'cause I can't take pain killers at the moment. There was no other relief and then you feel quite panicked and quite like, 'There's no escape, I can't get out of this 'cause I can't dose myself up and then kind of, get enough painkillers in me so I could sleep. I'm not gonna be able to sleep without this. So, I use some lavender body cream and then just really concentrate on trying to like, focus on the parts that weren't hurting and

get there like that and I just fall asleep. So, it did work'. (Naomi, intervention participant)

Having an awareness of the body as a whole and then moving on to each body part lead to a realization that pain 'is not everywhere'. This brought Naomi a sense of reassurance and calm.

'And I tried that, uh, mind mapping where I just laid in bed and focused on my breathing and I just thought about all of like the- my whole body and how everything was working and then just kind of tried to isolate, 'cause by the time the pain gets really bad, it feels like it's all over your body and just reminding myself- it's not everywhere.' Calm down, focus on your breathing'. And that does help.' (Danielle, intervention participant)

Danielle described practising mindfulness in situations where pain has worsened, bringing with it stress, anxiety and panic. She expressed dealing with these negative emotions by using mindful breathing and the Body scan exercise.

'The breathing, the breathing is something I really concentrate on. When I get anxious or stressed or in pain I get short of breath and I think about having a heart attack. It feels like it and now, if I'm getting that anxious feeling I can just say right, 10 minutes out, I don't need to do the full body scan but I can just concentrate on my breathing, being in the present moment and then talking myself out of it, which I could never do before. The more pain I was getting, the more stressed I was getting and the more everything seemed to be getting on top of me where is now no, everything's going to be fine, breathe through it and I talk myself out of it. Yes, I couldn't get my breath. And we did the Mindfulness, and at the end, I could take a deep breath. And I've done that since.' (Danielle, intervention participant)

This is consistent with research suggesting that daily mindfulness practices such as mindful breathing facilitates the development of interoceptive 1attention to bodily sensations (Farb et al., 2013).

1.5 Developing self-care and self-compassion

This category describes people's experiences of engaging in behaviours that lead to a healthy lifestyle including looking after their physical but also psychosocial wellbeing (self-care), as well as self-managing their condition

and exhibiting kindness and understanding towards oneself in difficult circumstances (self-compassion).

Several participants expressed that they become increasingly aware of having channelled most of their efforts towards caring for their families, friends or others and not placing enough emphasis on their own wellbeing.

'Yes that's really important. And I do think as you get older and you're working and you have a family, you always put them first. Even when they're adults, and have children you always seem to be putting them first. Whereas, I think you have to step back and think 'Well, yes I have to be doing these things for myself as well.' (Hannah, intervention participant)

' I think it's probably statistically, people in pain probably don't acknowledge themselves half as much as other people do. Um, I don't know if that's true or not but I'd assume. The people that I know, that are in chronic pain, generally do so *much for other people.*' (Naomi, intervention participant)

'This was something I didn't do at all. It was always ~everyone else comes first'. But now, if I need to take 5 minutes and sit down and have a cup of coffee or have half an hour sleep, I don't feel guilty. I think I actually need to do this to be able to be... better for them, better for my children, better for my husband, whereas before I would be like 'No, I can't sleep and I would battle through it.' (Simone, intervention participant)

In addition, some participants also pointed out that they rarely used to ask for help when they needed it or felt in pain, but they became more comfortable in taking a break or requesting support following the intervention.

'I obviously called in sick from work and I actually did take a break because I needed one and I was coming up to a flare and I knew that I had to do something. And, yeah, it seemed-I think, sometimes you need someone telling you to take a break because otherwise, you don't...' (Naomi, intervention participant)

Similarly, Diane expressed that it was important to learn to say 'no' when feeling overloaded and working extra time. She became aware of her tendency to be a 'people pleaser' at her own expense. Diane learned to be more self-compassionate and put her wellbeing first. For example, when a friend wanted to visit and she was unwell, she learned that it is acceptable

to say 'no, please come another time' and not feel guilty for it ('Putting yourself first and having that self-compassion is important').

Sara found that she needed around seven hours of sleep to feel rested and experience less pain. She described an example of engaging in self-care. She started making some changes to maintain this amount of sleep and reduced the time spent on her I pad. Sara also decided to put more effort into her oral hygiene, as her dentist advised her to brush her teeth for longer.

'If I've had six hours sleep, the pain is less, so I've found that I've identified I can manage seven hours and feel properly rested and you know the pain is not too bad so I'm trying to make an effort to have that amount of sleep so I have proceeded in doing that actually the last week so that's quite a big change, a positive change.' (Sara, intervention participant)

1.6 Understanding and identifying values

With regards to understanding the concept of values, some of the participants expressed that they were initially unsure about the difference between values and goals and needed additional clarifying and reflection. Due to the brief nature of the course, there was less emphasis on values, and it is possible that this might have influenced participants' experiences.

'Values and goals confused me a bit. But I'm good now. That was the only thing.' (Simone, intervention participant)

'The values um I initially struggled to tell the difference between values and goals, so that took a bit of thinking about but it was all like, yeah I really liked the workbooks that was probably one thing that I really liked.' (Sara, intervention participant)

Framework category 2. Taking part in the program

Participants in 'A Mindful Act' described their experiences as being very rewarding. Although some of them did not know what to expect initially, the participants have engaged well with the course and liked its content and structure. They also expressed that they 'gelled together' as a group and formed meaningful friendships. There were some suggestions for improvement, however, all the people who took part expressed their

satisfaction with the program, adding that they would recommend it to someone they cared about.

'Interviewer: Would you recommend this program to someone you care about? Hannah: Oh, yes very much so. And also to somebody I didn't care about. (laughter) It's quite an eye-opener for somebody of my generation.' (Hannah, intervention participant)

2.1 Expectations

This category illustrates people's expectations prior to starting the program. It is important to emphasize that they had no previous knowledge or experience of ACT. All of them have been given a brief explanation of what the intervention would entail, the mode of delivery and introduced to the facilitators before starting. Kevin describes how he felt slightly uncomfortable at the beginning because he did not know how to expect.

'Initially, I had ... hmmm... not fear and trepidation but certainly I was uncomfortable because it was something that I didn't know about. I did not know what to expect.' (Kevin, intervention participant)

However, this changed when everyone was introduced to ACT and also got to know the other participants. 'A Mindful Act' seems to have had a powerful impact on Kevin:

'But certainly after the first session, I realised how it was going to change.... well, change my life basically. It was one of those things that, not knowing what to expect, *I didn't know what I was gonna get out of it.'* (Kevin, intervention participant)

Jasmine found herself in a different situation. She had been taking part in many pain management programs and had very low expectations given her previous experience.

'But unfortunately I've been to too many pain management courses and I know what people are like and how many dropouts... [...] I'm the only one still in it (laughter) 'cos I was alongside this been doing pain management and its literally 'cos no one wanted to carry on.' (Jasmine, intervention participant)

2.2 Views on content and structure

'A Mindful Act' was structured as six distinct sessions over six weeks where each session included three parts: a chance to settle in and discuss the homework in small groups, followed by a presentation of the week's topic and hands-on exercises and activities. A workbook that everybody could take home and fill in complemented the program. The participants appear to have engaged well with the material and appreciate the variety of activities and the holistic approach (the program went beyond talking about pain management).

'Yeah. I felt like it– Because the session was, um, some of it– Looking at the, um, the board, some of it doing things, some of it chatting. I think it was nicely broken up.' (Emily, intervention participant)

'It was holistic, it really helped your whole being really, so I think I wasn't expecting that side of it.' (Hannah, intervention participant)

'I thrive on being being given knowledge and then like going away and actually finding out more about it myself I don't like being given anything on a platter 'cos it just bores me basically and I don't bother going to engage in it then I'd rather be given something and then go and look at it myself and...' (Jasmine, intervention participant)

You should be really proud, it was such a good course, so well put together and you deliver it amazingly. I know it's hard to hear isn't it, but it was really fabulous.' (Diane, intervention participant)

2.3 Facilitators

The people delivering the intervention play an important role in the participant's overall experiences of the program and its acceptability. It seems that the participants in 'A Mindful Act' enjoyed having two facilitators with different backgrounds complementing each other and keeping them engaged throughout the program, by using different activities, humour or examples from own life.

'I- I thought they were fab- I thought you're very different. So, I think it was a good *mix.*' (Emily, intervention participant)

'I enjoyed the contrast of you and C. (co-facilitator) and your different approaches. It is quite nice to have two people, because you know, for the two hours, It is nice to have a contrast of people as well, taking over, one doing one aspect, one doing another. That was good.' (Hannah, intervention participant)

Personality also played a crucial part in the way facilitators were perceived. The main facilitator came across as a good leader who is calm and empathetic, while the co-facilitator was seen as upbeat and entertaining.

'And then you and C. (co-facilitator) as well... you were so calming'. (Simone, intervention participant) 'Yeah, so calming and so understanding.' (Diane, intervention participant)

'I would give the skills to you as a person leading, I think the way the team, you know or the participants gelled and like I said before were able to sort of open up to each other. [... A

nd I say he's a lovely guy, and this is just part of what goes with personality and how he is, and he's upbeat, great and lovely. That, of course, made us on occasions, as you know sort of overrun a lot of the time.' (Sophie, intervention participant)

One of the most fundamental tasks of a facilitator is to make participants feel comfortable and open enough to share their views and experiences.

'I was so nervous and I got really emotional that week but really comfortable enough to feel emotional in front of everybody and then, when C. (co-facilitator) said about taking, you know... taking charge of the situation and concentrating on something that's going to happen after the event, that helped me so much.' (Diane, intervention participant)

2.4. Practical aspects of the program

This category referred to the logistics and organization of the intervention and includes the convenience and accessibility of the location, parking, the setting itself, and the perceived level of comfort. Participants expressed that HWBA was a convenient location, accessible and easy to reach, with parking available. In addition, the setting where 'A Mindful Act' took place was comfortable (padded chairs, cushions and mats were provided) and there were enough breaks throughout the program.

'The room was fine, the chairs were very comfortable, that makes the difference. $[\dots]$ It was nice to have a break, a 10-minute break, and that was plenty.' (Hannah, intervention participant)

'Yeah, parking was fine. Yeah, I was trying to think, was it easy to park. It was really easy to park every time. [...] It suited me. I think um, also if people- if people have been at work it's got a nice gap, before or after work and stuff, yeah, that's good *timing for me.'* (Emily, intervention participant)

'I: Was it convenient to come here, in terms of parking and the setting? Naomi: Oh, yeah, yeah, it was fine. Yeah, it was easy and it's nice. Nice area to be in.' (Naomi, intervention participant)

Some of the participants like Sara struggled to stay still for an extended period of time, however, they often changed position or moved around for a bit.

'I did struggle to stay still but that was just because um I struggle with sitting anyway um...and I did try to lie down and alternate my position um but that's you know an issue that I have wherever I would've been.' (Sara, intervention participant)

2.5 The experience of 'gelling together'

Other qualitative synthesis of people's experiences of living with persistent pain have shown that due to a series of factors such as not being believed, the symptoms being unpredictable, fear of the future, the disruption of self, this population is becoming more isolated and less engaged in social participation (Sim and Madden, 2008; Campbell et al., 2011). The mode of delivery was designed taking into consideration these previous reports and was meant to increase social support and facilitate the process of learning new skills. The group setting seemed to have benefited the participants. They expressed having 'gelled well together' despite living with different types of pain.

'Oh, yes we will be keeping in touch as a group. I think we gelled as quite a good group, though very diverse people, with very diverse ideas and thoughts, and yet as a group it worked very very well.' (Hannah, intervention participant)

'I think it was really nice to meet people of like similar situations which I don't get to do on an everyday basis 'cause you don't go up to everybody and go oh... and it was... I've made lifelong friends we still talk to each other now and uh it's really really nice.' (Jasmine, intervention participant)

'The group for a start, the group was good... Just in the three weeks I was there I felt as though we gelled together and there were people there that you could sit and *chat to.*' (Kevin, intervention participant)

Furthermore, the experience of pain became somehow 'normalized' and they felt that they were not alone.

'So, yeah, because sometimes you feel like it's just you and you're the only person who can feel it and it's good to be reminded that it's not just you and you're not alone. There are other- are other people that feel like it.' (Naomi, intervention participant)

'Yeah I guess it kind of normalised the feelings for me instead of feeling like it it's *just me dealing with it or it's, you know...'* (Sara, intervention participant)

The participants shared ideas, asked questions, discussed the homework practice, updated each other with the changes week by week and ultimately formed a support network. Another aspect that emerged in this context is that they became more actively engaged in social activities.

'And I think, obviously you feel better about yourself as well, you go out more, and you know, you make more effort with people.' (Hannah, intervention participant)

2.6 Suggestions for improvement

One of the things that the participants mentioned was better time management (going over the planned time allocated for each session). This did not seem to cause much inconvenience though and the participants were happy to stay until the end. One of the participants suggested that the course would have benefitted from having more mindfulness practice incorporated while another, with a teaching background, provided some useful feedback in regards to the presentation of the material.

'Mmm. I think as the course went on, the timings were better. The first couple were quite... but which is fine for me because I've driven a while to get here, so, the

longer I spend here the- the more variable it is for me. ' (Emily, intervention participant)

' I think that's a difficult one. I think I would like to practice mindfulness in every session. We didn't do it in every session, did we?' (Hannah, intervention participant)

'Speaking as a teacher, one thing I would never do is put up a PowerPoint presentation with all the points on there, to begin with. Because what happens then your students are reading ahead [...] I think on the slides there was too much information on one slide, and because it all appeared at the same time more often than not I tended to sit there and I'd read it.' (Kevin, intervention participant)

Sara suggested that having nametags would facilitate interaction with other participants.

 $^\prime\mathrm{I}$ suppose we didn $^\prime\mathrm{t}$ have any name tags \dots um and I found it then I couldn $^\prime\mathrm{t}$ remember people's names and I found that inhibited me from talking to people some weeks.' (Sara, intervention participant)

One recommendation coming from Sophie was to recruit more men in the program, as they tend to suffer in silence and not talk about their issues as much as women do.

if there is one recommendation is like how to get more men because I think men, you know, suffer, and don't... at least for women, generally we will talk about things, share things, seek to resolve things. I would recommend it to anyone and everyone.' (Sophie, intervention participant)

Framework category 3. Perceived changes following the program

This category describes the changes that occurred during and after the program seen from the perspective of the participants. Not only did the participants learn about the ACT model but they also provided examples of how they applied it to their circumstances. Most of the changes revolve around participant's perspectives on life in general but also on moving forward with their pain and shifting their attention towards their values. Although pain reduction was not the goal of 'A Mindful Act', a number of the participants expressed that they felt less pain.

One of the participants talked about the ways she benefited from the program:

'I really enjoyed it on a number of different levels. It's certainly been thoughtprovoking but in a sort of positive way, and it has made me change my behaviour perhaps to a certain degree or in a small way, as I would like to think going forward, but I am intending to sort of do some more things and I am more conscious about things. I've certainly found significant benefit to my health so it actually had a positive physical impact on me.' (Sophie, intervention participant)

Another participant realised after the first session that his perspective on life was about to change:

'But certainly after the first session, I realised how it was going to change.... well, change my life basically.' (Kevin, intervention participant)

3.1 A different perspective on living with pain

Participants illustrate the changes in their relationship with pain. They demonstrate increased confidence in managing pain and using their newly acquired knowledge to facilitate this process.

Jasmine suggested that a lot of her pain medication was reduced and she is placing more emphasis on mindfulness and self-care:

'Yeah, I've gone back and I've reduced a hell of a lot of my pain killers from just being more mindfulness more that I had to look after myself and accept that I, I can't do everything myself so, I've come down a hell of a lot on the pain killers and feel a *hell of a lot better for it.'* (Jasmine, intervention participant)

Similarly, Hannah reported that she became more confident in engaging in different activities and is also less avoidant of pain.

'Because I'm feeling less pain, I feel that I can do more things, I have the confidence to do more things, whereas before, I think 'oh, it's really painful, I can't do this and I can't do that [...] This morning I had a bit of pain, but then you breathe and think about yourself, put yourself in a good place and this is going to pass over, you don't need painkillers you don't need anything else, just you know go with it.' (Hannah, intervention participant)

Sara also mentioned a change in her perception of pain and in the way she feels about herself:

 $^\prime$ I really enjoyed the program and I felt like I got a lot out of it um \ldots and I do feel like it moved me forward in terms of my relationship with pain um...and I...my perception of it and my also about my feeling about myself as well...if that makes sense.' (Sara, intervention participant)

3.2 Increased confidence in own abilities

One of the most common recurrent themes among people who experience long-term pain is fear-avoidance as well as imposing limitations upon oneself and by doing so ultimately becoming isolated. The opposite of this is confidence in one's abilities and engaging in activities with the awareness and acceptance that this might involve feeling pain.

Sophie talked about a positive change that occurred simultaneous with the program (renouncing the walking aid):

'Yeah, totally, I'm more confident in the physical self which I think I mentioned to you before, that I was on a stick a lot of the time when I was first attending 6 weeks ago. I'm pretty much not on a stick at all and certainly haven't been for the last week, hardly at all.' (Sophie, intervention participant)

It appears that taking part in the program seemed to have enhanced the participants' confidence in engaging in social activities, which may be linked to a certain extent to the increased trust in one's own physical abilities. In Hannah's case, this can be illustrated by her re-engaging in meaningful social activities.

'Well, I did more walking, I used to work quite a lot but then I stopped. So, yes I've been out walking more. And I've gone back to do more social activities that I was involved in before, I go to sewing class, I go to my local church and I've been more involved in the social activities there then I was before. I used to say 'I'm not able to come and so and so because my back is not really good 'you know.' (Hannah, intervention participant)

Similarly, Sara expressed that she become more confident and less likely to be isolated.

'Yes, I suppose ... I feel more confident, a bit more in control now...like I'm ready to... um...or less inclined to isolate myself which is what I had been doing ... I feel more confident to take action I suppose um or take steps um...to make changes, to maybe look at how I can maybe do things that I want to do.' (Sara, intervention participant)

3.3 Slowing down and being more mindful

This category contains the experiences of two participants who noticed a shift, from constantly projecting into the future and worrying about being able to cope with multiple tasks to slowing down the pace and fully engaging in the present.

Diane recalled taking her children to swimming lessons and being present for them, without becoming concerned about ulterior things that needed to be done.

'And how stressful life is.... whereas before I used to be so worked up, I use to think 'I've got this to do, that to do, I've got to be here at this time, there at that time' whereas now I am like 'right, I have to be here at this time and I'm gonna be there for half an hour' and I'll go to the swimming lessons with the children and I'm there for that amount of time', then I won't think about what I am going to do until I leave whereas before I would be like constantly thinking 'I have this to do, that to do, I've got to be here' or 'will I be late for that?' whereas now I'm more aware of the situation I'm in at that moment.' (Danielle, intervention participant)

Similarly, Sophie talks about being able to shift her focus to the present moment and fully absorbing the beauty of the surrounding nature. This brought along a sense of gratitude.

'Then, in general, I've been conscious that when I've been out, we've had some really nice weather recently and I've been out really sort of taking notice, having a moment 'look at that sky, it's clear blue, look at the trees and the outline of the... isn't nature beautiful? What a lovely moment this is!', really absorbing that moment and being *grateful for it.*' (Sophie, intervention participant)

3.4 From self-criticism to self-compassion

Self-compassion plays an important part in self- regulating emotions (particularly painful feelings) by adopting a sense of awareness and kindness towards self instead of being increasingly self-critical or using avoidance strategies.

Being self-critical and judgemental towards oneself may have roots in the frustration of living with long-term pain and not being able to do the same things as before. This can be observed in Naomi's account:

'On a really bad day, sometimes it's really difficult to get- take your mind away from anything but the pain. I had a bad night the other night and I was in tears and nothing would stop it and I was getting frustrated at myself. And sometimes it is really hard to just pull yourself out. [...] Yeah, I'm kinda hard on myself anyway.' (Naomi, intervention participant)

In the same way, Jasmine expressed that she used to be very negative with herself, particularly when she could not perform all the daily chores that she planned to do. She also reflected on how, after taking part in 'A Mindful ACT' she became less angry with herself and more self-compassionate.

'Very very self-critical...I still am critical sometimes 'cos I'll set myself up to do something and then I'll have a bad day and... I am a bit like 'oh God I really wanted to do that', but I'm thinking right next time it comes down I'll do it next time and it's always, I'll always turn a negative frown into a positive whereas before I would've literally just dug a ditch and sobbed for a couple of days and... and sort of moped, whereas now it's like well, never mind, if I can't do that today we'll do this today then and I'll change it round instead. I can deal with it better, I've got better coping mechanisms if I don't get round to doing something one day it's like ah well I'll do it tomorrow and I'm not so critical when my house isn't like 100% spotless, it's like well, I can't do everything, everything in the same day so, I'll get it done tomorrow and, or the next day (laughter) I used to run myself ragged trying to do everything the same day. [...] It's just made my life a lot more happier and more fun and sort of be... and I don't seem to get so depressed with myself and so angry with myself 'cos I feel like I'm not doing this and I'm not doing that, I'm not *so negative on myself.'* (Jasmine, intervention participant)

3.5 Osteopathy & ACT work well together

This category includes the experiences of three participants, who had Osteopathy sessions simultaneously with 'A Mindful Act'. All of them reported positive experiences and suggested that ACT and Osteopathy complemented each other. Sophie referred to Osteopathy as being a holistic treatment; she also emphasized the importance of combining physical approaches with psychological modalities.

'Interviewer: Did the Osteopathy sessions and the ACT program work well together? Sophie: Yeah, totally. Definitely, because I think with Osteopathy it is a holistic treatment. I think people need to, in situations like this, you deal with the physical side, you deal with any rehabilitation or exercises and strengthening but you also need to deal with your head basically (laughter).' (Sophie, intervention participant)

This participant also expressed that attending the six sessions helped her be more confident and push herself harder in her physical rehabilitation. Additionally, she noticed that she had a more positive mindset and truly believed that she was going to get better.

'My focus has changed, over the 6 week period to say 'well, let's just try this'. You know, at the end of the day if something feels like it gets too much physically you can always stop, or you can always turn around and start again, or you can have a rest. Having that sort of pushed me harder at my rehabilitation, gone into my Osteopathy appointments with an even more positive mindset than before, that this is really gonna work, and just the belief, if you like, that I am getting better. I do see the progress that I made over this period of time.' (Sophie, intervention participant)

Another participant talked about how she changed her perspective on pain as a result of taking part in the program and having Osteopathy treatment at the same time.

'Interviewer: Would you say that you have a different perspective on pain right now? Hannah: Yes, and it isn't just because of the sessions, it's also from coming here and seeing the osteopath, and having the osteopathic treatment.' (Hannah, intervention participant)

Moreover, this participant emphasized the usefulness of having the Osteopath and the tutor help her make sense of her symptoms and provide her information in regards to the treatment, something that other healthcare professionals did not do.

'I found that because they're students and the tutor comes in you can ask anything and you have a greater understanding, and an awareness of what is going on. I find that it helps you cope with the pain. Sometimes you have treatment but nobody explains to you what is going on, you just have the treatment and then you go, and then there's no understanding really. [...] Yes, the clinic here year does that. So I was on the start of that, being helped to understand before coming to the program. The *two together really complemented each other.* ' (Hannah, intervention participant) Educating the patients is part of Osteopaths' responsibilities. This is outlined in the Osteopathic Standards for Practice (General Osteopathic Council Guidance, 2018, p.7):

'You should discuss care options, encourage patients to ask questions, and deal with these clearly, fully and honestly. You should inform your patients of anticipated benefits as well as any material or significant risks associated with the treatment you are proposing, and confirm their understanding of these.'

Last but not least, Ken provided a different account of how he benefited from Osteopathy and 'A Mindful Act'. He talked about using mindfulness to manage his neck and back pain. This meant that he only needed one more session with Osteopath, whose focus was holistic (getting his whole body to a state of relaxation), rather than specific (back and neck). He also stated that combining ACT and Osteopathy worked very well.

'She was working on things specific things to my neck and my back hm.... But it became the last session...two sessions... since I've been doing the Mindfulness stuff and getting my head working on other issues... rather than concentrating on freeing the back up or freeing the neck, and this sort of thing. It's got to the thing where she's just done a couple of overall body things, where it just relaxed the whole body rather than a specific area because I've been working with my own mind with easing the problems with the back and the neck. We're now in a position of, she's gonna do one more session probably where it will be an overall body relaxation thing. Yeah, I mean she did, she started with my feet and worked up the body and got to my neck, and that was it. It was sort of a relaxation thing, rather than the real manipulation of a neck problem or a back problem. So, combing the two works... well, it worked for me certainly, let's put it that way.' (Ken, intervention participant)

To sum up, three major categories emerged in the Framework Analysis: engaging with ACT, experiences of taking part and perceived changes. The participants reported positive experiences: they found being able to connect with people who experience similar issues valuable and also expressed that they liked the content, structure of the program of the facilitators. All of the participants reported some improvement and there were no barriers to taking part (see figures 7.1, 7.2 – 'A Mindful Act').

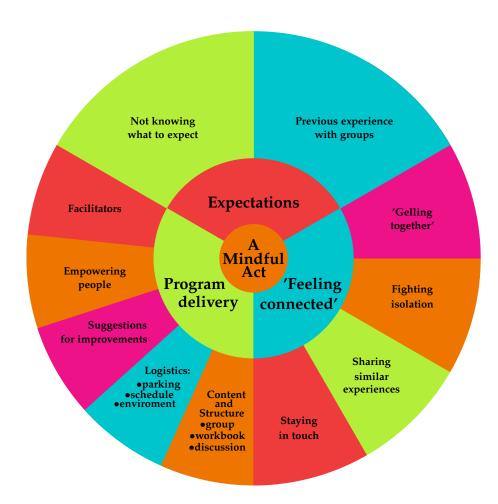


Figure 7.1: The experience of taking part in 'A Mindful Act'

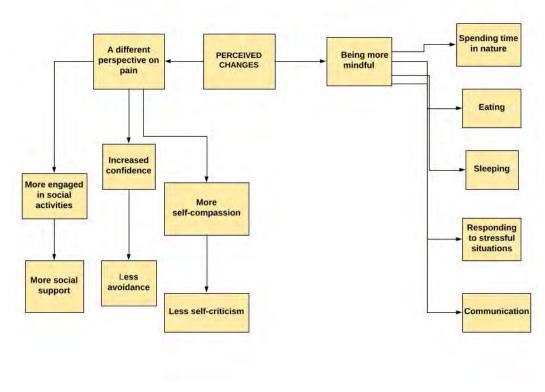


Figure 7.2: Flow chart illustrating the changes perceived by the participants after taking part in 'A Mindful Act'

7.2.2 Thematic analysis

Data collection

This study involved conducting a focus group with seven students enrolled in a Masters Osteopathy course who were also practising in the Osteopathy Clinic. All of them have volunteered to help with recruiting participants for the intervention and participate in the focus group. In addition, three of the osteopaths have also observed several sessions of the program. This group was made of five females and one male, all 18+ and enrolled in the last year of the course (Year 4, Level 7). Approval was granted from the College of Human and Health Sciences Ethics Committee and also from the Director of the Health and Wellbeing Academy.

The focus group took place in a multipurpose room within the HWBA in May 2018. The osteopaths were asked several questions (see appendix A.12) but had the chance to expand on them as well as long as they did not divert too much and respected the others' views. The focus group was audio recorded with the help of a digital recorder. The data was then transferred to a computer and transcribed verbatim.

Analysis

The preferred method for this study was Thematic Analysis (Braun and Clarke, 2006, 2012, 2013) a six-phase process employed for systematically identifying, analysing and interpreting patterns across the data. Thematic analysis has been increasingly used in health research and is well suited for such research as it offers flexibility, by accommodating both mainstream (individual experiences) and critical approaches (social construction of meaning) (Rohleder and Lyons, 2015).

TA fits well with the research question of this study, as it focuses on how a particular group (Osteopaths) perceive a certain health condition or intervention (in this case persistent pain and to a certain extent the novel psychosocial program).

Thematic analysis is based on an iterative and fluid five-phase process, involving moving back and forth between the stages, in a non-linear fashion. This process was carried out with the help of NVIVO 12.

Phase 1: Getting familiar with the data

This phase entailed getting to know the data through immerging into the content (reading and rereading the verbatim transcript) and starting to engage with the data analytically, by identifying potential points of interest. Given that the person carrying out the focus group was also transcribing and analysing the data, familiarity with the data was easier to attain.

In the initial readings of the interview, we picked up the osteopaths' great sense of openness and willingness to voice their views (particularly on Osteopathy as a profession). The focus group lasted little over one hour and the discussion flowed naturally, without much probing. This may have been due to the osteopaths knowing each other well and feeling comfortable to share their points of view freely. The participants used many examples from their practice to support their views (no names were given).

Phase 2: Generating initial codes

Coding was done by identifying patterns in the data, capturing the essence of the content and attributing meaning to individual words, phrase and passages. Codes were generated in NVIVO by breaking down the data and developing initial ideas. An excerpt illustrating the coding process is presented below (see table 7.4).

Phase 3: Identifying themes

At this stage, a search for initial themes was carried out by grouping the codes according to similarities and emerging patterns. The development of the themes was done with some considerations in mind, as recommended by Braun and Clarke (2012):

Codes Transcript

Nick: 'It's a little bit different, it looks at the body in a slightly different way ... and its approach is hands-on, it's physical rather than chemical and I really like that about it [...]

I had a patient last year actually who had... Parkinson's disease so he was in pain all the time (coughing noise in the background) and he knew he wasn't going to get any better and would probably get a lot worse. And I was just joyous working with him because Osteopathy... hmm made.... significant changes to his ability to move.

And reduced quite a lot of his symptoms. I was really pleased and surprised that I was able to do that with him. And umm... there was a psychological element to that as well, ... which was... alongside Parkinson's you often get depression, and so I was able to umm... keep him buoyant, actually.

His wife met me on the first appointment, she took me outside and said 'he gets very depressed sometimes, can you just be very upbeat with him?

So I was (smile) just celebrating every time something improved and it was...and he really enjoyed it and so did I. It was really lovely to see.

And sometimes he went backwards, sometimes he'd come in and he had a really bad episode of constipation for example and felt ill but then even able to work around that and hmm help him and give him a positive outlook.'

Preference for a handson approach, alternative to traditional biomedical

Patient with living Parkinson's experienced significant improvement in his ability to move

'There was a psychological element to that as well'

Patient's spouse made Osteopath aware of her husband's depression and suggested an upbeat attitude

Celebrating every small improvement

Supporting the patient through difficult times.

Table 7.4: An excerpt of coded data from NVIVO

- Whether a theme could be just a code
- Whether the theme says something useful about the data or related to the research question
- What does the theme include?

Phase 4: Reviewing themes

The data within each theme was reread and checked to make sure that it belonged within that category or whether it fitted better into a different (existing or new) theme. Given that only some of the Osteopaths observed 'A Mindful Act', the others could not share a lot about the program. However, a new theme has been created to illustrate the Osteopaths' perceptions of the intervention. This category was placed under the superordinate theme labelled 'Attitudes towards ACT'.

Phase 5: Defining and Naming Themes

During the fifth phase, a detailed analysis was written, telling the story behind each theme. At this stage, consideration was given to how each theme fits into the overall story and in relation to the data set. Finally, the names of the themes were revised several times, and quotes from the participants were included. Two researchers validated the themes independently and then came together to discuss and agree on the final version of the report.

An outline of the themes together with supporting quotes is presented below (see table 7.6). Each theme will be placed in context and discussed in relation to existing literature. Although there was no 'a priori' model (as with the Framework Analysis), one of the superordinate themes (Attitudes towards ACT) emerged as a direct result of prompting the Osteopaths to express their views on the ACT model and also their perceptions of the intervention (for those who engaged in observation).

Verbatim quotes	Codes	Theme
'I think it might also be beneficial to hear the same sort of things from different people. [] This patient was actually saying when they were doing the sessions they were reminded of things that I had told them' (Lilly, osteopath)	Same message delivered by different professionals will reinforce it	Running parallel sessions (Osteopathy & ACT)
'So, I really felt also that having those sessions separately from Osteopathy was beneficial. I don't think that incorporating the two into like one Osteopathy consultation would have been as effective.' (Laura) 'It does make sense that as a manual therapy yeah we do listen, we do educate, we do hands-on work but it's almost a bit too much going into the brain. [] And I think that if you have it all in one session then you're not attributing enough time to all of these important sections.'(Evie, osteopath)	Separating manual therapy from psychological therapy is beneficial Allowing enough time for all the different components	This theme includes several arguments to support the idea that running parallel sessions would be more beneficial for the clients but also the Osteopaths.
'It would be I think a really good way forward rather than just doing physical therapy, you're actually addressing emotions and psychological issues as well.' (Nick, osteopath)	Sessions need to be tailored according to people's needs Addressing psychological needs as well as providing physical therapy	

 Table 7.5: Excerpt illustrating the process of identifying themes

Theme	Subtheme	
1. Professional	1a Motivations to become an Osteopath	
identity	1b Educating patients and other health professionals	
	1c Early intervention is needed – 'They've given up themselves already'	
	1d Integrating Osteopathy into the NHS – 'In theory	
	it would be nice. In practice I can't see it happening'	
2. Supporting people living with pain	2a Managing expectations – 'It's gonna take time, it's	
	2b The challenge of psychological comorbidities	
3.Attitudes towards ACT	3a Perception of 'A Mindful Act' 'It seemed to really help people in the group'	
	3b Two different ways of incorporating ACT (Integration vs. Parallel sessions)	
	3c Training needs – 'If I could bring that into treatment more that would be amazing'	

Table 7.6: Table containing the final themes and subthemes

1. Professional identity

This category revolves around the osteopaths' attitudes towards their profession. In the first instance, they related to the different motivations behind the decision to study Osteopathy, and also the importance of educating patients and other health professionals about its remit. There was a consensus that Osteopathy has become 'a last resort' and that there is a need for early intervention. The topic of integrating Osteopathy into the NHS was also briefly touched upon and the participants expressed a sense of scepticism when discussing this issue. A more in-depth discussion of these themes will be presented below.

1a Motivations to becoming on Osteopath

Most of the osteopaths were motivated by an intrinsic desire to work in a supportive role that would involve having direct contact with people. Interacting with people and helping them by using a 'hands-on' approach seemed to be crucial to being an osteopath. This is consistent with previous qualitative findings suggesting that Osteopathy students emphasized handson techniques and considered them central to their approach (Clarkson and Thomson, 2017). In addition, having good communication and interpersonal skills were also deemed essential to being an Osteopath (Thomson et al., 2014).

'I wanted to be an Osteopath because I wanted to work with people, I wanted to work with patients and it was just the best avenue for me to do that in a hands-on way. ' (Heather, osteopath)

'I tried out several courses before and didn't like any of them and this one suited it perfectly and then as I did it the patient interaction was then one of the favourite things that then started coming into it.' (Evie, osteopath)

Some osteopaths expressed that their motivation stemmed from observing family members living with pain or physical disabilities and feeling inspired to take action in helping similar people.

'I decided to become an Osteopath generally just to help people after watching one of my family members who was disabled just suffer constantly, going to hospital, never getting any better and so I decided to just take up the opportunity to find out how I could help other people similar to them.' (Maya, osteopath)

'Similar to Maya, I had many family members that suffered from low back pain and.... general issues with their body so I always wanted to help. And I wanted to work with people, patients, and..see how I can help them. So basically that's why I got involved with Osteopathy.' (Rachel, osteopath)

Another recurrent motivation was the preference for an approach that is 'alternative' and uses ' more natural methods'. Two of the participants reported having had direct experience with Osteopathy, and having benefited from it, which then lead them to studying Osteopathy.

'Hmm, I've always wanted to do something in healthcare that involved more natural methods but haven't really found anything that fitted with me and then I had treatment and it was so successful for me that I was ... I felt really inspired and decided to do it.' (Laura, Osteopath)

'I chose to do Osteopathy for a number of reasons, hmm similar to Laura, I experienced treatment myself and I was really impressed by it, it also matched all my criteria [...] I then shadowed an Osteopath and I saw how he works and I saw that actually he had great work satisfaction but his patients were also really satisfied *with the service* [...]' (Lilly, Osteopath)

Osteopathy is considered part of CAM (Complementary and Alternative Medicine) and one of its distinguishing features is 'holism'; this is reflected in the belief in the body's ability to self-heal, as well as the integration between structure and function and the unity of mind, body and spirit (Turner and Holroyd, 2016). The holistic approach of Osteopathy seems to have motivated two of the participants to follow this pathway.

'I just like the holistic aspect of it really... for both the practitioners and the patients.' (Lilly, osteopath)

 $[\ldots]$ I looked at all the different healthcare professions and I liked the look and the ... history of Osteopathy. It's a little bit different, it looks at the body in a slightly different way ... and its approach is hands-on, it's physical rather than chemical and *I really like that about it.* '(Nick, osteopath)

1b Educating patients and other health professionals

Pain is one of the most prevalent reasons for entry into the health care system in the UK, New Zeeland and Australia; with neck pain and low back pain being the most frequent concerns when seeing an osteopath (Eccleston, 2001). This category illustrates the emphasis that osteopaths place on educating the patients about the nature of pain and also acknowledging that their pain is indeed real which seems to have benefits in terms of improved pain management. Communication is within most important themes outlined in the Osteopathic practice standards (2018) and considered key to forming an effective and trusting therapeutic relationship. The guideless emphasize the need for a patient-centred approach, where osteopaths provide the information that patients need to make informed choices about their care.

The osteopaths expressed that many of their patients were increasingly frustrated with navigating the healthcare system, not being listened to or not being believed. In addition, some of these patients wanted to be referred to a psychological intervention but instead, they would only be offered more medication. Three osteopaths also shared that what many patients needed was 're-education', after having been told that they were 'broken' by other health professionals with a more rigid biomedical view.

'I think I educate my patients a lot and that seems to ... to be a really strong key factor in helping them understand and dealing with their pain. From the feedback that they were saying some of them who had been in pain for so many years, they never had anyone explain why they are in pain and no had actually listened to them and I think having someone to relate what they were saying and kind of reflecting on that and understand why they are in pain, some of them responded very positively *to that* [...]' (Lilly, osteopath)

'So we have to kind of reconfirm that 'Yes, you are in pain, everyone does experience pain. Just because you've seen six different people who have just kind of brushed you off in a way it doesn't mean that we don't understand what you're going through.' And I think we all have to re-educatee our patients that the pain is there, we can manage it by using... different methods; there we go.' (Maya, osteopath)

'[...] They're sick of being in the system. The system isn't helping when it's ... you know, you're just been passed from department to department. Yeah, so patients

themselves said it's great having, you know... A lot of people they want to be referred for psychological interventions and it's not happening for some reason within the NHS, they're not getting referred for it, they just get referred to the pain clinic for *more medication.'* (Laura, Osteopath)

'The first couple of appointments at the Clinic A are all about re-educating them from their past experiences with the medical system, which is just... [...]: That's what I meant, by the time we get most patients they've already seen so many people and they've heard this terms being thrown around and they pick out what they want or, in their panic what they can understand at that stage. It's often actually those simple words 'broken' or 'out of alignment' that they can imagine and from there, that just goes downhill from there. (Evie, osteopath)

'Education but also re-education and what they think it's going on.' (Heather, osteopath)

When it comes to education, the importance of making other healthcare professionals aware of the Osteopaths' professional knowledge, values and beliefs was emphasized. Two of the osteopaths expressed that medical professionals exhibit a sense of scepticism and dislike towards Osteopathy, which may be stemming from a lack of understanding of its remit. This might in turn affect patients' choices, leaving Osteopathy 'as their very last option'.

'[...] Especially the medical profession, 'cause I think doctors and nurses, and even physiotherapists don't know what we do, don't understand how what we do works on patients. I think there is almost hostility still to osteopaths because we're outside; we're considered 'an alternative' by many doctors without understanding... ' (Nick, osteopath)

'They don't know, if you ask them 'Why don't you like Osteopathy?' They can't say, they've just... heard that is not ok to do. And then that's their opinion and they give that to their patients and that leads to them having it eventually as their very last option, 'cause they've tried everything else.' (Evie, Osteopath)

The osteopaths gave examples of patients whose negative beliefs were shaped by their previous encounters with medical professionals. Their work focused on helping those patients modify unhelpful beliefs. They suggested that medical jargon which is commonly used by the health professionals often contributed to fear avoidance and pain catastrophyzing. This is

consistent with previous research indicating that the language used by healthcare professionals can strongly influence people's attitudes and beliefs about pain (Darlow et al., 2012, 2013; Thomson and Collyer, 2017).

'I had the patient recently who... She was told by her surgeon that her bones were 'crumbling away'. She is 50 years old and her bones are not crumbling away. She has a little bit of osteoarthritis in her hip and so her hip was replaced but she had this image in her head that her bones were crumbling away so, for fear-avoidance yeah 'I'm going to avoid everything, my bones are crumbling away' (group laughter). It was really useful to say 'Well you're still standing up, you can still move your arms and legs, it doesn't look that there are crumbling to me.' And just simple things like that, just to change the way she is thinking is... I think we all probably do that every day.' (Nick, osteopath)

'Yes I've got a lot of those lately. So I've had people saying 'Oh well you know my back's broken, it will never be the same again' even if it's healed two years previously. And then things like' I'm twisted so that's never gonna straighten out so I will always have this pain'. And it seems to go... things that they've been told umm specific things like 'twisted', 'got one leg longer than the other' and things like that. [...] So I think the terminology that's used to explain things to laypeople... you've got to be really careful with it, 'cause it sets up a lot of beliefs.' (Laura, osteopath)

'That's what I meant, by the time we get most patients they've already seen so many people and they've heard this terms being thrown around and they pick out what they want or, in their panic what they can understand at that stage. It's often actually those simple words 'broken' or 'out of alignment' that they can imagine and from there, that just goes downhill from there. Then, like Laura said it takes forever to unpack that before you can actually target the issues at hand. Yeah, it's always a shame when that's happened over time by the time we see them.' (Evie, osteopath)

1c Early intervention is needed - 'They've given up themselves already'

This theme reflects osteopaths' belief that intervening early is essential in achieving good outcomes and preventing the condition from deteriorating. They also suggest that their profession has become 'the last resort' and that osteopaths see patients in a stage where they have already tried everything else. Timeline seems to be crucial in that the longer the person lives with pain, the more likely it is that comorbidities will also develop, together with maladaptive beliefs about pain. Osteopaths also suggest that the longer the

time a patient lives with pain, the more difficult it is for them to deal with the psychological issues that accompany the pain.

'The other thing as well, the longer something goes on for, the longer time there is for other comorbidities to set in. Umm and also from a purely musculoskeletal perspective I think it gets worse If it just has more time. Umm, I feel very much like if people would have come to us earlier, we could have helped them get better much quicker. [...] Which is a shame because quite often by that point they have been on a cocktail of drugs for two years. And it's a shame because in a lot of cases it's not necessary.' (Laura, Osteopath)

'I think with that as well it's a shame that Osteopathy is not more well known 'cause a lot of the patients we get from Clinic A, for example, it's the last thing, they've tried everything else. They weren't even aware that Osteopathy. What is there but it was the one thing they haven't tried and then it's somewhere at the end of the list. ' (Evie, osteopath)

'And then we do get the patients in at the stage where they've given up themselves already. They're at that stage of depression as Laura mentioned earlier, from that point on it so hard to get them out of it, whereas if you can catch them before they've drifted into that mindset it would be much quicker I think giving them relief.' (Lilly, osteopath)

'Again, by that point their muscles have deteriorated way more than they should have just because no one has taken the time to just say that. And again it's a psychological aspect. '(Evie, osteopath)

1d Integrating Osteopathy into the NHS - 'In theory, it would be nice. In practice, I can't see it happening'

There was a sense of scepticism in the participants' tone when discussing the integration of Osteopathy into the NHS. They argued that this might come with more challenges than benefits. There was a consensus that this shift would be too much of a compromise.

One of the Osteopaths suggested that Osteopathy would be a cost-effective intervention for managing pain, provided that osteopaths would not make any concessions on the duration of their appointments (45 minutes):

'Ironically, I think if Osteopathy was properly integrated into the health care system, so we had our 45-minute appointments with our patients, I think we would save

them millions of pounds. Because I think things like headaches, and low back pain, and I could go on and on, where there are controlled trials saying that we are effective, more effective than drugs and more effective than surgery in some instances that we could be actually saving the NHS a huge amount of money. But I don't think they would look at it that way, they will try to give us 15 minutes appointments, like physiotherapists get and therefore we cannot do our job. We won't have the same effect.' (Nick, osteopath)

Similarly, Laura pointed out that osteopaths would not be allowed to continue practising as before if it were to be integrated into mainstream:

'In theory it would be nice. Umm in practice I can't see it happening and as being allowed to continue our practices the way we do it so I think we would be too constricted then, too restricted. For example, there was an article in the news about a particular area where they stopped physiotherapists from using any hands-on technique and they were only to give exercises and advice. That which is completely undermining what we do.' (Laura, osteopath)

2. Supporting people who live with pain

The current understanding of the experience of pain goes beyond a structural or biomechanical problem and involves different cognitive (catastrophyzing, maladaptive beliefs), psychological (depression, anxiety) and social (family, relationships) factors. Consequently, pain management has seen a shift from a purely biomedical model to a biopsychosocial model (Anchin, 2015). Manual therapists have moved towards applying a biopsychosocial approach in the management of long-term pain (Harding et al., 2015; Sanders et al., 2013), however, this is not without challenges. Osteopathy, adopting a biopsychosocial approach raises several questions in regards to reconciling Osteopathic principles with evidence-based practice, clinical reasoning and education (Tyreman, 2011, 2013). A recently published qualitative study revealed that osteopaths were missing the necessary knowledge and skills to address psychosocial factors in the management of people living with persistent pain (Formica et al., 2018).

The osteopaths who took part in this focus group discussed some similar challenges that they encountered in their practice. Two themes emerged in this category: managing expectations and supporting people living with comorbidities.

2a Managing expectations- 'It's gonna take time, it's not gonna go overnight'

Some of the osteopaths suggested that they encountered difficulties in managing patients' excessive expectations. They reported having had to explain and emphasize that change occurs over time and improvements are the result of collaborative efforts, and that they cannot provide 'a quick fix'. This is illustrated in the account of two osteopaths:

'I find the most challenging thing to be managing their expectations. So, basically that it's gonna take time, it's not gonna go overnight and that it's a two-way street, that they have to um do something about it as well. So, some of them actually expect us to just solve the problem for them, if that makes sense. So, what we can explain is that it's gonna take effort from their part as well to like, umm do some exercises or move more, or do something about it anyway and just feel more positive.' (Evie, osteopath)

'I think with Osteopathy as well, there are so many ... patients were it's so easy to sort of give up in the early stages 'cause... you can see they're not engaging with it and it's frustrating for you then 'cause you're trying to help them and they're just not listening. And that...it is really... to just give up on them but then I've seen so many cases as well where if you do persevere and do keep drawing them in that they do start listening, and once you've got that tiny spark it tends to progress quite *quickly from there* . . . ' (Lilly, osteopath)

Similarly, Evie shared that supporting people who have a negative outlook is one of the biggest challenges she had to face, and that influenced her attitude by becoming less hopeful in their ability to improve.

'It's more difficult if they have a negative outlook or if they aren't ready to make the changes themselves. If they are really proactive or they are willing to change or they are willing to listen and hear what we have to say and take the advice that we give them it's a lot easier but when they (long pause, sigh) ... aren't as willing it's more difficult... and it makes treating them more difficult. It makes us less hopeful for their overall prognosis.' (Evie, osteopath)

2b The challenge of psychological comorbidities

There is a high rate of comorbidity in the occurrence of persistent pain and mental health issues, particularly depression and anxiety (Sigtermans et al., 2009, Rayner et al., 2106). Due to the nature of their work (treating people who experience pain, among others) osteopaths often face the challenge of treating people who experience more complex psychosocial issues.

When discussing their experiences of helping patients living with comorbidities, a mixed picture emerged. One osteopath suggested that she found it very demanding to treat people with depression, due to the factors associated with it such as negative beliefs, low self-efficacy and a sense of passivity as opposed to being proactive in managing their condition. She also suggested that when it comes to helping someone living with anxiety, using communication as a tool for providing appropriate information and reassurance is a good way to alleviate the fear and usually results in much better outcomes.

' Laura: Yeah, because, with anxiety, you know just explaining things... can alleviate a lot of fear umm and... You know people are willing to engage and they have the energy to to try and ... usually the results are much better. Interviewer: Are you suggesting that those living with depression are a bit more passive and not so active in making changes? Laura: Yeah. In my experience, they don't really believe they are going to have a good outcome. And there are loads of factors at play, you know, low self-efficacy, negative health beliefs, you know... It all comes together and...It's quite challenging. Treatment can go on for... many months and sometimes you feel *like you're not getting anywhere.'* (Laura, intervention participant)

Similarly, another osteopath recalled a recent experience, treating a patient living with depression who self-harmed. This seems to have put the osteopath in a difficult position, being confused about how to address the issue and feeling 'out of her depth'. This is important as it highlights the need for specific training on how to manage this type of situations. Despite that providing psychological support is not within the scope of Osteopathy, it is essential for osteopaths to be offered training on how to support people who live with mental health comorbidities within the boundaries of their profession.

'Building on that as well, I 've had one recent experience where I did feel out of my depth and I don't think we've had the proper training for that but I had someone with the level of depression where she was self-harming herself and at that stage I simply didn't know how to target that, because that's not really been addressed hmm to what extent I should be discussing that with her, or leave her to it or should I inform someone else. Where that's involved it gets a bit... difficult 'cause I don't know how much harm they will do themselves and that did really add another level to the pain she was already having and the depression she already had. ' (Lilly, osteopath)

A totally different experience was shared by another osteopath with a background in counselling who found it challenging to draw a line between providing osteopathic treatment and offering counselling.

'An issue I have is slightly different 'cause I have twenty-five years counselling experience and ... I had to really draw a line between being an Osteopath and being a counsellor because sometimes, particularly when we were at the A clinic, patients I kind of thought ' you need counselling more than you need me 'osteopatheing' you' (smiles) and it was... I had to draw a line in my head that I am not here to counsel, I'm supposed, and I'm here to give them Osteopathy. And that was quite *interesting.* ' (Nick, osteopath)

Fear-avoidance and catastrophyzing are also associated with long-term pain. It has been theorized that negative beliefs about pain may lead to a response in which people imagine the worst possible outcome, which in turn contributes to fear of activity and avoidant behaviours (Linton and Shaw, 2011). One of the osteopaths recalled her experiences of treating people with catastrophic beliefs and fear-avoidance behaviours:

'I think the amount of people I get who are convinced they are 'broken' or 'fragile' or if they do exercise, they want to do exercise but they can't, 'cause they might damage themselves more. So these are people that they want to be proactive and they would have been if one person would have told them 'you won't break, you're quite stable' (Evie, osteopath)

In this case, it appears that reassuring the person that they are not 'broken' and working to change their maladaptive beliefs could result in improvements as they may become more proactive and confident in their ability to exercise and manage their pain.

3. Attitudes towards ACT

When adapting Acceptance and Commitment Therapy (ACT) to persistent pain, this model posits that people should reduce their attempts to avoid or control pain and focus on pursuing their personal values through acceptance (McCracken et al., 2004). All the osteopaths who took part in the focus group had prior knowledge of ACT and were also informed about the ACT-based program being delivered with the HWBA. 'A Mindful Act' aimed to teach people about acceptance and self-compassion, how to become more mindful and clarify their personal values to live a more rich and meaningful life.

This category includes the osteopaths' perception of 'A Mindful Act', as well as their views on incorporating ACT into Osteopathy and the training that it would entail. Only three of the seven osteopaths attended the six sessions and observed the program, however, some of the other osteopaths noted some changes in the patients who took part in the intervention.

3a Perception of 'A Mindful Act' 'It seemed to really help people in the group'

The osteopaths held positive attitudes towards 'A Mindful Act' and suggested that it seemed to benefit the participants. Two osteopaths recall some improvements in their patients' ability to self-manage and become more accepting of the pain, as well as practising defusion and being more mindful as a result of engaging in the six sessions.

'I mean, from what I've seen with the program that you did, umm it seem to really help people in the group, especially people with chronic pain who didn't understand why it's been going on for so long and how to manage it and how to accept it to a certain extent.' (Heather, osteopath)

'So, they've been coming to me for a year nearly and... umm I've noticed over the course of the sessions suddenly there was a huge leap in improvement and ... their outlook hmm they seemed to be talking more about how they were going to manage it after they ceased receiving Osteopathy treatment and how they really felt they were almost there and it was going really well and ... it was a big leap in umm beliefs and also they were telling me that they were catching themselves throughout the day noticing ... umm, when they were thinking sort of catastrophically. There

was a lot of fear-avoidance in this particular case and it took a long time to work with this person. [...] I know my patient who went, so they said that they really benefited from the regularity of it, the time that was allocated to it, the group format and it felt like a big commitment from them, that they really benefited from it. ' (Laura, osteopath)

Similarly, Evie and Lilly highlighted some positive aspects of the program: the calm environment that helped people feel safe and relaxed, the professionalism of the facilitators but also the light-hearted way they delivered the sessions, the group setting that allowed people with similar experiences to interact and feel accepted instead of judged.

'They all felt safe, in a calm environment, a really good environment for those who were willing to... to kind of explore all the elements. It was a good environment for them to do so. And I think that umm topics were handled professionally but also in a slightly fun and less serious manner, still taking it seriously but not, not being too medical, prescriptive about it. [...] Yeah 'cause they were just engaged instantly, they saw that it wasn't just another lab coat, it was a human being. (Evie, Osteopath)

'I agree with that and I think people really relaxed, I think having other people with the same issues around them, I think it made them feel less judged. I think if you have someone with chronic pain that have been through the system so many times and...keep not being taken seriously.' (Lilly, osteopath)

In addition, another osteopath emphasized the importance of the group format, with people being comfortable to share personal experiences with each other and feel understood. Furthermore, she expressed having noticed improvements: people seemed to engage well with the exercises (such as the Body scan) as well as with the homework practice.

'Adding another thing to yours, it was the fact that they had each other to talk to as well. I think it's different talking to us as practitioners but then person-to-person is totally different. And having someone understand what you're going through kind of helps reaffirm that it's not just in your mind, it is actually happening. (coughing noise) And I think people responded very positively to that. I think it was the set-up as well, people just came in, sat down, and people you've never talked to, people who were just in pain like you and they're just sharing what they're going through. And I think that was a really good aspect for some people who haven't responded so well to Osteopathy; just talking sometimes is good for people. [...] I also noticed the difference with the body scan, from the beginning of the session when everyone was

a bit tense, a bit apprehensive, when towards the end everyone was just lying down, just totally relaxed, and just actually doing the exercise. So once again, so that education, reassurance- as the weeks go on you kind of start to see the improvements within people who actually are doing the exercises, who are taking the time to do the educational aspect of it- the homework and you start to see those changes as the weeks go on which is what I noticed, towards the end of the sessions.' (Maya, osteopath)

3b Two different ways of incorporating ACT (Embedding ACT vs. Parallel sessions)

In regard to combining ACT and Osteopathy, a mixed picture emerged. Some osteopaths were in favour of embedding ACT principles in their osteopathic practice (for example when talking to patients about pain) while others suggested that running parallel sessions might be more beneficial for the patients (Figure 7.3).

'I find it easier to be open to the principles of ACT and try to deliver information... the kind of information we deliver on pain education and things like that and talking to the patient about when they talk about their experience of their pain and ... like I use the principles of ACT when talking to them, but it's not a structured session obviously and I think that's easy enough to incorporate into an Osteopathy treatment.' (Laura, osteopath)

'I think like we said before probably the best way to target that bit would be to not call it ACT, Not physically go for 'Now we're going to do a bit of ACT' but really just kind of 'hide it' in your treatment with just your interaction, your day-to-day interaction with your patients, just the way you address them, the way you ask them about how they're doing and the way you inform them, just to 'hide it' in there rather than as specifically named bit of the treatment, just kind of have it woven *into it, more than anything.* (Lilly, osteopath)

Another osteopath raised some concerns regarding the practicality of incorporating ACT and felt particularly apprehensive about adding something extra to the treatment time. She also expressed her concern that they would have to take something away (from the Osteopathy sessions) to accommodate the embedding of ACT. One of the other osteopaths, with a background in counselling and experienced in providing brief therapy argued that in his opinion ACT could be incorporated in the way they

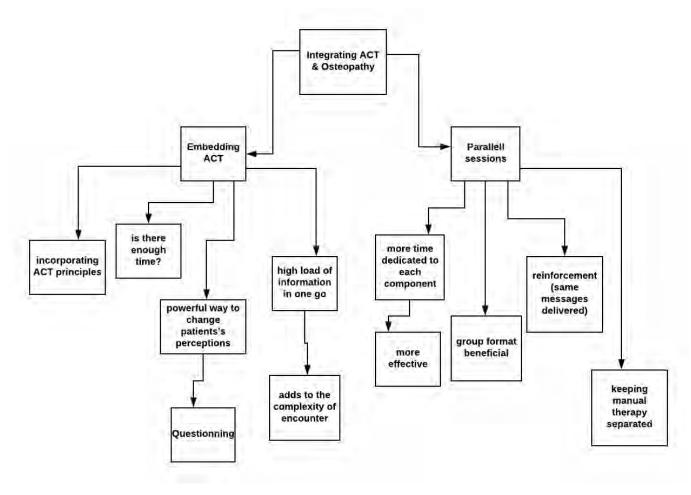


Figure 7.3: Flowchart illustrating two different ways of incorporating ACT

deliver Osteopathy sessions without problems and it would be a powerful way of helping people change their perception about pain.

'I would also look at the practicality of it so during a normal treatment session now, without any ACT in it, as a specific thing I already feel that I fail the treatment time easily ... and I would be slightly apprehensive about taking something away by adding something else to it. There is already so much going on I think it would... It would almost be overwhelming for us, not necessarily the patient but for us as well to juggle so many different approaches to one patient at the same time umm... It is quite a challenge that, 'cause you're trying to look at so many aspects of themto have another specific thing added to that though probably useful in specific cases, it would really add to the complexity of a clinical encounter, I would say.' (Evie, osteopath)

'I think of it slightly different 'cause I ran a behavioural unit for children and we used brief therapy and it's amazing how quickly you can... you can umm get people to change their perception of something and while you're working on them osteopathically just use a very, very brief question to them, to get them to think about their pain in a different way. I think it could be incorporated, just naturally, *just into the natural way that we're working.'* (Nick, osteopath)

The osteopaths who supported the idea of running parallel sessions suggested that this could potentially be more effective as there would be more time to address both the physical and psychological aspects of pain. In addition to that, there was a consensus that, if patients would be receiving the same message (e.g. pain education, advice on managing pain) from two professionals with different backgrounds, this would serve as reinforcement and they would be more likely to adhere to the recommendations. There was another subtle sense that osteopaths should be working within the boundaries of their profession and that delivering psychological interventions does not fit well with the remit of Osteopathy ('we're Osteopaths, we're doing osteopathic work').

'If it's one person you're talking to and they are telling you all these things you 've never believed and now you've suddenly have to change to that, you might, but you might also think 'Oh, that's what you think' whereas if you hear it from an additional person in an outside session along the same lines, obviously you're not going to say the exact same things, but along the same lines, it will strengthen each other. Both will be strengthened by it I think. [...] This patient was actually saying when they were doing the sessions they were reminded of things that I had told them when I was giving them pain education, advice about how to move around normally and manage their condition. And they said 'Oh yeah, it reminded me of what you said.' So they were drawing parallels between the two experiences, between your guidance and mine, and...it just reinforced everything.' (Lilly, osteopath)

'And I think it goes back to what Evie was saying, it's different when someone else it's saying it like if we all keep saying the same things to the same person it just doesn't go in anymore. But if someone new who has never seen them before says what you been saying for the last twelve sessions it's going to mean something different for them that they can finally gain an understanding, in a way...' (Maya, osteopath)

'It does make sense that as a manual therapy yeah we do listen, we do educate, we do hands-on work but it's almost a bit too much going into the brain and it's good I think to dissociate and separate issues I think, like giving specialised time towards umm catastrophyzing, fear avoidance and all. And developing an awareness of oneself is equally as important and deserves as much time as hands-on work deserves. And I think that if you have it all in one session then you're not attributing enough time to all of these important sections.' (Laura, osteopath)

3c Training needs - 'If I could bring that into treatment more that would be amazing'

A crucial factor in osteopaths' confidence in incorporating ACT (one way or another) is receiving appropriate training and supervision. There was a consensus that the osteopaths' knowledge and skills in delivering ACT are lacking. One osteopath pointed out that having someone 'specialized' would be more fitting.

'We had a brief, very brief lecture on the model ACT. I think it was in the first year, and it was very brief. Many of us did not attend. '(Maya, osteopath)

'We are not super well trained in delivering ACT and so having someone specialized for that is definitely more suitable.' (Lilly, osteopath)

Three osteopaths shared valuable insights suggesting that an effective way for osteopaths to be trained in delivering ACT would be to observe someone whilst delivering it to people living with different pain conditions. There is a strong sense that the osteopaths felt 'out of their depth' when having to treat people experiencing more complex biopsychosocial issues and demonstrated willingness to add to their existing knowledge and skills.

'To be honest I would prefer to observe somebody do it rather than just have a lecture on it 'cause now we had a lecture on it and we understand a bit more but still I haven't seen it in practice. So maybe third year before going to Clinic A would be beneficial, but actually seeing somebody do it with patients who have biopsychosocial issues. ' (Rachel, osteopath)

'A good time to do would probably be summer clinic, as you're going towards clinic A because that's where we see most of like biopsychosocial issues. You see them here but I think over there they are more exaggerated and we weren't unprepared for that, many of us weren't. And we felt a bit out of our depth, and so I think have we had that training some of us would be more confident handling these kind of situations.' (Maya, osteopath)

'To actually have this part of our course where perhaps we observe, participate in a session with people who have chronic pain and actually hear, listen to them, listen to their experiences and how the experience chronic pain 'cause I guess most of us don't. So I think that would be an invaluable way of learning about the conditions, and then how to work with those people and support them. '(Nick, osteopath)

Osteopaths are ideally positioned to provide additional psychological support for people with pain and also to empower self-management (Carnes et al., 2017). The fact that they have regular contact with patients, building a collaborative rapport based on trust and cooperation, and also considering the time that osteopaths dedicate to listening to people's experiences and educating about pain puts them in an ideal position to provide additional psychological support.

'If osteopaths were to be trained to an extent where they can provide a group session, and because they see their own patients day to day, they can easily identify which patients would possibly need it and would maybe be open to it as well. And I think if I still parts were trained in that, they could themselves maybe set up a group session... I don't know.... every half year or every three months, something like that, with the patients that need it.' (Nick, osteopath)

'Yeah, I mean some people might feel much more comfortable seeing an osteopath who delivers 'bite-size chunks' of ACT (smiles). Rather than going to... a psychological session.' (Laura, osteopath)

To sum up, three major categories emerged from the Thematic Analysis: professional identity, supporting people living with pain and attitudes towards ACT. The osteopaths expressed that providing early intervention

and educating patients and professionals about Osteopathy are two significant areas that need improvement. They also raised awareness of the necessity of being trained to support people with more complex psychosocial issues. Finally, the osteopaths exhibited positive attitudes towards ACT and appeared willing to learn more about it and integrate it in their practice (should they be trained to deliver it and provided adequate mentoring and supervision).

Quantitative findings **7.**3

7.3.1 Feasibility

The feasibility of the intervention was determined by assessing the recruitment process and the measurement tools. This is consistent with the MRC Guidance for developing and evaluating complex interventions (2013) (for more details see Chapter 5, section 5.2).

Recruitment process

The recruitment for this study was done through the Osteopathy clinic within the Health and Wellbeing Academy. Opened in March 2017, the Wellbeing Academy is an ARCH¹ initiative aiming to ease pressure on the health services and improve health and wellbeing through a range of approaches and treatments that enable people from South West Wales to manage their care.

Over six weeks (March-April 2018), the Osteopaths practising in the clinic referred twenty of their clients to the program. Fifteen people attended a brief pre-intervention discussion with the main facilitator, who informed them about the nature of the program and gave them the chance to ask questions. Six of them did not take part in 'A Mindful Act' due to different

¹ ARCH is made up of three partners. They are Abertawe Bro Morgannwg University Health Board (ABMU), Hywel Dda University Health Board and Swansea University.

reasons such as: undergoing psychological therapy, busy schedule, living with PTSD, feeling uncomfortable with sharing experiences with a group. In the end, there were nine people participating in the intervention.

The Osteopaths expressed that on average, there were more clients experiencing acute pain than persistent pain being seen in the clinic. However, they were very proactive throughout the whole recruitment process and closely collaborated with the facilitators. Ten Osteopaths also volunteered to observe the six sessions (with participants' consent).

Feasibility of measurement

The participants were asked to fill in five questionnaires (HADS, FABQ, CPAQ, MAAS and EQ5D-5L) at baseline, upon completing the program and after one month. They had the choice between filling in the questionnaires in the session (on I pads provided by the Health and Wellbeing Academy) or at home, on their personal devices. Data collection was done with the help of Qualtrics, a platform that made it possible to test the survey for flow and accessibility and therefore ensure that the survey is user-friendly. Furthermore, exporting data from Qualtrics to SPSS was very straightforward.

Time filling in survey

The participants reported spending on average 10 minutes completing in the questionnaires (Table 7.5) and also expressed that they did not experience any difficulties.

Missing data

Given that the Fear Avoidance Beliefs Questionnaire (FABQ) included a subscale addressing beliefs about work, and the fact that some of the participants had a different employment status (two were retired, one received disability support, and another was a job seeker) the participants were instructed by the main facilitator to leave the questions that do not

apply to them blank. There was no other missing data. The same was true for the end of the program survey and the follow-up.

Follow up response rates

One month after the end of the program, the participants were sent a link to the Qualtrics survey, followed by several reminders. They were also asked to fill in an additional five questions in regards to their knowledge of ACT principles and using the information and skills that they acquired during the program (see appendix A.13). The follow-up response rate was 100%.

7.3.2 Acceptability

Acceptability was conceptualised as the extent to which participants and facilitators consider the intervention appropriate (Sekhon et al., 2017). It included assessing prospective acceptability, intervention coherence and adherence.

Prospective acceptability

Barriers to taking part were assessed with the help of one to one interviews. The participants expressed that there was nothing hindering their participation.

Burden

As was mentioned before, six individuals chose not to take part. The reasons varied: one of the participants was living with PTSD and also had low mobility while another one was a researcher with a very busy schedule. Others were undergoing psychological therapy or did not feel comfortable in a group setting.

None of the nine people taking part in 'A Mindful Act' dropped out. One participant missed the last three sessions due to holiday plans while another one was working extra hours and could only attend two of the six sessions.

7.3.3 Intervention coherence and adherence

Attendance

The overall attendance over the six weeks of the program and the one to one interview following the intervention was 82.5% (see appendix A.14). The main facilitator sent frequent reminders (usually before each session) to the participants and was flexible in accommodating participants' preferences in terms of dates and time for the one to one interview. There was also flexibility in regards to arriving late for the sessions (sometimes, due to traffic some participants arrived slightly later).

Homework completion

The participants dedicated on average 30 minutes each week to fill in the homework exercises in the workbook. They also suggested that they reflected upon the homework throughout the week. Some of the participants expanded on the homework, for example, Sophie designed her own pie chart containing healthy self-care practices (see appendix A.15). Another example is Sara, who started a mindfulness journal containing entries about her bodily sensations and emotions, but also creative ideas and drawings (see appendix A.16). She also designed a pie chart on self-care and self-compassion and decided to use it as a screen background for her mobile phone. Simone also started a Mindfulness journal and a ' Happiness planner;' for day- to- day goals and ideas.

All of the participants actively contributed to the group discussions about homework that took place at the beginning of each session. They shared their experiences of filling in the exercises and also had the opportunity to get to know each other better through this activity.

ACT basic definitions quiz

By the end of the course, participants became familiar with the ACT tenets and were able to correctly link six statements to the corresponding ACT principles (see Appendix A.17).

Intervention adherence at one- month follow-up

One month after the end of the program, the participants reported that they still practiced the skills that they learned. All nine confirmed that they were still practising Mindfulness and were motivated to continue. They referred to the sense of peace and calmness that it creates, to relaxing effect, improved focus and better awareness and management of the symptoms (see appendix A.18).

'I enjoy how relaxed I am when practising mindfulness and this then enables me to enjoy being in the moment which made me realise how I never did this.' (Diane, intervention participant)

'Better awareness and management of my symptoms. Meditation practise give me a *short break from my symptoms.'* (Sara, intervention participant)

'The sense of calm and peace I get from it.' (Jasmine, intervention participant)

Participants expressed that they keep practising acceptance, self-care, values, self-compassion, defusion and self-as-context (see figure 7.4). All of them continued practising Mindfulness (in one way or another) and the majority integrated acceptance, self-care and self-compassion and values into their lives.

When asked the question: 'Have you encountered any difficulties to do with practising Mindfulness or ACT?' the participants enumerated different issues:

'Life events get in the way' (Sophie, intervention participant)

'I do find that I seem to think more about mindfulness when I feel stressed; when all is going well it takes a back seat.' (Kevin, intervention participant)

'Just finding some time during that day to focus on myself' (Hannah, intervention participant)

'Recent worsening of my symptoms has set me back with acceptance; being mindful of my symptoms at all times I find challenging, I am not always self-compassionate of my mistakes' (Sara, intervention participant)



Figure 7.4: Engaging with ACT at one month follow-up

'I felt guilty at first for taking half an hour or so a day to concentrate on my mindfulness, this soon went when I started to using mindfulness/ ACT in my everyday life; the more I practised the more natural this has now become.' (Diane, intervention participant)

'Sometimes the pain was too much to concentrate' (Naomi, intervention participant)

It was to be expected that the participants would experience some difficulties that could hinder their progress. This was discussed during the last session of the program when there was a consensus that challenges are normal and the best way to move forward is to go back to practising mindfulness, accept that this is part of life and be self-compassionate in spite of hindrance.

Being able to step back and reflect on the things that got in the way of practising ACT suggests an increase in self-awareness. In addition to that, participants identified that the longer they practise these skills the more they become integrated into their daily lives.

7.3.4 Statistical analysis

This section includes the results of investigating the differences in mean scores of depression, anxiety, fear-avoidance, mindfulness, psychological flexibility and general health status at four-time points (pre-, post-intervention and one-month follow-up). In an initial phase, the data was inserted into SPSS. Frequencies, as well as descriptive statistics (means and standard deviations), were calculated. In addition participants' reported pain type and associated conditions were presented (see table 7.7).

Frequency distributions

Most of the participants taking part in 'A Mindful Act' were women (8), which is consistent with the literature suggesting that more women are reporting to experience persistent pain than men (Breivik et al., 2006; Haukenes et al., 2014, Ahlgren et al. 2016). In regards to age, four of the nine participants were between 30-39 followed by two others who were between 60-69 years old and the three remaining between 50-59, 40-49 and 21-29 respectively. Most of the participants were married (56%), White (89%) and had obtained at least an undergraduate degree (44%). The majority of participants were in employment (four employed, two self-employed) while two were retired and one was on disability allowance.

Type of pain and associated conditions

The group was heterogeneous: the participants reported living with different types of pain: five out of nine experienced either back or lower back pain and two of them also lived with neck pain in addition. There were three participants diagnosed with endometriosis and reported experiencing severe pain in the pelvic region. One participant reported living with neuropathic pain and central sensitization, as well as chronic fatigue and depression.

Other participants also reported migraines (two), sciatic pain (two) and arthritis (one). The majority of participants experienced three or more types of pain and associated physical or psychological issues, which is in line with previous literature pointing out that individuals with pain often present with more than one pain condition (Davies et al., 2011).

Participant	Pain type and associated conditions
Kevin	Neck Pain, Lower Back Pain, Migraines, Arthritis
Jasmine	Fibromyalgia, Migraine, Sciatica, Carpal tunnel
Sara	Central sensitization, Neuropathic pain, Chronic fatigue
Sophie	Knee pain
Emily	Back pain
Naomi	Endometriosis
Diane	Endometriosis, Neck and back pain, Migraines
Simone	Endometriosis, Sciatic pain, Low back pain
Hannah	Back pain

Table 7.7: Self-reported type of pain and associated conditions

Descriptive statistics

Depression (HADS)

There was a decrease in mean depression scores, as measured by the HADS scale from baseline to completion of the program, followed by a slight increase at one-month follow-up (see table 7.8). The variance in mean scores seemed to be low and relatively constant across the three time points.

Depression (HADS)	Mean	SD	N
Baseline	17.1	4.56	9
Completion	13	3.42	9
Follow-up	14.8	4.54	9

Table 7.8: Descriptive statistics for depression (HADS)

Anxiety (HADS)

The trend in mean scores for anxiety was similar to the one in depression: there was a decrease from baseline to the end of the program, followed by a slight increase after one month (Table 10). The standard deviation was low, indicating that the data points tended to be close to the mean. Females reported higher anxiety scores at baseline, while upon completion and at follow up there were no gender differences in anxiety (see table 7.11).

Anxiety (HADS)	Mean	SD	N
Baseline	19	5.33	9
Completion	14.85	4.34	9
Follow-up	16.44	5.76	9

Table 7.9: Descriptive statistics for Anxiety (HADS)

Mindfulness (MAAS)

In relation to mindfulness, the mean scores seemed to be very similar across the three time points (Table 11). However, it appears that the variance at baseline was higher than upon the end of the 6 weeks or after one month. The level of mindfulness at baseline seemed to vary, with some participants reporting high scores and others scoring lower (see figure 7.5).

Mindfulness (MAAS)	Mean	SD	N
Baseline	49.44	15.15	9
Completion	54	6.63	9
Follow-up	54	7.33	9

Table 7.10: Descriptive statistics of Mindfulness (MAAS)

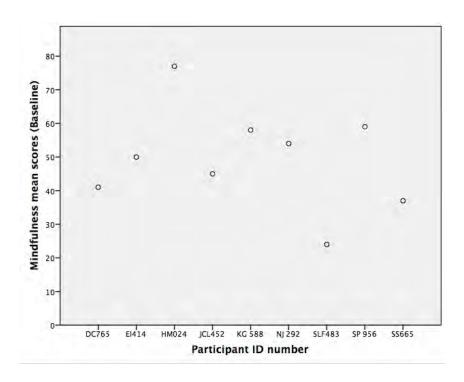


Figure 7.5: Scatterplot illustrating the distribution of Mindfulness scores at baseline

Fear avoidance (FABQ)

There was a decrease in mean scores for fear-avoidance from baseline to the end of the program, followed by an increase after one month (Table 12). The variance in scores at follow up was greater than at baseline and completion, which indicates that the fear-avoidance scores were widespread, with some participants obtaining low scores (20-30) and others scoring higher (50-70) (Figure 7.6).

Mindfulness (MAAS)	Mean	SD	N
Baseline	40.80	7.24	9
Completion	28.69	7.34	9
Follow-up	37.66	15.68	9

Table 7.11: Descriptive statistics for fear avoidance (FABQ)

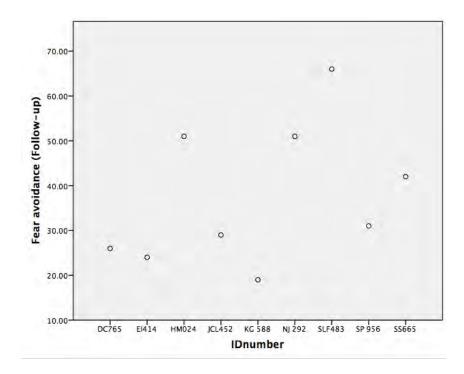


Figure 7.6: Scatter plot illustrating the variance in fear avoidance mean scores at one-month follow-up

Pain Acceptance (CPAQ)

An increasing trend can be observed in pain acceptance mean scores from baseline to the end of the program (66.11 to 77.37), followed by a decrease after one month. In addition, there was a similar trend I one of the two subscales of CPAQ, measuring activities engagement (from 40.55 to 49.12), the only difference being that the mean scores in activities engagement remained almost the same at follow-up (46.55). This is consistent with the participants 'accounts, suggesting that they increasingly engaged in social activities after taking part in the intervention and also became more confident.

Pain Acceptance (Total)	Mean	SD	N
Baseline	66.11	16.22	9
Completion	77.37	14.21	9
Follow-up	67.77	16.39	9
Activities engagement	Mean	SD	N
Baseline	40.55	6.85	9
Completion	49.12	8.60	9
Follow-up	46.55	8.87	9

Table 7.12: Descriptive statistics for pain acceptance (CPAQ) and activities engagement subscale

EQ-5D-5L

Considering participants' self-reported health status, descriptive profiles were compiled for each of the nine participants, in order to observe changes in the five dimensions of EQ-5D between baseline, end of program and follow-up (see table 7.15). Five out of nine participants reported improvements in their mobility, mostly from having moderate problems walking about to only slight problems (3 to 2). Similarly, five participants showed improvements in self-care (mostly from having slight problems washing and dressing themselves at baseline to having no problems at all at the end of the program and follow-up). In regards to performing their usual

activities, three participants reported having severe problems initially, while after six weeks and at one-month follow-up they only had moderate or slight issues. In addition, another two participants went from having moderate problems performing usual activities to slight problems or none at all. Three participants reported improvements in regards to pain and discomfort (from 5 'I have extreme pain or discomfort' or 4 'I have severe pain and discomfort' to 3 'I have moderate pain or discomfort'). Finally, five of the nine participants declared that there were changes in regards to feeling anxious or depressed (from being moderately or slightly anxious or depressed to not being anxious or depressed at all). One participant went from being severely depressed or anxious at baseline to only slightly at the end of the program and moderately at one-month follow-up (see table 7.15).

Health States (T1, T2, T3)	Mobility	Self-care	Usual activities
T1 22453 T2 22442 T3 21232	2 I have slight problems in walking about 2 2 I have slight problems in walking about	2 I have slight problems washing or dressing myself 2 1 I have no problems washing or dressing myself	4 I have severe problems doing my usual activities 4 2 I have slight problems doing my usual activities
T1 31442 T2 31331 T3 21331	3 I have moderate problems in walking about 3 2 I have slight problems in walking about	1 I have no problems washing or dressing myself 1	4 I have severe problems doing my usual activities 3 I have moderate problems doing my usual activities 3
T1 32331 T2 31232 T3 31331	3 I have moderate problems in walking about 3	2 I have slight problems washing or dressing myself 1 I have no problems washing or dressing myself 1	3 I have moderate problems doing my usual activities 2 I have slight problems doing my usual activities 3
T1 33333 T2 33332 T3 22343	3 I have moderate problems in walking about 3 2 I have slight problems in walking about	3 I have moderate problems washing or dressing myself 3 2 I have slight problems washing or dressing myself	3 I have moderate problems doing my usual activities 3 3

Health States (T1, T2, T3)	Mobility	Self-care	Usual activities
T1 21232 T2 11121 T3 11121	2 I have slight problems in walking about 1 I have no problems in walking about 1	1 I have no problems washing or dressing myself 1	2 I have slight problems doing my usual activities 1 I have no problems doing my usual activities 1
T1 32443 T2 31343 T3 31344	3 I have moderate problems in walking about 3 3	2 I have slight problems washing or dressing myself 1 I have no problems washing or dressing myself 1	4 I have severe problems doing my usual activities 3 I have moderate problems doing my usual activities 3
T1 31344 T2 31342 T3 31343	3 I have moderate problems in walking about 3	1 I have no problems washing or dressing myself 1	3 I have moderate problems doing my usual activities 3
T1 32322 T2 21221 T3 21222	3 I have moderate problems in walking about 2 I have slight problems in walking about 2	problems washing or dressing myself	3 I have moderate problems doing my usual activities 2 I have slight problems doing my usual activities 2
T1 43454 T2 44454 T3 33454	4 I have severe problems in walking about 4 3 I have moderate problems in walking about	3I have moderate problems washing or dressing myself 4 I have severe problems washing or dressing myself 3 I have moderate problems washing or dressing myself or dressing myself	4 I have severe problems doing my usual activities 4

Pain/Discomfort	Anxiety/Depression
5 I have extreme pain or discomfort 4 I have severe pain or discomfort 3 I have moderate pain or discomfort	3 I am moderately anxious or depressed 2 I am slightly anxious or depressed 2
4 I have severe pain or discomfort 3 I have moderate pain or discomfort 3	2 I am slightly anxious or depressed 1 I am not anxious or depressed 1
3 I have moderate pain or discomfort 3 3	1 I am not anxious or depressed 2 I am slightly anxious or depressed 1 I am not anxious or depressed
3 I have moderate pain or discomfort 3 4 I have severe pain or discomfort	3 I am moderately anxious or depressed 2 I am slightly anxious or depressed 3 I am moderately anxious or depressed
3 I have moderate pain or discomfort 2 I have slight pain or discomfort 2 I have slight pain or discomfort	2 I am slightly anxious or depressed 1 I am not anxious or depressed 1
4 I have severe pain or discomfort 4 4	3 I am moderately anxious or depressed 3 4 I am severely anxious or depressed
4 I have severe pain or discomfort 4 4	4 I am severely anxious or depressed 2 I am slightly anxious or depressed 3 I am moderately anxious or depressed
2 I have slight pain or discomfort 2 2	2 I am slightly anxious or depressed 1 I am not anxious or depressed 2 I am slightly anxious or depressed
5 I have extreme pain or discomfort 5 5	4 I am severely anxious or depressed 4 4

 Table 7.13: EQ-5D-5L: T1- Baseline; T2- End of program; T3- One-month follow-up

7.3.5 Inferential analysis

Repeated measures (within-subjects) ANOVA

A one-way repeated measures ANOVA was conducted in SPSS to reveal differences in depression, anxiety, mindfulness, fear-avoidance, pain acceptance and health status between the three time points (baseline, end of the program and one-month follow-up).

There was a decrease in fear-avoidance between baseline and completion $[F(2,16) = 6.54, \eta^2 = .450, p = .014]$ as shown by the Post-hoc test (Bonferroni).

A significant increase in activities engagement (CPAQ subscale) mean scores between baseline and the end of the program was revealed [F(2,16)]6.96, p = .012, $\eta^2 = .466$]. In addition, there was also an increase in activities engagement between baseline and follow-up (Mean difference= 6(1.74), p = .026).

In regards to the EQ5D-5L, there was a significant increase in mobility between baseline and follow-up $[-F(2, 16) = 5.46, p = .016, \eta^2 = .406;$ Mean difference = .556(.176), p = .040], as well as an increase in usual activities between baseline and completion $[F(2,16) = 4.53, p = .03, \eta^2 = .36]$. Finally, there was an increase in self-care between baseline and follow-up [F(2, 16)]4.53, p = .03, $\eta^2 = .36$; Mean difference = .556(.176), p = .040].

There were no significant differences in depression, anxiety, mindfulness, pain acceptance and health status (VAS)...

Summary of Chapter 7 7.4

To sum up, the intervention appeared to be feasible, with the support and collaboration of the HWBA, and the osteopaths who helped to engage the participants and aided in the delivery of the intervention. In regards to the measurement tools, the participants expressed that they were not burdened by having to fill them in and that it took them 10 min on average to do so. The follow-up response rate was 100%.

The intervention was found to be acceptable by those taking part, who reported that there were no barriers to participating and that they had positive experiences. The attendance rate was 82.5% and the participants appeared to have engaged well with the homework exercises and with the ACT model in general. At one-month follow-up, despite sharing that there were some difficulties in practising the skills acquired during the program, the participants reported that they continued to practice mindfulness, and applying their knowledge of ACT to their personal circumstances.

Finally, the statistical analysis revealed a decreasing trend in overall fear avoidance, as well as several increasing tendencies in what concerns activities engagement, mobility, performing usual activities and self-care. This is consistent with the qualitative findings, suggesting that the participants in 'A Mindful Act' became more confident in their abilities and thus engaged in social activities more, were more self-compassionate and devoted more efforts to self-care.

8 Discussion and Conclusion

8.1 Overview of the chapter

This chapter will present a discussion of the overall findings of this research and will comprise of several sections including: a synthesis of the key findings, a comparison with existing literature, an outline of the strengths and limitations, reflexivity, the implications of the findings for future research and practice, future directions and concluding remarks.

8.2 Summary of the overall key findings

The overall aim of this research was to develop a novel psychosocial intervention to accompany osteopathic treatment for people who live with persistent pain and psychological comorbidities, guided by the MRC framework for developing complex health interventions (Craig et al. 2000, 2008). The development process was iterative and contained a series of studies including: a preliminary qualitative study based on focus groups and interviews with people living with long-term pain and osteopaths (Chapter 5), a systematic review investigating the effects of osteopathic treatment on psychosocial outcomes in people with persistent pain (Chapter 3) and a study evaluating the feasibility and acceptability of the novel intervention (Chapter 7).

The preliminary qualitative study aimed to inform the development of a novel intervention by providing an insight into people's experiences of living with pain. The results showed that pain impacted participants' lives

in different ways, by leading to changes in self-perception, influencing their ability to perform daily activities, contributing to stigma and isolation but also helping them develop more compassion towards self and others. Participants shared different experiences with pain management and navigating the healthcare system but were willing to engage in a novel intervention based on mindfulness and ACT. The osteopaths who took part in the focus group held a range of different views in relation to their experiences that were described by three major categories: professional identity, experiences of engaging people living with persistent pain and osteopaths' attitudes towards training to deliver ACT. There was a consensus that holism and mind-body integration were fundamental to their profession, in contrast with the biomedical professions that held a dualistic view, regarding pain as a physical ailment. In addition, most of the osteopaths expressed their frustration with having to justify themselves to the medical professionals, however, they also seemed discontented with their own profession for lacking a clear identity and an established evidence base. In addition, osteopaths viewed pain as a subjective multifaceted experience that varied hugely between individuals, whose lives were impacted in different ways. The participants emphasized the role of osteopaths in proving patient education, addressing psychological aspects of pain that are usually overlooked (e.g. fear avoidance), and using simple language to remove the threat that patients perceive of pain or their condition.

The systematic review was one of the few to investigate whether osteopathic treatment affects psychosocial factors relevant to persistent pain. The trials included in the review revealed that Osteopathy does affect psychosocial outcomes to some extent. Participants undergoing osteopathic treatment were found to experience less anxiety and fear avoidance. The majority of trials also showed significant improvements in health-related quality of life in the Osteopathy groups.

The feasibility and acceptability study (see chapter 7) showed that the intervention was feasible with the support and collaboration of the HWBA and the osteopaths who helped to facilitate the recruitment process. The participants expressed that the measurements tools took 10 minutes on average to complete and did not burden them. The follow-up response was 100%. In addition, the intervention was found to be acceptable by those taking part, who reported that there were no barriers to participating and that they had positive experiences. The attendance rate was 82.5% and the participants appeared to have engaged well with the homework exercises and with the ACT model in general. At one-month follow-up, despite sharing that there were some difficulties in practising the skills acquired during the program, the intervention participants reported that they continued to practice mindfulness, and applying their knowledge of ACT to their personal circumstances. The statistical analysis revealed a decreasing trend in overall fear avoidance, as well as several increasing tendencies in activities engagement, mobility, performing usual activities and self -care. This is consistent with the qualitative findings, suggesting that the participants in 'A Mindful Act' became more confident in their own abilities and thus engaged in social activities more, were more selfcompassionate and devoted more efforts to self-care.

The analysis of the focus group involving the osteopaths who played a role in recruitment resulted in three major categories: professional identity, supporting people living with pain and attitudes towards ACT. The osteopaths expressed that providing early intervention and educating patients and professionals about Osteopathy are two significant areas that need further improvement. They also raised awareness of the need for training to better support people with more complex psychosocial issues. Finally, the osteopaths exhibited positive attitudes towards ACT and appeared willing to learn more about it and integrate it in their practice (should they be trained to deliver it and provided adequate mentoring and supervision).

8.3 Comparison with previous research

This section will place the findings of this research in the context of existing literature. A comparison with previous studies exploring the experiences of people living with pain will be provided. In addition, the results of the systematic review will be integrated with similar findings from the literature. The feasibility and acceptability of the intervention will be discussed in relation to comparable interventions.

8.3.1 Findings from the preliminary qualitative study

There is a substantial volume of research literature centred on gaining a better understanding of people's subjective experiences of persistent pain. The findings of this study are for the most part consistent with previous literature and add to this body of evidence.

Bunzli et al., (2013) conducted a meta-synthesis on eighteen qualitative studies exploring patients' experiences of living with chronic low back pain. One of the emerging themes focused on participants' perceived changes in identity, and the dichotomy between the past and present self, resulting in feelings of shame, self-loathing, distress and grief. Several studies described a sense of altered identity emerging as a consequence of pain. The present study revealed a similar theme, that captured the discrepancy between the 'old self' that was able to fulfil certain roles and the 'new self' having to renounce them due to the pain and redefine who they are. One participant, in particular, emphasized this dichotomy:

'It was a very, very trying time, it has been a very difficult journey because obviously I've gone from, you know, I was a workaholic, my profession was very important to me. I've lost my house, I lost my car, I lost everything. Oh, who are you?' then you say:' I'm this or that', and then to be nothing at all, you know...' (Gabriele, interview participant)

Bunzli et al. (2013) argued that people living with CLBP live in a 'suspended ' state, putting their life 'on hold' hoping to resume their former painfree lives. In addition, the meta-synthesis revealed another recurrent theme that is also present in this study 's findings: stigmatization. Participants in several of the studies included felt that society viewed them as burdens, without value or virtue, which lead them to withdraw from social contact and become isolated in order to avoid letting others down. This was also reported by two of the participants in this study, who felt misunderstood disbelieved and stigmatized by others due to the 'invisible' nature of their pain.

The findings of this study are also in line with a meta-ethnography of thirty-eight qualitative studies focusing on the subjective experience of CLBP (MacNeela et al., 2015). The themes that surfaced from these studies described the disruptive and disempowering influence of pain on all levels as well as unsatisfying relationships with professionals and frustration with medical treatment and learning to live with pain. The participants in the present study also reported having been negatively impacted by pain, describing a loss of roles and inability to perform functional daily activities, feelings of depression and isolation and difficulty in navigating the healthcare system.

Negotiating the healthcare system is a recurrent theme in pain literature. Participants in the present study shared they experiences of accessing an array of different treatments and modalities (e.g. pharmacological interventions, physiotherapy, mind-body interventions, manipulative therapies, natural products) and consulting various health professionals, reporting both positive and negative experiences. Some health professionals proved to be supportive and empathetic while others were dismissive, refusing to acknowledge the symptoms and denying treatment and support. At the same time, participants felt compelled to try different avenues in order to uncover the aetiology of their pain and find effective

pain relief. This is consistent with the results of a qualitative synthesis of sixty studies exploring people's experiences of chronic non-malignant musculoskeletal pain (Toye et al., 2013). They revealed that people were referred back and forth between different professionals, hoping to find a cure, in a system that failed their expectations but in which they felt 'trapped'. The synthesis also emphasized the loss of roles that people experienced, leading to a diminished self-worth as well as a struggle to find a balance between appearing like their old self and showing symptoms in order to maintain credibility and being acknowledged. Despite this struggle, the participants showed a sense of moving forward alongside the pain. This is similar to a theme from the present study (see chapter 5, section 5.3, theme 1.4), describing the experience of one of the participants, who viewed pain as an opportunity for self-development, an experience that lead her to becoming more compassionate with herself and others, and that have helped shift her perspective on life.

This qualitative study is similar to a study published by Snelgrove and Liossi (2009). They conducted semi-structured interviews with a sample of ten participants who were interviewed prior to their attendance at a chronic pain clinic. The study aimed to gain a detailed insight into the meaning of CLBP for people with long-lasting pain experiences. Although Snelgrove and Liossi (2009) utilized a different method of data analysis (IPA), the sample size was similar to the one employed in the current study. In addition, there are similarities in the findings of the two studies. Some of the themes emerging from their study were also reflecting the experiences shared by the participants in this study. The negative self-regard together with the impaired functioning appeared to affect participants' self-esteem. Pain was perceived as a threat, as something prohibiting people from performing daily activities and maintaining normality. This is also present in the current study. Reduced mobility and functioning, as well as the inability to perform usual activities (house chores, shopping), appeared to lead to a decrease in participants' self-esteem

'In fairness, I would like something to keep me going a bit longer so that I can do more of the things that I used to do before I had to stop. I found it very depressing.' (Jane, focus group participant)

Moreover, Snelgrove and Liossi's study revealed that the invisible nature of CLBP contributed to a lack of understanding by others (Snelgrove and Liossi, 2009). This matches well with the experiences of some of the participants in this study, who expressed that they felt misunderstood by others, who could not accept that although pain was not visible it was very real, or that living with pain is as difficult as living with a different chronic condition. One of the participants also emphasized the difficulty to preserve authenticity in spite of living with long-term pain

'So, you know, finding the path of authenticity is very difficult, and also the judgement that if you are having a good day, and you put your make up on, [...] when you do do those sorts of things, people think: 'There isn't much wrong with you, is there?' So you are really in a double bind situation with these sorts of *illnesses.'* Gabrielle, interview participant)

Although the findings of this study are similar to those existent in the literature, they add some novel aspects. The experience of pain as a guide to personal growth is an area that needs to be explored more. There are people living with persistent pain who regard it not as a threat, but as a 'teacher', showing them how to be more self-compassionate and caring. In addition, the current study also tried to gain an understanding of the willingness to engage in a novel intervention, which is a very useful aspect, since it can reveal people's beliefs about the new program and also highlight potential barriers early.

8.3.2 Systematic review findings

The current evidence base looking at the effects of Osteopathy on psychosocial factors associated with persistent pain is very limited. There are only a small number of studies in this area and more research is needed. The findings of this review are consistent with those obtained by Williams et al. (2003), authors of the first review of spinal manipulation examining psychosocial outcomes. Their review included twelve studies reporting psychological outcomes, six of which had a verbal comparator. The findings revealed a small benefit of spinal manipulation compared to verbal interventions. Additionally, there was a small benefit of spinal manipulation compared to physical interventions (exercise). It is important to note that it is unclear whether the improvements were due to the distinct characteristics of the compared interventions or due to incidental placebo effects. The authors acknowledged that the psychological effects resulted from certain characteristics of the treatment (reducing distressing symptoms such as pain and fear). The present review revealed similar effects to the UK BEAM trial that indicated a significant improvement in fear-avoidance beliefs as a result of manipulation and exercise.

The majority of studies included in the review reported significant improvements in health status (six out of seven) and quality of life (three out of four). These results are to some extent similar to those obtained by Verhaeghe et al., (2018). They carried out a systematic literature review evaluating the impact of osteopathic care for spinal complaints. The review selected nineteen randomized controlled trials conducted in high-income Western countries that examined pain and functional status as well as medication use and health status. The results revealed that osteopathic care might improve pain and functional status in patients with spinal complaints. In addition, the impact of osteopathic care on health status was investigated in six studies, two of which showed significant differences in favour of the osteopathic care compared to no intervention (Licciardone et al., 2003; Engemann and Hofmeier, 2009). Schwerla et al., (2008) revealed significant differences in health status between osteopathic care and a sham intervention, while Chown et al., (2008) suggested that health-related quality of life significantly improved in individuals receiving osteopathic care as well as in the physiotherapy group. The UK BEAM trial revealed a

significant difference between osteopathic care paired with best care vs. best care alone, for the physical component of SF36 at three months, and nine months follow-up and for the mental health component only at the end of the treatment phase (UK BEAM Trial, 2004). Although their review focused primarily on pain and functional outcomes while our review centred on the effect of Osteopathy on psychosocial outcomes, there was an area of overlap and that was health status. Both reviews suggested that osteopathic care may improve health status, however, more research needs to be done to further investigate these outcomes.

8.3.3 Feasibility and acceptability study findings

The only comparable intervention to date combining Osteopathy and ACT is OsteoMap, an innovative program piloted over a period of three years at the University College of Osteopathy (formerly known as the British School of Osteopathy) (Nanke and Abbey, 2017). It is important to mention that the scale of the OsteoMap project is much larger than the intervention developed during the three years of this PhD and benefited from extensive resources. However, at a conceptual level, both OsteoMap and 'A Mindful Act' are based on the same principle: integrating Osteopathy and ACT in a program designed for people who live with persistent pain. The findings of the present feasibility and acceptability study are similar to those reported by Nanke and Abbey (2017) describing the feasibility study they conducted as part of the first stage of developing the intervention. The participants taking part in their study were fairly similar in number and characteristics to the participants participating in 'A Mindful Act'. The inclusion and exclusion criteria used in the two studies were very similar, with the only exception that our study included people living with pain who also experienced experiencing one or more of the following: depression, anxiety, fear-avoidance, catastrophyzing. The intervention they piloted was comparable to our intervention in terms

of duration (6 weeks), structure and content. Both interventions touched upon understanding persistent pain, developing acceptance, learning about defusion, mindfulness and personal values, practising self-compassion and self-care. In addition, both programs were delivered by a psychologist in collaboration with an osteopath; they were both built on open-source materials, complemented by homework practice. Although both feasibility studies employed a mixed-method design, the outcome measures collected differed, except for the Chronic Pain Acceptance Questionnaire (CPAQ). In addition, the outcome measures were collected at similar time points with our study, with the exception of the follow-up (baseline, six weeks and three months). While Nanke and Abbey (2017) collected qualitative data using semi-structured telephone interviews at completion and after three months, we conducted individual face-to-face interviews two weeks after the end of the program. Although both Osteomap and 'A Mindful Act' integrated Osteopathy and ACT, these interventions differ in many aspects (see above points).

The findings of the two studies are similar to a certain extent. The experiences of the participants in Osteomap were described by four themes: increased awareness and acceptance, engagement with valued activities, peer group experiences and unhelpful aspects of the course (Nanke and Abbey, 2017). The major categories resulting from our analysis were similar: engaging with ACT, experiences of taking part and perceived changes. Both interventions were feasible and considered acceptable by the participants, who reported improvements in psychological flexibility. The participants in 'A Mindful Act' shared positive experiences: they found being able to connect with people who experience similar issues valuable and also expressed that they liked the content, structure of the program of the facilitators. This is very similar to the experiences of the participants in 'Living well with pain, who expressed that mutual support, sharing experiences and learning with other people was beneficial (Nanke and Abbey, 2017). Participants in the intervention described behaviour change related to physical fitness,

an increase in awareness and more engagement in social activities that brought them satisfaction. Participants in 'A Mindful Act' shared some similar changes, mostly in their perspective on moving forward with pain, shifting their attention towards values and engaging in social activities more. This finding was supported by the questionnaire data that revealed a decreasing trend in overall fear avoidance, as well as several increasing tendencies in what concerns activities engagement, mobility, performing usual activities and self -care. This supports the finding that there were small but sustained improvements in mean scores for activity and pain acceptance at three-month follow-up (Nanke and Abbey, 2017).

8.3.4 Experiences and perspectives of Osteopathy students involved in recruiting participants for the intervention

The student osteopaths who took part in the focus group addressed issues related to their professional identity and also discussed their experiences supporting people with persistent pain. In addition they expressed different attitudes towards 'A Mindful Act' and shared their perspectives on incorporating Osteopathy and ACT.

The view of Osteopathy endorsed by most of the participants revolved around holism, hands-on techniques, patient-centeredness and patient education. This is similar to a certain extent to the findings reported by Formica et al. (2018) who conducted a qualitative study based on semi-structured interviews with a sample of eleven osteopaths practising in Italy. The authors concluded that osteopaths showed a greater inclination towards the biomedical dimensions of pain, rather than the biopsychosocial model (Formica et al., 2018). Although their participants acknowledged the role of psychosocial factors in the experience of pain, they highlighted a lack of skills to address these factors, suggesting that osteopaths need further training to develop a more holistic view of persistent pain,

consistent with the biopsychosocial model. The osteopaths in our study also acknowledged the crucial role of psychosocial risk factors and stressed the need to intervene early, suggesting that the longer a person lives with pain, the more likely they are to develop maladaptive beliefs about pain and psychological comorbidities. They also reported feeling unprepared and 'out of their depth' when treating people living with comorbidities such as depression

'I 've had one recent experience where I did feel out of my depth and I don't think we've had the proper training for that but I had someone with the level of depression where she was self-harming herself and at that stage I simply didn't know how to *target that...'* (Lilly, osteopath)

that leads to the same conclusion that more training is necessary to equip osteopaths with the skills and ability to support these patients. Similarly to the osteopaths in this study, the Italian osteopaths stressed the importance of patient education and empowerment, to facilitate a productive therapeutic relationship.

Furthermore, a study based on a cross-sectional survey of UK registered osteopaths aiming to test the hypothesis that osteopaths have a more biopsychosocial approach to treating patients living with persistent pain reached similar conclusions (Macdonald et al., 2018). Although osteopaths acknowledged that pain is not entirely due to physical changes, they were found to be strongly biomedical in their approach to some aspects of pain management. The study also emphasized that osteopaths were able to engage with the psychosocial factors of the pain experience but that there was scope for improvement. The authors also advanced the idea that osteopaths' understanding of biomedical domain and potential in providing psychosocial care make them ideally placed to provide comprehensive biopsychosocial care to patients (Macdonald et al., 2018).

Osteopaths taking part in this study met the prospect of integrating Osteopathy within the NHS with a sense of scepticism and suggested that

integration would involve too much compromising and that challenges would outweigh the benefits. This is inconsistent with other studies, for example, Figg-Latham and Rajendran (2017). They employed a qualitative approach to explore the beliefs and attitudes of student osteopaths working in a British osteopathic education institution. One of the major themes they described revolved around the status of Osteopathy within healthcare. The findings revealed that Osteopathy was regarded as autonomous from other manual therapies and mainstream healthcare. Furthermore, practising Osteopathy within a private setting was considered preferable. Practising Osteopathy within UK NHS was acknowledged to be different, mainly due to financial and contractual limitations (Figg-Latham and Rajendran, 2017). Humpage (2011) analysed public documents published between 2003 and 2009 referring to osteopaths' hopes, objectives, concerns and perceived barriers related to research and evidence-based medicine. A mixed-picture emerged regarding the relationship Osteopathy has with other healthcare professions, with some osteopaths suggesting they wanted to remain separate from the orthodox medical profession while others believed that Osteopathy should become more integrated within the NHS, specifically for the management of musculoskeletal conditions (Humpage, 2011). The latter felt that integrating Osteopathy within the NHS would help produce more research and help the profession become more scientific, modern and progressive.

Osteopaths held different views concerning the integration of ACT and Osteopathy, with some appearing favourable to embed ACT principles in their practice while others believed that running parallel ACT sessions might benefit patients more. To date, there are no studies exploring osteopaths' perspectives on integrating ACT and Osteopathy, however, area of research is still in its infancy.

8.4 Strengths and limitations

This section will present a discussion around the strengths and limitations of the study by addressing several aspects such as the originality and innovation of the research, the strengths of the intervention and its limitations.

Originality and innovation 8.4.1

Originality can be described as the property of a piece of work as being new or novel, different from reformulating previously known results. First of all, this research project added to the existing body of literature related to the experiences of people who live with persistent pain and psychological comorbidities. In addition, new insights were gained into osteopaths' views on their profession and perceptions of supporting people who live with pain through their practice. The systematic review conducted as part of this project and published in the International Journal of Osteopathic Medicine (IJOM) contributed to the advancement of knowledge in regards to the role of Osteopathy in the management of persistent pain and it is one of the few to explore the effects of osteopathic interventions on psychosocial factors. This represents an original contribution to osteopathic research, a field of study that could benefit from more research in the future.

Moreover, 'A Mindful Act' is an innovative psychosocial intervention for persistent pain that was carried out in a unique setting and fostering an interdisciplinary collaboration between Osteopathy and Psychology. Although 'A Mindful Act' is largely built up of freely accessible material from Russ Harris and Kelly Wilson, this intervention was a unique program adapting ACT and mindfulness material for use with people living with pain. New material was developed, for example, the presentations accompanying each of the six sessions or the workbook used by the

participants to fill in the homework practice. To date, there is only one other intervention combining Osteopathy and ACT (Osteomap) and this area of research, although promising it is still emerging. This research project contributed to the advancement of this field, also fostering future interdisciplinary collaborations.

The pragmatic approach adopted in the process of developing the intervention demonstrates innovation. The pragmatic paradigm employed translated into employing a mixture of qualitative and quantitative methods to address the research aims. In particular, given that the interviews conducted with the participants in the intervention addressed some 'a priori' concepts (related to the ACT model), a Framework analysis approach has been utilized and adapted to explore people's experiences of taking part in the program and to understand the ways in which they made sense of and implemented ACT. Adapting existing methods to address novel research needs denotes innovative thinking.

8.4.2 Strengths of the intervention

One of the strengths of the intervention is brevity. The program consisted of six two-hour sessions delivered over six weeks, which were complemented by homework practice. Many of the people living with persistent pain do not have the physical or mental resources to engage in intensive programs; therefore, a brief intervention is well suited for this particular population. Some of the common barriers identified in the literature such as scheduling, travel distance, high cost of treatment and out-of-pocket costs have been considered when designing the intervention (the programme was offered for free, the location was easily reachable by public transport and travel expenses were expected to be low, the schedule was designed in a way to facilitate attendance). These are important aspects that need to be taken into consideration in the future, when designing interventions for people who

live with persistent pain, to ensure that there will be no practical barriers to participation.

Furthermore, 'A Mindful Act' was designed to actively promote pain self-management. This was done by equipping participants with a set of knowledge and skills (e.g. learning how to embed mindfulness in daily activities or identifying personal values and learning how to set realistic goals in line with their values) that they can apply in an autonomous and flexible manner, in order to live a more fulfilling and meaningful life. The participants were encouraged to take more responsibility for their own wellbeing and to engage in self-care activities that may help improve their quality of life (balancing exercise and relaxation, pacing, adopting a balanced nutrition, developing better sleep habits).

Given that a significant barrier of implementing interventions is the necessity of trained specialists (and virtually increased costs) an advantage of this research is that both the intervention facilitators possessed the necessary knowledge and skills to deliver 'A Mindful Act', which contributed to minimizing the costs related to training specialist staff. In addition, this collaboration between Psychology and Osteopathy yielded important insights into novel ways to support and empower people living with persistent pain.

In summary, the key strengths of the intervention revolve around the brevity of the program, which is advantageous for this specific population, the fact that it actively promotes self-management by equipping participants with relevant knowledge and skills and the reduced costs involved in delivering the intervention.

8.4.3 Study limitations

The findings of this study have to be seen in light of some limitations. It is essential to acknowledge that the generalizability of the results is

limited by different factors including the limited number of participants in the intervention, lack of randomization and control group. However, the research conducted represents merely the initial groundwork needed in developing an intervention. The MRC framework stresses the importance of preparatory work to assess the feasibility and acceptability of complex health interventions prior to embarking on a full-scale evaluation (Craig et al., 2008). Assessing feasibility and acceptability is crucial in uncovering potential issues related to acceptability, compliance, recruitment, retention and delivery of the intervention. Due to the nature of this study, it was not possible to randomize participants. In addition, running more than one group would have been a better test of feasibility, however, it was not possible due to time and resource requirements. Future studies are needed to build upon this work to assess the effectiveness of the intervention and gain an understanding of the change process. In addition, future trials may benefit from including measures of pain and functioning. An economic evaluation should also be conducted to assess the cost-effectiveness of the intervention and to ensure that the costs are justified by the potential benefit.

Another limitation arises from the heterogeneity of the sample employed. Pain is a very complex and subjective experience. Previous literature acknowledged that people with persistent pain have different coping styles and different levels of psychosocial and functional impairment, which is also true for the participants in this study (Cipher et al., 2002). In addition, the participants who took part in the preliminary qualitative study, as well as those who engaged in the intervention, lived with different pain conditions (e.g. neck pain, low back pain, fibromyalgia). Although there were many similarities in their experiences of living with pain, there were also marked individual differences. There were differences in participants' needs as well as the degree to which pain impacted on their lives. While some were confident and felt capable of implementing changes, others needed more support and reassurance. Nevertheless, this is a common

pattern in studies involving people who live with persistent pain. Individual differences exist even within samples of people diagnosed with the same condition (e.g. low back pain). On the other hand, the demographic data showed that the majority of the participants who took part in the intervention were white women who were married and had at least an undergraduate degree and were currently in employment. Sampling a more diverse group of people with different cultural and ethnic backgrounds would have been beneficial, however, the demographic characteristics of the participants reflect to some extent the population of Wales.

Furthermore, it is important to acknowledge that the findings of the statistical analysis cannot be generalized due to the very small sample size and also due to its secondary role. This data merely complemented the feasibility and acceptability measures that were essential in revealing information regarding the recruitment process and the measurement tools, the prospective acceptability, intervention coherence and adherence. A trial testing the effectiveness of the intervention including standardized clinical outcome measures is needed. Using a suitable measure of pain and function like the Brief Pain Inventory (BPI) would be useful to assess the severity of pain and its impact on functioning. Despite that function can improve without changes in pain and that the focus of ACT is not on pain reduction, these are nevertheless important outcomes, recommended for use in trials involving people living with pain.

Another potential limitation might have been the fact that the main facilitator of the intervention also interviewed the participants about their experiences of taking part in 'A Mindful Act'. Ideally, the intervention facilitator would be different from the researcher collecting and analysing the qualitative data, however, this was not possible in this case, due to limited resources. This might have influenced the findings, suggesting that due to the rapport built between the participants and the main facilitator, they might have

been inclined to share greater improvements resulting from taking part in the intervention. In the future, it would be advisable to assign the task of interviewing the intervention participants about their experiences to a neutral researcher.

Finally, Osteopathy lacks a strong evidence-base and despite the fact that efforts are made to expand it by conducting more good quality studies, it is still difficult to inform decision-making based on available evidence. For example, the body of literature looking at the effects of Osteopathy on psychosocial factors associated persistent pain is limited, with only sixteen trials reporting psychosocial outcomes, out of which only four were high quality (Saracutu et al., 2018). More research is also needed to determine the mechanisms underlying osteopathic treatment.

To summarize, the key limitations of this study are related to the lack of generalizability of the findings mainly due to the small number of participants in the intervention, lack of randomization and control group as well as the heterogeneity of the group and the involvement of the main facilitator in interviewing the participants about their experiences.

Reflexivity 8.5

Reflecting on oneself as a researcher and the research relationship, examining one's assumptions and preconceptions and exploring how these affected research decisions is known as reflexivity (Hsiung, 2010). Reflexivity entails questioning our own attitudes, thought processes, values, assumptions, prejudices and habitual actions, to strive to understand our complex role in relation to the research.

This section will include some considerations about my position in the context of this research, the training and observation that I have engaged with, as well as some considerations about facilitating the intervention and other activities that I have coordinated during my PhD journey.

8.5.1 Things I learned from training courses and workshops

It is important to emphasize that when I began to work on this research project I had a strong background in Health Psychology but limited knowledge of Osteopathy. What I brought to this PhD is an innovative portfolio of knowledge, skills and experience related to Health Psychology. My understanding of theoretical and applied bases of health and illness, as well as my research skills, were essential. Throughout this project, I familiarized myself with Osteopathy by reading relevant literature, and also through my collaboration with osteopaths, who have been eager to share their knowledge, views and previous experiences with me.

With regard to third wave therapies, I had a good understanding of their theoretical underpinnings however; I was a novice in implementing them in practice. I was eager to learn more and decided to engage in various training courses and workshops. The first course that I took part in was the nine weeks Mindfulness Base Stress Reduction provided by the Centre for Mindfulness-based Work & Research (CMWR). The course was based on the core MBSR syllabus of Jon Kabat-Zinn and consisted of eight consecutive weekly MBSR sessions of two hours, and a four-hour guided silent practice. Guided meditations were provided on CDs to support home practice. The course was facilitated in a group environment. This experience helped me gain a better understanding of mindfulness, as well as providing me with the resources to implement mindfulness in my own life. I have learned to use mindfulness to cope with stressful situations, to communicate, to walk, to eat and to behave more mindfully. The MBRS course helped me understand that a group setting can facilitate meaningful change through social support, reinforcement and motivation. This experience likely had an impact on the

development of 'A Mindful Act' in that I opted for a group format and encouraged the participants to talk about their homework practice and the changes they implemented in their own lives week after week, which was similar to the MBSR course.

Another course that I took part in was the 'ACTivate Your Life' facilitator training, that was provided by Consultant Clinical Psychologist Professor Neil Frude. The training was delivered over two days and helped me delve into the ACT model and become increasingly confident in speaking in front of an audience, given that we spent a considerable amount of time familiarizing ourselves with the content of the intervention and practising to facilitate it. I believe that Professor Frude's intervention is valuable in teaching people about stress and suffering caused by emotional issues and providing them useful tools to develop more acceptance and commit to the things they care about. AYL is an intervention designed to be delivered to a large audience and is based on PowerPoint presentations that are complemented by home activities and handout sheets. The format of AYL is advantageous, considering that ACT is transdiagnostic and can be adapted to different health problems and various audiences, however, this also translates into a limited interaction between the facilitator and the participants and within the group itself. I realized that although the intervention I was developing was also ACT-based, I was going to embrace a different approach to delivery. 'A Mindful Act' was going to involve small groups of people living with pain, who would have the opportunity to engage in discussions and interact with each other and the facilitator.

I also participated in the 'ACT with Self Care' workshop delivered by Professor Kelly G. Wilson, a prolific scholar who contributed to the development and dissemination of ACT and its underlying theory and philosophy for 25 years. This workshop was experiential and we were provided a set of tools and skills that we could use following the workshop. We observed how the interplay between mindfulness and values work in

ACT could promote meaningful change and a powerful therapeutic alliance. In addition, I realized that self-care and self-compassion have a unique role in ACT and decided to incorporate these two principles in 'A Mindful Act'. I believe that people living with persistent pain could benefit from developing more self-compassion and improving their level of self-care if provided the necessary tools and support.

In order to increase my understanding of the current multidisciplinary approach to pain management, I had the chance to observe the work of the chronic pain management team (CPAT) within one of the local health boards. Dr Nick Brace, who is a Clinical Psychologist provided me written permission to observe the team. This experience was valuable and allowed me to recognize different issues that people living with persistent pain are facing (e.g. medication that is ineffective, coping with the side effects of medication, depression, anxiety, functional limitations, relationship issues). The CPAT provided tailored support to their patients (optimizing medication, actively encouraging self-management, educating patients about pacing and exercise, referring patients to the pain management program). In my understanding, the majority of these patients appeared to have been navigating the system for a long period of time and dealing with multimorbidity and complex issues. Some of them seemed to be noticeably anxious and distressed. This made me realize that people living with pain are a heterogeneous population, reporting varying levels of pain intensity, physical functioning and pain interference with life activities and emotional functioning, entailing that these patients have different needs and support has to be tailored accordingly. What I also realized was that people with pain who were treated in the Osteopathy clinic seemed to be more proactive in self-management and experienced less severe psychological issues. This lead me to decide that I was going to meet the participants in 'A Mindful Act' before the beginning of the program to understand more about their needs, to assess if there were any barriers to participating and to allow them to clarify any aspect of the intervention that they were unsure about.

8.5.2 My views and experience of Osteopathy

On many occasions when I shared that I am developing a brief intervention to accompany Osteopathy for people with persistent pain I was asked: 'Why Osteopathy?' and I felt I had to provide arguments in support of the role of Osteopathy in the management of persistent pain. The more I learned about this profession, the more I understood the many benefits that it can yield. However, I also came to believe that Osteopathy needs a larger and more reliable evidence-base for its role to be acknowledged in mainstream healthcare. Another aspect I observed was a division between physiotherapists, osteopaths and chiropractors, culminating in bitter competitiveness and lack of collaboration. Despite the differences between these professions, I think there are also many similarities, and they would benefit from building partnerships and learning from each other. Therefore, I tried to be an advocate of inter-professional collaborations mostly by talking to different osteopaths and physiotherapists, trying to understand their perspectives and make them aware of the opportunity to find common ground. I strongly believe that having professionals integrate different concepts, perspectives, and techniques from two or more specialized disciplines is invaluable. This interaction contributes to a more advanced understanding of complex problems whose solutions are beyond the scope of a single discipline. My personal experience receiving osteopathic treatment was positive. I had several episodes of acute pain mainly as a result of sports-related activities, and Osteopathy sessions were beneficial in restoring my normal level of functioning and reducing the pain. This experience consolidated my belief that Osteopathy is holistic and that it has a valuable role in pain management.

8.5.3 Reflections on 'A Mindful Act'

Facilitating the intervention was by far my favourite part of this PhD and one of the most rewarding experiences I had so far, contributing both to my professional and personal growth. I truly believe in the importance of reflection, and I think meaningful learning comes from processing our experiences, in particular, those outside our comfort zone. This lead to the idea of recording a brief interview¹ with the co-facilitator of 'A Mindful Act' addressing some aspects of delivering the intervention, reflecting on the things we did well and the things that need further improvement.

First of all, we both agreed that our collaboration was successful and that we brought different skills and experience to the program. This contributed to interesting group discussions and new perspectives on things and was mentioned by the participants as an advantage. Charles² and I both believe we worked well as a team and that we supported each other throughout the six- week program. In retrospect, I think I could have allocated more time towards exploring each week's topic together with the co-facilitator and providing more explanation, however, Charles' s experience as an osteopath and educator proved to be very useful:

'I think the concept of living with and managing pain and a lot of things about personal self-development that kind of combined with trying to motivate people to improve are areas that I have engaged with you know probably for 14-15 years. [...] We had theoretical knowledge combined with different types of experiences engaging with people and I think they supported each other well.' (Charles, co-facilitator)

One area that needs further improvement is time management. Reflecting on the content of 'A Mindful Act' made me realise that I wanted to fit perhaps too many elements of ACT and Mindfulness in six sessions. In addition, the fact that we exceeded the time allocated was also due to the participants' willingness to discuss more, to ask questions and share their experiences, which are all positive aspects. In the future, the program's structure could

¹ The transcript is presented in Appendix 8.1

² Pseudonym for the co-facilitator (to ensure anonymity)

be refined to include eight weeks instead of six. Charles suggested that it was important to run the intervention and then work to refine it, which is also my position.

'A Mindful Act' was intended as an experiential program, with plenty of hands-on activities, group discussions, and mindfulness exercises. Although it was essential to provide participants information regarding the ACT model, it was equally important to allow them to experiment with applying what they have learned. Charles suggested that

'allowing them to, to utilize the information, to identify and analyse their own kind of way of behaving and lifestyle and then to allow them to kind of have a different perspective and create something. I think had it just been a presentation, this is this, this is this, and this is this I don't think that their engagement would have been the same. I don't think they would benefit the same.' (Craig, co-facilitator)

In his view, 'A Mindful Act' went beyond the ACT model, and also included pain education and elements of mindfulness.

'Because we know there was an understanding of what pain is, acceptance and therapy is one thing but the understanding of turning up and turning down pain you know, there were elements of mindfulness that were built into it, not just the Acceptance and Commitment Therapy. So I think you've drawn together areas of benefit from different theories to create something a little bit more applied, or a little bit more specific to chronic pain.' (Charles, co-facilitator)

Other important aspects of the program that we both identified were: sending reminders to participants before each session, creating a friendly and relaxed environment enabling people to share their views and learn new skills, facilitating social interaction and social support. The peer support network that this intervention helped create is a positive element.

'There's another thing I thought went well that I think often gets overlooked and that is the social interaction, the peer support and I, to my knowledge through social media some of these people have remained in contact. So I think that you've actually, you know they've actually created a little bit of a support group there.' (Charles, co-facilitator)

I believe that the group format was beneficial and fitted well with the participants' preferences however; I acknowledge that this approach might not be suitable for everyone.

Furthermore, both Charles and I agreed that training health professionals to empower people who live with pain is a worthwhile and feasible initiative, however, they need to have the willingness to improve their knowledge and skills.

'There's a big drive now within musculoskeletal care in empowering participants, sorry patients and given them the information they need. I think it needs to be built in as part of a treatment plan and I don't necessarily think that the information they can give in one session can have that effect So I think that the way the program is structured over a period of weeks allows people to incrementally improve their knowledge, apply it, reflect on it and apply something new and build. I do think it's the osteopaths but a lot of healthcare professionals could be upskilled with knowledge of empowering patients. But again you have to be specific. You have to have the want and desire to have that approach to knowledge. '(Charles, co-facilitator)

In retrospect, one of the things that I would do differently is finding an impartial researcher who was not involved in the delivery of the intervention and giving them the task to interview the participants about their experiences of taking part in 'A Mindful Act'. I felt that the participants were very grateful for being offered the chance to take part in the intervention, which may have influenced their responses. In addition, the close rapport that I build with the participants throughout the program may have contributed to them being reluctant to share criticism.

The experience of developing and delivering this intervention had a great impact on my personal and professional development. It taught me to be more mindful and self-compassionate and to develop more acceptance of the things I cannot change. I am a driven individual, oriented towards problem-solving and very analytical, which meant that it was not always comfortable living the present moment fully, without constantly projecting into the future or showing myself compassion during difficult times. But the more I practiced mindfulness, the more I engaged with the present and

a whole new world opened to me, a place that accepted both pleasant and unpleasant thoughts and feelings, memories and sensations, without any judgement or struggle. My great empathy towards people who suffer meant that I often found it difficult to listen to painful and traumatic experiences without being affected. But I have learned to accept that suffering is part of our common humanity, and also that it can be empowering.

8.5.4 Pain Toolkit Workshops

My willingness to help people from Swansea who live with persistent pain and give something back to the community lead me to organize a series of workshops focusing on pain self-management delivered in March 2018 by Pete Moore, author of the Pain Toolkit. The participants learned the importance and benefits of self-management as well as equipping themselves with useful tools including how to work effectively with health professionals. There were two workshops for health professionals as well, and they centred on effective techniques to help patients self-manage. The attendees gave positive feedback and were grateful for this opportunity.

8.6 Implications and future directions

8.6.1 Implications for research

This study has shown that delivering a brief ACT-based intervention for people living with persistent pain was feasible with the collaboration of osteopaths and considered acceptable by the participants, who reported positive experiences and the absence of barriers to participation. The participants appeared to have engaged well with ACT and continued to practice mindfulness, and applying the skills they learned after the end of the program. Despite the promise shown by these findings, this is merely a

small-scale feasibility and acceptability study and more studies are needed to optimize and evaluate the intervention. Mixed-method studies are necessary to explore these improvements and better understand the process of developing more psychological flexibility.

In the future, more research is needed to explore the effectiveness of brief ACT-based interventions for persistent pain and to understand the mechanisms of change underlying ACT. Important questions should be addressed focusing on 'what works for whom, how and in which circumstances' (Burns, 2016; Moore, 2013; Vlayen and Morley, 2005). More research is needed to investigate the feasibility and acceptability of different delivery modalities (e.g. group format) for this specific population. These questions apply to third wave therapies as well as to the field pain management at large. Although third wave therapies are supported by empirical research and widely adapted to different contexts, there is a need for more health economic evidence to determine whether ACT-basedd interventions are a cost-effective option for the management of persistent pain. This area is still in an incipient phase and needs to be expanded.

The findings of this study revealed that integrating ACT and Osteopathy is feasible. The collaboration between osteopaths and psychologists in supporting people who live with pain is innovative and demonstrates potential. It would be useful to investigate whether a combined course of osteopathic treatment paired with a brief ACT intervention is more cost-effective than the standard treatment for persistent pain. Osteopaths in this study were eager to collaborate and played an important role, particularly in recruiting participants for the intervention. In addition, an experienced osteopath assisted the main facilitator in delivering 'A Mindful Act'. The level of involvement they demonstrated suggests that osteopaths are interested in this type of collaboration. However, this view may not be representative of all osteopaths and this needs to be further examined. The

collaboration between osteopaths and psychologists in supporting people who live with pain is innovative and demonstrates potential.

Implications for osteopathic education

The experiences shared by the Osteopathy students who took part in the focus group highlighted a need for additional education and training to recognize the role that psychosocial factors play in the experience of pain and acquire skills to identify and address these factors. The osteopaths reported that they felt challenged and 'out of their depth' when treating people with pain who also presented with psychological comorbidities or maladaptive beliefs. For example, one osteopath suggested that she found it very demanding to treat people with depression, due to their negative beliefs, low self-efficacy and a sense of passivity in managing their condition. Another osteopath recalled a difficult experience when she had to treat a patient living with depression who self-harmed. These examples emphasize the urgency of providing osteopaths specific training on how to manage this type of situations. Offering psychological support is not within the scope of Osteopathy, however, it is essential for osteopaths to be knowledgeable about the ways they can support people who live with mental health comorbidities within the boundaries of their own profession. Osteopaths are ideally positioned to educate patients about how depression, anxiety or fear avoidance contribute to the onset and maintenance of persistent pain. The fact that they have regular contact with patients, building a collaborative rapport based on trust and cooperation and also considering the time that osteopaths routinely dedicate to listening to people's experiences and educating about pain puts them in an ideal position to provide this type of support.

The Osteopathic Practice Standards (2012) state that osteopaths must possess enough knowledge and skills of psychology and social

determinants of health to provide a context for patient management and decision-making. The same guidance also highlighted that osteopaths must recognize the importance of physiological, psychological and social factors in patients' complaints (The Osteopathic Practice Standards, 2012). It is the responsibility of people involved in developing, implementing and evaluating osteopathic education programs to ensure that osteopaths are competent and well equipped to identify and address psychosocial factors. This is likely to entail some changes in the curriculum to include modules and supervised training in the area abovementioned. Educational programs should be made available to Osteopathy students and practising osteopaths to improve their existing knowledge and skills that will allow them to better understand the complexity of persistent pain. Becoming more aware of the role of psychosocial factors might signify a better understanding of the pain experience and the context in which persistent pain occurs. This additional set of skills and knowledge will help their professional development and also enable them to support patients with persistent pain more effectively.

8.6.3 Implications for practice

The present study contributes to the advancement of knowledge concerning the role of Osteopathy in the management of persistent pain. The findings of the systematic review, in particular, highlighted that osteopathic treatment may have some effects on anxiety, fear-avoidance, quality of life and general health status in populations living with persistent pain (Saracutu et al., 2018). Consequently, there are important implications in terms of improving pain management by aligning current osteopathic practice with the biopsychosocial approach. In addition, there is scope for pairing osteopathic treatment with psychological interventions in order to enhance the health and wellbeing of people with persistent pain.

Persistent pain has been conceptualized as a complex biopsychosocial phenomenon; therefore effective interventions focusing on pain management must address the biological, psychological and social dimensions of pain (Disorbio et al., 2006). The biopsychosocial model of pain is congruent with osteopathic principles and philosophy (particularly holism), widening the scope for osteopathic intervention beyond providing manual treatment to include a broader range of therapeutic tools (Penney, 2010). Previous research suggests that osteopaths are still strongly biomedical in their approach and their ability to engage with the psychosocial factors of the pain experience still needs to be improved (Macdonald et al., 2018). In order to understand pain from a biopsychosocial perspective osteopaths need to update their repertoire of knowledge with the current advances in psychology and neuroscience. This has implications for education but also for developing professional networks to support osteopaths in adopting a more biopsychosocial, evidence-based approach (Smith, 2019). Osteopaths play different roles: they are educators, hands-on treatment providers, they contribute to actively empowering patients and encourage self-management, they signpost and also work collaboratively with other healthcare professionals (Smith, 2019).

The findings of this research suggest that osteopaths are willing to receive training in ACT, and integrating this model either through running groups in parallel with Osteopathy treatment or through adopting ACT principles in their practice. However, a crucial factor in osteopaths' confidence in incorporating ACT (one way or another) is receiving appropriate training and supervision. There was a consensus that the osteopaths' knowledge and skills in delivering ACT are currently lacking. Osteopaths also expressed a preference for experiential learning as opposed to merely learning the theory underlying this model. They highlighted that observing a trained specialist would be an effective way for them to learn how to integrate ACT in their practice and would benefit them more than taking part in lectures. This highlights the need for collaboration with psychologists, who could provide their expertise and offer osteopaths adequate training and supervision in third wave therapies. An experiential-based learning program would enable osteopaths to integrate ACT in their practice. Receiving appropriate supervision and reflecting on their development will be paramount in the success of this program that despite being challenging would benefit both osteopaths and their patients greatly.

8.7 Future directions

Pain may become an area easy to ignore in the current political climate, as it may be seen by some as a non-threatening condition whose consequences are not immediately visible. It is essential to stress the importance of improving the current state of pain management and reduce the personal and societal costs associated with this condition. This area should be recognized as a high priority, and future efforts should focus on increasing public awareness and political support both at national and international levels.

The biopsychosocial framework is currently the most widely accepted approach to treating persistent pain and also supported by a vast evidence base. Addressing the physical, psychological and social dimensions of pain and disability has demonstrated to be the most therapeutic and cost-effective avenue for managing the often-recalcitrant pain conditions. Involving different professions and disciplines coordinated in a common effort to reduce the burden of pain on individuals and on society is a promising avenue for the future. The current standard medical approach to pain is unsustainable, contributing to an increased healthcare utilization, augmented costs and interventions that are considered high risk (e.g. drug interventions or surgical procedures). In this context developing interventions characterized by low-risk and low-cost is paramount. Integrating appropriate health-care strategies and disciplines has a considerable potential to improve the lives of people with persistent pain. A

more holistic approach to pain needs to be adopted that will focus on the whole person and not only the pain. This is in line with the biopsychosocial model, recognizing that human beings are complex and multidimensional and cannot be reduced to a set of symptoms. Given the high prevalence of distress, socioeconomic disadvantage and psychological comorbidity in this population, providing integrated patient-centred care focused on people's needs and enabling active self-management is imperative.

Prudent healthcare principles outlined by the Bevan commission and applicable to health services in Wales emphasized the importance of prevention and efficiency, recommending the establishment of a biopsychosocial assessment within the community ensuring that early self-management is available early to people living with persistent pain (Core Standards for Pain Management Services in the UK, 2015). In addition, the commission suggested that multi-professional teams working across primary, secondary and social care should work together to ensure early and effective pain assessment and management. Fully exploiting the resources that are already available as well as identifying interventions and initiatives that are cost-effective and promoting healthcare that fits the needs of the patients are within the most important prudent healthcare principles. In recent years, pain services in Wales have shown improvement; however, there is still some variation in provision and delays in accessing appropriate treatment (Khot and Lewis, 2014). Further work is necessary to improve access to pain management programmes and specialized interventions. There are still issues that are yet to be addressed: the problem of fragmented care, inefficient communication and coordination between primary and secondary care, too little efforts focusing on prevention and timely intervention.

The NHS long-term plan (2019) acknowledged the significant burden that pain exerts on the individuals and on the healthcare system and committed to building on existing work to improve the current state of pain management in the U.K. Some of the initiatives focus on ensuring that patients have direct access to musculoskeletal first contact practitioners (FCPs) without needing a GP referral. In addition, the number of physiotherapists working in primary care will be expanded, as well as supporting the access to online support programs (such as ESCAPE-pain, Enabling Self-management and Coping with Arthritic Pain through Exercise) for people who live with pain. Other commitments include allocating sufficient funds to increase the number of planned operations, cutting long waits and investing more resources into mental health services.

Perhaps there are many barriers to improvement, however powerful initiatives and collaborations, paired with joint efforts in research and policy have the potential to create meaningful change and improve the lives of people who live with persistent pain.

8.8 **Conclusions**

This study set out to develop a novel psychosocial intervention to accompany osteopathic treatment for people from Southwest Wales who live with persistent pain and psychological comorbidities. The MRC framework guided the development process. The study employed a pragmatic approach, based on a mixture of qualitative and quantitative methods and procedures that were chosen because they fitted well with the research aims.

To my knowledge, 'A Mindful Act' is to date it is the only ACT-based intervention delivered to people living with persistent pain in a group setting in parallel with osteopathic treatment. This type of pairing may lead to additional benefits for this specific population.

A six-weeks ACT-informed program was developed and aimed to teach people how to develop more acceptance and self-compassion, be more mindful and clarify their personal values in order to live a more rich and meaningful life. A group of nine participants were recruited with the help of osteopaths practising within the Health and Wellbeing Academy. Based on ACT principles, the intervention focused on increasing psychological flexibility and consisted of: basic ACT tenets, mindfulness practice, holding self-stories lightly, practising self-compassion and self-care, acceptance and values identification and committed action towards a meaningful life.

Qualitative interviews were conducted to provide an insight into peoples' experiences of taking part. In addition, quantitative data was collected at baseline, on completion of the programme and at 1 month and 3 months follow-up to reveal any differences in psychological flexibility, depression, anxiety, fear avoidance and general health status.

The findings of the feasibility and acceptability study suggested that the intervention was feasible with the support and collaboration of the HWBA, and the osteopaths who helped facilitating the recruitment process. The participants in 'A Mindful Act' found the intervention acceptable and shared positive experiences: they found being able to connect with people who experience similar issues valuable and also expressed that they liked the content, structure of the program and the facilitators. In addition, data showed a decreasing trend in overall fear avoidance, as well as several increasing tendencies in what concerns activities engagement, mobility, performing usual activities and self –care. Osteopaths participating in the focus group appeared willing to receive training in ACT and integrating this model either through running groups in parallel with osteopathic treatment or through an ACT-informed practice.

These findings have to be considered in the light of several limitations such as a very small sample size, lack of control or comparison intervention and limited generalizability. Nevertheless, these findings will be valuable in enhancing the intervention and making appropriate modifications to the processes and procedures involved. A larger-scale study is envisaged to follow, to investigate the full effectiveness and cost-effectiveness of the programme. A future trial will aim to integrate ACT with Osteopathy, train osteopaths to deliver 'A Mindful Act' and investigate the full effectiveness and cost-effectiveness of the programme.

In conclusion, the collaboration between Psychology and Osteopathy yielded important insights into novel ways to support and empower people living with persistent pain. This collaboration holds a lot of promise and should be further explored.

8.9 The way forward

The next steps will be to refine and build upon 'A Mindful Act'. I envisage a trial aiming to determine the effectiveness of the intervention and to compare it to treatment as usual or other active interventions for persistent pain. I truly believe that this is only the beginning of a journey and not the end. I also think that the idea of incorporating ACT and Osteopathy is innovative and has a great potential to improve the lives of people who experience pain and psychological comorbidities.

> 'Come, come, come whatever you are... Good or bad, *It doesn't matter.* Ours is not a caravan of despair. Come, even if you have broken your vow a thousand times Come, yet again, come, come.' Rumi (extracted from contextualscience.org)



A.1 Systematic Review

International Journal of Osteopathic Medicine 27 (2018) 23-33



Contents lists available at ScienceDirect

International Journal of Osteopathic Medicine

journal homepage: www.elsevier.com/ijos



The effects of osteopathic treatment on psychosocial factors in people with persistent pain: A systematic review



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ARTICLE INFO

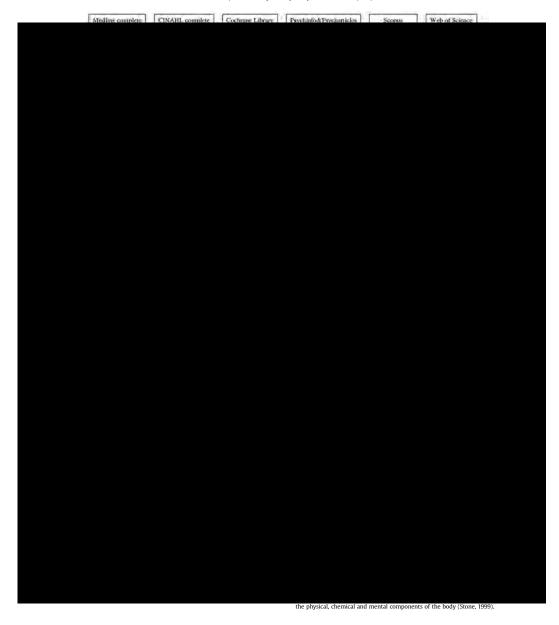
Article history: Received 22 November 2016 Received in revised form 18 September 2017 Accepted 6 October 2017

Keywords: Persistent pain Osteopathy Psychosocial factors Depression Anxiety Avoidance

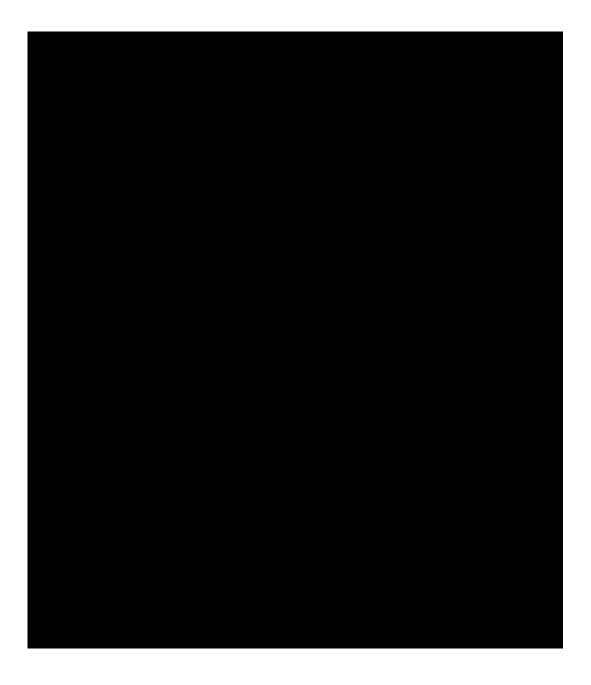
ABSTRACT

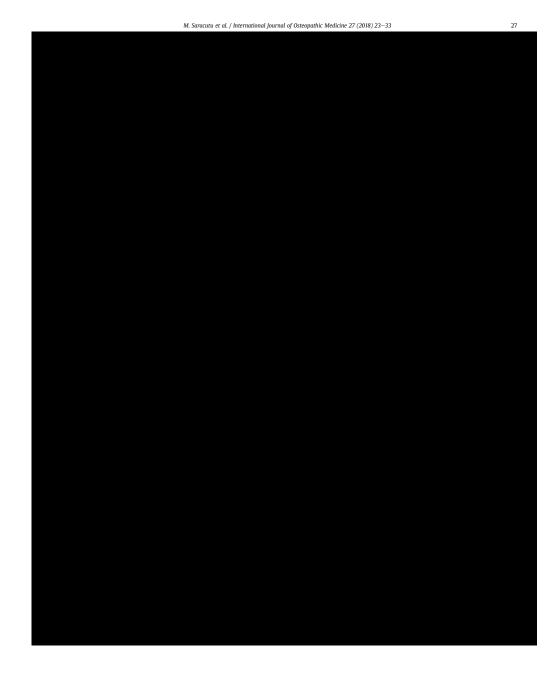
Persistent pain is considered a complex biopsychosocial phenomenon whose understanding and management is yet to be improved. More research is needed to determine the common paths that lead to developing persistent pain, to identify the populations most at risk and to develop and evaluate interventions. The last decades have seen a shift in pain management, from the biomedical model to a biopsychosocial model. There is also a significant body of evidence emphasizing the effects of osteopathy in persistent pain management. Given the relevance of psychosocial factors in aetiology and maintenance of pain, it is essential to investigate whether osteopathy has an influence on depression, anxiety, fear avoidance or pain catastrophyzing. This review will identify and synthesize relevant primary research focused on the effects of osteopathic interventions on psychosocial factors in patients living with different pain conditions. Studies were identified by searching seven databases (Medline complete, CINAHI, Cochrane Library, Psychinfo, Psycharticles, Web of Science and Scopus) between 1980 and 2017. Peer reviewed articles reporting effects of: Osteopathic manual therapy, Osteopathic Manupulation, Mobilization, Spinal manipulation, high velocity and low amplitude manipulation, massage and soft tissue treatment were extracted. A total of 16 RCTs were selected. Two out of five reported significant differences in depression; in regards to anxiety, all the four trials found significant effects; two out of three trials reported a significant reduction in fear avoidance while six out of seven trials found a significant enfects; two out of five reported significant and three out of four found an increase in quality of life. The findings of this review are encouraging; suggesting that osteopathic treatment may have some effects on anxiety, fear avoidance, quality of life and general health status in populations living with the presistent pain.

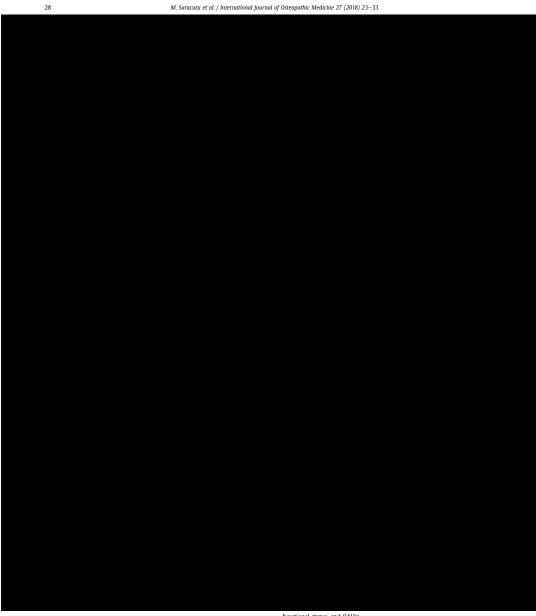










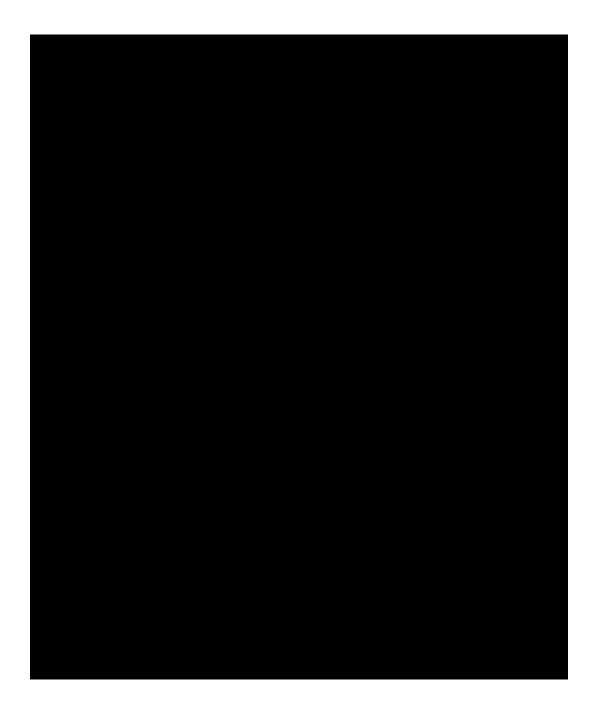


functional status, and QALYs.

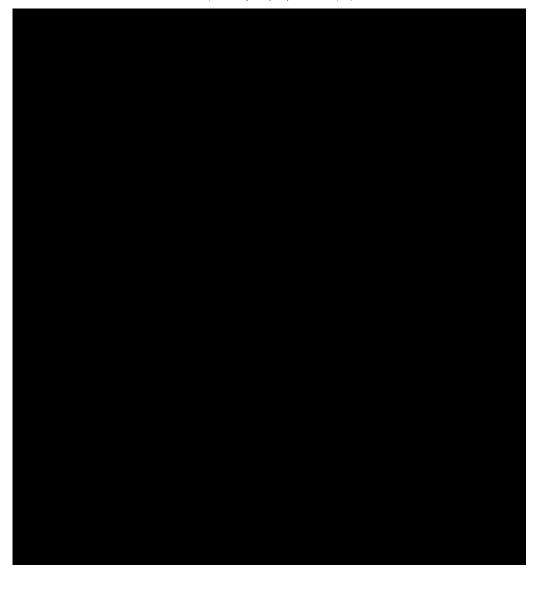












Trials in the updated review **A.2**

Appendix A2. Study characteristics (updated review)

Author	Type of pain	Intervention	Duration	Control	Outcomes	Results
				group		
Marti-	Chronic non-specific	OMT protocol	5 OMT	Sham-	Spanish version of the	Sig. decrease in fear
Salvador et	low back pain	with specific	sessions, 45	diaphragm	Fear Avoidance Beliefs	avoidance, depression,
al., 2018	N=66 (Mean age	diaphragm	min each	intervention	Questionnaire (FABQ);	anxiety and pain
	OMT=43.4,SD=10.8;	techniques 1		with manual	Spanish version of the	catastrophyzing at 4
	Mean age Sham=41.7,			contact	Hospital Anxiety and	and 12 weeks in the
	SD=10.3)				Depression Scale	intervention group
					(HADS); Spanish	compared to sham
					version of the Pain	(Between group mean
					Catastrophyzing Scale	differences after 4
					(PCS)	weeks: FABQ
						(-25.9, 95% CI, p<
						.001), HADS (-5.2, p<
						.001), PCS
						(-6.9, p<.001); at 12
						weeks: FABQ (-23.1,
						p<.001), HADS (-6.3,
						p<.001), PCS
						(-6.5, P< .001)

¹ Functional diaphragm balancing technique, muscle fiber stretching technique, phrenic-center inhibition technique, global abdominal hemodynamic maneuver

Sarker et al.,	Chronic non-specific	Spinal	15 treatment	Core stability	EQ-5D-3L (mobility,	Both groups showed
2017	low back pain	manipulation	visits within 15	exercises;	self-care, usual	an increase in health
	N=100 (18-60)	(HVLAT) on	days	postural and	activities,	related QoL; the mean
	50 per group	lumbar region;		ergonomic	pain/discomfort,	difference between
		postural and		advice	anxiety/depression)	groups was 4.78 (95%
		ergonomic advice				CI; $p < .001$).
Tamer et al.,	Chronic non-specific	Visceral OMT	10 sessions for	OMT (soft-	SF36 (physical function, Improvement	Improvement
2017	low back pain	(standard	five weeks (two	tissue	physical role	observed in all
	N=39 (19 assigned to	manipulation,	sessions/week)	mobilization,	limitations, pain,	subgroups of SF36
	OMT, 20 assigned to	mobilizations		manipulation,	general health, energy,	scores in vOMT after
	vOMT)	plus lymphatic		muscle energy	social function,	the treatment (p <
		drainage and		techniques)	emotional role	0.05). Improvements
		fascial			limitations, mental	in the physical
		mobilization for			health)	function (p = 0.028),
		visceral organs)				energy ($p = 0.034$) and
						total physical score (p
						= 0.025) parameters in
						vOMT better
						compared to the other
						variables.

There were significant improvements in QoL according to SF-36 after treatment (p < 0.001), with no significant difference among group sexcept the "bodity pain" subgroup of SF-36 (p <0.05)
SF36- short form
Spinal stabilization exercise program
Three sessions/ week for 6 weeks (18 sessions in total)
Manual therapy (MT) (soft tissue mobilizations, muscle-energy techniques, joint mobilization and/or manipulations)
Chronic low back pain Manual therapy Three sessions/ Spinal SF36- sh N=113 (MT group: (MT) (soft tissue week for 6 stabilization N=57, mean age= mobilizations, weeks (18 exercise 41.6; SG N=56, mean muscle-energy sessions in program age=43.1) nobilization and/or manipulations)
Ulger et al., 2017

A.3 Consent form for focus group participants

	Swansea University Prifysgol Abertawe	
	CONSENT FORM	
	tle of Project: Exploring patients' perspectives of living with chronic pain eir views on a novel intervention through focus groups	and
Na	ame of Researcher: Madalina Saracutu	
PL	EASE INITIAL YOUR CONSENT IN THE BOXES	
1.	I confirm that I have read and understand the Participant Information Sheet (PIS) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or legal rights being affected.	
3.	I understand that all data relating to me obtained for the purpose of the study will be handled in confidence	
4.	I agree that the research report may contain direct quotations from my responses, but that these quotations will be given a pseudonym, and therefore anonymous.	
5.	I consent to the researcher informing my GP of my participation in this study, if I so wish.	
6	I would like the researcher to inform my GP of my participation in this study (initial the box for YES, leave blank for NO).	

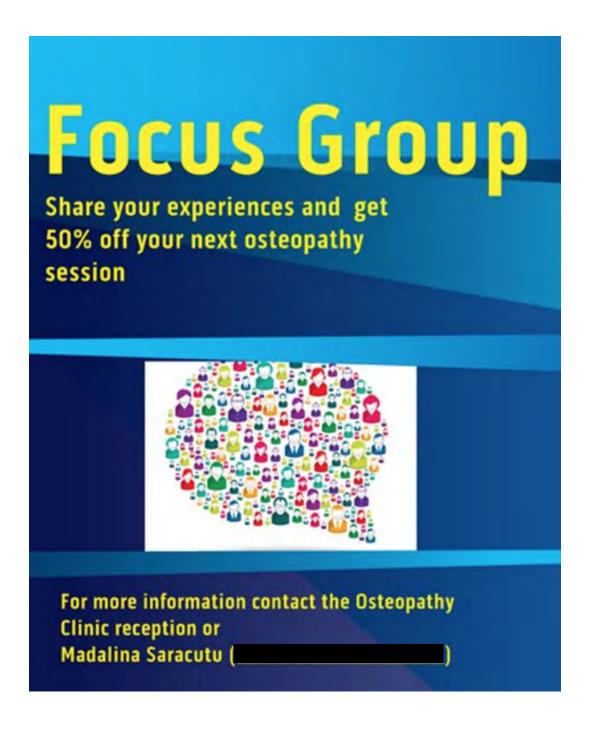
I agree that the intervi anonymously.	ew will be tape-reco	orded and transcribed	
8. I agree to take part in	the above study.		
Name of Positions	//	- Circotor	
Name of Participant	Date	Signature	
Name of Researcher	Date	Signature	
complaints or concerns about	t this research, you cai	p, please ask the researcher. If y n direct these, in writing, to the ices, Swansea University, Single	Research
complaints or concerns about Ethics Committee, College of	t this research, you cai	n direct these, in writing, to the	Research
complaints or concerns about Ethics Committee, College of	t this research, you cai	n direct these, in writing, to the	Research
complaints or concerns about Ethics Committee, College of	t this research, you cai	n direct these, in writing, to the	Research
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complaints or concerns about Ethics Committee, College of	t this research, you cai	n direct these, in writing, to the	Research

A.4 Focus group ground rules

Ground rules

- · One person speak at a time
- Speak for yourself, using "I" statements
- Participate in both talking and listening
- Be critical of ideas but respect different points of view and different perspectives
- Stay on the topic and don't digress too much
- Maintain the confidentiality of opinions expressed in this discussion
- Focus on issues that need to be discussed and not individuals
- Wait for one person to finish speaking and don't interrupt others

A.5 Poster advertising Focus Group



Focus group topic guide **A.6**

Focus Group topic guide

Opening question: Can you tell me a bit about the beginning of your journey, when you started feeling in pain?

Walk me through the whole experience step-by-step. What happened first?

How has your pain affected your life? How was your life before? What were the things you use to do that you don't do anymore?

Can you give me some examples?

How has your life changed? (Work, relationships, social life, activities, exercise, mood, emotions)

Please tell me (more) about that. Is there anything else you would like to add?

How do you manage your pain? What were the things that helped you? (Painkillers, Rest, activity, exercise, CBT)

What are the strategies that you use to manage your pain?

Does anyone want to add to that?

Introduction to Mindfulness & ACT / Video followed by a brief discussion

Comfort break (15 minutes)

How do you perceive your pain in 12 months' time? What will be the challenges to overcome? What do you think it is going to change?

What would have to happen to make your condition improve?

How do you see your future of living with chronic pain?

What do you think about ACT? Would you be interested to take part in a future program it was available to you?

Concluding question: Of all the things we've discussed today, what would you say are the most important issues you would like to express?

Participant information sheet and consent form A.7 (osteopaths)

Participant Information Sheet (Osteopaths)

Exploring patients' perspectives of living with chronic pain and their views on a novel intervention through focus groups

I would like to invite you to take part in a research study that will involve you discussing your experiences of supporting people with chronic pain. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. The researcher will go through this information sheet with you and answer any questions you have. This should take about 15 minutes.

You should take this sheet home with you to keep and you can discuss it with your friends and relatives if you so wish. Please ask if there is anything unclear or you would like more information on. Please take time to decide whether you wish to take part in the study.

Please ask me if there is anything unclear or if you would like more information.

What is the purpose of the study?

The present study aims to explore the needs of patients with chronic pain who are receiving Osteopathic treatment at Swansea University Osteopathic Clinic. This research will also aim to reveal the experiences of osteopaths who support patients in managing their condition.

Who is carrying out the evaluation?

The Chief Investigator is Madalina Saracutu who is currently a PhD student based at the College of Human and Health Sciences at Swansea University. This study will make up part of a PhD thesis.

Why am I being invited to take part?

You have been invited to participate because you have been identified as someone who is eligible for this study. Your experiences and thoughts are invaluable in gaining a better insight into how Osteopaths make sense of their rapport with chronic pain patients.

What will happen to me if I do take part?

You will be asked to take part in a focus group, conducted by the Chief Investigator. This will consist in a group discussion about your thoughts and feelings towards supporting people with chronic pain.

The focus group will last between 1hour and 1 hour and 15 minutes although if you would like to talk for more or less time that is fine. It will take place within the College of Health and Human Sciences at a time convenient for you. The focus group discussion will be facilitated by the main investigator with the support of an additional researcher who will mainly be in charge of the audio recording. Anything you say will be kept strictly confidential.

Do I have to take part?

No, it is up to you to decide whether you wish to take part. After reading this Information Sheet and asking any questions you may have you should make an informed decision whether you want to participate or not. This includes taking time to discuss with family and friends before making this decision.

If you agree to take part, you will need to read and sign the consent form and return it to Swansea University Osteopathy Clinic. The researcher will then arrange a convenient time and location in which to conduct the focus group.

If you decide to take part, you are still free to withdraw at any time during the study period without giving any reason.

Do I have to do anything else following the completion of this session?

No, once the focus group has been conducted then the researcher will not contact you again. However should you wish to contact the researcher the contact details are at the end of this information sheet.

What happens after the focus group?

On completion of the focus group, we will transfer the audio recording onto a computer and transcribe the discussion. The researcher will remove any information that identifies you or anybody else, such as names, locations and treatment centres. The interviews from all participants will be analysed together to build up key themes and issues. Some of the words you use in the interview may be taken as direct quotations and included in the final report. These quotations will be completely anonymous.

What are the possible disadvantages of taking part?

Discussing about your experiences of supporting people with chronic pain may bring up some emotions that have not been felt or experienced in a long time.

Should you become upset through the focus group then the discussion can be paused (until you feel comfortable to continue talking) or terminated completely. Topics of discussion can also be changed if you feel uncomfortable discussing a certain aspect of your story. Additionally if you feel you need any further support after the interview has ended then the researcher will be able to provide you with details for support groups or organisations.

What are the benefits of taking part?

There are no direct clinical benefits as a result of taking part, however by contributing your story and experiences you will be actively helping us to gain better understanding of chronic pain.

Will my participation be kept confidential in this study?

Yes. We will follow ethical and legal practice to ensure all information about you will be handled in strict confidence. All data will be held securely at the College of Human and Health Sciences, Swansea University on password-protected computers and in locked filing cabinets.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher immediately; who will do their best to answer your questions (contact details listed below). If you remain unhappy, or feel uncomfortable speaking to the researcher please contact the researcher's academic supervisor Dr Jaynie Rance at the College of Human and Health Sciences, Swansea University (contact details below) or the Manager of the Osteopathy Clinic (Craig Tout).

What will happen to any data that I give?

Any spoken data you give will be immediately transcribed and in the process any identifying information you give will be removed and replaced with a pseudonym. For written data, you will be given a unique participant code only known to the researcher so that it remains completely anonymous. The information will then be used as part of a thesis for a PhD. The data will also be used in developing reports for publication in academic and professional journals. Your name or any identifying details will not appear anywhere within these reports or thesis.

Who is organising and funding the study?

The Chief Investigator for this study is Madalina Saracutu, a PhD student at Swansea University. The College of Human and Health Sciences at Swansea University are funding the project.

ief Investigator:	Academic Supervisors	
Madalina Saracutu	Dr Jaynie Rance	
Email:	Tel:	
	Email:	
	Dr Darren Edwards	
	Tel:	
	Email:	
	Dr Helen Davies	
	Tel:	
	Email	

Consent Form (osteopaths)

Study Title: Exploring Osteopaths' view acceptability of integrating the ACT be		· ·
Name of researcher: Madalina Saracu	ıtu	
Contact details: Tel no:		
Email:		
Please initial each box		
1.I confirm that I have read and under have had the opportunity to consider answered satisfactorily. 2. I understand that my participation withdraw at any time, without giving a reason, years.	the information, ask questions and h	nave had these
3. I agree to participate in in the focus	s group to the best of my ability.	
Name of participant	Date	Signature
Name of researcher	Date	Signature

A.8 Semi-structured focus group topic guide (osteopaths)

Semi-structured focus group topic guide (osteopaths)

What motivated you to become an osteopath in the first place?

What do you like most about your profession?

What are some of the challenges you face in your osteopathic practice?

What are the benefits of Osteopathy for people who live with chronic pain?

In your opinion, what are patients' expectations of Osteopathy?

How do people you treat manage chronic pain?

What are the issues that people with chronic pain receiving osteopathic treatment are experiencing most commonly?

 $How \ do \ you \ support \ individuals \ experiencing \ comorbidities \ like \ depression \ or \ anxiety?$

How do you help people experiencing fear avoidance or pain catastrophysing?

What do you do to address different people's needs?

What improvements have you noticed in people experiencing chronic pain following osteopathic treatment?

Have you ever come across Mindfulness? What about Acceptance and Commitment Therapy (ACT)?

If there were training available in Mindfulness and ACT, would you be willing to take part?

A.9 Pre-intervention questions

Pre-intervention discussion
Date of interview:
Name:
E-mail:
Phone number:
Q1. Is there anything you feel is important for us to know in regards to your health? YES NO
If YES, please expand
Q2. Do you have any physical limitations that can be challenging?
YES NO If YES, please expand
Are you ok for lying down, doing gentle stretches? YES NO
Q3. Have you experienced a close bereavement in the past 12 months?
YES NO If YES, please expand
O4. Have you received any asychological treatment during the past 12 months?

YES
NO ISVES allows
If YES, please
expand
Q5. Do you have an alcohol or drug addiction problem?
YES
NO
If YES, please
expand
Q6. Is there anything else you feel we should know in relation to your health?
If YES, please expand
Q7. Do you have an exercise/yoga mat, blanket and cushion?
YES
NO NO
NO
Q8. Reiterate the integral nature of the homework (30 minutes a day over the 6 weeks) not just a 1hour course once a week for six weeks. Is this ok?
YES
NO
Comments

Qualitative interview schedule A.10

Qualitative interview schedule

How would you describe your experience of taking part in 'A Mindful Act' program?

What did you learn from this program?

What was the aspect of the program that you liked the most? What was your favourite activity (or session)?

What did you least like about the program? What do you think could be improved about 'A Mindful Act'?

Were there any difficulties to taking part?

Are there any changes in your perspective of living with pain? If the answer is 'Yes', what are they?

Do you practice Mindfulness? How often?

Have you noticed any differences in your life as a result of taking part in 'A Mindful Act'? If 'yes', what are these differences?

Would you recommend this intervention to someone you care about?

A.11 Framework analysis results

	Emily
1.1 Understanding and practicing acceptance	Although Emily is sometimes searching for something that will make her pain better, she acknowledges that she feels better when she tries to accept living with the pain. Emily tries to focus on things that she can do (for example going to the gym, although not back on the rowing machine or lifting weights). She believes that acceptance comes over time and recognises that avoidance of pain or negative thoughts is not a helpful coping strategy in the long run.
1.2 Views on 'acceptance physical exercise'	Emily liked the exercise and thinks it is simple but powerful. She implemented it at her workplace, where she did a demonstration in front of her colleagues. They were surprised in the beginning but then started to understand it better. They thought it was great and that it can be used for any type of situation.
1.3 Experiences of learning about defusion	Emily feared doing things because they might have caused back pain. In the session about Defusion, after the co-facilitator described defusion, she started to become increasingly aware of thoughts such as 'Oh, no, don't do this because of' and understood the avoidance mechanism better. Emily liked the 'Passengers on the bus' metaphor and thought that it was easy to relate to and fun. Emily then started to challenge her thoughts and engage in low intensity exercise, with breaks and pacing.
1.4 Experiences of practicing mindfulness	Emily had practiced mindfulness sporadically before the course and expressed that she become more committed afterward, because of the positive effects that she experienced. She believes that unless one fully understands this concept and is open to it, one will not have the same benefits. In the past she was quite sceptical and believed that mindfulness was 'stuff for hippies'. Emily uses a mindfulness app, that reminds her to do some practice early in the morning, before doing anything else. She also practices before going to sleep and also finds it beneficial when dealing with stressful situations. Emily tries to teach her daughters how to cope better with stress by using mindfulness. She thinks that once one gets into the habit of practicing, it does get easier.
1.5 Developing self-care and self-compassion	For Emily, self-care is a memorable topic. She realised that looking after her own wellbeing is not the same as being selfish. Emily also become more aware that she has too many responsibilities and does not dedicate any time to relaxing or stepping back and reflecting on how things are going. She started implementing 'Self-care Sundays', where she takes some time off from her duties and focuses on her wellbeing. By doing so, she felt more relaxed, refreshed and energetic. This also helped her become more productive. Emily is committed to this practice and has a much better understanding of the role of self-care.
1.6 Understanding and identifying values	

	Hannah
1.1 Understanding and practicing acceptance	
1.2 Views on 'acceptance physical exercise'	
1.3 Experiences of learning about defusion	Hannah thought that the content of the program was good and the participants were given a lot of good examples, on of which is the 'Passengers on the bus'.
1.4 Experiences of practicing mindfulness	Hannah had heard about Mindfulness but had no experience of it, and found it easy to practice alongside the group. She thought that the fact that the Mindfulness exercises were placed towards the end of the sessions, when people felt more relaxed was beneficial. Mindfulness helped Hannah relax and be more aware of her body (e.g. body posture, breathing). She believes that if she wouldn't have been invited to take part in the course, she probably wouldn't have had the chance to discover Mindfulness, as most of the elderly people are sceptical about 'this new, fangled thing'. Hannah expressed that she is very happy to have had this opportunity. She uses a Mindfulness app on her iPad, that helps her cope with pain better. She practices a little bit every day, on most days.
1.5 Developing self-care and self-compassion	Hannah recalled that someone was talking about self-care and explaining that one would not advise a child or someone they loved to lie down and not be active. Hannah related that to her own grand daughter, and expressed that if she would have asked her to go to the park or do some exercise, she would not refuse. For Hannah this was important, as she become more aware of the difference between the way people look after themselves and the advice they give to their loved ones. She also became aware of having always put her family first, and although her children have become adults things did not change. She now realises the importance of stepping back and focusing on her own wellbeing a bit more ('Well, yes I have to be doing these things for myself as well').
1.6 Understanding and identifying values	

	Jasmine
1.1 Understanding and practicing acceptance	Jasmine reduced a lot of her medication, with the help of mindfulness and understanding the importance of looking after herself by also accepting that she cannot do everything on her own but that it is ok to ask for help or take a break.
1.2 Views on 'acceptance physical exercise'	Jasmine thought that the the acceptance exercise was one of the most memorable activities. She recognised her own coping mechanisms in the part of the exercise illustrating avoidance and expressed that this never worked for her in the past. Jasmine expressed that in order to accept something, one needs to have an open stance (as in opening your arms up and letting the soft balls touch you).
1.3 Experiences of learning about defusion	
1.4 Experiences of practicing mindfulness	Jasmine did not have a good understanding of Mindfulness previous to the taking part in the course. She has been advised by GPs and counsellors to practice Mindfulness,but did not know how to do it and could not find an introductory book that was easy to understand. After taking part in the 6 week program, she expressed that she now has a much better understanding of Mindfulness and that she uses Mindfulness to manage pain and reduce the amount of pain killers and strong opioids that she takes. This has also contributed to experiencing less side effects such as lack of energy, anxiety and stomach problems. 'So it's made a hell of a big difference' she says, and also helping her sleep better. Jasmine also talks about improvements in memory and concentration (being able to focus on tasks and remember things more easily). She is practicing Mindfulness around three times a day (early in the morning, around midday, and before going to bed). She is also keeping a Mindfulness diary.
1.5 Developing self-care and self-compassion	Jasmine become increasingly aware of the importance of self-care and and asking for support when she needs it. She also realised a trait that she and some the other participants had in common - they were all in caring positions and inclined towards helping others, but finding it difficult to look after their own wellbeing.
1.6 Understanding and identifying values	

	Kevin
1.1 Understanding and practicing acceptance	
1.2 Views on 'acceptance physical exercise'	
1.3 Experiences of learning about defusion	Kevin started to understand defusion better when he stepped back and became aware of some thoughts that he had when stepping out of his comfort zone (exploring a new place on his own, while on a cruise trip). He learned some useful techniques, such as thanking the mind and then going sightseeing on his own, despite the fear of getting lost or not making it back on time. For him, this was a revelation, as he was more aware of the impact his thoughts had on his behaviour, by stopping him from doing things.
1.4 Experiences of practicing mindfulness	Kevin was also new to Mindfulness and use to did things automatically ('jump in, dive in and have a go'). He is now stepping back and thinking before taking action, for example when talking to someone, he first listens mindfully and then replies, as opposed to 'talking at them'. Having been a teacher for most of his life, Kevin experienced stress and is now becoming increasingly aware of it. During the course he could not think of any negative thoughts that he was experiencing, however afterwards he became better at recognising them. He is embedding Mindfulness in his daily life, for example he uses the Body Scan meditation, he engages inmindful walking and mindful communication.
1.5 Developing self-care and self-compassion	
1.6 Understanding and identifying values	

	Naomi
1.1 Understanding and practicing acceptance	Naomi struggles a lot with accepting pain or her new version of self, with pain. She loved running long distance and lifting weights and now finds herself unable to do that anymore. Naomi is aware of that the body ' can do wonderful things' (she gives the example of having two children) however she still feels 'useless'. Naomi also struggles with losing weight (' no matter what I do, I can't lose it'). She feels like a failure for being in pain all the time and not being able to do things. She he tries to work as hard as she can, to prove herself that she is not a failure, and worthy of her partner's love. Naomi expressed that she had a problem watching Vidyamala's video on acceptance and managing pain with the help of mindfulness. She expressed that, although the video could have been helpful for some people, she was quite negative about it at the time, and felt jealousy. 'The only thing I didn't like is that bloody woman talking about how she doesn't take painkillers anymore cause she's accepted her pain and it's her friend.' Later on, Naomi talked about helping a patient accept that it takes time to regain his mobility. She works in healthcare and finds it easier to help others and help them accept their problems than working on accepting things herself.
1.2 Views on 'acceptance physical exercise' 1.3 Experiences of learning	
about defusion	
1.4 Experiences of practicing mindfulness	Naomi realised that she was already integrating mindfulness in her life, for example walking mindfully and 'taking in everything'. She is focusing her attention on the environment (the smell of the rain, the sound of the birds, gazing at the sea) in an attempt to distract herself from the pain that she is experiencing. She also engages in the Body Scan exercise, in order to be more aware of her whole body and try to isolate the areas that are painful and remind herself that pain is not everywhere ('cause by the time the pain gets really bad, it feels like it's all over your body'). Naomi is responding differently to negative emotions, by stepping back and acknowledging them instead of struggling ('the more upset you get,the more it hurts'). She expressed that Mindfulness helps her be more calm and relaxed, and helps her manage pain without taking painkillers (due to pregnancy N. cannot take her pain medication). Naomi also uses Mindfulness alongside aromatherapy (lavender oil) to improve her sleep.
1.5 Developing self-care and self-compassion	Naomi had to call in sick from work as she was having a flare and knew that she needed a break. Similarly to Jasmine, she became aware that it is not always easy for healthcare workers to ask or accept help from others when they feel the need (' Sometimes you need someone telling you to take a break because otherwise you don't'). Naomi also realised the importance of being self-compassionate and taking some time off when in pain or feeling poorly.
1.6 Understanding and identifying values	

	Sara
1.1 Understanding and practicing acceptance	Sara acknowledged that acceptance is still work in progress. She finds it more difficult to accept her situation recently, as pain had got significantly worse. Sara had a more stable level of pain before, which was easier to come to terms with.
1.2 Views on 'acceptance physical exercise'	Sara volunteered to help the facilitator demonstrate the exercise in one of the sessions and she thought that it took her longer to understand it than the others. She found it easy to understand, however she needed a bit more time to reflect on it.
1.3 Experiences of learning about defusion	Sara thought that the defusion exercise was the thing that made the biggest difference in the way she relates to her thoughts. She acknowledged that she is ruminating often and getting stuck in the same thoughts and feeling upset. Sara learned that she can detach from her thoughts and look at them 'almost scientifically' although she needs more defusion practice to master it. At first, Sara used the defusion technique where she had to speak in a funny voice every time she had a negative thought and it proved useful. She now regards defusion as a switch, giving her the opportunity to step back an challenge or analyse her thoughts instead of getting caught up in them.
1.4 Experiences of practicing mindfulness	Sara previously took part in an online Mindfulness course (a few hours a week). She engaged in regular Mindfulness practice (listening to audio guides) for a while but then she stopped. For her it was a matter of picking it up and finding the motivation to practice and turn it into a habit once again. She thinks that it is only a matter of practicing. Sara finds that Mindfulness helps her enjoy and appreciate the present moment more, and switching from automatic pilot to being more present in her daily activities (e.g. brushing her teeth). Sara also became more aware of some habits that are unhelpful such as watching TV too much, or spending too much time on social media and is trying to reduceor replace them with some different activities.
1.5 Developing self-care and self-compassion	Sara found that she needs around seven hours of sleep in order to feel rested and experience less pain and starting making some changes in order to maintain this amount of sleep. She started reducing the time spent on her iPad and making sure that she switches it off, in order to avoid watching Netflix for a long time. Sara also decided to put more effort into her oral hygiene, as her dentist advised her to brush her teeth for longer.
1.6 Understanding and identifying values	Sara found it hard to understand the difference between values and goals, but after some reflection she grasped it. She also liked the exercises from the workbook.

	Simone
1.1 Understanding and practicing acceptance	
1.2 Views on 'acceptance physical exercise'	Simone also took a while longer to make sense of the exercise and to understand its message. Then 'the penny dropped'.
1.3 Experiences of learning about defusion	Simone became more aware of her thoughts and expressed that she never imagined thoughts as passengers (as illustrated in the metaphor) before. She learned to recognise and manage them better.
1.4 Experiences of practicing mindfulness	Simone has been practicing Mindfulness before, however she is using it increasingly since she participated in the program and she talks about herself as a happier person, less negative about things and less affected by different situations that occur. She uses Headspace and likes doing different Body scan exercises, which she finds beneficial. Simone uses Mindfulness to communicate better with other people, and focus her attention on what she is trying to transmit, rather than doubting herself and thinking about wether they will be judgemental. She is also advocating Mindfulness to those around her, and talking to them about its benefits ('And I tell everyone that they should be doing mindfulness').
1.5 Developing self-care and self-compassion	Simone recalls experiencing pain and choosing to have a break and rest, without feeling guilty. She realised that her husband can take some of the responsibility and make sure that the children will be fed. Therefore, she did not cook on that particular occasion and chose to focus on her own wellbeing by practicing mindfulness instead. Simone understood that it is important for her to step away and 'recharge her batteries'. This is different to the way she responded before, when she would have struggled to get everything done on her own, only to feel much more irritable and frustrated if the children did something wrong. Simone learned that self-care is crucial, therefore she is now taking time off when she feels the need, and listens to her body more.
1.6 Understanding and identifying values	Simone grasped the concept of values and the difference between values and goals, although she found it a little bit confusing initially.

	Sophie
1.1 Understanding and practicing acceptance	Sophie recalls having read a book several years ago, that predicated the importance of being happy at all times in order to live a meaningful life. The biggest message that Sophie got from 'A Mindful Act' is that human beings experience a whole range of emotions, and this is normal. She understood that the reality of life will also encapsulate all sorts of problems, but what makes the difference is how people respond to them. Accepting that this is the nature of things had a powerful impact on her.
1.2 Views on 'acceptance physical exercise'	Sophie liked the acceptance exercise and thought that it was a simple activity that was put across very well, in a way that was easy for people to understand, despite the complexity of the message. She recognised the difference between avoiding negative thoughts and feelings that arise (batting the balls away) and opening up to them (allowing the balls to fall) while focusing on the present moment and on the important things (values).
1.3 Experiences of learning about defusion	Sophie expressed that she became more aware of certain thoughts surrounding pain ('I cannot do this because') and managed to become more detached from them and not let them influence her behaviour.
1.4 Experiences of practicing mindfulness	Sophie started using Mindfulness to help her with her sleep. She uses the Headspace app and also explores other mindfulness exercises on Youtube. She falls asleep easier and does not get up as many times during the night as before, which also means that she is feeling more refreshed in the morning. Sophie started using Mindfulness to help her with her sleep. She uses the Headspace app and also explores other mindfulness exercises on Youtube. She falls asleep easier and does not get up as many times during the night as before, which also means that she is feeling more refreshed in the morning. Sophie started a practice of eating mindfully, for example she switched from having winter soups to summer salads, and she is experimenting with different textures and flavours (pumpkin seeds, pomegranate, beans and raw ingredients).
1.5 Developing self-care and self-compassion	
1.6 Understanding and identifying values	

	Diane
1.1 Understanding and practicing acceptance	Diane found that the program helped her open up to new ways of dealing with issues and also develop more acceptance of pain. Sometimes she feels that she had enough, however most times she tries to be mindful, by living in the present moment and accepting things as they are. Danielle also tries to engage in activities and not wait until she will have had the operation to do start doing the things she loves.
1.2 Views on 'acceptance physical exercise'	Diane expressed that the exercise was a fun way to physically demonstrate what acceptance means in the context of ACT.
1.3 Experiences of learning about defusion	
1.4 Experiences of practicing mindfulness	Diane did not believe in Mindfulness, but now she embraces it. She thought that it wasn't going to work for her, but was convinced of the contrary after starting to practice Mindfulness. She became more aware of the present moment and realised that a lot of her thoughts are projected into the future. She likes the Body Scan and shared an episode where she was very anxious about having an operation but managed to cope with it successfully with the help of breathing and visualisation, techniques that she learned during the program ('And we did the Mindfulness, and at the end I could take a deep breath. And I've done that since.') She responds to stressful situations, anxiety and pain by concentrating on her breathing, being aware of the present moment and reassuring herself that everything is under control. Diane integrates Mindfulness into her daily activities, for example, when taking her children to the park, she pays attention to the surroundings (trees, birds chirping). Diane also advocates mindfulness and encourages those close to her to practice it.
1.5 Developing self-care and self-compassion	Diane expressed that it was important to learn how to say no for example at work, when feeling overloaded and working extra time. She became aware of her tendency to be a 'people pleaser' at her own expense. Diane learned to be more self-compassionate and put her wellbeing first when a friend wanted to visit and she was unwell, she learned that it is acceptable to say 'no, please come another time' and not feel guilty for it ('Putting yourself first and having that self-compassion is important'). Diane always cared about everyone else more than for herself, and struggled to fulfil her family's needs first, although she was not feeling well. This has changed recently, for example when Diane needs to sleep, she just takes some time off to rest and then returns to her activities.
1.6 Understanding and identifying values	

A.12 Topic guide Osteopathy students

Opening questions

- What led you to become an osteopath?
- What does being an osteopath mean to you?
- Supporting people living with persistent pain
- Can you share your experiences of supporting people who live with persistent pain?
- How do you help people who present with pain and additional psychosocial issues (depression, anxiety, catastrophyzing, fear avoidance, low self-esteem, isolation)?

Acceptance and Commitment Therapy (ACT)

- How familiar are you with the ACT model?
- What are your views on using the ACT model to help people experiencing persistent pain to live a more meaningful life?
- What are your views on using the ACT model to help people experiencing persistent pain to live a more meaningful life?
- If you had the necessary training, would you be willing to integrate ACT in your Osteopathic practice?
- What type of support would you need in order to be confident in using ACT with clients?

'A Mindful Act 'program

- What are your views on the program? (facilitators, content, practical aspects, delivery, participants' response)
- What are the things that you liked about 'A Mindful Act'?

- How do you think this intervention could be improved?
- What is your view on integrating brief psychosocial interventions and Osteopathy?

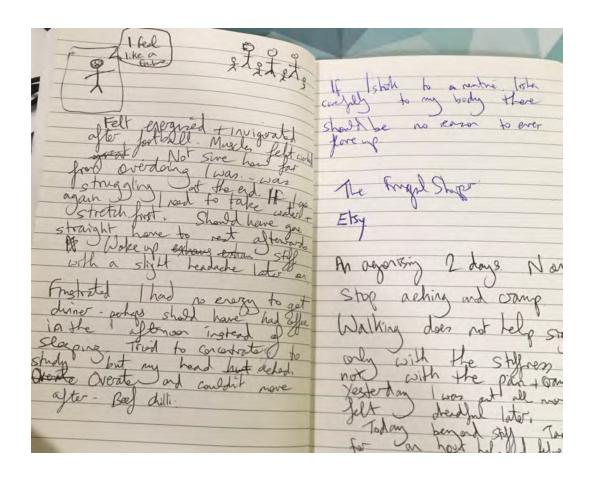
A.13 A Mindful Act - Follow up survey

- 1. Which of the ACT principles have you embraced? (You can choose more than one)
 - Mindfulness
 - Acceptance
 - Values
 - Self-care
 - Self-compassion
 - Defusion
 - Self-as-context
- 2. Are you still practicing Mindfulness? If you do, how many times a week?
- 3. What motivates you to continue practicing Mindfulness?
- 4. Have you explored any ACT resources (videos, books, podcasts, websites) since the end of 'A Mindful Act'? If you did, please give a few examples in the space bellow.
- 5. Have you encountered any difficulties to do with practicing Mindfulness or ACT? If you did, what are they?

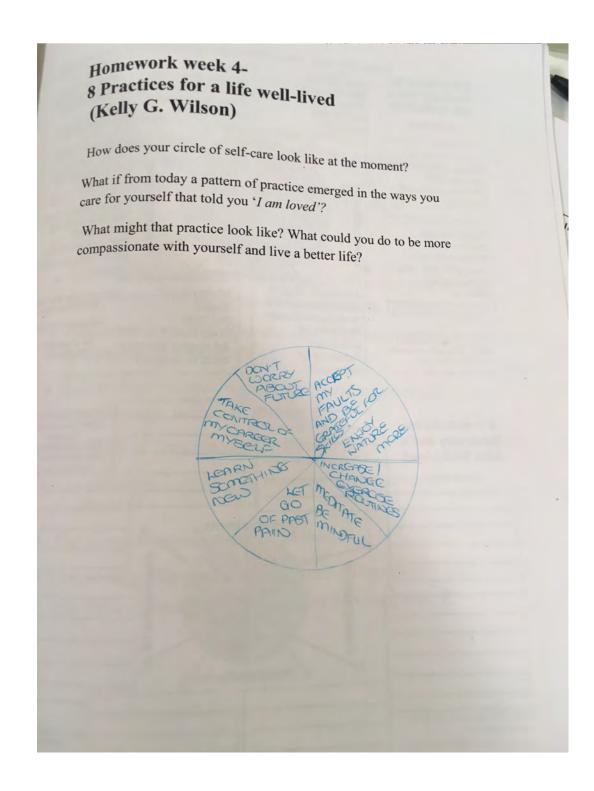
A.14 Attendance Record

Name	1st	2nd	3rd	4th	5th	6th	Interview	#	%
Diane		X	X	X	X		X	5	71.4%
Kevin	Х	Х	Χ				X	4	57.1%
Jasmine	Х	Х		Χ	X	X	X	6	85.7%
Sara	Х	Х	Χ	Χ	X	X	X	7	100%
Sophie	Х	Х	Χ	Χ	X	X	X	7	100%
Emily	Х	Х		Χ	X	X	X	6	85.7%
Naomi		Х			X		X	3	42.9%
Simone	Х	Х	Χ	Χ	X	X	Χ	7	100%
Hannah	Х	Х	Х	Х	X	X	X	7	100%
# in attendance	7	9	6	7	8	6	9		82.5%

A.15 Sara's diary



A.16 Sophie's pie chart



A.17 ACT Basic Definitions Quiz

Below are a list of things an ACT therapist might say when working with a client. Try to match each phrase to the process the therapist is trying to use. It is OK if you are not sure. Just give it your best try.

1.	'What is coming u	up for you right 1	now? What are you noticing about
	a) Acceptance	b) Defusion	c) Contacting the Present
2.	'Let's practice wa floating down a st	9	thts as though they are like leaves
	a) Acceptance	b) Defusion	c) Contacting the Present
3.	'Would you be wi	lling to make roo	m for that emotion?'
	a) Acceptance	b) Defusion	c) Contacting the Present
4.	'Let's make a list improve your hea	-	steps you can take this week to
	1		c) Committed Action
5.	-	-	ways present. It's the part of you
	looking out from	behind your eyes	.'
	a) Self as Context	b) Values	c) Committed Action
6.	'Deep down in yo	ur heart, what is	most important to you?'
	a) Self as Context	b) Values	c) Committed Action

A.18 Table illustrating feasibility results

Name	Time taken to fill in survey	Missing data from survey	Time dedicated to homework	Mindfulness practice	Mindfulness diary/journal	Workbook engagement & Group discussion
Sara ¹	10-15 minutes	No missing data	30 minutes/ week	30 min twice a week Body scan Sitting meditation	Mindfulness diary (entries a couple of times a week, recording: Bodily sensations and emotions; Creative ideas (Sara is an amateur writer); Drawings Blog ideas	pie chart (Self-care and self-compassion) and
Sophie	10-15 minutes	No missing data	1h/ week Reflecting on the homework during the week	30 min sleeping meditation (to help with insomnia) Mindful walking Mindful eating	Mindfulness diary includes entries on practices: mindful driving, mindful eating, connecting with nature	workbook activities Designed her own pie chart for healthy

Sara expressed a preference for filling in the survey at home, in a noise free environment and without distractions

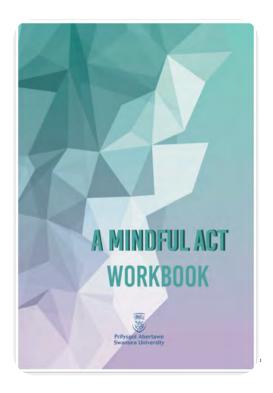
Name	Time to fill in survey	Missing data from survey	Time dedicated to homework	Mindfulness practice	Mindfulness diary/journal	Workbook engagement & Group discussion
Kevin	5-10 minutes	No missing data	10-15 minutes/ week	Different approach: embedding Mindfulness in daily activities: walking the dog, driving, traveling abroad.	Headspace Different body scans and sitting practices.	Kevin preferred to reflect on the homework and contribute to the group discussion rather than filling in the workbook.
Emily	5-10 min	No missing data	1h/ week	Twice a day (morning & night time) for 10-30 min Throughout the day (e.g. when stuck in traffic)	Headspace Body scan Mindfulness at work	Engaged in homework discussion (beginning of each session)

Name	Time to fill in survey	Missing data from survey	Time dedicated to homework	Mindfulness practice	Mindfulness diary/journal	Workbook engagement & Group discussion
Jasmine	5-10 minutes	No missing data	15-20 minutes/week	20 minutes-1hour (daily) Mindfulness for pain management Jasmine expressed that she practices more on bad days than on good days.	Headspace Other meditation exercises Reading books on Mindfulness Explored the resources provided in the workbook	Jasmine filled in the homework exercises weekly.
Diane	15 minutes	30 min/ week	10-30 minutes daily	Body Scan Mindful breathing (favourite type of meditation)		Actively contributed to the group discussions
Simone	10 minutes	30 min/week		Embedding mindfulness in daily living (walk in the park with children, driving)	Mindfulness journal 'Happiness planner' for goals and ideas	Attended all the six sessions and engaged in discussions about homework

Name	Time taken to fill in survey	Missing data from survey	Time dedicated to homework	Mindfulness practice	Mindfulness diary/journal	Workbook engagement & Group discussion
Naomi	10 minutes	No missing data	Two/three times a week	Mindfulness for relaxation		Was too busy to fill in workbook but contributed to the discussions
Hannah	10 minutes	No missing data	20 minutes/ week	30 minutes daily		Hannah was very proactive, made notes during the sessions explored the resources and contributed to the discussions.

A Mindful ACT Workbook A.19

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Introduction

Welcome to 'A Mindful Act' program! This is a six-week course aiming to help people with persistent pain live a more fulfilling life with the pain.

'A Mindful Act' is designed for people who are ready and willing to actively participate in their own care and embrace a more flexible approach to living with pain.

We will accompany you on an exciting journey where you will learn about Mindfulness and identify ways to incorporate it in your daily activities; you will also learn about practicing openness and hold self-stories more lightly as well as identifying your personal values and practice growing these

Every week you will encounter something new, and we encourage you to explore it with the curiosity and kindness of a child. We will be there alongside in case you need any clarification or support!

Enjoy each step of the journey!

About the author



Madalina Saracutu has a background in Health Psychology. Madalina is a third year PhD student at Swansea University whose project is centred on developing an intervention for people living with persistent pain.

Madalina is an enthusiastic individual whose experience ranges from supporting people with mental health issues through volunteering, as well as implementing personalized programs for children and adults with learning disabilities.

Madalina has a genuine interest in ACT (Acceptance and Commitment Therapy), mindfulness-based therapies, and wellbeing and stres management.

Some of her favorite leisure activities include: playing volleyball and travelling.

How to use this workbook

In order to get the most out of this program, we encourage you to do the homework practice. This should not take more than 20 minutes.

It is important that after each session you go back to the workbook, read the summary of the topic that was addressed that particular week and complete the homework activity. We also recommend for you to do some further reading and explore the resources provided (videos, activities,

For each of the six weeks there will be: an overview of the topic discussed that week, homework practice, suggested reading and additional resources.

We would like you to reflect on the things you learned during the sessions but also to start implementing some changes in your life (e.g. start practicing Mindfulness), in a kind and non-judgmental manner and of course, at your

The ACT model

Steven C. Hayes developed Acceptance and Commitment Therapy (ACT) in 1986. ACT is a type of therapy aiming to help people accept what is out of their control and commit to actions that can enrich their lives. Unlike other therapies, ACT does not focus on reducing symptoms. Instead, ACT aims to maximize human potential for a meaningful life by teaching you skills to deal with painful thoughts and feelings in such a way that they have much less impact on your life. ACT also helps you clarify what is truly meaningful, and then use that knowledge to guide, inspire, and motivate you to change your life for the better.

What is psychological flexibility?

In everyday language, psychological flexibility means holding our own thoughts and emotions a bit more lightly, and acting on longer- term values rather than short -term impulses, thoughts and feelings.

What are the core processes of ACT?

There are six core processes of ACT that guide people through therapy and provide a framework for developing psychological flexibility (Harris, 2011). These are: present moment (mindfulness), acceptance, defusion, self- processes (or self as context), values and commitment. We will be exploring each of these processes together, week by week.

The Psychological Flexibility Model PRESENT MOMENT ACCEPTANCE A formula for day-by-day liberation. © 2016, Kelly G. Wilson

Homework week	1	
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Attempted solutions and their long-term effects

 $Long\ term:\ Did\ symptoms\ return?\ \ Did\ they\ worsen\ or\ increase?$

What has this strategy cost you in terms of: wasted time, energy or money, health, vitality, relationships? Has it brought you close to a rich, full, meaningful life in the long term?

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Resources week 1

Books

- Get Out Of Your Mind And Into Your Life: The New Acceptance and Commitment Therapy (2008) by Steven C. Hayes and Spencer Smith
- The Happiness Trap (Based on ACT: A revolutionary mindfulness- based programme for overcoming stress, anxiety and depression) 2008 by Russ Harris
- Living Beyond Your Pain: Using Acceptance and Commitment Therapy to ease chronic pain (2006) by JoAnne Dahl PhD, Tobias Lundgren MS, Steven C. Hayes

Videos

Psychological flexibility: How love turns pain into purpose (Steven Hays) https://youtu.be/o79_gmO5ppg

Pain and Me: Tamar Pincus talks about chronic pain, acceptance and commitment (Professor Tamar Pincus) https://www.youtube.com/watch?v=ZUXPqphwp2U

ACT Coach (Android and App store) ACT companion: The happiness trap (Russ Harris

Discovering Mindfulness

"All men's miseries derive from not being able to sit in a quiet room alone" Blaise Pascal

What mindfulness is and what mindfulness is not



In simple terms, Mindfulness is about being aware of what is happening in the present on a moment-by-moment basis, on purpose and non-judgmentally. Kabat Zinn (1996) suggested that Mindfulness should not be thought of as

a technique but rather a a way of being. It is practiced for its own sake, and cultivated daily.

We all have the capacity to be mindful. It simply involves cultivating our ability to pay attention in the present moment and allows us to disengage from mental "clutter".

What are the benefits of Mindfulness?

There are many documented benefits of mindfulness. The most common of these include: an alleviation of stress and a better mood, an enhanced resilience and ability to deal with illness (mindfulness may not take away symptoms, but it can help make them more manageable), better sleep, improved personal relationships, decreased anxiety and depression symptoms; improved general health and quality of life. These benefits are known to persist as long as the practice of mindfulness is sustained.

Connect with Nature (humans are a part of nature, and nature is a part of humans. Breathe deeply and feel the nature flow through you



Let go of the need to control your body and mind (be open and curious about all experiences, not only the positive ones)

Go outside and enjoy nature.

Connect with someone you love (Being present for each other will help you feel more deeply connected)





Take time to observe your thoughts and start to see their patterns. Notice when thoughts are taking over and realise that thoughts are simply 'mental events' that do not have to control us.

Ways to embed mindfulness in our daily

Mindfulness requires commitment to regular practice. If there is no commitment, then the mind can easily be drawn back into its old ways. The following are some of activities that you can do in a mindful way



Eat your food slowly and mindfully focusing on its flavour, texture, smell, sensations

Move mindfully (stretch throughout the day or start a mindful walking practice)





Homework week 2

Mindful practice enables you to develop several skills:

- the ability to focus, and engage in what you are doing
 the ability to let thoughts come and go without getting caught up in them
 the ability to refocus when you realize you are distracted
- the ability to let your feelings be as they are without trying to control them

Start a Mindfulness Journal

I suggest you create a mindfulness journal, a blank book that you use to write about your sensations, thoughts, feelings, images, creative ideas, words that inspire you, as you become mindful of them.

You could record:

- the type of mindfulness practice done and the duration
- your experience during the practice why you might have experienced it

When you practice Mindfulness, it is important to simply sit with your sensations, thoughts and feelings and allow them to reveal themselves. Afterwards, as you write in your journal about your experience think about where that feeling or sensation might come from.

Keeping a meditation journal helps us have a better sense of what is actually going on. A journal also allows us to look back at our experience as it has changed over a period of time.

Difficult thoughts and feelings that showed up	Benefits and/or difficulties

Resources week 2

Mindfulness websites

http://www.freemindfulness.org/home http://www.mindful.org/resources/ mindfulness-audio-guided-practices/ http://www.mindfulnet.org/

 $\underline{http://franticworld.com/free-meditations-from-mindfulness/}$

Mindfulness Apps

Headspace https://www.headspace.com Smiling Mind https://smilingmind.com.au/ Smiling Mind https://smilingmind.com.au/
iMindfulness available on Apple and Android Mindfulness Daily http://www.mindfulnessdailyapp.com/

Books

- Mindfulness: A Practical Guide to Finding Peace in a Frantic World by Mark Williams and Danny Penman
- · Full catastrophe living by Jon Kabat-Zinn
- The Little Book of Mindfulness by Dr Patrizia Collard
- The Power of Now by Eckhart Tolle
- Mindfulness for Health: A practical guide to relieving pain, reducing stress and restoring wellbeing by Vidyamala Burch and Danny Penman
- The Mindfulness Solution to Pain: Step-By-Step Techniques for $Chronic\ Pain\ Management\ by\ Jackie\ Gardner-Nix$

Defusion

Defusion refers to learning to perceive thoughts and memories as bits of language as opposed to seeing them as threatening events or objective truths. Harris (2009) explains defusion as:

- looking at thoughts rather than from thoughts
- noticing thoughts rather than becoming caught up in thoughts
- letting thoughts come and go rather than holding onto them

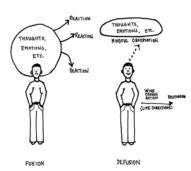
A thought is *just* a thought. Thoughts are not more powerful than what we allow them to be. Just because you have a thought, it doesn't mean it's necessarily true and that action needs to be taken.

Defusion techniques

- Treat 'the mind' as an 'external event', almost as a 'separate person' (e.g. a housemate)
 T'm having the thought that...
 Who is in charge here? You or your thoughts?
 'ok, you are right, now what?'

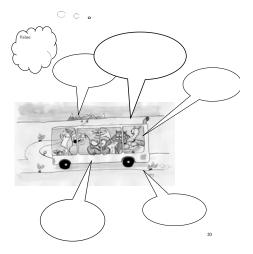
We all have a tendency to get caught up in our thoughts and over-identify with them. We often amplify thoughts in our minds and then they become 'the truth'. Now think about your own life and how attached or fused you are to your thoughts.

Harris, R. (2009). ACT made simple. Oakland, CA: New Harbinger Publications, Inc



Homework week 3- Passengers on the Bus

Identify the direction you would like to go (your value) and write it in the space provided. Now identify the "passengers" on your bus—the difficult thoughts, feelings, memories, and sensations that, if you listen to them, will guide you off of your valued path.



Resources week 3

Videos

Passengers on the bus metaphor https://www.youtube.com/watch?v=Z29ptSuoWRc

Struggling with Internal Hijackers? https://www.youtube.com/watch? v=NdaCEO4WtDU&index=2&list=PLAzHK3IqMPw8 CQh73 A840XdTp-mWwACsZ

Struggles by Dr. Russ Harris https://www.youtube.com/watch?v=dz_nexLqY_8Interna

Websites and exercises

 $\underline{http://www.dbtselfhelp.com/Defusing_Exercises.pdf}$

 $\underline{http://portlandpsychotherapyclinic.com/defusion_exercise}$

 $\underline{http://resilient\text{-}traveling.umich.edu/skills/cognitive-}$ defusion

http://www.mindfulnessmuse.com/acceptance-and-commitment-therapy/leaves-on-a-stream-cognitivedefusion- exercise

https://www.actmindfully.com.au/upimages/ Using the ACT Companion App for defusi on.pdf

Self-compassion and self-care

What is self-compassion?

Having compassion for oneself is not very different from having compassion for others. Tohave compassion is to notice when a person is suffering. Then, compassion involves feeling moved by one's suffering and feeling the desire to help the person who is suffering. Having compassion also means that you offer understanding and kindness to others rather than judging them harshly.

Instead of mercilessly judging and criticizing yourself for various inadequacies or shortcomings, self-compassion means you are kind and understanding with yourself.



Selfcompassion is not:

self-pity self-indulgence self-esteem

Self-compassion exercise

Think about someone you love with all your heart, beyond all measure Close your eyes and see their face. Let them catch that look of love in your eyes. Now imagine them knowing of their shortcomings and flaws. Would you give them another chance? Imagine you were someone loved like that. What would an act of self-compassion look like today?

Some self-care practices









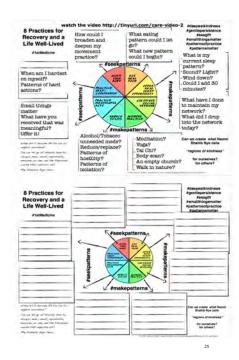




How does your circle of self-care look like at the moment?

What if from today a pattern of practice emerged in the ways you care for yourself that told you 'I am loved'?

What might that practice look like? What could you do to be more compassionate with yourself and live a better life?



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Resources week 4

Websites and free materials

http://onelifellc.com

 $\frac{https://tinybuddha.com/blog/45-simple-self-care-practices-for-a-healthy-mind-body-and-soul/\\$

http://self-compassion.org/what-self-compassion-is-not-2/

Books

- The mindful path to self-compassion: Freeing yourself from destructive thoughts and emotions by Germer C.
- Emotional alchemy: How the mind can heal the heart by Bennett- Goleman, T
- Soul without shame: A guide to liberating yourself from the judge within by Brown, B
- The Gifts of Imperfection by Brown, B
- Compassion: Listening to the cries of the world by Feldman C
- The compassionate mind by Gilbert P
- Uncovering Happiness: Overcoming Depression with Mindfulness and Self-Compassion by Goldstein, E

Acceptance and values

Acceptance

Acceptance doesn't mean resignation or giving up. Acceptance means opening up and making space for painful sensations and emotions.



Instead of avoiding them, fighting them or getting overwhelmed by them, we openup and allow them to be. This doesn't mean we like them, but simply that we make room for them.

Pain acceptance

Accepting persistent pain may seem contrary to common sense. Acceptance in this context may seem unnatural. Most approaches focus on eliminating or reducing pain and aversive experiences. However, ACT is different. Its focus is on increasing openness to all that comes our way (including negative sensations and experiences). There is a reasonable amount of evidence suggesting that greater acceptance of pain is associated with fewer pain-related difficulties and better overall quality of life (McCracken & Vowles, 2014; Scott & McCracken, 2015; Vowles & Thompson, 2011).

Some ways you can try to cultivate acceptance:

- acknowledge the experience you aren't accepting
- notice which part of your body feels tense and imagine your breath going into and out of the area of tightness

become really curious about your experience. Where did this feeling come from? Where do I feel it? What's interesting about it?

Values

A value is like an internal compass guiding us throughout life. Most people mistake values and goals, but they are different.

Values are life-long. Theygive life meaning and purpose. Values are what matter the most to us, what we would like to be remembered for.

What is important to you in life?

Is it being a good parent?

Is it your career, connecting with nature, living a healthy life or making a difference? What is the legacy you want to pass on?



Why are they important?

We often live 'on autopilot' and fail to reflect on whether or notwe are living a we otten tive on autoput and rait to retrect on whether or notwe are inving; valued life (a life consistent with our values). Also, life can feel confusing when we are unsure of what is most important to us. That's why identifying and living consistent with our values helps us feel the most at peace with ourselves. Staying connected to your values helpsyou to feel empowered and motivated!



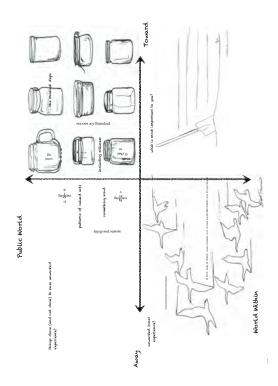
Homework week 5. Matrix interview (Kelly G. Wilson)

Think about some things that are important to you (record it in the the bottom right). Now take some time to reflect on what stops you from acting on your values (unwanted experiences, thoughts, emotions, sensations).

E.g. 'Health is important to me' – 'I feel too tired to exercise', 'I am not good enough'

What do you do to cope with these unwanted inner experiences? Do you avoid or struggle with them? Now think about implementing some patterns of valued acts to help you live a better, more meaningful life (e.g., practice acts of kindness, embed some stillness in your life, do something bold)





Resources week 5

Activities

Values worksheet (Adapted from Kelly Wilson's Valued Living Questionnaire)

http://thehappinesstrap.com/upimages/Values_Questionnaire.p

Life values inventory (a free developed online platform to help individuals clarify their values)

http://www.lifevaluesinventory.org/

Clarifying your values (Adapted from Tobias Lundgren's Bull's Eye Worksheet)

https://thehappinesstrap.com/upimage s/ Long_Bull's_Eye_Worksheet.pdf

Values vs Goals - Dr. Russ Harris https://www.youtube.com/watch?v=LDVpUBB moNU

Values from A Life Worth Living https://www.youtube.com/watch?v=wI0dFvNYkh8

Committed action-A way forward

"What one does is what counts. Not what one had the intention of doing." - Pablo Picasso

From values to committed action

While it is important to have an awareness of the values you wish to live by, it is also essential to translate that understanding into committed by, it is also essential to translate that understanding into committed action-making your values manifest through your behaviour. You should expect drawbacks, they are normal, however no matter how many times your actions fall short, you can always take some time to reassess your actions and get them back in line with your values. Remember that values are a constant driving force for behaviours.

4 steps towards committed action (Harris, 2009)

- (1) Choose a domain of your life that is a high priority for change (2) Choose what values you wish to pursue in this domain. (3) Develop goals that are guided by those values. (4) Take action mindfully

Homework week 6- The willingness and Action plan

The Willingness and Action Plan
My goal is to (be specific):
The values underlying my goal are:
The actions I will take to achieve that goal are (be specific):
The thoughts/memories, feelings, sensations, urges Γ m willing to make room for (in order to achieve this goal):-
Thoughts/memories:
• Feelings:
4.5
* Sensations:
+ Urger:
+ It would be useful to remind myself that:
• If necessary, I can break this goal down into smaller steps, such as:
+ The smallest, easiest step I can begin with ix:
+ The time, day and date that I will take that first step, is:
O Dr Ross Metris, 2008 very Johnspironsering 2005

Resources week 6

Videos

 $\underline{https://www.brattlebororetreat.org/act/values-committed-action}$

Acceptance and Commitment Therapy: Values and Committed Action $\underline{v=yoVmoOnjscM\&index=3\&list=PL\ wXbJqg9HUpou5REMaWnAEV}$ Lq9aIKsZx

The choice point (Russ Harris) $\underline{https://www.youtube.com/watch?v=tW6vWKVrmLc}$

Activities

Goal setting exercise (Russ Harris) https://thehappinesstrap.com/upimages/The Reality Slap - Appendix_4_-_Goal_Setting.pdf

The life change list (Russ Harris) https://thehappinesstrap.com/upimages/ $\underline{complete_worksheets_for_The_Confidence_Gap.pdf}$

The five-step plan to changing your life (Joseph Ciarocchi) $\underline{http://josephciarrochi.com/wp\text{-}content/uploads/2012/03/The\text{-}five\text{-}}$ step-plan-to-changing-your-life.pdf

Thank you for taking part in 'A Mindful Act! We hope that you found it worthwhile.

Our primary focus was to get you familiar with the ACT model and teach you some important skills that you can apply to live a better, rich and meaningful life with persistent pain.

There were six topics covered in 'A Mindful Act'. Every week you were faced with a new challenge (How can I use Mindfulness? What are my values? How can I practice defusion?).



Hopefully you have started implementing some small changes that will take you closer to living the life you want. Remember that this is not an easy journey. Show yourself some kindness!



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