# LIVING WELL WITH PAIN WHILE SEEING AN OSTEOPATH: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

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Abstract

**Background**: In the United Kingdom 8 million people are living with chronic pain and

health practitioners are encouraged to move towards a biopsychosocial framework to

account for the unpleasant sensory and emotional experience associated with pain.

Those experiencing pain can seek the advice of an osteopath to help manage their

pain experience.

**Methods:** This research sought to explore, analyse, and interpret the lived experience

of those who self-identify as living well with pain and the role of the osteopath. Three

male and two female participants were interviewed in a semi-structured format. These

accounts were analysed using Interpretative Phenomenological Analysis (IPA) to

understand how participants live well with pain and the role of osteopathy in their

experience.

**Results:** There were four main experiential statements derived from the IPA analysis:

i) Living with pain is exhausting – The participants described an exhausting battle as

they learn to live with pain; ii) Osteopathy reconnects me to life – The osteopaths gave

them the freedom to live with pain and the participants felt accepted for who they were;

iii) Managing pain is like developing a skill - The participants adopted a problem-

solving, trial and error approach to manage their pain; iv) Living well has its ups and

downs – The participants had experienced living well through a process of acceptance

and used previous suffering as a form of gratitude as they felt they had been given a

new life, one in pain.

Conclusion: The participants in this study explained living with pain as a process

leading to a point of change. They saw osteopathy primarily as a form of support and

encouragement enabling them to engage in their own positive health behaviours.

Fundamentally, the participants had learnt to live-well despite pain.

**Key words:** Pain, living well, osteopathy, health psychology.

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#### 1. INTRODUCTION

#### 1.1 Pain

The World Health Organisation (2018) recognises that musculoskeletal pain conditions are common across the lifespan. The International Association for the Study of Pain (IASP) (2020) defines pain "as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage". In addition, IASP (2020) suggests that pain is always a personal experience that may be influenced by biological, psychological and social factors. Low back pain, the most common musculoskeletal condition, is estimated to affect over 551 million people worldwide and continues to be the leading cause of disability burden (Ferreira et al., 2023, Mills et al., 2019). Furthermore, The National institute for Health and Care Excellence (NICE) (2021) offers examples of chronic primary pain which have no clear underlying cause and include conditions such as fibromyalgia, chronic widespread pain and complex regional pain syndrome. Also, to be taken into account is acute (pain lasting no longer than three months) nociceptive pain. Nociceptive pain is defined as involving the neural process of encoding noxious stimuli (IASP, 2020, Yezierski and Hansson, 2018). Noxious stimuli are recognised as thermal (temperature), mechanical (stretch or strain) and chemical (inflammatory processes) (Vardeh et al., 2016).

One of the many functions of nociceptors is to detect and signal homeostatic threats (Xanthos and Sandkühler, 2014, Brodal, 2017). For example, these basic properties of nociceptors enable them to constantly monitor the composition of the various tissues and the mechanical and thermal forces they are subjected to, although they elicit pain only under certain conditions and contexts (Brodal, 2017). Acute nociceptive pain, as described and neuropathic pain (pain caused by a lesion or disease of the somatosensory nervous system (Murnion, 2018)) do not account for altered nociceptive states such as when there is absence of actual tissue damage or threatened tissues that may activate peripheral nociceptors (Lenoir *et al.*, 2020). As IASP (2020) states, pain is a personal, subjective experience that can only be measured by self-report while brain imaging only measures the neural processes related to nociception, but these processes alone may not be enough to generate pain (lannetti *et al.*, 2005, Stilwell and Harman, 2019).

Long-term pain, chronic pain, or persistent pain (these terms will be used interchangeably throughout the current research) is recognised as pain lasting for longer than three months or past normal tissue healing time (Mills *et al.*, 2019, van Hecke *et al.*, 2013). Chronic pain that has exceeded this amount of time is often driven by central sensitisation and altered descending control of nociceptive input (Gauntlett-Gilbert and Brook, 2018, Woolf, 2011). In the UK around 8 million people live with chronic pain and 13% of the UK population reported pain lasting for longer than six months of moderate to severe intensity (Fayaz *et al.*, 2016). Chronic Low Back Pain (CLBP) accounts for 6-9% of adult visits to general practice, with 80% of those patients still reporting pain a year later; approximately 90-99% of back pain has no pathological or anatomical cause for symptoms and is considered a non-specific type of diagnosis (Stilwell and Harman, 2019, Storheim and Zwart, 2014, Vos *et al.*, 2016).

Recent understandings in the area of pain have highlighted the need for health practitioners to go beyond the long-established biomedical approach and include the psychological and social components of the patient's pain experience (Johnson and Acabchuk, 2018). Pain is a complex human experience in which the individual has to adapt to a variety of symptoms on a daily basis (Linton and Shaw, 2011). The pain experience is placed within a social context and is a challenge for the patient to explain and a healthcare provider to understand (Dueñas et al., 2016, Burr, 2015). For example, the individual has to explain a complex experience that may have no pathophysiological signs and the healthcare provider has to attempt to make sense of an issue that may have no underlying physical cause (Quintner and Cohen, 2016). Qualitative research has identified key themes associated with persistent pain, mainly, the impact of pain on the self (Smith and Osborn, 2007, Van Griensven, 2016), the individual's relationship to the outside world and healthcare providers (Toye et al., 2017, MacNeela et al., 2015) and coping (Bunzli et al., 2013). A specific example is low back pain, which is described as a complex condition involving social factors, psychological factors and biological factors, and is a challenge for healthcare providers to isolate the specific nociceptive source (Hartvigsen et al., 2018). Therefore, this complex pain experience could affect the patient on different social and psychological levels, and they may become trapped in a healthcare system that finds the management of chronic pain a challenge, placing a strain on frontline services and resources (Cohen *et al.*, 2021, Margham, 2011).

The (musculoskeletal) MSK system comprises of muscles, joints, bones, cartilage, tendons and ligaments (Drake *et al.*, 2009). Chronic Musculoskeletal Pain (CMP) is experienced in the back, neck, shoulder, or knees and can have a lifestyle impact including activity limitation, fatigue, and mood disturbance (Aili *et al.*, 2018, Babatunde *et al.*, 2017b). In the context of low back pain, advanced imaging has been used to understand the structural causes (Rao *et al.*, 2018). Advanced scans can often identify disc degeneration, facet hypertrophy and disk herniations as the causes of low back pain leading to the prescription of pain-medication or surgical interventions (Berry *et al.*, 2019, Brinjikji *et al.*, 2015). However, a systematic review conducted by Brinjikji *et al.* (2015) concluded that scan findings were common in asymptomatic individuals and increased with age. Hence, these findings may be a normal part of aging and unassociated with low back pain (Brinjikji *et al.*, 2015) adding further confusion to the individual experiencing pain.

## 1.2 Lived Experience of Pain

Phenomenology is a philosophical method for exploring the lived experience, it is a method of investigating the subjective human experience as it is lived (Carel, 2011). This phenomenological approach enables researchers to understand the individual, subjective, lived experience of pain (Smith *et al.*, 2009, Smith and Osborn, 2007, Carel, 2011). Persistent pain is best understood from the person living with pain, so first-person accounts will shed light on the ever-changing experience of pain (Belton, 2019). Pain is personal to the individual experiencing it, people often speak of having pain in their back or their knee as if it is outside of themselves (Morris, 2013, Belton, 2019). For example, people often complain of pain in 'the' knee as if it were a joint outside of their body, similar to a form of disengagement with a body part (Moore *et al.*, 2022). Some research has referred to this as a form of 'catastrophising', that could be seen as a form of coping with pain to manage a painful experience (Jensen *et al.*, 2011). Pain catastrophising is defined as a negative cognitive-affective response to an actual or anticipated pain event (Quartana *et al.*, 2009). If pain persists, there are

personal reports of pain changing everything about the individual's life (Smith and Osborn, 2007). Belton (2019) shares a similar experience of pain changing everything about her as a person, her identity as a firefighter and ultimately her sense of who she was. Therefore, pain can lead to a great deal of psychosocial distress for the individual as they accommodate the uncertainty engendered by pain on a day-to-day basis.

Persistent pain is a common health problem and has led to considerable amounts of research exploring a range of pain mechanisms (Thompson, 2019). Historically this research has offered clinicians in-depth knowledge and understanding of pain physiology but with a limited understanding of how a person experiences pain (Rocca and Anjum, 2020). The pain experience is also influenced by environmental and contextual factors and is a function of the whole person (Wideman et al., 2019). For instance, the individual may see their environment as either a place of threat or safety (Borsook et al., 2018). Psychological factors including fear-avoidance and pain catastrophising play a significant role in some patients' attempts to cope with the pain experience (Tabriz et al., 2019). Fear avoidance or kinesiophobia is recognised as the avoidance of activities based on fear around pain (Vlaeyen and Linton, 2000). A systematic review evaluating psychological risk factors found a significant association between fear-avoidance beliefs and increased pain and disability (Keefe et al., 2004). When the pain experience is placed within a biopsychosocial context, psychosocial factors, including pain catastrophising or fear-avoidance beliefs, may limit the individual's quality of life and interaction with their environment, potentially increasing the risk of chronic pain (Meints and Edwards, 2018).

As the evidence base grows, there have been developments in the concept of pain-related suffering. Cassell (1982) defines suffering as severe distress generated by the imminent threat to the integrity of the person in pain. Further accounts of pain-related suffering have highlighted the need to account for the on-going or prolonged suffering that is experienced when coping with the fluctuating states that are common in those experiencing pain (Bueno-Gómez, 2017). In this context of suffering there is an ongoing threat to quality of life and well-being (Bustan, 2019). Individuals who are experiencing psychosocial distress, anxiety or depression may say they have 'poor mental health' or that pain affects their mental health (Alegría *et al.*, 2018). The World Health Organisation (WHO) defines mental health as "a state of well-being in which

the individual realises their own abilities, can cope with the normal stressors of life, can work productively and fruitfully, and is able to make a contribution to their community" (WHO, 2004). Therefore, the term 'poor mental health' could be used by those in pain to explain psychological distress.

Psychosocial distress is recognised as an unpleasant experience of an emotional or psychological nature, including anxiety, depression and other mood-related disorders (McCarter et al., 2018). In the context of pain, this could be experienced as painrelated anxiety, which is defined as a physiological state characterised by cognitive, somatic and behavioural components leading to fear and worry (Woo, 2010). Fear is recognised as a psychological factor that is defined as an emotional reaction to an identifiable and immediate threat that may lead to distinct cognitive, physiological and behavioural responses to manage that threat (Adolphs, 2013, Martinez-Calderon et al., 2019). In humans fear can be learnt from the social environment, for example fear could be verbally transmitted through cultural learning (Mertens et al., 2018, Olsson and Phelps, 2007). The fear of movement is recognised as the fear of completing physical activity that may unjustifiably be assumed to cause an injury or reinjury (de Jong et al., 2005). These constructs together may influence pain-related behaviour in individuals experiencing pain (Cresswell et al., 2020, Zale and Ditre, 2015). Therefore, pain is an influential motivator for learning, the individual predicts the possibility of pain or threat and adapts their behaviour to avoid or minimise the impact on the self (Meulders, 2019). In the acute phase, pain serves to reduce threat and is adaptive. However when pain becomes chronic it can reduce quality of life as the individual withdraws from enjoyable activities that may improve well-being (Meulders, 2019). Individuals who experience chronic pain may become trapped in a cycle of increased sensitivity to pain, reduced quality of life and disability, further increasing their fear of pain (Vlaeyen et al., 2016). The fear-avoidance model (Vlaeyen et al., 2016, Vlaeyen and Linton, 2000) provides a conceptual framework to understand the complex, multidimensional processes whereby psychosocial factors are thought to influence the transition from acute to chronic pain (Vlaeyen and Linton, 2000, Gatchel and Turk, 1996). In this model, avoidance behaviours are recognised as a maladaptive response to a threat and lead to an increase in fear and pain that could in turn lead to increased levels of depression and anxiety (Edwards et al., 2016, Vlaeyen and Linton, 2000).

Depression and low mood have been correlated with pain severity (Vadivelu et al., 2017). For instance, a range of longitudinal and observational research has supported a bidirectional link between persistent pain, depression and anxiety which are recognised as strong predictors of chronic pain and are included in the fear-avoidance model (Jensen and Turk, 2014, Linton et al., 2011, Meints and Edwards, 2018, Nicholas et al., 2011). Therefore, this relationship demonstrates that experiencing a higher level of pain is associated with a higher level of depression (Roughan et al., 2021, DeVeaugh-Geiss et al., 2010). As suggested above, individuals use mental health as an umbrella term, and, similarly people may use trauma as an overarching term that includes violence, workplace and school bullying or accidents to describe an experience personal to them (Havaei, 2021). Therefore, events such as intense physical and psychological stress may have resulted in the experience of trauma (Bisson et al., 2015). Similarly, posttraumatic stress disorder (PTSD) is recognised as an anxiety disorder that develops in some individuals after exposure to uncommon, traumatising events including violence or accidents (Siqveland et al., 2017). Furthermore, Sigveland et al. (2017) suggest that, while the association between PTSD and persistent pain is unclear, there is evidence to support that PTSD is common in those experiencing persistent pain, fibromyalgia, and migraines.

These definitions may have advanced an understanding of pain-related care but those experiencing pain may not explain their day-to-day life in these medical terms. Johnston-Devin *et al.* (2019) explains in detail the experience of living with complex regional pain syndrome (CRPS). CRPS is difficult to diagnose, difficult to treat and is recognised as a severe painful state that develops in 0.5-2% of patients following tissue injury or fracture (Johnston-Devin *et al.*, 2019, Russo *et al.*, 2018, Bruehl, 2015). Therefore understanding the lived experience of those diagnosed with CRPS is fundamental to allow clinicians to understand their patient's daily struggles and support their quality of life (Johnston-Devin *et al.*, 2019). In light of pain related suffering and psychosocial distress people living with CRPS spoke of dealing with an unknown enemy and adopted language associated with war and battling against a moving target (Johnston-Devin *et al.*, 2019). These themes were used to capture the confusing nature of an injury that physiologically should have healed, individuals losing self-confidence in their own abilities and not being able to trust their bodies (Johnston-Devin *et al.*, 2019). Furthermore, individuals described the challenge of finding a

balance of maintaining daily activities, while trying not to overdo those tasks for fear of pain the following day (Johnston-Devin *et al.*, 2019). Fundamentally Johnston-Devin *et al.* (2019), using a qualitative approach, highlight the disconnect between how an individual experiences a condition and the way experiences are defined in academic literature. Qualitative research adds rich meanings and experiences to these academic definitions from a first-person experience.

## 1.3 Communicating Pain to Others

Long-term pain can be a challenge to communicate and people may use metaphors (understanding and experiencing one kind of thing in terms of another) to convey meaning (Launer, 2022). In terms of pain-related language, metaphors offer the individual experiencing pain the language to communicate to the world how pain feels (Munday et al., 2021). Munday et al. (2021) qualitative focus group study identified five key themes: Isolation, Physical Sensations of Pain, Pain Personified, Pain as Overwhelming and Coping with Pain. They found that pain was difficult to express through language (Munday et al., 2021). Interestingly, Munday et al. (2021) found that their participants rarely spoke about specific painful body parts, rather they describe pain in a way that affects their whole life and the individual person suffering pain. This could explain why clinicians in pain management struggle to understand first person accounts of pain (Stilwell et al., 2021). The person in pain is making an attempt to explain how they feel compared to the clinician who is trying to understand their experience in terms of single word adjectives like sharp, burning or exhausting (Melzack, 1975, Munday et al., 2021). The language used by healthcare providers to explain pain may lead to further harm and delay the patients' recovery (Dixon et al., 2016, Rossettini et al., 2018). Therefore, communicating and understanding an individual pain experience is a challenge for the individual experiencing pain and the clinician trying to support them.

## 1.4 Osteopathy

Osteopathy was developed by Andrew Taylor Still, MD. It began in the late-19<sup>th</sup> century and has grown around the world, with 196,861 clinicians in 46 countries (Skinner et al., 2022). The University College of Osteopathy (UCO) defines osteopathy as a person-centred manual therapy profession that aims to enable patients to respond and adapt to changing circumstances (UCO, 2023). Osteopathy is regulated by the General Osteopathic Council (GOsC) and is a recognised allied healthcare profession (GOsC, 2018). Historically, osteopathy has accorded a central role to the biomechanical assessment of the health of the musculoskeletal system, which includes examination of the structure of the human body (Fryer, 2017b, Grace et al., 2016b). Osteopaths diagnose a range of MSK conditions and offer safe and effective treatment that aims to promote the health of individuals (GOsC, 2018). The osteopathic training includes education on the importance of viewing the patient in their individual context in order to construct a treatment plan and support them back to health (Grace et al., 2016a). However osteopathic education offers little in relation to fostering longer-term behaviour change and osteopaths could learn problem-solving techniques from patients self-managing MSK pain (Pincus, 2006). NICE guidelines support osteopathic treatment and manipulation alongside education and reassurance in the management of low back pain (NICE, 2020b). The management of these conditions is based on three key areas of osteopathic philosophy which can be aligned with elements of the biopsychosocial model (BPSM) (Fahlgren et al., 2015, Penney, 2010):

- 1) the body is a unit of mind, body and spirit; [aligns with the idea of physical/cultural/social interaction]
- 2) the body is capable of self-regulation, healing and health maintenance; [aligns with psychosocial illness behaviour, beliefs and coping strategies]
- 3) structure and function of the human body are reciprocally interrelated [aligns with the biological and with neurophysiology]

The formation of a diagnosis and treatment plan has been placed in the biomechanical model, which is based on the structure of the human body in the search for a cause of pain (Fryer, 2017a, Penney, 2013). In addition, there are early signs that osteopathic manual therapy (OMT) reduces co-morbid psychological conditions (Edwards and Toutt, 2018). Edwards and Toutt (2018) found that self-care increased, while pain, anxiety and mental health disorders significantly decreased but that OMT was not effective in reducing depression and fear avoidance. Even though this was an evaluation study and not a randomised control trial, with no follow-up data, these are still interesting findings that warrant further investigation (Edwards and Toutt, 2018).

## 1.5 Health Psychology

Health psychology is defined as an interdisciplinary field concerned with the application of psychological knowledge and techniques to health, illness and healthcare (Marks et al., 2018). In addition, health psychology recognises the importance of the individual's understanding of experiences and the meanings they assign to them (Brocki and Wearden, 2006). Furthermore, psychological interventions could support the management of depression, anxiety, catastrophic thinking, psychological flexibility and beliefs associated with pain (Castelnuovo and Schreurs, 2019). Therefore, health psychology could support osteopathic care by offering empirical contributions to health behaviour, the application of psychological theory and the management of chronic health conditions from a psychosocial perspective. Both osteopathy and health psychology aim to develop interventions that are aligned with the biopsychosocial (BPS) model of care (Engel, 1977, Engel, 1980). The BPS model as explained above is consistent with osteopathic philosophy and offers a framework for treating individuals experiencing pain (Fryer, 2017a, Penney, 2010). Similarly, the BPS approach to understanding health and illness is at the core of health psychology and identifies the impact of biological, psychological and social factors on well-being and chronic illness (Hilton and Johnston, 2017). There is a body of research offering frameworks for managing patients with long-term pain. The long-standing biomedical model that focusses on pain sensation does not necessarily account for the psychosocial aspects of the pain experience (Bendelow, 2013). A biomedical approach may not guarantee a positive therapeutic outcome as it may focus on the

structural causes of pain (Carlson and Carlson, 2011). However, osteopaths who utilise a BPS approach may be alert to relationships between the psychological and the social elements of pain, incorporating solutions into a management plan which may improve patient outcomes (Johnson and Acabchuk, 2018).

#### 1.6 Pain Interventions

Over the next sections there is an overview of the wide range of interventions available to those people living with persistent pain. Included in the overview is a critique of the widely accepted biopsychosocial model suggesting that this model has created a 'silo effect' (Caneiro et al., 2020) where the individual is either more of a biological or a psychosocial presentation. Against the backdrop of a range of interventions, including behavioural interventions, the section pinpoints the enactive model. Given that pain is a complex, subjective experience (IASP, 2020) the enactive model could be more suitable as a framework when working with individuals in pain (Cormack et al., 2022)

There are many treatment options available to the individual experiencing chronic pain mainly delivered by primary practitioners including general practitioners, osteopaths, physiotherapists and chiropractors (Babatunde *et al.*, 2017b). The National Institute for Health and Care Excellence (NICE) recommends that paracetamol, non-steroidal anti-inflammatory drugs including aspirin and ibuprofen, benzodiazepines or opioids should not be offered to those experiencing chronic pain. NICE reports there should be a move towards patient-centred care with a focus on good communication to foster a supportive relationship between the patient and healthcare professional (NICE, 2020a). Outside of non-pharmacological treatments patients may be offered a range of self-management advice, psychosocial interventions or exercise therapy (Shipton, 2018). These complex intervention therapies have demonstrated some positive results in clinical trials but may not suit all patients (Leboeuf-Yde and Manniche, 2001).

International guidelines suggest a focus on self-management strategies including physical exercises, mindfulness-based techniques and treatment programmes tailored to the individual (Kurz and Hebron, 2022a, Meroni *et al.*, 2021). Self-management

recognises, harnesses and develops people's assets, empowering, and working with them as partners rather than emphasising their deficits and reinforcing dependency (Rodham, 2020). These self-management strategies have been shown to improve the outcomes associated with non-specific low back pain (Carlson and Carlson, 2011, Gauntlett-Gilbert and Brook, 2018, NICE, 2020b). However, guideline-based care is seen as a challenge for those working in pain management and practitioners report poor adherence to home-based exercise programmes (Argent *et al.*, 2018). A range of Interventions that have shown some successful outcomes have involved guided support and physical activity, however a Cochrane review (Jordan *et al.*, 2010) explains there is still uncertainty around which strategies will work best to support those in pain.

Health-related behaviours are important adaptable risk-factors suitable for interventions as they attempt to change the behaviour of patients through education or exercise programmes but may only provide small short-term benefits (Babatunde *et al.*, 2017b, Leboeuf-Yde and Manniche, 2001, Mills *et al.*, 2019). Fundamentally, Gauntlett-Gilbert and Brook (2018) suggest that clinical management of chronic pain is challenging and a systematic review by Babatunde *et al.* (2017b) found moderate to strong evidence for exercise therapy and psychosocial interventions highlighting a range of interventions available for pain management. The challenge that faces many clinicians working in pain management, is selecting the correct amount of intervention sessions for those experiencing pain. Despite these challenges, NICE (2021) suggests developing an understanding of the individual's lived experience of pain and supports the use of psychological therapy for chronic primary pain, including Acceptance and Commitment Therapy (ACT) and Cognitive Behavioural Therapy (CBT).

## 1.6.1 Psychological Interventions

Cognitive behavioural therapy aims to modify patients' dysfunctional beliefs and behaviours to reduce distress and improve long-term health (Vitoula *et al.*, 2018). Padesky and Mooney (2012) adopt a different approach and rather than focus on distress they adopt a four-step model to develop resilience. They incorporate the best available practices as suggested by Beck (1995) meaning their approach involved a

therapist and client collaboration and guided discovery to foster learning of new behaviours (Padesky and Mooney, 2012). This intervention's focus was towards resilience and not directly associated with pain. However, in relation to the fearavoidance model of chronic pain empirical research has demonstrated that reductions in pain-related fear will improve disability outcomes (Zale and Ditre, 2015). Gardner et al. (2019) employed patient-led goal setting where the participants set specific goals with a trained physiotherapist to achieve these personal goals. They found patient-led goal setting was more effective than standard exercise advice and demonstrated significant improvements in self-efficacy and fear of movement (Gardner et al., 2019). Employing patient-led goal setting shifts the responsibility of recovery to the patient and the clinician is placed in a supportive role. This engages the patient in personal and valued life goals which may increase their internal locus of control. The latest fearavoidance model incorporates positive affect and optimism that may counteract inflexible engagement in pain control and focus on valued life goals (Flink et al., 2020, Vlaeyen et al., 2016). Babatunde et al. (2017b), reviewing of treatment options for chronic pain, found only limited strength evidence in favour of psychosocial interventions for shoulder and knee pain but found them to be beneficial for neck, back and multi-site pain. In addition, they suggest psychosocial interventions have beneficial effects for patients with a poor treatment prognosis (Babatunde et al., 2017b).

Acceptance and Commitment Therapy (ACT) is a transdiagnostic cognitive behavioural approach that has been shown to address a range of mental health problems and support those experiencing long-term pain (Dindo *et al.*, 2017). ACT is a third wave cognitive behavioural therapy which focusses on a core treatment process known as psychological flexibility (Barker and McCracken, 2014). Psychological flexibility is defined as changing or persisting in behaviour that is guided by individual values and contacting the present moment fully as a conscious human being, (McCracken and Morley, 2014, Dindo *et al.*, 2017, Gloster *et al.*, 2020, Harris, 2019). Gloster *et al.* (2020) report that the impressive growth in ACT has been matched with positive results, however, studies have found that outcomes were not significantly better than CBT or waitlist control. For ACT interventions specifically for fibromyalgia, Haugmark *et al.* (2019) concluded that mindfulness and acceptance-based interventions were associated with small to moderate uncertain effects on pain,

depression, anxiety and health related quality of life mainly for females with fibromyalgia. However, the studies included in the systematic review mainly included middle-aged women which limits the generalisability to this population (Haugmark *et al.*, 2019). Ultimately, both CBT and ACT which are both recognised by the National Institute for Health and Care Excellence (NICE, 2021) have some effect on pain and quality of life, but the reasons remain unclear (Flink *et al.*, 2020, McCracken and Morley, 2014). However, they differ in their approach, CBT aims explore the links between thoughts, feelings and subsequent behaviours, whereas ACT aims to accept thoughts and feelings, with a move towards acceptance-based, mindful living (Fenn and Byrne, 2013, Hayes *et al.*, 2013) The studies presented here were mainly focused on pain, depression or anxiety which tend to have a negative valance (Tabibnia, 2020). There is clearly a need to explore the positive aspects of living with a chronic health condition as any insights arising may be included to further support those who are suffering with a chronic health issue.

## 1.6.2 The Biopsychosocial Model

Since the introduction of the BPS model there has been a growing knowledge of the role of anxiety, depression and fear contributing to the person's pain experience (Stilwell and Harman, 2019, Lumley *et al.*, 2011). However, the BPS model is beginning to come under heavy criticism and is often applied by practitioners in a fragmented way that may reinforce dualistic and reductionist approaches to pain (Stilwell and Harman, 2019). For example, the BPS model is often displayed as a circle separated into three parts but fails to demonstrate the dynamic nature of the three sections and largely ignores the first-person account (Benning, 2015, Stilwell and Harman, 2019). Therefore, pain management interventions that are informed by the BPS model may aim to understand patients by using a battery of questionnaires to understand contributing factors to the individual's pain experience (Cormack *et al.*, 2022). These tests may be seen as reductionist in nature, as they aim to quantify the patient's subjective experience, rather than show an appreciation for the lived experience of pain (Cormack *et al.*, 2022, Stilwell and Harman, 2019).

## 1.6.3 An Enactive Approach

An enactive approach to pain appreciates the first-person experience and avoids the separation of the individual as seen in the BPS model (Stilwell and Harman, 2019). This novel approach developed initially for cognitive science explores the relationship between the individual's mind, body and world (de Haan, 2021). Health psychology is grounded in the BPS model which allows for a broad conceptualisation of health but there is still a major research focus towards psychosocial factors rather than the direct influence of the body on both physical and psychosocial health (Ghane and Sweeny, 2013). Embodiment theory, part of enactivism, begins with the view that psychological processes are influenced by the body, including morphology, sensory systems and motor systems (Glenberg, 2010). Therefore, in a move away from a linear relationship between noxious stimuli and pain (biomedical model) or a compartmentalised biopsychosocial model (BPSM) understanding of pain, Stilwell and Harman (2019) conceptualise pain as; Embodied, Embedded, Enacted, Emotive and Extended (the enactive approach). This new and emerging model aims to build upon Engel's BPS model, to incorporate the phenomenological first-person experience of pain and the individual's relationship to their social environment and to overall appreciate the complexity of the human experience (Stilwell and Harman, 2019, Cormack et al., 2022). Therefore, from an enactive perspective, the sections of the BPS model are integrated and demonstrate that living bodies require interactions with their environment to be able to make sense of these environments (de Haan, 2021, Stilwell and Harman, 2019). For example, for an individual experiencing chronic low back pain there may be an ongoing concern of fear of reinjury, an increase in the intensity of pain or a reduction in the inability to engage in valued activities, possibly increasing their opportunity to live well (Stilwell and Harman, 2019, Cormack et al., 2022). Coninx and Stilwell (2021) suggest that chronic pain is a bodily sensation that infiltrates all aspects of the individual's life, alters their attitude towards the world and alters the structure of their thoughts and feelings. An enactive approach aims to support these wide-ranging experiences and perspectives by placing a strong focus on the individual's lived experience as a whole (Cormack et al., 2022). This novel approach is being introduced to osteopathic practice, Cerritelli and Esteves (2022) are calling for a move towards an enactive approach for the understanding of pain, cognition and mental health, suggesting this way may support osteopathic concepts. Similarly in health psychology,

with a move towards phenomenology in understanding the lived experience of an individual (Brocki and Wearden, 2006, Smith and Osborn, 2015), enactivism offers a novel way of seeing the individual in motion through their environment (Shapiro, 2019).

## 1.7 Living Well and Coping with Pain

To date there is limited patient perspective in qualitative literature, specifically on how individuals understand the contemporary concept of 'living well'. This means, those individuals that are engaging in coping behaviours that the individual perceives to be positive (Ryan et al., 2008, Thompson et al., 2014). In the wider field, living well is assumed to be a socially constructed concept which can be developed from the social processes and interactions that may occur between the participant and the healthcare practitioner or in day-to-day interactions between the individual and their environment (Ryan et al., 2008). Individuals who live well may not consider themselves as sick even though they are living with a chronic condition; instead they adopt coping behaviours enabling them to preserve personal autonomy, maintain competence in their daily lives and experience a relatedness to others (Thompson et al., 2014, Ryan et al., 2008). In the light of this, living well could be viewed as a cognitive and behavioural process rather than an outcome, with the individual actively striving for what is worthwhile to them and pursuing goals that are intrinsically valued (Ng et al., 2012, Deci and Ryan, 2012). Therefore, living well is not only a subjective experience but also the process and content of intrinsic goal pursuits to maintain a deep inner sense of wellness (Deci and Ryan, 2000). Multidisciplinary pain-management teams could benefit from learning more about the lived experience and behaviours of individuals who are living well while managing long-term pain, which can be better achieved through qualitative methods (Santana et al., 2018b).

In a recent study, Kurz and Hebron (2022a) explored the journey of coping with persistent low back pain. This phenomenological enquiry explored six participants' experiences who self-identify as coping with low back pain (Kurz and Hebron, 2022a). The authors described a journey of loss of self, while patients battled with pain and slowly moved towards a new 'normal'. However, Kurz and Hebron (2022a) were unclear in their definition of 'coping' or the impact of living well nor did they explain

how individuals might cope with persistent pain. Two other studies, Snelgrove and Liossi (2009), a phenomenological study, and MacNeela *et al.* (2015), a metaethnography, explore similar concepts when an individual experiences pain. They mainly investigated how people manage their pain and the practices the individual adopts to live with their ongoing pain experience. Both studies found themes relating to the emotional distress and loss of self that someone experiences with persistent pain and the uncertainty of flare-ups associated with long-term pain (MacNeela *et al.*, 2015, Snelgrove and Liossi, 2009). These experiences are well documented, and this knowledge has allowed healthcare practitioners to develop a sense of compassion when working with individuals in pain. Other research suggests that when healthcare practitioners adopt knowledge-supported person- or patient-centred care patients report feeling validated as a human being, they feel listened to and that the clinician is on their side (Kongsted *et al.*, 2021, Hutting *et al.*, 2022).

Outside of the area of pain, there have been similar reports in those who have been diagnosed with metastatic breast cancer. Lewis et al. (2016) explored the experiences of women living with this lifelong metastatic disease. They found these women were striving for normality by finding a purpose, they revaluated the way they viewed their life and how they felt restricted by their condition (Lewis et al., 2016). Metastatic disease is a life-changing event and produces feelings of uncertainty, anxiety, and fear, and this has been magnified with the recent COVID-19 pandemic (Lewis et al., 2016, Bandinelli et al., 2021). Therefore, when people experience a chronic, life changing event they could be subjected to a process of fear and uncertainty as they move towards their new normal of living with a long-term health condition. However, Lewis et al. (2016) recognise that even though these women were diagnosed with a life-changing condition, some of them described being able to live well. This was achieved by 'living in the moment', enjoying life and feeling grateful for being alive. Interestingly, Kurz and Hebron (2022b) found that to live a meaningful life their participants felt the need to accept their condition over time and accept their new normal. This seems to differ from living well, where those who deem to live well are seen to be pursuing intrinsic goals via action-based living (Ryan et al., 2008). Therefore, rather than cognitively accepting chronic pain the individuals adapt their behaviour to live well (Ryan et al., 2008, Ryff and Singer, 1998). For example, Lewis et al. (2016) found that their participants developed strategies to live well which involved self-care, practicing relaxation and seeking social and professional support. The participants also described the importance of remaining hopeful and strong despite their diagnosis (Lewis *et al.*, 2016). Unfortunately, Lewis *et al.* (2016) like Kurz and Hebron (2022a) were unclear in defining living well or coping, they only explain their key themes. Therefore, this highlights an area for research. As mentioned above, there are studies explaining the negative effects of chronic conditions, but the research suggests, participants at times can live well despite being diagnosed with a chronic health condition. The author of this present study believes that healthcare practitioners working with individuals diagnosed with long-term health conditions could learn directly from those successfully managing long-term health conditions and that research in this area would enable practitioners better to support those experiencing the fear and uncertainty associated with a chronic health condition.

## 1.8 Positioning the current study - Aims of the current research

Since there is limited research in the area of living well, both health psychology and osteopathy would benefit from exploring these factors from a patient perspective in order to understand their influence on living well. The combination of osteopathy and health psychology is a unique and developing concept with growing evidence to support the possible benefits of collaboration. For example, Jäger *et al.* (2021) and Abbey *et al.* (2021) developed an intervention which focussed on the main concepts of Acceptance and Commitment Therapy including mindfulness-based and self-compassion practices, acceptance and committing to actions in line with personal values to support a meaningful life with pain. Both interventions were conducted in osteopathic institutions parallel to the patient's osteopathic care (Abbey *et al.*, 2021, Jäger *et al.*, 2021). Both interventions involved the collaboration between psychologists and osteopaths to support and empower those living with persistent pain (Abbey *et al.*, 2021, Jäger *et al.*, 2021, Jäger *et al.*, 2021).

This current research proposes to utilise phenomenology to understand the individual's experience of positive health behaviours while experiencing pain and not be constrained by a healthcare framework that reduces the individual into distinct parts (Lima *et al.*, 2014). This phenomenological approach does not reject the naturalistic

view of the individual which offers insight into the biological process and measurement of the person in pain using objective scales (Carel, 2011). Rather, this study utilises a phenomenological exploration to allow the expression of experiences to come to light (Carel, 2007).

A unique study that explores patients' understanding of positive health behaviours and the meaning they assign to them would benefit both health psychology and osteopathy by producing interesting insights into how individuals self-manage chronic conditions while seeking osteopathic care, with the overarching aim of supporting multidisciplinary collaboration. This study will adopt an Interpretative Phenomenological Approach (IPA) and explore the social mechanisms and individual processes involved in living well (Smith et al., 2009, Willig, 2013). This should provide a rich and in-depth insight into the participants' experience (Finlay et al., 2018, Willig, 2013). Furthermore, exploring the positive aspects of the pain-related human experience could enable other individuals who experience pain to also live well and it could further develop pain-related care (Csikszentmihalyi and Seligman, 2000). Therefore, this study will aim to explore and understand how individuals construct living well when experiencing pain and how this phenomenon is developed, alongside osteopathic services.

#### 2. METHODOLOGY

#### 2.1 Research Aim

To explore and understand how individuals construct living well when experiencing pain and how this phenomenon is developed alongside osteopathic services.

#### 2.2 Overview and Rationale

This aim was suited to qualitative methodology to allow for an in-depth understanding of the individual's lived experience (Smith *et al.*, 2009, Smith and Nizza, 2022). A phenomenological framework is the philosophical method for studying the subjective, personal lived experience (Carel, 2016). This framework provided a suitable context in which to explore how participants construct living well through social processes within their own social environment including interactions with an osteopathic practitioner (Banton, 2019, Williamson, 2013).

In light of this, the study employed Interpretative Phenomenological Analysis (IPA) to explore the individual human lived experience and their relationships with their environment (Smith *et al.*, 2009, Kirkham *et al.*, 2015). IPA is concerned with examining through semi-structured interview data how a phenomenon appears and the current research is concerned with how people live well while experiencing pain and how this phenomenon is developed alongside osteopathic care (Smith *et al.*, 2009). This has provided a rich and in-depth insight into the participants' experience (Finlay *et al.*, 2018, Willig, 2013). Furthermore, exploring the positive aspects of the pain-related human experience could enable other individuals who experience pain to also live well and further develop pain related care (Csikszentmihalyi and Seligman, 2000).

The following sections outline methodological, critical reflective and other choices available to the researcher and the eventual decisions made about how to organise, design, and implement this qualitative research project.

## 2.3 Rationale for Adopting a Qualitative Approach

Qualitative approaches seek to make sense of phenomena, and to understand meaning and how individuals make sense of their world (Thomson *et al.*, 2014, Smith *et al.*, 2009, Willig, 2013). For example, a qualitative approach seeks to understand how an individual may experience a chronic health condition and what this experience means to them (Willig, 2013). Therefore, this piece of qualitative research is interested in the experience of living well despite pain and how the individual made sense of their situation. Qualitative research aims to 'give voice', interpret what the participants in this study were saying and capture the subjective experience of pain and how they live well (Willig, 2013).

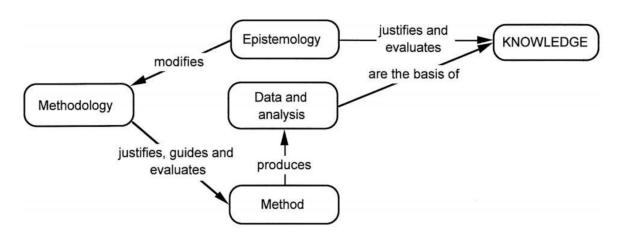
Shaw et al. (2019) explains that there has been a major shift in qualitative research methods employed by psychologists. A similar shift has been witnessed in osteopathy as the profession embraces a patient-centred approach and utilises the biopsychosocial framework of healthcare (Thomson et al., 2014). Historically, quantitative research using randomised controlled trials drove patient care to inform the 'technical-rational' aspects of the patient interaction, such as problem solving by utilising reliability and validity of clinical tests (Schön, 2017, Thomson et al., 2014). Shaw et al. (2019) have recognised similar issues within health psychology, for example, an attempt to establish cause and effect relationships by using measurement of psychological variables. These quantitative methods in osteopathy and health psychology assume there is a knowable, testable, and objective reality which can be tested on many subjects. This approach does have value, but omits the patient experience, specifically of those people living with pain (Guba and Lincoln, 1994, Thomson et al., 2011). As Osborn and Rodham (2010) explain, a qualitative approach allows access to the "insider experience" and explores the personal, spiritual, social, cultural, cognitive and emotional domains of pain.

Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage (IASP) (2020). IASP (2020) build on this definition and explain that pain is a personal experience that is influenced by biological, psychological, and social factors. Considering these definitions and explanations of pain from IASP (2020) and the individual experience of living with complex, subjective health experiences,

qualitative methodology is best suited for exploring these individual and personal experiences (Stilwell and Harman, 2021, Osborn and Rodham, 2010). With the adoption of the biopsychosocial model both in osteopathy (Penney, 2013) and health psychology (Marks *et al.*, 2018) qualitative methods provide insight into pain related behaviour and individualised meaning (Bunzli *et al.*, 2013).

## 2.4 Epistemology and Phenomenology

Epistemology is the theory and study of knowledge (Carter and Little, 2007, Fryer, 2020). Carter and Little (2007) suggest a model which draws on three fundamental parts of research – epistemology, methodology and method - to justify and evaluate knowledge (figure 1). This model was adopted here to support the planning, implementing, and evaluating of the quality of this piece of qualitative research and to justify the methods used for gathering and analysing data. Therefore, using Carter and Little (2007) as guide, this section aims to present phenomenology as an epistemological position, which supported Interpretative Phenomenological Analysis (IPA) as a methodology and justified the research methods:



**Figure 1**: The simple relationship between Epistemology, Methodology and Method. Used with permission of the author, Carter and Little (2007).

Phenomenology is a philosophical approach to understanding and ordering human experience (Smith and Nizza, 2022, Carel, 2011). Therefore, this approach is suited to the study of the first person experience of complex subjective health conditions like

pain (Carel, 2011, Smith and Osborn, 2007, Stilwell and Harman, 2021). Carel (2007) suggests that phenomenology seeks to understand illness through the individual lived experience of a health condition and the relationship between the sufferer and their personal world. The twentieth-century philosopher Martin Heidegger is closely associated with the development of phenomenology (Smith et al., 2009). Heidegger's version of phenomenology highlights the subjective experience as we engage with daily practical activities (Carel, 2016, Smith and Nizza, 2022). Heidegger believed that the meaning of individual experience was not always clear, hence understanding the personal experience involved exploring and interpreting individuals' accounts (Carel, 2016, Smith and Nizza, 2022). For this reason, this study adopted Heidegger's hermeneutic approach to phenomenology, as such the researcher utilises a double hermeneutic approach of making sense of the participant making sense of their personal experience of a phenomenon (Larkin et al., 2021, Brocki and Wearden, 2006). Therefore phenomenology provides a philosophical position suited to search for meaning the lived, individuals' accounts of embodied life experiences like 'living well' and pain (Carel, 2011, Carel, 2016, Smith and Nizza, 2022).

## 2.5 Interpretative Phenomenological Analysis (IPA)

IPA was first introduced by Smith (Osborn and Smith, 1998, Smith and Nizza, 2022, Smith, 1996) to explore in detail how participants make sense of their personal and social world (Smith *et al.*, 1999). In this research study, IPA has been used to understand what the participant thinks or believes about the topic under investigation, from their perspective (Osborn and Smith, 1998, Smith *et al.*, 2009). IPA is grounded in phenomenology and symbolic interactionism, which suggests that human beings are active perceivers of reality and aim to understand their lifeworld by forming stories which support making sense of their experience (Brocki and Wearden, 2006). This involves a double hermeneutic approach (Smith *et al.*, 1999) which means the researcher is trying to make sense of the participants making sense of their personal experience (Smith and Nizza, 2022, Smith, 1996). Therefore, IPA is well suited to exploring the lived experience of complex phenomena such as pain, as it allows the participant to explore their experience in their own terms and express these to the researcher (Smith and Osborn, 2015).

There are close ties between IPA and health psychology. Health psychologists have recognised the importance of understanding how the individual experiences of long-term health conditions affect the patient's interpretation of their symptoms (Brocki and Wearden, 2006). IPA allows researchers to explore the personal subjective experience by analysing individual interview transcripts and develop an insider's perspective on that experience (Reid *et al.*, 2005). However, the current researcher recognises there are limited publications within the field of osteopathy, making this form of analysis a novel approach in this field.

## 2.6 IPA and Quality Criteria

Quality criteria for this current research was informed by Lucy Yardley's (2000, 2008), Levitt *et al.* (2018) and (Nizza *et al.*, 2021) broad principles for assessing the quality and credibility of qualitative research. They are addressed separately below:

## 2.6.1 Sensitivity to Context and Commitment

This principle was addressed through the nature of data collection. As a practicing osteopath I regularly work with people experiencing pain. Since I qualified in 2016, I use a case history to understand the patient's presentation. This requires a variety of clinical interview skills to understand the patient's perspective and their personal pain experience. I was able to draw on these skills during the participants' interviews. I was able to put the participant at ease, build rapport, show empathy and use probing questions to generate rich data (Smith *et al.*, 2009). Furthermore, I engaged in regular supervision to check my personal impressions and influences on the data and also to consider the meanings (Appendix 6.6) generated by the participants and maintain the double hermeneutic approach in analysis (Yardley, 2008, Levitt *et al.*, 2018, Nizza *et al.*, 2021).

## 2.6.2 Rigour

This refers to the thoroughness of the study in the context of the quality of the interview. Also, the interview questions and structure were informed by feedback from the two pilot interviews as explained in 2.7.1 (Appendix 6.5). Rigour also relates to the appropriateness of the sample in relation to the research question (Smith *et al.*, 2009). The recruitment strategy and sample are presented in detail in 2.7.2 (Smith *et al.*, 2009, Smith and Nizza, 2022). Five participants were selected who identified as living well with pain to allow for the completeness and detailed analysis required (Yardley, 2000, Yardley, 2008, Levitt *et al.*, 2018). The concept of triangulation involves gathering data from various sources, using different methods, and differentiating between behaviour and expressed intentions. For this research question I was exploring the participants' lived experience of living well as they would provide the most complete and consistent description (Yardley, 2000). As part of the triangulation process I used member checking as a different method to allow the participants to reflect on the accuracy of their responses and all participants were satisfied with their interview transcripts (Morse *et al.*, 2002).

#### 2.6.3 Transparency and Coherence

I have maintained transparency by presenting in detail how the participants were selected (2.7.3), I explain how the interview schedule (Appendix 6.5) was constructed and conducted (2.7.6), the steps used in the analysis as informed by Levitt *et al.* (2018) (2.8) (Appendix 6.6 & 6.7) and my personal reflexivity (2.7) to demonstrate how my own perspectives shaped the analysis of this study (Levitt *et al.*, 2018, Nizza *et al.*, 2021). The data analysis and interpretation was informed by the common principles of IPA as suggested by Smith *et al.* (2009), close analytic reading of participants' words as described by Nizza *et al.* (2021) and described in the analytic strategy (2.9) (Yardley, 2008). To address coherence, throughout the process of writing up this study I completed the results section first to allow the interpretation to develop further and form a coherent narrative (Smith and Nizza, 2022). The phenomenological approach and Interpretative analysis suited the research question which was focussed on the lived and subjective experience of pain and living well (Yardley, 2000). Regular

supervision allowed for the discussion of feedback and the consideration of appropriate amendments. Ultimately, due to the focussed research question, idiographic depth and comparison between participants (Nizza *et al.*, 2021), and the steps taken, credibility, trustworthiness and coherence can emerge from a small sample (Malterud *et al.*, 2016). Insofar as the study focusses on the individual experience, it does not aim for generalisability, although there may be transferability to others who view themselves as living well with pain (Hefferon and Gil-Rodriguez, 2011).

## 2.6.4 Ecological Validity

Ecological validity Is concerned with the relationship between the real world and research. In this instance interviews were conducted online due to COVID. This meant the participants were interviewed in their own surroundings. I conducted two pilot interviews, and the participants offered feedback which I discussed with my supervisors. This led to a change in the structure of the questions but not the questions themselves. However, these processes may still not account for interviewer influence and social desirability, where there is a mismatch between the way the participants present their reality to the research and their genuine, lived reality (Bergen and Labonté, 2020). In other words, my expectations or opinions may interfere with their subjective experience (Pannucci and Wilkins, 2010). However, Braun and Clarke (2013) suggest qualitative research recognises that subjectivity exists and refers to the idea that what we see and understand reflects our experiences and identities. Hence the process of personal reflexivity (2.7) where I reflect on my own experience of being an osteopath and the positive aspects of living with pain.

## 2.7 Personal Reflexivity

My interest in living well alongside seeing an osteopath stemmed from my work as an osteopath and working with people in pain. I view myself as a healthy, middle class, white male and I am married with two young children. I have no experience of managing a long-term health condition or persistent pain. Interestingly, throughout this study when participants explained their personal lived experience of pain, I found the thought of pain taking over my whole life difficult to comprehend. Thankfully, I can walk out into the world freely with no thought of how pain might affect me on any given day, which is something that I take for granted. My view of the world is that individual reality is shaped by past life experiences, social environments, and language. The individual's life is made up of personal narratives which shape their personal views of the world including any experiences of pain. I keep this in mind when I am working as an osteopath and feel this will also support me as a future health psychologist.

I qualified as an osteopath in 2016. I work as a Practice Educator at the University College of Osteopathy in Borough, Southeast London. Here I help students develop their osteopathic approach while supporting their patients in pain. Also, I work in private practice in Wandsworth, Southwest London and I recognise that people experience pain on a personal, individual level and use a variety of behaviours to express their experience.

I have been inspired by patients who live with long-term persistent pain and how they conducted themselves in osteopathy appointments. They had a deep sense of acceptance around their condition, were kind to themselves if they were in pain and they had learnt specific ways of managing their pain. This made me question my role as an osteopath and a trainee health psychologist. My osteopathic education led me to believe that the body could be 'fixed' by manual therapy techniques practised by osteopaths. This was a practitioner-focussed approach to pain management, but I felt we could learn from those who 'live well' with pain. Similarly, as a trainee health psychologist, I became interested in Acceptance and Commitment Therapy as this intervention aims to develop psychological flexibility, which includes acceptance of a chronic health condition (Dindo et al., 2017). I have also been fortunate enough to work with people recovering from alcohol and drug abuse. I have been an observer at

open meetings of Alcoholics Anonymous and witnessed how people recover from substance and alcohol misuse. These people viewed themselves as having a second chance at life. I am truly grateful for those members who would share honestly in a group of people, they would cry and laugh over shared experiences. They also seemed to be living well despite self-identifying as an addict or an alcoholic. These people changed the way I saw myself practicing as a health psychologist and possibly working with people in pain. Those in recovery were able to learn and adopt positive, valued behaviours to enable them to live well. The individuals I worked with in pain and those individuals recovering from alcoholism were a living demonstration of living well despite a chronic health condition. My main realisation was the amount of time it took them to finally come to terms with their condition, then to develop their own idea of living well, it was a process over a number of years. This had a direct impact in my work as an osteopath and as a trainee health psychologist: rather than trying to support people over a few weeks, I now recognise that some intervention plans would have to be spread over a period of years.

My aim was to explore the positive areas of living with pain such as hope and optimism rather than pain-related anxiety or pain-related depression. I was interested to understand the positive aspects of living with a condition rather than the negative. Fundamentally my intention was to understand individuals who self-identify as living well with pain and explore the interplay of osteopathy with this phenomenon. Tabibnia (2020) suggests that, historically, psychological models have focussed on the negative aspects of human experience and functioning, with a focus on reducing the negative rather than promoting the positive. But according to Tabibnia (2020) psychological research has begun to push towards investigating the role of positive experience and resilience.

The approach of 'promoting the positive' guided my research question as well as the development of the interview questions. I do not experience persistent pain but my experience of working with people in pain and with recovering alcoholics and addicts influenced the way I interviewed the participants and engaged with them over their experience of living well with pain.

## 2.8 The Design: Procedures

#### 2.8.1 Pilot Work

Interview questions (Appendix 6.5) were guided by previous IPA approaches exploring the pain experience and informed by two patients (Katherine and Ivan) who live with fibromyalgia and long-term pain (Murray *et al.*, 2015, Thompson *et al.*, 2014, Smith *et al.*, 2009, Brett *et al.*, 2014). These questions were submitted to the Director of Studies (SB) and the second supervisor (JB) for a reflective discussion. Hoddinott *et al.* (2018) suggest that patient and participant involvement can be included in data collection and Katherine and Ivan were both involved in interview development and interview structure. The questions were sent back to Katherine and Ivan for further review. Then, Katherine and Ivan both consented to be interviewed as part of the study and to reflect on sections of the interview. This meant the flow of the questions was discussed in supervision meetings since Ivan had commented that the 'osteopathy' and 'pain' sections could be swapped as he had found the interview structure disjointed. The process of patient involvement, reflection with research supervisors and pilot interviews is to allow for methodological transparency and rigor (Brett *et al.*, 2014).

Katherine and Ivan both have experienced long-term pain, self-identify as living well and have had experience of osteopathy. For this reason, they were, as explained, involved at certain stages of the research process. For instance, they both read and reflected on the interview questions and order. Brett *et al.* (2014) found that patient involvement at stages of the research process means that topics and questions are grounded in day-to-day reality of the individual experience.

#### 2.8.2 Recruitment

Recruitment was a reflective process to develop a homogenous sample and allow for the recruitment of five participants (Smith et al., 2009, Brocki and Wearden, 2006). Participants were recruited through a private osteopathy clinic in Wandsworth, Southwest London. The author conducting this study works as an associate osteopath at the clinic and had discussed recruitment of participants with the clinic manager. The other osteopathic practitioners were briefed on the nature of the study, with an explanation of the inclusion/exclusion criteria, and had the opportunity to ask questions and develop an understanding of those who self-identify as living well. The author did not interview any patients or clients they were themselves working with. Participants were contacted via the referral method, whereby osteopathic practitioners who were aware of the study would share information and select potential participants who selfidentified as living well (Smith et al., 2009, Thompson et al., 2014). In addition, potential participants were sought through social media. An advert was placed in the group 'Chronic pain champions – no whining allowed' (support group). The author contacted the group administration for permission and the recruitment advert was discussed in supervision. Potential participants could make contact through a direct message. This approach through osteopathic practitioners and social media allowed for potential participants to arrive at a decision themselves and aimed to minimise possible recruiters' bias on the part of the researcher (Robinson, 2014). However, no potential participants contacted the author through social media. Therefore, once the author received an enquiry from people interested in the research they were approached via telephone or email and asked if they were interested in participating. Potential participants were given a Participant Information Sheet (Appendix 6.1) and a Consent form (Appendix 6.2) by their osteopathic practitioner, then those wishing to take part were invited to contact the author to arrange an interview (Kirkham et al., 2015).

## 2.8.3 Sampling Considerations

When designing quantitative studies researchers use power calculations to determine which sample size is required to detect statistical significance (Jones *et al.*, 2003). This qualitative study adopted the suggestion by Smith *et al.* (2009), Smith and Nizza (2022) to recruit between three and six participants and was supported by the concept of information power (Malterud *et al.*, 2016). My aim was to interpret and make sense of living well with pain from an idiographic stance. Initially, my goal was to recruit up to six participants. However, recruitment proved to be challenging. The main issue was that people who self-identify as 'living well' with pain were probably not seeing an osteopath, as they were confident with their own pain management strategies.

In line with IPA and the aim of investigating how participants construct the idea of living well, the sample was selected purposively (Smith *et al.*, 2009). IPA works with small purposive homogenous samples (Kirkham *et al.*, 2015, Smith *et al.*, 2009). This method allowed access to the phenomena being explored. Therefore, this study recruited five participants who were seeking osteopathic services for long-term musculoskeletal pain and who self-identified as living well. Five participants allowed for the depth of analysis needed whilst remaining contextualised to the defined setting (Smith *et al.*, 2009, Robinson, 2014). In addition, five participants allowed the author to manage the data and intensive analysis required for IPA (Robinson, 2014). Inclusion and exclusion criteria are outlined in table 1. Conditions including acute pain, those individuals under medical supervision or individuals diagnosed with inflammatory or neurological conditions were excluded from this study. These conditions may have a known biological or neurological cause of the pain experience unlike Chronic Musculoskeletal Pain (CMP) which may have an unknown cause (Treede *et al.*, 2015).

When the author attempted to recruit through social media and after supervision discussions, the inclusion criteria was updated to specify United Kingdom residents. This has to be specified, as osteopathic services are different outside of the UK. In the UK osteopathy is regulated by the General Osteopathic Council, whereas in some countries osteopathy is still unregulated. This means that in osteopathy, in countries that are not regulated, there may be a variation in the standard of care.

Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Residing in the United Kingdom	Outside of the United Kingdom
Adults 18 years +	Under the age of 18
Diagnosed with chronic musculoskeletal pain (> three months duration)	Diagnosed with an acute musculoskeletal condition (< three months duration)
Seeking osteopathic services for pain experienced in the axial skeleton and peripheral joint complex.	Under medical care for cancer, fracture, bone pain, post spinal or joint surgery.  Diagnosed with inflammatory conditions or progressive neurological conditions.
Three or more osteopathic appointments	< three osteopathic appointments
Adults who self-identify as "living well"	

# 2.8.4 Participant Demographics

Qualitative studies that seek to understand underlying experience or phenomena have been shown to benefit from multiple lenses (Fernandez *et al.*, 2016). Therefore the demographic questions (Appendix 6.3 & 6.4) were developed to place the sample in context and aim to collect rich responses (Fernandez *et al.*, 2016). The questions were structured with open-ended questions which allowed the participants to express themselves and not feel constrained by a label, group or a specific bracket. Appendix 6.4 displays in detail the full text demographic data.

Five participants were interviewed and self-identified as living-well with pain. They were aged between 29 and 56 years of age. Two participants described themselves as female and one described themselves as gay. They identified as white British/European. They were educated up to master's level, four of the individuals were

employed and one was retired. The participants described their income as low to above average. They had been experiencing pain for between three and 42 years and had had between five and 30 osteopathic treatments. One participant described themselves as having no disabilities and four participants described themselves as experiencing pain in a range of areas in their body.

## 2.8.5 Interviews: Descriptions and Procedures

Data collection was conducted via semi-structured interviews exploring how adults construct and understand the idea of living well, their pain experience and their views of osteopathy (Appendix 6.5). The one-to-one interviews were conducted via online video-conferencing software. The interviews allowed the participants to think, speak and be heard (Reid *et al.*, 2005). Focus groups were considered for data collection as they allow for a range of voices to be heard in one sitting (Smith *et al.*, 2009). However, a group discussion could lead to participants comparing pain experiences rather than expressing detailed accounts of living well (Finlay *et al.*, 2018). The interview schedule was structured with open questions to invite participants to offer a rich, detailed account of their experience (Smith *et al.*, 2009, Collins and Stockton, 2018).

The interviews were organised between the author and the participants at a time that suited them. Due to COVID restrictions (GOV.UK, 2020) all interviews were conducted over MS-Teams. Before any interviewing took place, I explained the research and checked to see if they had any questions relating to the research or to the previously distributed Participant Information Sheet (Appendix 6.1). The consent forms (Appendix 2) were signed and sent back to me in electronic format. Once the participant agreed, I started the voice recorder, and the interview began. I had organised my screen with the video on one side and the interview guide on the other. This allowed me to check the questions with little distraction to the interview process.

The first two questions 'How are you feeling today?' and 'Please tell me more about yourself?' were designed to establish rapport and were general questions with little relevance to living well, pain or osteopathy. My intention was to settle the participants and let them talk about what was important to them at that stage of the interview.

(Smith *et al.*, 2009, Smith and Nizza, 2022). The semi-structured nature of the interview meant the relevant questions were asked when appropriate to try and collect deep, rich data.

There were three main areas to the interview: Osteopathy, their pain experience and living well. Prior to the pilot interviews, I planned to explore the participants' view of osteopathy. However, after the two pilot interviews the participants said on reflection that felt wrong and did not flow correctly. They suggested to start with the pain experience questions as this is what they were keen to discuss. Therefore, based on their feedback and the discussions in supervision I rearranged the structure, which meant with the remaining three participants I explored their pain experience first, then osteopathy and finally their idea of living well.

All five of the interviews had a duration of approximately one hour. I was conscious of the fact that the participants were living with persistent pain and if they seemed uncomfortable or looked as if they needed a break, I would offer the opportunity to pause the interview. When the interview was ending, I asked them to sum up, in three words, what living well means to them. This was to understand their individual perspective of living well, then I asked if they had any further issues they wished to discuss. I thanked them for their participation and their vivid descriptions of their experience.

# 2.9 IPA Analytic Strategy

Analysis (Appendix 6.6 & 6.7) of the data was informed by Smith *et al.* (2009), Smith and Nizza (2022). There is no single method for IPA and working with interview data but more of an analytic focus (Smith *et al.*, 2009). Fundamentally the aim was to develop an insider's view of living well. For this study I used the new IPA terminology in line with Smith and Nizza (2022). They suggest using experiential statements which are interpretative summaries of specific portions of interview text, to account for an understanding of the participants' experience. In this way, personal and overall group experiential themes are an expression of the combination of experiential statements (Smith and Nizza, 2022). I adopted an idiographic approach, which meant each participant's contribution was fully analysed on their own terms, as in an individual case study. Then I repeated for the other participants in order to familiarise myself fully with each interview (Smith and Nizza, 2022).

The first stage involved individually transcribing the interviews into a Word document while removing all personal participant information in line with confidentiality. This allowed me to develop an in-depth understanding of each participant (Smith *et al.*, 2009). Initially, I planned on analysing the transcripts in NVIVO. However, for IPA this software seemed to offer limited flexibility for reflective notes. It seemed to me that the coding was too descriptive and the one-word codes were not capturing enough of what was being said by the participants. Therefore, I copied the interview transcripts onto MS OneNote which allowed for a greater depth of reflection and development of exploratory notes.

For the second stage, I completed a second listen-through and read-through of the interviews. I noted my initial reactions and exploratory thoughts on language and participant emotion to familiarise myself with the data. This was a nonprescriptive process and, with no structure to my comments, they felt reactive to what the participant was saying rather than providing any depth of analysis at this stage (Smith and Nizza, 2022). I moved on to the second read-through of the transcript and completed notes in the colour blue. Using a different colour allowed me to distinguish between reflective notes and initial thoughts based on the richness of what the

participants were saying, it was a more detailed process than the first listen-through of the interviews (Appendix 6.6, 6.6.1, 6.6.2).

In the third stage (Table 2), I listened again with my exploratory notes to hand and compared them to what the participants were saying in the interview. This procedure allowed me to stay grounded in the interview data. To stay close to the data I would engage in regular supervision to discuss the analytic process and check I was analysing interview data, rather than my exploratory notes. At this stage I made rough experiential statements in green so myself and supervisors could clearly see a distinction between exploratory notes and development of experiential statements. My aim with the experiential statements was to capture the meaning of the participant's experience (Smith and Nizza, 2022).

**Table 2:** Example of the final MS OneNote analysis

Personal	Transcript	Interpretation	Author
Statement	Transcript	interpretation	comments
Since my thinking has changed, I want to care for myself and my wife,	[Pause] only since my way of thinking has changed, only since I realised I have to give a damn about myself erm I am prepared to sacrifice my physical being for my mental health erm but I do realise that my physical being also plays a huge role in my mental health and I also realise, which has been another big thing, it's not just me, I have a wife, I have a partner here of 26 years we've been together and she needs me, it's not just, I have not just to keep health for myself, I have to do it for her as well,	My way of thinking has changed, I now know I have to care for myself, I have to be the focus, I have to focus on my mental health, alongside my physical health, But I have a wife, we need each other, I am doing this for us both to live well	This seems like a purpose, a drive to change and maintain this change, he wants to live well and repay his wife for when she was really concerned about him.
I have made huge strides and others see that; I am proud of myself.	when my quality of life disappears, so does hers, so it's only really that I was saying, the last sort of couple or three or four years, since I have been in this round of therapy, my therapist is, I call her the head, she is the head, yeah the therapist erm the work I have been doing with her erm I think I have made huge strides, she thinks I have made huge strides, my wife thinks I have made huge strides erm yeah I have made huge strides and that's what has changed everything	This has been a recent change in relation to my whole life, but I am seeing progress, as well as others, this has been worth it	M has a positive happy tone to his voice, I feel like he has self-worth, and this has been through support from the 'head' and his wife

Key: Green - Personal statement; Black - transcription text; Blue - Summary of personal statements;

Red - Author comments

The process of transcription, listen-through (twice) and read-through (one), reading and completing exploratory notes and a third round of hearing an interview while generating experiential statements was too time intensive. I completed this process for two interviews (Katherine and Ivan). As a solo researcher I discussed these concerns with the supervision team and we concluded that I could complete one listen-through with exploratory notes, then one read-through with a more in-depth exploration of the data, while generating experiential statements. This refined process, we felt, maintained the process of moving from the descriptive to the interpretative and a commitment to understanding the participants' point of view (Smith *et al.*, 2009). I used this adapted analysis with Michael, Darren, and Julia.

After these stages of analysis, I grouped all the experiential statements by participant on to an Excel spreadsheet (Appendix 6.7). I started with Katherine and superficially arranged her 180 experiential statements into groups depending on theme. Smith and Nizza (2022) labelled this type of grouping as 'what should go with what'. At this level of analysis six areas emerged – the pain experience, trauma, recovery, management, osteopathy and living well. This method supported the management of experiential statements.

As indicated, I organised the experiential statements into personal experiential themes. At first, this was completed at a superficial level, for example, similar words or similar statements. As the inductive process evolved and personal experiential themes were forming, the experiential statements were organised into chronological order or seriousness of experience as defined by the participants. This was an iterative process informed by Smith *et al.* (2009) of fluid descriptions, engagement with the transcripts creatively and variation in a multidirectional process. I was able to move the statements around and understand similarities and dissimilarities between the participants. Once I felt I had organised the personal experiential themes into group experiential themes I would summarise personal experiential themes by writing in the first person (Table 3), I was trying to channel the participants' language and emotion. Due to the flexibility of IPA this action meant I was immersed in the data; I had an opportunity to empathise with their experience and use their language. I felt this process supported the narrative account of the participants' experience of pain, living well and visiting an osteopath.

**Table 3:** Excel screenshot example of the grouping into experiential statements

#### Living well isn't always sunshine and rainbows, its hard work

I have found that new experiences now offer me the opportunity to understand the root caouse because at times living well with pain can be a constants battle and hard work, however I am enjoying life. I found that living well is about managing my pain within a certain threshold and its important to be in the background. Self knowledge has been key, i can make sense of an experience, then nip it in the bud early. This gives me a chance to find a work around. Then I ask, what can i learn from this? For me its about learning and understanding pain, then how I balance training and recovery. I now know that my experience is modifiable and I can live in the uncertainty of pain. Therefore, living well is staying below my pain threshold and going about my day with a smile on my face and not a grimace. This means at times, I just have to get on with stuff and when I am living well, I can deal with pain better. I think everything is connected, thats how I see living well, if one thing is out, it has a knock on effect on everything else.

Personal Statement	Part.	Time	Quote
New experiences are opportunities to heal and understand root causes	К	51.42	You know in life will always challenge us and bring new ways of being so this for me is another healing process. Its like of here is another root that I am looking at now,
Living well with pain is a constant battle and is hard work, but I do it to enjoy life	М	1.01.44	[Pause, sigh] a constant battle, now that might just be for me not other people, but for me it's hard work erm but for the first time in my life I am actually prepared to put in the work. I don't like it but I have accepted at this point if I am to live with any standard of, quality of life, If I am to live well, I have to work on this (points to head) and I have to work on this (body) so that is what I will do. I'm not happy about it, I don't like it but I have got to do it, no choice, simple as that
Living well is about managing pain in my threshold	DG	42.10	which as I get older will probably reduce erm im not going to be doing extreme sports in my 80s I doubt but erm living well with pain sort of managing it and keeping it below the threshold where its manageble, I suppose the threshold is really where it starts to become overwhelming and leave me in a bad mood I cant sort of warm up and sort of feel ok
Not being in pain is important or just in the background	DG	35.54	I suppose not being in so much pain every day that its all you can think about erm you know its something you can ignore preferably if its something that is aching but you can get on with what you are doing and constantly thinking about erm because when it becomes too much to forget about then its that's when you start getting, that's when I start getting a bit depressed and you know when you are walking about and ahh my legs are hurting, this is really hurting, trying to cook dinner and I am like, I want to sit down but I am busy I have got to stir the past
Self knowledge	I	41.13	I think self-knowledge, self-understanding being able to self- manage I think and that's probably wisdom to some degree and that would probably be you know the three big components that I can think of off the top of my head for living well

**Key:** Green – Experiential statement; Blue – Summary of personal statements; Black – transcription text.

The analysis continued during the process of 'writing up' the themes and receiving comments from the supervision team. Braun and Clarke (2013) suggest the writing up of analysis is an iterative process which brings ideas into being. For instance, there was a discussion point regarding the number of experiential statements and whether

these should be reduced to allow the in-depth analysis required by IPA (Smith *et al.*, 2009, Smith and Nizza, 2022). Therefore, the experiential statements were checked against the transcripts and similar experiential statements were merged. For example, 'Pain makes me feel like sh\*t it's exhausting' was merged with 'Fighting with pain is exhausting'. In addition, and on reflection, participants' experience of other healthcare disciplines was added to increase the 'participant voice'. However, with ongoing supervision discussions I tried to reflect on my role as an osteopath and my own views of other healthcare professions, and, in order to reduce any biases, to stay as close to the participants' accounts as possible.

#### 2.10 Ethical Issues

This study was in line with the British Psychological Society's Code of Research Policy (2014) and the University of the West of England's (UWE) Code of Conduct and Research ethics. Full ethics approval was confirmed (Appendix 6.8) by the UWE Faculty Research Ethics Committee (FREC) and permission also granted from the osteopathy clinic, which satisfied the osteopathic service requirements. Prior to recruitment and as part of the ethics application there were discussion with the clinic manager to allow the osteopaths to discuss the research with their patients. In addition, this qualitative study minimised harm and avoided placing the participants in a physically uncomfortable position by offering time to move if they felt pain. Before the study began the participants had the opportunity to read the Participant Information Sheet (Appendix 1) outlining the nature of the study and completed an Informed Consent Form (Appendix 2). The participants had the option to leave the study at any time and request the removal of their data. However, there was a time restriction for withdrawal set for one month after the interview date to limit potential issues with data analysis. All participants were sent their transcripts for review, which gave them the opportunity to amend or remove any data. To protect anonymity, pseudonyms were allocated to each participant during the transcription, analysis, and write-up of the study. The names selected in some way resonated with the participants and pseudonyms were used to allow readers to follow the individual narratives (Saunders et al., 2015).

# 3. RESULTS – Findings and analysis

#### 3.1 Overview

The participants in this study were interviewed to explore their experience of living well with pain while seeing an osteopath. All five accounts explained that living well was a process through time, and that osteopathy played a supportive role. They had their own ideas of living well, but fundamentally to the participants this did not mean a life without pain. It meant being able to live a life with purpose and compassion for themselves and others, despite pain.

Katherine, Ivan and Michael explained their own personal versions of trauma and how these experiences may have had a role in their pain experience. Darren and Julia did not report experience of individual trauma, but they all shared the term 'mental health', possibly as an umbrella term for anxiety, depression, and pain-related avoidance. However, these personal ideas of trauma (or not) and the effect of pain on their mental health helped them shape their own idea of living-well.

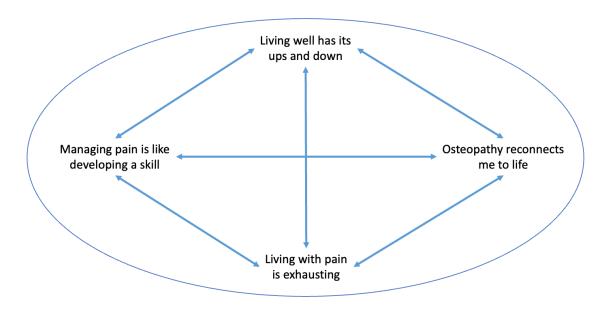


Figure 1: Connection of group experiential statements

The four main experiential statements work together, as is displayed in Figure 1. The participants' construction of living well may have begun with the participants saying that living with pain is exhausting, as this includes their first experience of pain and formed a base which the participants could build on. However, through time, one experiential statement does not necessarily precede the other and there is a dynamic interaction between all of them. Even though the participants self-identify as living well, they may still experience episodes of pain that are 'annoying and exhausting'. Participants had developed ways to manage their painful episodes, like building a skill, and could draw on a variety of ways to support themselves through a painful flare-up. This may at times involve seeing an osteopath as a source of hope and support. Ultimately, living well with pain is placed at the top of Figure 1 because over time, this has required a great deal of physical and mental effort over many years to arrive at that point where they can say they are 'living well'. The themes are displayed in Table 1.

**Table1:** Group and personal statements

#### 3.2 Living with Pain is Exhausting

- 3.2.1 I can clearly remember my first experience of pain
- 3.2.2 Living with pain is like a physical and emotional pressure cooker
- 3.2.3 Pain makes me feel like sh\*t, it's exhausting
- 3.2.4 The pain of staying the same was far worse than the pain of starting to change

#### 3.3 Osteopathy Reconnects Me to Life

- 3.3.1 Osteopathy has allowed me the freedom to live with pain
- 3.3.2 The osteopath sees me differently
- 3.3.3 Osteopathy allowed me to feel connected to myself and another human being

#### 3.4 Managing Pain is like Developing a Skill

- 3.4.1 Pain management is a constant
- 3.4.2 Daily movement helps me stay in an upward trend of recovery
- 3.4.3 I manage pain like I manage a cold

#### 3.5 Living well has its Ups and Downs

- 3.5.1 Through a process of suffering to reach new realms
- 3.5.2 Acceptance is a process
- 3.5.3 Living well requires action in many forms
- 3.5.4 Living well isn't always sunshine and rainbows, it's hard work

# 3.2 Living with Pain is Exhausting

All the participants explained how they learnt to live with pain. They were able to clearly describe their first experience of pain in vivid detail. From that first experience they felt they had to learn to live with pain, but it was exhausting trying to avoid pain and battle against their experience. However, for some participants the process of understanding their own pain experience ran parallel to the process of trauma. These learning experiences enabled them eventually to confidently manage their own pain.

### 3.2.1 I can clearly remember my first experience of pain

Ivan, Julia and Michael clearly remember their first experience of pain by detailing their age and what happened.

I think the first, I had a couple of injuries when I was at secondary school where I think I fell down in a rugby scrum and something happened between the spine and the shoulder blade, bottom of the neck, I didn't really think much of it until I was doing push-ups in class one day and started getting this shooting headaches, everything went into spasm shooting pain all up into right side of my head (Ivan)

I had a back injury when I was 16 and I think honestly that kind of runs through a lot my other injuries, even though it's not a problem for me today, it's just something I think affects probably how my body is aligned and how I move, I think there is a lot of knock-on effects from that (Julia)

At the age of 14, that was the very first time I experienced physical pain and my neck locked up, I woke up one morning it was just solid any attempt to move it or any attempt to hold it up was so painful it locked solid, it lasted a good week or more, we went to the doctor's and of course it was: well we can't really do anything (Michael)

They were similar ages when they first experienced pain, around the time of secondary school. Interestingly, Julia describes how her first experience has affected her body

alignment till the present day (Julia is 32) which effects the way she moves in her day-to-day life:

Obviously, your back is such a big part of your body, so I think just not having the right structure for my back probably, I think had a knock-on effect on other injuries that I get, that's my assumption (Julia)

Michael and Ivan clearly explain what it felt like to be in pain at that moment in their life and used terms such as 'shooting pain' and said that even supporting their own head was painful. Julia has potentially formulated a belief that her back is a major part of her body and if her back 'isn't right' it may have 'knock on' effects elsewhere. Ivan illustrated his first experience and then describes how the experience changed through time:

I was around 17, 18 was when it started but I wouldn't have said I had chronic pain then I probably didn't have continuous pain until I was 20 but at 18 you know things were going on and then it wasn't until I was 23, I think I had finished university, I did a year in Spain and things got really bad (Ivan)

Ivan highlights the progression of his pain over a period of five years, indicating the slow development of his experience, possibly from when he was leaving school. This progression could have coincided with a time when he was developing his identity as a young adult, this slow development of uncertain pain episodes possibly leading to social withdrawal and an avoidance of certain activities.

## 3.2.2 Living with pain is like a physical and emotional pressure cooker

All the participants painted a graphic picture of the feeling and individual experience of pain. These experiences could be viewed in the context of their individual life histories, how their pain began and how their individual experiences of trauma built up over time, like physical and emotional experiences squeezing into a pot. Experiencing a 'flare-up' of pain could result in the experience of anger and fear. A flare-up may be triggered by 'pushing themselves' too much, for example through physical activity or

attempting to take on too much at work. The fear participants experience limits what they do, and they try analysing their flare-ups by using a biomechanical understanding for their cause of pain. The common factor is the sense of reaching a low point that these participants convey in describing their experience. Katherine explains that she uses her experiences of trauma to try and understand her root causes of pain, below she associates this with feeling pointless. Michael felt that he was good at school but as he moved through his life and his career, he felt the added pressure and responsibility manifest towards pain and a mental breakdown.

I am reading this amazing book... she has got a fantastic way of just getting to the root... and the term that came up for me was, hold on, I am, what was the thought, this is the root for me, pointless, yeah, I am pointless, my existence is pointless, that is the root for me (Katherine)

I was always smarter than all the kids around me but yeah school killed it for me, I absolutely detested schools, I didn't go to university and then I have just done jobs, I have had three different careers, I started basically as the tea boy, reached management level and then I had a mental breakdown, so I quit that and I tried something else... the last time that happened to me it was 10 years ago and I haven't worked since (Michael)

Below, Katherine is trying to understand her own experience and her feeling unsafe in her body. Like an onion, with many layers, Katherine suggests these are like wounds of the past which may have been a build-up from her life experiences:

It's been a journey I mean it started after my mum passed away, that was the real trigger, I mean watching someone die of cancer is traumatic, so it definitely did raise the trauma response in my body, but it was before that as well, I was struggling to cope with the workload of teaching and the abuse (Katherine)

Katherine's pain and trauma story seems to start with seeing her mum pass away from cancer and struggling with abuse she described at work, which she says, 'raised her trauma response'. This could indicate a build-up of trauma and as Katherine has said

earlier, adding to 'layers of her onion'. Ivan discusses the beginning of his journey and his first experience of fatigue which could have started when he was bullied at school:

I mean it was tied up in other mental health issues like I was bullied very badly at secondary school for three years like kind of complex PTSD type territory mild, but still long-termish PTSD type stuff and that triggered that with the glandular fever is what I think triggered the fatigue and the ongoing sensitivity in, central sensitisation ultimately was that kind of perfect storm and cascade of events (Ivan)

Here Ivan describes this sense of hopelessness as a cascade of events of bullying which started the fatigue, similar to Katherine who feels her root cause started with feeling 'pointless'. Michael's trauma seemed to develop over many years, and he felt he needed to stop work. Here Ivan is using the term central sensitisation (an amplification of neural signalling within the central nervous system that can lead to pain hypersensitivity retrospectively (Nijs *et al.*, 2021)). The medical studies he has completed may support his understanding of fatigue and glandular fever and the effect on his body.

Interestingly, whereas Michael, Ivan and Katherine mention traumatic or stressful events, Darren and Julia have not shared this experience of a build-up of trauma. If they push themselves too much, the pain is too intense, and they collapse. Julia expresses her anger when she is forced to avoid training due to pain:

Yeah, I mean I definitely would have to change what I am doing in the gym the next day, I might not even go at all which then also p\*sses me off because if I am in a lot of pain, you are always told to oh listen to your body, let it rest but then I try not to push it because I am afraid that I will injure myself more because when it originally happened it was very painful, walking was painful (Julia)

Julia suggests that she is confused between what she feels her own body can do versus the message that society projects about the human body. In comparison to Darren, if he has a painful episode, he will tend to ignore it and adopt a different type of approach:

Yeah when you are in lots of pain it's always hard to rationalise it, I have mentioned earlier I tweaked my arm in the gym it's hard to ignore, its painful but I am thinking meh I will ignore it as much as I can, it may be a bit sore later but I will probably stick an ice pack or I might stick it in the bath or wrap it up with a compression bandage and tomorrow, will it be better? (Darren)

Darren is trying to reduce the intensity of his pain by using an ice pack or compression and saying he will ignore it as much as possible but still asking a question, 'will it be better?' Suggesting an uncertainty about what pain will be like the next day. Darren considers the reason for feeling 'tight' which could lead to further injury:

If I am feeling a bit tight, well that's not right this is going to lead to something worse later on, if something is a bit tight, sore, I leave it then I might be running or sprinting or doing something in the gym and then it is hurting, now suddenly a bit of tightness turned into an injury and it didn't have to be (Darren)

Darren suggests that if he exercises when he is feeling tight, it may lead to a painful episode in the future suggesting a juggling act between exercising and the possibility of an injury later. Julia and Darren express some level of pain-related anxiety and a fear or reinjury. Katherine and Ivan build on this further and analyse what happens when they are in pain:

You have joint pain which prevents you from doing certain movements and like my knees lock quite a lot, my wrists lock, that kind of thing... Then you have the muscle burning from the top of your head down to your toes, every muscle feels like you have worked out in the gym and that lactic acid kind of burning (Katherine)

I get a kind of mid-back like into my shoulder, trappy kind of pain and if I want to go climbing or if I want to do pull-ups or an upper body workout or something like that, I will probably change how I do that, I will probably drop the intensity way down, I may stop a session early, it may stop me from doing that (Ivan)

Katherine says it prevents her from doing certain movements and points out a sensation of burning from her head to her toes. Ivan builds on this and says how he

reduces the intensity of his exercise depending on where he feels pain at the time. Katherine, Michael and Ivan employed expressive metaphors to try and make sense of living with pain which requires a detailed imagining of pictures and use of language:

Both shoulders flare up every now and again, so this one is a bicep tendon issue this is a triceps tendon issue, so this one pulls on the front and this one pulls on the back [laughs] my neck leans one way, I mean you can't really see it but if I stand up straight my neck leans, and when my neck is bad, I have seen my neck 45 degrees, so my body is straight, my back has a 45 degree bend at the bottom and a 45 degree bend at the top [laughs] extraordinary the way it goes over, my shoulder goes up, up and up, I am like Quasimodo [laughs] (Michael)

You know it felt like a lot of my life I was living with this twisted corset around me that was pulling here and twisted there and cinched there and too tight here (Ivan)

There are moments when the pain is so intense, it is like you are being eaten alive, can you imagine living like that and believing it will never end, this is life forever (Katherine)

Michael and Ivan provide a picture of how they experience pain, both alluding to the feeling of 'tightness'. This sensation pulls on areas of their body which gives the impression they resemble 'Quasimodo', or their muscles are acting like a "corset", pulling their body in different directions. Katherine adopts a different emotive view of her painful episodes, 'a never-ending feeling of being eaten alive' and tries to get the researcher to feel what it is like to be eaten alive by pain. For the participants to communicate in this way suggests an experience that has been there for some time, they are able to clearly articulate how they feel and how they perceive the outside world views and judges them. All the participants in this study allude to the experience of pain in their own imaginative, individual way. By using imaginative, colourful language it was as though they were trying to enable the researcher to understand their emotional experience of pain. As the researcher, it felt to me that the participants were attempting to make me feel their painful episodes in their own terms. For Michael, Ivan and Katherine these experiences should be viewed in the context of the earlier

personal statements which are magnified by their personal trauma and mental anguish.

## 3.2.3 Pain makes me feel like Sh\*t, it's exhausting

All the participants spoke of debilitating pain, feeling frustrated and physically and emotionally exhausted. Their frustration seems to stem from the constant thinking about pain and adapting their behaviour to manage their pain. Rather than let their experience pass, they discuss battling and resisting their experience which makes them feel worse and exhausted. Ultimately, they experience pain as a dark and lonely place that robs them of optimism about their life. Julia explains how she questions the way she sits, her spinal alignment and her issues with using a standing desk. Julia demonstrates the exhausting self-analysis that happens just to sit down, Ivan and Katherine build on the exhaustive nature of pain:

It makes me question my back, how I am aligned and adjusted or sitting at a desk all day, I know I don't have the best posture, even sitting for my hip, I have a standing desk and I don't use it very often, I forget to use it, but actually standing for long periods of time bothers me (Julia)

The neck one is quite debilitating it usually comes with a headache and, it triggers like a migraine, it triggers a little bit of nausea and fatigue I feel quite woah [tired sigh] but really wiped so that one can creep up (Ivan)

The exhaustion to the point like you've been hit by a car, so many people describe it that way. Like no energy. Like the flu, the worst version (Katherine)

Julia questions her back and posture and may have sought help from her employers. They supplied a standing desk which she forgets to use, possibly because long periods of standing aggravate her pain experience. Katherine compares her exhaustion to the worst ever flu and not having the energy to engage with the world. Ivan shares a similar view of exhaustion and explains as his pain built up over time he

felt wiped out, he found he had to withdraw from impactful sports and activities as they hurt too much:

I never feel rested I go to sleep, and I wake up exactly the same level of tired as I was, it's that fatigue you get, like flu, when you have flu when you wake up the next day and you just try and do something and you can't, it's like that most days (Ivan)

It gradually got to the stage where I couldn't really do any impact sports just anything impactful hurt, so at one point I was mostly swimming, doing capoeira, gentle flowy martial arts dancing but I had to modify my activities kind of reducing down to like less impact sports and things like that because anything too intense would just cause a headache or spasm (Ivan)

Julia analyses her posture but is still able to work. However, Ivan who experienced pain at a young age started to reduce his activity from impactful exercise to more flowing type of movements like capoeira. He realised that the impact sports would lead to headaches or spasms, so he played less team sports and did more individual based exercise. This may have been at a time in his life where his friends were involved in team sports, which he had to withdraw from due to headaches and spasms (Hainline et al., 2017).

All the participants found their painful episodes something to be avoided or resisted. They would avoid or resist by using strong pain killers or strong painful massages, but Darren found that his pain would impact the way he engages in play with his 3-year-old daughter:

Even playing with the kids, it can effect that sometimes, like if I have a bad flare-up of lower back pain or hip pain, the thought of playing a jigsaw puzzle with a 3-year-old is like ahh no, please no because it's on the floor and she is like yeah let's play a game here and I am like well getting down on the floor and crouching over and kneeling or sitting down on the floor for too long can aggravate things and it's not very comfortable (Darren)

At first it was avoidance, I wasn't able to sit with the pain or look at the pain and be with it, give me all the painkillers you can to numb this out and I lived that way for a long time (Katherine)

I mean there is definitely times where you just get really annoyed with it, I will just hit my leg sometimes and just like stop f\*\*king hurting me, I mean I don't self-harm [laughs] (Julia)

By the time we moved to London, I was at the point where I was unable to do anything, the less I did the less I could do, so I did nothing, I sat in a chair, and I lived with almost constant pain. Then every month or two something would kick off and I would be crippled, I mean, my back, I would need a walking stick to walk it was ridiculous (Michael)

Katherine, Julia and Michael all share similar impacts of pain on their decisions and family choices. They just want their pain to go away. Katherine used painkillers to remove pain and 'numb' out, to avoid her experience. Julia uses violence against herself, not in a self-harm manner but with anger towards her own painful limb, whereas Michael, arrived at the point of no more movement, he was going to sit in his chair and do nothing. If he moves, he fears he will be in worse pain so feels he needs to protect his body and support himself with a stick. Like Ivan with his sport and Julia at her desk, Darren has to consider his engagement in activities with his 3-year-old daughter, which removes the spontaneity involved with random play. His daughter could be unaware that her father is in pain, but he explains the impact of pain when moving into awkward positions. Therefore, when Darren experiences pain, rather than avoid playing with his daughter, he modifies the way he engages in play. Both Darren and Julia shares frustration in different forms:

It's quite depressing really at times, I notice I am more aware of it now than I perhaps used to be, but I sort of notice that my mood is down, and I am annoyed, maybe a bit snappy with people at home and I tend to be a bit more aware of it now than I used to be (Darren)

I think it's more an emotional thing but when it does flare up I do get frustrated because I do all these things for myself, I try and be as healthy as I can be, I don't smoke, don't drink, don't eat too much sh\*tty food, sleep well, I do all these things and if it does flare-up again, it's kind of like, what else do you need from me to not cause you pain (Julia)

Darren's mood changes and he feels he gets angry and short-tempered with those around him. Whereas Julia feels frustrated because none of the steps she takes seem to help. This frustration could contrast with her values and freedom to engage in any activity she wishes to. Similarly, when Ivan withdraws from impact sports this possibly impacts on his social life as he removes himself from team sports (Hainline *et al.*, 2017) Katherine suggests different values, they may not be exercise but she does value her career and ambitions, but pain is her barrier:

For somebody like me who is ambitious and been successful in different areas of my career, then to suddenly not be able to work, have to claim benefits and to feel the shame of that, it's awful and humiliating (Katherine)

Katherine has experienced success in her career but when she had to withdraw from work due to pain, she felt humiliated having to stand a in a queue with other people who were claiming benefits. Katherine, Julia and Darren describe experiencing shame and frustration with themselves. Michael experiences pain in relation to his family and has grown up with other family members experiencing pain and is also explicit in the way his inability to do anything affects his wife. Also, Michael highlights his brother's response to his painful episodes:

All my family have issues.... Members of my family have said in the past are you sure this is serious pain, my brother says, are you not just a wuss, can you not just take pain. At the end of the day it doesn't matter, in here [points to temporals] which is what's important I am in chronic pain and I can't describe it, now am I a wuss that cannot take pain? I don't know, I have had broken bones, I have had my appendix out I didn't suffer any worse than anyone else, so no but for some reason my brain is very sensitive to my skeleton and its structure (Michael)

I really couldn't do anything, I was stuck in a chair, if I did anything, I was going to hurt myself simple as that, it was dire, my wife was really concerned (Michael)

Interestingly, there is a suggestion Michael believes that he has inherited pain from his family and his brother suggests that he is weak by not being able to cope with pain. Rather than inherited pain he may have learnt from his family how to experience pain. It could be interpretated or assumed that there is a possibility that when Michael was younger at family events someone in his family was either experiencing pain or preparing for an operation due to pain. Therefore, pain may have been the centre of discussion in social situations which may magnify his individual experience of pain (Tracy, 2017), to the extent that his life reduced to one chair in one room. Darren explores how at times pain is overwhelming and it can be a struggle to complete everyday tasks. However, Michael takes this point one step further to where he completely gave up:

When it's really bad it can feel like all these pressures of family life, of work life trying to balance all your different aspects of your finances and that stuff and if you are struggling just to like go and do something basic like change the bin bag or whatever it just gets on top of you and you feel overwhelmed (Darren)

I had given up, I completely given up, yeah. I just figured it was going to be a slow decline and at some point, I just wouldn't take it anymore (Michael)

All the participants here have expressed a range of emotions relating to when experience pain. Pain has been a large part of their life which has developed over time, as their pain experience has grown it has led to them to reducing exercise or the way they engage with others, at times, also, having to consider what may happen if they complete a task, leading to fear and anxiety as they are unsure how their body will feel after exercise or social activities. However, Michael had completely given up, to a point of no return and his life reduced to a single chair in a room. The exhaustion, anger, and frustration that pain has caused the participants forces them into a point in their life where they have no option but to change.

# 3.2.4 The pain of staying the same was far worse than the pain of starting to change

Katherine, Michael, and Ivan share similar experiences with pain and mental suffering, they felt forced to do something different and live another way. Julia and Darren were not as explicit in this readiness to change and their stories did not include graphic details of trauma and mental anguish, but their pain experience affected them in other ways. Katherine and Michael mentioned their struggle with work which manifested as overwhelm or a build-up of stressful experiences, this forced them to a point of change:

I was struggling to cope with the workload of teaching and just the abuse. I was working at quite a few different schools that were challenging and not feeling supported by department heads and had kids trying to set my hair on fire, throwing chairs across the room and for somebody like me who has already been through trauma, to be working in that environment and then to have the response when you would approach senior leadership teams, to say this is actual abuse, this is not acceptable behaviour, where is the support here? and it's: well they are just kids and there is nothing you can do, you just have to tolerate it (Katherine)

Katherine expresses herself vividly, she previously comments on the trauma of seeing her mum pass away from cancer and now she is trying to do her best in a challenging environment which is not recognised by her leadership team. Michael refers to his 'issues' and highlights how these struggles magnify his pain experience:

I have a number of issues and different things... When my mental health goes, I have got pain on the way, my body, the back, the tension, the shoulders, the neck, my hip, knee will go out, everything will just fall apart... I just went into the most awful place, physically and emotionally but that was because of living with the pain had it just been some mental anguish, I don't think I would have dropped to the lowness that I did because I had the physical pain as well and one was just feeding the other (Michael)

Therefore, the mixture of trauma, physical pain and mental pain builds until something breaks and in Michael's case, he feels his body falls apart. However, Katherine, Michael and Ivan spoke about being left with no choice other than to heal and their

readiness to recover. Katherine builds on her experience of trauma and feeling unsafe in her own body.

The more trauma I experienced the more unsafe I felt in my body and then my body was rejecting just existing, that's my experience and obviously I have done a lot of work to get from that point to where I am now, so from there avoiding pain completely I was unable to function my whole life fell away so I had no choice but to try and find ways to heal (Katherine)

Ivan shares a similar experience but explains a process where he felt the pain was too much and he had to change, despite how uncomfortable building a new way of life may be:

I mean, it didn't happen at once and it was stages. There was a point where the suffering was so much that I have to do something about this, the pain of staying the same was far worse than the pain of starting to change and the pain of responsibility like ownership of my life and all the things I had to take account for and all of that kind of stuff, I was like well staying the same just isn't an option anymore this is too sh't so then starting to do that which meant starting to look back into my past and why I was limited here, why I was so fearful of these situations, all that kind of stuff and so it all came part and parcel of the kind of same process of recovery (Ivan)

Both Katherine and Ivan say that they had no 'choice' or 'option' but to seek change, indicating there was a moment in their life where they both felt enough was enough and they began a journey of recovery and 'healing', and Katherine saw an opportunity to surrender to her experience:

Everyone has like a landmark year where things all happen at the same time so from then it's been one thing after another, like one stress after another, and I guess I tried to, I just tried everything I could but realised then I was pushing too much and I had to surrender a bit more and allow some things to be (Katherine)

Considering Katherine and Ivan recognised a need to change for themselves, Michael needed some encouragement from his wife which may have stemmed from her concern over his health:

It was dire, it was really my wife was really concerned.... My wife managed to convince me to go and see the osteopath and give her a chance, see if she could help me, I was at the point where I just didn't care anymore and I was just going to sit in the chair and just try to avoid as much pain as possible but I wasn't going to actively do anything, so yeah my wife introduced me to the osteopath (Michael)

Michael may have realised the suffering he was causing his wife as she constantly saw him stuck in a chair. This realisation led him to his own point of change. Therefore, rather than an internal feeling of 'I must do something' his wife acted as a catalyst to spark a moment of change. There is an indication that at some point the pressure of trauma and external pressures weighed so much, that something in their lives needed to change. As Katherine recognised in herself and says, 'I was pushing too much' and was trying to be a certain way and live up to what society expects of her. In addition, the term 'landmark year' indicates that all her issues were just too much and this was her point of change. Ivan also refers to a moment of change and explains what he started do and how he started to take responsibility for the way he lived:

There was a definite moment when I changed and that was when I took responsibility for it and that was when I decided enough is enough, I am going to do what it takes and that was during that period of depression. I also found a yoga teacher and I did yoga for two years, the first thing that got me consistent relief from pain was yoga that had meditation and breath work and that was the first time, ahhhh my body is not just a place of pain and anxiety, this body can feel safe and comfortable to be in and that was nice, that was probably the first time I was like, ok, cool, yeah I can live with this now because I have a way to relieve myself even when it gets bad (Ivan)

Through these experiential statements the participants present a process of living with pain to a point of change. This point has been reached after they have lived through experiences of trauma and stress, and they feel forced to try a new way of living. Ultimately, these experiential statements highlight a point in life where the participants

felt something needed to change. The pressure of trauma and stress that was leading to mental anguish forced them to change and begin a new way of life.

# 3.3 Osteopathy Reconnects Me to Life

The participants felt with the support of an osteopath they were given the freedom to live with pain. In the context of the participants' past, three out of the five participants were able to express their trauma and be accepted for who they are, they felt they were treated with compassion. Fundamentally they felt connected to another human after having experienced a life of isolation from society.

# 3.3.1 Osteopathy has allowed me the freedom to live with pain

The participants felt supported by the osteopaths they worked with, but each in a different way. Michael feels that when he pays a fee, he is motivated to manage his pain and learn from the osteopaths he sees. Darren manages his pain in a similar way by visiting the osteopaths in his gym but supports his rehabilitation with his exercise knowledge to assist his recovery. Katherine uses osteopathy as a movement reset. Michael suggests that osteopathy requires minimal effort on his part:

I understand that with osteopathy and Pilates they are routes that can keep me in a decent place with the minimal effort required on my part... It's kind of ludicrous that I am paying the money I am paying to have video rehab or Pilates sessions this should be something I can sit down and do myself, I cannot if I don't pay someone to do it, I won't do it, I have to pay someone to watch me and tell me what do and make sure I am doing it otherwise I won't do it (Michael)

The practitioners that Michael visits use a combination of osteopathy and Pilates to support Michael's recovery. He views this as minimal effort. This could mean that he relies on the practitioners to help him move as he is unsure how to use the movements correctly (Caneiro *et al.*, 2017). Also, he is motivated by paying a fee. This means he has an allocated time with the osteopath for an hour and is accountable for that

session. This is different to Darren who believes in daily maintenance, and who would only see an osteopath if an area of his body is painful. His sense of freedom may well stem from the insight he received from the osteopath and he can use this to understand his body more to support his idea of prevention:

I tend to see an osteopath if there is something really painful and I can't manage it but also over time I have realised that a bit of daily maintenance every now and again goes a long way it's almost preventative rather than waiting for something to flare-up... Some gentle mobility work, stretching, which sometimes helps sometimes it doesn't sometimes it can aggravate certain things, I must be careful about that. Seeing an osteopath or a physio if it's really bad just trying to get that extra sort of insight and sort of manual therapy type of stuff (Darren)

Darren seems to use osteopathy as a supplement to his daily movements of mobility work and stretching. He seeks advice from an osteopath or physiotherapist if a body part is painful or for a deeper understanding of his condition, and manual therapy techniques which consist of massage, stretching and supported joint movements. Michael builds on the manual therapy part of osteopathy and explains how the osteopaths can move joints that he cannot:

Its gentle manipulative treatment, it's all about the girls, it's the way they make me move, my biggest problem, when something hurts other people could move that joint, but I can't move it myself. It's the muscles and tendons that's the problem, I mean there will be an ache, but the biggest pain is when I try and move it (Michael)

Michael possibly feels safe and reassured when he is with an osteopath (Traeger *et al.*, 2017). This contrasts with before he saw an osteopath, when he was sat alone in a chair scared to move, which could suggest his confidence in his body is low, alongside a high fear of pain, which limits what he can do when he experiences pain. Now with the support of an osteopath, Michael feels he has developed the ability to support his own bodyweight with less fear of pain, which means he has the freedom to move and accomplish more:

I mean that's another huge thing, conditioning and repairing, also strengthening and everything, so that's very much into the prevention as well as the cure, isn't it, so that's made a huge difference to my strength, I mean I have actually got a core, I have got some core support, I mean that made such a huge difference [laughs] when you can actually hold up your own body, I mean it's brilliant [laughs] (Michael)

As Michael has developed strength and confidence in his ability, he can engage with life again and support his bodyweight. He says, 'it is brilliant' and seems surprised at something he can do now, compared to before and he is happy with himself. Katherine feels osteopathy is like a movement reset that engages with the tiniest movements:

The tension in my neck right now so just literally moved my head forward and lifted it and that feels there is space from the reaction back to like the reset mode, like in Alexander technique, I don't know if you know much about that but they teach you how to walk again based on how your body should be as a baby so you really feel into the tiniest movements until you're intuitively set back into that mode, osteopathy feels very similar to that (Katherine)

Katherine feels as if there is freedom and space between her reaction to neck tension and the reset mode, and compares osteopathy to Alexander technique. She experiences a body response which could be like Michael, where he feels the osteopath is able to move joints that he cannot. Both Darren and Michael report positive experiences after seeing an osteopath and its effects on their life:

I suppose I want to walk out feeling like I have had something, that I probably couldn't do myself. That has positively impacted my health and recovery from whatever pain or you know misalignment I have got, so even if I go and I have got no pain, when I feel like I have left with freely moving hips or more supple muscles that have had a bit of you know relief (Darren)

Oh, crikey, hugely, I can go months now without actual pain, I mean there is never a day without pain, it's discomfort and pain are never far away but I can actually do things, I could actually consider moving house, we did all of our own moving, all of our own boxing, we did everything ourselves (Michael)

Darren feels something more within his body, he can move freely after something being 'done' to his muscles by the osteopath. Michael goes further saying he can go months without pain, and he can do things, that before he could only dream of. In this context, osteopathy has supported Michael's confidence in his body which has meant he can move house and pack boxes despite pain. However, Michael had a desire and readiness to change which indicates he was motivated to follow the suggestions from the osteopaths. Similarly, Darren may have adapted his movement recommendations with guidance from the osteopaths to support his own recovery and prolonging the therapeutic experience. Therefore, these positive experiences may not have been due to the osteopath themselves, but the whole treatment experience of being cared for and listened to as a person.

## 3.3.2 The osteopath sees me differently

Osteopathy was viewed by the participants as a holistic way of working and they felt they were treated differently than by the more mainstream medical community. Katherine, Ivan and Michael spent time trying to explain their pain experience to doctors and consultants, but because their blood tests were clear, they were all told they were fine. This would often result in a prescription of painkillers and a feeling of being dismissed. Katherine and Ivan explain how they felt when they visited their doctors:

Especially those with invisible illnesses, because you are shamed into believing you are fine, and you are making it up (Katherine)

I think dismissed would be the way to put it, yeah, just kind of having my concerns dismissed and that you just kind of, need to you know, button up and crack on with it there is nothing wrong with you stop whinging (Ivan)

Given the severity of Katherine's and Ivan's pain, they had turned to the medical community for support. However, due to the invisible nature of pain they both felt their experiences were dismissed. They displayed no signs of a condition and they may

have found their experience a challenge to explain to healthcare professionals. Both Katherine and Ivan suggest this as a form of 'medical gaslighting':

When I complained of fatigue, multiple blood tests were saying there is nothing wrong with you, there is no reason for your fatigue so by the UK definition I have chronic fatigue. I have had no official diagnosis at any point... I was going to the GPs telling them I was fatigued, and they were telling me your blood tests are all clear [pause] go away (Ivan)

To have no support from anyone, to be told it's all in your head, you are making it up, like medical gaslighting, it's abuse it's awful (Katherine)

This form of 'medical gaslighting' may lead to Katherine and Ivan feeling confused by their symptoms. They are experiencing pain and fatigue, but their tests are displaying no markers of fatigue or inflammation which might have offered some medical explanation for their symptoms. When they were offered pain relief, Katherine makes a connection with a cocktail of drugs and Darren says he was prescribed a large dose of codeine:

I was on a cocktail of so many drugs, citalopram, they were giving me two different antidepressants at one point which I realised contradicted each other and could cause severe reactions. So that was amitriptyline, citalopram, I was taking tramadol like six a day (Katherine)

There was one GP who just handed me a hundred tabs of codeine prescription. Hundred tabs! It was enough to kill a horse, it was more than a year's supply, you only need like one or two a day and that wipes you out... so that was bit demoralising, fine If you are desperate but I thought it was quite bad, they handed me so many, they are addictive as well, you don't want to end up taking codeine every day just out of habit because it's almost a drug addiction at that point (Darren)

Katherine and Darren are both explicit about their experience of using pain medication. Katherine felt like she was a consuming a 'cocktail of drugs' and Darren felt like he was prescribed enough codeine 'to kill a horse'. The metaphors that they both use are

imaginative and expressive. They explain what it feels like to be taking those painkillers and the long-term effect it could have. After a while the participants were referred on to other healthcare professions to help manage their pain experience and in the beginning, Julia felt these appointments offered her a clearer understanding of pain:

I think talking to people that work in the health field or stuff to do with the body and getting their points of view on things, because they study that sort of thing, I think it also helps you have a better understanding of how your body works connecting you to exercises and things that are supposed to be specific to what would help (Julia)

Initially Julia found her appointments useful, and she was able to learn from those in the 'health field' to gain a deeper understanding of her pain experience. She along with Darren and Ivan was referred on to physiotherapy sessions with mixed results:

The physio, I just don't think gave me the right exercises to do and they didn't do any real manual therapy that I felt made any significant difference. I remember one or two of them gave me stuff for my hip flexors and they didn't really do much (Darren)

The physios were quite unidimensional, whatever it was they were focussed on the main presenting factor discounting the rest of it. So, if one day my upper back was the worst bit, they wouldn't take into consideration the fact there was a hip thing going on and a shoulder thing going on and a neck thing going on and it was the upper back and I had various different diagnoses of like hypermobility, I am not hypermobile, I have just done martial arts, I am a bit flexible (Ivan)

They gave me exercises and I feel stupid lifting a one-kilogram weight, you know like the old grandmas, but it is helpful (Julia)

Darren, Ivan, and Julia felt the exercises or one-dimensional approach offered by physiotherapists limited the impact on their pain experience. Interestingly, Julia feels the rehabilitation exercises were helpful, but she 'felt stupid' using a one-kilogram weight. This feeling may have been a barrier to recovery and contradicts the way she views exercise, adds to her frustration and the way she is viewed by others in the gym

(Bethancourt *et al.*, 2014). These healthcare and physiotherapy experiences may have influenced their views of osteopathy. The participants felt osteopaths explored their sleep quality, their nutrition, and other areas of their life. Ivan felt that an osteopath was a multidisciplinary practitioner all in one and they could use this approach to understand the complexities of chronic pain. Manual therapy was viewed as a small part of osteopathy, but Katherine felt the pressure applied with massage enabled her to identify where she was holding the emotional and physical stress. Katherine and Darren both share their views of osteopathy:

As a real holistic way of working that feels like it treats the whole of the individual rather than just parts so that's what it means to me (Katherine)

My experience with osteopathy is they tend to use a bit of both, they will use some manipulations, they will use some manual therapy, some acupuncture, some physical corrective stuff and they also tend to delve a bit deeper into your lifestyle and ask me things about the nutritional side of things, lifestyle habits and sleeping patterns and stuff that can affect your health overall (Darren)

Darren expands on Katherine's holistic point of view by using the term 'delve deeper' into his lifestyle. The osteopath may be attempting to identify barriers and facilitators to recovery, and Darren was given the opportunity to reflect and makes sense of his lifestyle behaviours (Cormack *et al.*, 2022, Morera-Balaguer *et al.*, 2018). Ivan compares his chronic experience to a bunch of tangled wires, a situation where osteopathy uses a variety of approaches to understand the complexity of chronic pain and his individual experience:

You know the bunch of tangled wires at the back of the TV, it's like that. It's like you are looking at it, where the hell do I start and you can't really tell which ones are which and where it's tight, where shall I push, where shall I pull, where shall I give it space. It's quite hard unpicking it like that but osteopathy gives a nice lens, osteopathy gives the colour to the different wires and you see which ones are going where but it doesn't stop, you still have to do all of the work but you can actually make sense of all of the components of it and I think that is what osteopathy does for me (Ivan)

In Ivan's example osteopathy is helping him understand the complexity of chronic pain but importantly Ivan recognises the work he needs to do to support himself. This did not arise from his experience of seeing a physiotherapist who he felt was one-dimensional. Ivan is critical of the manual therapy approach though he understands that osteopathy is not only a manual therapy profession. However, Katherine feels the pressure from manual therapy techniques allowed her to make sense of her stress and felt safe to experience her rise in muscles tension:

You know the five kind of component osteopathic view of the person and the self and all that kind of stuff that for me is the key, but that means something to me. The manual therapy is fine, it's one piece of the puzzle but I define it by the philosophical lens not what you do with your hands, it's nice but it's vastly overrated (Ivan)

I realised how stressed I was throughout the process, like how there was this resistance to not feeling good enough, not being worthy and that brought up that need to heal that aspect and looking at how my body reacted to it, my body literally went into a state of tension, my head moved backwards and then as she was holding, cos her hands were on that part as we were talking, I could really feel the way it was moving. Where if I hadn't had that pressure... it probably would not have been that obvious that I had that reaction (Katherine)

Katherine was able to feel the tension in her neck while the osteopath was exploring her response to stressful experiences. Katherine was able to reflect on her personal barriers and see the effect these were having on her body which allowed her the opportunity to heal. In short, the participants felt they were treated differently by osteopaths. However, these experiences may be viewed in the context of the national healthcare issues. Osteopaths working in private practice in the United Kingdom have more appointment time available than doctors and physiotherapists working under the restraints of the National Health Service (GOsC, 2018). Therefore, osteopaths have more time to explore other areas of the patient's life and have the freedom to understand the patient's pain experience and adapt their treatment interventions towards the patient's life values.

# 3.3.3 Osteopathy allowed me to feel connected to myself and another human being

Katherine, Ivan, and Michael discussed their experiences with feeling connected to the osteopaths they were working with. They felt safe in their company and found the osteopaths reconnected the participants to their bodies. Michael found their 'bedside manner' played a role in the management of his pain and Ivan left his sessions feeling hopeful. Previous statements in 3.2.3 and 3.2.4 explored the isolation the participants felt and the disconnect they felt from their own bodies. Katherine and Ivan share similar experiences:

It was being held, having a safe space, it felt like counselling but for the mind, body, and soul as well. That's probably the best way to describe it. Working intuitively with momentary experiences and then being able to transition those experiences (Katherine)

I had a very tough year, quite physically and psychologically tough and then I think seeing the osteopath helped me at a time when I was very vulnerable and how they contorted themselves, I was like, if I was like that, that would be amazing, I would love to be someone like that (Ivan)

Both Katherine and Ivan felt safe at a time of vulnerability. Katherine describes her experience in a spiritual way, for example, when she says she was able to 'transition those experiences' and allow her thought processes to arise. Ivan feels that the osteopath he was working with 'contorted themselves'. In this instance, Ivan could mean, he felt accepted as he was at that moment in time and the osteopath adapted his approach to support him. Katherine goes further with her spiritual experience:

I think it was the start of this the mind, body connection like I said really being able to observe what was happening with my body reactions to my thoughts, then led me to become more conscious, led me to start healing core wounds and for me the biggest thing osteopathy has brought has been that dialogue between mind, body, and connection and even Darwin in a way I mean I know it's not inherently a spiritual

practice but because of the safe space held, it becomes spiritual, it becomes nurturing through love, that's what spirituality is, so that's my experience (Katherine)

Katherine uses 'nurturing through love' or 'dialogue between mind and body' to explain her experience of osteopathy. Katherine was explicit in previous statements, suggesting that her pain experience was isolating and that she had had the sense of being eaten alive. Now, with the support of an osteopath, Katherine can observe her bodily reactions to her thoughts, which offered her the opportunity to heal core wounds. Katherine feels safe and loved as a human being compared to before, where she felt unsafe and unlovable in her body. Michael explains that the osteopaths he worked with made him feel human through their 'bedside manner':

It's the whole bedside manner thing and I think plays a huge role, the fact that these two osteopaths genuinely care about my health and want to make my life better, that placebo effect, bedside manner, these things, we know they are real and I think they work strongly for me, I really do because it's a huge difference, they make me feel like I am worth the effort, I have always found that in osteopathy (Michael)

In the same was as Katherine felt nurtured, here Michael feels cared for as a human being; as with Katherine, previously he had discussed low self-worth and not deserving of self-care. Michael develops this further, this positive attitude that he receives from his osteopathy sessions supports his recovery, but he must be careful not to put the osteopaths on a pedestal:

I mean it's not a part of osteopathy but both osteopaths (E) and (A) they're two of the angels, I have met angels in life... my therapist says you must not put people on a pedestal they are not angels, they are not superhuman but they are above human beings there is something about them where they are next level carers so yes they are health practitioners professionally but they are also the people that genuinely care and genuinely want to help you out of pain (Michael)

Michael's therapist has warned him not to place the osteopaths on a level above him, they are human like everybody else. However, this needs to be viewed in the context of Michael's history. He experienced debilitating pain, to the point he could not leave

a chair. This pain experience left him with a choice, to see someone for physical support or stay limited to a single chair while the world moved on without him. Now he feels that the osteopaths he sees want to help him out of pain and want him to live well. Katherine and Ivan share similar hopeful therapeutic encounters:

I was honestly so blown away by the compassion and just like the way everyone holds space I mean they have this fantastic way of holding that safe space to listen and when you're suffering with fibromyalgia or any chronic pain you don't really have that from any other form of healthcare... I really felt heard and that there was hope, that was my first initial response and that was when I was very sick. My life was just falling apart honestly in so many different ways, so it provided me with hope (Katherine)

I did definitely feel like this guy started me on a course of pain relief, he explained it really well to me, he explained that he had seen this kind of thing before, that it was something that could be altered, that he knew he had an action plan and treatment plan and that he was going to call me in between sessions to check that I was ok and that I was getting on with stuff, so it was just the level of care was completely different (Ivan)

Katherine and Ivan express their experiences of compassion and care that the osteopaths offered. They had both explained previously that through other healthcare disciplines they were made to feel shameful or were not believed, now they feel the opposite. Ultimately the participants were able to connect to another human being, felt safe and nurtured and felt hopeful that there was a way out of pain. It is important to recognise that the participants could have seen any other healthcare practitioner and have had a similar positive experience but at the time, these participants decided to see an osteopath rather than another healthcare professional.

### 3.4 Managing Pain is Like Developing a Skill

The participants have expressed ways in which pain and trauma have affected them. They have felt 'forced into a corner' and possibly faced a choice in how to manage their experiences. They have adopted a problem-solving attitude towards their own experience and developed their own personal approaches to help themselves.

# 3.4.1 Pain management is a constant

The participants have expressed a process they go through to manage their pain episodes. Michael says how self-care is a chore but it is something that needs to be completed for his own self-worth:

The five years of therapy that I have, I had therapy in Dublin, this time my own self-worth has changed and an understanding that I need to take care of myself and the beginnings of actually caring for myself are developing now so things are actually very different, but in the past I just had no interest, because it meant making the effort on my part, I wasn't prepared to make an effort, for me (Michael)

In the context of Michael's story, he was constrained to a chair and ready to give up on life. He uses the phrase 'are developing' suggesting a work in progress and mentions 'in the past' which suggests a comparison to his life before. He can reflect on his life experiences and recognise the value and effort that self-care requires. Darren and Julia both recognise their own boundaries and seem to have developed their own limits while exercising and realise when to stop or 'power through':

I tend to try and manage that, sort of tone it down on whatever activities I am doing so if that means having to miss a week of football or do something different in the gym, work on a different body part, then I will do that or just go lighter or less dynamic so trying to adjust or work around things is usually what I end up doing often end up sort of implementing more recovery strategies, so things like foam rolling I sometimes do, I have got a massage gun at home, I might have long hot baths try and soak the joints warm up the joints and get some blood flowing (Darren)

It's kind of constant, I mean most of the time I just kind of power through at this point. It's more like if it flares up, but that's more like trying to rest it, stretch it out and worst case ice it, I don't even know if that helps but at least it numbs it (Julia)

Julia and Darren have adopted similar strategies to manage the way they feel when they are in pain. They seem to value exercise and have similar recovery strategies. These involve stretching, hot baths or ice to help 'numb' their pain. Ultimately the participants have developed personal strategies. For example, Michael tries not to complete tasks in 'one go', something which, with support from his wife and his therapist, he has realised he does not have to do. Similarly, Darren has realised that he needs to live with his pain rather than to eliminate it:

There is nothing in my life, right now, that has got to be done, today, or even this week, there's lots of things that have got to be done but they don't have to be done in one go, they don't have to be done in two goes, and that is the strategy, that is the new thing that I have just recently discovered is possible, I didn't think it was but I have realised and with the help of the therapist, my wife and other people around me (Michael)

Treating it more like something to keep under control and manage as opposed to eliminate has been helpful and because I don't feel like I am failing at what I am doing the goal isn't to be completely pain free anymore because I don't feel that is realistic (Darren)

Darren manages his pain with exercises parallel to his understanding that his pain is not something that can be eliminated, rather pain is something to be managed. Also, there is a suggestion his goal was to be pain free and he realises that is not realistic. Therefore, for these participants pain management has been a process of recognising that their pain can be managed with variations in exercise intensity along with a change in perception towards their pain experience.

# 3.4.2 Daily movement helps me stay in an upward trend of recovery

In the previous theme the participants acknowledged their pain experience and came to understand that pain can be managed. Also, they have recognised their own recovery strategies if they overdo movements or exercises. Julia is 'figuring it out for herself', possibly indicating that she adopts an active coping strategy to help her maintain her exercise in the gym. Darren's approach is to see how he wakes up in the morning, start his exercise slowly and see how he feels:

I feel like I am having to figure out a lot of that and I am not a medical professional, but I think I also like to achieve full mobility and not having to be restricted in exercise, even if it did hurt a little bit I can power through (Julia)

I wake up and I am a bit sore and a bit stiff, a bit achy, a couple of joints might be hurting, my back is probably a bit stiff, if after a couple of hours, train a few clients and then start warming up for my training and after the warm up I feel fine that's good, I was in pain, I'm not, I can do my workout, make sure I don't push too hard maybe if I was particularly sore, finish the workout, I probably feel better than I did when I woke up (Darren)

They both indicate that a small amount of pain is ok, but they know what a 'little bit of pain' means to them which may have been a process of trial and error. Julia says she can 'power through' compared to Darren who hopes to feel better after his exercise routine. Darren seems to assess his joint stiffness in the morning and from that sensation he can see how he feels after his warmup routine. Darren and Julia prefer training in the gym and exercising within their own identified limits, compared to Katherine and Ivan who enjoy stretching into tension and adopting a more peaceful approach to movement:

This morning my body was feeling a bit tight, so I noticed you need to stretch into that and it's more yin, I don't do hardcore yoga, it's just breathing and stretching into areas I feel the tension (Katherine)

Now I am much more kind of relaxed with them, much looser with them, I pick them up as and when and I drop them as and when, it's a much more kind of gentle steering and managing of things, also everything is generally a lot better you know I am in less pain on a daily basis (Ivan)

Ivan and Katherine seem more relaxed in their movement. Ivan suggests here that he is gentler with himself, he knows what works for him depending on how he is feeling at a specific point in time. Fundamentally, Darren suggests he will do anything that promotes recovery rather than enter a downward trend of over-exercising:

Like soft tissue, foam rolling, long baths, stretching meditation or whatever or maybe just relaxing anything that is going to promote recovery... keep yourself on an upwards general upwards trend of recovery and trying not to spend too long in a downward trend of digging yourself a hole, too much exercising, not enough recovery so that has been the best strategy of managing my load (Darren)

Darren seems to have a range of options to promote recovery similar to the other participants. They all have active movement options which they adapt depending on how they are feeling. The participants rely on exercise to support their mental health and it is part of the solution to their pain experience. Julia views herself as a healthy body weight but being less active is a concern for her, compared to Darren who values exercises for different reasons:

I am going to sound very much like a girl here or not a girl but, I guess the fact that if I am not as active, I am not getting super fat [laughs] I'm ok, it is not the end of the world, I can do other things and my body still receptive of this sort of size it's not like I have to be some gym bunny, running ten miles a day to achieve a figure that I am comfortable with, while still having a hip injury, I am not putting on a ton of weight (Julia)

Physical activity is just so fundamental to my way of life that the idea of giving up and being sedentary is just unthinkable, why bother, why live, I have to be doing something as I get older, I am expecting to have to change those things eventually, maybe no

more running, probably cycling or maybe swimming or definitely no more football (Darren)

Darren and Julia value their exercise. Julia suggests that she is willing to exercise with pain to maintain her bodyweight. Darren, who works as a personal trainer, views physical activity as 'fundamental to [his] way of life'. These engrained values mean they will still maintain exercise in some form, despite their pain. Michael values his life now, he does not want to return to the loneliness, isolation and frustration of being limited to a chair:

I am at that point now where I know I have got to do it for myself, and I am going to do it. I am not going to join the gym and I am not going to do this, that and the other, but I am going to do two sessions every week if I am physically able. I have got to, otherwise I'm going to end up back where I was and I don't want to go back there again (Michael)

Movement is a way of life for the participants which has developed over a long period of time They have learnt which type of exercise to use depending on how they feel and these strategies have become fundamental to their way of life.

#### 3.4.3 I manage my pain like I manage a cold

The participants over time learnt individual approaches to managing their own pain experience which seemed to be in the form of pacing or trial and error. As they found their own individual solution to dealing with their pain, at the time of interviewing, they were '100% confident' in managing their pain experience. They made sense of their episodes by using metaphors to explain how they managed pain, and they knew the episodes would pass with, for example, painkillers or rest. Ivan adapts himself to how he feels when he is experiencing pain:

I will take it easy, I will pay attention to how I feel tomorrow morning and see whether I take the afternoon off or don't go in the next day, because I have pushed myself slightly too far and I need to rest, take some time for me, and take care of myself (Ivan)

Darren previously explained how he understands pain as something to be managed rather than eliminated. This understanding means he can adapt the exercise that he planned to do:

A concept of living with pain and managing it rather than trying to think of it as being something you eliminate, was a quite helpful thought process or mindset... Yeah I think I am definitely way better at sort of managing it, I think in the past I would get an injury and I would just stop all exercise of a certain type (Darren)

It is noteworthy that Darren uses the word 'process'. A process indicates a method of learning and identifying his personal barriers to exercise and his own concept of living with pain, which is something to be managed rather than eliminated. He has accepted that he is going to be in pain, where previously his goal may have been to eliminate pain. He builds on this concept by explaining that his flare-ups are like colds or an episode of hay fever:

I almost think of it, in the, having the susceptibility to getting a cold, alright you have got a cold now we treat it, you rest recover, you get better, the idea that you are never going to get a cold again is silly. Obviously it's not exactly the same as that because pain can be a bit more ongoing and steady ... Something like hay fever, you can take tablets and do whatever to try and make your hay fever better but you are going to have to manage it, if you go and run around in a field full of flowers you are probably not going to feel great (Darren)

Darren has made a personal connection between a cold and pain episodes. He appreciates that he is going to catch a cold, like he experiences a pain flare-up. Then to manage a cold, like his flare-up, he rests or reduces his activity to recover. Interestingly, he knows he will catch a cold, just as he knows he will have another flare-up, if he thinks he is not going to get a flare-up, he thinks that is 'silly'. Therefore, he expects a pain episode but he has used the idea of a cold to make sense of his pain experiences. In addition, he uses hay fever to explain his trigger events, he realises if he moves in a certain way it could trigger a pain event, just as running in a

field of flowers would trigger an episode of hay fever. Like Darren, Katherine and Ivan let their pain episodes pass and burn out:

Yeah, I had a flare up about 3 months ago and I just literally sat with it (Katherine)

It's bad at the moment, I have got painkillers and or relaxation techniques, hot bath, I know things that work and don't work, and I know that it will burn itself out (Ivan)

Katherine and Ivan now appreciate their pain will pass. Both the participants have experienced at points in their lives, debilitating pain. Now, they believe pain will pass, they have the option of 'sitting with it' or as Ivan says, use painkillers or relaxation techniques. Ultimately, these participants have experienced horrific, debilitating pain which stopped them from living the way they wanted. But now, they have learnt how to manage their pain in their own individual ways. Julia and Ivan both express how confident they feel in managing their pain:

Yeah like 100% confident, I am also confident that if I get to a point where I can't manage it, I have got people that I can turn to for help, so I suppose my friends understand, people that I know understand (Ivan)

I mean I guess pretty confident that in the sense of, I have done it, so don't really know any other way to do it, I know how to manage it, had to do other things around it, I have had other injuries since, that I have had to work with or work around, you know and if something else came up I am just looking for the wood to knock [laughs] (Julia)

Previously Ivan has explained his pain experience in graphic detail and now he is '100% confident' in managing his pain. For him, it has been a process of discovery and of learning what works for him. Similar for Julia, she knows no other way of managing her pain, she knows what works best for her.

### 3.5 Living Well Has Its Ups and Downs

In this study the participants used their suffering as an experience to be grateful for, they felt they have been given a new life. They explain that acceptance has been a process of accepting the good and the bad experiences associated with pain. This has been with regular practices to support their idea of living well and they can use these tools as and when they need them. At times being able to live well is hard work and can be a 'battle'.

#### 3.5.1 Through a process of suffering to reach new realms

As we have seen, three of the participants expressed in vivid detail their experience of pain and how they were forced through trauma to a place of change. Michael, Ivan and Katherine explained how their perceived experience of trauma in their life was personal to them. Their perception of trauma possibly involves suffering but could be used to enable them to build a new life (Dell'Osso *et al.*, 2022). All the participants used their initiative to seek outside help and change their perception of their pain experience. They were able to reflect on their trauma if needed to 'clear the wreckage of the past'. Therefore, rather than battle against their pain experience, they were able to surrender and relax into their pain. Darren and Ivan explain what it used to be like:

I used to quite be quite defeatist about it, quite a few years ago just sort of I have tried everything it's never going away blah blah blah it's a very sort of dogmatic sort of approach to it where, it is what it is, I can deal with it (Darren)

I was ready to help myself, I am not sure, whether it was the situation I was ready to heal, ready to help myself therefore anybody could have done the trick or it was the osteopath? But the confluence of those things together seemed to around the same time seemed to start me on a road to recover to get to a point of where I live well with it (Ivan)

Both Darren and Ivan expressed how they dealt with pain and how they were both ready to help themselves. Darren seems to have shifted his perception of his

experience from a 'defeatist' attitude towards pain and now it is something 'he can deal with'. Ivan's experience is more in-depth. He says it could have been several events that supported his recovery but he seems to be certain that he was 'ready to help himself'. Katherine had a similar experience to Ivan:

This why I have had to take this route on my own to find alternative tools because there was no support (Katherine)

Even though Katherine felt isolated, she was ready to take her own route on her own. Katherine has already explained why this may be the case. She felt isolated from work, the medical profession and those around her. Darren and Ivan also speak about their process of recovery:

I have gone from this kind of semi all-consuming, life-limiting suffering, I cannot take this anymore like my life is dominated by the fact that I can't do a lot of things because I am in pain all the time and I am sick of it, to: hello my old friend, it's you again you b\*\*tard, here we are again yeah, I can tolerate this, I know how to adapt, I know how to manage my life around it a little but occasionally when it's there and I know it's not life-threatening damage or anything like that (Ivan)

I think it was a process that took a while because, I think where I had had back pain for so long before I realised that, well that's life anyway, I have been dealing with this for years I know that my back flares up every now and then, I know that I struggle when it is bad (Darren)

Ivan reflects on his pain experience and explains the process he went through, his pain has gone from 'all-consuming, life-limiting suffering to: hello my old friend, it's you again you b\*\*tard', which suggests a sense of compassion towards himself. With these metaphors he has explained a process of change through time. Darren recognises a similar process of acceptance through time. He has been experiencing and managing pain for 'so long' he has recognised that he struggles when his pain is bad. Katherine explains her experience in spiritual terms, like Darren and Ivan, she has had to work hard to come to terms with her experience:

I have done a lot of work to get from that point to where I am now... It's been a journey. How can I make this more conscious, what are my reactions to my environment, what are my thought processes that are coming up? What are the traumas that I need to heal and diving deeply into all these different things? (Katherine)

Darren, Ivan and Katherine had explained a process of making sense of their pain experience through a period of time. Katherine says her process was over six years. She alludes to the need to gain greater consciousness, which for her could mean developing awareness of her reactions to thoughts, feelings, and past trauma. In addition, Katherine suggests, to 'heal' means exploring these past experiences. Before Katherine may have battled against these opportunities as she mentions below. For her it has been a process of surrender and acceptance. Ivan shared this idea of surrender:

You need to surrender to a certain degree and accept what's happening and not keep battling against it, so I have had to get to that point where I've had to surrender and accept the pain but from a loving space of acceptance and just be more compassionate with what is (Katherine)

Other than that, it's kind of I relax into it, breath work, little bit of meditation, like body scan type stuff with some maybe gentle self-massage or get my girlfriend to just give me a little massage but mostly you know not freak out, I know it goes away, it normally goes away if I sleep so it's ok (Ivan)

Katherine has adopted a loving approach to her experience, where previously she may have felt shame for not being able to pursue her career due to pain. Ivan similarly adopts an approach involving kindness, he does not 'freak out' and he expects his pain to 'go away'. Katherine summarises her experience by suggesting it is only through suffering that we can experience what life has to offer. Similarly, to Katherine's 'surrendering', Ivan speaks of 'relaxing' into his pain but instead of using it to seek beautiful realms, he finds in his suffering a sense of purpose and shares it with others who may also be experiencing persistent pain:

I think it pushes you in a beautiful way into these unseen realms that we very rarely explore unless we suffer and that's why I say it's a gift (Katherine)

In a state of constant suffering with no clear idea as to why, that's just desperation, now I kinda understand why and I have things to do with it, and even suffering with it, it has a purpose now in a sense that I can, you know use those things and use the ways I find to improve it and use the experience of it to relate to the people I work with (Ivan)

Katherine and Ivan now see their experiences as a gift. Ivan at the time of the interview was training to be in healthcare. He feels that he can use his experience of pain to support others. He can use suffering as a form of empathy to support others in persistent pain. Ultimately the participants have developed their own interpretation of pain, and this has enabled them to be compassionate towards themselves and use their suffering in a positive way.

### 3.5.2 Acceptance is a process

All the participants spoke of acceptance of their situation. They found they had to accept that their pain may never go away. However, this led to a state of surrender, from that point, they were able to make peace with their situation. Acceptance for them involved realising who they are as a person with pain and admitting to others when they are not ok. Given their history of trauma and pain, this process of acceptance allowed them to be grateful for what they do have in their life and feel proud of themselves when they feel their life is going well. Julia's and Darren's acceptance began when they realised that their pain may never go away:

I am accepting that there is a possibility that it will never get better... I think it's just the idea that it will never go away, is kind of what I have been trying to accept (Julia)

It's trying to keep on top of it and being aware that it's something that you are susceptible to or something that is going to come back if you are not careful or even if you are careful, it just can happen (Darren)

Interestingly, Julia and Darren both use the word 'trying'. They are trying to accept their pain may never go away or will never get better. This suggests that acceptance is an ongoing, moment-to-moment process and also that they are working towards their own understanding of acceptance. In this instance, acceptance is related to their pain. Katherine, Ivan and Michael express the idea of 'acceptance' perhaps in a more positive way:

It's changed from a resistance and a battling and the need to find answers otherwise what will I be, a real surrendered state of acceptance and healing (Katherine)

I think at peace like kind of you feel kind of comfortable in yourself, in my own skin (Ivan)

I mean my therapy is all about realising who I am, accepting who I am and then trying to see the signs of when things are not going so well and then ways of dealing with that (Michael)

Here, they explain their own process of acceptance. Katherine reflects on her shift from battling to surrender and healing. Ivan mentions that he is at peace with himself and comfortable in his own skin. Michael's form of acceptance is realising when 'things' are good or bad and ways of 'dealing' with that moment. Again, this process should be viewed in the context of Michael's history of pain and trauma. When he was in pain, his world was limited to a chair as his life fell away and now he can accept his past and, with support, understand ways of dealing with challenging situations. Julia and Ivan suggest they have been able to change their outlook on their life:

I think it's just having an outlook on it, at least I have a leg to walk on, at least I have another leg, but I think its just dealing with that and be more accepting of the reality than not accepting it (Julia)

my body is not just a place of pain and anxiety, this body can feel safe and like comfortable to be in and that was nice, that was probably the first time I was like, ok,

cool, I can live with this now because I have a way to relieve myself, even when it gets bad I can do a ten minute yoga practice and feel good again (Ivan)

Julia and Ivan express a form of gratitude for what they can do. Julia is grateful for what she has (at least one good leg) and thinking this way aids her form of acceptance and Ivan is grateful that his body is a place of peace rather than a place of pain anxiety. However, Michael suggests his work Is not complete, and he still feels there is work to do with his anxiety and procrastination:

I mean, there is work to do, I do struggle with everyday life, having anxiety is huge... when I have got things to do, chores what I call them, chores I have such an issue, procrastination, getting things done, getting things started, I just procrastinate on and on and the longer I procrastinate the more anxious I become and it's just a spiral, I mean, yeah, keeping that under control [laughs] (Michael)

Michael describes his ongoing issues with anxiety and day-to-day life and suggests there is still work to do. He recognises that he has to keep the anxiety and procrastination episodes under control. However, he was laughing through this passage and making a joke of his situation, and he can reflect on his life achievements and see the progress he has made:

The last sort of couple or three or four years, since I have been in this round of therapy, my therapist is, I call her the head, the work I have been doing with her I think I have made huge strides, she thinks I have made huge strides, my wife thinks I have made huge strides, yeah, I have made huge strides and that's what has changed everything (Michael)

Michael explains his process in terms of 'huge strides' and seems proud of himself for what he has achieved. His wife has also recognised the progress he has made from the life in a chair. Fundamentally, this realisation has been over several years, possibly longer, as Michael is 60 years of age. For him, acceptance in his particular situation requires a daily recognition of personal thoughts and actions. All three have described their own process of acceptance which has developed over time.

# 3.5.3 Living well requires action in many forms

The participants explained the strategies they had developed to live well. This may involve movement or breathing practices or noticing harmful thought processes. These strategies support their own idea of living well. Ivan explains the tools he used at the beginning of his journey to live well and Katherine imagines tools she can use depending on how she feels:

I think in the early years, like the first two or three years of starting to, I was almost religious in my adherence to them and when they started to help I was almost dogmatic and I was evangelical in my obsession with them and, like, needed them, there was this desperate need for them and I couldn't give up, if I gave up on one day, like sh\*t is going to hell in a hand basket (Ivan)

I'm getting this visual of, like, a circle around me of so many different tools that once I knew what all these tools were, I was then able to access the ones that worked the best for me... yoga, meditation, reiki, mindfulness, and osteopathy (Katherine)

Ivan explains in the first two or three years of his journey, he became obsessed with the activities that supported him. This could be fuelled by fear. He has experience of living a life of pain and fatigue which he is worried about experiencing if he does not use his new practices. Therefore, 'sh\*t is going to hell in a handbasket'. Katherine visualises the best tools she can reach for when she needs them. For Katherine they are movement-based — yoga and osteopathy, or breath-based — meditation, mindfulness, and reiki. Ivan similarly adopts an active self-management approach which involves research and a range of strengthening exercises, while Katherine uses techniques to reframe her thought processes:

I am doing research regularly like approaches to it, strengthening exercises kind of self-assess, so t-spine [thoracic spine] and neck stuff, so I am doing martial arts-related strengthening exercises which are helping and they sometimes work with immediate pain relief as well (Ivan)

I have now reframed my brain to the point where every day I now have healthy practices and when things come up, I am able to deal with them. There are now things outside the box that are more emotionally charged that require a bit more work, so the emotional charge has meant that I have had to focus a bit more, be a bit more patient, with myself... I did about a year's work of reframing with these kinds of thought processes, yeah, it's been a journey (Katherine)

Importantly, Katherine has highlighted a 'year's' work of reframing old thought processes. This suggests a regular practice of noticing and recognising unhelpful thoughts and then learning how to reframe them. In addition, she has alluded to the idea that, when she is 'emotionally charged' her reframing requires more effort and patience with herself. Ivan has not highlighted a timeframe in this passage, but the researcher assumes that these practices would also require time, patience, and effort, completed on a regular basis. All three of these participants have indicated the daily action required for them to live well. Michael suggests that living well is having the mental capacity to choose the right course of action and he refers again to his 'chair'.

[Pause] living well Is being in a mental place where I have choices, where I want to do something other than just sit in a chair, I love movies and I love computer games, but I also love the natural world, wildlife and nature (Michael)

Fundamentally, the participants have adopted learnt behaviours over a period of years. There has been an element of fear influencing their behaviour, if the participants do not complete their daily practices, they fear they will lose everything they have worked for and return to a life of unmanageable pain.

# 3.5.4 Living well isn't always sunshine and rainbows, it's hard work

All the experiences presented here have been accomplished through daily effort and hard work, such as developing skills, as is supported by experiential statements in 3.4. The participants maintain a daily, regular practice. They appreciate there is hard work involved in understanding the root causes of their pain experiences. They understand their own limits and if they go through those limits, they may experience a flare-up. But these flare-ups are managed with a change in activity, or they show themselves compassion and kindness. Katherine sees new experiences as opportunities, where Michael views living well as a constant battle and hard work:

You know, life will always challenge us and bring new ways of being so this for me is another healing process. It's like, here is another root that I am looking at now (Katherine)

[Pause, sigh] a constant battle, now that might just be for me, not other people, but for me it's hard work but for the first time in my life I am actually prepared to put in the work. I don't like it, but I have accepted at this point if I am to live with any quality of life, If I am to live well, I have to work on this [points to head] and I have to work on this [points to body] so that is what I will do. I'm not happy about it, I don't like it but I have got to do it, no choice, simple as that (Michael)

Katherine views the challenges of life now as opportunities and part of her healing process, in contrast to Michael who views living well as hard work. However, he reflects on this point and realises that to live with any quality of life he must work both on his thought processes and his physical body. Darren recognises living well as managing his pain and his levels of overwhelm. Ivan shares this view but sees this as self-knowledge:

As I get older, I will probably reduce, I'm not going to be doing extreme sports in my 80s I doubt but, living well with pain sort of managing it and keeping it below the threshold where it's manageable, I suppose the threshold is really where it starts to become overwhelming and leave me in a bad mood (Darren)

I think self-knowledge, self-understanding, being able to self-manage I think and that's probably wisdom to some degree and that would probably be, the three big components that I can think of off the top of my head for living well (Ivan)

Darren realises that when he becomes overwhelmed, he is starting to reach his upper limit and could tip into a pain flare-up. Ivan seems to understand this as self-knowledge and self-understanding, he sees pain as a type of messenger:

I am going to feel that for a bit, in fact the pain is here and I am going to let it burn out for a bit, I know it's telling me something useful so I will just let it happen (Ivan)

Ivan has developed enough knowledge about his pain experience, where before he used painkillers to avoid his pain, now he knows his pain will 'burn out' and he uses it as an opportunity to learn why he is in pain. Therefore, living well for the participants seems to be a constant monitoring of how they are feeling. Julia feels that if she is living well, she feels a sense of connection and in this context, the connection in her body, rather than the way she is connected to other people, whereas Ivan sees living well as a connection socially:

I think it gets you to think more about how things are connected and how it works, which as to my point of how I define living well I think everything is connected so if one thing is not really working, I think it has a knock-on effect on everything else. I think long story short, it does make you think a bit more about how you are living and what impacts, that I mean there is definitely things that I have changed in my life that made me healthier and better (Julia)

living well, I mean having good relationships with family and friends. I mean these are probably components of a good life rather than living well exactly (Ivan)

Julia indicates that she has made changes in her life which has led to her to understanding how everything is connected internally compared to Ivan who sees the connection with others as components of a good life. For the participants living well requires an ongoing process of learning and recognising when they are pushing themselves too much. If they do push themselves too much and experience a flare-

up, they have developed strategies to help them manage their pain experience. For the participants, living well does not mean a life without pain, it means they have choices and that they now also have a sense of compassion towards themselves and others.

#### 4. DISCUSSION

# 4.1 Summary of Findings

This research was developed to understand how individuals living with long-term pain have learnt to live well, and the role of osteopathy in their experience. A phenomenological approach was used to understand how the participants lived with pain and how they experienced pain in daily life, and to explore the multiple realities of an individual experience (Belton, 2019, Braun and Clarke, 2013, Willig, 2013). This study interviewed five individuals who self-identified as living well with pain and who had seen an osteopath. Then Interpretative Phenomenological Analysis (IPA) was adopted to gain an in-depth understanding of their pain experience (Smith *et al.*, 2009, Smith and Nizza, 2022). This method was found to be valuable as it allowed an exploration into the individual accounts of pain, which is known to be highly subjective, emotionally-charged, in order to capture the unique view of the individual (Smith and Osborn, 2015, IASP, 2020, Dunn *et al.*, 2022)

The experiential statements presented here are discussed alongside the existing literature and have been ordered for presentation but for the participants this was an ongoing movement between all four of the key statements identified. They could wake up in the morning in a pain flare-up, manage their experience with behaviours they had learnt themselves, accept their experience and do something personally meaningful. However, they may not arrive at that point of a meaningful activity, they may revert into their pain. Ultimately living well with pain seems to be a process of acceptance that pain is here to stay, but showing compassion towards themselves when they are in pain. The participants all expressed the view that living with pain was exhausting, they were able to clearly articulate their first experience of pain and explain a moment in their life where they felt ready to change and live a different way. For the participants, osteopathy played a supportive role and allowed them the freedom to live with their pain. The participants felt the osteopath viewed them differently compared to other health care professionals but fundamentally, the participants felt reconnected to themselves and another human being. Managing pain was like developing a life skill and was viewed as an ongoing, daily practice. This mainly involved a range of movement practices that were personal to the participants, and they felt that they could manage a pain flare-up like the same way they manage a cold. Living well has its ups and downs, for some of the participants their personal experience of suffering allowed them to enter new realms. They felt acceptance of their pain experience was a process and to live well with pain requires action in a range of forms. Ultimately living well is hard work and is not always 'sunshine and rainbows'. This section aims to discuss each of the main experiential statements and provide suggestions for future research.

# 4.2 Living with Pain is Exhausting

The participants in this study were able to clearly recall their first memory of pain and describe it in vivid detail. They were able to explain the exhausting nature of their pain experience and what they did to avoid or battle against their experience, although over time they realised that the pain of staying the same was far worse than the pain of changing.

The headline statement includes the term 'living with pain'. For the participants in this study who lived with pain, pain had taken them over, it had become their main personal and emotional experience. The exhausting nature of the participants' pain includes not only the ongoing thinking about pain but also the way it made them feel. Katherine (3.2.3) experienced this exhaustion as the worst possible flu and to the point of feeling as if she had been hit by a car. Schütze et al. (2017) in their qualitative study explored 'metacognitions' in people with chronic pain, specifically involving elevated levels of pain catastrophising. Metacognitive theory proposes that perseverative thinking is generally maintained by higher order beliefs called metacognitions (Schütze et al., 2020, Matthews and Wells, 2000). Pain catastrophising is a form of repetitive thinking and a negative psychological response to pain that includes a variety of dimensions such as exaggerating a pain threat, rumination about a pain experience and concerns over an ability to cope (Schütze et al., 2017, Quartana et al., 2009, Schütze et al., 2020). Schütze et al. (2017) distinguish between positive metacognition where the participants would use rumination as a form of problem solving and negative metacognition where rumination was seen as unhelpful, uncontrollable, and destructive to their subjects' mental state.

In this study, rumination and concerns over pain had impacted the participants' emotion and behaviour. For instance, Julia (3.2.3) explains her frustration as she engages in positive health behaviours but cannot understand why she still experiences pain. Here Julia seems to separate herself from pain, as if it is something outside of her that she needs to control, it is as if her pain demands something from her that Julia cannot satisfy, as if she were trying to solve a cryptic puzzle. Grīnfelde (2023) suggests that in these pain experiences the body is viewed as an object, like a material thing in the world, because the body itself 'demands our attention'. In Julia's example, she asks herself, what else do you need from me to not cause you pain? using the word 'you' as if she sees her body as something separate from herself. This may be explained from an enactive point of view, which offers a novel outlook on the relationship between the mind, body and the world, specifically the 'life-mind continuum', where sense-making is central to living (de Haan, 2021, Di Paolo and Thompson, 2014). Specifically reflexive sense-making, where as humans we experience things, but we are also aware of these experiences and how others see us (de Haan, 2021). Therefore, in Julia's case she may separate her body and her pain to help her make sense of her experience (de Haan, 2021, Di Paolo and Thompson, 2014). Her frustration and possible anxiety arise from her constant attempt to try and understand and make sense of her pain. Belton (2019) shared Julia's experience of needing a solution and needing an answer became more urgent. When the answer did not show this led to further despair and a rollercoaster ride of relief and high hopes (Belton, 2019). Therefore, the exhaustion in this context is derived from the constant need to ruminate over possible solutions and ongoing attempts to make sense of their situation.

When individuals experience their pain, at that moment, it is their whole world (Leder, 2016) and the participants in this study seemed to exemplify this. For example, Darren (3.2.2) explains that when he is in pain, he often finds it a challenge to ignore, Katherine (3.2.2) was more expressive in her language by using terms such as 'being eaten alive and it never ending' to explain her pain experience. Both Darren and Katherine allude to the out-of-control nature of their lived experience of pain. Katherine is very clear that she believed it would never end. There is a sense that when their pain 'comes on' there is something very terrible happening and they have no control over the intensity or how long the episode will last (Leder, 2016). Katherine goes

deeper by trying to pull the researcher [myself] into her pain, by asking me to imagine what it must be like to be eaten alive by pain. On reflection I found this impossible to comprehend. I have never experienced chronic pain or a chronic illness and found this idea of pain taking over my whole being difficult to fully understand. I believe I have a healthy body and this means I can walk out into the world, enjoy a day with my family and engage in playful activities with my young children, with no thought about pain or body limitations, which I take for granted. Therefore, when Katherine asked this question, it was hard to find the words to formulate a caring, empathetic answer. Biro (2011) p.18 shares a similar experience to Katherine and writes: "Pain is an all-consuming, internal experience that threatens to destroy everything but itself – family, friends, language, the world, one's thoughts and ultimately even oneself."

Despite these personal experiences, pain was seen as a motivator to change. A number of qualitative studies explore the impact of pain on the individual (Toye *et al.*, 2017, Bunzli *et al.*, 2013, Johnston-Devin *et al.*, 2019, MacNeela *et al.*, 2015). However, there is limited research that explores a readiness to change specifically related to pain. A novel point from the current study found Ivan (3.2.4) clearly recognising a point in his life where he felt enough was enough. The suffering was so much that he felt he needed to change. Ivan arrived at a point in his life when the pain and the suffering had been too much to bear and he could no longer go on living in this suffering state. He realised that staying the same would be worse and even though he recognised change to be painful, for him, it was the easier option, and he began his own process of recovery. Leder (2016) suggests that pain can be productive for the individual and the pain experience could trigger specific insights and a process of transformation. This seems true for Ivan, where he has reflected on his past experiences and rather than dwell on past events, he is able to use this as a source of motivation to change.

### 4.3 Osteopathy Reconnects me to Life

Osteopathy was viewed by the participants as a profession that had time for communication and support, that encouraged positive health behaviours and engagement with life. Pain is a private subjective experience (IASP, 2020) and it has been reported that the pain experience is hard to communicate to others, especially to healthcare providers (Buchman et al., 2017). Furthermore, those who are managing chronic health conditions are at times subject to social judgements, accusations of malingering, hypochondria and attention seeking (Nicholls, 2022). Although, this is not limited to Healthcare Professionals (HCPs), family members may also question their experience of pain (Buchman et al., 2017, Kleinman, 2020). In this context, issues with epistemic injustice could arise. Epistemic injustice occurs when people, individuals or social groups transmit knowledge where the listener could view this information as wrong (Buchman et al., 2017). For example, the participants spoke of not feeling believed by HCPs. Specifically, Katherine and Ivan who both discussed issues of explaining an invisible illness to HCPs which often resulted in a breakdown of trust. There can be an unfair downgrading of credibility and harm done to those experiencing pain as their ability to contribute and benefit from knowledge is questioned by those in power (Fricker, 2007). In this example of social power, HCPs have completed extensive training and ongoing education to accurately diagnose and manage various medical issues, which possibly includes influencing health behaviour (Buchman et al., 2017, Vanstone and Grierson, 2022). Therefore, this expertise places medical HCPs on a social hierarchy which is a 'rank order of individuals or groups with respect to a valued social dimension' such as control of resources or ability to influence behaviour (Magee and Galinsky, 2008, Vanstone and Grierson, 2022). For example, when a patient explains their experience, it is never delivered as a coherent structured account, it contains emotional upset, different forms of language and psychological reflections (Komesaroff, 2001). In this form of epistemic hierarchy the patient is seen to lack the required training or knowledge to explain their symptoms in medical terms, which means the HCP is in a position to override the patient's self-reported experience or preferred method of treatment (Buchman et al., 2017, Carel and Kidd, 2014).

Difficulties with communication should also be viewed in the context of system issues within the NHS and even more widely. Low back pain is a major concern for international health systems (James *et al.*, 2018). In 2014 the United Kingdom GP appointment times average 9.2 minutes which has been steadily increasing over time (Irving *et al.*, 2017). Given the comorbid concerns with patients presenting in pain there have been calls for longer appointment times to reduce the likelihood of polypharmacy, overuse of antibiotics and improve patient communication (Irving *et al.*, 2017). Considering these issues and reports from the participants in this study, the fact that the participants felt isolated and unsupported, it seems clear that the NHS struggles to cope with patients managing long-term pain conditions where there is limited time required to explore the individual pain experience.

Previous qualitative research has found similar concerns with healthcare professionals: people experiencing pain or seeking support for chronic health conditions visit HCPs to make sense of their symptoms and seek reassurance for their experience (Komesaroff, 2001). Wallis et al. (2019) found that experience of HCPs can be both negative and positive. As reported above and similar to the findings in this study, the participants included in the review by Wallis et al. (2019) experienced a dissatisfaction with limited information about knee osteoarthritis (OA), they had a sense of not being listened to, not receiving a sufficient amount of attention and being told to 'live with it'. Wallis et al. (2019) suggest a holistic assessment of knee OA to understand the effect on the whole person. Bunzli et al. (2013) found similar with interactions with healthcare providers but expanded on the negative experience with HCPs, labelling the experience as iatrogenic distress. Where HCPs encouraged rest and avoidance of activities, this fostered participants' anxiety, pessimism and hopelessness with regards to a diagnosis of chronic low back pain. However, there were positive experiences with HCPs. The participants reported that being listened to and given management advice including weight loss recommendations made the participants feel hopeful about the future (Wallis et al., 2019). The clinical encounter for those experiencing pain can be a variable experience, dependant on the clinician or presenting symptom, which is a challenge for those seeking help. Komesaroff (2001) says the experience is contingent on contextual factors and the dialogue between the patient and the HCP can create memories and suggest causes, and can alleviate pain, dissemble, and enjoins promises.

All the participants in the current study reported a sense of being listened to. They discussed they felt safe and felt connected to the osteopath. Ivan shared that he felt his osteopath gave him a way out of pain and most importantly was contactable between sessions if Ivan had any questions. Where previously, the participants felt isolated from their care, they now felt part of their recovery process with the support of their osteopath. They could express their lived experience without feeling judged, as they could explain what pain was like for them. This form of communication Is supported by the patient taking control of their encounter. These patient-practitioner encounters could be explained by the concept of therapeutic alliance (TA). TA is defined as the working relationship between therapist and client through collaboration, communication and therapist empathy (Cole and McLean, 2003, Babatunde et al., 2017a). This definition is shared among therapists conducting Acceptance and Commitment Therapy (ACT). Walser and O'Connell (2021) suggest the interaction between therapist and client is fundamental and can lead to meaningful and transformative experiences for the client. The participants in this study responded well to this approach, specifically Michael who thought the osteopaths he was working with had his best interests at heart and he left those sessions with hope. A positive TA has been shown to enhance communication, improve adherence to self-management suggestions and improve quality of life (Babatunde et al., 2017a, Joyce et al., 2003). The participants' negative experiences of other HCPs was in contrast to their osteopathy sessions where they were able to experience hope and empathy. But rather than pitting two professions against one another, we should view the less positive experiences in the context of the wider NHS system as described earlier in this section. Nevertheless, the findings from this study support an enactive approach that focusses on the lived experience and how someone makes sense of their pain (Coninx and Stilwell, 2021, Cormack et al., 2022, Stilwell and Harman, 2019). Therefore, when the participants felt listened to, they felt they could share their lived experience without feeling judged, as they felt connected to the osteopath. This gave them hope and the confidence to engage with their own life values.

# 4.4 Managing Pain is Like Developing a Skill

No one theory, framework or model can explain the complexity of pain management and associated health behaviour but an integration of frameworks may support an understanding of self-management (Breland et al., 2020). The participants in this study all engaged in activities to manage their pain experience. They would engage in some type of movement that would offer them pain relief which was selected depending on how they felt both emotionally and physically. Ivan and Katherine shared similar tools to manage their pain depending on the intensity. They both said they would sit with their pain and let it 'burn out' or they would use relaxation techniques such as breathing or stretching. Therefore, in the context of individual pain management there could be elements of the Common Sense Model of Self-Regulation (Leventhal et al., 1998) and the Self-Efficacy framework (Bandura, 1999) complementing each other (Breland et al., 2020, Lau-Walker, 2006). Lau-Walker (2006) found common ties between the two models and developed an integrated model which focusses on the individual experience, initial conceptions of a condition and the individual confidence in their ability to maintain health behaviours. The participants in this study believed that when they had a pain flare-up, that it would be temporary, and they could manage it themselves with their own tools. In line with the integrated model (Lau-Walker, 2006), this suggests they knew the pain would pass (timeline), they could control it (control/cure) and it was a minor consequence on their day. Also, they felt confident in their self-identified positive health behaviours such as breathing or movement. In terms of self-efficacy, the participants were able to enact specific behaviours, in specific situations to manage their pain intensity (Breland et al., 2020, Lau-Walker, 2006). However, there is limited acknowledgement of the role of motivation, specifically intrinsic motivation (Ryan and Deci, 2000). Intrinsic motivation is defined as the tendency to seek out novelty and challenges to extend and exercise individual capacities to explore and to learn (Ryan and Deci, 2000). For example, Ivan, Katherine, and Michael arrived at a point in their life when they were ready to change (3.2.4), from this point they developed an intrinsic desire to change, learn positive, individual heath behaviours and seek help from an osteopath.

Most international guidelines suggest adopting a biopsychosocial (BPS) approach (Engel, 1980, Engel, 1981) when supporting people to manage their pain (Kurz and Hebron, 2022b). These may consist of self-management strategies including physical and psychological treatment suggestions that are developed with those experiencing pain (Hutting et al., 2020). Self-management is defined as 'the ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition' (Hutting et al., 2020). The participants in this study had developed their own individual strategies to manage their pain mainly due to trial and error but based on their individual values. This suggests that there is a sense of self-efficacy, the participants had developed confidence in their individual approach to manage their pain (Dineen-Griffin et al., 2019) and they persevered with their approach despite their pain. All the participants adopted a similar view that pain is to be managed. This was developed mainly through self-reflection and acceptance of their pain experiences. For example, Darren explained that he previously viewed his pain flare-ups as a sign of failure, compared to now where he views pain as something to be lived with. This view enables him to understand his own boundaries of when to exercise versus when to rest. Therefore, according to the above definition Darren would be self-managing his pain. Rodham (2021) suggests that selfmanagement involves a range of factors including engaging in a range of healthy lifestyle behaviours, managing the condition and learning and becoming informed about a health condition. Darren fits this view of self-management, he works in a gym, he values exercise and movement to manage his pain experience and he has access to gym space to engage in physical activity. He has completed postgraduate education in strength and conditioning which supports his self-management strategies based on his health literacy (a personal understanding of his pain) (Nutbeam, 2009) and his access to gym space, which means he is placed in a position to successfully selfmanage his pain.

This approach may not be suitable for, or available to, everyone in pain. Rodham (2021) suggests that the phrase 'self-management' places all the responsibility for successful self-management onto the person living in pain. Therefore, where this active, physical approach works for Darren, it may not work for another patient who does not have the same exercise knowledge or someone that does not have access to gym space. Gordon *et al.* (2017) explored barriers to self-management strategies

in consultations between healthcare professionals (HCPs) and patients with chronic pain. They found four main barriers, i) self-management advice came too late in the consultation and communication was a challenge, ii) patients felt unsupported and the emotional impact of pain was too difficult, iii) there was overmedicalisation and lack of treatment options, iv) there were short appointment times and long waiting lists (Gordon *et al.*, 2017). Because of these barriers and similarly to Gordon *et al.* (2017), when suggesting self-management strategies, Rodham (2021) recommends a move towards 'collaborment' which combines collaboration and management (Rodham, 2020). Collaborment recognises that the person living with a chronic health condition is the expert and has a personal understanding of what works for them in the context of their life (Rodham, 2020, Rodham, 2021). Julia (3.3.2) found an approach like this supportive when she was working with her musculoskeletal therapist, she developed a better understanding of how her body works and the specific exercises she received were personal to her which helped her engage in that physical activity.

Ultimately, the participants seemed to develop their own form of pain management based on their values. They were patient and kind to themselves if they experienced a flare-up, but they knew what worked best for them depending on how they felt. As shown above there are several psychological theories that could apply but individual pain management can be explained best when these are integrated together. This is further supported by the collaborment concept, the participants are experts in how they manage their chronic condition and to support pain management HCPs could incorporate this approach to support those with a chronic health condition (Rodham, 2020).

# 4.5 Living Well Has Its Ups and Downs

The participants in the current research self-identified as living well despite their own pain. Some participants explained in detail their own perception of trauma and how that was a factor in their understanding of living well. For the participants, this involved daily maintenance and pacing of their activities. If they did push themselves too far, they were kind and patient with themselves. They had accepted the good and bad experiences as part and parcel of a life with pain. All the participants described a process of hard work to get to where they are now. Katherine says 'it's been a journey' of recognising her reactions to her environment and examining her thought processes. She goes one step further and adopts a spiritual approach where she discusses surrendering, accepting, and not battling against her pain when she experiences a flare-up. The qualitative literature base views these experiences as a 'pain battle' and 'learning to live with pain' (Kurz and Hebron, 2022b, Bunzli et al., 2013, MacNeela et al., 2015). Ivan explains a shift in understanding his pain, from life-limiting suffering to recognising his pain as an 'old friend'. This shift suggests a process of acceptance of his pain experience and compassion towards himself. Owens et al. (2016) found similar themes in those who self-identify as living well with pain, such as 'changing defensive reactions' where the participants reported a shift in perspective towards their pain. In the study by Kurz and Hebron (2022b) exploring coping with persistent low back pain, they described this shift as temporality – involving the meaning of time and its relationship with coping. Their participants also experienced a sense of travelling through chaos while adopting a trial and error strategy to support coping with pain and a process towards acceptance (Kurz and Hebron, 2022b, Thompson et al., 2014).

There are many psychological models of chronic pain with varying levels of specificity, assumed causes and main outcomes of interest (McCracken and Morley, 2014). For example, the biopsychosocial (BPS) model (Engel, 1981), the fear avoidance (FA) (Lethem *et al.*, 1983) model and more recently the enactive approach to pain (Stilwell and Harman, 2019), all of which have offered support to those in pain. Like theories of motivation, illness beliefs and self-efficacy explained above, there are elements of all these models that can be drawn upon to support those in pain. More importantly, the FA model has been seen as more specific than the BPS model with a focus on avoidance behaviour and pain-related fear which have been shown to maintain chronic

pain (Flink *et al.*, 2020). However, what the FA model and BPS model fail to account for is hope, optimism, and acceptance, which have been shown to support recovery and treatment effects (Flink *et al.*, 2020).

The participants in the current study explained the process of acceptance in terms of their pain experience. For them acceptance was an ongoing, moment-to-moment process which accounted for pain, to some degree, always being a part of their life. Alongside their experiences of acceptance was a sense of gratitude for the life they have now. For three of the participants this gratitude was compared to their past life with trauma. Julia (3.5.2) was grateful for having a leg that is not in pain and she is able to walk. Ivan (3.5.3) was grateful for feeling safe and realising his body is not just a place of pain and anxiety. Michael (3.5.2) was grateful for the validation he had from others and the recognition of his effort into his recovery process. This could be understood in the context of psychological flexibility, which is defined as "the ability to recognise and adapt to situational demands in pursuit of personally meaningful longerterm outcomes" (Dawson and Golijani-Moghaddam, 2020). According to McCracken and Morley (2014) the definition of psychological flexibility is conscious, open contact with thoughts and feelings, an appreciation of what the situation affords and being guided by personal goals and values. In relation to this, the participants had demonstrated the ability to adapt certain types of behaviours or 'useful tools' to help them manage their pain experience and ultimately 'live well'. Where Katherine and Ivan used forms of breathing and exercising, Michael (3.5.3) enjoyed spending time in nature, watching movies or playing computer games. It is noteworthy that Katherine, Michael, and Ivan, over a period of years, had developed these approaches themselves and with the support of others, not only with an osteopath.

The Broaden and Build theory suggests that positive affect broadens individual's visual awareness, attention, thoughts, and behaviours leading to a wider range of behavioural options (Fredrickson, 2001, Fredrickson, 2013, Garland *et al.*, 2010, Goubert and Trompetter, 2017). The theory proposes that small pleasurable positive emotions can have a long-lasting impact on functional outcomes and resilience leading to enhanced well-being and social connectedness (Garland *et al.*, 2010, Goubert and Trompetter, 2017). Goubert and Trompetter (2017) suggest that pain management could be considered as a recovery and sustainability process. The recovery process

involves a reduction in fear, catastrophising and avoidance, and in the presence of pain a sustainability process consists of acceptance, mindfulness and personal positive values (Goubert and Trompetter, 2017). For the participants, living well with pain was not a type of utopia where they never thought they would never experience pain anymore, but for them it meant having choices along with a sense of compassion towards themselves and others. Thompson et al. (2014) suggest that the process towards living well with pain involves a reorganising of the self-concept, where old aspects of the self are left behind and space is made to adopt new values and practices, so that individuals can view the world as a different place and live comfortably with a new self. This idea of living well requires work and effort daily, Michael describes living well as a constant battle. However, for Michael (3.5.4) this hard work was viewed as something worthwhile in order to live well and have a quality of life that involved enjoying his new home and being there for his wife. There is sense here that Michael values a quality of life and a sense of connection with his wife that being in a new home may offer. Katherine was expressive in her pain narrative and now seems to adopt a different view of challenges in life as an opportunity to learn a new way of being which suggests a spiritual approach to living well and openness to new life experiences (Owens et al., 2016, Thompson et al., 2014). For Ivan (3.5.4) living well means self-knowledge, self-understanding, the ability to self-manage his pain by having the confidence and the experience of knowing that any bout of pain will eventually itself burn out. According to Broaden and Build theory (Fredrickson, 2001), and Thompson et al. (2014) Ivan seems to be experiencing a sense of hope (resilience and optimism), inspiration (a motivation for personal growth) and serenity (new priorities and new views of himself). Ultimately for the participants in this study living well with pain has developed over time with a deep understanding of their pain experiences but fundamentally the fostering of positive emotions that has influenced their self-management behaviour.

### 4.6 Strengths and Limitations

Health psychologists recognise the importance of understanding the meanings individuals apply to their personal experience (Brocki and Wearden, 2006). This Interpretative Phenomenological Analysis (IPA) study has allowed for an in-depth account of how people live well with pain but has also explored the role of osteopathy in supporting these individuals. The analysis was informed by the quality criteria as suggested by Yardley (2000), Yardley (2008), Levitt et al. (2018), Smith and Nizza (2022) and Braun and Clarke (2013) to support the validity of this research. In addition, regular discussions with the Director of Studies and second supervisor encouraged me to ground my themes and discussions in the narrative accounts of the participants. These discussions allowed for the author's biases on living well with pain to be reflected upon, so as to be certain that the participants' accounts were being analysed rather than my own personal thoughts and feelings (Smith et al., 2009, Smith and Nizza, 2022). The participants valued being heard in their interviews and the author's clinical experience allowed for gentle probing of personal experiences of pain both negative (sense of loss and mental anguish) and positive (hope, compassion and gratitude).

With regard to limitations, small sample sizes are normal in IPA research as this allows for the phenomena to be explored in detail but this does limit the transferability of this research (Brocki and Wearden, 2006, Smith and Osborn, 2007). However, transferability was not the purpose of this study, which was, rather, to explore personal experiences which may offer suggestions to those working in pain management. Therefore, the conclusions drawn from these findings are specific to this sample and not representative of those in pain (Smith *et al.*, 2009, Smith and Nizza, 2022). A further limitation of the study could be seen in the fact that the participants had, as is usually the case, accessed osteopathy through private practice and were able to choose osteopathy only because they had the financial ability to pay for this form of intervention. Having to pay may have made them more likely to see the interventions as working. For example, Michael highlights this point by saying 'I have to pay someone to watch me and tell me what to do and make sure I am doing it otherwise I won't'. The financial transaction involved may, as Michael suggests, slant him towards the positive aspects of osteopathy and increase his commitment to the treatment being

offered. In addition, the analysis was conducted by one researcher and it is recognised by advocates of IPA that no two analysts will find the same and that critiques may question the validity and reliability of the findings (Smith *et al.*, 2009, Smith and Nizza, 2022, Smith and Osborn, 2015, Yardley, 2008). However, steps were taken to be transparent in this study by offering a reflexive account of the researcher's stance.

### 4.7. Implications for Practice and Future Research

Health psychology and osteopathy adopt a biopsychosocial (BPS) approach to client/patient care. This framework has enabled both professions to formulate interventions and support those in pain (McCracken and Morley, 2014, Sampath et al., 2020). However, the stories from the participants in this study demonstrate that viewing them through a BPS lens may not allow practitioners to explore the full lived experience of these individuals. For example, the BPS lens may force them to silo the person into distinct parts and to direct interventions towards the psychological, the social or the biological and thereby miss the integrative nature of all the components (Caneiro et al., 2020, Cormack et al., 2022). Therefore, both health psychologists and osteopaths may benefit from adopting an enactive approach (Cormack et al., 2022, de Haan, 2021) to understand the individual's experience of living with pain and respond to their story. Health psychology benefits from interventions such as Acceptance and Commitment Therapy which has a focus towards valued, guided, moment-by-moment living and is proving somewhat successful with those in pain (Harris, 2019, McCracken, 2023). Osteopathy is a profession whose patient management may have a tendency to be practitioner-focussed and there are suggestions of a weak theoretical basis which is not aligned with current research (Thomson and MacMillan, 2023). However, academics within osteopathy who aim to provide a critique of the profession are calling for a shift in patient care that is guided by the current evidence and are calling for a move towards a phenomenological theoretical perspective (Thomson and MacMillan, 2023).

Phenomenology is a philosophical view that moves away from the study of the 'reality' of things to focus on the phenomena of the lived experiences of thinking and knowing (Carel, 2011). Therefore, adopting this view could allow a range of experiences to be

explored that can account for the body's central role in human life (Carel, 2011). This would require both health psychologists and osteopaths to sit with the person in pain over many sessions to understand individual suffering. As this study demonstrated, it took time for the participants to understand their own pain experiences and even more time to develop pain management strategies that worked for them. Furthermore, as this study showed there was a point in three of the participants' lives where they became willing to change. At this point the osteopath was seen as a person who supported them through this change by suggesting breathing techniques or movement-based strategies to support their recovery process. Future research could explore the point in an individual's life when they have specifically voiced a readiness to change to live well with pain. Qualitative methods could investigate this in more depth, as it facilitated the participants' willingness to seek care and live well with pain. If health psychologists and osteopaths understood more around the readiness to change, the timings of interventions could be more effective, as they are based on an individual's intrinsic motivation and desire to learn. Even if the individuals are not ready to change, there is still vast scope to support them.

Carel (2011) suggests adopting phenomenological research methods to understand and report illness experiences which go beyond the standard interview or questionnaire. For example, an embodied phenomenological method could use videotaping to understand not only verbal accounts of the experience but also non-verbal accounts that may offer information about certain types of pain behaviour in reaction to certain clinical words or language (Carel, 2011). Santana *et al.* (2018a) indicates that such research methods may build on the current qualitative literature that is changing patient care by seeing the patient as the expert in their condition.

#### 4.8 Conclusion

This exploration into living well with pain while attending osteopathic services has sought to add to our understanding of the lived experience of pain. It has demonstrated the process of development which, in the case of the participants, has led to living a valued life alongside pain and the time and the persistence required of the participants to try new ways of living and develop resilience in order to live a life based on their own values. Therefore, living well for the participants involved a life with choices and with a sense of compassion towards themselves and others. It was also clear that the participants saw their osteopaths not simply as narrow practitioners with a strict focus on relieving pain through the manipulation of the body's framework but, more broadly, as healthcare professionals who supported them and encouraged them to develop and maintain positive health behaviours which enabled them to live well despite pain. Ultimately, if the health practitioner - in the context of this study, the osteopath - adopts an enactive approach, it allows for the individual experiencing pain to be heard and feel supported in his or her ongoing endeavours to develop new ways of living well.

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## 6. Appendices

## 6.1 Participant Information Form

# Study title

How do adults with long-term musculoskeletal pain attending osteopathy services construct 'living well'?

## Invitation

You are invited to take part in research taking place at the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information, please contact:

Danny Miller,

Faculty of Health and Social Sciences, University of the West of England, Bristol danny2.miller@live.uwe.ac.uk

# Who is organising the research?

Lead researcher: Danny Miller, doctoral student in health psychology.

Director of Studies: Dr Sarah Brown

Supervisor: Dr Julian Bath

### What is the aim of the research?

This study aims to explore how individuals experiencing long-term pain, live well while attending osteopathic services. The research question this study seeks to answer is: **How do adults with long-term pain attending osteopathic services develop and discuss/experience 'living well'?** To help us answer this question we will be conducting interviews with participants that are able to choose either online or face-to-face (depending on local COVID restrictions). The aim of the interviews will be to collect information about your experience. All information will be made anonymous.

The results of this study will be analysed and included in the final doctoral research thesis. the anonymised results may also be used in conference papers and peer-reviewed academic papers.

# Why have I been invited to take part?

As an individual who identifies as living well with pain, we are interested in gaining more information about your experience of living well with long-term pain while attending osteopathic services. So, the interview will ask you about these things. The purpose of the questions will be to understand your pain experience and your personal experience of living well during your osteopathic care.

# Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form. If you do decide to take part, you are able to withdraw from the research without giving a reason up to one month after your interview date at which point your data will be anonymised and can therefore no longer be traced back to you This point will take place one month from the date you signed your consent form and compete your interview.

If you want to withdraw from the study within this period, please write to Danny Miller via email <a href="mailto:danny2.miller@live.uwe.ac.uk">danny2.miller@live.uwe.ac.uk</a>. Deciding not to take part or to withdrawal from the study does not have any penalty and no information will be shared with your osteopath.

# What will happen to me if I take part and what do I have to do?

If you agree to take part, you will be asked to take part in an interview either online or face-to-face (depending on COVID restrictions). This will be conducted by the lead researcher, Danny Miller. The team are all experienced in the subject matter and are sensitive to issues it may raise. The interview will take approximately one hour. The interviewer can travel to an area convenient to you or can be organised online. The subject and focus of the discussion will be some general demographic questions followed questions on your lived experience, where there are no right or wrong answers. All these answers will be fully anonymised.

Your interview will be recorded on a voice recorder, but the recording will not contain your name. A unique identifier will be used to re-identify you if you choose to withdraw from the study within the period. At the point of transcription, the voice recording will be transferred to secure data storage and your voice recording will be deleted from the recorder. Your data will be anonymised at this point and will be analysed with interview data from other anonymised participants.

# What are the benefits of taking part?

If you take part, you will be helping us to gain a better understanding of how you live well despite your long-term pain condition. Your experience could lead to interesting insights on the health behaviours you adopt to self-mange your pain while seeking osteopathic care.

# What are the possible risks of taking part?

We do not foresee or anticipate any significant risk to you in taking part in this study. If, however, you feel uncomfortable at any time you can ask for the interview to stop. If you need any support during or after interview, then the researchers will be able to put you in touch with suitable support agencies. The research team are experienced in conducting interviews and are sensitive to the subject area. The interview questions have been designed with these considerations in mind. If you require further support, please follow these links —

NHS Psychological therapies services (IAPT) <a href="https://www.nhs.uk/service-search/find-a-psychological-therapies-service/">https://www.nhs.uk/service-search/find-a-psychological-therapies-service/</a>

The Samaritans <a href="https://www.samaritans.org/">https://www.samaritans.org/</a>
MIND signposting service - <a href="https://www.mind.org.uk/information-support/helplines/">https://www.mind.org.uk/information-support/helplines/</a>
Online CBT Therapist Register <a href="https://www.cbtregisteruk.com/">https://www.cbtregisteruk.com/</a>

# What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and anonymised at the point of transcription.

The only circumstance where we may not be able to keep your information confidential is if there was an immediate concern of risk to yourself or others, this would be discussed with yourself before the release of information.

Hard copy research material will be kept in a locked and secure on a university approved hard drive to which only the researchers will have access in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements. Voice recordings will be destroyed securely immediately after anonymised transcription. Your anonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point. Your anonymised data will be only held for as long as necessary and appropriate. If your data is needed after the study completion, the lead researcher will seek guidance from UWE library.

# Where will the results of the research study be published?

A Report will be written containing our research findings. This Report will be available on the University of the West of England's open-access Research Repository.

A hard copy of the Report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication in a journal and presentation purposes.

# Who has ethically approved this research?

The project has been reviewed and approved by the Faculty/University of the West of England University Research Ethics Committee. Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

# What if something goes wrong?

If there are any concerns, queries or complaints please contact the Director of Studies, Dr Sarah Brown.

# What if I have more questions or do not understand something?

If you would like any further information about the research, please contact in the first instance:

Danny Miller Faculty of Health and Social Sciences, University of the West of England, Bristol danny2.miller@live.uwe.ac.uk

Thank you for agreeing to take part in this study.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

### 6.2 Consent Form

## Consent Form

How do adults with long-term musculoskeletal pain attending osteopathy services construct 'living well'?

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions, please contact a member of the research team, whose details are set out on the Participant Information Sheet

If you are happy to take part in an interview lasting up to 1 hour, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form;
- I have been given the opportunity to ask questions about the study;
- I have had my questions answered satisfactorily by the research team;
- I agree that anonymised quotes may be used in the final Report of this study;
- I understand that my participation is voluntary and that I am free to withdraw at any time until the data has been anonymised, without giving a reason;
- I agree to take part in the research;
- I agree to the interview being audio recorded;

Name (Printed)	
Signature	Date

## 6.3 Demographic Questions

# Demographic questions

- 1. What is your current age?
- 2. How do you describe your gender identity?
- 3. How do you describe your sexual identity?
- 4. With which racial and ethnic group do you identify?
- 5. How would you describe your occupation?
- 6. What was your highest level of education?
  - a. Have you attended any courses since leaving your highest level of education?
- 7. How would you describe your income?
- 8. How many Osteopathic treatments have you had??
- 9. How do you describe your disability/ability?
  - a. How long have you been experiencing pain?

# **6.4 Participant Characteristics**

Pseudonym	What is your current age?	How do you describe your gender identity?	How do you describe your sexual identity?	With which racial and ethnic group do you identify?	How would you describe your occupation?	What was your highest level of education?	Have you attended How would any courses since you leaving your describe highest level of your education? income ?	How would you describe your income?	How many osteopathic treatments have you had?	How do you describe your disability/ability?	How long have you been experiencing pain?
Dатеп	32	Male	White Heterosexual British	White British/European	Personal trainer and Strength and conditioning coach	r Master of Science	No	Modest	More than 20 Able bodied	Able bodied	Over 15 years on and off
Ivan	29	Male	Straight	White British	Self-employed & Part-time student	Bachelor of Science	Level 5 & Level 3 Diploma and final year of the M.Ost (osteopathy)	Median	30 or so	No disability	10 years
Julia	34	Female	Heterosexual White	White	Financial analyst	Bachelor of Science	Currently pursuing MBA	Above average	5 or 6	Pain on the right side of my hip	3 years
Michael	56	Male	Hetero	White European	Retired	Comprehensive	Tech/IT qualifications attended at adult college	Comfortable	Hundreds, I have seen an osteopath on and off for 40 years	Physical pain from spine and joints is closely linked to my mental health with which I struggle	My neck first locked up solid (for a week) at the age of 14
Katherine	43	Female	Gay	White British	Teacher/life coach	Master of Arts	Yes many	Low due to part-time hours	30 plus	High functioning considering pain levels, pain levels are moderate to high	8 years

# 6.5 Interview Questions

Number	Question
1	How are you feeling today
1.1	Please tell me more about yourself
2	When you notice pain, what do you do?
2.1	When you notice, what goes through your mind, does that feel?
2.2	How does the pain experience make you change what you are doing? Or how does this pain experience impact your day?
2.1.2	How do you react to your pain?
2.3	How do you feel when you experience pain?
2.4	How do you seek help?
2.4.1	When would you decide to see an osteopath?
3	Can you tell me why you see an osteopath/Can you tell me how you came to osteopathy?
3.2	What does osteopathy mean to you?
3.3	why did you choose to see an osteopath?
3.3.1	What do you aim to achieve when you visit osteopath (eg, remove pain, manage pain
4	Can you tell me about your experience of living with pain?
4.1	Were you diagnosed, or did you receive a diagnosis?
4.1.1	Has this meaning changed since you were diagnosed?
4.2	At the time, what did this mean to you?
4.3	Has there been a time when you felt like giving up trying to get rid of pain?
5	What do you understand by the idea of living well?
5.1	Can you tell me when you started to live well with pain?
5.1.1	What does living well with pain mean to you?
5.2	Has osteopathy influenced/had an impact of living well?
5.3	What are strategies do you have to live well with pain?
5.3.1	How have these developed or changed since you were diagnosed with chronic pain?
6.1	When you are experiencing pain does your understanding of living well change?
6.1.1	How do you change what you are doing?
6.2	How confident do you feel in your ability to self-manage your pain experience?
7	Closing questions, in a few words how you would <b>sum up</b> living well with pain

7.1	Thank you for agreeing to take part in this interview, is there anything else you would like to add?

## 6.6 Example of interpretation and analysis notes

50.51 Michael - Transcript example

[Pause] only since my way of thinking has changed, only since I realised I have to give a damn about myself erm I am prepared to sacrifice my physical being for my mental health erm but I do realise that my physical being also plays a huge role in my mental health and I also realise, which has been another big thing, it's not just me, I have a wife, I have a partner here of 26 years we've been together and she needs me, it's not just, I have not just to keep health for myself, I have to do it for her as well, when my quality of life disappears, so does hers, so it's only really that I was saying, the last sort of couple or three or four years, since I have been in this round of therapy, my therapist is, I call her the head, she is the head, yeah the therapist erm the work I have been doing with her erm I think I have made huge strides, she thinks I have made huge strides, my wife thinks I have made huge strides erm yeah I have made huge strides and that's what has changed everything

50.51 Micheal Analysis of text

## Since my thinking has changed, I want to care for myself and my wife,

[Pause] only since my way of thinking has changed, only since I realised I have to give a damn about myself erm I am prepared to sacrifice my physical being for my mental health erm but I do realise that my physical being also plays a huge role in my mental health and I also realise, which has been another big thing, it's not just me, I have a wife, I have a partner here of 26 years we've been together and she needs me, it's not just, I have not just to keep health for myself, I have to do it for her as well, my way of thinking has changed, I now know I have to care for myself, I have to be the focus, I have to focus on my mental health, alongside my physical health, But I have a wife, we need each other, I am doing this for us both to live well. This seems like a purpose, a drive to change and maintain this change, he wants to live well and repay his wife for her when she was really concerned about him.

### I have made huge strides and others see that; I am proud of myself.

when my quality of life disappears, so does hers, so it's only really that I was saying, the last sort of couple or three or four years, since I have been in this round of therapy, my therapist is, I call her the head, she is the head, yeah the therapist erm the work I have been doing with her erm I think I have made huge strides, she thinks I have made huge strides, my wife thinks I have made huge strides erm yeah I have made huge strides and that's what has changed everything This has been a recent change in relation to my whole life, but I am seeing progress, as well as others, this has been worth it M has a postive happy tone to his voice, I feel like he has self-worth, and this has been through. support from the 'head' and his wife

Black – Original transcript text Green – Indication of personal statement Blue – Authors early-stage interpretation Red – Authors own notes and thoughts.

## 6.6.1 Example of interpretation and analysis notes

#### 16.02 Katherine

Not at all, I felt so isolated and alone with it. This is why I have had to take this route on my own, to find alternative tools because there was no support, honestly there have been moments where throughout this journey I have thought to take my own life because the pain has been so awful and there has been no support so if I hadn't taken the initiative to so this work myself and I know some people don't have that drive its honestly disgusting how there is such little support for people that are suffering and vulnerable, especially with invisible illnesses because you are just shamed into believing you're, you know fine, and you are making it up and for somebody like me as well who is really ambitious and to have been successful in different areas of my career and then to suddenly be you know, not able to work, have to claim benefits and to feel like the shame of that, that was just awful, so humiliating and then to have no support from anyone and just be told it's all in your head, you are making this up, like a medical gas lighting, its abuse, it's awful.

**16.02 (3k)** Isolation, I have to take this route on my own, at the jumping off point, medical gas lighting, shame, and humiliation of claiming benefits

Not at all, I felt so isolated and alone with it isolation like above with work. We turn to the health service for answers and K's questions were not answered (7.22). This is happening again, work stress and received no support. I am isolated on my hill (9.23), (13.06) my whole life fell away, I felt like my life was over. Now I am alone.

This why I have had to take this route on my own to find alternative tools because there was no support This may have been the catalyst, the decision to find alternative tools. There is a fork in the road - to learn a new way of life, to seek tools for well-being or take my own life, route to living well, to healing away from pain and disappointment,

Honestly there have been moments in this journey where I have wanted to take my own life because the pain has been so awful and there has been no support in this journey up, the pain has been so awful, is k here referring to emotional pain, the recognition that my life has ended, k has a choice. There has been no support so if I hadn't taken the initiative to do this work myself self-reflection and recognition of where she could have gone, hopeful. I am on my own, and you have proved this to me, so I am going to heal myself.

I know some people don't have the drive its honestly disgusting (K seems upset and shocked as she re-lives the experience) how there is little support for people that are suffering and vulnerable comparing to others, K is using her drive and ambition in a different way. Recognises the lack of support, but this seems to be a thread through this interview, when people are suffering a vulnerable, this is when they need the support - This is a resources issue, lack of resources mean people who are vulnerable are not receiving the support, instead they are prescribed medication or poorly funded pain groups. However, has this changed through time?

Especially those with invisible illnesses, because you are shamed into believing you are fine, and you are making it up Invisible illness, look you are fine, you have arms legs and are mobile, you are not ill. Being told how to feel, not being listened to (similar to 9.23) Havi Carrels view of the naturalistic approach to illness, natural or physical facts are sufficient to explain the human world. This is an objective, neutral and third personal (p9 Kindle), Or the normative approach to illness - using common social terms to capture illness. This approach thinks that the concept of disease is valueladen, normativists focus on the way society perceives the ill person, they see illness as something that must be socially evaluated as negative.

For somebody like me as well who is ambitious and to have been successful in different areas of my career, then to suddenly not be able to work, have to claim benefits and to feel the shame of that,

it's awful and humiliating shift in identity, from a powerful ambitious successful lady to not being able to work, to claim benefits, the shame in that, this is not me, I don't claim benefits, I am ambitions, successful people do not claim benefits. Another confirmation of this is how bad my life has become. Queuing up in to claim money, with others that can't work or take part in society, societies impression of those that claim benefits. The stories in the national press that reinforce this societal expectation <a href="Check this is with supervisors">Check this is with supervisors</a> - I am a middle class male and have no experience of claiming benefits or being told I have a life changing condition. What must that feel like? Claiming from the state?

To have no support from anyone, be told it's all in your head (K seems fed up), you are making it up, like medical gas lighting, its abuse its awful no support, then medical professionals are making you question your own individual reality, K's truth of experience (ontological questioning) not being believed as a woman, paternalistic care, the professional is right and the patient is wrong. K Is being denied her experience.

Black – Original transcript text Green – Indication of personal statement Blue – Authors early-stage interpretation Red – Authors own notes and thoughts.

## 6.6.2 Example of interpretation and analysis notes

#### 23.37 Ivan

Errr I mean it wasn't, it didn't happen at once and it wasn't, it was stages. It was , there was a point where the suffering was so much that I have to do something, I have to do something about this, I said to you before that the pain of staying the same was far worse than the pain of starting to change and the pain of responsibility like you know ownership of my life and all the things I had to take account for and you know all of that kind of stuff I was like well staying the same just isn't an option anymore this is too shit so then starting to do that which then meant starting to look back into my past and why I was limited here why I was so fearful of these situations why I was, you know all that kind of stuff and so it all came part and parcel of the kind of same process of recovery

# 23.37 (3i) The pain of staying the same was far worse than the pain of starting to change, clearing the wreckage of the past to recover

Errr I mean it wasn't, it didn't happen at once and it wasn't, it was stages. It was , there was a point where the suffering was so much that I have to do something, I have to do something about this, I said to you before that the pain of staying the same was far worse than the pain of starting to change and the pain of responsibility it was a process that started with the recognition, like a rock bottom, I had to do something, I couldn't go on like this

The pain of responsibility like you know ownership of my life and all the things I had to take account for and you know all of that kind of stuff I was like well staying the same just isn't an option anymore this is too shit he has used pain here in a different context, not musculoskeletal pain, like emotional pain or experiencing a new life, could this be fear of new things, of learning to live the way he wants to so then starting to do that which then meant starting to look back into my past and why I was limited here why I was so fearful of these situations why I was, you know all that kind of stuff and so it all came part and parcel of the kind of same process of recovery courage to look back at past events to recovery, look at limitations, barriers, previous fears, very internal type approach, clearing the wreckage of the past

Black – Original transcript text Green – Indication of personal statement Blue – Authors early-stage interpretation Red – Authors own notes and thoughts.

## 6.7 Experiential statement example

Consider the transtheoretical model of change and possible time to intervene in pain management

This could also blend in with pain somewhere Place at the end of the pain management section

The pain of staying the same was far worse than the pain of starting to change - Readiness to change

I was left with no choice, I had to heal. It was a landmark year everything that could have happened, happended. As they say, when the student is ready to the teacher appeats. I just couldn't live like that anymore, enough was enough. It was like the pain of staying the same was far worse than the pain of starting to change. It was then, I was looking for a way out and I found one. It really help clear the wreckage of the past to recover

Personal Statement	Part.	Time	Quote	
I was left with no choice, I was forced to heal	K	9.23	so the more trauma I experienced the more unsafe I felt in my body and then my body was rejecting just existing, that's my experience and obviously I have done a lot of work to get from that point to where I am now I just trying to think about in a brief, so from there avoiding pain completely I was unable to function my whole life fell away so I had no choice to try and find ways to heal	
I was looking for a way out, I found one	ı	50.55	Its that thing that gets mistaken as manifestation in new age circles its that I am ready to pay attention to it and now I see it you know, so now, I now, I am looking for it, I saw it now I am actually looking for a way out I found a way out but I	
If you pay attention you will see it	ı	50.55	probably would of found that way out with a physio or chiro had that been the thing that was near had a physiotherapy practice been there or sports medicine practice or whatever that would have been the start of a way out regardless	
When the student is ready the teacher appears	ı	49.38	think at the time it's one of those like I can't remember what the phrase is but you know when you are ready to be taught a teacher appears that kind of thing I was ready to take on by then, I then took what they said and ran with it	
The pain of staying the same was far worse than the pain of starting to change	1	23.37	Errr I mean it wasn't, it didn't happen at once and it wasn't, it was stages. It was , there was a point where the suffering was so much that I have to do something, I have to do something about this, I said to you before that the pain of staying the same was far worse than the pain of starting to change and the pain of responsibility like you know ownership of my life and all the things I had to take account for and you know all of that kind of stuff I was like well staying the same just isn't an option anymore this is too shit so then starting to do that which then meant starting to look back into my past and why I was limited here why I was so fearful of these situations why I was, you know all that kind of stuff and so it	
Clearing the wrwckage of the past to recover	ı	23.37	all came part and parcel of the kind of same process of recovery	

**Key:** Red – Authors comments; Green – Experiential statement; Blue – Summary of personal statements; Black – transcription text.

## 6.7.1 Experiential statement example

I feel 100% confident in managing my pain, like I can manage a cold

Nowadays I pay attention to pain where low grade pain means I can carry on with what I am doing. Now I realise that I can manage pain rather than eliminate it and I am now better at managing pain, where before I would just stop everything or push through. I have realised how i feel, effects the pain intensity, so now i reduce the stressors in my life and increase my recovery. My experience with pain hopefully means the flare ups will become less frequent and now i can just sit with them. For me, flare ups are like a cold or hayfever, I am always going to get a cold but it depends on how i manage it, i wouldn't run in a field if i had hayfever! This shows me I can manage pain, just dont do anything silly. I feel like i need to chill out to let pain burnout and the pain will pass. This attitude helps me manage my flare ups and recognise that if I have one, i am not a failure, it is part of me. All this experience and learning means i am 100% confident it managing my pain experience.

Personal Statement	Part.	Time	Quote
pay attention to pain	I	35.17	I will take it easy I will pay attention to how I feel tomorrow morning and see whether I take the afternoon off or don't go in the next day just because I have pushed myself slightly too far and I need to rest and you know take some time for me and take care of myself
Low grade pain means I can carry on	I	36.16	I get low grade kind of gluteal pain, SI (sacroiliac joint) discomfort that doesn't really change what I do other than like antalgically, like other than doing some stretching things will relieve it erm but it doesn't really change anything that I do activity wise
We can manage pain rather than eliminate it	DG	23.30	a concept of living with pain and managing it rather than trying to think of it as being something you eliminate erm and it was quite, I think it was quite helpful thought process or mindset was that you know the chances are if you are prone to injuries and you have had lots of injuries in the past you will probably not going to completely eliminate pain
I am better at managing it now, before I would stop everything or just push through	DG	48.45	Yeah I think I am definitely way better at sort of managing it erm yeah I think in the past I would get an injury and I would just stop all exercise of a certain type I might stop lifting for a little while or might even push through it and try and warm up a bit and feel like I might be alright and I'm not

**Key:** Green – Experiential statement; Blue – Summary of personal statements; Black – transcription text.

## 6.7.2 Experiential statement example

The osteopath sees me in a dffierent light compared to others

Osteopathy for me tends to be more holistic and look at the whole rather than the parts. They achieve this by using a bit of everything and delve deeper into your life. It is a comprehensive lens to look at the puzzle that is chronic pain. So, they are like a mulitsicplinary practitioner in one, which enables them to un-tangle the wires with a variety of approaches. For example, the osteopath I see shares the same idea of the physio, that we are not here to cure pain, we are here to help you manage it. Manual therapy is a tiny part of osteopathy but there was something to the needling. I found the pressure that was used created space away from the trauma and the osteopath allowed me to feel the reaction. Osteopathy seems like a bit of science mixed with a bit of woo woo!

Personal Statement	Part.	Time	Quote
Osteopathy tends to be more holistic	DG	16.23	Oh that's a big question I don't know a huge amount about osteopathy erm I know that I mean osteopaths tend to be a bit more holistic in their approach which I have seen physios many many times in the past over the years for various complaints and reasons and it is always sort of generally they use similar sort of manual therapy combined with sort of corrective exercise combined with maybe I think some acupuncture from a physio before like taping or stuff like that I have seen chiropractors many years a go who did more manipulations and realigning you know bits that are stiff and joints that are not moving freely
Treats the whole rather than the parts	к	4.20	as a real holistic way of working that feels like it treats the whole of the individual rather than just parts so thats what it means to me
Osteopaths will use a bit of everything and delve deeper into your life	DG	16.23	yeah my experience with osteopathy is that they tend to use a bit of both of those they will use some manipulations they will use some manual therapy some acupuncture some physical corrective stuff and they will also tend to delve a bit deeper into your lifestyle and ask me things about you know what I am doing, you know nutritional side of things, you know lifestyle habits and you know sleeping patterns and stuff that can effect your health more overall
Osteopathy combined the two approaches, taking a bit of everything	DG	19.29	I suppose osteopathy sort of combined the two approaches and doing some manipulations for that short term sort of relief and erm movement erm sort of aligning combined with you know putting in some corrective stuff, putting in some manual therapy stuff erm just sort of made sense in terms of you know well, taking a bit of each approach and putting it together and it seems to have helped more a long with other sort of, I have done more core training and stuff on top of that
Osteopaths have a bit of everything	М	38.17	Well its exactly that, it's the techniques and methods and different therapies that you will use as opposed to the GP and let's be honest on the GP you are talking specialists and they are mega specialised you know, they are literally just one thing so, they have got a big toolbox but they are only for working on that one thing so you know they might have a little scalpel and a little hammer but they won't have a big hammer and a big, you guys have got a bit of everything you know

**Key:** Green – Experiential statement; Blue – Summary of personal statements; Black – transcription text.

### 6.8 Ethical Approval



Faculty of Health & Applied Sciences
Glenside Campus

Blackberry Hill

Stapleton Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.21.07.177

15<sup>th</sup> September 2021

Danny Miller Postgraduate Research Student

Health and Social Sciences Faculty of Health & Applied Sciences

**Dear Danny** 

Application title: How do adults with long-term musculoskeletal pain attending osteopathy services construct 'living well'?

Thank you for responding to the conditions raised in my letter to you of 2<sup>nd</sup> September 2021.

I can now confirm full ethics approval for your project, but please note that despite the easing of lockdown in England and across the devolved nations, you must continue to follow guidance as set by the UK Government and the relevant devolved administrations. If you have any questions about how this may affect starting your research project or for further information, please contact res.admin@uwe.ac.uk.

In the UK, face-to-face research and fieldwork can be undertaken but there should still be consideration of whether the activities could be delivered in an alternative way. There must still be appropriate mitigations related to Covid-19 risks included within risk assessments, including account taken of requirements from stakeholders. If you wish to undertake face-to-face research or fieldwork, you will need Senior Management approval from your Faculty, in line with Faculty requirements.

At the present time overseas travel on UWE business is not permitted. Please see the guidance at https://intranet.uwe.ac.uk/tasks-guides/guide/coronavirus-advice#part6. If you are planning any overseas activities involving personnel already located in the country concerned, then you must first contact researchgovernance@uwe.ac.uk. Please see COVID guidance: FAQs on conducting face-to-face activity and fieldwork (PDF).

The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

- 1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
  - You must notify the Research Ethics Sub-Committee if you terminate your research before completion.
  - You must notify the Research Ethics Sub-Committee if there are any serious events or developments in the research that have an ethical dimension.

Please ensure that before proceeding with your research:

- you have sought contractual advice from the UWE Contracts Team Amy.Charles@uwe.ac.uk if your research involves external funding and/or contracts with partner organisations;
- You have sought advice from the UWE Data Protection Team (dataprotection@uwe.ac.uk) if, in relation to collecting and/or sharing personal data, a third party (i.e. any person or institution extraneous to UWE) is involved in the research project.

Please note: The RESC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research. Yours sincerely

Dr Julie Woodley Chair Faculty Research Ethics Committee

c.c. Dr Sarah Brown

## 6.8.1 Ethics Amendment Approval

### **Amendment to Existing Research Ethics Approval**

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

**UWE** research ethics reference

number:

HAS.21.07.177

Title of project:

How do adults with long-term musculoskeletal pain attending osteopathy services construct 'living well'?

Date of original approval:

15<sup>th</sup> September 2021

Researcher:

Danny Miller

Supervisor (if applicable)

DoS: Sarah Brown

2<sup>nd</sup> Supervisor: Julian Bath

**1. Proposed amendment:** Please outline the proposed amendment to the existing approved proposal.

The current recruitment process is through osteopaths working at Phoenix osteopathy, situated in London which has so far limited my access to participants. I have interviewed three participants and I am aiming to complete a further 3-5.

I propose to invite other osteopathy clinics in the UK to widen the access to participants. In addition, I would adopt a snowballing approach with previous participants.

I aim to complete recruitment by the end of March 2022 and if I have limited participants by this date I would like to propose to recruit via social media. This would involve recruiting UK participants from living well with chronic pain groups. I would aim to recruit participants from the United Kingdom to avoid potential language complications.

2. Reason for amendment. Please state the reason for the proposed amendment.

People who self-identify as living well are likely to be managing their condition themselves and may not visit an osteopath. Therefore, this approach would allow access to more participants, seeking osteopathic care, living in the United Kingdom.

**3. Ethical issues.** Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

This ethical amendment has been discussed and agreed with the director of studies and 2<sup>nd</sup> supervisor. There will be no new ethical issues arise from this amendment as potential clinics would be covered by UWE research ethics. Potential participants will have the opportunity to read the participant information sheet and have the opportunity to ask questions.

To be completed by supervisor/ Lead researcher: Signature: Lead Researcher 4th February 2022 Date: To be completed by Research Ethics Chair: Send out for review: Yes X No Comments: This change of recruitment strategy would appear sensible. All associated risk have been addressed so this can be approved. Please also change the wording of the information sheet to reflect this change (If necessary) Outcome: X Approve Approve subject to conditions Refer to Research Ethics Committee 16<sup>th</sup> February 2022 Date approved:

Guidance on notifying UREC/FREC of an amendment.

Signature:

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary, please consult your departmental ethics lead or Chair of FREC.

Dr Julie Woodley (via e-mail)