

An Online Mindfulness Intervention for Pain and Wellbeing

by

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Abstract

Chronic pain is a prevalent health care issue that needs to be better addressed. Mindfulness techniques are a promising method to help individuals reduce the negative impact of chronic pain. Research has also indicated the effectiveness of delivering psychological interventions online for a variety of health problems including chronic pain. This thesis aimed to investigate presenting a mindfulness intervention for chronic pain via the internet. An online mindfulness intervention was developed and initially trialled in post joint arthroplasty patients. The failure to recruit adequate numbers and high dropout rates led to a qualitative study, which aimed to explore the lived experiences of individuals who had undergone a joint arthroplasty including: their thoughts and attitudes surrounding their pain, online treatments, and mindfulness. A third study trialled the intervention on a different population who potentially experience chronic pain, limb amputees, to investigate the user experience of the intervention structure and online resources. Taken together these studies demonstrated that this online intervention could be used to successfully deliver mindfulness techniques for chronic pain conditions. Qualitative results demonstrated that psychological treatments are currently underutilized in individuals experiencing chronic pain prior to joint arthroplasty. Online interventions could be feasibly delivered to these individuals to help with their pain management.

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List of Abbreviations

MBSR: Mindfulness based stress reduction

MM: Mindfulness meditation

OMCP: Online mindfulness course for pain

THA: Total hip arthroplasty

TKA: Total knee arthroplasty

Publications

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CHAPTER ONE

CHRONIC PAIN, MINDFULNESS AND ONLINE INTERVENTIONS

Pain is a universal human experience. It serves an essential biological function alerting us to potential tissue damage allowing us to protect an injured area. However, when pain extends beyond normal healing and into the domain of chronic pain it can cause a myriad of problems. Despite an increasingly sophisticated pathophysiological understanding of pain, there still remains a large gap in the field of chronic pain treatment (Brennan, Carr, & Cousins, 2007). Approximately one fifth of the adult population experiences chronic pain that seriously affects their quality of their life (Blyth, et al, 2001; Breivik, Collett, Ventafridda, Cohen, & Gallagher, 2006). An ever present challenge for health professionals is to develop effective treatments for chronic pain.

Chronic pain is a significant health care issue both in New Zealand and internationally (Breivik, et al., 2006; Dominick, Blyth, & Nicholas, 2011). Recent studies show that 16% of New Zealand adults report chronic pain with numbers increasing to 25-30% in adults over the age of 65 (Ministry of Health, 2012). Chronic pain also has a significant financial impact that is not limited to those that experience it. In Australia the cost of chronic pain due to health sector costs, loss of productivity and indirect costs was estimated to be \$33.4 billion (Access Economics, 2007).

Although the full cost of chronic pain in New Zealand is unknown, arthritis (a chronic pain condition) had an estimated financial cost of \$3.2 billion in 2010 (Access Economics, 2011). These numbers demonstrate that the financial burden of chronic pain is significant and improved treatment of chronic pain could lead to financial savings in the healthcare sector.

Defining Chronic Pain

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (IASP; Merskey & Bogduk, 1994, pg. 210). Pain is a conscious, multidimensional experience that results from sensory, emotional and cognitive components and is not simply a primitive sensation (Clark, et al., 2002; Charlton, 2005; Kumar, et al., 2002). Acute pain is pain that lasts for a limited amount of time and is part of the natural course of healing (IASP; Merskey & Bogduk, 1994). In contrast, chronic pain is sustained pain that lasts longer than the usual time of healing. The general threshold for which acute pain is then classified as chronic pain is if it lasts for over three months (IASP; Merskey & Bogduk, 1994).

Chronic Pain Outcomes

Chronic pain is complex condition that is associated with a diverse range of syndromes and ailments (IASP; Merskey & Bogduk, 1994). Chronic pain can arise from an initial injury or have an ongoing cause but it can also be present in the absence of any biological damage (Crombie, Croft, Linton, LeResche, & Von Kroff, 1999).

Due to the different conditions associated with chronic pain and the subjective nature of the pain experience, symptoms vary in intensity and type across individuals (Smith, Eliot & Hannaford, 2004). Chronic pain is a challenging condition which impacts all aspects of individual’s mental, physical, and social well-being (Lohman, Schleifer, & Amon, 2010; Gureje, et al., 2008; Gureje, Von Korff, Simon, & Gater, 1998; Smith, et al., 2001). Chronic pain’s presence can impede negatively on quality of life (Gureje, et al., 1998; Winkelmann, et al., 2011), sleep (Smith & Hawthornthwaite, 2004) rates of obesity (Wright, et al., 2010), fatigue (Kato, Sullivan, Evengard, & Pedersen, 2006), medical utilization (Winkelman, et al., 2011) and mortality (Torrance, Elliott, Lee & Smith, 2010).

Individuals who experience chronic pain also have poorer psychological outcomes than the general population (Dominick, et al., 2011; Gureje, et al., 2008; Gureje, et al., 1998). There are well documented associations between depression, anxiety and chronic pain (Baune, Caniato, Garcia-Alcaraz, Berger, 2008; Dominick, Blyth, & Nicholas, 2012; Dominick, Blyth, & Nicholas, 2011; Gureje, et al., 2008; Jordan & Okifuji, 2011; Magni & Moreschi, 1994; Miller & Cano, 2009; McWilliams, Cox, & Enns, 2003; Scott, Buffaerts, & Tsang, 2007; Tsang, et al., 2008). A study conducted by the World Health Organisation (WHO) including fourteen countries and 25,916 participants concluded that individuals with chronic pain are four times more likely to experience depression and anxiety when compared to those without chronic pain (Gureje, et al., 1998). Individuals with persistent pain were also more likely to report their overall health as poor and twice as likely to have a work disability (Gureje, et al., 1998). A further investigation of pain in a multinational study across seventeen countries including 85,088 participants found that as the number of chronic pain problems increases so too does the prevalence of depressive and anxiety disorders (Gureje, et al., 2008).

The relationship between pain and psychological disorders is not unidirectional. The comorbid presence of depression can lead to more pain complaints, more intense sensations of pain, amplification of pain symptoms, and a longer duration of pain experiences (Blair, Robinson, Katon, & Kroenke, 2003; Gureje, Simon, Von Kroff, 2001; Van Puymbroeck, Zautra, Harakas, 2007). It is clear that the impact of chronic pain is significant and understanding and treating it is an important challenge for the healthcare community.

Treatments for chronic pain

Chronic pain experiences are understood to be grounded in the biopsychosocial model (Melzack, 2005; Turk & Okifuji, 2002). The biopsychosocial model extends understanding of a condition beyond just biological factors to include psychological and social variables (Turk

& Okifuji, 2002). The biopsychosocial model asserts that chronic pain is a complex experience that includes biological (e.g. tissue damage), social (e.g. cultural expectations) and psychological (e.g. depression) variables. Each variable contributes to a pain experience. A complete understanding of an individual's pain response requires consideration of not just the biological but the psychological and social dimensions as well (Gatchel, Peng, Peters, Fuchs & Turk, 2007; Gatchel, 2004; Keefe, Rumble, Scipio, Giordano, & Perri, 2004; Kerns, et al., 2011; Turk & Okifuji, 2002).

Consequently for most chronic pain conditions there is no single cure or treatment that is wholly effective (Turk & Monarch, 2002). As such, multidisciplinary approaches that include a range of pharmaceutical, physical, educational and psychological treatments are recognised as the best method for treating chronic pain (Flor, Fydrich, & Turk, 1992; Guzman, Esmail, Karjalainen, & Malmivaara, 2002; Scascighini, Toma, Dober-Spielmann, & Sprott, 2008).

Analgesics are one of the most frequently prescribed methods for managing chronic pain (Breivik, et al., 2006; McDermott, et al., 2006; Reid, et al., 2011). In a European sample, 78% of individuals experiencing chronic pain had taken prescription pain medication at one point with nonsteroidal anti-inflammatory drugs (NSAIDs) and opioids being the most commonly used (Reid, et al., 2011).

However, individual's responses to analgesics are diverse and they only work well for a small percentage of individuals (Moore, et al., 2013). Forty one percent of individuals on prescribed medication for moderate to severe chronic pain felt that their pain was not accurately managed (Reid, et al., 2011). While the success of analgesics varies across conditions they generally have high failure rates (Moore, et al., 2013). The expected failure of analgesics emphasises the need to explore other methods of treating pain.

Although analgesics are a widely used, there is a vast range of treatments options available to individuals for managing chronic pain. Therapies including: exercise and physical therapy, massage, education, acupuncture, and psychological treatments can all used to help treat and manage individual's chronic pain (Airaksinen, et al., 2006; Kumar, 2008; Reid, et al., 2011). As pain is such a subjective experience treatment should be tailored to the individual's needs and condition (Turk & Monarch, 2002).

The emergence of integrated pain models has highlighted the importance of psychological factors that perpetuate, and contribute to the development of chronic pain (Kerns, et al., 2011). Psychological factors including: negative affect and appraisal, maladaptive beliefs, catastrophizing and fear-avoidance, perceived control over pain and poor self-efficacy, as well as issues with vulnerability and resilience are all known to contribute to the pain experience (Gatchel, et al., 2007) therefore comprehensive treatment of pain requires consideration of psychological methods to address these factors.

Current psychological treatments for pain

Research in the field of chronic pain has demonstrated the effectiveness of psychological treatments in a number of common chronic pain problems including headaches, lower back pain, and arthritis (Kerns, et al., 2011; Morley, Eccleston, & Williams; 1999). Psychological treatments are specifically designed to alter an individual's psychological processes that are thought to underlie their pain (Eccleston, et al., 2009). Two meta-analyses investigating the effectiveness of psychological interventions have further demonstrated the effectiveness, and cost-effectiveness of such psychological treatment (Flor, et al., 1992; Hoffman, Papas, Chatkoff, & Kerns, 2007). Psychological approaches provide an effective basis for which pain can be treated and can be roughly divided into three categories, self-regulatory approaches, cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) all of which are detailed below.

Self-regulatory approaches

The Self-Regulatory Model (SRM) proposes that the patients' perceptions of their illness directly impacts on their ability to implement adequate coping responses and self-management strategies (Hobro, Weinman, & Hankins, 2004). Treatment targets both the emotional and psychological components that may contribute to the development or exacerbation of the physical sensations, as well as the physical experiences that influence changes in psychological well-being (Kerns et al., 2011). Self-regulatory approaches include biofeedback (Gatchel, Robinson, Pulliam, & Maddrey, 2003; Hadjistavropoulos & Williams, 2004), relaxation (Kaushik, Kaushik, Mahajan, & Rajesh, 2005; Kerns et al., 2011), and hypnotherapy (Elkins, Jensen, & Patterson, 2007; Patterson & Jensen, 2003) which all aim to increase a patient's sense of control over both physiological and psychological experiences that they may initially feel unable to control (Kerns, et al., 2011).

Cognitive Behaviour Therapy

Cognitive Behaviour Therapy (CBT) is the most thoroughly researched of psychological treatments for chronic pain. CBT is grounded in the theory that symptoms of psychological distress are developed and maintained partially by conditioned behaviours and maladaptive thoughts (Brewin, 1989). Therefore CBT focuses on changing maladaptive cognitive and behavioural responses to pain into adaptive and beneficial ones (Keefe, 1996).

CBT interventions for pain typically focus on assessing thoughts and behaviours related to pain. Various techniques such as, psychoeducation and goal-setting are used to help individuals identify negative thought patterns and then works to alter them (Hadjistavropoulos & Williams, 2004). By modifying maladaptive cognitions CBT aims to help individuals better manage and cope with their pain.

There is a large body of research that demonstrates the effectiveness of CBT in reducing the negative experience of chronic pain (Eccleston, et al., 2009). Morley, Williams

and Hussian (2008) investigated the clinical effectiveness of four weeks of CBT on patients with chronic who had been referred to a national pain management service. In a sample of over 600 participants they found clinically significant improvements in individuals on measures of pain experience, psychological distress, catastrophizing and walking post treatment. Similar results have been seen for the effectiveness of CBT across a range of chronic pain conditions (Eccleston, Malleson, Clinch, Connell, & Sourbut, 2003; Kaapa, Frantsi, Sarna, Malmivaara, 2006; Lohnberg, 2007; Turner, Mancl, & Aaron, 2006).

A Cochrane review of 40 psychological interventions using CBT and/or behavioural treatments found small to medium effects for pain, disability and catastrophizing however they also found a number of inconsistencies in the literature (Eccleston, et al., 2009). Eccleston, et al., (2009) note that the dramatic increase in CBT studies including an increase in poor quality trials which may have diluting the effect sizes seen in meta-analyses of CBT. Despite these limitations, the authors concluded that CBT has the potential to be a generally effective treatment for chronic pain.

Acceptance and Commitment Therapy

Acceptance and Commitment Therapy (ACT) is a fourth wave therapy derived from CBT (McCracken & Vowles, 2014) and is increasingly recognised as an effective treatment in chronic pain research (Pincus & McCracken, 2013). ACT seeks to address cognitions leading to avoidance behaviour and emphasise behaviour in line with an individual's own values and goals in life (Hayes, 2004). ACT aims to encourage psychological flexibility by teaching purposeful acknowledgement of the present moment thereby combating avoidance, negative self-beliefs, and supporting adherence to core values (Kerns, et al., 2011). ACT acknowledges that it is not just the painful experience of pain that causes individuals to suffer (Dahl & Lundgren, 2006). Instead, it is the struggle associated with day to day life that also contributes to their disability (Dahl & Lundgren, 2006).

ACT has demonstrated promising results in individuals experiencing chronic pain, including: improving emotional, social, and physical functioning (McCracken, et al., 2005; Vowles & McCracken, 2008; Wetherell, et al., 2011; Wicksell, et al., 2008), depression (Vowles & McCracken, 2008; Wetherell, et al., 2011; Wicksell, et al., 2008), pain-related anxiety (Vowles & McCracken, 2008; Wetherell, et al., 2011), the number of health care visits (Dahl, et al., 2004; McCracken, et al., 2005; Vowles & McCracken, 2008) and sick days from work (Dahl et al., 2004; Vowles & McCracken, 2008), as well as pain intensity (Vowles & McCracken, 2008). While there is encouraging evidence for the use of ACT in treating chronic pain, there is insufficient research to determine whether it is a more effective treatment than other more established CBT interventions (Hayes, et al., 2006; Veehof, Oksam, Schreurs & Bohlmejer, 2011).

Mindfulness for Pain

Mindfulness is a self-regulatory treatment for chronic pain that is also a component of both CBT and ACT. Mindfulness based therapies are a rapidly growing cohort of healthcare interventions (Day, Jensen, Ehde & Thorn, 2014). Mindfulness is not restricted to clinical interventions, and has proliferated in popular culture with health blogs extolling the benefits of being mindful and TIME magazine proclaiming the “Mindful Revolution” (Pickert, 2014). Mindfulness techniques have been shown to be effective at treating pain in their own right (Reiner, Tibi, & Lipsitz, 2013) and are a focus of this thesis. Isolating and testing mindfulness techniques separately to CBT and ACT can serve two purposes. Firstly, to strengthen our understanding of the active components of CBT and ACT, and to improved treatment outcomes for mindfulness based therapies.

Defining mindfulness

Mindfulness can be simply defined as “paying attention in a particular way; on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 1994, p.4). While the

roots of mindfulness practices can be traced back to the eastern philosophies, mindfulness is considered a secular exercise that is not bound to a specific ideology (Baer, 2003).

Mindfulness is a way of focussing attention on the present moment and can be understood by two general overarching principles (Bishop, et al., 2004). The first is focusing your attention on the present moment. Whether you are walking, eating or singing you are “in the moment” and not thinking about past or future events, simply what you are doing at the time (Kabat-Zinn, 1982; Brown and Ryan, 2003). The second component of mindfulness practices is to acknowledge and accept whatever feeling you have in the present moment. Individuals are instructed to view the current sensations and thoughts in a non-judgemental and unemotional way. Emphasis is placed on being unreactive to emotions and sensations but accept them as they are (Kozak, 2008). Unlike CBT techniques, mindfulness does not aim to change an individual's thoughts but instead alter how they respond to said specific thoughts (Kabat-Zinn, 2003; Brown & Ryan, 2003, Kozak, 2008). In relation to pain, mindfulness techniques aim to decrease the negative response to pain, thereby making pain less salient and distressing for the individual (Kozak, 2008; Sharpe, et al., 2010).

Mindfulness is a broad term, and its exact definition is still contested. Mindfulness is both a state to achieve and methods to achieve a specific state (McCracken & Vowles, 2014). Despite disputes surrounding its definition it is agreed that the term mindfulness is inclusive of a wide array of techniques and programmes. Theoretically mindfulness is sustained attention on the moment to moment stimuli in an accepting manner.

Mindfulness Based Interventions

Mindfulness meditation (MM) refers to an activity that systematically trains the mind to attend to the present moment in an accepting and open manner (Day, et al., 2014). MM practices are the core components of mindfulness based interventions (MBI's). Commonly used mindfulness programmes integrate meditative exercises such as breathing exercises, the

body scan, mindful walking and mindful eating (Kabat-Zinn, 1992). These techniques serve as “scaffolding” to help cultivate mindfulness and integrate mindfulness practices into individual’s daily lives (Kabat-Zinn, 1985, Kabat-Zinn, 1990).

Mindfulness skills can be taught in a variety of ways. Mindfulness interventions reflect this varying widely from a brief seven minute (Swain, & Trevana, 2015) or one hour session (Zeidan, Gordon, Merchant, &, Goolkasian, 2010) to an extended eight week course with daily practice and homework (Kabat-Zinn, 1985). Mindfulness –based stress reduction (MBSR) and mindfulness based cognitive therapy (MBCT) are two central, structured programmes which inform other MBIs (Baer, 2003).

Mindfulness-based stress reduction (MBSR) developed by Kabat- Zinn and colleagues (Kabat-Zinn, 1982) is one of the earliest and most researched of the MBI’s. MBSR is a structured eight- ten week course which participants attend once a week for approximately two hours. Over the course of the programme, participants are taught mindfulness techniques including the “body scan” meditation (focussing your attention on each individual body part in turn), sitting meditation and hatha yoga postures. Participants are also provided with guided audio recording and instructed to practice for 45 minutes once a day for the duration of the course. These interventions aim to help participants to become more mindful in their everyday lives (Kabat-Zinn, 1985). The structure of MBSR provides the basis for many other MBI’s (Baer, 2003).

Mindfulness based cognitive therapy (MBCT) is also an eight week group intervention heavily based on MBSR (Segal, Williams, & Teasdale, 2002). MBCT differs from MBSR in that it incorporates exercises from CBT that teach participants to explore the links between their thoughts and behaviour/ bodily sensations. This method encourages a detached view of one’s cognitions preventing rumination on negative thoughts (Segal, et al., 2002).

Mindfulness based interventions have been identified as effective interventions for a range of physical and psychological conditions (e.g., Baer, 2003; Fjordbak, Arendt, Ornbol, Fink, & Walach, 2011; Grossman, Niemann, Schmidt, & Walach, 2004; Keng, Smoski, & Robins, 2011; Khoury, et al., 2013). Examples where mindfulness interventions have been shown to be effective include: reducing stress and increasing quality of life in health care professionals (Shapiro, Astin, Bishop, & Cordova, 2005), psoriasis (Kabat-Zinn, et al., 1998), fibromyalgia (Kaplan, Goldberg, & Galvin-Nadeau, 1993), reduce anxiety and depression (Hofmann, Sawyer, Witt & Oh, 2010; Miller, Fletcher, & Kabat-Zinn, 1995; Shapiro, Schwartz, & Bonner, 1998), prevent relapse of major depression (Teasdale, et al., 2000; Teasdale, Segal, & Williams, 1995) and reduce stress in incarcerated individuals (Samuelson, Carmody, Kabat-Zinn, & Bratt, 2007), binge eating disorder (Kristeller & Hallett, 1999), cancer patients (Carlson, Ursuliak, Goodey, Angen & Specia, 2001), and irritable bowel syndrome (Garland, et al., 2012).

Mindfulness Mechanisms

There is debate about the specific mechanisms underpinning mindfulness; however Hölzel, et al., (2011) present a detailed model which relates mindfulness to enhanced self-regulation. The authors identified four components: attention regulation, body awareness, emotion regulation and change in perspective on the self, through which mindfulness facilitates increased self-regulation. Each component does not work in isolation of the others but instead they work synergistically together. This model utilizes both behavioural and neuroimaging data (e.g. magnetic resonance imaging and functional magnetic resonance imaging) which will be discussed for each of the four individual components below.

Attention regulation. Mindfulness practices emphasise focussed attention, that is sustaining attention on a single object, the present moment and everything that moment holds. Training in focused attention supports the development of executive attention (i.e. the

ability to focus on one task while simultaneously ignoring other distractions) leading mindfulness practitioners to have better attentional performance and increased immunity to distractions (Hölzel, et al., 2011). This premise is supported by behavioural data that shows experienced meditators have better performances on cognitive tests for executive function tasks (Jha, et al., 2007; van den Hurk, et al., 2010).

Further evidence for increased attention regulation in meditators is provided by neuroimaging studies. The anterior cingulate cortex (ACC) is a brain area that is involved in executive attention (van Veen & Carter, 2002). Functional MRI (fMRI) studies demonstrate that regular meditators have both greater activation in the anterior cingulate cortex (ACC) (Hölzel, et al., 2007; Gard, et al., 2010) and increased cortical thickness in the dorsal ACC (Grant, Courtemanche, Duerden, Duncan & Rainville, 2010). Taken together these results suggest that mindfulness meditation increases executive attention, one of the four components of the mindfulness mechanisms that Hozel, et al., (2011) hypothesise can lead to increased self-regulation.

Body Awareness. Mindfulness practices encourage people to be aware of their body through attention to internal experiences such as breathing. Mindfulness techniques also encourage awareness of emotions. This aspect of mindfulness could lead to an increased ability to notice bodily sensations and feelings which in turn leads individuals to greater awareness of their own body (Hölzel, et al., 2011). Self-report findings demonstrate that individuals who participate in mindfulness meditation report increased bodily awareness (Carmody & Baer, 2008) however these self-reported changes are not supported by empirical evidence (Nielsen & Kaszniak, 2006).

Neuroimaging and data indicates that mindfulness might facilitate changes in brain regions implicated in body awareness. The insula, an area commonly associated with bodily awareness (Craig, 2003) shows increased activation in individuals after a mindfulness course

(Farb, et al., 2007). Experienced meditators also have increased grey matter (Hölzel, et al., 2008) and cortical thickness (Lazar, et al., 2005) in the right anterior insula. Hölzel, et al., (2011) hypothesise that an increase in body awareness could lead to greater empathy and emotional regulation which supports the notion of increased self-regulation as a result of mindfulness practices.

Emotion Regulation. Emotion regulation is defined as the ability to influence emotional responses and selectively alter how we experience and express said emotions (Gross, 1998). There is an established evidence base that suggests mindfulness practices support emotion regulation. Mindfulness meditation can reduce emotional interference (Ortner, et al., 2007), negative mood states (Jha, Stanley, Kiyonaga, Wong, & Gelfand, 2010), reactivity to negative thoughts (Feldman, Greeson, & Senville, 2010) and increase positive moods (Jain, et al., 2007).

This is further supported by neuroimaging data that shows mindfulness meditation can lead to increased activation of the prefrontal cortex (PFC) and reduced activation of the amygdala, a pattern of activation linked to emotion regulation (Creswell, Way, Eisenberger, & Lieberman, 2007, Farb, et al., 2007; Hölzel, et al., 2007; Goldin & Gross, 2010). Mindfulness clearly influences emotional regulation however it has been hypothesised there are two processes through which this could be done, reappraisal and extinction.

Mindfulness practices support the open, non-judgmental, acceptance to all stimuli. This potentially leads to changing the emotional response to said stimulus termed “reappraisal” (Hölzel, et al., 2011). Behavioural and neuroimaging data support this assertion, mindfulness practices lead to increases in positive reappraisal (Garland, et al., 2011) and increased activation of the dorsomedial PFC, a brain area that supports reappraisal (Modinos, et al., 2010).

The second process through which emotional regulation potentially occurs is extinction, an elimination of a negative response to stimuli. Instead of diverting attention away from a stimulus or emotion, mindfulness practices encourage an individual to fully experience the stimulus even if it is negative such as fear or pain. This repeated exposure to specific stimuli while practicing non-reactivity towards means that an individual is able to better regulate their emotional response. Meditators show increases in non-reactivity to inner experiences (Carmody & Baer, 2008) this is supported by neuroimaging data that demonstrates meditation induces changes in the ventro medial PFC, hippocampus and amygdala, brain areas that are associated with fear extinction (Hölzel, et al., 2008; Hölzel, et al., 2010; Hölzel, et al., 2011; Lazer, et al., 2000; Luder, Toa, Lepore, & Gaser, 2009) .

Change in self-perspective. Practicing the fundamental tenants of mindfulness that is actively attending to cognitions and sensations in an open and non-judgemental way may lead an individual to have a fundamental shift in perspective. This is termed “reperceiving” (Carmody, Baer, Lykins, & Olendzki, 2009; Fresco, et al., 2007; Shapiro, et al., 2006). The meta-mechanism of reperceiving is said to give individuals a greater internal awareness. Shapiro, et al., (2006) stress that reperceiving does not involve an individual detaching themselves from their experience but instead is a greater acceptance and clarity of ones thoughts and feelings.

Empirically measuring the change of self-perception is difficult and there is currently little research investigating reperceiving (Hölzel, et al., 2011). Individuals who have completed an eight week mindfulness course report a “meta-perspective” or increased awareness of their internal thoughts/emotions and how they affect their experiences (Kerr, et al., 2011). Further research using self-report shows that individuals experience a shift in their self-perspective which is coupled with increases in self-esteem, self-acceptance and self-

representation after extended mindfulness practice (Emavardhana & Tori, 1997; Haimerl & Valentine, 2001).

Neurological research also provides preliminary support for the change in self-perspective. Brain networks that are related to self-referential processes are functionally impacted by mindfulness practices. Together the medial prefrontal cortex, posterior cingulate cortex/anterior precuneus and the inferior parietal lobule are referred to as the “default mode network” (Buckner, Andrews-hanna, & Schacter, 2008; Gusnard & Raichle, 2001). The default mode network is associated with self-knowledge (Lieberman, Jarcho, & Satpute, 2004), memory of self traits (Kelly, et al., 2002), and individual assessment of the relevance to the stimulus to the self (Gusnard, et al., 2001). This default mode network is highly active at rest, when the mind is wandering and during freethought. Decreased activation of the default mode network is observed during mindfulness meditation (Ott, Walter, Gebhardt, Stark & Vaitl, 2010). Additionally, brain areas related to the experience of self, including the posterior cingulate cortex, temporo-parietal junction and the hippocampus, also demonstrate a structural impact of mindfulness showing an increase in grey matter post a mindfulness based stress reduction course (Hölzel, et al., 2011). The neuroimaging data lends support to the idea that mindfulness practices can change the way an individual’s perceives themselves and their experiences.

The four identified mechanisms of mindfulness (attention regulation, body awareness, emotion regulation and perspective of self) do not work in isolation but are instead heavily interconnected to bring about an increase in self-regulation in mindfulness meditators (Hölzel, et al., 2011) Each component might be differentially important at different time of mindfulness meditation but all lead to increased self-regulation. While not complete, this integrated model of mindfulness provides a framework for understanding the underlying processes of the mechanisms of mindfulness meditation.

Mechanisms in mindful pain regulation

Pain is a complex experience that can be influenced by a range of factors including attention, beliefs, mood, expectations and sensory experiences (Gatchel, et al., 2007).

Mindfulness techniques have been shown to modulate both chronic and acute pain (Kabat-Zinn, et al., 1985; Kingston, Chadwick, Meron, & Skinner, 2007; Zedion, et al., 2010).

Attempts to develop a cohesive model of how mindfulness modulates pain are still in their infancy. A recent review by Zeidan, Grant, Brown, McHaffie, & Coghill (2012) explored unique brain mechanisms associated with mindfulness meditation and pain regulation. The authors proposed that mindfulness practices diminish pain experiences by changing the sensory representations of pain via cognitive control and emotion regulation in which the prefrontal cortex and cingulate cortices are heavily involved (Zedion, et al., 2012).

Zedion, et al., (2012) first examined the research surrounding prior meditation practice on pain. Experienced meditators demonstrated different patterns of activation in brain areas related to pain sensations and emotion appraisal. Electroencephalography (EEG) data investigating the traits of experienced meditators reported a decrease in unpleasant pain sensations aligned with an increase in evoked potentials in brain regions associated with cognitive modulation and appraisal of pain (Brown & Jones, 2010).

In direct contrast to the results of Brown and Jones, (2010), Grant, et al., (2011) using functional fMRI to examine experienced meditators found that decreased pain responses were related to a decrease in the activation of emotion and appraisal areas (medial prefrontal cortex, orbitofrontal cortex, dorso-lateral prefrontal cortex and amygdala) and an increased activation in areas which are responsible for encoding sensory aspects of noxious stimuli (insula, thalamus, mid-cingulate cortex). This was interpreted as suggesting that meditators were paying attention to the painful stimulus but were not appraising or responding to it (Grant, et al., 2011).

Zedion, et al., (2012) concluded that despite these discrepancies, together these results suggest that meditation induces changes in the brain structure of the individual. These changes allow for differential processing of pain even in the absence of active meditation although further studies are required to better understand and unify these two different results.

Differences in specific brain regions have also been observed in individuals actively meditating while receiving a painful stimulus. Active meditation during pain demonstrates greater activation of areas associated with sensory pain processing including the posterior insula and the secondary somatosensory cortex (Gard, et al., 2012). This increase in sensory processing is correlated with a decrease in reported pain unpleasantness from participants. Greater activation of areas related to the pain evaluation, cognitive control and, pain and emotion regulation were also seen after individuals participated in a brief 8 week mindfulness meditation training (Zeidan, et al., 2011). Regression analysis of fMRI's showed that decreases in pain unpleasantness were associated with greater activation in the rACC (associated with cognitive modulation of pain, emotion and pain regulation), right anterior insula (connects somatosensory cortex to other brain regions) and orbitofrontal cortex (OFC) (contextual evaluation of pain). (Zeidan, et al., 2011). The neurological data indicates that mindfulness techniques alter both the contextual evaluation and sensory experience of pain through networks involving the cingulate and prefrontal cortices (Zeidan, et al., 2011).

Empirical Research on Mindfulness Based Interventions for Pain

Mindfulness meditation has been explored across a wide range of conditions associated with chronic pain. MBSR, one of the earliest mindfulness interventions, was initially designed for individuals with chronic pain (Kabat-Zinn, 1985). The success of MBI's across different chronic pain conditions is mixed (Chiesa & Serretti, 2011; Veehof, et al., 2011).

For example, a clear consensus regarding the overall effects of MBI's on pain intensity has not been reached. In a meta-analysis Veehof, et al., (2011) demonstrated that MBI's have small to medium effects (0.37) for pain intensity making MBI's comparable to CBT as a treatment method. Similar conclusions were drawn in two other reviews that found there were significant improvements in pain intensity across a range of chronic pain conditions (Reiner, et al., 2013; Baer, 2003). In contrast to these findings a further systematic review of the mindfulness based interventions for chronic pain found that MBI's did not influence pain intensity (Chiesa & Serretti, 2011).

Despite a lack of consistent findings on effects on pain intensity, results suggest MBI's have a positive impact on secondary factors associated with chronic pain. Patients who complete MBI's have increased levels of pain acceptance and pain tolerance and significant improvements in quality of life measures including positive affect and functional status (Chiesa & Serretti, 2011; Veehof, et al., 2011). Given the proposed mechanisms of mindfulness meditation these findings are unsurprising. Mindfulness meditation does not aim to change individual's pain but the way they interpret it

Mindfulness interventions for disease-specific chronic pain

Chronic Pain. MBSR was initially developed to treat chronic pain. In an early study, Kabat- Zinn, (1982) reported the success of MBSR with 51 individuals experiencing chronic pain. Of those who completed the course, 65% of patients reported a greater than 33% improvement in pain ratings, medical symptoms and mood disturbance. These results were sustained at 15 months (Kabat-Zinn, Lipworth, & Burney, 1985) and four years post intervention (Kabat- Zinn, Lipworth, & Burney, & Sellers, 1987). Unfortunately no controls (Kabat-Zinn, 1982) or active controls (Kabat-Zinn, et al., 1985; Kabat-Zinn, et al., 1987) were included in these studies making it difficult to draw conclusions about whether the improvement was due to MBSR or another factor.

The strong support of mindfulness meditation from early uncontrolled studies is only partially supported by more recent rigorous work. A pilot study that compared the effects of MBSR and massage therapy reported no changes in pain intensity for the MBSR condition (Plews-Ogan, Owens, Goodman, Wolfe and Schorling, 2005). However, improved mental health ratings were maintained at 12 weeks post intervention emphasising that mindfulness benefits can be sustained and long lasting as seen in the earlier MBSR interventions (e.g., Plews-Ogan, et al., 2005). Similarly a study that exclusively investigated the psychological factors of chronic pain saw reduced grieving, depression and anxiety in individuals who completed a MBSR programme compared to waitlist controls (Sagula & Rice, 2004).

Two further studies analysed the results of a MBI delivered both in person (face to face) and via video conferencing in a sample individuals experiencing chronic pain (Gardner-Nix, Blackman, Barbati, & Grumitt, 2008; Gardner-Nix, Barbati, Grumitt, Pukal and Raponi Newton, 2014). Both studies found significant improvements in pain catastrophizing, pain related suffering but no changes in physical quality of life. However as is a common problem with MBI's neither study included an active control.

A study which included an active control found that a MBI treatment lead to reductions in pain severity and less desire for opioids when compared to an active support group control for individuals experiencing chronic pain. These results continued to be maintained at three months follow up (Garland, Manusov, Froeliger, Kelly, Williams, & Howard, 2014). This indicates that the benefits of MBI's might not be limited to psychological outcomes in chronic pain. Further promising results were seen in a randomised, comparative clinical trial in which the effectiveness of MBSR was compared to a multidisciplinary pain intervention (MPI) for chronic pain patients. Both the MBSR and MPI showed significant positive improvements in pain intensity and pain related distress (Wong, et al., 2011).

Despite methodological flaws in some research it is clear that MBIs are likely to have some benefit for individuals with chronic pain. However, outcomes of mindfulness based interventions may vary as a function of the chronic pain condition. Rosenzweig, et al. (2010) investigated the effects of MBSR across variety of different chronic pain conditions including, arthritis, back/neck pain, fibromyalgia and headache/migraines. In this study, individuals with arthritis and back/neck pain showed significant changes in pain intensity and functional limitations Rosenzweig, et al., 2010). Individuals with arthritis also showed the largest treatment effect for health related quality of life and psychological distress while the smallest changes were seen in individuals who experience migraines (Rosenzweig, et al, 2010). Given the heterogeneous nature of chronic pain samples it is important to review the evidence for each condition individually.

Fibromyalgia. Fibromyalgia is a chronic pain disorder characterised by joint and soft tissue pain, insomnia and fatigue (Wolfe, et al., 1995). Results for MBI's alleviating symptoms of fibromyalgia have been mixed. Goldenburg, et al., (1994) reported a significant improvement in perceived pain following completion of an MBI for individuals with fibromyalgia. Similar results were seen in Creamer, Singh, Hochberg and Berman (2000) who reported sustained benefits of completing an MBI four months after completion for pain threshold and tender points. Sephton, et al., (2007) demonstrated that mindfulness meditation alleviates depressive symptoms in individuals with fibromyalgia at completion of the intervention and at 2 months follow up. However none of these studies included an active control condition making it difficult to conclude if it was mindfulness that contributed to the positive outcomes or it was due to other mechanisms.

Further promising results were found for MBIs in treating fibromyalgia. Grossman, Tiefenthaler-Gilmer, Raysz and Kesper (2007) used a quasi-randomised design to compare a

MBSR to an active social support control. MBSR provided significantly greater benefits on a range of measures including pain, pain coping, anxiety, depression and quality of life.

Unfortunately these encouraging results are contradicted by a study from Schmidt, et al., (2011). They conducted a 3-armed trial comparing MBSR to an active control and a wait list control and found that while patients showed overall improvement in their health related quality of life, pain, anxiety and depression there were no significant differences between the intervention and active controls in females with fibromyalgia (Schmidt, et al., 2011). These results were mirrored in earlier studies by Astin, et al., (2003) and Mannerkorpi and Arndorw (2004) who found while individuals showed significant improvements in pain, disability, anxiety and depression there were no significant differences between individuals who completed an MBSR or education support (active control). Taken together these results suggest that MBI's can be beneficial for individuals with fibromyalgia however it is not clear if it is the specific mechanism of mindfulness that leads to these improved outcomes.

Rheumatoid arthritis. Another condition characterised by chronic pain is rheumatoid arthritis (RA). Pradhan, et al., (2007) found that participants who completed a MBSR intervention noted improvements on measures of well-being and psychological distress however none of these improvements were significantly different from those made by the control group. Interestingly at six months follow-up (four months post intervention) they found that there were still significant improvements on measures of well-being and psychological distress for those who received MBSR which had not been sustained for controls. This indicated the potential for MBSR to have long lasting effects.

Zautra, et al., (2008) compared the outcomes of a MBI to a CBT intervention for individuals with rheumatoid arthritis. Both approaches were beneficial compared to an education control but, in different ways. Individuals who completed the MBI showed the greatest change in pain catastrophizing, pain coping and had better emotion regulation than

those in the education and CBT group. However the CBT group demonstrated more improvements in pain control and reductions in interleukin-6 (a pro-inflammatory cytokine marker associated with the joint destruction). The authors noted that individuals with RA and depression benefited the most from the mindfulness intervention suggesting that there is a place for MBI's in pain management treatments for individuals with RA.

Chronic lower back pain. MBI's have also been investigated in individuals with chronic lower back pain. A systematic review of MBSR for low back pain concluded that evidence for the effectiveness of pain or disability was inconclusive, however there was limited support for MBSR use in pain acceptance (Cramer, Haller, Launche, & Dobos, 2012). Three studies this review investigated have explored the effectiveness of MBI's for chronic back pain. Individuals with chronic pain as a result of failed back surgery syndrome (FBSS) experienced improvements in pain acceptance, quality of life, pain, and sleep quality after completing MBSR (Esmer, Blum, Rulf & Pier, 2010). Similarly Morone, Greco, and Weiner (2008) found that older adults with chronic lower back pain who completed an 8 week MBI had significant improvements in pain acceptance and physical function with sustained benefits at a three month follow up compared to wait-list controls.

In a follow up study Monroe, Rollman, Moore, Qin and Weiner, (2009) included an active control condition. While improvements were seen in measures of pain, disability and self-efficacy there were no significant differences between the MBSR and the education control.

Despite these findings, qualitative analysis has provided support for the use of MBI's in chronic back pain conditions. Monroe, Lynch, Greco, Tindle and Weiner (2008) conducted a qualitative analysis of older adults accounts of their experience with mindfulness meditation. Individuals attributed improved quality of life, mood elevation, pain coping, less pain, better sleep to involvement with mindfulness. Doran, (2014) found similar results with

individuals describing themselves less reactive to pain. Over the course of a MBI individuals noted shifts in how they perceived their pain. Instead of fearing and resisting pain they began looking for ways to manage it allowing them to consciously manage maladaptive pain responses.

Critiques of mindfulness interventions for chronic pain

The field of MBI's for chronic pain is relatively young and as such there are many gaps in the research that need to be addressed. A critique of MBI's in the literature is the need for rigorously designed, properly powered studies which was first recognised by Baer, (2003) and has yet to be resolved as noted in more recent reviews (Chiesa & Serretti, 2011; Fjordbak, et al., 2011; Grossman, et al., 2004). MBI's are limited by the low number of studies, methodological flaws, a lack of active control conditions, and heterogeneous samples that makes drawing adequate conclusions about the effectiveness difficult.

Research surrounding mindfulness also focuses on the immediate effects of treatment and outcome. Further studies which investigate the long term outcomes of MBI's are required (Fjordbak, et al., 2011; Grossman, et al., 2004). While the number of MBI's continues to proliferate the underlying mechanisms of mindfulness and the role it plays in chronic pain reduction needs to be further researched (Fjordback, et al., 2011; Zeidan, et al., 2012). The development of more cohesive models of mindfulness will allow for more targeted and effective interventions.

Conclusions for MBI's for pain interventions

MBI's have been shown to be effective at reducing a variety of pain symptoms across a range of conditions. While there is still a need for more rigorous studies it is clear that there is a potential benefit of including MBI's within integrated pain treatment packages with the challenge being to deliver them in effective ways.

Internet Interventions for Pain

The internet is a promising medium for delivering psychological interventions. Despite the need for adequate pain management, many individuals are unable to relieve their discomfort due to a number of nonmedical barriers (Bender, et al., 2011). These include – but are not limited to – poor training of health care professionals, inadequate ability to identify and report pain sensations, over consideration of common misconceptions about pain, and the inaccessibility of multidisciplinary pain treatment (Lohman, et al., 2010; Peng, et al., 2007). Such barriers prevent cost effective and adequate pain management in the majority of cases (Bender, et al., 2011). Online based interventions could help pain treatments become more accessible.

Prolific growth of the internet usage in daily life makes it a difficult medium to ignore for health care interventions. In 2012, 1.3 million (80%) of New Zealand homes had some form of internet connection (Statistics New Zealand, 2013) and this number is only expected to rise with the increasing availability of computer technologies including smart phones (Jones & Fox, 2009; Rini, et al, 2012). There are many predicted benefits of utilising the internet medium for healthcare. Online interventions have the potential to overcome specific treatment barriers typically associated with more traditional delivery mediums for managing pain including geographical location, cost and accessibility (Rini, et al, 2012).

Benefits and challenges of online interventions

Ease of access has been identified as a huge potential benefit of offering psychological interventions online (Rini et al., 2012). Accessibility of psychological interventions has been identified as one factor for the limited use of psychological interventions for pain (Sierpina, Levine, Astin & Tan., 2007). When using an online intervention, participation is not dictated by a specific time of day or the availability of the therapist. Individuals can participate in an intervention at a time that is convenient and

appropriate for them allowing a flexibility that is not always present in traditional face to face methods.

Geographic location of an individual is also is not a limiting factor for online interventions. Individuals who live in remote geographic locations, have mobility issues, social phobias, or are unable to travel in at specific times are not disadvantaged (Rini, et al, 2012). The ability to access an intervention from the comfort of your own home or a place of your choosing allows anonymity that can help to overcome the stigma that often accompanies seeing a therapist (Gega, Marks, & Mataix-Cols., 2004; Sirey, et al, 2001). The ability to participate in programmes at their convenience also gives individuals a sense of self control over their treatment which could lead to better healthcare outcomes (Murray, et al., 2009). This is particularly relevant to individuals with chronic pain as people who feel more control over their situation exhibit have greater improvements in both physical and psychological variables (Jackson, 2011).

The economic benefits of online interventions, especially from a public health perspective have been widely lauded. General consensus is that there is a potentially a large financial benefit of online treatments (Howards, et al., 2008). While initial development costs can be expensive, once an intervention is set up the price of running it is minimal compared to visiting a health care professional. Tate, Finkelstein, and Khavjou (2009) conducted a review of research investigating the cost-effectiveness of internet-based treatments. Only eight published studies had been conducted. Of these eight studies, seven indicated the cost-effective nature of using internet-based treatment (Tate, et al., 2009).

There is a general level of public support and acceptance for online healthcare interventions (Gun, Titov, & Andrews, 2011; de Graaf, Huibers, Riper, Gerhards & Arntz, 2008; Wootton, Titov, Dear, Spence, & Kemp). With individuals who have previous

experience with an online intervention reporting significantly higher ratings of acceptability compared to those that have not experienced an online interventions (Gun, et al., 2011), A recent survey of patients in primary care found 49% of patients would be willing to try an online intervention (Mohr, et al., 2010). While this percentage might seem like a small percentage this number is only expected to grow exponentially with the greater inclusion of technology in our lives and exposure to online interventions (Mohr, et al., 2010; Rini, et al., 2011).

Online interventions are typically challenged with high dropout rates ranging from between 2-83% (Christensen, Griffiths, & Farrer, 2009; Melville, Casey, Kavanagh, 2010; Rosser, Vowles, Keogh, Eccleston & Mountain, 2009; Waller & Gilbody, 2009). While more recent interventions have had greater success at retaining participants (Dear, et al., 2014) dropout typically occurs before the beginning of the programme in what is termed pre-treatment dropout (Christensen, et al., 2009; Farvolden, et al., 2005; Wangberg, Bergmo, & Johnson, 2008; Waller & Gilbody, 2009). A systematic review of barriers to the uptake of computerised CBT found that patients had a 38% chance of actually beginning an intervention they were recruited for, with the reasons for this statistic not well understood (Waller & Gilbody, 2009).

Christensen, et al., (2009) found that there was not one single, strong predictor of participant drop –out. Patients reasons for adherence to interventions is varied and often multifaceted including physical, psychological, social and emotional factors (Christensen, et al., 2009; Dimatteo, Haskard, Williams., 2007).

Another issue that needs to be addressed is determining the differences in effectiveness between face-to-face treatment and internet-based treatment for pain. In two reviews of internet-based interventions, effect sizes for internet based pain treatment were

found to be equal to those found for face-to-face therapy (Bender, et al., 2011; Cuijpers, et al., 2008). It may therefore, be equally effective to administer CBT for the treatment of pain over the internet as it is face-to-face.

Online interventions present their own unique set of challenges and limitations however it is clear that there are compelling reasons to consider delivering psychological interventions for pain online. In summary, the research shows that online interventions are a promising vehicle for the delivery of healthcare interventions with clear benefits for overcoming specific barriers to pain treatment.

Types of online intervention

The breadth of tools and techniques for online interventions means there is large variability in how they are defined. Internet intervention all have unique features however they can be loosely categorised into one of three types: guided, unguided and mobile applications (Rini, et al, 2012).

Guided interventions are unique in that they combine online content with regular contact from a health care professional. Professionals can guide the intervention, offer feedback and support and help users come to term with the techniques being offered in the intervention. The large majority of psychological interventions for pain are guided (Rini et al., 2012). Unguided interventions differ from guided in that they involve no contact from a health care professional. Unguided interventions require the patient to be self-directed while they navigate the course content.

Mobile applications are the final and least developed of the three fields of online interventions for pain. Interventions are delivered via applications to smartphone or tablet devices. Interventions using mobile applications are generally empirically untested; however as the usage of smartphones increases applications have huge potential to play an important

role in the delivery of healthcare interventions (Rini, et al 2012). Technology giant Apple also recently announced their new framework, ResearchKit (www.apple.com/researchkit). The ResearchKit includes a selection of applications to be used for collecting health related data further underscoring the important role that applications will play in the future of healthcare interventions.

The internet is a growing medium for healthcare initiatives. Internet interventions aimed at treating a variety of health problems have increased dramatically (Ritterband, et al., 2003). To date, research has investigated the use of online interventions for a vast range of health problems including smoking (Schneider, Walter, & O'Donnell, 1990), weight loss (Tate, Wing, & Winett, 2001), body image (Celio et al., 2000; Winzelberg et al., 2000), posttraumatic stress (Carlbring, et al., 2006; Knaevelsrud & Maercker, 2009), panic disorder (Kenwright & Marks, 2004; Kiropoulos, et al., 2008), tinnitus (Andersson, Strömberg, Ström, & Lyttkens, 2002; Kaldo, et al., 2008), diabetes management (McKay, Glasgow, Feil, Boles, & Barera, 2002), encopresis (Ritterband, et al., 2003), as well as anxiety and depression (Andersson, et al., 2005; Bee, et al., 2008; Christensen, et al, 2006; Clarke, et al., 2005; Gega, et al, 2007; Kenardy, McCafferty, & Rosa, 2003; Proudfoot, et al., 2004; van Straten, Cuijpers, & Smits, 2008; Wright, et al., 2005).

All of these studies have found promising evidence for the effectiveness in treating a variety of health problems using internet-based treatments. While results vary across different conditions and different treatment modalities, the general consensus is that there is strong support for the continued development of online interventions.

Online Interventions for pain

Pain treatments have not been neglected in the proliferation of online health interventions. Research has begun to investigate the effectiveness of internet-based treatment

for a number of different pain experiences including treating chronic back pain (Buhrman, Nilsson-Ihrfelt, Jannert, Strom & Andersson, 2011; Carpenter, Stoner, Mundt, & Stoeld, 2012; Chiazzi, et al, 2010; Krein, et al., 2013; Lorig, et al., 2002; Schulz, Rubinell, & Hartung, 2007) and headaches (Andersson, Lundstrom, & Strom, 2003; Strom, Petterson, & Andersson, 2000; Devineni & Blanchard, 2005; Trautman & Kroner- Herwig, 2010). These studies have showed improvements in a range of various factors such as pain catastrophizing, quality of life, pain symptoms, health education, chronicity, disability, depression, stress, physical activity, and severity of pain, as well as reduction in medical consultations and use of painkillers (Bendar, et al., 2011; Cujpers, et al., 2008). However, the studies' individual results greatly vary due to the application of various treatment modalities and differences in target populations (Bendar, et al., 2011).

CBT based interventions have dominated the field of online interventions for chronic pain. The aptly named "Pain Course" (Dear, et al. 2013) is a promising recent online intervention addressing chronic pain. The Pain Course is a comprehensive 8 week programme centred on cognitive behavioural therapy. Included in the course were five online lessons paired with lesson summaries and homework assignments with additional resources for specific areas such as sleep hygiene and managing attention. The Pain Course was not condition specific but designed to generally accommodate all individuals with chronic pain. A RCT of the Pain Course demonstrated the treatment group had decreased severity of pain, disability, and anxiety compared to wait-list controls. Encouragingly the improved outcomes were sustained at a three month follow up. The Pain Course also had a 96% adherence a further promising sign as online interventions are often plagued by high dropout rates.

Another CBT intervention, the longer "Pain Workshop", was developed by Brattberg (2006). This 20 week intervention consisted of viewing of 19 films of recorded discussions based on conversations with individuals from earlier pain workshops (including topics such

as “Crisis and Chaos” and “setting limits”) and taking part in a CBT based discussion group. Each week, participants watched one video and then answered a set of reflection questions. After this they then had the opportunity to discuss the videos with other group members via an online forum. At the end of the intervention participants had significant improvements in health, quality of life and an increased work capacity compared to wait-list controls however there were no significant differences in pain intensity.

Online CBT interventions are not restricted to adult with chronic pain. An online programme called web-based Management of Adolescent Pain (web-MAP) was developed for adolescents with chronic pain and their parents (Palmero, Wilson, Peters, Lewandowski & Somhegyi, 2009). Over the course of eight weeks participants completed online modules which included a range of subjects such as relaxation training, cognitive strategies, and parent operant techniques. The results were promising showing a decrease in pain intensity and activity limitation that was sustained at three months follow up. Additionally parent and children both found the course acceptable and helpful. Online interventions for pain can also be tailored to suit children and young adults.

There is potential for online interventions to supplement to prior pain treatments as a part of a multidisciplinary approach. Buhrman, et al., (2011) conducted a study that used eight week online CBT course as a follow up for individuals who had received prior pain treatment. Small but significant reductions were seen for catastrophizing but there were no significant differences between the treatment and active control group.

CBT has not been the only focus of online interventions for chronic pain. Berman, Iris, Bode, and Drengenberg, (2009) investigated a mind-body intervention for older adults with chronic pain. This intervention involved a detailed website that included six self-care modules grounded in complementary and alternative medicine (CAM) such as relaxation or

positive thinking. Participants were encouraged to log on and view the website at least once a week. The results were promising as compared to waitlist controls: participants in the intervention group had significant reductions in pain and improvement in awareness of responses to pain, pain intensity and pain interference.

Further recent research has looked at the online application of ACT (Burhman, et al., 2013). The ACT intervention consisted of seven modules that included: guided activities, mindfulness exercise audios, and access to a moderated online forum. Participants had an average pain duration of 15 years and upon completing the course had reductions in pain related distress, anxiety and depression and pain catastrophizing. At six months follow up the results were maintained indicating the benefits of continuing to develop and research ACT interventions for pain.

Mobile applications are a relatively unexplored area of online health interventions (Rosser & Eccleston, 2011) however with the increasing access to smartphones application are predicted to play an increasingly larger role in healthcare interventions. One empirically tested study investigated the use of pain diaries for individuals with chronic pain (Kristjánssdóttir, et al., 2013). Every day over the course of four weeks participants submitted 3 pain diary entries via smartphone an application. These diary entries were read by a therapist who could then provide tailored feedback to the individual. Individuals in the treatment group showed a decrease in catastrophizing compared to controls that was maintained at three months post intervention (Kristjánssdóttir, et al., 2013).

Meta-analytic reviews of online CBT interventions for pain have found that there is a small but clinically significant improvement for individuals who complete iCBT interventions for pain (Bendar, et al., 2011; Macea, et al., 2010). In another systematic review found comparable effect sizes for face to face treatment for online CBT and pain (Cuijpers, et

al., 2008). In summary, there are a large number of studies that have made use of the internet to deliver interventions that have shown a positive effect on pain. However the variety of effect sizes and approaches to the intervention mean that further work in this area is still warranted.

Online Mindfulness Interventions

There currently exists a plethora of online resources for those wanting to explore mindfulness practices. Guided mindfulness audios and applications are readily downloadable from sources such as itunes and available free to listen on sites like YouTube and Vimeo. There are also paid online courses where a user once signed up can receive guided tuition through skype calls (www.mindfullivingprograms.com). One prominent commercially available application is Headspace (www.headspace.com). Headspace offers a free guided meditation application in which participants are encouraged to take part in ten minutes of guided meditation for ten days before signing on to extended periods of mindfulness meditation at a cost. While all online mindfulness programmes tout the benefits of mindfulness meditation none of these courses has been empirically researched so their effectiveness and validity is unknown.

Online mindfulness interventions for addressing specific health conditions are still in their infancy and are relatively unexplored. This is unsurprising as both the fields of mindfulness and online interventions for health are relatively new. Two studies have analysed the feasibility of an online mindfulness intervention for reducing stress in a healthy cohorts.

Gluck and Maercker (2011) conducted a pilot study investigating the effects of a brief online mindfulness on stress. The mindfulness course spanned two weeks and included two modules. Each module required daily 20 minute sessions for six days. The sessions included audio files, animations and text to teach them mindfulness techniques. Medium effect sizes

were observed for reduction of stress and negative affect. Similar results were found in a longer online mindfulness course spanning four weeks that demonstrated significant reduction in stress in an uncontrolled study (Krusche, Cyhlarova, King and William, 2012).

Building on these studies Cavanagh, Strauss, Cicconi, Griffiths, and Wyper, (2013) conducted a RCT examining the effects of a brief online mindfulness intervention on stress in medical students. The mindfulness intervention was presented via a web page that included resources to explain mindfulness, a guided mindfulness audio and information surrounding frequently asked mindfulness questions. The intervention lasted for 14 days in which participants were encouraged to complete the 10 minute, guided audio meditation practice daily and received regular e-mails at three day intervals offering encouragement and reminding them to practice. Small to medium effect sizes were seen in reducing stress, anxiety and depression in students in the intervention group. Taken together these studies suggest that self-guided online mindfulness intervention are feasible and may offer benefits for individuals seeking stress reduction techniques.

Online mindfulness interventions for pain

Mindfulness components have been incorporated into online interventions for pain (Buhrman, et al., 2013; Kristjánisdóttir, et al., 2013). One study to date that has focussed exclusively on chronic pain is the mindful socioemotional regulation (MSER) intervention for pain coping in individuals with fibromyalgia (FM) (Davis & Zautra, 2013). MSER aims to encourage positive social and emotional experiences while also enhancing awareness and acceptance in FM patients. MSER intervention consisted of twelve, 15 minute modules. Each module was presented via adobe reader and contained written text, animation and recorded audio content and brief activities relating to the topic of the module. Modules covered a range of mindful socioemotional regulation topics including acceptance of emotions, mindful living

with pain and pacing yourself mindfully. Participants were given access to a new model when they had completed the previous one.

Results demonstrated that participants in the treatment group experienced improvements in their ability to cope with pain and stress, had increased social engagement and decreased loneliness. While there was no reduction in pain or negative affect there were clearly social and emotional health benefits for individuals with FM.

Conclusion of online interventions for chronic pain

Online pain treatments are a fast developing field that is still in infancy. While there is a huge positive potential, interventions need to be vigorously scrutinised so that we have the best possible outcome for patients. The huge variability features and materials of online interventions makes it hard to draw general conclusions about the medium as a whole however it is clear that online interventions could be a feasible, cost effective complementary or primary intervention for pain. As technology rapidly advances we should take the opportunity to make health care as accessible as possible, capitalising on the positive aspects of the internet while seeking to minimise any unique barriers that it might provide.

The current studies

This thesis aimed to explore presenting a mindfulness intervention for chronic pain via the internet. The effects of pain can be debilitating and even more so if treatment is inadequate, inaccessible, and expensive. With the ongoing advancement of technology comes the opportunity to reduce some of the barriers associated with pain treatment by implementing internet interventions. Research to date has indicated the effectiveness of implementing treatment online for a variety of health problems including chronic pain. Mindfulness techniques have also been shown to be a promising means of helping individuals reduce the negative impact of chronic pain. Three studies were conducted which include

developing and testing an online mindfulness course for post-arthroplasty pain, a qualitative exploration of arthroplasty patient's experiences with pain, mindfulness and the internet and finally an investigation into an online mindfulness course for amputees.

CHAPTER TWO

ONLINE MINDFULNESS INTERVENTION FOR POST ARTHROPLASTY PAIN

Persistent chronic pain due to arthritis is the predominant reason people seek total knee arthroplasty (TKA) and total hip arthroplasty (THA) (Liang, et al., 1986; Norman-Taylor, Palmer & Villar, 1996; Robertsson, Dunbar, Knutson & Lidgren, 2000). TKA and THA are considered effective treatments for both reducing pain and improving function (Jones, et al., 2000; Ritter, et al., 1995). Unfortunately, a significant subset of patients continue to experience chronic pain and reduced quality of life after joint arthroplasty (Kim, et al., 2009; Jones, et al., 2000; Escobar, et al., 2007) even in the absence of adverse clinical outcomes (Brander, et al., 2003; Harden, et al., 2003; Kennedy, et al., 2006).

Chronic pain post-surgery is common, affecting between 10% to 50% of post-surgical patients (Kehlet, Jensen, & Woolf, 2006). Surgery is also the second most common reason for patients attending pain clinics (Crombie, Davis, & Macrae, 1998). In joint replacements up to 44% of individuals experience moderate to severe chronic pain post TKA (Wylde, Hewlett, Learmonth, & Dieppe, 2011) with anywhere between 7-20% reporting severe to extreme persistent pain (Baker, van der Meulen, Lewsey, & Gregg, 2007; Brander, Gondek, Martin, & Stulberg, 2007; Puolakka, et al., 2010; Wylde, et al., 2011). Similar results are seen in THR with 27 % experiencing persistent pain post-surgery (Wylde, et al., 2011) and of those, 2-8% reporting severe to extreme pain post-surgery (Nikolajsen, Brandsborg, Lucht, Jensen, & Kehlet, 2006; Singh, & Lewallen, 2010; Wylde, et al, 2011).

There have been no studies investigating the use of mindfulness based interventions on post-surgical pain in joint replacement patients. As described earlier mindfulness based therapies have been identified as effective interventions for a range of physical and psychological conditions (Baer, 2003 Chiesa & Serretti, 2011; Veehof, et al., 2011). Mindfulness interventions can reduce pain and psychological distress in individuals with a

diverse range of ailments from chronic lower back pain (Morone, Greco, & Weiner, 2008) to anxiety and depression (Hofmann, Sawyer, Witt, & Oh, 2010). Mindfulness is also predictive of lower levels of disability and chronic pain (Cassidy, Atherton, Robertson, Walsh, & Gillett, 2012; McCracken & Velleman, 2010).

A recent study by Riddle, Wade, Jiranek, and Kong (2010) found that the only significant psychological predictor of poor outcomes post knee arthroplasty was pain catastrophizing. Catastrophizing is described as the exaggerated negative response to a painful experience (Cassidy et al., 2012). The tendency to catastrophize has been linked to more intense pain, increased emotional distress and pain related disability (Sullivan, et al., 2002). Interventions that target catastrophizing have real potential to improve patient outcomes. Mindfulness has been identified as a significant negative predictor of catastrophizing (Schutze, Rees, Preece, & Schutze, 2010). It is suggested that mindfulness can inoculate against pain catastrophizing and therefore lower the risk of disability (Kozak, 2008).

An intervention that aims to deliver mindfulness techniques would be highly beneficial for post-surgery recovery. A mindfulness based intervention would first serve to teach patients mindfulness skills which could be beneficial for dealing with their post-surgical pain and reducing the risk of continued chronic pain post-surgery. Delivering intervention online could be cost effective way to deliver a mindfulness interventions and allow it to be used in conjunction with other rehabilitation programmes (Rini, et al., 2012). Individuals recovering from a joint replacement surgery also have limited mobility so accessing an online intervention from the comfort of their own home would be a further benefit.

The aim of the current study is to develop and investigate the effectiveness of an online mindfulness-based intervention for post joint-replacement pain. An online mindfulness intervention, named the “Online Mindfulness Course for Pain” was developed to introduce mindfulness concepts to patients and encourage the use of mindfulness in their daily lives. This intervention can be considered an automated programme (Rini, et al., 2012).

Hypotheses

1. Participants in the intervention group will demonstrate a decrease in pain ratings immediately after the intervention.
2. Participants in the intervention group will demonstrate an increase in mindfulness compared to the controls immediately post intervention.
3. There will be a negative relationship between mindfulness and pain across participants.

The Online Mindfulness Course for Pain

The Online Mindfulness Course for Pain (OMCP) comes under the category of automated or unguided programmes (Rini, et al, 2012). Participants were required to complete the programme in a self-directed manner with no active involvement of any health care professionals. Ethical approval for this study was granted by the Northern B, Health and Disability Ethics committee (reference number: 13/NTB/136, 16.09.2013).

The intervention was modelled on the Pain Course (Dear, et al 2013) and consisted of four different modules. The modules were designed to be completed in sequence with the information of each new module building on that of previous weeks. Each module contained a questionnaire (or a series of questionnaires if it was week one) an introductory video, a guided mindfulness audio to listen to and a debrief video. When developing the course there

were many factors to take into consideration, including the content, the methods of content presentation and the length of time of the course (both overall and for each session).

Time Period of the Course

An important consideration when developing the intervention was the number and length of the mindfulness sessions to be presented to the participants. Regular, sustained practice is considered central to the practice of mindfulness (Kabat- Zinn & Hahn, 2009), however, there is no universally agreed upon “dose” of mindfulness. Research investigating the minimum required amount of mindfulness exposure and practice to achieve positive outcomes is inconclusive (Vettese, et al., 2009).

Generally mindfulness interventions promote extended practice based on the general idea of the more the better (Del Re, Fluckiger, Goldberg & Hoyt, 2012) but there appears to be a disparity between what is suggested for mindfulness practices (Kabat-Zinn et al., 1982; Kabat –Zinn & Hahn, 2009) and what is empirically known (Vettese, et al., 2009). A comprehensive review conducted by Vettese, et al., (2009) found that of 98 published mindfulness interventions reviewed only 24 evaluated the link between reported practice and clinical outcomes. Of those 24 studies 13 demonstrated at least partial support for the benefits of increased practice.

One of the most widely recognised mindfulness programmes is the Mindfulness-Based Stress Reduction programme (MBSR). It consists of 8 weekly, therapist lead, group sessions of 2.5 hours complemented with 45 minutes of home practice (6 days per week) and one all-day class. However sessions of this length were considered impractical for presentation over the internet and unlikely that participants would maintain focus or continue with the programme.

Evidence for dose-response effects in the MBSR is mixed. Carmody and Baer (2008) and Speca, Carlson, Goodey and Baer (2008) both found a relationship with increased practice and psychological wellbeing. However other studies have found no direct link between the amount of mindfulness practice time and positive outcomes (Astin, 1997; Carmody, Reed, Kristeller & Merriam, 2008; Davidson, et al., 2003).

In contrast to the extended time commitment of the MBSR a prominent commercial online mindfulness intervention (Headspace, <http://www.getsomeheadspace.com>) encourages participants to commit to just doing 10 minutes of guided mindfulness practice per day for 10 consecutive days before extending the practice to increasingly larger amounts. However no research has investigated if this is an effective means of increasing mindfulness.

The difficulty in quantifying a mindfulness dose is in part due to the fact that mindfulness interventions can contain many different components (for example the MBSR contains a combination of techniques such as yoga, breath meditation (Kabat-Zinn & Hahn, 2009) while others can consist 20 minutes a day for three days (Ziedan, et al., 2010). The research into mindfulness interventions also covers diverse populations from cancer patients (Speca et al., 2008) to participants who experience chronic pain (McCracken, Gauntlett-Gilbert & Vowles, 2007). This makes it difficult to draw general conclusions about the dosage and type of mindfulness practice required for best outcomes.

The presentation medium had to be taken into consideration when developing the length of each of the sessions. As this intervention was delivered online, completing all the tasks would be largely self-directed and therefore the time taken to complete the online course should not be a burden for participants.

The decision was made to have the mindfulness intervention reach a middle ground between the length of the MBSR and Headspace. One goal was to make this programme

comprehensive yet manageable to encourage participants to continue with all of the sessions and to ensure positive outcomes from the mindfulness exposure.

It was decided that the OMCP would span four weeks. It would consist of 4 sessions with one session to be completed each week. Each session was to last for a maximum of 30 minutes (including all components). This was considered by the researchers as a manageable amount of time for the participant yet enough to give a thorough introduction to mindfulness.

Throughout the duration of the course participants were strongly encouraged to partake in daily practice of the mindfulness techniques they had been taught with the mantra “one minute of mindfulness is better than none” however it was entirely at the discretion of the participants how much they practiced.

Structure of the intervention sessions

Considering that our participant pool would likely belong to an older demographic that are likely to be less familiar with navigating the internet, it was concluded that a successful intervention had to be easy to navigate, enjoyable, and concise.

Modelled on the method of presentation in the *Pain Course* (Dear, et al, 2013) it was decided that to best teach mindfulness techniques participants should first receive introductory material followed by a guided audio which they would follow along to and then finish with debrief information explaining the task they had just done, providing a case study of a person experience with mindfulness and a “take home task” or homework task which would provide participants with a way of further integrating the mindfulness concepts into their daily lives.

Platform

The Online Mindfulness for Pain course was delivered on the Dunedin Medical School's Moodle platform (Version 2.7, Moodle Pty Ltd, 2013). Moodle is an open-source Learning Management System that allows for a variety of content presentation types, user access control and questionnaire functions. This platform was chosen because it was easy to use and there was readily available access to people who had experience developing and modifying Moodle courses.

After signing up, participants were each assigned a unique username and password that allowed them to access the online programmes. The course information that each participant had access to was controlled by the researcher.

Access to the weekly modules was manually controlled by the researcher. Participants were only granted access to the following week once they had completed the previous week's session. Completion was measured by the participant logging on and completing the questionnaires assigned to that session.

Method of content presentation

Available resources and cost had to be taken into account when developing the intervention. Initially the introductory and debrief mindfulness content was to be presented to the participants using an embedded PowerPoint presentation. This was because it was free and there was no specific expertise required to develop a PowerPoint presentation and was based on similar usage in other internet interventions (Davis & Zautra, 2013).

This method of presentation was developed and piloted. This method presents written information and pictures on slides. Participants would have to click through and read each slide before they listened to the guided audios.

The slides for session one were presented to two informal focus groups. Both focus groups were recruited by the researcher via word of mouth. One group comprised of ten individuals, seven female and three male ranging in ages from 19-29 (median age 24) and the second consisted of eight individuals, four male and four female ranging in ages from 51-62 (median age: 54). Each group was presented with the slide show and were asked to give feedback and generally discuss the method of presentation. When the slideshows were presented to each group the resounding feedback was that the slides were not an engaging means of presentation. It was reported that there was too much content to get through and that people lost interest and didn't read all the slides. Individuals also commented that the PowerPoint method of presentation meant that they would be inclined to click through without reading the slides. Individuals also commented that they would be more likely to attend to the information if I was presented in a more engaging way using videos or animations.

In responding to this feedback the decision was made that the best method of presentation of the material would be using animated videos. While it would take a significant amount of time to develop these videos they were considered to be a far more user friendly and engaging way to present the mindfulness content.

All the videos (2 for each module) were created using the animation software Sparkol VideoScribe (<http://www.videoscribe.co>). The animations were first created and then the researcher recorded the voice over scripts and embedded them over the animations. The animations were then uploaded to a private YouTube channel belonging to the researcher. Videos were then shown in an informal setting to two separate cohorts. The first was to a group of five adults between the ages of 19-25 (median age: 24). The second was to a group of 5 adults between the ages of 51-82 (median age: 55). Feedback was sought on the content

and design of the videos and they were modified accordingly. All the participants except two (one from each group) had viewed the intervention in the PowerPoint format. The overwhelming feedback was that the videos were a much more engaging way to present the information and participants preferred the animated videos to the PowerPoint slides. After the final modifications the final updated videos were embedded onto the Moodle platform in the appropriate weekly section.

Questionnaires

Questionnaires were selected to accurately measure participant's pain and mindfulness levels. The surveys were recorded and stored using the online survey tool; Survey Monkey (<https://www.surveymonkey.com>). Survey Monkey was chosen to deliver the questionnaires as it was free to use and each of the surveys could easily be embedded into the Moodle platform.

Each set of questionnaires were embedded onto the session's page. Questionnaires were the first item presented to the participants and they were requested to complete them before they moved down to the mindfulness activities.

At the beginning of module one, participants were required to complete a set of questionnaires that included a demographics questionnaire (appendix A), and a comprehensive questionnaire package (appendix B) that included the following scales:

McGill Pain Questionnaire (short form). The McGill Pain Questionnaire (short form) is a widely used tool to measure pain (Melzack & Katz, 2001). It consists of fifteen descriptors which participants rate on a scale of 0 (none) to 3 (severe). Adjectives are ordered according to intensity and assigned different values within their subscales. Higher scores are indicative of increased pain levels.

Short Version of the Depression Anxiety Stress Scale (DASS-21). The DASS-21 is used to measure negative emotional states of depression, anxiety and stress (Henry & Crawford, 2005). The DASS-21 consists of 21 items divided equally across three separate scales: depression, anxiety and stress.

Tampa Scale of Kinesiophobia-11 (TSK-11). The TSK-11 is the shortened version of the Tampa scale of Kinesiophobia (Kori et al., 1990) and is a frequently employed measure for assessing pain related fear in patients (Woby, Roach, Urmston & Watson, 2005). It consists of 11 items which patient's rate on a 4 point Likert scale with the options of "Highly disagree", "Somewhat disagree", "Somewhat agree", "Highly agree".

Pain Anxiety Symptoms Scale-20 (PASS-20). The PASS-20 (Roelofs et al., 2004) is a short form of the Pain Anxiety Symptoms Scale (PASS) and is used to assess four separate components of pain related anxiety (cognitive, fear, escape/avoidance, physiological). Participants rate how often they engage in each of the 20 thoughts or behaviours 20 statements with zero being "never" and five being "always". Higher scores of each of the subscales is said to indicate high levels of pain related anxiety.

Mindful Attention and Awareness Scale (MASS). The MASS is considered the best current measure of the mindfulness level of an individual (Brown and Ryan, 2003). It consists of 15 items rated on a 6 point Likert scale (1= almost always and 6= almost never) with higher scores pertaining to a great present moment awareness.

Brief Pain Inventory (BPI). The BPI (Cleeland, 1994) is used to measure an individual's pain levels. It consists of a series of questions pertaining to an individual's current pain and average pain to be ranked in a Likert scale of zero (no pain) to ten (as bad as they can imagine). Participants also have to rate of a likert scale how much their pain it has affected aspects of their daily life.

In modules two, three and four participants were only required to complete the BPI before continuing onto the mindfulness activities for that week. One week after the final module had been completed participants were again requested to complete the comprehensive questionnaire package and the BPI. One week after the completion of module 4 participants had to again complete the comprehensive questionnaire and the BPI.

Online Mindfulness Course Content

The content in each of the four modules was drawn from suggested mindfulness explanations and exercises from mindfulness programmes developed by Kabat-Zinn and Hahn (2009), Harris (2009), Segal, et al., (2002), Sadler, (2009) and through discussion with mindfulness practitioners. Although the modules cover the general idea of mindfulness, they were also designed with a specific focus on teaching participants how to use mindfulness to work with any pain they are currently experiencing

All the mindfulness techniques used in the intervention (e.g. body scan, mindful breathing etc.) are widely accepted and used by mindfulness practitioners to develop mindfulness (Kabat-Zinn & Hahn, 2009; Harris, 2009; Segal, et al., 2002; Sadler, 2009). No current research exists concerning what specific mindfulness techniques are more effective or better at increasing mindfulness. However it was reasoned that presenting a range of different mindfulness techniques gave participants exposure to variety of techniques to cultivate mindfulness. All course content including animations, audios, and homework tasks were validated by a registered clinical psychologist who was also a mindfulness practitioner. The outline of each of the modules is detailed in the table below.

Table 1. Module content for the OMCP.

Module	Audio (running time)	Practice task	Questionnaire	Total animation run time(minutes)
One	Breathing meditation (5 mins)	Take 5	Demographics, Comprehensive and BPI	12.9
Two	Mindfulness for working with difficulties (7 mins)	Mindful daily routines	BPI	8.65
Three	Body Scan (9 mins)	Mindful eating	BPI	6.2
Four	Loving kindness meditation (17 mins)	Mindful walk	BPI	10.34

Introductory and Debrief Animations

The animations served to introduce and reinforce the concepts of mindfulness. The introductory animation for the first module introduces the key concepts of mindfulness practice and why it is relevant. The other four introductory videos for modules 2, 3, 4 served to reinforce the mindfulness concepts discussed in earlier sessions and provide new metaphors and ways of understanding mindfulness.

The debrief animations to be watched after the guided audio had been listened to contained further explanations about the guided mindfulness activity that had just been completed, a case study detailing an individual's experiences with mindfulness techniques and an explanation of that week's take home task.

The explanations and metaphors used to describe mindfulness are all adapted from descriptions in Kabat-Zinn and Hahn, (2009), Harris (2004), Segal et al., (2001) and Sadler (2009). Once the animation scripts (Appendix C) had been developed the content of the each one was reviewed by a registered clinical psychologist who was also a mindfulness practitioner and offered suggestions. Alterations were made to the scripts before the voice overs were recorded and included in the animations.

Case Studies. Each debrief video contained a case study which was a description of a specific individuals experience with mindfulness. The case studies were developed by the researcher however they were based on common experiences and challenges faced when practicing mindfulness. The use of case studies was to make the mindfulness techniques more relatable, encourage them to practice and to aid in their understanding of mindfulness.

An example of a case study in Module three where participants hear a testimony from “Greg” about his experiences with mindfulness. Below is a sample of “Greg’s” testimony.

“It meant I would have to move (rearrange my knee) and I just wanted to change the channel to stop watching the ridiculous show that had just came on. It was also like dropping the remote made my knee hurt more. I think when you’re in a little pain even small things just get harder and you get that immediate rise of irritation over something that would normally be an inconvenience. “

Homework Tasks. The debrief video for each module also contained a homework task. Homework tasks are included in numerous interventions both online (Dear, et al, 2013) and offline (Carmody and Baer, 2009). The aim of the homework tasks was to help the participants integrate mindfulness practices into their everyday life. The homework tasks can be classified as informal mindfulness practice (i.e. not at a specific assigned time).

The homework tasks are an important bridging step to bring the mindfulness techniques learnt in formal guided mindfulness practice (in the case of the current intervention the audios) to the individuals everyday lives (Kabat- Zinn & Hahn, 2009).

While the literature on the amount of homework required in mindfulness practice is inconclusive (Vettese, et al., 2009) the research surrounding the homework in cognitive behavioural therapy (CBT) suggests that individuals have better psychological outcomes if they complete assigned homework (Kazantzis, Whittington, & Dattilio, 2010; Scheel, Hanson, & Razzahavaikina, 2004) therefore it was appropriate to include basic homework tasks for the participants to complete.

One example of a homework task from Module Three was ‘Mindful Eating’. For this homework activity participants are encouraged to try and eat one meal mindfully. Instructions such as “*Observe the food you have in front of you. Notice the different colours and textures of the food. How does the light bounce off different parts? What are the contours?*” shows participants how they could use mindfulness techniques in their daily lives.

The content of each of the homework tasks is described in the video animations (Appendix C). Participants were also able to download and print infographics which summarised the homework activity (Appendix D).

Audios

Each module contained a guided mindfulness audio. This made up the main part of the formal mindfulness practice that the participants had to complete in each module.

All of the audios included were already developed by recognised mindfulness practitioners. Three of the guided audios (week 1, 2 and 4) were taken with permission from the University of California Los Angeles, Mindful Awareness Research Centre

(<http://marc.ucla.edu/>). They were developed and narrated by Centre's director Dr Diana Winston. The body scan guided audio contained in the week three module was produced by Dr Lisa Rambaldo from the Department of Family Medicine, University of Wisconsin (<http://www.fammed.wisc.edu/our-department/media/mindfulness>).

The guided exercises got progressively longer as the modules progressed. As participants became more familiar with mindfulness techniques they could extend their practice times. The audios were embedded in the module below the introductory video for that week. Participants had to click on the large button that said "Click to Play Week 1 Audio" and the audio would begin playing immediately. There was a control panel that would appear when the audio was playing allowing the participant to pause, stop or skip backwards or forwards with the audio. Participants were also able to download the audios so that they could listen to them offline at whatever time they wanted to.

Additional Resources

At the end of the Week One module, participants were provided with a practice chart that they could print off and fill in to help them monitor their mindfulness practice (Appendix E). At the end of Module Four participants were provided with an Additional Resources PDF for viewing and printing. This PDF contained a list of other books, website and resources that the participants could access if they wanted to continue to expand their mindfulness practices and knowledge (Appendix E).

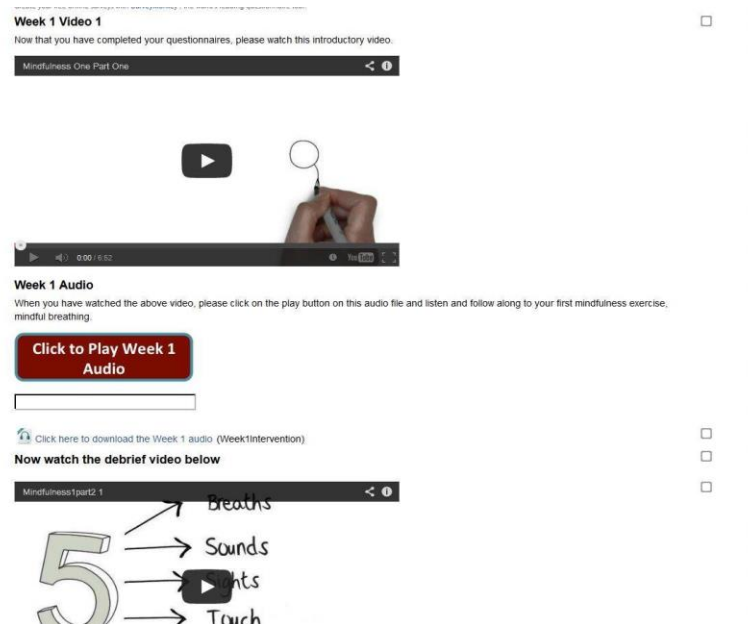


Figure 1. A screenshot of the online intervention showing what the participant would have seen after they had completed the initial questionnaires.

Recruitment

Participants were recruited from a Hip and Joint Education Clinic that was organised by the Southern District Health Board. The clinic is run fortnightly and is for patients who were scheduled to have a knee or hip joint replacement surgery within 4 weeks of the clinic. Attendance at the clinic was not compulsory however patients were strongly advised to attend. Nursing staff estimate that roughly 90 percent of joint replacement patients attend however no statistics are available.

Participant's surgery date from the time of the clinic was variable; most patients were scheduled for surgery within 2 weeks of the clinic however the delay between the clinic appointment and the time of the surgery varied for each participant.

The clinic was designed to inform the patients about the procedures and requirements of their upcoming surgery. Patients first listened to members of the nursing, physiotherapy and occupational therapy teams inform them of what to expect post -surgery and what

preparation they should do for their upcoming surgery. Patients were then addressed by the researcher who gave them a brief 5 minute overview of the study and explained what their participation would require and invited them to take part. Inclusion criteria was that participants must have access to the internet for the duration of the course and must have adequate English comprehension.

When patients were waiting to talk individually to the physiotherapist or occupational therapist they were approached by the researcher and offered information sheets and consent forms (Appendix F). Participants were then given the opportunity to ask the researcher any questions and to discuss the project. They were encouraged to fill out the consent form.

If participants requested more time before giving consent they were invited to leave their contact details for the researcher to get contact them at a later date

Procedure

Once participants were enrolled in the study they were randomly assigned to one of two groups; either the intervention or the control condition. Random assignment was conducted by another researcher in the Department of Psychological Medicine who had no other involvement in the study. At the time of entering the study participants were assigned a number that corresponded to the order they entered the study. Randomisation was done via a random assignment programme on GraphPad software. There were two groups: Group 1 being the control condition and Group 2 being the intervention condition.

The average stay in hospital post joint replacement surgery is four days. On the day of their operation a detailed information packet (Appendix G) describing how to access and navigate the online programme was mailed to the patient's postal address. Patients were not given access (i.e. unable to log in to the online site) until one week after their surgery.

Seven days after their surgery patients received a call from the researcher. The researcher inquired as to how their recovery was going and if they had received the information packet in the mail. They were then invited to log in and complete week one of the online programme if they hadn't done so already. Participants were asked to get in contact with the researcher if they had any problems with accessing the intervention online.

If participants had not completed the online component within four days of their first contact they were given another reminder call and sent an email to ask them to complete the online course. In total three reminder contacts were made. If after the third contact participants still didn't complete the intervention they were considered to have dropped out of the study.

Each week a new session was made available and participants were called to inform them of this. As with week one, three reminder contacts were made if needed.

Wait List Control Condition. The intervention included a wait list control. Participants in this group also received access to the online platform however under each module they could only access and view the questionnaires. Each week participants in this condition were required to log on and to complete the required questionnaires for that module.

At the completion of 5 weeks the control participants were given access to all of the mindfulness content from each of the modules. They were mailed out a detailed instruction sheet advising them how to use the intervention (Appendix G) and advised to contact the researcher if they had any problems or concerns.

Participants

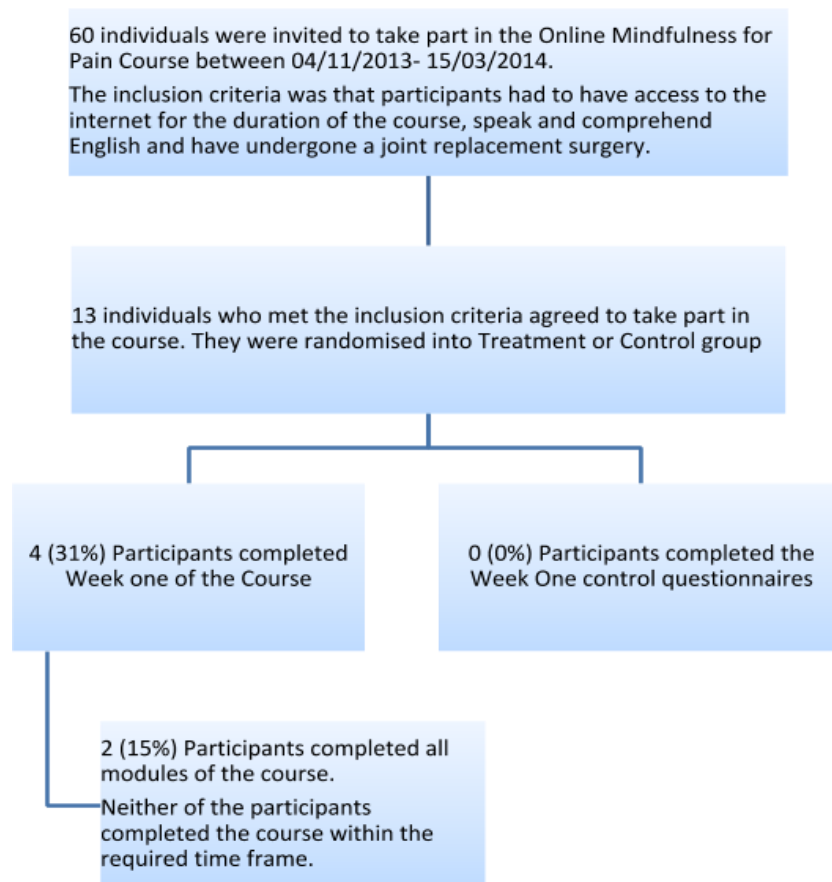


Figure 2. Flow chart detailing the participation in the OMCP

Results

Adherence and Completion

Thirteen individuals were recruited to take part in the intervention study after receiving joint replacement surgery. Seven of these participants were allocated to the intervention condition and six were allocated to the control.

Four participants (all from the intervention group) logged on and completed the first week of the course, of these, two participants completed all four weeks of the ‘Online Mindfulness Intervention for Pain’ course. Both of these participants completed the intervention outside of the time parameters assigned by the researcher. One participant completed the course 3 weeks after their assigned completion time and the other participant completed the course 4 weeks after the assigned completion time.

Only one participant completed the final set of questionnaires at week five. None of the participants allocated to the control group completed week one of the questionnaires or any further parts of the course.

Participants. There were no significant differences at week one for, pain, fear of movement, depression, anxiety, pain catastrophizing or mindfulness ratings between the two participants who completed the course and those that did not continue after week one. The two participants that did complete the course were the two youngest of the cohort being 53 and 58 respectively.

Reasons for participation. When the two completers were questioned on their motivation to complete the course one participant remarked that they themselves had conducted research in the past and aware of the difficulties in recruitment wanted to help the researcher. This participant was also interested in mindfulness techniques and thought that they could be beneficial. The second participant completed the course because he had a general interest in

mindfulness techniques and wanted to have the fastest recovery possible. The reasons for the two participants dropping out after the first module are unknown.

Discussion

Low recruitment numbers and high dropout meant that this study failed to collect adequate data. No conclusions about the effectiveness of the OMCP could be drawn, and therefore none of the hypotheses were supported. Thirteen individuals were recruited to take part in the intervention study after receiving joint replacement surgery. Only four participants completed week one and of those, two went on to complete the course. There were no significant differences between the two participants who completed the course and those that did not continue after week one. Participant's pain, fear of movement, depression, anxiety, pain catastrophizing and mindfulness ratings were all similar.

There are a range of possible reasons for participants failing to complete the intervention including: a lack of motivation, beliefs about the intervention or online medium, inability to navigate the online site, and bad or irrelevant content (Christensen, et al., 2009; Waller & Gilbody, 2009). The small sample makes it difficult to draw solid conclusions about why participants failed to complete the intervention however it is still possible to speculate on potential reasons for dropout occurring.

Consistent with previous research, the majority of dropout in study one occurred before participants even began the online intervention (Christensen, et al., 2004; Farvolden, et al., 2005; Wangberg, et al., 2008; Waller, & Gilbody, 2009). A systematic review of barriers to the uptake of computerised CBT found that patients had a 38% chance of actually beginning an intervention they were recruited for, with the reasons for this statistic not well understood (Waller & Gilbody, 2009). This pre-treatment dropout is important to note because it would suggest that it was not the content of the intervention or navigating the

online medium but instead either accessing the intervention, beliefs about the intervention content, beliefs about the online medium or a combination of these three factors, which prevented participants from completing the OMCP course.

The reasons that patients fail to adhere to interventions are varied and often multifaceted, and include physical, psychological, social and emotional factors (Christensen, et al., 2009; Dimatteo, et al., 2007). Online interventions are typically challenged with high dropout rates ranging from between 2-83% (Christensen, et al., 2009; Melville, et al., 2010; Rosser, et al., 2009; Waller & Gilbody, 2009). Adherence and dropout in online interventions is not well researched or understood. A systematic review conducted by Christensen, et al.,(2009) found self-reported reasons for dropout in online interventions was for a vast range of reasons including: time constraints, lack of motivation, technical or computer access problems, lack of face to face contact, preference for medication, perceived lack of treatment effectiveness, improvement in condition and the burden of the programme. However the authors found no single, strong predictor of dropout. A further systematic review that focussed on adherence in computerized CBT interventions found that personal circumstance was more likely to contribute to drop out than technological problems (Waller & Gilbody, 2009). Despite calls for a more detailed investigation into adherence and attrition in online interventions (Christensen & MacKinnon, 2006; Eysenbach, 2005; Melville, et al., 2010) there is limited research into it this issue. Online studies primarily focussed on supporting the validity of specific online interventions and not reasons for adherence.

Lack of post-surgical pain

A potential reason for participants choosing not to log in a complete the course could have been their lack of post-surgical pain. A lack of severe pain may have led to decreased motivation to complete an online course specifically targeting pain. Disease severity is a predictor of patient adherence: a meta-analysis conducted by DiMatteo, Haskard, and

Summer (2007) found that individuals with poorer health outcomes in conditions rated as low seriousness are more likely to adhere to an intervention while the reverse is seen in conditions of high seriousness. It is possible that if participants were not experiencing significant pain they might have believed that investing their time in an online intervention was irrelevant and therefore were not motivated to complete the intervention.

Individuals who undergo a joint replacement are subject to post-surgical pain. Up to 44% of individuals experience moderate to severe chronic pain post TKA (Wylde, et al., 2011) with anywhere between 7-20% reporting severe to extreme persistent pain (Baker, van der Meulen, Lewsey, & Gregg, 2007; Brander, et al., 2007; Puolakka, et al., 2010; Wylde, et al., 2009; Wylde, et al., 2011). Similar results are seen in THR with 27 % experiencing persistent pain post-surgery (Wylde, Hewlett, Learmonth, & Dieppe, 2011) and of those, 2-8% reporting severe to extreme pain post-surgery (Nikolajsen, et al., 2006; Singh, & Lewallen, 2010; Wylde et al., 2009; Wylde, et al., 2011). It is possible that the small sample failed to adequately capture participants that experience severe post-surgical pain and are thus motivated to use the intervention.

All participants who were allocated to the control condition were aware that they would receive access to the online mindfulness course at five weeks post-surgery. None of the participants who were allocated to the control condition logged on to complete the first week questionnaire. As none of the participants even logged on to the site it cannot have been the length or the tedium of completing the questionnaires that dissuaded the participants from completing the questionnaire and thus gaining access to the intervention. It could be speculated that if the participants were not experiencing severe pain or did not believe that mindfulness would be beneficial for them either at that time or in the future, they would be disinclined to complete the online questionnaires and thus receive access to the mindfulness intervention.

Beliefs about the course content and online medium

Another possible reason for the lack of uptake of the online intervention is individual's beliefs about mindfulness meditation or psychological treatments for pain. An individual's beliefs about a health care intervention can influence their desire to start and continue on with a healthcare intervention (Ajzen, 1985; Rosenstock, Strecher & Becker, 1988; Weinstein, Rothman, Sutton, 1998). If individuals held the belief that mindfulness techniques would not be beneficial for their pain they would be disinclined to take part. Participants were given sufficient information detailing what mindfulness was before the intervention so it could be assumed if participants did not believe in the effectiveness of the intervention content they would have not signed up initially. No previous research has investigated individual's general beliefs about mindfulness mediation (prior to participating in a mindfulness intervention).

Participant's beliefs about the online medium also could have prevented them from taking part in an online intervention. If participants did not believe that a mindfulness intervention could be effectively delivered via the internet (i.e. perhaps they believed interventions require face to face contact) then they would be unlikely to participate. An investigation into primary care participants demonstrated that 49% would consider using an online treatment suggesting that there is definite interest in using online interventions (Mohr, et al., 2010). As with the mindfulness components of the course, participants were aware that the intervention was being presented online. It would be assumed that if participants did not believe in the effectiveness of the online medium they would not have originally consented to take part in the intervention or that they would have attempted the intervention before discontinuing use.

Technological challenges with accessing the intervention

Technological challenges including accessing the intervention online and navigating the online site may have also contributed to low adherence. While participants had to have access to the internet to be included in the study, just having access to the internet does not account for an individual's ability to interact and navigate online content. If participants did not feel confident in their computing skills they might have been disinclined to participate. However it seems unlikely that this is the case for low adherence to the programme as most participants did not even log on to the first week.

Steps were also taken to ensure even participants with limited computer skills could access and use the intervention. All participants were mailed detailed instruction sheets explaining at a very basic level how to log on and access all the different parts of the online site in a logical step by step fashion. Participants also received both phone and SMS/email contact from the experimenter in the first week of the intervention encouraging them to log on and asking if they needed any help with the intervention.

One technical challenge that could have affected the online intervention was also impeded by a system upgrade that occurred to the operating system. This upgrade made the online intervention inaccessible for five days. Two participants tried to log on during this time and alerted the researcher to the inaccessibility however when the problem was resolved neither of the two participants continued to access the site. Technical issues are inevitable with online interventions especially those that are newly developed. However this technical problem might have further dissuaded participants that were already unmotivated to complete the course. With such a small sample size the loss of two participants is significant.

The usability and interface of an online intervention plays an important role. Eysenbach, (2005) noted that poor quality interfaces and unintuitive design of online

interventions could result in increased dropout. Again however as the large majority of participants did not even log on to the intervention it seems unlikely that it was the online interface that resulted in the pre-treatment dropout. However, while we know that four participants logged onto the site, we do not know how many of the participants tried to log on or perhaps tried to access the online site but could not for whatever reason get to the log-on page. It also seems unlikely that this is the possible cause of the high pre-treatment dropout as participants had multiple opportunities to inform the researcher that they could not access the online site.

The age of participants could also have been a contributing factor to the pre-treatment dropout. The mean age of individuals who receive joint replacement surgery is 70 years (Carr, et al., 2012). Although age is potentially a factor, previous research into online healthcare interventions demonstrates that older adults (individuals over the age of 60) have greater adherence rates in online programmes for smoking cessation (Japuntich, et al., 2006) and weight management (Verheijden, et al., 2007). These two studies indicate that including older adults in a cohort could lead to better adherence. Many seniors have embraced the internet and an increasing number are competent users of online technologies (Wagner, Hassanein, & Head, 2010; Wood, et al., 2005).

Techniques for encouraging adherence

Researchers have suggests that the use of “push reminders” that is, phone calls, SMS messages, and emails reminding participants to participate are beneficial for promoting participation in online interventions (Clarke, et al., 2005; Eysenbach, 2005; Ritterband et al., 2005; Wangberg, et al., 2008). Several systems were put in place in the current study to encourage participants to use the intervention and support them throughout. In the week after their surgery participants were mailed a detailed information package providing them with clear and logical instructions on how to access the intervention programme online.

Participants also received an introductory phone call from the researcher one week post their surgery confirming that they had received the information package and encouraging them to log on to the intervention (if they had not already) and asking them to contact the researcher with any problems. If after this contact participants still had not logged on to the intervention they received one text/or email (two days post the first phone call) and one further phone call (five days post the first phone call) encouraging them to log on to and complete the programme.

This level of repeated contact did not appear to encourage logging on and completing the programme however it was theorised that further contact could have been irritating to the participants and it was sufficient to conclude that after three contacts if participants had not logged on they were not going to complete the intervention.

The use of incentives (e.g. prize packs, monetary rewards, vouchers) has also been suggested to encourage intervention utilization (Eysenbach, 2005; Munoz et al., 2006). This study did not use any incentives to encourage individuals to participate. Future research could include using rewards or prize packs to motivate individuals to complete the online intervention. While ideal for collecting data on an intervention the use of incentives is not necessarily indicative of real world uptake and may mask adherence and dropout rates that would be seen in real world situations.

Timing of the intervention presentation

A further possible reason for the failure to complete the intervention is that recruitment and testing for the study were conducted over the months of November until March. This encompassed the holiday period in New Zealand including the Christmas and New Year celebrations. This time is traditionally associated with visiting family and vacations. The combination of holiday activities and recovering from surgery could have

made participants less inclined to partake in the online intervention especially if they did not feel that they already lacked motivation to complete the intervention. While the time of the year should not affect the intervention use, the time that the intervention was rolled out in this study combined with small sample size may have hindered uptake.

Time Constraints

Neither of the participants completed the intervention within the time parameters set by the researcher. The ability to complete an intervention in their own time at their own pace has been identified as one of the potential benefits for online interventions (Bender, et al., 2011; Rini, et al., 2012). It is possible that the time allocated to complete the modules (a week) was too short and participants required a more flexible time period to complete the modules in. Further research could examine if participants need more than one week to complete modules and if this affects the quality of the intervention.

Future Research

The online intervention for pain could better serve joint arthroplasty patients if it was offered at a different time in the course of their chronic pain and surgery. It could be argued that it would be better to offer the online intervention prior to participants receiving surgery. One of the eligibility criteria for joint replacement surgery is chronic pain thus giving participants increased motivation to complete the intervention. Participants could also gain valuable mindfulness skills which could then be applied to any pain they experienced post-surgery. Recruitment prior to surgery was investigated before the initiation of this study however it was concluded that gaining access to and recruiting individuals prior to surgery would have been difficult within the required time frames and access constraints.

Another time where it could be better to offer the online intervention could be 3-6 months post joint replacement surgery. If participants were part of the cohort still

experiencing chronic pain post-surgery the might receive greater benefit and be more motivated to complete the online intervention.

The OMCP could also be successful for other pain conditions. While it may not be suited to individuals with post-surgical pain it may be appropriate for different conditions such as osteoarthritis, fibromyalgia or chronic lower back pain. Trialling the online course on these conditions could yield further results about the use of mindfulness and online treatments for individuals with chronic pain.

Further research is also needed into the pain experiences of individuals both prior and post joint replacement surgery and their beliefs surrounding mindfulness and online interventions. This would provide valuable insights into individuals experiences and help to inform the development of intervention for post-surgical pain.

Additional research could also investigate successful methods to both recruitment and maintain adherence to online interventions. One of the problems with the current study was encouraging individuals to begin the programme. Best practice techniques to prevent drop out would be incredibly beneficial for the future development of online healthcare interventions.

Conclusions

Pre-treatment dropout was a large challenge to the current intervention. The high drop out at the beginning of the programme and low adherence seen in this study is not unusual for online interventions. Reasons for this drop out before even logging on to the intervention are not well understood but could be related to a combination of factors including lack of motivation (possibly due to reduced pain levels) and beliefs about mindfulness or the online medium. A clear barrier is getting participants to complete the earlier sessions and experience the online course. Understanding reasons for adherence and drop out is important for the continued development of online interventions.

While this study failed to recruit and maintain participants in the online course it cannot be concluded that the intervention does not offer potential benefit for post-surgical patients. High levels of mindfulness are associated with decreased levels of disability and chronic pain (Cassidy, Atherton, Robertson, Walsh, & Gillett, 2012; McCracken, & Velleman, 2010) therefore including mindfulness training post-surgery could still be beneficial for decreasing the risk of developing chronic pain and improving recovery time.

CHAPTER THREE

QUALITATIVE STUDY OF PAIN EXPERIENCES IN JOINT REPLACEMENT PATIENTS

As noted earlier, persistent chronic pain due to arthritis is the predominant reason people seek total knee arthroplasty (TKA) and total hip arthroplasty (THA) (Liang, et al., 1986; Norman- Taylor, et al., 1996; Robertsson, et al., 2000).

In New Zealand the Clinical Priority Access Criteria (CPAC) is used for determining who qualifies for a joint replacement surgery and will be placed on the waiting list (McLeod, et al., 2004). Individuals must be referred to an orthopaedic surgeon for assessment on a series of standardised checklists. If participants are scored above a specific threshold they are considered eligible for surgery. Patients must receive surgery within five months of being on the waiting list (Gwynne-Jones, 2013).

TKA and THA are considered effective treatments for both reducing pain and improving function (Jones, et al., 2000; Ritter, et al., 1995). Unfortunately, a significant subset of patients continue to experience chronic pain and reduced quality of life after joint arthroplasty (Kim, et al., 2009; Jones, et al., 2000; Escobar, et al., 2007) even in the absence of adverse clinical outcomes (Brander, et al., 2003; Harden, et al., 2003; Kennedy, et al., 2006).

Pre-surgical pain also needs to be managed as effectively as possible. Pre-surgical pain is not only distressing but can also impact post-surgical recovery. In THA and TKA higher levels of pre-surgical pain is a predictor of greater levels of pain post- surgery (Fortin, et al., 1999; Sullivan, et al., 2009). Greater pre-operative pain is also predictive of complex regional pain syndrome at three and six month's post- surgery in TKA patients (Harden, et al., 2003). Chronic pain is also associated with a decreased quality of life (Dysvik, et al.,

2004; Lame, et al., 2005; Schlenk et al., 1997). Individuals with a lower quality of life before receiving surgery also experience higher levels of pain post-surgery and slower recovery times (Fortin, et al., 1999, Mahon, et al., 2002).

Previous qualitative research has explored general patient experiences before receiving a total joint replacement. The journey to receiving a THA or TKA is often characterised by an extended battle with chronic pain, rapid reduction in quality of life and the reluctant increase of medications (Demierre, Castelao & Piot-Ziegler, 2011; Fujita, Makimoto, & Hotokebuchi, 2006; Hall, et al., 2008; Hawker, et al., 2008; Montin et al., 2002).

Understanding individual's pre-surgical and postsurgical pain and their pain management is important to the success of post-surgical recovery long term as well as a priority for individuals quality of life. The aim of this study was twofold. Firstly, to conduct an in-depth investigation of patients' experiences with pain before and after their knee or hip replacement surgery. Secondly, to explore individuals beliefs and attitudes towards internet intervention for pain and mindfulness techniques.

Method

A semi-structured interview (Appendix H) was developed to explore the participants experiences and thoughts surrounding their pain experiences, the use of internet interventions for pain and the use of mindfulness as a treatment for pain.

The semi structured interview is one of the most commonly used techniques for the collection of qualitative data (DiCicco- Bloom & Crabtree, 2006; Hale, Treharne & Kitas, 2008; Smith, 2008; Smith, 2011) and is based on a series of predetermined, open-ended questions (Britten, 1995; Smith, 2008; Smith, 2011). These questions can be accompanied by qualifying questions to prompt more detailed responses from the interviewee. The semi structured

interview also allows for flexibility in the interview style so that questions that arise from the conversation between the interviewer and the interviewee can also be included (Murray, et al., 2009; Smith, 2008; Smith, 2011).

All of the interview questions and the overall structure of the Experiences of Pain interview were reviewed and approved by a clinical psychologist. The first section explored the interviewee's current knee/hip pain. Questions aimed to investigate individuals:

1. Pain sensations
2. How pain affected their daily life
3. How they managed pain in the past and present
4. How interviewees conceptualised their pain and what factors contributed to their pain experience.

Examples of questions in this section are "*Can you tell me about your current knee/hip pain?*" followed by qualifiers like "*How did the pain in your knee/hip begin*" and "*Where else do you currently experience pain? When, and for how long?*" The Pain section of the interview was the longest and contained eight questions including qualifiers.

The second section of the Pain Experiences Interview investigated the interviewee's views on using the internet to receive pain treatment. Aspects covered include:

1. Any barriers they perceived in using an internet-based intervention
2. Whether there were ways in which these barriers could be overcome
3. Whether there is any other form of treatment (aside from the internet) that would be useful for the interviewee
4. How much time each week they would be willing to contribute to their pain treatment

Examples of questions in this section include:

“Do you think you would use an internet based pain treatment?” with the qualifiers *Why/why not?* The internet interventions section of the pain interview was the second largest consisting of six questions including qualifiers.

The final section of the interview addressed the interviewee’s views regarding mindfulness as a treatment for pain. Specifically:

1. What did they already know about mindfulness?
2. Whether they would be interested in trying mindfulness to manage their pain.

This included questions such as: *“Have you heard of a technique called mindfulness?”* with the qualifier *“What can you tell me about mindfulness?”*

The interview ended on one final general question: *“Overall, how satisfied are you with your life right now?”* This was put in place to finish the interview in a positive way and bring the interviewee back to the positive experiences in their life at the present time. At the completion of the interview participants were thanked for their contribution and wished a successful recovery.

Participants

Twenty people, eight males and twelve females, aged 55 to 82 years (median age: 68) participated in the interviews. One participant identified as Māori and the remaining participants identified as New Zealand European. Two of the participants held a postgraduate degree, six held an undergraduate qualification, eight had a trade certificate and four had school certificate or equivalent. All participants were receiving surgery for arthritic degeneration in their hip or knee joints. Eleven of the patients were undergoing knee replacements and nine were receiving hip replacements. Ethical approval for this study was granted by the Northern B, Health and Disability Ethics Committee (reference number: 13/NTB/136, 16.09.2013)

Recruitment

The method of recruiting was the same used for the Online Mindfulness Course for Pain programme (OMCP) described in chapter two of this thesis (pg. 38-52). Participants could participate in both OMCP study (detailed in chapter two pg. 36-64) and the current qualitative study as they ran concurrently. At the Pre-Surgery information clinic when the researcher was explaining the “Online Mindfulness intervention for Pain” she also detailed what would be involved in the “Experiences of Pain” interview. Participants were invited to take part in both studies but could choose to take part in one, both or neither. They were provided with an information sheet (Appendix I) about the Pain Experiences interview and, after having the opportunity to ask any questions about the experiment and discuss it with the researcher, they were requested to complete the consent form (Appendix J). The only inclusion criterion was that participants had to be able to speak and understand English and to have recently undergone a joint replacement surgery. Sixteen participants who consented to take part in the interviews were also taking part in the Online Mindfulness for Pain study; of this number two of the participants completed the Online Mindfulness for Pain study while the remaining fourteen did not. At the time of interview the fourteen non-completers had assured the researcher that they would be completing the OMCP.

Procedure

Seven days after having the surgery participants were called by the researcher at the time that they indicated was best for them on their consent forms. This time delay post-surgery was selected after consultation with the orthopaedic nursing staff. Individuals are typically discharged between two-four days post-surgery. This time delay in contacting the individual accounted for this and allowed for any complications that may have arisen and for participants to settle into their home before considering the interview. During the call the researcher asked them how their recovery was going and if they were still interested in taking

part in the experiences of pain interview. If the participant agreed the researcher arranged to come out and visit the participant at their home at a time convenient for them within the next week if possible. Two individuals who had originally consented to the interview could not take part. One participant was uncontactable and the other was staying outside of the greater Dunedin region and it was not feasible for the researchers to meet with him. All interviews were conducted by two researchers, researcher A (the author) and researcher B. Researcher A was present for all interviews, while researcher B attended nine of the interviews. At interviews when there were two researchers present, researcher A conducted the interview while researcher B was observing and able to ask any further questions they had at the completion of each section.

Researchers travelled to the participant's house at the agreed time. Upon arrival the researchers began rapport building to make the interviewee feel at ease with sharing personal experiences with the interviewer. It has been recognized that rapport building is an important component of the interview as it establishes a safe and respectful environment for participants to share their personal experiences and thoughts (Smith, 2009; Smith, et al., 2011; Hale, et al., 2008). Interviewers began by asking rapport building questions about general topics such as how their day had been, the weather, family members, pets or their garden. Researchers then asked the interviewee if they were comfortable and ready to begin the interview. Participants were required to fill out a demographics form before starting the interview (Appendix K).

After they had completed this, the researcher reiterated the purpose of the interview, what the questions would cover and that the interview would take approximately an hour. Participants were asked if they had any questions about the interview so far and if they were ready to continue.

Once the researcher had answered any questions that the interviewee had they then went on to explain to the participant that their interview was confidential and that it would be recorded for ease of analysis. The researcher confirmed the interviewee's willingness to proceed. All participants agreed to the recording.

At the completion of the Pain Experiences section of the interview, the researcher provided the interviewee with an information sheet that contained the contact details of several healthcare providers such as the Emergency Psychiatric Services and the Depression Helpline (Appendix L). It was explained to the interviewee that sometimes when an individual experiences pain they can also have feelings of depression, distress or anxiety. It was recommended that if they were experiencing any of these feelings they should initially discuss these feelings with their general practitioner but that there were also other agencies available to them if they needed them that were detailed on the information sheet.

The Pain Experiences section of the interview was then followed by the internet and the mindfulness sections. At the completion of each set of questions the participant was asked if they had any further questions or comments and were okay to continue.

All interviews were recorded using a voice memo application on an iPhone5 or an OLYMPUS WS-811 digital voice recorder. Once recorded the interviews were transcribed from the audio format to a written format by the researcher using the OLYMPUS AS-5000 transcription kit.

Once the interviews were transcribed they were then e-mailed, or if no email address was provided, mailed to participants with an accompanying letter (Appendix M) requesting participants to review the transcripts and if there were any inaccuracies, or items they wanted to remove to contact the researcher. No participants returned their transcripts with any corrections. Transcripts are available on request.

Analysis

Interpretative phenomenological analysis (IPA) was used to analyse the experiences of the participants in the interviews. IPA is a technique that allows for an in depth understanding of the personal lived experience of participants (Reid, Flowers & Larkin, 2005). In this study, the personal lived experience relates to their pain experience pre and post joint arthroplasty, their thoughts about using the internet for pain treatment and, mindfulness.

IPA is an inductive approach that requires a detailed exploration of participants reported experiences (Hale, et al., 2008; Smith, 2008; Smith, et al., 2011). IPA theory is grounded in phenomenology, hermeneutics and idiography and is one of the most frequently used qualitative methodologies in psychology (Reid, et al., 2005; Smith, 2011). The analysis was based on the methods of IPA analysis outlined in Smith, (2008). Smith, (2008) note that the structures they suggest are guidelines and that the researcher should allow for flexibility when using these methods to interpret their own data. The nature of IPA is that it can be modified to fit both the researcher and the data.

Successful IPA requires interpretation in which the analyst must enter into the research process therefore IPA needs to be recognised as subjective process (Smith, 2011; Smith, 2008) and the results are not facts but are instead concise overviews of a specific groups experiences (Reid, et al., 2005).

As the semi-structured interview was divided into three sections (pain experiences, the use of the internet, and mindfulness) a separate analysis was conducted on each of the three sections. However this was completed with the awareness that the interview must still be viewed as a whole and that information and ideas that had been discussed in a separate section of the interview could be related to or informed by details discussed in another

section. Interpretation across sections aimed to accommodate this. Themes were identified with the knowledge of both the section of the interview they pertained to and in the context of the interview as a whole.

The first stage of the analysis was familiarisation with the data. The transcribed interview was read through once to get a general understanding of the experiences of the participant. After this initial reading the interview was then read through twice more and annotated in a side column by the researcher with their initial impressions of the interview. Annotations identified interesting or important ideas that were present in the interview. There was no specification as to what had to be commented on.

After the initial annotations were completed the transcript was read through again and emerging themes were identified with initial annotations expanded on and developed to give a more coherent explanation of the emerging themes. Potential quotes to support these emerging themes were also highlighted. This process was followed for each interview and allowed the researcher to develop ideas about consistencies and emerging themes across the interviews. Analysis of later interviews was informed by the coding of earlier interviews.

The next step of analysis then began. The emergent themes from each of the interviews were transferred to a separate word document. Connections and similarities between the themes across the interviews were identified and the themes were ordered into specific patterns and clusters of meaning.

The analytical methods of the data analysis were reviewed and verified by an independent researcher with experience in qualitative research methods, specifically IPA. One of the researchers completed this process for all twenty of the interviews. A second researcher completed this analysis for eight of the interviews independently of the first researcher. The themes and supporting quotes that each of the researchers had identified were

then compared. Consistency themes were identified by both the researchers and as well as the quotations selected to support these themes.

The next step was the refinement and reordering of the themes. Some of the themes were closely linked and could be combined together. Other themes that had originally been considered to be main themes were reordered to subthemes and broader themes were created. Themes that were considered minor or that did not have enough supporting data were removed. Themes were organised into a hierarchical structure with broad core themes identified along with related sub themes.

The last step of the analysis was consolidation and summarisation. This involved taking the identified themes from each of sections and turning them into a narrative account which encapsulated the participants lived experiences. The narratives explored the identified themes and are accompanied by verbatim quotes from the interviewees to illustrate and support the choice of themes decided upon for the final write up. The narrative account of each three sections is presented below.

Pain Experience

The first and largest section of the interview investigated participants pain experience both pre and post- surgery. Four main themes with embedded sub themes were identified. These were:

- Pain explanations:
 - Pre-surgery pain
 - Post-surgery pain
 - Pain conceptualised
- Life with pain:
 - Quality of life

- Sleep
- Time period of the pain
- Life without surgery
- Good life with pain
- Treatments for pain:
 - Pharmaceutical treatments for pain
 - Other treatments for pain
- Healthcare system

Each of themes and subthemes are explained below with supporting quotes from the interviews.

Pain explanations

This theme explores the way participants choose to describe their pain both pre and post- surgery and contrasts the difference between these two times. “Pain explanations” also details the way that participants conceptualized their pain and the components they believed contributed to it.

Pre-surgery Pain. Pre-surgical pain was described as debilitating and unrelenting. Participants used adjectives such as, constant and unrelenting to describe the severity of their pain which is best portrayed in the quotes below:

P19: “On a bad day excruciating, it was like someone putting a knife under your knee cap and giving it a wee turn. On a good day it was like a toothache, it wasn’t, there were no days where there was no pain.”

Pre-surgery the pain was described as inescapable and constant:

P15: "Constant, oh it was definitely constant you can't escape it. Some days were worse than others."

P12: "No, no, pre-surgery it wouldn't go away like that, you can't get it to go away. You'd have to take a voltaren and I mean you could sit there and have the pain dissipate quite a bit but as soon as you start moving it's bone and bone and there isn't any medication that can help that."

Participants also commented on the fact the pain was constantly getting worse:

P12: "You know and it's just excruciating pain and that was just getting more and more and more regular."

P13: "Well I was just going downhill, the difference in the couple of months was pretty big and the pain jumped up and it was getting to the point where I couldn't see the end."

On a scale of one to ten with zero being no pain at all and ten being the worst pain imaginable all participants rated their pre-surgical pain above a five. Participants reported an average rating of 7 pre-surgery.

P5: "Never under a five. That's on a good day too."

P19: "Oh before I had it cut open? Around a 7 average but near the end there it was sitting on an 8 or 9. I tell you it wasn't fun."

Post -surgery Pain. In direct contrast to their pre-surgical pain experiences the post-surgical pain was described as qualitatively different. Participants were often hesitant to refer to what they were experiencing as pain and preferred to instead describe it as a discomfort.

P6: "So I, to me in my definition I don't really have any hip pain. I have some discomfort and most of that is at night."

P10: "My knee pain? That one probably just a bit uncomfortable (sic) and a bit chunky because it's just not getting the use of it. That one, about a one...nah, it's more of an annoyance than pain."

The difference in the pain participants were feeling post-surgically was also reflected in the ratings they gave for their average pain over the last week. On a scale of one to ten with ten being extreme pain and one being barely there most participants rated their average pain for the last week as one with the worst rating given a four.

P12: "Current knee pain sitting here right now at the moment is out of the scale of one to ten it would only warrant a one. It's ah it's lovely. Yea."

P3: "Oh probably 0.5 or 1."

The post-surgical pain that the participants were experiencing was minimal and tolerable

P11: "Correct yes, so it's more just a throb at the moment which is not that annoying just a little inconvenient. But yea."

Pain conceptualized. When asked how they conceptualised their pain participants responded that it was purely physical. Their pain was simply a result of having a damaged joint:

P1: "Joints worn out. That would be about all that is causing it I would say."

P15: "What makes up my pain? Well just the fact that I've got a bugged knee. The cartilage is all worn out and the bone is grinding on the other bone which 'causes my pain.'"

When asked about the different factors that could make their pain better or worse participants once again responded that their pain was a symptom of a physical problem and as soon as they had the surgery and recovered it would recede.

When asked if they thought there were any psychological components to their pain participants reiterated that the pain they experienced was a physical phenomenon:

P4: "Just physical. There is nothing psychological about this...well my pain is because yeah I think, I think in my own mind it's probably the fact that the two, well that I know that the two bones...cuz I've seen the x-rays and there's nothing there. And it's just bone on bone. There's a wee bit of cartilage on this side, but nothing on the inside grinding away."

Interestingly in the context of this discussion participants frequently reported that stress and mood (arguably psychological components) could have a direct impact on the pain they felt:

P15: "If I'm a bit grumpy say or if I'm frustrated that makes the pain worse like then I get angrier because I'm in pain and it starts this vicious cycle off"

Life with Pain

This theme explores participant's experience of living with pain. Sub themes identified are: quality of life, sleep, a good life with pain, time period of their pain, and life without surgery

Quality of Life. Participant's quality of life had been severely affected by their pain and they could talk at length about how much their pain had impacted on the different areas of their lives. Participants would often become emotional when describing the effect that their pain had had on their life. The most frustrating part of their pain was their loss of independence and inability to do things that they loved:

P2: "But there's a lot of things it affects you probably don't realise what it does, like you, I've two small well smaller grandchildren and you know they want you to play ringa-ringaroses and those things and you can't get down on the floor and do things you really can't. They're the kind of things you miss out on. Um or even playing at you know a game of basketball with them you know to, yeah, yeah."

Pain increasingly restricted their activities leaving them with increasingly less things they were able to do:

P1: "Yeah it restricts you but you can't be bothered doing much, you know. It's an effort to go and get in the car and go somewhere, you know. I used to play bowls and I don't play bowls anymore.."

Even simple tasks like going to buy the groceries or walking to the letter box were challenging for participants:

P8: "I think it certainly detracts from your quality of life 'cause you, yea you think twice about doing everything, you know about doing whatever you know. Like I mean for some people, you know I mean there's been times when just going to the supermarket and getting the groceries is all I can do and it's like a major excursion"

Pain affected all facets of their lives. Participants described how the pain changed their personalities and made them different people. They became more antisocial and less tolerant of others. They would often describe themselves as "crabby", "grumpy" and "mean" as demonstrated in the quotes below:

P20: "...just grumpy, I can be a grumpy bugger. Just you know you lose your cool with people. I didn't want to socialise either and that is strange for me because I like to get out. When you're my age you need to be busy and talking to people. It's important but I just didn't want to, couldn't handle it and the rigmarole it would involve. I got a bit mean too, even with the people who were trying to help."

P4: "...depressed, I was starting to get depressed because I couldn't move, I was in pain and everything was just getting too much for me. I was tired. Pain for all those years makes you tired and I just couldn't face it anymore."

The increasing restrictions that their pain placed on their lives is best encapsulated in the quote below:

P9: “the thing I noticed the most, was the things I could do got narrower and narrower, like I could do fewer and fewer things. Like I haven't been able to walk on a beach for ages, oh I did it about a year ago, but I only got about 10 steps on the sand, and it was so sore. So things like that, but when you're doing things you can do, you don't really notice it, it's only when you think, “ Oh no I can't, can't really go for a, you know for a 45 minute walk because it's going to hurt”, you know, so yeah, so you adjust your what you can do, to how you are feeling.

Time period of the pain. The pain that participants had been experiencing in their respective hip/knee joints had been ongoing for an extended period of time. Pain was identified in their joints and they had gone to see their GP about it at least two and a half years prior. All participants reported experiencing pain in their respective joints for at least two and a half years although most had felt it for longer - with an average of five years.

P1: “No, well as I say my memory's not that good, but it's ah, I can't remember when I didn't have pain in my leg. I mean I must have had it more than 12 years ago otherwise I wouldn't need the doctor with it, you know?”

P5: “Good god. Um it's been years. Years. But it has got worse, I'd say it started um how many years have I been in pain? Like this, 6 or 7 at least ”

Life without the Surgery. Participants predicted that without the surgery their lives would have got rapidly worse and their quality of life would have completely deteriorated.

P8: “It would have continued deteriorating until the point that um I wouldn't be able to walk without crutches umm and that yea I wouldn't be able to sleep... plus the drugs that I would

need to take for me just to function would need to increase significantly so I'd end up taking more heavy pain killers like ocycontin and oxynorm and um and there not very good especially when you're in a position of responsibility at work when you're trying to make key decisions that affect a lot of people and money um yea you, not the best to be tripping off your head if you know what I mean. Um yea."

P6: "when I thought about people who were on the waiting list and stuff because I could see the deterioration over a few months so if you were never able to get surgery...pretty, well you wouldn't be mobile anymore. You couldn't get around um and the bad thing with hips is it's not just walking it's sitting and everything, right? SO your whole life would be a mess."

It was clear that participant's believed that their life would have been severely impacted had that not had the surgery. One participant even suggested amputation as an alternative if they had not received the surgery.

Sleep. Sleep was an important sub theme when discussing life with pain. All twenty participants mentioned how their sleep had been effected both pre and post-surgery. Participants reported having disrupted sleep due to their pain and the inability to sleep through the night:

P8: "sleep patterns are disturbed and that but it um if it got as bad as it was before the surgery then I wouldn't be able to sleep at all through the night and I'd be sleeping in 20 minute lots and um yea totally"

P2: "Um I wasn't getting the sleep because I would get into bed and then the pain would, once your body relaxed the pain started...It's horrible. So I sort of, basically you don't really just sleep through the night, you wake after two hours and you sort of got to try and unwind, unwind your leg, if you know what I mean."

However participants found that while they were still having sleep issues post-surgery they were resolving themselves:

P19: “well I’m still not a good sleeper and sometimes it wakes me up you know it’s getting better. I can get a good couple of hours in now and I think it’ll only get better.”

Good life with pain. Despite the challenges that their knee/hip pain presented, participants still attempted to live a good life even with the pain they were experiencing. Participants endeavoured to make the most of what they could do and continue with their life as best they could:

P13: “..you just think well this is what’s happening. No point in moaning or feeling sorry for yourself, you adjust. No point in wasting your time thinking bad like. You can live a good life with pain maybe not all the time but it’s still good.”

Participants expressed a practical attitude to their pain and would often refer to “sucking it up” and “getting on with it”. Their pain was something that they had to manage and reduce the effect it was having on their lives:

P11: “ow yea, I don’t let it, I try to minimise the effect it has on my personal life and my work life you know. You get on with it. Um like works really good they know my situation they accommodate me and like I said I’m used to living with pain and discomfort so you know you don’t let it get to you or bother you.”

Treatments for pain

Pharmaceutical treatments for pain. The main pain management treatment identified for both pre and post-surgery was pharmaceuticals. When asked what they did for pain relief participants would inevitably reel off a list of pain relief medications ranging from

Panadol to slow release morphine. Participants felt that while they didn't get complete relief, medications were the best at reducing their pain levels:

P18: "It's a necessary evil. I mean it doesn't make your pain go away completely but you sure as hell notice it if you don't take them. By gum I tell you, you need them to get through the day."

While they recognised the importance of medications for coping with their pain, participants didn't like having to take medications and would prefer not to be on any at all. They would often offer qualifiers such as "I'm not a pill person" and "I don't usually like to take drugs for anything" before describing the medications that they were on. Participants were trying to reduce their medications as fast as possible and were looking forward to the day when they didn't have to take any pain medication:

P8: "I try not to um which is why I'm so keen to start reducing my medications. 'Cause when I had my hip before I had my hip done I was on a phenomenal amount of pain killers all the time you know and um yea it was horrible and I couldn't function properly. Um then you know you have that and you have a bottle of wine as well and it's a bit of a crazy lifestyle. So um yea. So um yea it would be good if I could just stop the pain killers all together."

Other treatments for pain. Participants didn't get complete relief from their medications and had actively sought a range of treatments for their pain besides pharmaceuticals. However no treatments were able to offer them any long term relief:

P15: "Oh god well I've been to masseuses, I've been to the physio, the pool um I've tried every different potion to rub on it. Hell before surgery if someone had told me to put a poached egg on my head and run around the block I would have I'll try anything but nothing really worked. I mean going to the pool loosened things up a bit but it was short lived."

Unsurprisingly the reason that participants no longer continued with these treatments was because they had no effect or the effect was very short term:

P11: "nah 'cause they don't work. Oh well the do but just not for a very long time. Just they do work short term and by the time you go and do them and then waste the time getting there and all for 10 minutes relief it's just not worth the effort."

Common theme that arose when discussing pain management techniques was that surgery would be curative and that all other treatments were just measures to manage the pain while they waited:

P5: "Yea this knee, so no amount of needles or hoodoo is going to help. A surgeon with a sharp scalpel is what fixed this."

P10: "Well it's the surgery you need and well everything else, that's just to help you get through but really, really it's the surgery. That's what fixes you up."

Psychological Pain Management. Participants never directly acknowledged that they used psychological techniques, however they frequently described psychological techniques for managing their pain. The first technique participants deployed when dealing pain was usually psychological. Participants would first try to distract themselves with another task to draw their focus from the pain:

P5: "I've tried ignoring it. Just saying oh get on with it and don't... Try and think of something else or get...do my painting or do something haven't I? That's the other thing I try to do. Try and get interested in other people and other things and just use that as a type of tool for forgetting, trying to forget the pain. If it's real bad I can't, I find that difficult."

Participants also referred to taking a moment to calm down, take a few deep breaths to access the pain:

P17: "I'd just stop, relax and take a few breaths. You know, see how you that helps. Don't get worked up just breathing can help."

Healthcare system

Participants routinely expressed frustration, anger and confusion with the process of qualifying for a joint replacement surgery. The interview contained no specific questions about the participant's experiences within the healthcare system however it was a subject that was repeatedly brought up by the participants and discussed at length.

In New Zealand to qualify for a joint replacement surgery and be placed on the waiting list individuals must be referred to an orthopaedic surgeon where they are assessed on standardised checklists. If participants reach a specific threshold score of points they are considered eligible for surgery (Gwynne-Jones, 2013). In the quotes when participants talk about "points" this is what they are referring to.

A lot of the anger with the system arose from the fact that participants had debilitating pain but they didn't meet the threshold for surgery. However they knew they would need a surgery at some point and this meant that they had to wait until the pain got "bad" enough to qualify them for it. Participants expressed the frustration they felt when they were not considered bad enough to qualify for surgery yet they had felt they needed surgery and were experiencing what they considered severe pain:

P20: "They know you need it. I knew I needed it and so did my surgeon and my doctor but it's all about the money and points, all about the points. Do you have enough points? So you can still be in a lot of pain but if you don't have the points well nothing. Come back in 6 months and we'll try again."

P5: "Got to be on two crutches they said. Not even able to walk before you can get a surgery. Here I am thinking geez, I'm in enough pain now and I've got to wait till I have to get my hubby to drag me round before you'll look at me. What kind of life is that? I felt bad 'cause see my pain, well I thought my pain was bad but it's like it just isn't this enough, go home and wait."

Participants often felt that the nature of the pain they were experiencing was not fully understood and they had been simply reduced to a number in a cost benefit analysis:

P13: "Um well they don't, you know. Lots of people don't understand until they have to have it. Like I get these top surgeons saying to me nah your pain, it's all in your mind and then they don't do anything. Well even if it's all in my mind it's still pain isn't it and then another one looks at it and shows you that there is something wrong with ya that you didn't make it all up, how's that meant to effect ya. You know these people. They don't get it. It's all clinical."

Regardless of their pain, there was the need for them to be fully incapacitated before they could be considered for surgery:

P2: "My family did complain. Every time they'd see me they'd say, my son in Invercargill, his sister in law is a doctor and we were there for Christmas and she said to him your mother needs to be in hospital and she needs to be in now. So she knew that, you know, by the way I walked and moved. She said she can't go on like that so. But you see when I'd go see the doctor he'd say to me, well they won't look at you until you're on morphine tablets and you're on 2 crutches coming in to see me. But one day I went in and I was just so sore and he said, well you're still not on the 2 crutches and you know, and I said, but I come early to see you, Ian takes me round I go into the side...and I sit there for quarter of an hour so I've got enough strength to walk across and see you and then walk back out. But I'd never do

anything like that again, you just let them say. And um yeah so he's all "Oh I think I better write again," so I did get in with that system."

There was also confusion with how the points system of qualifying for surgery worked and how you needed to learn to use the system to get the surgery you needed:

P4: "So then he sent me about a year ago, he sent me to the surgeon and he looked at and then the questions...I probably could have been in earlier because the questions he asked me...I didn't realise that they were for the points to get on the waiting list and of course I'm saying, I'm telling him...he said, cuz he said to me you know, does my injury affect me at work and I'm saying "No, no, no I'm still going to work", and I still struggle at work but what I didn't realise was that these were for the points. So then when I went back ah cuz he said to me then and afterwards, after that interview he said to me "When you come back next time", you know, "make sure you're on crutches and make out...you know, not make a [profanity] of it, really tell me the honest truth" and, and then that was probably my problem, that I didn't really tell him the honest truth that it really was a pain in the backside and it was, I was having difficulty at work."

Participants also expressed frustration over being sent backwards and forwards for rescored between different healthcare departments:

P12: "Yea, yea and they sent me into the fracture clinic and I went in there and they said "Oh yes it's pretty bad alright" but not bad enough and that happened twice and then the third time I went to the fracture clinic the nurse in there said "oh no we've got to do that" so I come home and then I've got a letter saying that they weren't going to do it 'cause it didn't have enough points although the surgeon had said I did um then I went back to my doctor and told him that and he send me right back and then that time I didn't even have to go in

and see a surgeon I just got send another letter saying you're back on the list. So I have no idea how that happened but you know."

Participants also voiced the opinion that they had to be constantly fighting to get the treatment they needed:

P17: "You've just got to actually push your barrel and say to your GP I want to go and see a surgeon. The surgeon saw my x-ray and he said "oh my dear", my GP saw my x-ray and said "oh yes, mmmm arthritis, oh you've got between one and 4 years". The surgeon didn't think that. They know more."

There was a general lack of satisfaction with the system of qualifying for the joint replacement surgery. Patients often felt that the severity of their pain was not fully understood and that the consequence of this pain was not given adequate importance.

Internet

The second section of the interview explored participant's thoughts on using the internet as a method of delivering healthcare interventions. Five main themes were identified, with embedded sub-themes as listed below:

- Using an internet intervention
- Credibility of the intervention
 - Reliability of internet sources
 - Healthcare recommendation
 - Face validity
- Effectiveness of the intervention
- Accessibility
- Preference for face-to-face contact

Using an internet based intervention

Of the twenty participants interviewed sixteen had access to the internet. Of those sixteen participants fourteen said they would try using an internet based intervention for pain. Participants with internet access expressed an open minded and positive attitude towards using an internet based intervention:

P20: "I'm more than happy to use the internet."

P6: "Yes if I have um...it's harder to picture at the moment because I don't have pain but yes I'm, I'm not adverse to actually to try a variety of things if I think they're going to be helpful."

Unsurprisingly, those participants who didn't have current access to the internet showed no interest in trying an internet based intervention. Participants noted that even if the internet was provided for them they wouldn't use an online intervention as they felt that they were too old to learn how to use the internet:

P1: "I'm not into that modern stuff... No. I wouldn't have the patience...There's no use starting at my age. I have enough trouble working the phone to ring the TAB."

P7: "Oh I wouldn't know how to use it. No too old to learn."

Credibility of the intervention

The credibility of an intervention was an important theme when participants were discussing what would make them more or less inclined to use an internet intervention. The subthemes of: reliability of the information on the internet, healthcare provider's recommendations and individual perspective relate to this.

Reliability of Internet Sources. The main issue that participants expressed with using the internet for a healthcare intervention was credibility of the source material.

Participants expressed the concern that the internet contained a plethora of information and that it could be hard to discern what a reliable source of information was. This made them wary of using the internet for a health intervention because it could be hard to establish if an intervention was legitimate or not.

P6: “you learn with the internet is that the internet is a wonderful source of information, and it’s a horrible source. So you had to be careful.

P14: There is a lot of information out there and here’s the thing anyone can put stuff on there so there is this well what I’m trying to say is that sometimes it’s hard to know what is credible and you know good and what is just rubbish and well how do you tell? I think you have to be careful ‘cause people they’ll say “Oh yes Doctor Someone said this and he has a Harvard education” but how do we know and one can say that, you know where as if I see this doctor in person well you know they are the real deal.”

The main barrier that participants identified with using the internet was if the information they were being provided with was appropriate:

P19: I don’t know see my problem is there is just so much stuff out on there. What do you trust and how do you know it’s good?

Healthcare recommendation for the intervention. Also related to the theme of credibility is *healthcare recommendation*. Participants expressed that they would be most likely to try an intervention on the internet if their general practitioner (GP) or surgeon recommended it to them. GP’s were who participants first sought healthcare advice from and they expressed the belief that if an intervention was going to be beneficial, their GP would know about it and would recommend it to them.

P11: ...If I had a recommendation from a GP or another one of those I'd be more likely to use it and my doctor would be the sort of guy that would let me know about those sort of things.

P16: 'Well I trust my doctor. She's who I go to for this sort of advice so if she said "Hey [participants name] I think you should try this it could help" then yea I'd be more likely to give it a go.

GP's were considered credible sources of information for the healthcare treatments:

P8: so maybe evidence that it worked I guess. Some scientific base behind it, it would probably reduce my cynicism yea. Like my doctors recommends it or something.

Face validity of an intervention. How the participants viewed the programme was also important factor in using an online intervention. If an intervention made sense to the participant and they thought it had merit they would be more inclined to try it:

P20: I'll take a look and see if it makes sense. You know and if it looks like rubbish well I won't go near it but if it makes sense then yea, no worries I'll give it a go. Like when my physio wanted me to do cupping do you know what that is?...Yea well I wouldn't do it because it just didn't sound right and now it's the same with anything if it makes sense I'll give it a go"

Effectiveness of the Intervention

Participants felt it was important that an intervention made an impact. Participants needed to feel an improvement or change to continue with an intervention.

P8: "if I thought it was going to be effective and it meant I could access it immediately online. I guess, I don't see why I wouldn't."

P14: So if it worked I'd keep using it. If I could tell that it was helping yeah. "cause you know you just know when something is working"

If participants didn't feel that the intervention was working they would be quick to discard it and stop using it.

P5: If my doctor recommended it I'd go and have a look and if it worked I'd have another look. If it doesn't work I'd lose faith in it quite quick

P17: " I'd try it out once and if I didn't see any difference well then I'd just stop using it."

Feeling an effect of the intervention was also linked to the time participants would be willing to invest on an internet based intervention. There was no consensus on the amount of time participants would be willing to spend on an intervention however a clear theme emerged that the time participants were willing to spend on an online intervention would be directly linked to the results they were seeing from doing said intervention.

P9: "so it would be in my own interest to spend whatever time doing it, if I felt it was helping. I wouldn't put a limit on how long."

P8: "It depends how effective it was you know like if I found that it was working for me then I would put more time into it but if it wasn't then I'd put less. You know, be prepared to put 20 minutes in and then if that worked you'd put longer in or you know do even a couple of sessions a week."

Accessibility

The main benefit identified across participants was the ease of access that using an internet based treatment afforded. Internet interventions were described as immediate, meaning for those with a connection could accessed it any time when other services were not available.

P8: "um well it's immediate so you know you can just have it there. Access would be 24 hours a day. Quite often a lot of your pain is a 3 o'clock in the morning so if there was something that you could do and you know you're awake anyways so if you could go online and access something then. That would help you and give you some steps and you'd be working through while you're in the peak of your pain that would be really handy I think. You know."

For many of the joint arthroplasty patients mobility pre and post-surgery is limited and they are often reliant on others to get them to appointments and treatment. Participants clearly identified that online interventions could overcome these challenges:

P17: Well with me, getting around before the surgery was a bit of an issue I had to have someone drive me everywhere. You know, just getting to the letter box was a challenge. It all involved quite a bit of planning as well you know to get somewhere. So I guess if I was doing something over the internet well I could just do it in my chair"

The easy access of the internet could also help to overcome waiting for treatments and the time involved in seeing a healthcare professional:

P: Well you can get up to date. Programme, you know you're not waiting around on someone else to tell you what to do. At the moment if you have nothing you don't know what you've got up to. Easy to I guess. Don't have to go anywhere. Can have it in your home, anytime.

Preference for face to face contact

When discussing the internet and methods of interaction both participants with and without the internet expressed a strong preference for face-to-face treatment. When faced with a choice participants would always to prefer to have in person interactions with their

healthcare providers. They viewed face-to-face contact as the highest standard of delivery and the most effective for them.

P15: Yea face to face is the best. Brilliant really

P9: "I'd rather have a face to face contact with someone about it... I think to start with I think it's good to have a 1 on 1, like for example I'm hopeless with diagrams, so if someone said follow these instructions on the diagram to do these exercises I would be hopeless....I don't think anything beats somebody being there and saying 'oh no you're doing that wrong' or 'do this'. I don't see how you could get around that."

With face to face interaction feedback from a practitioner is more personalised and specific to their personal needs. Something participants think is unlikely to be achieved through other means of presentation.

P16: ... sometimes you know you really need that one on one feedback to help to do things um when you first do something you go like hell the trouble is sometimes you don't know what things you've done and it really takes a lot more expertise.

P13: I prefer to do things face to face. 'cause then they can tell you straight if you're doing it right and what else you need to be doing. It's not like a guess you know.

Mindfulness

The last section of the interview investigated participants thoughts on mindfulness concepts. Three main themes were identified and will be outlined in detail below. Themes include:

- Participants understanding of mindfulness
- Relevance of mindfulness techniques
 - Mindfulness would be more beneficial prior to surgery.

Participants understanding of mindfulness

The first question of the mindfulness section asked participants what they knew about mindfulness. The majority of participants were unfamiliar with the term “mindfulness” and generally stated that they could not tell the interviewer anything about the concept:

P15: I haven't got a clue sorry

After being provided with a brief definition and description of what mindfulness is participants were asked once again what they thought of the concept now they knew what mindfulness was. Participant's responses were overwhelmingly positive when asked what they thought of the concept:

P9: I think it's great. I'd like to know more about it, it's absolutely true. We do spend lots of our time here or there. I think it would be a really good thing to learn about your pain, think and practice.

Mindfulness concepts made sense to the participants and they believed it could be beneficial:

P19: Yea, sounds good. I mean makes sense doesn't it. Just shifting perspective and not getting too bogged down just getting on with it. What you've told me makes sense and I'd give those things a go. It's all that mind/body connection whatever that means.

When asked if they would be interested in trying mindfulness techniques fifteen out of the twenty interviewed indicated that they would be open to trying mindfulness techniques.

P4: "Sure. I don't see why not."

P10” Why not? Try anything, see I want to get better and I want to do something. After 30 plus years of pain I’ll try anything once.”

One of the five participants who were not interested in mindfulness made it clear that this because he didn’t think it was valid:

P1: “I think you can just about answer that yourself I think. I don’t think there’s much in it to be quite honest. You know, that’s, that doesn’t make sense to me.”

Interestingly a theme that emerged for why the other four participants wouldn’t be open to learning mindfulness techniques is that participants thought they were already mindful and therefore wouldn’t benefit from learning mindfulness techniques.

P11: well yea I don’t think I need it really. To be honest. It’s what I do now, it’s what I am. I don’t let stuff get me down. I’ve have the odd telling off at work you know tear a strip off a truck driver and I can make you feel pretty good. Not for them. But yea so no I don’t think I need this

Relevance of mindfulness techniques to recovery and healing

While participants were asked general questions about mindfulness they typically viewed it in the context of their pain experiences and their surgery. Participants believed that mindfulness was relevant to dealing with pain and made frequent reference to the “mind-body” connection and how it was important for recovery:

P20: Well they’re not separate are they, the physical and the mental. It’s the mind body connection. I know if I’m in a bad mood it can make my pain worse. So if your mindfulness is working on the brain part it would still help me with my physical right? ...yea I can see that. It’s all in the up here really

Participants had an appreciation that one's psychological state could influence your pain and that mindfulness could address this:

P15: "Well it's about how you think isn't it. This stuff is pretty important, you've got to have a positive outlook 'cause if you have a negative and get all down and then you don't heal as fast. There are studies on it, you would know don't you [...] Yea well I think it's the same you've got to be in a positive frame of mind. The mind/body stuff is pretty important

P5: "Right? It's throughout the brain and body. Everywhere in my body I've got the nervous system operating so it's all connected."

Mindfulness Techniques would be more beneficial prior to the surgery. While the majority of participants indicated that they would be open to trying mindfulness techniques participants also clearly expressed that they thought learning and practicing mindfulness techniques would be more beneficial before receiving surgery as oppose to post surgery when the mindfulness internet intervention was offered.

P2: "Quite frankly I think that what you're offering would be better if I had it beforehand, might have been more sense than after an operation that's going to work. I think it would be a lot better. It would help you manage what you've got um yeah...I would hate to think by doing that you put off the surgery because I mean I guess it couldn't halt it, but it would make the people in the pain cope a lot better. Not necessarily stop the operations but you would cope a lot better."

P16: " Well I like the idea of this mindfulness, it makes sense right 'cause your pain is , well it's a, it's 'cause of your knee or whatever being bung but I guess like you say it's how you deal with it and sort of look at that pain. I see it with different friends all the time but really I would have liked to do this beforehand. Don't you think?"

The explanations as to why mindfulness would be better pre-surgery followed a consistent pattern. Participants were not experiencing the same levels or type of pain that they had been prior to the surgery. Participants post -surgery pain was minimal and constantly improving therefore they believed learning mindfulness techniques would be superfluous as the pain was already manageable. This was in contrast to the pain they had felt before having the surgery which was considered hard to cope with and there was a greater need for pain management techniques. This is clearly encapsulated in the quotes below by participants seven, nine and seventeen.

P7: I think it would have merit. This pain I feel now I don't see it as bad pain. I see it as good pain because it's not getting worse and it's actually getting better daily so it's got to be good pain and I've thought that since I've had it done. So maybe I don't need this [mindfulness] but definitely before the surgery maybe more so.

P9: " could you have this beforehand, I mean before the surgery? 'cause that's when you're in the most pain and that's when you need it, I mean after the surgery it's a bit pointless.... That's just what I think I mean it's not bad to have it after but maybe better before."

Although initially unaware of mindfulness, participants were positive about the concept and could see the benefit of using mindfulness especially in the context of healing and for their pain. Participants did believe mindfulness techniques would be better served prior to the joint replacement surgery as their pain was greater and harder to manage.

Discussion

Pre-surgery pain dominated the conversations. It was clear from the interviews that participants were experiencing what they perceived to be unrelenting pain before their surgery. With no treatments able to offer them adequate relief, they were living a lives constricted by pain. While this is unsurprising, as unmanageable pain is the primary reason

for receiving a joint replacement (Liang, et al., 1986; Norman- Taylor, Palmer & Villar, 1996; Robertsson, Dunbar, Knutson & Lidgren, 2000) the results reinforce the extent of pain experienced pre-surgery (Demierre, et al., 2011; Fujita, et al., 2006; Hall, et al 2008, Hawker, et al., 2008; Montin, et al., 2002).

Participants generally reported that their pain pre-surgery affected most aspects of their lives. Simple tasks had become challenging and they could no longer participate in activities they enjoyed. This is consistent with both qualitative (Demierre, et al., 2011; Fujita, et al., 2006; Hall, et al., 2008; Montin, et al., 2002) and quantitative (Hirvonen, et al., 2006) research, that suggests decreased quality of life in individuals waiting for a joint arthroplasty. Pain, reduced function and low quality of life are all associated with poorer post -surgical outcomes (Fortin, et al., 1999; Sullivan, et al., 2009). As such, it is important to address pre-surgery pain issues not only to reduce individuals suffering while they wait, but to maximise the positive outcomes of surgery.

The impacts of arthritic pain are not limited to physical function but extend to the person's very identity (Ballantyne, et al., 2007). Not only were participants unable to engage in their usual activities but they also became more antisocial, depressed and withdrawn as a result of their pain. There is a documented link between chronic pain, reduced life satisfaction (Laborde & Powers, 1985) and depression (Bookwala, et al., 2003) in individuals with osteoarthritis and chronic pain in general (Dworkin & Gitlin, 1991; Swain and Johnson, 2014). Brownlow, et al., (2001) found that a quarter of individuals on the waiting list for THA had a clinically significant mood disorder. Mental health is an important for individuals undergoing joint replacement surgery as a low preoperative mental health is associated with increased pain and decreased function post surgically (Vissers, et al., 2012).

All participants reported a disrupted sleep prior to surgery. There is a well-documented relationship between chronic pain and sleep issues (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Menefee, et al., 2000; Smith & Haythornthwaite, 2004). Research suggests that the relationship between pain and sleep is bidirectional (Lautenbacher, Kundermann, & Krieg, 2006; Smith & Haythornthwaite, 2004). Sleep deprivation and insomnia can arise due to chronic pain (Smith & Haythornthwaite, 2004) however poor sleep quality can also exacerbate pain and lead to a range of further adverse outcomes including increased disability and depression and anxiety in individuals with chronic pain (McCracken, & Iverson, 2001; Smith & Haythornthwaite, 2004; Tang, Wright, & Salkovskis, 2007). Sleep disturbance was a consistent theme and clearly need to be addressed in pre arthroplasty patients with chronic pain. While treating insomnia is difficult, CBT approaches for treating insomnia in chronic pain patients have been successful (Currie, Wilson, & Curran, 2002; McCracken, Williams, & Tang, 2011; Smith & Haythornthwaite, 2004). This lends further support to the importance of giving patients access to psychological treatments for their pain or factors such as disrupted sleep that might be a result of and further influence their pain.

Post-surgical pain. Post-surgical pain was described completely differently to pre-surgical pain. Any pain that they did feel was minimal and incomparable to their pre-surgical pain experiences. Participants were often reluctant to refer to what they were experiencing post-surgery as pain and would refer to it as a “healing pain”. Participants were improving rapidly and no longer saw their pain as a barrier in clear contrast to their pre-surgical pain which was all consuming and debilitating. These feelings are consistent with those reported in an exploration of the postoperative period of arthroplasty patients (Fujita, et al., 2006). Fujita, et al., (2006) found that participants were beginning to feel significant reductions in their pain and a reported freedom from their previous restrictions of chronic pain.

The current study was conducted on participants two-three weeks post- surgery. While it is encouraging to see such reductions in pain it would also be interesting to conduct further follow ups at six months or twelve months post-surgery. It would be interesting to evaluate how participants are managing with their new joint replacements and to see if there are any persistent problems with their surgery or pain which may not have been noted so recently after surgery.

Individuals understanding of pain. How individuals understand their pain could have an influence on the treatments they will try and use to combat pain. There is an increasing acknowledgement amongst the healthcare professions of the importance of adopting the biopsychosocial model for understanding pain (Gatchel, et al., 2007). This model includes a complete consideration of not only the physiological but the psychological and social factors that influence an individual's experiences of pain (Keefe, et al., 2004; Turk & Okifuji, 2002; Turk & Monarch, 1996). Participant's understanding of their own pain does not reflect this model. They perceived their pain as purely a result of a physical condition and when asked specifically did not acknowledge any psychological or social factors that influenced their pain.

Participants understanding of pain is related to the treatments that they will seek to minimise it. This is an important consideration, as health care professionals have been shown to underestimate their patient's ability to understand their pain which could lead to simplified explanations and deficiencies in pain management plans (Moseley, 2003). Communicating to patients the complex nature of their chronic pain could lead to a more complete understanding and improved management of their pain symptoms.

Pain Treatments. Participants acknowledge pharmaceuticals have an observable effect and were the current best way to manage their pain however medications were not

wholly effective (Moore, et al., 2013). Approaches towards medications categorised drugs as a necessary evil for managing their pain. This attitude is aligned with previous research in both arthritis (Demierre, et al., 2011) and chronic pain (Lansbery, 2000; Sale, Gignac & Hawker, 2006) in which individuals expressed a preference for not being reliant on medications.

Participants sought a range of other treatments to minimise their pain. This was consistent with research that demonstrated individuals in chronic pain are not restricted to one modality and will try a range of treatments to reduce their suffering (Fujita, et al., 2006, Lansbury, 2000). Participants reported little success with other methods and unsurprisingly did not continue with pain treatments if they did not see a reduction in their pain.

Participants may not have experienced formal psychological interventions, but techniques that many participants used to deal with their pain were invariably psychological. Participants referred to deep breathing exercises, relaxation and distraction techniques as one of their first responses to their pain. Research has recognised psychological treatments for pain including Cognitive Behavioural Therapy (Morley, Eccleston & Williams, 1999) and Acceptance Commitment Therapy (Wetherall, et al., 2011), mindfulness (Grossman, et al., 2004), hypnotherapy (Elkins, et al., 2007) as potentially effective treatments for managing chronic pain (Kearns, et al., 2011). However, no participants reported trying any type of formal psychological intervention for their pain.

Research in the field of chronic pain has demonstrated the effectiveness of psychological treatment in a number of common chronic pain problems such as headaches, lower back pain, and arthritis (Kerns, et al., 2011; Morley, et al, 1999). Two meta-analyses investigating the effectiveness of psychological interventions have further demonstrated the efficacy, effectiveness, and cost-effectiveness of such psychological treatment (Flor, et al.,

1992; Hoffman, et al., 2007). Psychological approaches provide a promising basis for which pain can be treated, a multidisciplinary approach to pain management is often considered a “gold standard” in treatment (Kerns, et al., 2011; Peng, et al., 2007). Integrating psychological interventions into pain treatment options could be incredibly beneficial for individuals waiting to receive surgery.

Experiences within the healthcare system. Many participants had been in persistent chronic pain for an extended period of time however, to qualify for what is considered a curative treatment they believe that they need to be almost unable to function. This level of debilitation is not only a source of misery for the individual as noted in Browlow, et al., (2001) and Fujita, et al., (2006), but reduced function pre-surgery is also related to decreased function post-surgery (Fortin, et al., 1999).

In addition to coping with their pain participants had difficulty navigating the healthcare system to qualify for a joint replacement surgery. As participant’s pain was ongoing it is easy to understand their irritation (Moran, et al., 2003). They felt marginalised in the system and that their pain was not clearly understood. An earlier study of waitlist experience found that participants were also confused and frustrated within the system of qualifying for a joint replacement (Derret, Paul & Morris, 1999).

This frustration was often compounded by the knowledge that they needed the surgery but had to wait until their pain and function was considered bad enough to qualify. In a public healthcare system restricted by financial constraints waiting lists are inevitable. However, it may be important to question whether more should be done for individuals while they wait to qualify for and receive surgery and how their confusion with the system can be minimised. Roseman, et al., (2006) found when interviewing individuals with osteoarthritis that while pain and disability were the most important concerns of the patients, general practitioners

(GP) focussed on the physical nature of the disease. Greater investment in understanding and treating the current pain while individuals wait to receive surgery could lead to increased satisfaction within the healthcare system.

Pain Conclusions. Pre-surgical pain is severe and debilitating for individuals before undergoing a joint arthroplasty. Participants view their pain as purely physical and are willing to try a range of treatments to minimise their pain. Results from the pain section of the interviews highlights the need for further interventions prior to the surgery. Effort should be made to minimise pre-surgical pain with benefits being twofold; individual's risk factors such as high levels of pain can be identified and treated to maximise post-surgical outcomes and addressing these issues will enhance the quality of life for individuals while they wait to receive total knee and hip arthroplasty.

Psychological treatments for chronic pain appear to be underutilized in the current sample with treatments restricted to addressing the physical components of an individual's pain. There is clearly room for integrating psychological techniques into pain treatment packages.

Internet

Overall there was a general level of acceptance and openness to online interventions for pain, with the majority of individuals that had access to the internet expressing a willingness to try an online intervention. This is in line with a recent survey on delivery of psychological interventions found that 49% of primary care participants would be interested in taking part in an internet treatment (Mohr, et al, 2010).

Older adults are stereotypically categorised as technologically averse but results show that those who have access to the internet express openness to actively engage with the medium. This is consistent with earlier research that demonstrates older adults have

embraced and use online technologies (Hart, Chaparro, & Holcomb, 2008; Wagner, et al., 2010; Wood et al., 2005). As online technology continues to develop, acceptance of online healthcare interventions is only expected to grow (Bender, et al., 2012; Rini, et al., 2011) highlighting the need to further investigate how and why individuals interact with online interventions. Participants in this study provided insights into what would influence their engagement with online interventions for pain.

Participant's perceptions of online credibility. Participants expressed the idea that there was what they viewed as an overwhelming amount of information available on the internet. Distinguishing between reputable and non-reputable sources could be difficult making individuals wary of what is available on the internet. This emphasises the need for online interventions to have credible support from individuals and institutions that the participants trust and will receive their healthcare advice from such as GP's or pain clinics. It also highlights the need for online interventions to be transparent and clear about their specific goals and methods and what research or evidence the techniques are based on.

Recommended by clinician. Participants indicated that they would be more likely to take part in an online intervention if it was recommended to them by their GP or another healthcare professional. This is unsurprising as GP's are gatekeepers to healthcare treatments and participants look to them to inform and guide them on their healthcare choices. GP's are considered to have relevant healthcare knowledge therefore their endorsement would lend credibility to an intervention. This also aligns with one of the proposed factors influencing attrition in online interventions. In "The Law of Attrition", Eysenbach (2005) proposes that encouragement, endorsement and support for healthcare providers can play an important role in an individual's use of online interventions. Participants may be less likely to use an online intervention if they do not receive active support (or are discouraged) by a healthcare

professional. This finding highlights the active role that primary health care providers will play in integrating online interventions into treatment protocols.

In light of this result health professionals understanding and acceptance of online interventions is an important consideration. There has been no exploration of attitudes surrounding online interventions for pain, however, research on health practitioners attitudes to online psychological treatment have been mixed (Gun, et al, 2011; Stallard, Richardson & Velleman, 2010; Wangberg, Gammon, & Spitznogle, 2007).

Gun, et al., (2011), found while both lay people and healthcare professionals found online interventions acceptable there was a trend towards healthcare professionals being slightly less accepting of online interventions than lay people. A greater proportion of lay people also reported that they would use online treatments in the future. In a similar vein clinician attitudes towards online CBT for children and adolescents were positive yet cautious (Stallard, et al., 2010). This is in contrast to another study that found New York based psychologists offered low levels of endorsement for online treatments (Mora, Nevid, & Chaplin, 2008).

Little is known about primary care and GP's attitudes towards online interventions however, as these professions play a central role in an individual's care and pain treatment it is key to understand their beliefs and impressions of online interventions for pain. It is important to inform and consult healthcare professionals on the development and availability of online interventions as the continued success of online interventions relies on not only convincing the patients but their GP's of the value of online interventions for pain.

Observable Change. Another theme that arose from the interviews was that online interventions had to provide participants with a noticeable change. Participants had to be able to "feel" the intervention making a difference or they noted that they would be quick to

discard it. This is an important consideration for individuals developing psychological interventions as mindfulness along with other psychological interventions do not offer a quick fix like many pharmaceuticals but instead require prolonged practice to demonstrate sustained results (Brown & Ryan 2003; Harris, 2014; Kabat-Zinn, 1994). Interventions should emphasise how the techniques work and what changes are expected to be seen so that participants do not give up after one session because they feel no effects but instead are motivated to continue with the programme.

Unsurprisingly, participants noted that an intervention had to have face validity for them to use it. If the concept made sense and they understood it they would be inclined to try it. This is a further important consideration for intervention design as it highlights the need for developers to clearly communicate the purpose, methods and benefits of the intervention. Interventions need to provide quality clear information about the expected outcomes from participation so that individuals can form realistic expectations about what they can get from the programme (Eysenbach, 2005).

Preference for face- to face initiatives. Participants expressed a preference for face-to-face contact in health care delivery. This view is consistent with previous research that demonstrates participants would prefer face to face treatment (Mohr, et al 2010). Participants also raised concerns that online interventions might not be efficient as they would be too generic and not tailored to the individuals specific needs. Subtle issues that patients might have that could be noted in face to face interactions might go unseen and therefore untreated in online interventions. These concerns have also been voiced by healthcare professionals who worry that the nuanced care that comes from in person contact might not be present in online interventions (Lovejoy, Demireva, Grayson & McNamara, 2009; Stallard, et al., 2010; Wangberg, et al., 2007). These concerns are important to remember when developing and trialling online interventions. Well-designed interventions that take full advantage of current

technology will allow for more complex and detailed interventions. Further studies to also compare the long term outcomes of individuals who experience psychological interventions online compared to those who receive in person training are also required.

Accessibility of online interventions was a consistently identified benefit of online interventions. As all participants had had restricted mobility due to their condition and the associated chronic pain they found an intervention that could be completed from their homes one of value. Accessibility of online interventions is an often cited benefit of online interventions (Bender, et al., 2011; Perle, Langsam, Nierenberg., 2011; Rini, et al., 2012) and the views of the participants acknowledge this.

Internet Conclusions. Individual's responses to the internet were largely positive with the majority of participants who had access to the internet expressing a willingness to try an online intervention. As technology becomes increasingly more integrated into daily life utilization of available online healthcare technologies is only expected to increase, judging by the responses it appears that older adults will not be left behind when it comes to embracing online healthcare interventions. Participants expressed caveats in relation to online intervention use, which were in line with the current research of online internet intervention adherence and beliefs.

Mindfulness

Participants were not familiar with the term "mindfulness" however when it was explained to them the overall response was resoundingly positive. Participants could see the logic and value of mindfulness techniques, especially in pain management. They acknowledged that an individual's pain could be influenced by one's psychological state with frequent reference to the "mind-body" connection and believed that mindfulness was relevant to recovery and managing pain.

Despite not previously knowing what mindfulness was participants expressed acceptance and understanding of mindfulness concepts and a willingness to try mindfulness techniques. This is promising for the integration of psychological interventions into pain management packages as it demonstrates that firstly individuals had an understanding of the role of psychological factors in pain and that they were open to trying psychological interventions for pain management.

While participants expressed an interest in mindfulness techniques a common theme was that they would have benefited more from a mindfulness intervention prior to their surgery. Participants identified the need and motivation to complete a mindfulness intervention was greater pre-surgery. This offers an interesting insight into individual's pain experiences and the implementation of pain interventions for joint replacement patients.

Mindfulness meditation has been explored across a wide range of conditions associated with pain with promising results (Reiner, et al., 2013; Baer, 2003). As seen in the earlier pain section participants generally had no experiences with psychological treatments for pain. Integrating mindfulness techniques into pain treatment packages could be beneficial for individuals in pain both pre and post joint surgery.

Limitations

Participants were interviewed between two and three weeks post-surgery. This does not provide a complete understanding of the individual's pain experience post-surgery. Follow up interviews at three or six months could provide further insight into the individual's recovery and any persistent pain issues.

Another limitation was that this experiment was conducted in one centre in New Zealand meaning participants experiences with their pain and the treatments available could be specific to the New Zealand healthcare system and unable to be generalised to similar

patients within other systems. However as specific experiences with pain, loss of quality of life and pain treatments were consistent with studies from Switzerland (Demierre, et al., 2011), Japan (Fujita, et al., 2006), Finland (Montin, et al., 2002) and Canada (Hall, et al., 2008) suggests that these results are representative of the pain experience before joint replacement surgery.

Overall Conclusions

Despite these limitations the comparatively large sample size and methodology allowed for a deep exploration of individuals pain experiences before receiving joint replacement surgery, beliefs about online interventions and mindfulness. This study highlights the need for improved pain treatments for individuals waiting to receive a joint replacement so that when they going into surgery they are in the best state possible to ensure a successful recovery. It also demonstrated that individuals had openness to exploring pain treatments offered via the internet and interventions that included mindfulness techniques.

CHAPTER FOUR

ONLINE MINDFULNESS INTERVENTION FOR AMPUTEES

Amputees are another population of individuals who experience chronic pain that could be suited to trial an online mindfulness intervention. In New Zealand alone over 4.000 people have an amputation (New Zealand Artificial Limb Service, 2015). Significant proportions (80-90%) of amputee patients experience phantom limb pain (Chahine & Kanazi, 2007; Knotkova, Cruciani, Tronnier, & Rasche, 2012). Phantom limb pain (PLP) is a neuropathic pain that arises after the removal of a limb (Flor et al., 2006). PLP combined with the physical loss of a limb and functionality can contribute to individuals with an amputation experience increased levels of depression and anxiety as well as decreased life satisfaction and quality of life (Desmond, & MacLachlan, 2010; Horgan & MacLachlan, 2004; Østlie, Magnus, Skjeldal, Garfelt, & Tambs, 2011).

As with many chronic pain conditions there is no one single treatment method for phantom limb pain. Pharmaceutical treatments are only moderately successful at alleviating PLP (Black, Persons, & Jamieson, 2009; Huse, Larbig, Flor, & Birbaumer, 2001; Muraoka, Komiyama, Hosoi, Mine, & Kubo, 1996). A range of other treatment modalities have been trialled on individuals including visual mirror feedback (Chan, et al., 2007; Hasanzadeh Kiabi, et al., 2013; Ramachandran & Roger-Ramachandran, 1996), biofeedback (Belleggia, & Birbaumer, 2001; Harden, Houle & Green, 2005), and hypnosis (Bamford, 2006; Oakley, Whitman, & Halligan, 2002), to varying levels of success.

A recent review conducted by Moura, et al., (2012) concluded that mind-body therapies are important components of pain management plans for amputees however there is a need for more rigorous research into individual treatments. No published studies have assessed mindfulness interventions for amputees however the authors of the review suggest that it is a treatment method that should be investigated for amputees (Moura, et al., 2012).

This provides support that amputees could personally benefit from taking place in an online mindfulness study. Amputees would also be placed to provide valuable feedback about the content and course structure.

Study one's recruitment and retention failures meant that no conclusions could be made about the course content and structure. The qualitative results from the earlier study outlined in chapter three (pg. 65-110) suggest that a lack of motivation (due to minimal pain) lead to post arthroplasty individuals not completing the intervention however there is still a need to assess the adherence and acceptability of the online course and included resources. The aim of this study was to examine adherence to the online mindfulness programme. This study also aims to examine individual's experiences with the online programmes content.

Methods

Participants

Eight participants (five male and three female) between the ages of 29 and 72 (median age: 55) took part in the study. All participants identified as New Zealand European. Two participants had a tertiary degree, three had school certificate or equivalent and four participants had a trade certificate or diploma. Seven of the participants had a lower limb amputation and one participant had an upper limb amputation. The time since amputation ranged between 10 and 45 years (median time: 20 years and 2 months).

Recruitment

Participants were recruited through the New Zealand Artificial Limb Service (NZALS). Recruitment posters (Appendix N) detailing the study were placed in thirteen NZALS centres around New Zealand. Twenty three individuals from NZALS Dunedin branch were also mailed a recruitment letter (Appendix O). These twenty- three were participants identified by the Dunedin branch of NZALS as individuals who were computer

literate and who they believed would be able to take part in the study. Nine participants registered their interest in the study by contacting the researcher via an e-mail address provided on the posters and letters. The inclusion criteria for this study were that participants had access to the internet for the duration of the study period, were proficient in the English language and had a limb amputation. The recruitment period was the month of December 2014. Ethical approval for this study was granted by the Northern B, Health and Disability Ethics committee (reference number: 13/NTB/136, 16.09.2013)

Procedure

Participants that contacted the researcher expressing interest were sent a standardised e-mail (Appendix P) that contained an information sheet (Appendix Q), links to complete an online consent form (Appendix R) and a demographic survey (Appendix S) presented via survey monkey (<https://www.surveymonkey.com>). Once the consent and demographics form had been completed participants were then e-mailed a unique username and password that they could use to login and access the intervention as well as a detailed instruction sheet explaining how to navigate the intervention (Appendix T). Nine individuals contacted the researcher expressing interest in the online course.

Participants completed the “Online Mindfulness Course for Pain” outlined in detail in Chapter Two (pg. 36-64). As described in Chapter 2, the online mindfulness course consists of four modules. The content in each of the four modules was drawn from suggested mindfulness explanations and exercises from mindfulness programmes developed by Kabat-Zinn, (1990), Harris, (2009), Segal, et al., (2002), Sadler, (2009) and through discussion with mindfulness practitioners. While the modules cover the general idea of mindfulness they have been designed with the specific focus on teaching participants how to use mindfulness to work with any pain they are currently experiencing.

All the mindfulness techniques used in the intervention e.g. body scan, mindful breathing etc. are widely accepted and used by mindfulness practitioners to develop mindfulness (Kabat-Zinn, 1990; Harris, 2009; Segal, et al., 2002; Sadler, 2009). No current research exists concerning what specific mindfulness techniques are more effective or better at increasing mindfulness. However it was reasoned that presenting a range of different mindfulness techniques gave participants exposure to variety of techniques to cultivate mindfulness. All course content including animations, audios, and homework tasks were validated by a registered clinical psychologist who was also a mindfulness practitioner. The contents of each of the modules are outlined in the table below.

Table 2. Module content for the OMCP

Module	Audio (running time)	Practice Task	Questionnaire	Total animation run time (minutes)
1	Breathing Meditation (5 min)	Take 5	Demographic, comprehensive, BPI	12.9
2	Mindfulness for working with difficulties (7 min)	Mindful daily routines	BPI	8.65
3	Body Scan (9 min)	Mindful eating	BPI	6.2
4	Loving Kindness Meditation (17 min)	Mindful Walk	BPI	10.34

Subtle changes were made to the online presentation which altered the online intervention from that outlined in Chapter Two. All the surveys presented in the online course detailed in Chapter Two were removed. At the end of the course a feedback survey consisting of ten questions displayed through survey monkey was added (Appendix U). A gratitude journal task was also included for each week. The gratitude journal required participants to simply list three things that they were grateful for. The results of the gratitude journal are part

of a further well-being study and are not reported here. The course was not directly advertised as an online mindfulness course for pain but instead as a “wellbeing course” to enhance individuals overall health.

Participants were required to access the module within a week of it being made accessible to them. Participants did not receive access to the following module until they had completed the previous week’s module. Reminder emails were sent to participants four days after receiving access to the intervention to remind them to logon and view the intervention. If they still had not accessed six days post receiving access they received a reminder call from the researcher and a second reminder email. Participants were able to contact the researcher at any time via email with any problems they were having with the intervention.

At the completion of Week Four participants were asked to complete a feedback survey to assess their experience within the course (Appendix U). The survey consisted of ten questions including questions that required rating course components on a Likert scale e.g. “Did you enjoy the course?” with one being “Yes, I enjoyed it a lot” and ten being “No, I did not enjoy it at all” and open answer questions e.g. “What was your experience with the presentation and navigation of the course?” Participants received a letter thanking them for their participation (Appendix V) and a \$20 supermarket voucher at the completion of the final module.

Results

Adherence and Completion. Of the nine participants recruited, eight completed the full four weeks of the intervention giving 88% completion. All participants who completed the intervention responded to the feedback survey with the results presented below. One participant completed up to and including the week three module before being lost to follow up. Reasons for this participant not completing the intervention are unknown.

At the completion of the online course participants completed a feedback survey consisting of ten questions. The first three questions of the survey required participants to select one response on a Likert scale ranging from one to ten as presented below.

Question 1: “Was the course easy to use?” On Likert scale of one to ten with one being “very difficult to use” and 10 being “Very easy to use”. The mean rating:8.9 (SD: 1.17, range: 6).

Question 2: “Did you enjoy the course?” on a Likert scale with one being “Not I didn’t enjoy it at all” and ten being Yes I enjoyed it a lot”. The mean rating: 7.25 (SD: 2.16, range 3)

Question 3: “Would you use the course again” On a Likert scale with one being “No, not at all” and ten being “Yes, definitely” The mean rating was 9.5 (SD: 0.71, range: 2)

Participants were then asked to rate each of the mindfulness tasks and homework tasks on a Likert scale from one to five with five being the highest rating “Really liked it and used it a lot” and one being the lowest rating “didn’t like it at all”. The average ratings for each task were calculated across participants. The results are presented below in Table 3.

Table 3. Mean rating of online resources (out of a possible five) for each of the online resources.

Online Resource	Mean Rating	Standard Deviation	Range
Mindful breathing	4.3	1.39	4
Mindfulness for working with difficulties	4.1	1.39	2
Body Scan	3.3	1.16	4
Loving Kindness Meditation	4.0	1.20	3
Mindfulness in your daily routine	4.1	0.83	2

Mindful eating	4.4	0.90	2
Mindful walking	4.4	0.73	2

Qualitative Feedback. Questions six to ten were open questions where participants could comment and provide detailed answers to the questions. Due to the brevity of the answers in depth qualitative analysis could not be completed. The responses of each participant to the specific questions are presented in the tables below.

Table 4. Participants responses to question six, "Would you recommend this course to someone else? Why?"

Participant	Response
1	<i>I would recommend it solely, that they could experience it, and form their own views</i>
2	<i>It keeps one in a positive mood</i>
3	<i>Absolutely- it made me personally more aware and appreciate things around me esp. the simple things like making a cup of tea.</i>
4	<i>I feel the course has been helpful for me and I would like to share it with others</i>
5	<i>Yes, I found it a good way to cope with the now so would be good for someone struggling to cope with things in everyday life that can be overwhelming</i>
6	<i>I would recommend this to my wife because she is always stressing out about stuff and worrying about what needs to be done. Always bring up what has has [sic] been done and generally not living in the moment but she wouldn't do it as she thinks her reaction are perfectly normal and everyone else around her needs to change to reduce her stress.</i>
7	<i>Yes, some good ideas and ways of being more 'centred'. Found the techniques relaxing</i>
8	<i>Yes. I found the techniques incredibly helpful particularly when faced with an ongoing health emergency with my Husband in Australia 2 weeks ago. The deep breathing and loving kindness parts of the course especially. I would recommend it to others as it is so flexible, easy to use wherever you are has such a wide range benefits.</i>

All participants said yes, that they would recommend it to others. Reasons given for this recommendation was that participants had found the course beneficial and think it could help others. One participant that did not follow this general trend was P1, who stated that he would recommend it so others could make their own informed decisions about the course.

Table 5. Participant's responses to question seven, "What did you like or not like about the course?"

Participant	Response
1	I found some of the exercises incompatible with my temperament
2	I really appreciated that it is designed to help the very needy
3	Very easy to navigate and didn't take up too much time
4	I tend to use escapism in the mind to deflect the realities of life around me. This course has enabled me to be able to return and cope with my situations rather than postpone or ignore them
5	I liked the course because it helped me to remain centred and positive even when faced with someone else's stress and worries. My only difficulty was not making enough time for the course. I should have made it a priority.
6	I liked the visualisation techniques, I try to use the leaves on a river and waves on a beach. The audios would have been nice if it was said with a kiwi accent
7	Sometimes the audio started to play before the other video had finished.
8	Liked the self-paced learning opportunity and how information was presented in an easy to listen to and understand process. Liked the support provided when online issues arose. Did not like all the poor online issues I experienced.

Elements of the course that participants reported they liked included the content and the design. In relation to what they liked about the course three participants (P2, P3, P8) mentioned that they found the site easy to navigate and enjoyed the structure of the course. Participants 4, 5, and 6 referred to the techniques and specific exercises that they had found beneficial and how elements of the course helped them to cope with difficult situations. Things that participants did not like related to a range of factors including technical difficulties and content. Participant 1 mentioned that a number of the exercises did not fit with their personal preferences. Participant 8 experienced technical difficulties which affected their online experience.

Table 6. Participant's responses to question eight, "What was your experience with the presentation and navigation of the website?"

Participant	Response
1	<i>Difficult, I'm getting on in years and I am in awe of the computer and the computer age. However I completed the course and -"sent it off"-I can only hope that you receive it. I have my doubts</i>
2	<i>easy, very easy</i>
3	<i>Well presented with easy to follow instructions</i>
4	<i>As I am starting to get on in years now (73) I found it necessary to go through the entire weekly programme first to grasp what was require [sic] and then put it into action</i>
5	-
6	<i>Great experience, very easy to navigate</i>
7	<i>On the computer it was fine but I tried doing some on my smartphone and the web pages didn't format properly.</i>
8	<i>I did struggle early on with getting the course to display properly. Once I swapped to use my husband's computer though it was much easier to read. A good computer is necessary to do this course. It would be great to see it in another format as well.</i>

Participant's responses to the navigation experience of the website were mixed.

Participants 2, 3 and 6 commented that the intervention was easy to navigate and they encountered no problems. The two eldest participants (70 and 73 respectively) in the study reported that they had some problems with the navigation and structure. Both participants made reference to their age, alluding to the fact that the difficulties they experienced could be related to their skills with technology. Two participants also mentioned that they had experienced some technical difficulties.

Table 7. Participant's responses to question nine, "What could have made the course better/easier to use/more interesting?"

Participant	Response
1	<i>bear in mind the computer savviness of oldies</i>
5	<i>It did take a while to work out the audio downloads, seemed quite slow then had to download and set up the itunes U app.</i>
6	<i>Have it possible to do everything on a smart phone</i>
8	<i>The whole online experience needs to dramatically improve as it impacts adversely on the information/experience you wish to provide.</i>

Participants made a range of suggestions focussed on the technical aspects of the course. Some participants experienced difficulty with specific aspects of the intervention like playing the audio files and viewing specific pages. Improvement of the intervention was related to the online presentation and not the content of the course.

Table 8. Participant's responses to the question, "Do you have any other comments, questions or concerns?"

Participants	Response
2	<i>communication between participants might be beneficial</i>
3	<i>Thanks for giving me the opportunity to participate- nice start to 2015</i>
4	<i>Thank you for giving me the opportunity to stop and appraise my situation. I will definitely carry on and practice as I have found more I go back and redo the various exercises the better I become at not only focussing but being able to accept when my mind wanders.</i>
5	<i>thank you for having me on the course it has been a great help for me in dealing with other peoples stress and a dealing with a stressful marriage.</i>
7	<i>Overall once I passed the early problems I did settle in to it and enjoyed it. I found it useful especially in moments of stress or extra pain. Breathing part was especially good for centring in the moment.</i>
8	<i>I've found this whole experience extremely positive despite the online issues. I will continue to use the techniques I found helpful. Would be happy to further participate in similar research if required. THANKYOU.</i>

Overall the qualitative feedback for the online mindfulness intervention content was positive. Participants had found participation valuable and were grateful to have been given the chance to participate in the online trial.

Discussion

Adherence

Eight out of the nine participants recruited completed the online programme. There was no pre-treatment drop-out as the one non-completer finished up to the third module. The

high pre-treatment dropout and low adherence that is often observed in online interventions (Christensen, et al, 2009; Melville, et al, 2010; Rosser, et al., 2009; Wangberg, et al, 2008; Waller & Gilbody, 2009) was not present in the current sample. The high levels of completion are encouraging for the online intervention as it demonstrates that individuals can complete the modules included in the online mindfulness course.

Reasons for adherence to online programmes are complex and varied (Christense, et al., 2009; Dimatteo, Haskard, & Williams., 2007). There were a number of factors of this online intervention that encouraged individuals to complete the course. The first was a monetary incentive. Participants received a \$20 grocery voucher at the completion of the final feedback survey. This may have served to motivate individuals to complete the online mindfulness course. However, while incentives might be a beneficial way to encourage adherence to a programme, rewards may mask the potential dropout rates that would be seen if the intervention was offered in real world healthcare settings were no monetary incentives are offered.

It has been proposed that interventions with the endorsement and support of healthcare professionals encourage adherence to online programmes (Eysenbach, 2005). Recruitment of participants for this study was conducted through the New Zealand Artificial Limb Service (NZALS), a government agency that aims to meet the rehabilitation needs of and support individuals who have undergone a limb amputation. Going through this agency to recruit participants may have lent credibility to the intervention and might have made participants more inclined to sign up (compared to if they had seen it advertised elsewhere) and helped to ensure the success of the intervention.

It is possible that participants did not engage with the online resources but instead just logged onto the site without reviewing some or any of the information or exercises provided. The inclusion of a more nuanced monitoring system that provided better feedback on when

participants use and interact with the intervention (including how many times they click on a video or do they click on a video) could provide valuable feedback on the online resources. Unfortunately the moodle platform used to present this study was not configured to easily summarise these kinds of measurements. Adjusting the platform or the format of the presentation could lead to more sophisticated monitoring tools that gave a better insight into how individuals use the online course.

It is important to note that the uncertainty of how much of the intervention participants interacted with always be present for online interventions. With online interventions that are largely self-directed, there is no way of knowing what the participant is also doing or how much they attend to the intervention. Even if monitoring told us that a participant played the video right through, we still would not know definitively that participant watched the video. Perhaps the participant played the video while reading a book simultaneously or left the computer altogether while pausing the video to engage in another task. All interventions that rely on self-report are open to misreporting however including better monitoring techniques would provide a clearer insight into how individuals interact with the online intervention.

Online Resources

Individual's experiences with the online content were overwhelmingly positive. Participants had enjoyed taking part in the online intervention and feedback indicated that they believed the mindfulness component had been beneficial for them. All participants said that they would use the course again and reported high levels of enjoyment. All participants would also stated that they would recommend the course to someone else, with the primary reason cited as they had found the course valuable and thought that others could also receive benefits from completing it.

Participant's rated the online resources highly. All the resources received an average rating over four (with five being the highest possible) with the exception of the body scan which received a mean rating of three (neutral, neither liked nor disliked). Participants were presented with an array of different exercise and techniques to encourage them to integrate mindfulness techniques into their daily lives. While the tasks and resources were developed to be as universal appealing as possible it was understood that some participants might not enjoy or benefit from specific tasks. The results demonstrated that generally the resources appealed to the participants and were well received. Mindfulness techniques are accepted and useful to individuals.

Internet/User experience

Overall, participants reported that the intervention was easy to use and navigate however qualitative responses to the usability were mixed. Some participants commented that the intervention was easy to use and navigate while others found it more challenging. This is to be expected as online skills and capabilities will vary within a population. The large completion rate of the study indicates that there were no major technological barriers prohibiting individuals from finishing. Individuals provided constructive feedback on issues they faced and how their online experience could be improved.

Qualitative feedback expressing dissatisfaction or difficulty with the intervention was related to the technical aspects of the course. One participant expressed having repeated trouble at accessing the online site; this was resolved with the help of the researcher however it made the experience difficult for the individual. Another comment such as the audios would often start playing over each other. The researcher made every attempt to troubleshoot any problems that the participants were having as quickly as possible.

Problems with the online site might not have been purely the fault of the design and platform instead also reflecting the technology that the individual was using in their home or

their internet connection. Online interventions should however be designed so that they can accommodate a range of different operating systems (mobile devices) and a range of different internet speeds. This would increase accessibility to a larger cohort of people. Usability is an important consideration when designing an intervention. The quality of the content will not matter if the site is not usable and an individual cannot access and navigate the site (Eysenbach, 2005). There is a constant need to ensure that the online site is easy and intuitive to navigate as possible.

The two oldest participants (70 and 73) commented on the fact that they sometimes found the intervention hard to navigate and reasoned that this could have been due to their advanced age and lack of familiarity with technology. Both however managed to complete the course. This does however highlight the fact that the needs of specific populations need to be considered when developing online resources. Older adults have been recognised as having specific needs that need to be catered for in online interventions including options of having larger text and less fine motor control tasks requiring the mouse (Wagner, et al., 2010). For future intervention designs to be successful they need to consider the type of individuals who will potentially engage with their intervention and make sure their design accommodates this (e.g. including large fonts).

Two participants also raised the problem with accessing the intervention via smartphone and the possibility of providing the intervention in the form of an App. Presenting the intervention via App and/or making it smart phone compatible were both considered during the development of the intervention but due to the cost of development it was not considered viable for this project. The increasing use of smartphones (Rini, et al., 2011) means this is an important consideration when developing an intervention. Further research surrounding the online medium should investigate making future versions of the online intervention smartphone capable.

A further constructive suggestion from a participant was to include a chat forum so that participants could engage with other completing the task. The use of online forums has been shown to be beneficial addition to online healthcare interventions (Smith, 2011; Jones & Fox, 2009). However, while this is an excellent suggestion it also comes with additional considerations and precautions. A chat forum would require an online moderator to ensure the conversation is safe and constructive. The additional cost of and time commitment to the intervention would need to be considered against the potential benefits of including the online forum.

While the sample in the present study was relatively small it covered a large range of ages with the youngest being 29 and the oldest 72. Age did not appear to be a barrier with both of the older participants completing and engaging in the course. This demonstrates the appeal of both mindfulness and online interventions is not restricted to a specific age demographic or technological skill set but can have a universal appeal.

Limitations

A notable omission for the present study is quantitative measures reporting individual's pain, quality of life, and mindfulness levels both before and after the intervention. Due to earlier failures of recruitment and adherence the main aim of the current study was to see if participants could complete the course and to get their feedback on the different components of the course. The inclusion of quantitative measure would have greatly improved the quality of the study. Individuals self-report demonstrated that individuals felt that the course was beneficial but further quantitative measure would have added either further support or doubt to this claim. Future studies should include both qualitative and quantitative measures to assess any possible effects of the intervention.

As little is known about the baseline characteristics of the individual (i.e. their mindfulness levels) it is hard to draw conclusions about the effects the mindfulness

techniques had on the individuals. While all participants had undergone an amputation the shortest time period since amputation was 10 years. It is possible that individuals with more recent amputations would respond differently to the course and available resources.

Individuals reported benefiting from participation in the mindfulness course however further quantitative data is required to confirm this.

This study also had a small sample size. This could be partly due to the fact that the recruitment period was also small only covering only one month. This time period was unavoidable because of time constraints of the project, however, further studies could increase the recruitment period allowing for a larger sample and stronger data.

The present study could also have benefited from a more in depth evaluation of the online resources and methods of presentation. Budget restraints meant that the feedback questionnaire was limited to ten questions. Regular weekly questionnaires, an in person interview and observation of the user experiencing and navigating the site and further detailed questioning on the feedback study at completion could give a more cohesive picture of individuals experiences when completing the online intervention.

While the completion results are promising, the true extent of the adherence to this programme is not fully understood. Adherence was measured by an individual logging on to the online course. If an individual logged on to the site each week it was recorded as a completion of the module for the corresponding week. It was assumed that if the participant has taken the time to log on to the intervention they would review the material provided for each module. Researchers could only view when a participant last logged on to the site. It was not possible to see how many times the participants accessed the site during each week (if they repeatedly went back to review resources) or how long each participant spent per session.

Conclusions

The current online intervention is a feasible method to communicate mindfulness techniques. Amputees who completed the online course found it beneficial and enjoyable with the online resources well liked. Further studies could explore the effects of an online mindfulness intervention for pain and general well-being on different pain populations using quantitative measures to assess the effects of mindfulness on chronic pain.

CHAPTER FIVE

GENERAL DISCUSSION

Chronic pain is a prevalent health care issue that needs to be better addressed (Blyth, et al., 2001; Breivik, et al., 2006). This thesis aimed to develop and trial an online intervention that was designed to teach mindfulness techniques for coping with pain. This intervention was developed and initially trialled in post-joint arthroplasty patients (study one). The failure to recruit adequate numbers and high dropout rates lead to a second qualitative study (study two). Study two aimed to explore the lived pain experiences of individuals and their thoughts and attitudes surrounding online treatments and mindfulness.

A third study (study three) was included, which trialled the intervention on a different population of potential individuals experiencing pain, limb amputees, to investigate the user experience of the intervention structure and online resources. Taken together these studies demonstrated that the online intervention could be used to deliver mindfulness techniques. The qualitative results of study two demonstrated that psychological treatments are currently underutilized in individuals experiencing chronic pain, due to arthritis prior to joint arthroplasty and interventions could be feasibly delivered via online interventions to these individuals.

Recruitment and adherence

Due to low recruitment and drop out study one failed to collect adequate data that would allow conclusions about the effectiveness of the online intervention to be drawn. Study one only had two individuals complete the programme and they did it outside of the time parameters they were given. These results were in contrast to the completion rates in study three which saw no pre-treatment dropout. Of the nine participants recruited, eight completed the intervention and the final participant completed up to the third module. There are a range of possible reasons for these differences in adherence across the two studies, including

participants believing they did not need to use the internet intervention, presentation of the intervention and incentives (Christensen, et al., 2009; Waller & Gilbody, 2009).

In study one dropout occurred before beginning of the programme which would suggest it was not the content, but instead accessing the intervention, beliefs about the intervention or the online medium that prevented participants from completing the “Online Mindfulness for Pain” course. Online interventions are typically challenged with high dropout rates (Waller & Gilbody, 2009). While more recent interventions have had greater success at retaining participants (Dear, et al., 2014), dropout typically occurs before the beginning of the programme (Waller & Gilbody, 2009). This was seen in study one, where of the thirteen participants recruited, only four completed week one and only two went on to finish the course.

Qualitative results from study two provide some potential reasons as to why participation in the online intervention was so low in post-surgery patients. Firstly, participants reported minimal and manageable pain post-surgery. They were recovering quickly and positive about their long term outcomes. This is in contrast to the findings of a large, longitudinal study which reported 44.4% of participants experienced severe pain four weeks post knee joint replacement surgery (Brander, et al., 2003) with similar results being seen in hip replacement participants (Wylde, et al., 2011). It is possible that the small sample sizes of both studies failed to adequately capture individual’s experiencing severe post-surgery pain.

Participants also conceptualised their pain as completely different to their chronic pre-surgical pain. They viewed their post-surgical pain as good and healing. Their current experience of pain might have contributed to a lack of motivation to attempt and complete the online course which was framed as aiding them in dealing with their pain post-surgery.

Experiencing little pain, participants may have thought that participating in the online intervention was pointless.

In further support of high pre-treatment drop out due to low pain post-surgery, a consistent theme that came from the interviews was that mindfulness training would be more beneficial prior to surgery. Participant's pain post -surgery pain was minimal and constantly improving therefore they believed learning mindfulness techniques would be superfluous as the pain was already manageable. This was in contrast to the pain they had felt before having the surgery which was considered hard to cope with and there was a greater need for pain management techniques, such as mindfulness training. The degree of pain and ability (or inability) to cope with it could be a motivator for participating in the online intervention.

A further issue, which may have affected participation in study one, is the way that the intervention was presented to potential participants. The online intervention was called "Online Mindfulness Course for Pain" and was described in information sheets as an intervention primarily designed to help manage pain. A better way to describe this course to this specific participant sample could have been "Mindfulness for Well-being" or "Mindfulness for Recovery" not emphasising the pain aspect (although the intervention would still aid in pain management), but instead focussing on holistic overall recovery. Refocusing of how the intervention was described might have encouraged participants to use it (in study one) while still providing the same mindfulness techniques and benefited their recovery.

In study three the online intervention was described as a mindfulness course to promote overall well-being in individuals while still using exactly the same resources. The focus was shifted away from specifically coping with pain. This is a potential reason as to why study three saw greater completion and lower pre-treatment drop out, as individuals

were not alienated from using the course because they believed it was not just for pain but for their holistic well-being.

While study one failed to recruit and maintain participants in the online course it cannot be concluded that the intervention does not offer potential benefit for post-surgical patients. Research suggests a significant proportion of post-surgical patients experience severe pain post-surgery (Wylde, et al., 2011). Low recruitment numbers mean that the small sample may have failed to capture participants that experience severe post-surgical pain and are thus motivated to use the intervention. Recruiting a larger sample size or identifying individuals with severe post-surgical pain could be beneficial for future studies evaluating the online mindfulness intervention.

Qualitative results from study two also demonstrated that the lack of uptake of the intervention may not be due to the mindfulness content. Participants expressed positive and accepting attitudes towards mindfulness concepts and an interest to take part in an online course.

This is also supported by qualitative feedback offered by the participants in study three. Overall, the online mindfulness resources were rated highly; participants enjoyed taking part in the course, and had found the techniques beneficial in their everyday life. These results demonstrate that mindfulness intervention may be welcomed by individuals looking to improve their well-being and techniques to cope with their pain.

Monetary incentive might also have provided the motivation to complete the programme. Unlike in study one, participants in study three received a \$20 grocery voucher in remuneration at the completion of the course. This could have supplied sufficient motivation to complete the course in full. Offering post arthroplasty patients an incentive might have encouraged them to complete the course. However, offering incentives in a study

may lead to better participation which would not necessarily follow in an environment without incentives (Giuffrida, & Torgerson, 1997; Sutherland, et al., 2008).

An interesting consideration is if participant's attitudes match their behaviours towards online interventions. Sixteen of the twenty participants (four did not have access to the internet) who were interviewed for study two, were also offered the online mindfulness programme. Only four accessed the online site and only two completed the course. This is despite the majority of participants expressing an interest in online interventions and mindfulness in the interviews.

Study two interviews revealed some possible reasons for this low uptake including most prominently, a lack of pain. Further in depth investigation as to what features dissuade or encourage participants from taking part in online interventions and how these features differ across ages, cultures and socioeconomic status will be important to the continued development of online courses.

Recruitment was challenging for both study one and study three. Study three was limited by a very short recruitment period. Had this period been longer there might have been an increased number of amputees participating in the intervention. Study one also faced difficulty recruiting significant numbers to the course. This could be related to the specific population or the time that recruitment happened.

Future studies could also investigate the use of various recruitment methods. Shifting recruitment to the online medium, utilizing online facebook groups, support pages/groups and advertising on appropriate websites, might all aid in recruiting larger samples. Recruiting online would capture those who are already technologically savvy and who are generally interested in the intervention (Dear, et al., 2014; Graham, Milner, Saul, & Pfaff, 2008; Murray, et al., 2009; Ramo & Pochaska, 2012). The beauty of an online intervention is that it

can be run remotely with the experimenter not needing to be in the same geographic location as the participant. Extending recruitment beyond local area to national or even international participants could also garner larger sample sizes and should be considered in future online studies.

Pain

It is clear from the results in study two that participants were experiencing what they perceived to be unrelenting pain before their surgery. With no treatments able to offer them adequate relief, they were living lives constricted by pain. While this is unsurprising, as unmanageable pain is the primary reason for receiving a joint replacement (Liang, et al., 1986; Norman- Taylor, et al., 1996; Robertsson, et al., 2000) the results reinforce the extent of pain experienced pre-surgery (Demierre, et al., 2011; Fujita, et al., 2006; Hall, et al., 2008, Hawker, et al., 2008; Montin, et al., 2002). Participants also felt that their preoperative pain was not well understood by healthcare professionals.

Participants sought a range of other treatments to minimise their pain. This was consistent with research that demonstrated individuals in chronic pain are not restricted to one modality and will try a range of treatments to reduce their suffering (Fujita, et al., 2006; Lansbury, 2000). Participants reported little success with other methods and unsurprisingly did not continue with pain treatments if they did not see a reduction in their pain.

Participants may not have experienced formal psychological interventions, but techniques that many participants used to deal with their pain were invariably psychological. Participants referred to deep breathing exercises, relaxation, and distraction techniques as one of their first responses to their pain. Research has recognised psychological treatments for pain including Cognitive Behavioural Therapy (Morley, et al., 1999) and Acceptance Commitment Therapy (Wetherall, et al., 2011), mindfulness (Grossman, et al., 2004),

hypnotherapy (Elkins, et al., 2007), as all potentially effective treatments for managing chronic pain (Kearns, et al., 2011).

These results highlight the need for further pain interventions prior to the surgery. Psychological interventions could be invaluable in improving the quality of life of individuals waiting to receive joint replacement surgery or experiencing chronic pain due to osteoarthritis. Offering the online mindfulness intervention to these individual could help to address these pain issues and provide a more inclusive and holistic pain management plan.

Mindfulness perceptions

Participants in study two were not familiar with the term “mindfulness”, however when it was explained to them the overall response was resoundingly positive. Participants could generally see the logic and value of mindfulness techniques, especially in pain management. They acknowledged that an individual’s pain could be influenced by one’s psychological state, with frequent reference to the “mind-body” connection and believed that mindfulness was relevant to managing pain.

Qualitative research has not explored individual’s perceptions and attitudes surrounding psychological interventions for chronic pain conditions. Research in this area is important because participant’s perceptions could influence their uptake and involvement in psychological interventions (Ajzen, 1985; Rosenstock, et al., 1988; Weinstein, et al., 1998). Despite not previously knowing what mindfulness was participants expressed acceptance and understanding of mindfulness concepts and a willingness to try mindfulness techniques. This is promising for the integration of psychological interventions into pain management packages as it demonstrates that firstly, individuals had an understanding of the role of psychological factors in pain and that they were open to trying psychological interventions for pain management.

Individuals in study three enjoyed the mindfulness techniques, rated them highly and commenting that they had benefited from participation in the course. Qualitative feedback from study three also showed that participants had used the mindfulness techniques in their daily life. This supports the continued use and development of online interventions that focus on mindfulness.

Future Studies

The studies discussed in this thesis provide the groundwork for continued research into online mindfulness interventions for pain. The high completion rate of study three demonstrates that the online course can be feasibly used to deliver online mindfulness content. Further investigation is required to quantify if the online mindfulness course can increase positive outcomes such as pain coping, health related quality of life, and decrease negative outcomes such as pain, depression and anxiety. Properly powered, randomised controlled trials assessing online mindfulness effectiveness in chronic pain conditions could provide a valuable asset to pain management programmes.

One chronic pain population that merits further support and access to pain treatments is individuals waiting to receive a joint replacement surgery. As the results from study two suggest there is a real need to better treat and address the debilitating chronic pain individuals endure before receiving joint replacement surgery.

Conclusions

Chronic pain is a healthcare issue that needs to be better addressed in New Zealand. Mindfulness meditation techniques have the potential to help individuals alleviate suffering due to pain and warrant further investigation. As technology becomes more integrated into daily life harnessing online technologies to deliver pain and mindfulness interventions could

widen the reach of interventions making them more accessible and successful for the population at large.

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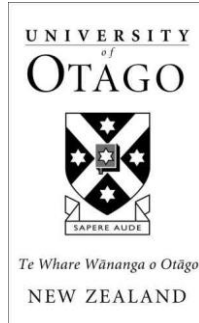
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APPENDIX A: Online Mindfulness Training for Coping with Pain, Demographics Questionnaire

Study Number _____



Online Mindfulness Training for Coping with Pain

Demographics Questionnaire

This information is used to determine eligibility and for statistical purposes only. It will be kept strictly confidential.

- **How old are you (years)?** _____

- **What gender are you?** (Please tick one)
 - Female
 - Male
 - Other

- **What is your living situation?** (Please tick the one closest to your situation)
 - I live alone
 - I live with my partner
 - I live with others who are related to me
 - I live with others who are not related to me

- **What is your highest qualification?** (Please tick one)
 - School
 - Diploma/Certificate or trade
 - Degree
 - Higher degree

- **What is your current employment status?** (Please tick all that apply)

- Working full time (>37.5 hrs per week)
 - Working part time (< 20 hrs per week)
 - Retired
 - Homemaker
 - Unable to work due to illness
 - Student
- **What would be the total income that you *personally* received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
 - **What would the total income (including your own) that your household received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
 - **How would you describe your ethnicity?**(Please tick all that apply, continued over page)
 - Maori
 - New Zealand European
 - Other (such as Dutch, Japanese, Fijian) Please state

Questions continued over the page

What are your current medications?

Please list all of the current medications you are currently taking.

Please list both over the counter and prescription medications. Name and dose is written on the medication container.

	<u>Medication</u>	<u>Dose (mg)</u>	<u>How</u> <u>often</u>	<u>Problem used for</u>	<u>Length of time used</u>
1.)	_____	_____	_____	_____	_____
2.)	_____	_____	_____	_____	_____
3.)	_____	_____	_____	_____	_____
4.)	_____	_____	_____	_____	_____
5.)	_____	_____	_____	_____	_____
6.)	_____	_____	_____	_____	_____
7.)	_____	_____	_____	_____	_____
8.)	_____	_____	_____	_____	_____

Thank you for taking the time to complete this form

APPENDIX B: Online mindfulness for pain intervention, questionnaire Package

All questionnaires were converted to an online form and presented over survey monkey. Questionnaires and accompanying instructions for completion were unaltered

Short-form McGill Pain Questionnaire (MPQ-SF)

Short-form McGill Pain Questionnaire

Instructions: The purpose of this checklist is for you to give us an idea about what your pain feels like. Each of the words in the left column describes a quality or characteristic that pain can have. So, for each pain quality in the left column, check the number in that row that tells how much of that specific quality your pain has. Rate every pain quality.

Example: Throbbing (0)___ (1) ✓ (2)___ (3)___

PAIN QUALITY	NONE	MILD	MODERATE	SEVERE
1. Throbbing	(0)___	(1)___	(2)___	(3)___
2. Shooting	(0)___	(1)___	(2)___	(3)___
3. Stabbing	(0)___	(1)___	(2)___	(3)___
4. Sharp	(0)___	(1)___	(2)___	(3)___
5. Cramping	(0)___	(1)___	(2)___	(3)___
6. Gnawing	(0)___	(1)___	(2)___	(3)___
7. Hot-burning	(0)___	(1)___	(2)___	(3)___
8. Aching	(0)___	(1)___	(2)___	(3)___
9. Heavy	(0)___	(1)___	(2)___	(3)___
10. Tender	(0)___	(1)___	(2)___	(3)___
11. Splitting	(0)___	(1)___	(2)___	(3)___
12. Tiring-exhausting	(0)___	(1)___	(2)___	(3)___
13. Sickening	(0)___	(1)___	(2)___	(3)___
14. Fearful	(0)___	(1)___	(2)___	(3)___
15. Punishing-cruel	(0)___	(1)___	(2)___	(3)___

A. Please make an 'X' on the line below to show how bad your pain is right now.

_____ |
 No pain | worst possible pain
 you can imagine

B. Please check the one descriptor below that best describes your present pain.

- 0 no pain
- 1 mild
- 2 discomforting
- 3 distressing
- 4 horrible
- 5 excruciating

C. Is your pain... (check one word)

Brief Intermittent Continuous

Brief Pain Inventory- Short Form (BPI-SF)

1. Please rate your pain by circling the one number that best describes your pain at its worst in the last week. (0= no pain and 10=pain as bad as you can imagine)

0 1 2 3 4 5 6 7 8 9 10

2. Please rate your pain by circling the one number that best describes your pain at its least in the last week. (0= no pain and 10=pain as bad as you can imagine)

0 1 2 3 4 5 6 7 8 9 10

3. Please rate your pain by circling the one number that best describes your pain on average. (0= no pain and 10=pain as bad as you can imagine)

0 1 2 3 4 5 6 7 8 9 10

4. Please rate your pain by circling the one number that tells how much pain you have right now. (0= no pain and 10=pain as bad as you can imagine)

0 1 2 3 4 5 6 7 8 9 10

5. In the last week, how much relief have pain treatments or medications provided? Please circle the one percentage that best shows how much relief you have received (0%=No relief 100%=Complete relief).

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

6. Circle the one number that describes how, during the past week, pain has interfered with each item listed below where 0= Does not interfere and 10= Completely interferes:

a. General activity

0 1 2 3 4 5 6 7 8 9 10

b. Mood

0 1 2 3 4 5 6 7 8 9 10

c. Walking ability

0 1 2 3 4 5 6 7 8 9 10

d. Normal work (includes both outside the home and housework)

0 1 2 3 4 5 6 7 8 9 10

e. Relations with other people

0 1 2 3 4 5 6 7 8 9 10

f. Sleep

0 1 2 3 4 5 6 7 8 9 10

g. Enjoyment of life

0 1 2 3 4 5 6 7 8 9 10

Depression Anxiety and Stress Scale (DASS-21)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3

Tampa Scale of Kinesiophobia-11 (TSK-11)

TAMPA SCALE - 11

INSTRUCTIONS:

With this questionnaire, we measure how you look at pain. Therefore, you are requested to complete *all* questions by indicating on a 4-point scale to what extent you agree or disagree with each of the statements. This is not a test of your medical knowledge and there are no good or bad answers. We are interested in your opinion, not that of others.

	Highly disagree	Somewhat disagree	Somewhat agree	Highly agree
1. If I were to try to overcome it, my pain would increase.	1	2	3	4
2. I can't do all the things normal people do because it's too easy for me to get injured.	1	2	3	4
3. My body is telling me I have something dangerously wrong.	1	2	3	4
4. I wouldn't have this much pain if there weren't something potentially dangerous going on in my body.	1	2	3	4
5. I'm afraid that I might injure myself if I exercise.	1	2	3	4
6. People aren't taking my medical condition seriously enough.	1	2	3	4
7. My accident has put my body at risk for the rest of my life.	1	2	3	4
8. Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my pain from worsening.	1	2	3	4
9. Pain lets me know when to stop exercising so that I don't injure myself.	1	2	3	4
10. Pain always means I have injured my body.	1	2	3	4
11. No one should have to exercise when he/she is in pain.	1	2	3	4

Pain Anxiety Symptom Scale (PASS-20)

Individuals who experience pain develop different ways to respond to that pain. We would like to know what you do and what you think about when in pain. Please use the rating scale below to indicate how often you engage in each of the following thoughts or activities.

Circle one number from 0 (NEVER) to 5 (ALWAYS) for each item.

1. I think that if my pain gets too severe, it will never decrease.

0 1 2 3 4 5

2. When I feel pain, I am afraid that something terrible will happen.

0 1 2 3 4 5

3. I go immediately to bed when I feel severe pain.

0 1 2 3 4 5

4. I begin trembling when engaged in activity that increases pain.

0 1 2 3 4 5

5. I can't think straight when I am in pain.

0 1 2 3 4 5

6. I will stop any activity as soon as I sense pain coming on.

0 1 2 3 4 5

7. Pain seems to cause my heart to pound or race.

0 1 2 3 4 5

8. As soon as pain comes on, I take medication to reduce it.

0 1 2 3 4 5

9. When I feel pain, I think that I may be seriously ill.

0 1 2 3 4 5

10. During painful episodes, it is difficult for me to think of anything else besides the pain.

0 1 2 3 4 5

11. I avoid important activities when I hurt.

0 1 2 3 4 5

12. When I sense pain I feel dizzy or faint.

0 1 2 3 4 5

13. Pain sensations are terrifying.

0 1 2 3 4 5

14. When I hurt I think about the pain constantly.

0 1 2 3 4 5

15. Pain makes me nauseous (feel sick to my stomach).

0 1 2 3 4 5

16. When pain comes on strong I think I might become paralyzed or more disabled.

0 1 2 3 4 5

17. I find it hard to concentrate when I hurt

0 1 2 3 4 5

18. I find it difficult to calm my body down after periods of pain.

0 1 2 3 4 5

19. I worry when I am in pain.

0 1 2 3 4 5

20. I try to avoid activities that cause pain.

0 1 2 3 4 5

Mindfulness Attention and Awareness Scale (MAAS)

Day-to-Day Experiences

Instructions: Below is a collection of statements about your everyday experience. Using the 1-6 scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what really reflects your experience rather than what you think your experience should be.

Please treat each item separately from every other item. Scale: 1-Almost Always, 2- Very Frequently, 3- Somewhat Frequently, 4- Somewhat Infrequently, 5- Very Infrequently, 6- Almost Never.

I could be experiencing some emotion and not be conscious of it until sometime later.

1 2 3 4 5 6

I break or spill things because of carelessness, not paying attention, or thinking of something else.

1 2 3 4 5 6

I find it difficult to stay focused on what's happening in the present.

1 2 3 4 5 6

I tend to walk quickly to get where I'm going without paying attention to what I experience along the way.

1 2 3 4 5 6

I tend not to notice feelings of physical tension or discomfort until they really grab my attention.

1 2 3 4 5 6

I forget a person's name almost as soon as I've been told it for the first time.

1 2 3 4 5 6

It seems I am "running on automatic," without much awareness of what I'm doing.

1 2 3 4 5 6

I rush through activities without being really attentive to them.

1 2 3 4 5 6

I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.

1 2 3 4 5 6

I do jobs or tasks automatically, without being aware of what I'm doing.

1 2 3 4 5 6

I find myself listening to someone with one ear, doing something else at the same time.

1 2 3 4 5 6

APPENDIX C: Scripts for all the videos presented in the Online Mindfulness for Pain course

Week One Video A

Hello, and welcome to your first Mindfulness session, an introduction to mindfulness. An important question you probably have is what is mindfulness? What do you mean when you say be mindful?

Mindfulness is often defined as: Paying attention in a particular way: on purpose, non-judgementally. Simply as being in the moment. I know what you're thinking "This still isn't a very clear definition". So let's explore it more. It can be easy to divide mindfulness into two broad but separate components.

The first part of mindfulness is:

Paying deliberate attention to the current moment. If you are being mindful you are aware of the here and now experience and any sensations, emotions and thoughts that includes. This is the "being in the moment" part. That isn't all, the second part of mindfulness. The second part of mindfulness is approaching the current experience with openness, receptiveness and interest. This means trying not to interpret the present situation (be it an event, a sensation or a thought) as good or bad but instead just letting it be.

Let's look at these concepts in even more detail. What is this being in the moment part. We use mindfulness to regain contact with the present moment because while our body may be present in the moment our thoughts often aren't. We spend a lot of time worrying about past events. Thinking about things that have already happened, that we can't change. We also spend a lot of time agonizing over the future. Stressing about what needs to be done and how we can do it. Making extensive plans and commitments.

Mindfulness is about letting go and paying attention to what is happening right now with no attached feelings, just observing. While the first concept of mindfulness is easy to understand (paying attention to the current moment) in practice it is a little harder.

Most individuals can draw their attention to the present moment but maintaining focus for an extended period of time is somewhat more difficult. This is because our minds tend to wander onto other things. One minute you are focussing on what you are doing and the next minute you find yourself thinking about the weather, planning dinner and how to get home.

Mindfulness is about focussing your attention and is sometimes referred to as exercise for your brain. Like with exercise the more you practice the better you become. So that was the first part but remember there is a second part to mindfulness.

While you are focussing on the present moment you have to approach any experiences, thoughts and sensations that arise in that moment in an

-open

-receptive

-unreactive

-interested manner

Our responses are usually automatic and we don't realise we are doing it. Mindfulness is about taking a step back and trying not to respond automatically to an event but instead just observing feelings as they arise.

We are conditioned to respond to specific experience in a certain way. Take pain for example, when we feel pain it is rarely in isolation. There are a lot of thoughts that accompany it. Often these thoughts are automatic and we don't think to question them. Mindfulness is about taking a step back and while acknowledging the experience of pain trying to be unreactive not get caught up in all the other feelings surrounding it. We are going to discuss how you can do this using mindfulness in a minute.

Okay, hopefully you have an understanding of what mindfulness is your next question is why should I practice this? Mindfulness interventions have been shown to reduce pain and psychological distress in individuals with a diverse range of ailments from chronic lower back pain to cancer.

Mindfulness is also predictive of lower levels of disability and chronic pain. How do we think mindfulness works for reducing pain? When practicing mindfulness your attention is in the present moment so you are not agonizing over what has and what could happen. Mindfulness is also about approaching current sensations (such as pain) in a non-reactive way. Mindfulness works to help change the way you perceive pain. Not to ignore it but to decrease the negative response to pain making it less salient and distressing.

Now you know what mindfulness is and why you should practice it but there is still the How, when and where. The great thing about mindfulness is you can do it anywhere at any time. From exercising to housework. However you don't become mindful instantaneously. For most people mindfulness is something that needs to be practiced.

That's where these sessions come in. Over the course of the next four we will provide you with four different audios of a guided mindfulness exercise to complete.

You will need to listen to these easy to follow audios. After that we will also give you some take home tasks to help you incorporate mindfulness into your everyday life. All of the audios will be available for you to use whenever you want. You can download or stream the audios online.

The aim of these exercises is to introduce you to techniques that let you practice bringing your awareness to the current moment and familiarise you with the methods of mindfulness.

That's enough talk from me. Are you ready to try your first guided mindfulness exercise? Your first guided mindfulness is a breathing exercise. It can be accessed by clicking on the link below

You can do this audio exercise sitting at the computer (or where ever you are accessing this from). The audio only runs for 5 minutes, all you have to do is follow along with what is being said. After you have finished listening to the audio click and watch the second debrief video. Happy listening and we will see you soon.

Week 1 Video B

Congratulations, you just finished your first guided mindfulness exercise. We hope you enjoyed it.

You might be wondering, why was it just breathing and sitting? Well breathing works as an anchor to the present moment. It is something we are constantly doing from the day we are born until the day we die. Paying attention to your breathing is the easiest way to bring your focus back to the here and now. It's a good place to start for mindfulness practices.

A lot of people say: But my mind was wandering! I don't think I'm very good at being mindful, I was thinking about all these random things.

Don't worry if this is what happen to you. It's completely normal. All you need to do is acknowledge any of the thoughts and feelings that have arisen and then bring you attention back to the present moment. It takes practice to learn to be aware of the present for extended periods of time

This is Joan, Joan is an accountant, a mother of three, a huge fan of the outdoors and playing hockey. Here is Joan's story about her first experiences with mindfulness for pain

I wasn't really sure if this mindfulness would work at all but I decided to give it a go because I thought it couldn't hurt. In the beginning I guess I wasn't that good at being present because my mind was always wandering off during the audio exercises.

I would be listening to my breathing one minute and before I realised I was thinking about who was going to walk the dog, had I given the dog dinner, what should I cook for dinner etc. I would get flooded by all these thoughts about things I needed to do and how I was feeling. It took me a while to realise that this was okay and to just go with it.

The first couple of times I listened to the audios I was probably mindful for about one minute total. I can tell you now you don't become an instant Zen expert from listening to one session.

For me it was a slow change over time. I guess I just started to notice how I was feeling more and instead of getting caught up in it like "ow it's so sore" I was more "okay so there is pain

and that's what's happening now". I would say I'm more mindful but it isn't easy and some days I don't manage to be very mindful but it's a process and you do notice changes in the way you think and react to things.

So that's was Joan's experience with mindfulness practice in her own words but remember the mindfulness audio isn't the only thing you can do

Mindfulness isn't limited to sitting down and listening to an audio. These are just provided to help you practice techniques that will make it easier for you to focus on the present moment. In fact mindfulness is great because technically you can practice it anywhere, any time! In fact you can do everything mindfully, from washing the dishes to sitting on the toilet. The only thing that can't be done mindfully is sleeping (as you are unconscious).

However as we said earlier for most people it is something that needs to be practiced and it can take time to integrate being mindful into your life. That is why we recommend you try and listen to the audio once a day. It's only five minutes but can make a big difference to how you think and feel.

We have also provided you with some suggestions or take home tasks to try and integrate mindfulness into your daily life. Remember mindfulness is about bringing your attention to the current moment and what is happening in the here and now.

Every week we'll give you a take home task that you can practice daily at home in conjunction with the audios. This week's task is a simple one called "Take 5".

The Take 5 task

This is a simple task that can be used anywhere. It can be used to centre you and bring your focus back to the here and now.

- Pause for a moment and take 5 deep breaths focussing on your breathing
- Next notice 5 sounds that you can hear. Maybe you can hear cars on the street or your children talking.
- Next shift your attention to 5 things you can see. What is in your surrounding environment?
- Now focus on five things you can touch? What sensations do you notice? Is your foot resting on a the ground? What surfaces are near you? Are they smooth or rough?
- Now take another 5 deep breathes

You can use it when you start to feel overwhelmed and frustrated or even if you just want to readjust your situation. When thoughts arise, acknowledge them and return your focus back to what you were doing.

Your attention will wander! This is normal and expected. Don't be concerned if your attention slips away from the present moment. Just acknowledge it and gently bring your attention back to the current activity.

Mindfulness Practice is just that *practice*. It takes time to get better and the more you often you do it the more you will improve and the more benefits you will see.

Be gentle with yourself. You cannot be expected to be an expert at mindfulness techniques the first time you try them.

Integrating Mindfulness into your daily life

Developing a routine to practice mindfulness can be very beneficial for your mindfulness practice. Here are some tips to make it easy to introduce mindfulness into your daily life.

- Set aside a specific time of the day that you will practice a mindfulness exercise. You could decide to do it before you eat breakfast or after you have watched the 6pm News on TV.
- Set an alarm or a reminder. So people find that if they have an alarm it is easier to do
- Use a mindfulness chart. Here you can download and print a mindfulness chart that you can fill in when you do a mindfulness activity. This is just for your use so that you can see how you are going with incorporating mindfulness into your daily life.
- Stick post it notes where you will see them reminding you to practice mindfulness
- Get other people to practice. As we mentioned earlier there are a lot of benefits for those who practice mindfulness.

While we recommend you practice at least once a day we realise that it's not always possible and sometimes you do just forget.

Mindfulness Recap

Mindfulness is simply *purposeful attention to the present without judging the events/thoughts that arise*.

Remember you can practice doing anything mindfully from cleaning your teeth to sitting on a chair.

We recommend you attempt to do the mindfulness breathing exercise once a day. The idea is to start small with just 5 minutes a day and slowly build mindfulness into your daily life.

The audio is available to you whenever you have time and can also be downloaded. It's only 5 minutes long but can make a difference to the way you feel.

There is also the "Take 5" exercise to practice.

Try your best to practice daily, remember one minute of mindfulness is better than not practising at all.

We hope you enjoyed your first mindfulness session. Happy practicing, see you next week.

Week Two Video A

Hello and welcome back to your second mindfulness session. We hope the first week went well.

This session is going to follow the same format as the previous one. First you will watch the introduction video (what you are watching now) followed by a mindfulness audio and finishing up with a summary video and take home task.

Let's quickly revise the two central concepts of mindfulness.

- * The first part is paying deliberate attention to the current moment. You are aware of the here and now experience and any sensations, emotions and thoughts that includes. When your mind wanders onto other things you simply acknowledge them and bring your attention back to the present moment.
- * The second part of mindfulness is approaching the current experience in an open, unreactive curious way. That is trying not to interpret the present situation (be it an event, a sensation or a thought) as good or bad but instead just letting it be.

One of the big problems people have with mindfulness practice is being **unreactive** or **switching the auto pilot off**.

The idea behind mindfulness is to not get carried away by ones emotions and thoughts, simply observe them as they arise.

This is easier said than done, especially with challenging sensations such as pain.

One metaphor for helping to understand the concept of non-reactivity is *leaves on a stream*.

You are standing on a bank watching a stream. Thoughts are like leaves on a stream. Different leaves represent different thoughts. You can watch leaves as they float down a stream.

You don't have to wade in a grab them. In fact you can stand on the bank and watch them float past. You can acknowledge the leaves and point but you don't have to interact with them.

Try and approach feelings of frustration or pain like this. You can acknowledge that these feelings are here but you don't have to interact with them. Just observe them as they float past.

You don't have to like or enjoy a sensation but you can stop fighting with it and breathe into it.

Observe feelings as they arise without getting swept downstream with them.

Why is it important to stay in the present moment?

- * It is important to stay in the present moment as we often get “caught up” in thoughts and can be dragged down by negative feelings.

Mindfulness is about stepping back and not interacting with these feelings.

Today’s audio is titled “Mindfulness for Working with Difficulties.” It runs for 7 minutes and can be done where you are sitting. As with the previous audio we ask you to listen and follow the instructions of the narrator.

Click on the link below that looks like this.

Once you have finished listening to the audio remember to click through to the debrief video.

Happy listening and we will see you soon.

Week Two Video B

Congratulations, you just finished your second mindfulness exercise. We hope you enjoyed it.

Mindfulness for working with difficulties aims to help you practice mindfulness while you are dealing with difficult sensations such as pain.

Mindfulness practice aims to decrease the negative response to pain therefore making it less noticeable and debilitating.

Meet Greg, Greg is a vineyard manager and huge rugby fan although thanks to the arthritis in his leg he’s hasn’t been on the field for a while. He enjoys the outdoors with his dogs Buddy and

Tiny and relaxing with a glass of red wine.

Here is Greg’s story about how he began using mindfulness techniques

One evening I was sitting on the couch watching T.V. There was a bit of pain in my knee, as you’d expect and I was just trying to relax and rest it. When I was reaching for the remote I dropped it down the side of the couch. I know this seems like something really small but I immediately got really frustrated.

It meant I would have to move (rearrange my knee) and I just wanted to change the channel to stop watching the ridiculous show that had just came on. It was also like dropping the remote made my knee hurt more. I think when you’re in a little pain even small things just get harder and you get that immediate rise of irritation over something that would normally be an inconvenience.

Anyway I remembered about the breathing exercise. I took deep breaths. The first couple I didn't notice any difference but once I got to about 10 I noticed I was starting to feel better the pain didn't go away but how I annoyed I felt about it did. Then I told myself "don't be stupid getting worked up about dropping the remote."

It's that awareness thing, realising how you are feeling. I started trying (when I remembered) to do the mindfulness for difficulties every day. I realised I was getting worked up over things that were pretty irrelevant.

I mean the pain is still there but if you look at it from a different way it can make it seem better. I liked the phrase "You don't have to want it simply make room for it." That helped me look at things in perspective and focus on my recovery instead of moping. That was Greg's story.

Mindfulness in everyday life

Remember mindfulness is something you can do anywhere at any time. The audios and the take home task are just exercises to help you practice bringing your awareness to the present moment.

Last week you had the take home activity "Take 5." This week's take home activity is mindfulness in your daily routine.

Choose one activity you do on a daily basis. It could be making a cup of tea, sweeping the floor, putting your makeup on or even doing the washing.

Once you have selected that task put all your focus onto what you are doing.

What movements is your body making? Where are your arms? What are your legs doing?

What sensations can you feel?

What noises does this task make? What can you hear?

Pay attention to the details of what you are doing

For example if the task you select is making a cup of tea. Notice the sensation of the tea cup, is it rough or smooth. What does it smell like? Can you feel the hot steam from the tea? Focus your attention on the act of making the tea (or whatever exercise you have chosen). What sound does the water make when you pour it into the cup.

When thoughts arise, acknowledge them and return your focus back to what you were doing.

Your attention will wander! This is normal and expected. Don't be concerned if your attention slips away from the present moment. Just acknowledge it and gently bring your attention back to the current activity.

Try and do this exercise everyday with one of the activities in your daily routine. You could mix it up and do a different activity mindfully each day. Whatever works best for you. We

recommend you practice some form of mindfulness every day. Remember Mindfulness Practice is just that *practice*. It takes time to get better and the more you often you do it the more you will improve and the more benefits you will see.

For maximum benefit we recommend you listen to one of the mindfulness audios once a day.

You can choose from either “Breathing Mindfully” or “Mindfulness for working with difficulties”. Both are great for practice. In fact you could even use both daily if you felt like it.

There are also the two tasks to practice either the “Take 5” task from session 1 or the “Mindfulness in daily routines” that was described earlier.

Try your best to practice daily, remember one minute of mindfulness is better than not practising at all.

Have a great week! Happy practicing

Week Three Video A

Welcome back to week 3 of your mindfulness session. We hope everything is going well and you have been enjoying your mindfulness exercises.

Let’s get We will begin with the a brief reminder about the two parts of mindfulness (hopefully this sounds pretty familiar by now):

Mindfulness is paying attention, on purpose, in the present moment non-judgementally. As feelings, sensations and thoughts arise you acknowledge them and try to respond in an accepting, open and non-reactive way. As you have probably discovered this isn’t always as easy as it sounds.

Last week we talked about a leaves on the stream metaphor. This week there is a similar one called “waves on the beach”.

You can think of your thoughts and feelings like waves on the beach. Each thought is a wave that rises up from the sea before falling back in. You can watch the waves from the shore without being caught up in them. Just watch as the waves comes, lands on the beach and then retreats back into the sea. Try and approach feelings of frustration or pain like this. You can acknowledge that these feelings are here but you don’t have to interact with them.

Non-reactivity can be really hard to practice, especially with sensations like pain. Another way to understand non reactivity is to observe events and sensations with the beginners or child’s mind. Approach the moment as if it the first time you have experienced it.

Let go of all your preconceptions and embrace the moment as it is. Often our beliefs and assumptions about something can cloud the way we interpret it. Some people find it helpful to silently say to themselves “I don’t like this feeling, but I have room for it,” OR “It’s unpleasant, but I can accept it.”

Mindfulness is about being in the present moment. Open, unreactive and accepting. This week's audio mindfulness practice is the body scan. Find a position that is most comfortable for you. It can be done where you are sitting but it can also be done lying down on your back.

The audio runs for 12 minutes and can be accessed by clicking on the link below. Remember after listening to the audio to click through to the debrief video.

Happy listening and we will see you soon.

Week Three Video B

Hello and welcome back

How did that feel? You just completed the Body Scan.

The body scan is an excellent mindfulness task because it allows you to experience how each part of the body is feeling without trying to change it instead just letting it be. It can also be used to help you get to sleep at night and can be done while lying on your bed.

This is Sophia, Sophia is a nurse and enjoys gardening, tramping and picnicking with her family.

Here is Sophia's Story about how she used they body scan to help with her post-surgical pain.

I started using the body scan audio every night. For me it was like a "body debrief." I do this because at the end of the day was always when my knee was a bit sore. If you're moving around, putting weight on it just going about your business by dinner time it was getting painful.

Just seeing where all the different parts of your body are at and how they are feeling. I was amazed at how disconnected you can get from the rest of your body because for me all my focus was going into my knee. It also helped remind me that although I had pain in one area I had a lot of parts that were working fine like my arms and hands. This probably sounds strange but during the body scan I realised how great they were.

So that's was Sophia's experience with the body scan.

This week's take home task is mindful eating. This is the third week of mindfulness sessions so some of these instructions might be starting to sound familiar. The underlying concepts of mindfulness are the same the take home tasks and audios are just different suggestions of how to bring mindfulness into your daily life.

Mindful eating

Eating is something we do every day but how often do we pay attention to what we are putting in our mouth? Often we eat our meals in auto pilot, not realising what we are putting in our mouths as we focus on other tasks like watching the television or reading the newspaper.

This is mindfulness eating exercise that involves a piece of chocolate (a great excuse for a sweet treat). However if you don't like chocolate or don't have any available you can use other food items, perhaps a small piece of cheese or an apple.

Before you sit down and begin turn off any other distractions like the T.V and your cell phone. While you can still practice mindfulness when there is the T.V going or your cell phone beeping it can be easier to focus your attention on the present moment if you don't have the extra distractors

Throughout this exercise, all sorts of thoughts and feelings will arise. Let them come and go, and keep your attention on the exercise. If you realise that your attention has wandered, briefly note what distracted you, then bring your attention back to the chocolate

- * Take hold of the piece of chocolate
- * First look at it as if you're a curious scientist who has never seen such a thing before. Notice the shape, the colour, the different shades of colour, the parts where light bounces off the surface, the contours.
- * Notice the weight of it in your hand and the feeling against your fingers: its texture and temperature
- * Raise it to your nose and smell it. Notice the aroma
- * Raise it to your mouth and pause for a moment before biting into it. Bring your attention to what is happening inside your mouth: notice the salivation around your tongue and the urge to bite into it
- * Now slowly bite it in half, noticing your teeth breaking through the chocolate and the sound that makes, and the sensation on sweetness on your tongue
- * Notice your teeth meeting and the feel of the chocolate falling onto your tongue, and the urge to chew it and swallow it
- * Chew it slowly, notice the taste and texture. Notice the movement of your jaws, the sound that chewing makes, the sensation of the chocolate breaking down. Notice how your tongue shapes the food
- * Notice your urge to swallow - and as you do swallow, notice the movement in your throat, and the sound it makes
- * And after you've swallowed, pause and notice the way the taste gradually disappears from your tongue. Notice your growing urge to eat the remaining half

- * Now eat the rest of the chocolate

Remember you can do this with any item of food. It doesn't have to be chocolate and it could be a whole meal. The aim of this task is to mindfully eat.

Mindfulness Practice

- * You now have three audios to choose from: Mindful breathing, mindfulness for working with difficulties and the body scan.
- * We recommend that you try and practice mindfulness exercise daily however it's up to you which one you listen to. You could listen to them all each day or alternate them on different days. It's all up to you and what you feel comfortable with.
- * There are also the delicious mindfulness eating tasks to try. You can also continue with the take 5 and mindfulness in daily routine tasks.

Try your best to practice daily, remember one minute of mindfulness is better than not practising at all.

Happy practicing, have a great week.

Week Four Video A

Welcome back to your final mindfulness session

We hope you have been enjoying the sessions. The mindfulness concepts are probably very familiar to you by now.

Here is a really simple break down of mindfulness to refresh the concepts we've discussed so far.

In simplest terms mindfulness is: Purposeful attention to the present without judging the events/thoughts that this moment contains. You need to:

Observe

Breath

Expand

Allow

- * **OBSERVE**- be aware of the feelings in your body
- * **BREATHE**- Take a few deep breaths. Breathe into and around these feelings
- * **EXPAND**- Make room for these feelings. Create space for them

* ALLOW -Allow them to be there. Make peace with these feelings

Feelings of pain, annoyance, frustration or distress are not easy to deal with sometimes they can be entirely overwhelming. Practicing mindfulness techniques and doing these four simple things can help us better deal with them.

Why do I have to try and stay in the moment again?

Being in the moment (no matter what that moment contains be it happiness or pain) is important. This is because if we are in the moment we don't have anything to struggle against.

Remember how last session we described the process of being non-judgemental as like watching waves on a beach. Another way to understand non reactivity is to imagine you are sitting on the side of the road watching cars drive past. Try and think of feelings and sensations like these cars.

You can observe as different feelings come and go.

As the car drive past you can acknowledge them. May identify what each one, some cars might be more frequently seen on the road than others.

BUT you don't have to go onto the road a try and block the cars or stop one of the cars and get in.

Some feelings might be more frequent than others but you can be unreactive to them and watch them as they come and go. Don't get carried away by a feeling. Just step back and let it be.

What is happening in the moment is neither good nor bad but it is how we choose to interpret the situation. It is simply sensations and events.

Mindfulness teaches an individual to be non-judgemental. Try and approach feelings of frustration or pain like this. You can acknowledge that these feelings are here but you don't have to interact with them.

Today's audio is an extended mindful breathing exercise. It runs for 17 minutes which is a little long than what you're used to and can be done where you are sitting.

Sometimes people equate their inability to continuously focus on the present moment as failure.

This isn't true at all. Mindfulness practices aren't easy and you shouldn't get disheartened if find them difficult. If you are trying to practice regularly you are well on your way to becoming mindful.

As with the previous audio we ask you to listen and follow the instructions of the narrator. Click on the link below. Remember to watch the debrief video after.

Happy listening, see you soon.

Week Four Part Two

Welcome back to your last mindfulness video. Thank you for continuing through all four weeks.

As with the previous debrief videos we will have a case study and then give you a take home task. We hope you have enjoyed your mindfulness journey so far.

The final case study we will look at today is George. Here is what George has to say about his journey with mindfulness and mindful walking.

After I had my knee surgery I was a little bit apprehensive to walk on it. I guess it just came down to the fact that I was scared of messing it up and ruining the surgery. I was tentative about putting weight on it and moving it around. The Mindful walking helped because it gave me focus. It brought all new meaning to “one step at a time.”

As an ex-rugby player and a farmer I used to be obsessed with physical conditioning I guess mindfulness is all about mental conditioning. Teaching yourself how to focus and live in the moment. Sometime I think doing weights and building muscle was a lot easier than this.

With practice I realised that mindfulness started to become more unconscious. Without prompts I would focus on what was happening in the now and if I got a negative thought instead of going with it and responding I'd have a think about it before I got fully involved. It's a slow process but worth the training.

That was what George had to say about his experiences with mindfulness and he also mentioned the mindful walking task. That is your take home task for this week, mindful walking outside.

The aim of this exercise is to simply go for a mindful walk outside. It has to be a distance that is comfortable and safe for you. The walk doesn't need to be long, maybe it is just to your letter box or around your garden. If you are able you could go for a longer walk around your block or if you can get to the beach.

So here are some things to think about when you begin your mindful walk.

- Once you step outside take several deep breaths in and out. Ground your awareness in your breathing. Notice the weight of your body going through your feet and into the ground.
- As you begin to walk notice the sensation of raising your leg and then setting your foot back down on the ground. Notice the different muscles that contract and relax as you move. How does the ground feel beneath your feet?
- While you walk expand your awareness to your surroundings. What can you hear? Is it traffic, the neighbour's dog or birds? What can you smell? Do you feel the air on your skin? Is it cold or humid? Use each of your senses to interact with the environment.
- If at any time this exercise becomes too uncomfortable or painful stop.
- If you have feelings of pain, acknowledge them, let them be and bring your attention back to the walking motion.
- If boredom or frustration arises, simply acknowledge it, and bring your attention back to the task at hand.
- When thoughts arise acknowledge them, let them be, and bring your attention back to what you are doing.
- Again and again your attention will wander. This is normal and expected. Don't be concerned if your attention slips away from the present moment. Just acknowledge it and gently bring your attention back to the current activity.
- Remember the walk can be as long or as short as you want it to be. There is no specification or regulation as long as you try to complete it mindfully.

Here is a recap of some hints that help remind you to do daily mindfulness practice

Mindfulness Hints

- Set aside a specific time of the day that you will practice a mindfulness exercise. You could decide to do it before you eat breakfast or after you have watched the 6pm News on TV.
- Set an alarm or a reminder. Some people find that if they have an alarm it is easier to do
- Use a mindfulness chart. Here you can download and print a mindfulness chart that you can fill in when you do a mindfulness activity. This is just for your use so that you can see how you are going with incorporating mindfulness into your daily life.

- Stick post it notes where you will see them reminding you to practice mindfulness
- Get other people to practice. As we mentioned earlier there are a lot of benefits for those who practice mindfulness.
- Get rid of distractions. While mindfulness can technically be practiced anywhere at any time it can be easier for people new to the practice to do it in a space that is quiet. So turn off the TV and your cell phone for just 5 minutes while you practice your mindfulness exercises.

You have 4 mindfulness audios you can use:

- the mindful breathing
- Mindfulness for working with difficulties
- Body scan
- Extended breathing and loving kindness meditation

5 take home tasks

- Take 5
- Mindful meal
- Mindful daily task
- Mindful walking

Thank you for completing the online Mindfulness course. We really appreciate the time and effort you have put into it and we hope you found it beneficial.

The audios and slides shows will still be available for you to access whenever you want. There is more information available in the document belong about other mindfulness resources if you are interested in continuing your mindfulness journey.

Just because you've finished the mindfulness sessions doesn't mean that you should finish practicing mindfulness. Mindfulness is a way of experiencing and living.

Thank You and happy practicing

APPENDIX D: Take home task infographics

Take Five

Mindfulness Exercise




This is a simple exercise that can be used to centre you and bring your focus back to the present moment. The best thing is you can do it anywhere at any time

What to do:

- 

1. Take five deep breaths in and out. Focussing on your breathing
- 

2. Acknowledge five things that you can see. What is surrounding you?
- 

3. Shift you attention to five things you can hear. What sounds are there?
- 

4. Now notice five things you can feel or touch. What surfaces can you feel? Are they rough or smooth?
- 

5. Finish with 5 deep breaths. Slowly in and out.

Simply take five minutes to reset and refocus

Mindfulness in your daily routine



Mindfulness is something you can do anywhere at anytime BUT it takes practice.

Mindfulness in you daily routine is an exercise to help you incorporate mindfulness practices into your daily life.

Chose an activity

One you do on a daily basis. It could be brushing your teeth making a cup of tea or putting on your clothes



Once you have selected a task you are going to attempt to do this mindfully.

This means giving your full attention into the activity and being in the moment.



Pay attention to what movements your body is making.
Where are your arms?
What are your hands doing?



What noises does this task make? What can you hear? Gurgling? Scratching?



What sensations can you feel? What textures do you notice? Hot or cold? Rough or smooth?

If your attention wanders acknowledge it and bring your focus back to the task. Try to do this everyday with one task.

Happy Practicing

MINDFUL WALKING

A mindfulness practice exercise



The aim of this exercise is to go for a **mindful walk outside**. It can be as long or short as you want. Just a comfortable and safe distance for you.

Remember when practicing mindfulness try to keep your attention in the **present moment**.

Once you step outside take several **deep breaths**. Ground your awareness in your breathing.



Pay attention to your **surroundings**. Can you feel the wind on your face? What can you see, smell and hear?

Notice the different muscles that contract and relax as you move.

As you begin to walk **notice the sensation** of your leg rising and then setting your foot back down on the ground.



Acknowledge thoughts that arise and then return your attention back to the present moment.

Remember if your attention wanders **deep breaths** can help you return to the ground your awareness.

Enjoy your walk outside.

APPENDIX E: Mindfulness practice sheet and additional resources sheet

Mindfulness Resources

Listed below are some additional resources that could help you on your mindfulness journey. Thank for participating in the intervention and we hope you continue to use the mindfulness techniques.

Books

- *“Full Catastrophe Living : how to cope with stress, pain and illness using mindfulness meditation”* by Jon Kabat-Zinn
- *“Mindfulness Meditation for everyday life”* by Jon Kabat-Zinn
- *“The Happiness Trap”* by Russell Harris
- *Pain Relief without Drugs: A Self-Help Guide for Chronic Pain and Trauma* by Jan Sadler

Online

- www.getsomeheadspace.com – free mindfulness program and information
- www.calm.com – online guided mindfulness sessions
- www.marc.ucla.edu –free online mindfulness audios and resources

Mindfulness Practice Chart

This chart can be used to record your mindfulness practice and remind you to do it. Fill in the amount of time you practiced mindfulness and what type of practice it was e.g. 10 minutes of mindfulness, 5 mins breathing exercise and 5 mins mindful dish washing.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Week 1							
Week 2							
Week 3							
Week 4							

APPENDIX F: Online Mindfulness Training for Coping with Pain, information sheet and consent form for participants

[Reference Number: 13/NTB/136]
[16.09.2013]



Online Mindfulness Training for Coping with Pain

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is [x] pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the Aim of the Project?

The aim of the current study is to investigate the effectiveness of an online mindfulness based intervention for post-surgical pain. This research aims to help inform healthcare professionals in developing comprehensive treatments for post-surgical pain. This project is being undertaken as part of the requirements for Jessica Leov's Masters of Health Science.

What Type of Participants are being sought?

- To take part in this study participants will need to be undergoing a joint replacement surgery.
- As this study involves an online mindfulness course participants will need to have access to the internet for the duration of the study so that they can complete the modules and questionnaires.
- Participants will need to be fluent in English

What will my participation involve?

If you agree to take part in this project you will be asked to complete an online mindfulness program. Mindfulness is a practice that aims at changing the way you think about sensations (like pain) and emotions you might have. It is about learning to focus your attention on the present moment. Some people refer to mindfulness practices as going to the gym for your brain.

The Mindfulness course consists of four online sessions to be completed once weekly over the course of 4 weeks. These sessions can be completed for the comfort of your own home at whatever time of day is best for you.

Each session will take approximately 20 minutes to complete and will include mindfulness tutorials, guided mindfulness audio exercises, case studies and a take home practice task.

Don't worry if you don't feel confident navigating the internet. There will be detailed information sheets about how to use the program and the researcher (Jess) will be available to help you with any technical difficulties.

All participants will have access to the online mindfulness module but at different times. When you sign up to the study you will be randomly assigned to one of two groups. Participants in **Group One** will be asked to begin completing the online mindfulness program approximately 1 week after their surgery. Participants in **Group Two** will be given access to the same online mindfulness program at approximately 4 weeks post-surgery.

Participants in both groups will also be asked to complete 5 weekly online pain questionnaires beginning one week post-surgery.

Participants will receive weekly text and email reminders to complete the online module and questionnaire. They will also receive a weekly phone call from the researcher to check on their progress and discuss any problems they are having with accessing the online components.

This study has been approved by the Health and Disability Ethics Committees (HDEC),

What are the benefits?

Mindfulness programs have been shown to reduce pain in diverse groups of people. Taking part in this program could be beneficial to your post-surgical recovery. Additional benefits of mindfulness are increased self-awareness and calm.

What Data or Information will be Collected and What Use will be Made of it?

The weekly questionnaires will ask about you are feeling and if you are experiencing any pain. There will also be questions about mindfulness and the mindfulness program. These questionnaires will be filled out online.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 10** years in secure storage. Any personal information held on the participants may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

The results of this research project will be written up into a Master's thesis and will be available in the **University of Otago Library** (Dunedin, New Zealand). Material from the thesis will be independently written up for publication in scientific journals. As with the thesis, your responses to questions in the questionnaires will continue to be anonymous and your name will never appear in either the thesis or in any journal article.

Is the information confidential and will it be reported anonymously?

You will be given a study number and your name will not be stated on the questionnaires and it will never appear in any report on the study. Any potentially identifying information will also be removed so your participation is entirely anonymous. No material that could personally identify you will be used in any reports on this study. Your information is confidential to the researchers (listed below) involved in the project.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Jessica Leov

and

Dr. Nicola Swain

Department of Psychological Medicine

Department of Psychological Medicine

University Telephone Number:- ...

University Telephone Number:- 474700

Email: jes.leov@gmail.com

Email: nicola.swain@otago.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Consent Form: Online Mindfulness Training for Coping with Pain



Online Mindfulness Training for Coping with Pain CONSENT FORM FOR

PARTICIPANTS

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Participant Contact Details

Address:

Home Phone Number:

Cell phone Number:

Email Address:

Date of Birth:

Please indicate the best time of day to get in contact with you:

Estimated date of Surgery (if known):

Declaration by participant:

I hereby consent to take part in this study.

YES/ NO (*please circle*)

Participant's name:

Signature:

Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature:

Date:

This project has been approved by the Health and Disability Ethics Committees

Reference Number: 13/NTB/136

Date: 16.09.2013

Appendix G: Online Mindfulness for Pain, Information Package (treatment group)
Mindfulness for Pain Study

Dear [participants name]

Thank you for signing up for the Mindfulness for Pain course. We appreciate your participation and hope you find it beneficial. This information pack contains instructions on how to navigate the online course. We take you through the components step by step making the course easy for you to use.

The course aims to teach you mindfulness techniques for you to use in your daily life. The fantastic thing about this course is that you can log on and use it at whatever time you like, whenever is easiest for you. However you do need to complete a topic on the week it becomes available to you.

You should complete one topic (questionnaire, video, audio, questionnaire) in one sitting and it should take you approximately 20 minutes.

First here are some important details:

Your study number:

User name:

Password:

These details will be used to allow you to gain access to the program online. Are you ready to get started?

Part One -Logging on to the Mindfulness and Pain Course

- 1.) You need to open up your internet browser. Your computer may use Internet Explorer, Mozilla Firefox or Google Chrome. Open up your preferred internet browser by clicking on its icon.

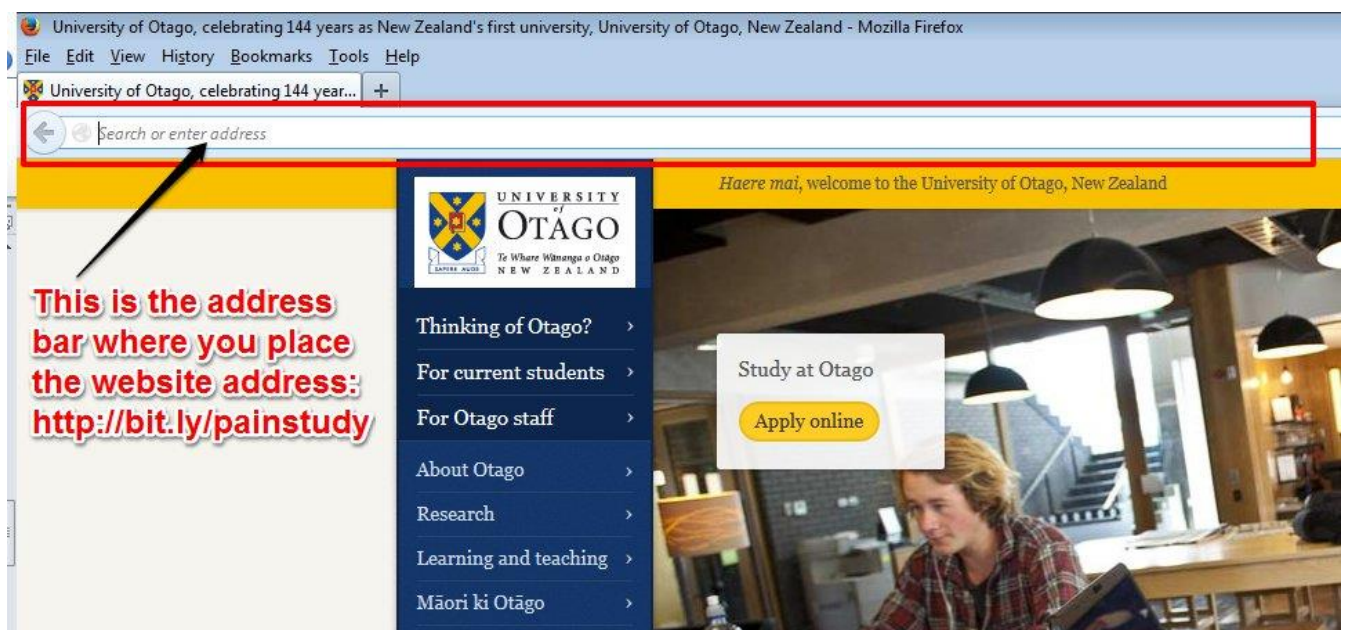


- 2.) Type this website address (located below in blue) in the address bar which is located at the top of your internet browser screen and then press the enter key (on your keyboard).

Website Address:

<http://bit.ly/painstudy>

Below is an example of where the *address bar* is on the Firefox browser window. It looks similar for all different types of browser.



A page should appear that looks like this:

Faculty of Medicine Moodle: Login to the site - Mozilla Firefox
File Edit View History Bookmarks Tools Help
Faculty of Medicine Moodle: Login to... × New Tab
https://medschool.otago.ac.nz/login/index.php

UNIVERSITY of OTAGO
Te Whare Wānanga o Ōtago
NEW ZEALAND

My Moodle ELM 2 ELM 3 ALM 4 ALM 5 ALM 6 PostGrad Help

Faculty of Medicine Moodle

Home » Login to the site

Returning to this web site?

Login here using your username and password
(Cookies must be enabled in your browser) ?

Username
Password
 Remember username
[Forgotten your username or password?](#)

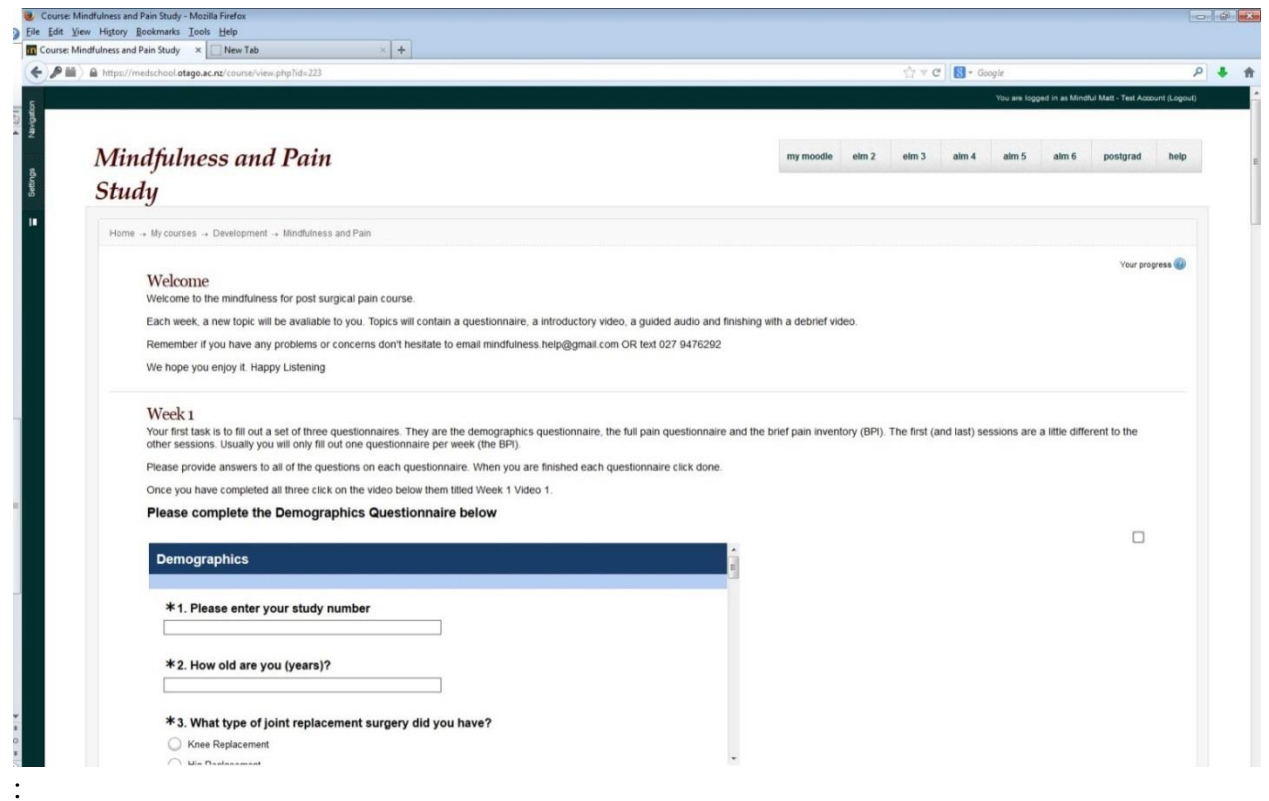
This is where you enter you username and password

This is the login button, click this when you have entered your details

Home

- 3.) In the place that says Username and Password please enter your unique username and password that was provided on page one. Then click on the Login button.

A page should appear that looks like this:



Congratulations! You have successfully logged on. Now let's get started on the course.

Part Two- Welcome and the Questionnaires

The screenshot shows the course interface. At the top right, a dark bar contains the text "You are logged in as Mindful Matt - Test Account (Logout)". Below this is a navigation menu with items: "my moodle", "elm 2", "elm 3", "alm 4", "alm 5", "alm 6", "postgrad", and "help". The main heading is "Mindfulness and Pain Study". A breadcrumb trail reads "Home → My courses → Development → Mindfulness and Pain". The "Welcome" section includes a message about the course structure and contact information. The "Week 1" section is highlighted with a red box and contains instructions to complete three questionnaires, with a bolded instruction: "Please complete the Demographics Questionnaire below". A red arrow points to the "elm 3" menu item with the text "Ignore this bar. It is not relevant." Another red arrow points to the "This is the week one overview" text. A third red arrow points to the scroll bar on the right with the text "This is the scroll bar Use this to move the page up and down".

The first thing you will see is the welcome note, introducing you to the course. This is followed by the overview for Week One. All the tasks for Week One are presented in a chronological order, one item below the next. You will have noticed that the first thing you need to do for Week One is to fill out three questionnaires. The questionnaires are located below the information panel for week one. The first one you need to fill out is the demographics questionnaire that looks like this:

The screenshot shows the "Demographics" questionnaire. It includes the following questions:

- * 1. Please enter your study number
- * 2. How old are you (years)?
- * 3. What type of joint replacement surgery did you have?
 - Knee Replacement
 - Hip Replacement

At the bottom, it says "Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool." and "Now please complete the comprehensive questionnaire". A red arrow points to the first question with the text "Answer these questions". Another red arrow points to the scroll bar on the right with the text "Each of the questionnaires have their own scroll bar. Use this to see more of the questions.".

Please list both over the counter and prescription medications. Name and dose is written on the medication container.

List the medication, dose (mg), how often it is used, problem used for, length of time used.

Paracetamol, 500mg, 4 times a day, pain relief, since surgery
Codeine, 30mg, 3 times daily, pain relief, since knee problems began (sometime in early 2011). |

Once you have filled out all the questions click the done button



Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Then you will see this appear in the place of the survey:

Please provide answers to all of the questions on each questionnaire. When you are finished each questionnaire click done.

Once you have completed all three click on the video below them titled Week 1 Video 1.

Please complete the Demographics Questionnaire below

Thank you for taking the survey!

powered by



[Learn More](#)

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Now please complete the comprehensive questionnaire

Phew that was your first survey done (only two more to go).

The next questionnaire you need to do is the Comprehensive Questionnaire. This is located below the demographics questionnaire and is a little bit larger spanning 5 pages.

Thank you for taking the survey!

powered by
SurveyMonkey
[Learn More](#)

Below the Demographics Questionnaire

Has it's own scroll bar for moving through the survey.

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Now please complete the comprehensive questionnaire

Comprehensive Questionnaire
DASS-21

*1. Please enter your study number

*2. Please read each statement and select an answer which indicates how much the statement applied to you over the past week.
There are no right or wrong answers.
Do not spend too much time on any statement.

Did not apply to me at all, Applied to me to some degree, Applied to me to a considerable degree, Applied to me very much.

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Once you have filled out the first page you will see a button that says *next* click on this to take you through to the next page of the survey.

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Now please complete the comprehensive questionnaire

to stop exercising so that I don't injury myself	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain always means I have an injured body	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No one should have to exercise when he/she is in pain	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

[Prev](#) [Next](#)

Powered by **SurveyMonkey**
Check out our [sample surveys](#) and create your own now!

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Click next to go to the next page

Scroll bar for moving up and down the survey

When you have completed all the pages of the survey you will see a done button. Click on the done button to finish the survey. Or use the previous button to go back and adjust answers.

Now please complete the comprehensive questionnaire

- Milder
- Excruciating

***8. Is your pain ... (check one word)**

- Brief
- Intermittent
- Continuous

To finish click the Done button

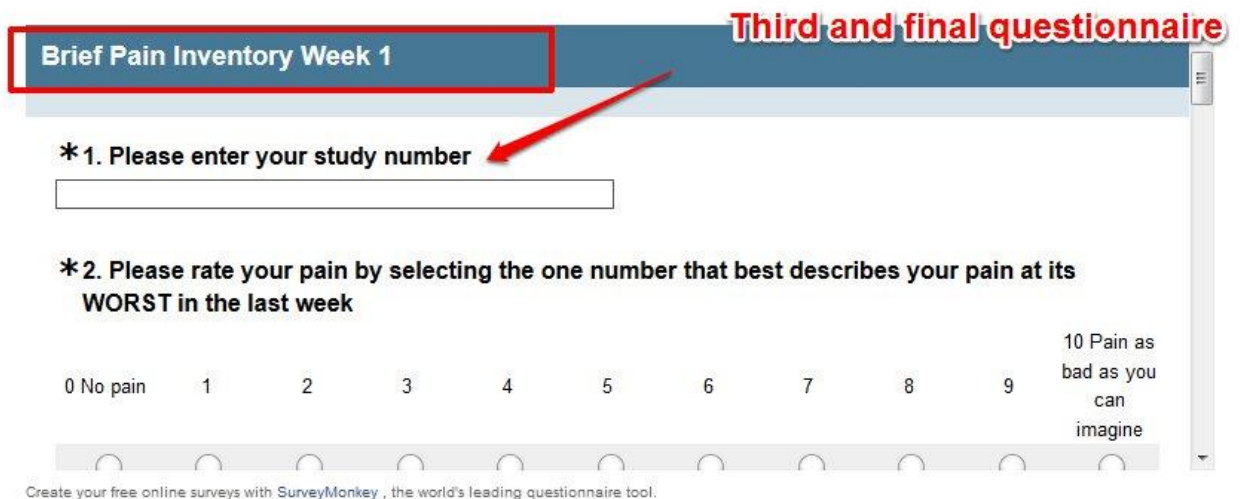


Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Now complete your final questionnaire for this week. The brief pain inventory (BPI)

We know that was a long questionnaire. Thanks for filling it out. The last questionnaire is a quick one. It is the Brief Pain Inventory (BPI) you will see it located at below the Comprehensive Questionnaire. Like the Demographics questionnaire the BPI is only one page long. It looks like this:

Now complete your final questionnaire for this week. The brief pain inventory (BPI)



Week 1 Video 1

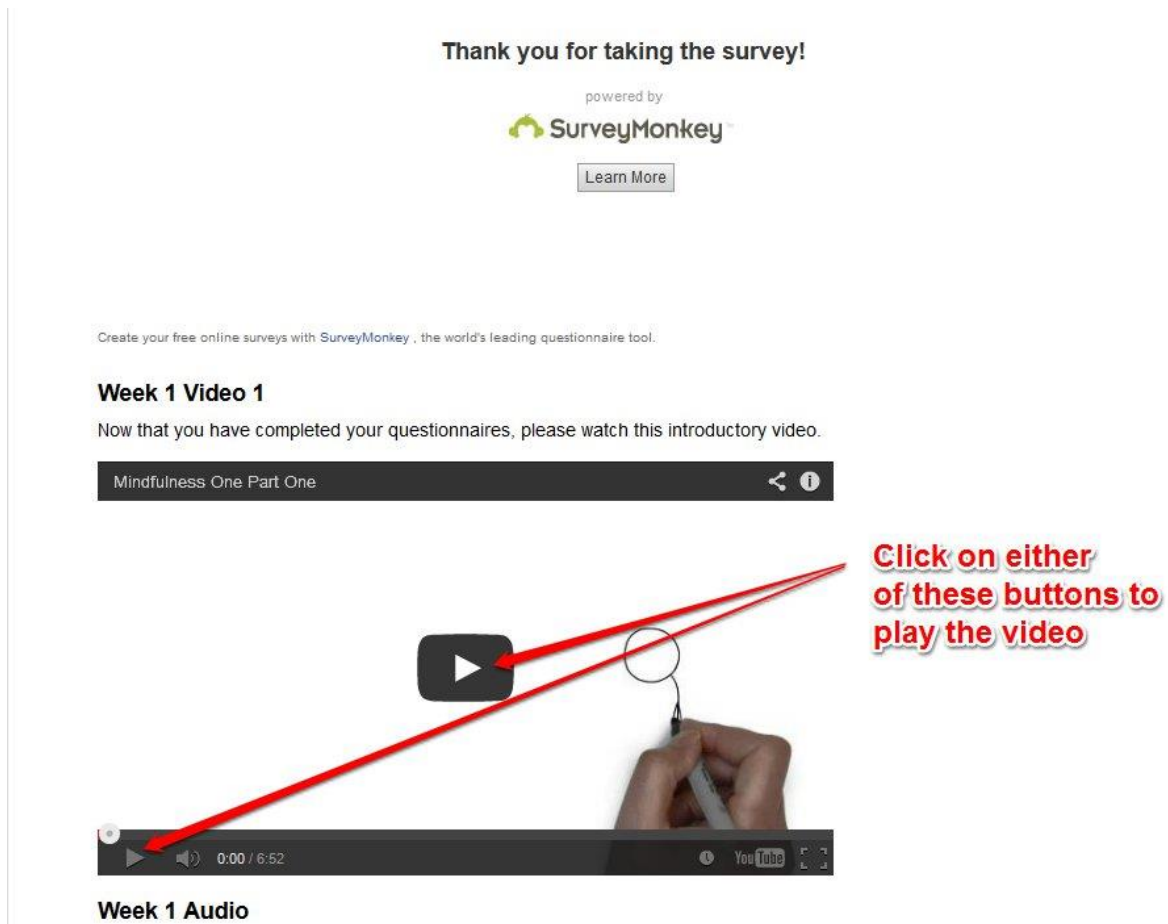
Follow the same procedure that you did for the two previous questionnaires. Fill out all the questions and click done.

Okay so the hard part is over you have filled out the questionnaires! From now until the last week you will only have to fill out one short questionnaire at the beginning of each session (the BPI) then on week 5 you will have to fill out all three questionnaire again (but let's not think about that now).

PART THREE- The Videos and Audio

Now the fun part, the course can begin.

- 1.) Below the BPI Questionnaire you will see the video one. Click on the play button, sit back and enjoy the introductory video.



The screenshot shows a survey completion page. At the top, it says "Thank you for taking the survey!" followed by "powered by SurveyMonkey" and a "Learn More" button. Below this is a section titled "Week 1 Video 1" with the text "Now that you have completed your questionnaires, please watch this introductory video." A video player is embedded, showing a play button and a hand holding a pen. A red arrow points from the play button to a text box that says "Click on either of these buttons to play the video". Below the video player is a section titled "Week 1 Audio".

- 2.) Once you have watched that video you need to listen to the week one audio.
Do this by clicking on the button that says “*Click to Play Week 1 Audio*”

Pressing this will pause the audio

Click anywhere on this red button to hear the Week 1 Audio

Click on this to adjust the sound

Click on this to download the audio file to your computer

Click to Play Week 1 Audio

Click here to download the Week 1 audio

Now watch the debrief video below

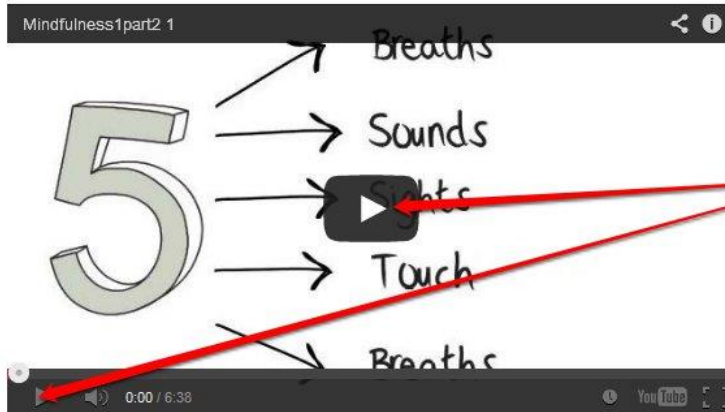
If you want to download the audio to listen to it offline click on the text that says “*Click here to download the Week 1 audio.*”

3.) Once you have listened to the audio it is now time to watch the debrief video, located below the audio. Click play and sit back and watch it.



[Click here to download the Week 1 audio](#)

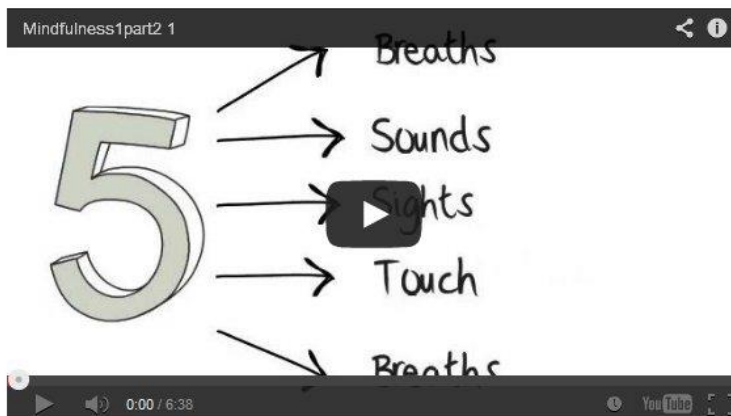
Now watch the debrief video below



Click on either on these buttons to play the video

You have now finished Week One! Below the debrief video is the Mindfulness Practice Chart. Click on the text that says ‘Mindfulness Practice Sheet’ to download and print the sheet.

Now watch the debrief video below



Congratulations you have completed Week One!

We hope you enjoyed it. Below is the Mindfulness Practice sheet. Click on the link to print it on and keep a record of your you mindfulness practice.

[Mindfulness Practice Sheet](#)

Click here to download the mindfulness practice sheet.

In a weeks' time, Week 2 materials will appear on the same page below all the resources for week one. You access this page by logging in and scrolling down. You will receive a text and e-mail to say that Week 2 resources are available.

Remember you can access this online course as often as you want, whenever you want. It is there for you to use.

If you have any problems or comments don't hesitate to call (between 9-5), text or email Jess and she will get back to you as soon as possible.

Jessica Leov

474 0999 ext 7387

027 947 6296

Mindfulness.help@gmail.com

Happy practicing!

APPENDIX H: Semi-structured Interview Script/Questions

Purpose of the Interview

Thank you for agreeing to take part in this study. I'm aware that it can be a stressful time after surgery, so we really appreciate the time you are giving us today. As you will be aware from the information we gave you when you signed up for this study, is that today all we will be doing is talking about your experiences of pain, both past and present. We hope that by interviewing you and others who are receiving knee or hip replacement surgery we can begin to develop more accessible and effective methods of managing post-surgery pain. The interview will take just under an hour. Is that OK with you?

Confidentiality

Everything that we talk about today is confidential to myself, and my supervisor. The information is stored in a secure file that can only be accessed by us. Also, any identifying information will be removed from the record so that there is no way to connect the information back to you specifically. We will be recording the interview so that we can refer back to what we talk about later on. Is that OK with you?

Before we begin do you have any questions?

The first questions that I'm going to ask are about your pain, from your perspective.

Their Pain Experience

1. Can you tell me about your current knee/hip pain?

Qualifiers (depending on the answer the participant gives)

- *Where else do you currently experience pain? When, and for how long?*
 - *How did the pain in your hip/knee begin?*
 - *What things make it better, what things make it worse? Eg. Stress, weather, sleep etc.*
 - *How severe is the pain right now? On a scale from 0-10; 0 being no pain and 10 being the worst pain you've ever experienced (Can you describe why you chose that as your answer?)*
 - *Is the pain constant? How constant in last week 0-10*
 - *Worst pain in the last week? 0-10*
 - *Least pain in last week 0-10*
 - *How has your pain been over the last week? Scale 1-10*
 - *What words would you use to describe what the pain feels like? E.g., burning, stabbing, throbbing, sharp, cramping, gnawing, shooting, aching, heavy, tender, splitting, tiring, sickening, fearful, punishing.*
 - *Can you remember a time when you didn't have pain? Tell me about that?*
 - *Do you think your pain will get better or worse in the future?*
2. How do you currently manage your hip/knee pain? Eg. Medication, rest, compresses
 - How effective are they at giving you some relief from pain?
 3. What other things have you tried in the past to manage your pain?
 - *Why don't you use this method anymore?*
 4. What treatments are you aware of that you have not tried or would be interested in trying? *E.g., pharmacological, physiotherapy, psychological, alternative medicine.*
 5. Why haven't you tried them?

6. Are you able to live a good life, even with pain?
7. Do you think people can live a good life and have daily pain?
8. How do you conceptualise your pain? What factors do you consider to be contributing to you pain experience?
 - *Are you aware of any psychological components that may contribute to your pain experiences?*
 - *What are you expecting this surgery to do for your pain?*
 - *What do you think would happen if you didn't have the surgery?*
 - *6 months after surgery how do you think you will rate your hip/knee pain?*
 - *What might you do if your hip/knee is still painful?*

“Before we go on to the next questions, I have some information to give you that may be helpful now or in the future.”

“When a person experiences chronic pain it is relatively common to also feel a little anxious, sad or upset. If you are experiencing feelings of anxiety, distress or depression, there are a number of things that can help. To find out more, we recommend you discuss how you are feeling with your GP. There are also other agencies available that you can get information from, and I have a list here I will leave with you.”

“The next set of questions are about treatment for pain over the internet.”

Internet Interventions

9. Do you think you would use an internet based pain treatment? *Why/why not?*
10. What would stop you from using the internet for an intervention?
11. Is there any way these barriers could be reduced for you?
 - *E.g., provided with internet for the duration of the intervention, given a tutorial on how to use the internet/intervention program, given an i-pad to use (if they don't have a computer)*
12. Are there other means of providing an intervention that you would be more willing to carry out?

- *E.g., sent paper forms for the intervention each week, phone instructions from a clinician*

13. How long each week would you be willing to spend completing an intervention session and homework tasks? Why?

14. Can you see any benefits in a treatment being offered on-line?

“Thanks so much for your contribution so far. These last questions are about a psychological technique that you may or may not be familiar with. The technique is mindfulness.”

Mindfulness

15. Have you heard of a technique called mindfulness?

- *What can you tell me about it?*
- *OR Give a brief explanation of mindfulness e.g., Mindfulness teaches an individual to be present focused by bringing all their attention to all their feelings, sensations and thoughts in the present moment. It aims to teach a person how to consider all these experiences in a non-judgemental way while ignoring the past and the future.*

16. What do you think about the concept of mindfulness?

17. Would you be interested in trying mindfulness techniques to help alleviate some of your pain?

- *Why/why not?*

“And one final general question.”

General

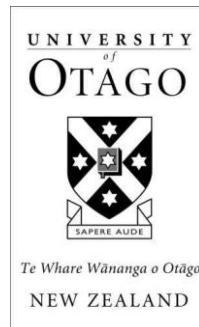
1. Overall, how satisfied are you with your life right now?

- After the surgery, how satisfied do you think you will be.

“Thank-you and good luck with your upcoming surgery/with your recovery.”

APPENDIX I: Information Sheet: Pain Experiences

Reference Number: 13/NTB/136
16.09.2013



Experiences of Pain and Online Interventions

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 6 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the Aim of the Project?

The aim of the current study is to investigate participants' views on their pain experiences and to discuss the use of online interventions for post-surgical pain. This research aims to help inform healthcare professionals in developing comprehensive treatments for post-surgical pain. This project is being undertaken as part of Ella Barrett's summer research in the Department of Psychological Medicine.

What Type of Participants are being sought?

- To take part in this study participants will need to be undergoing a joint replacement surgery.
- Participants will need to be fluent in English

What will my participation involve?

If you agree to take part in this project you will be asked to complete an hour-long interview. The interview will focus around your current and past pain experiences as well as your views on using an online-based intervention for post-surgical pain. Online interventions for pain aim to increase accessibility to post-surgical pain treatment.

Interviews will take place in an interview room attached to the hospital. However, if it is more convenient the interview can take place in your own home.

This study has been approved by the Health and Disability Ethics Committees (HDEC), *13/NTB/136*, *16.09.2013*

What are the benefits?

The information you provide will be useful in informing health care professionals in developing comprehensive treatments for post-surgical pain.

What Data or Information will be Collected and What Use will be Made of it?

The interviews will be recorded and transcribed for purposes of collecting relevant data. The information you provide will be used to identify common themes in participants' experiences of pain. There will be no way to identify you through the information you provide.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 10** years in secure storage. Any personal information held on the participants may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

The results of this research project will be written up into a summer research report and will be available in the **University of Otago Library** (Dunedin, New Zealand). Material from the report will be independently written up for publication in scientific journals.

Is the information confidential and will it be reported anonymously?

All information you provide during this study will remain confidential to the researchers (listed below) involved in the project. Any potentially identifying information will also be removed so your participation is entirely anonymous. No material that could personally identify you will be used in any reports on this study.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Ella Barrett

and

Dr. Nicola Swain

Department of Psychological Medicine

Telephone: 474 0999 ext 7387

Email: ellajbarrett@gmail.com

Department of Psychological Medicine

Telephone: 474700 ext 7299

Email: nicola.swain@otago.ac.nz

and

[Jessica Leov](#)

[Department of Psychological Medicine](#)

[Telephone: 474 0999 ext 7387](#)

[Email: mindfulness.help@gmail.com](mailto:mindfulness.help@gmail.com)

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

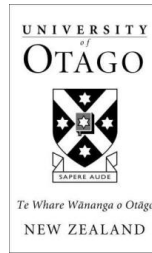
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdec@moh.govt.nz

APPENDIX J: Consent Form: Pain and Online Experiences



Pain and Online Experiences

CONSENT FORM FOR

PARTICIPANTS

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Participant Contact Details

Address:

Home Phone Number:

Cell phone Number:

Email Address:

Date of Birth:

Please indicate the best time of day to get in contact with you:

Estimated date of Surgery (if known):

Declaration by participant:

I hereby consent to take part in this study.

YES/ NO (*please circle*)

Participant's name:

Signature:

Date:

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name:

Signature:

Date:

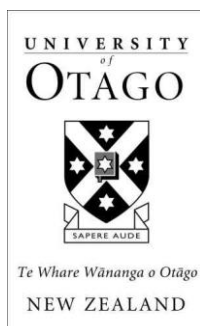
This project has been approved by the Health and Disability Ethics Committees

Reference Number: 13/NTB/136

Date: 16.09.2013

APPENDIX K : Pain and Online Experiences: Demographics Questionnaire

Study Number_____



Pain and Online Experiences Demographics Questionnaire

This information is used to determine eligibility and for statistical purposes only. It will be kept strictly confidential.

- **How old are you (years)?** _____

- **What gender are you?** (Please tick one)
 - Female
 - Male
 - Other

- **What is your living situation?** (Please tick the one closest to your situation)
 - I live alone
 - I live with my partner
 - I live with others who are related to me
 - I live with others who are not related to me

- **What is your highest qualification?** (Please tick one)
 - School
 - Diploma/Certificate or trade
 - Degree
 - Higher degree

- **What is your current employment status?** (Please tick all that apply)

- Working full time (>37.5 hrs per week)
 - Working part time (< 20 hrs per week)
 - Retired
 - Homemaker
 - Unable to work due to illness
 - Student
- **What would be the total income that you *personally* received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
- **What would the total income (including your own) that your household received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
- **How would you describe your ethnicity?**(Please tick all that apply, continued over page)
 - Maori
 - New Zealand European
 - Other (such as Dutch, Japanese, Fijian) Please state

Questions continued over the page

What are your current medications?

Please list all of the current medications you are currently taking.

Please list both over the counter and prescription medications. Name and dose is written on the medication container.

	<u>Medication</u>	<u>Dose (mg)</u>	<u>How</u> <u>often</u>	<u>Problem used for</u>	<u>Length of time used</u>
1.)	_____	_____	_____	_____	_____
2.)	_____	_____	_____	_____	_____
3.)	_____	_____	_____	_____	_____
4.)	_____	_____	_____	_____	_____
5.)	_____	_____	_____	_____	_____
6.)	_____	_____	_____	_____	_____
7.)	_____	_____	_____	_____	_____
8.)	_____	_____	_____	_____	_____

Thank you for taking the time to complete this form

APPENDIX L: Contact Details Sheet for Other Services

Who should I contact if I have any other concerns relating to my pain?

Sometimes when a person experiences chronic pain they can also feel anxious, sad or upset. If you are experiencing feelings of anxiety, distress or depression, there are a number of things that can help. To find out more, we recommend that you discuss how you are feeling with your GP. The following agencies can also provide you with more information:

Emergency Psychiatric Service	Phone 111 for emergencies
Urgent Doctors	479 2900
Arai Te Uru Whare Hauora Ltd	471 9960
Depression Helpline	0800 111 757
LifeLine	0800 543 543
Salvation Army Community Ministries	477 9852
Presbyterian Support Otago – Family Works	477 7115
Catholic Social Services	477 3403
Anglican Family Care Centre	477 0801
Methodist Connect	466 4600

Information websites

www.depression.org.nz

www.depression.com.au

www.chronicpinaustralia.org.au

www.painmanagement.org.au



APPENDIX M: E-mail Accompanying Transcripts for Corrections

Dear [participants name]

Thank you for taking part in the Pain Interview after for your joint replacement surgery. We hope your recovery is still going well and we appreciate you giving up your time to share your experiences with us. We have now finished the data collection stage of this study and have transcribed all the interviews into a written a format.

Please find attached a transcript of the interview you completed. In this transcription “P” refers to you as the participant and “I” refers to the interviewer. If there is any content in this interview that you would like removed, you believe is inaccurate or alternatively if there is anything that you would like to have added to your interview please make the appropriate correction and send the transcript back to me.

Once again thank you for taking part in this study. If you have any further questions, comments or concerns please do not hesitate to contact me.

Yours Sincerely,

Jessica Leov

APPENDIX N: Amputee Recruitment Poster



Volunteers wanted

Do you want to start the New Year working towards being happier?

Are you interested in taking part in an online study researching the effect mindfulness and gratitude has on wellbeing?

Mindfulness is about being present in the moment without judgement and can be done anywhere at any time. It has been shown to increase wellbeing, positive emotions and even relieve pain in some people.

Participants can be of any age but need to have access to the internet and be able to navigate online forms and videos.

The study will run from the 3rd of January till the 1st of February 2015 and will consist of 4 short sessions (20-40 mins each). Participants will be asked to provide feedback about how they found the online course on completion of the course.

For further information contact:
Dr Nicola Swain at nicola.swain@otago.ac.nz

To enrol contact:
Tessa Stewart at stete661@student.otago.ac.nz

APPENDIX O: Recruitment Letter

To whom it may concern.

18/12/2014

Volunteers wanted

Do you want to start the New Year working towards being happier?

I am looking for participants to take part in an online study researching the effect mindfulness and gratitude has on well-being.

Mindfulness is about bringing your conscious attention to the present moment in a non-judgemental way. It can be done anywhere, at any time, and has been shown to increase wellbeing, positive emotions and even relieve pain in some people. *Gratitude journaling* is the process of taking note of what you are grateful and thankful for. It can increase life satisfaction and happiness.

I am interested to find out whether an online course that teaches these skills through videos and audio files would be beneficial to people with an amputation and would be something that people would take part in and enjoy doing.

I am looking for anyone who has had an amputation and who has access to the internet and can use computers easily as the study is completely online. The study runs from the 3rd of January till the 1st of February as is comprised of 4 short (20-40 minutes) online sessions teaching mindfulness techniques and a gratitude journal. There is one session per week and this can be done whenever it works best for you. As well as the videos and audio tasks, it shows you how you can use the techniques off-line and in your everyday life. **All participants go into the draw to win one of ten \$20 New World vouchers**

If you would like to learn a new way to increase your well-being in an easy (and enjoyable) way or would like more information, please don't hesitate to contact:

Dr Nicola Swain at nicola.swain@otago.ac.nz or our student researcher:

Tessa Stewart at stete661@student.otago.ac.nz

APPENDIX P: Welcome/participation Email

Hello [participants name]

Thank you for considering taking part in this online Mindfulness and Gratitude study for people with an amputation.

Attached is the information sheet detailing more about the study and what is required as part of the study. Please read it carefully. If you have any questions, don't hesitate to email me.

If you agree to take part, please complete the consent form **AND** demographics using the links below. If these do not work, please email Tessa at stete661@student.otago.ac.nz

- 1) Online consent form <https://www.surveymonkey.com/s/LRNL38C>

AND

- 2) Demographics questionnaire <https://www.surveymonkey.com/s/LXJ28Z3>

Once these have been completed you will be sent a confirmatory email.

Before the 3rd of January and a reminder email will be sent out containing your username and password as well as how to access the online course. There is also a manual available detailing how to use the website if needed.

Thank you for your interest.

Sincerely

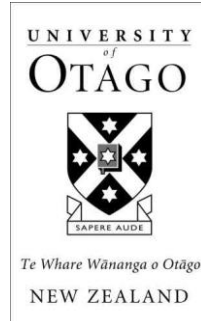
Tessa Stewart

Student Researcher.

APPENDIX Q: Online Mindfulness and Gratitude Course for People with an Amputation, Information Sheet

[Reference Number:13/NTB/136]

[Date: 16/09/2013]



Online Mindfulness and Gratitude Course for People with an Amputation.

INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

If you agree to take part in this study, you will be asked to select YES to the Consent Form Questionnaire below. You will be emailed a copy of both the Participant Information Sheet and the Consent Form to keep.

What is the Aim of the Project?

The aim of the current study is to determine if an online self-managed, self-guided course teaching mindfulness techniques and gratitude journaling would be beneficial to people with an amputation and would be something that they would choose to engage in as a way to increase their well-being.

This research aims to be a helpful addition for clinicians who would like to recommend a holistic well-being or coping intervention for their clients.

This project is being undertaken as part of the requirements for Tessa Stewart's summer studentship.

What Type of Participants are being sought?

- To take part in this study participants have to have had an amputation.
- As this study involves an online mindfulness course and gratitude journal, participants will need to have access to the internet for the duration of the study so that they can complete the modules and questionnaires.
- Participants will need to be fluent in English

What will my participation involve?

If you agree to take part in this project you will be asked to complete an online mindfulness program. Mindfulness is a practice that aims at changing the way you think about sensations (like pain) and emotions you might have. It is about learning to focus your attention on the present moment. Some people refer to mindfulness practices as going to the gym for your brain.

The Mindfulness course consists of four online sessions to be completed once weekly over the course of 4 weeks. These sessions can be completed for the comfort of your own home at whatever time of day is best for you.

Each session will take approximately 20 minutes to complete and will include mindfulness tutorials, guided mindfulness audio exercises, case studies and a take home practice task. At the beginning of each session there is a short (5 minutes) gratitude task as well.

Don't worry if you don't feel confident navigating the internet. There will be detailed information sheets about how to use the program and the researcher (Tess) will be available to help you with any technical difficulties.

All participants will have access to the online mindfulness module, and each week a new session will become available to you.

Following the last session, participants will be requested to give their feedback on how they found the course. As this is a pilot study, the more feedback given, the more the course can be adapted to suit future users.

Participants will receive a reminder email if they have not completed the task for the week.

This study has been approved by the Health and Disability Ethics Committees (HDEC),

What are the benefits?

Mindfulness programs have been shown to reduce pain and how pain affects daily living, increase helpful thoughts, lower stress and disability and promote well-being and coping. Gratitude journaling has been shown to increase life satisfaction, positive emotions and well-being.

What Data or Information will be Collected and What Use will be Made of it?

There will be a questionnaire asking about your demographics, such as age, gender, type of amputation. There is also a general health questionnaire that will ask you about your physical, mental and emotional well-being. At the end of the study we will ask you for your feedback about how the study went for you. These questionnaires will all be filled out online and will not personally identify anyone.

The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. Data obtained as a result of the research will be retained for **at least 10** years in secure storage. Any personal information held on the participants may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

The results of this research project will be written up as part of a summer studentship at the University of Otago (Dunedin, New Zealand). Material from this may be written up for publication in scientific journals. As with the studentship, your responses to questions in the questionnaires will continue to be anonymous and your name will never appear in either the summary write up or in any journal article.

Is the information confidential and will it be reported anonymously?

You will be given a study number and your name will not be stated on the questionnaires and it will never appear in any report on the study. Any potentially identifying information will also be removed so your participation is entirely anonymous. No material that could personally identify you will be used in any reports on this study. Your information is confidential to the researchers (listed below) involved in the project.

Can Participants Change their Mind and Withdraw from the Project?

You may withdraw from participation in the project at any time and without any disadvantage to yourself of any kind.

What if Participants have any Questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Tessa Stewart

and

Dr. Nicola Swain

Department of Psychological Medicine

Department of Psychological Medicine

University Telephone Number:- ...

University Telephone Number:- 474700

Email: stete661@student.otago.ac.nz

Email: nicola.swain@otago.ac.nz

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

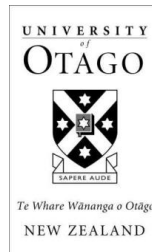
Email: advocacy@hdc.org.nz

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

APPENDIX R: Consent Form: Online Mindfulness and Gratitude Course for People with an Amputation.



Online Mindfulness and Gratitude Course for People with an Amputation.

CONSENT FORM FOR

PARTICIPANTS

Please tick to indicate you consent to the following

I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whanau/ family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I know who to contact if I have any questions about the study in general.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand my responsibilities as a study participant.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Participant Contact Details

Address:

Home Phone Number:

Cell phone Number:

Email Address:

Date of Birth:

Declaration by participant:

I hereby consent to take part in this study.

YES/ NO (*please circle*)

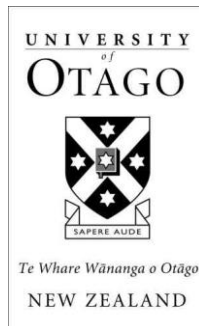
Participant's name:

Signature:

Date:

APPENDIX S : Online Mindfulness and Gratitude Course for People with an Amputation: Demographics Questionnaire

Study Number_____



Online Mindfulness and Gratitude Course for People with an Amputation

This information is used to determine eligibility and for statistical purposes only. It will be kept strictly confidential.

- **How old are you (years)?** _____

- **What gender are you?** (Please tick one)
 - Female
 - Male
 - Other

- **What is your living situation?** (Please tick the one closest to your situation)
 - I live alone
 - I live with my partner
 - I live with others who are related to me
 - I live with others who are not related to me

- **What is your highest qualification?** (Please tick one)
 - School
 - Diploma/Certificate or trade
 - Degree
 - Higher degree

- **What is your current employment status?** (Please tick all that apply)
 - Working full time (>37.5 hrs per week)
 - Working part time (< 20 hrs per week)
 - Retired

- Homemaker
 - Unable to work due to illness
 - Student
- **What would be the total income that you *personally* received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
 - **What would the total income (including your own) that your household received from all sources before tax during the previous 12 months?** (Please tick the one closest to your situation)
 - No income
 - Up to \$25,000
 - 25,001-50,000
 - Over 50,000
 - Don't know
 - **How would you describe your ethnicity?**(Please tick all that apply, continued over page)
 - Maori
 - New Zealand European
 - Other (such as Dutch, Japanese, Fijian) Please state

Thank you for taking the time to complete this form

APPENDIX T: Online Mindfulness course for amputees, instruction sheet

Online Mindfulness and Gratitude study for people with an amputation

Thank you for signing up for the Mindfulness and Gratitude online course for amputees. We appreciate your participation and hope you find it beneficial. This information pack contains instructions on how to navigate the online course. We take you through the components step by step making the course easy for you to use.

The course aims to teach you mindfulness techniques for you to use in your daily life. The fantastic thing about this course is that you can log on and use it at whatever time you like, whenever is easiest for you. However you do need to complete a topic on the week it becomes available to you.

You should complete one topic (questionnaire, video, audio, questionnaire) in one sitting and it should take you approximately 20 minutes.

First here are some important details:

User name:

Password:

These details will be used to allow you to gain access to the program online. Are you ready to get started?

Part One -Logging on to the Mindfulness and Pain Course

- 4.) You need to open up your internet browser. Your computer may use Internet Explorer, Mozilla Firefox or Google Chrome. Open up your preferred internet browser by clicking on its icon.

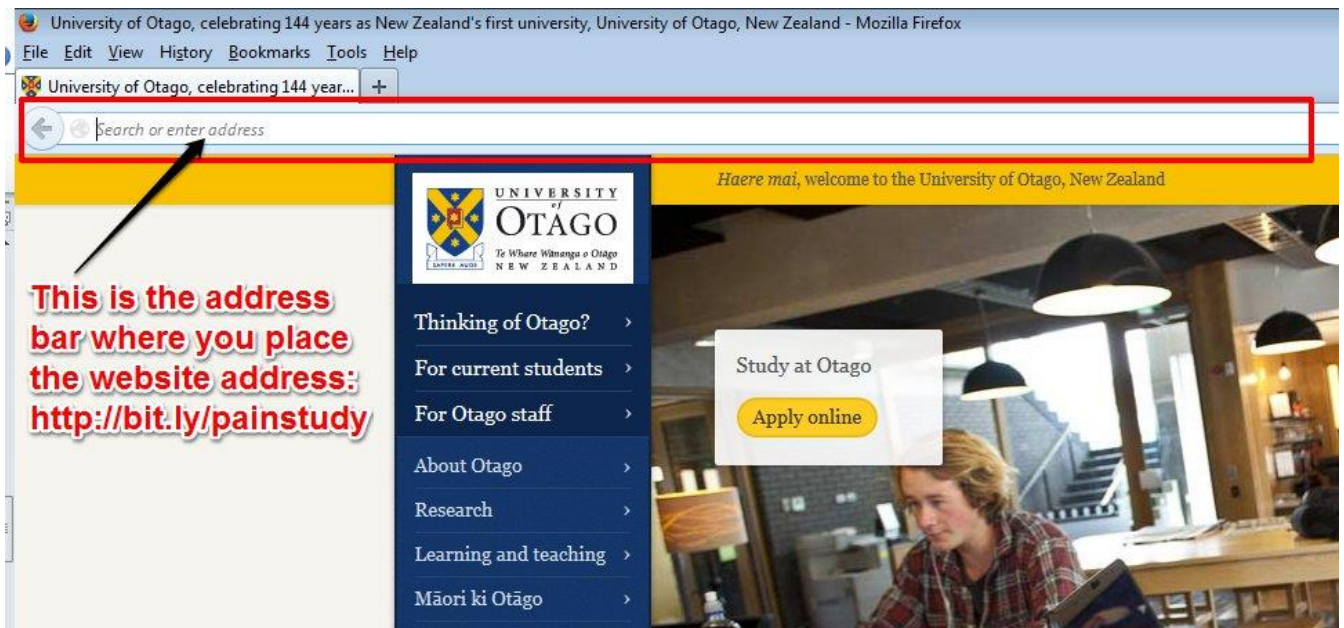


- 5.) Type this website address (located below in blue) in the address bar which is located at the top of your internet browser screen and then press the enter key (on your keyboard).

Website Address:

<http://bit.ly/painstudy>

Below is an example of where the *address bar* is on the Firefox browser window. It looks similar for all different types of browser.



A page should appear that looks like this:

Faculty of Medicine Moodle: Login to the site - Mozilla Firefox
File Edit View History Bookmarks Tools Help
Faculty of Medicine Moodle: Login to... x New Tab
https://medschool.otago.ac.nz/login/index.php

UNIVERSITY of OTAGO
Te Whare Wānanga o Ōtago
NEW ZEALAND

My Moodle ELM 2 ELM 3 ALM 4 ALM 5 ALM 6 PostGrad Help

Faculty of Medicine Moodle

Home » Login to the site

Returning to this web site?

Login here using your username and password
(Cookies must be enabled in your browser) ?

Username
Password
 Remember username
[Forgotten your username or password?](#)

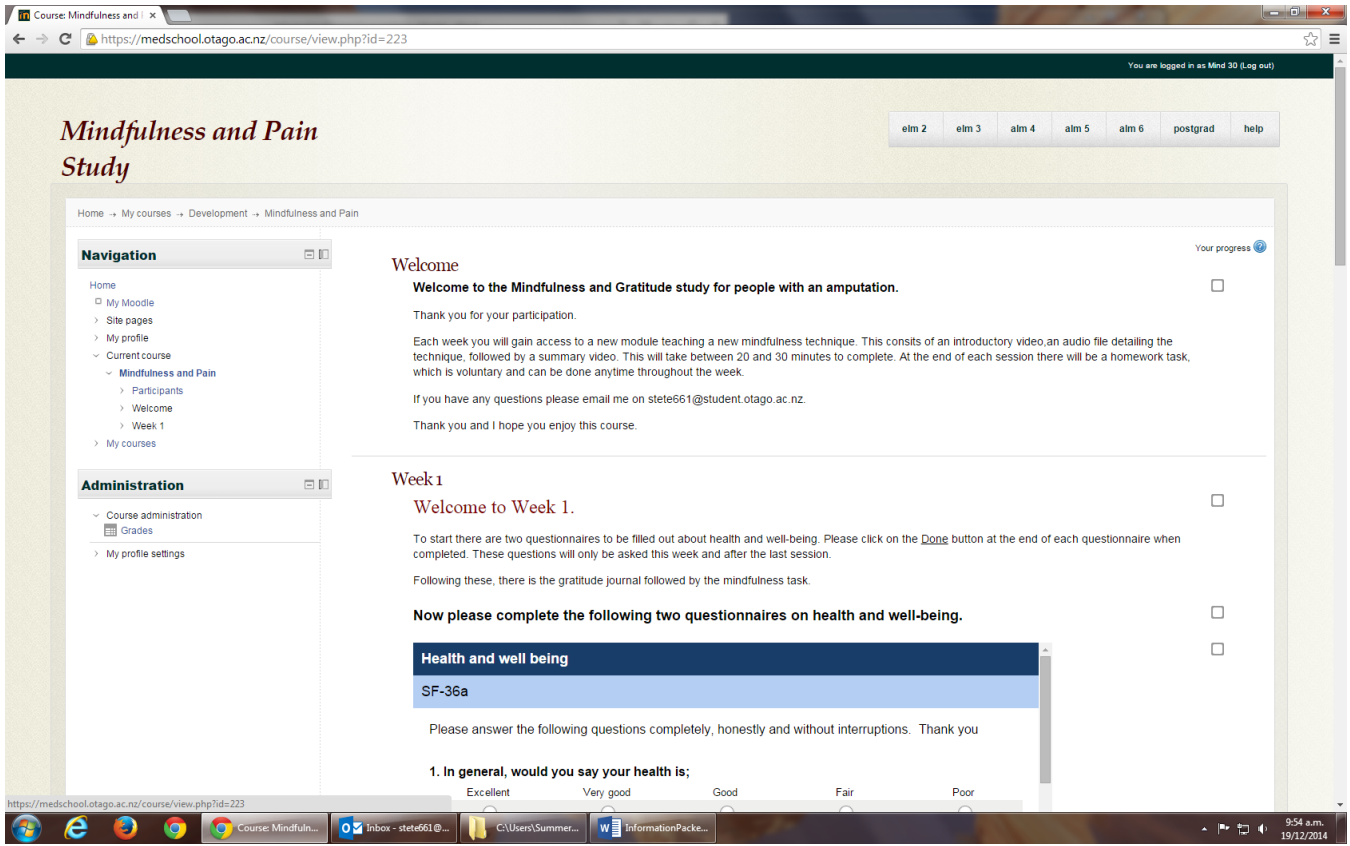
This is where you enter you username and password

This is the login button, click this when you have entered your details

Home

- 6.) In the place that says Username and Password please enter your unique username and password that was provided on page one. Then click on the Login button.

A page should appear that looks like this:



Congratulations! You have successfully logged on. Now let's get started on the course.

PART TWO- The gratitude journal and mindfulness tasks

Now for the fun part.

- 1) Below the Health Questionnaire you will see the Gratitude Journal.
Please enter your responses into the text box required and to select 'Done' when completed.
- 2) Below this is the introductory video for the mindfulness task.

The image shows a screenshot of a SurveyMonkey questionnaire and a YouTube video player. The questionnaire is titled "8. How TRUE or FALSE is each of the following statements for you?" and includes a dropdown menu with options: "Definitely true", "Mostly true", "Don't know", "Mostly false", and "Definitely false". Below the questionnaire, there is a section titled "Please complete the Gratitude Journal below" with a text box for answers and a "Done" button. A red arrow points from the text box to the "Done" button. To the right of the text box, there is a red text box that says "Type into the text box your answers and click 'Done' when completed." Below the questionnaire, there is a section titled "Week 1 Video 1" with a YouTube video player. The video player shows a play button and a progress bar. A red arrow points from the play button to a red text box that says "Click on either of these buttons to play the video".

8. How TRUE or FALSE is each of the following statements for you?

Definitely true Mostly true Don't know Mostly false Definitely false

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Please complete the Gratitude Journal below

In recent years, reasearch in psychology has established that performing certain activites can result in increases in well-being and happiness. One of such activities is the 'Gratitude Journal'.

Gratitude Journal

There are many things in our lives, both large and small, that we might be grateful about. Think back over the last week and write down below up to five things in your life that you are grateful or thankful for.

All responses will be kept confidential.

1. Type below what you are grateful or thankful for.

Done

Create your free online surveys with SurveyMonkey, the world's leading questionnaire tool.

Week 1 Video 1

Now that you have completed your questionnaires, please watch this introductory video.

Mindfulness One Part One

Click on either of these buttons to play the video

Week 1 Audio

- 4.) Once you have watched that video you need to listen to the week one audio. Do this by clicking on the button that says “Click to Play Week 1 Audio”

Pressing this will pause the audio

Click anywhere on this red button to hear the Week 1 Audio

Click on this to adjust the sound

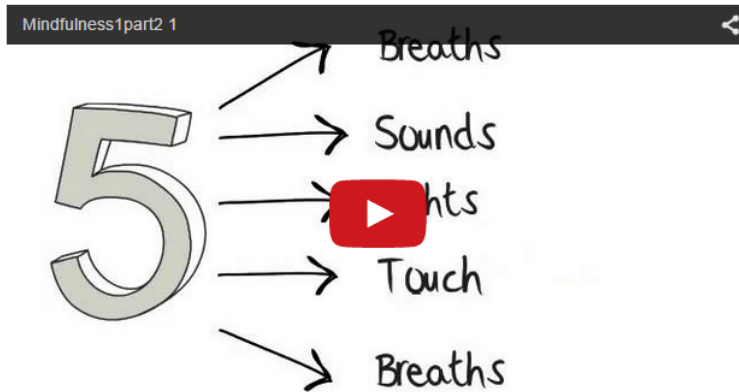
Click on this to download the audio file to your computer

If you want to download the audio to listen to it offline click on the text that says “Click here to download the Week 1 audio.”

- 5.) Once you have listened to the audio it is now time to watch the debrief video, located below the audio. Click play and sit back and watch it.

Click on either on these buttons to play the video

You have now finished Week One! Below the debrief video is a paper version of the Take 5 Mindfulness task and the gratitude journal that you are welcome to download or print off if you would like to practise these skills off-line during the week. Just click on the link below to download them.



Congratulations you have completed Week One!

We hope you enjoyed it. Below is the Mindfulness take 5 homework sheet. Click on the link below if you would like an easy to read reminder of what you have just learnt to use during the week.

Gratitude journaling is the same as Mindfulness, in that more you do it, the easier it becomes and the more beneficial it is.

Below is a print out to help guide you if you want to continue with gratitude journaling throughout the week - but you can also write down the things that you are grateful and thankful for anywhere. Even just taking a moment to think about and acknowledge what you are grateful for has been shown to have positive outcomes.

[Take 5 Mindfulness task](#)

[Gratitude Journal](#)

Click on the blue links if you would like to download these.

In a weeks' time, Week 2 materials will appear on the same page below all the resources for week one. You access this page by logging in and scrolling down. You will receive an e-mail to say that Week 2 resources are available.

Remember you can access this online course as often as you want, whenever you want. It is there for you to use.

If you have any problems or comments don't hesitate to email Tess and she will get back to you as soon as possible.

Tessa Stewart

stete661@student.otago.ac.nz

Happy practicing!

APPENDIX U: Online Intervention Evaluation Survey

Online Intervention Evaluation Survey

One of the main reasons behind this trial was to see what people thought about an online mindfulness and gratitude course. In order to get your feedback, please fill in the following questionnaire.

Feel free to say whatever you want, be it nice or harsh. The more feedback we receive the more we can learn from and change the intervention to suit. If you would like to leave more feedback, please email me at stete661@student.otago.ac.nz

Thank you again for your participation and I hope you enjoyed the course!

1.) Did you enjoy the course? 1=Not I didn't enjoy it at all and 10=Yes I enjoyed it a lot

1 2 3 4 5 6 7 8 9 10

2.) Was the course easy to use? Where, 1=very difficult to use and 10= Very easy to use

1 2 3 4 5 6 7 8 9 10

3.) Would you use the course again? 1= No, not at all and 10= Yes, definitely

1 2 3 4 5 6 7 8 9 10

4.) Which tasks did you use during the course. Please select a rating for each activity.

1=Didn't like it at all/didn't play it- 5= Really liked it-used it a lot

Mindful Breathing

1 2 3 4 5

Take 5

1 2 3 4 5

Mindfulness for working with difficulties

1 2 3 4 5

Mindfulness in your daily routine

1 2 3 4 5

Body Scan

1 2 3 4 5

Mindful Eating

1 2 3 4 5

Loving and Kindness Meditation

1 2 3 4 5

Mindful walking

1 2 3 4 5

6.) Would you recommend this course to someone else? Why?

7.) What did you like or not like about the course?

8.) What was your experience with the presentation and navigation of the website?

9.) What could have been better / made easier to use / more interesting?

10.) Do you have any other comments, questions, or concerns?

Thank you for completing the survey, your feedback is appreciated.

APPENDIX V : Thank You Letter to Participants

[Date]

Dear *[participants name]*,

Thank you for taking part in the online Mindfulness and Gratitude course for people with an amputation. The feedback you provided was very insightful and will help develop the course further. I am glad that you enjoyed aspects of the course, and found some of it helpful. Please find included a \$20 New World voucher in appreciation of your participation.

I wish you all the best for the future.

Sincerely

Tessa Stewart

Student Researcher.

Here we are,
trapped in the
amber of the moment.

There is no why

- Kurt Vonnegut