The process of acceptance in older adults living with chronic pain: a qualitative study.

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Abstract

Background: Chronic pain is a prevalent condition among older adults, and older adults often endure their pain for long periods. Due to the complexities of aging, the management of chronic pain among older adults has been criticised as inadequate. By investigating the role of acceptance from a qualitative stand point, the aim was to provide further insight into understanding how older adults cope with living with chronic pain.

Question: The aim of this research was to understand the process of acceptance among older adults living with chronic pain.

Design: Chronic pain is reported to be a subjective and individualistic condition, and interpretative phenomenological analysis (IPA) was the methodological approach used to focus on understanding the meaning of individual's experiences with chronic pain.

Participants: Eligible participants recruited for this study were also part of a longitudinal study Talking about Health. A total of 20 participants consented to the study and they were aged between 68-93. Data was collected through semi-structured interviews, of the 20 interviews conducted 18 participants consented to having their transcripts analysed.

Results: Through participants' accounts of their pain experiences, four general themes were identified and they were: 1) different aspects to the experience of pain, 2) acceptance, 3) begrudged acceptance and 4) learning to live with pain. The general theme of acceptance was commonly described in each participant's interview, yet there were threads of resistance that were present during participants' accounts of their pain experiences.

Conclusion: Participants' identified different aspects of acceptance and struggles between accepting and not accepting. In particular, older adults accepted the normal occurrence of pain as part of living; yet, at the same time this acceptance could be begrudged with some participants' resisting the idea of acceptance. Despite a begrudged acceptance, participants also described the importance of accepting their pain in order to continue to live their life. The different aspects of acceptance could have a bearing on the management of chronic pain in older adults, and clinical implications are discussed. Further research is warranted to develop more efficient

and cohesive strategies to facilitate the process of acceptance among older adults living with pain.

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Chapter one: Introduction

Pain is a normal and common occurrence that is considered to be an important aspect of human experience and central for our survival (Eccleston, 2011). The complexities of pain can be appreciated by considering its definition as being an unpleasant stimulus that can occur with or without tissue damage, and can evoke both sensory and emotional experiences (International Association for the Study of Pain (IASP), 2018). The definition provided by the IASP (2018) indicates the complex and multifactorial aspects of pain, and considers the experience of pain to be more than just physiological or biological changes, as it may have an emotional component. The emotional component of the definition becomes more relevant when attempting to understand the complexities of chronic pain.

There are other definitions of chronic pain that have been offered, such as that of Fordyce, Fowler, Lehmann, and De Lateur (1968) who used the term chronic pain to describe pain that has a fluctuating and persistent nature. While Eccleston (2011) considers chronic pain to be an experience that exceeds the normal tissue healing time, and has an impact on the productivity and functional ability of an individual. Within these definitions, the importance of chronic pain as a survival mechanism becomes irrelevant, as the presence of persistent pain will become more restrictive and interrupts the individual's ability to function in their normal day-to-day activities.

Chronic pain and the older adult

Chronic pain affecting the musculoskeletal system is common and can affect people of all ages and from different backgrounds. Woolf, and Pfleger (2003) consider osteoarthritis (OA), rheumatoid arthritis (RA), osteoporosis and low back pain (LBP) to be the four most common musculoskeletal conditions that people suffer from. Older adults are reported to be high sufferers of chronic musculoskeletal conditions, and chronic low back pain (CLBP) is considered to be the most common musculoskeletal pain complaint amongst the elderly (Makris et al., 2014; Makris et al., 2015; Makris et al., 2017; Stensland, & Sanders, 2018 a, b).

As the population ages, the presence of chronic pain amongst the elderly population is expected to increase. Tsang et al. (2008) predicts chronic pain will become a common complaint amongst the elderly, and Schofield (2016) expects the rate of chronic pain in the elderly will supersede their younger counterparts. Due to the commonality of chronic pain among the older adults, Reid, Eccleston, and Pillemer (2015) refer to chronic pain in later life as a worldwide problem.

Despite the common occurrence of chronic pain in the aging population, literature surrounding the prevalence of chronic pain and age remains inconsistent. There are studies that suggest an increase in the prevalence of chronic pain with aging (Dominick, Blyth, & Nicholas, 2011; Fayaz, Langford, Donaldson, & Jones, 2016; Hoy et al., 2012; Manchikanti, Singh, Falcom, Benyamin, & Hirch, 2014). While a study by Fejer, and Leboeuf-Yde (2012) indicate a decline in the prevalence of chronic pain, especially in the oldest adult group. Given this uncertainty, what appears to make sense is that the prevalence of chronic pain is expected to increase with an aging population rather than its incidence rate (Dionne, Dunn, & Croft, 2006; Fejer, & Leboeuf-Yde, 2012; Gagliese, & Melzack, 1997). Therefore, older adults are expected to endure their pain for longer periods and have greater experiences to describe.

The role of aging on the understanding of chronic pain is complex, and assumptions that pain complaints among older adults are commonly attributed to aging remain untested (Gagliese, 2009). Despite this, there continues to be a consensus in society that pain is a normal part of aging. As people age, it is normal to expect some structural changes that occur within our body, such as wear and tear of the joints, and as a result a degree of pain is expected (Hadjipavlou, Tzermiadianos, Bogduk, & Zindrick, 2008). Tsang et al. (2008) offer support to this assumption and suggest there is an increased vulnerability to arthritic joint pain with aging. From a patho-physiological perspective, structural changes that occur during aging would be an acceptable explanation for the presence of pain. The simplicity of this explanation is challenged when considering the complexities of chronic pain and its experiences. The experience of chronic pain can be influenced by multiple factors, and attributing the onset of pain to be solely related to aging does not account for individual differences.

Research evidence that dispute the idea, that age alone is the main cause of pain, includes a study from Loeser (2010). Loeser considered age to be a risk factor for

the onset of pain, rather than as a primary cause. Whilst Hadjipavlou et al. (2008) criticise the use of degeneration or degenerative changes to denote age as a factor in the onset of pain. The authors felt the use of degeneration as a diagnosis for the pain as insufficient, and consider other factors like mechanical or genetic factors to have a role in the development of pain. Age and pain remains a complicated relationship. In one aspect, there is a common expectation that pain is part of aging, yet in another aspect, aging does not necessarily account for the development of chronic pain.

The relationship between chronic pain and aging can be further complicated by the fact that not all aging individuals with arthritis or degenerative changes will go on and develop chronic pain. Gignac et al. (2006) using radiographic evidence of spine pathology were able to demonstrate an inconsistent relationship between the severity of pain and presence of arthritic joint changes. Gignac highlighted the complexities of pain and that the degree of structural changes does not always correlate to the clinical presentation of pain. Pain experienced by older adults may not always be indicative of the structural changes that are occurring with aging. The role of aging in the experience of pain remains unclear (Dionne et al., 2006; Makris et al., 2017). Further research is warranted to understand the complexities of pain and aging, in particular what role does aging play in the experience and management of chronic pain.

The process of aging can add to the complexities of chronic pain. Not only is chronic pain prevalent among older adults, but also older adults are expected to be prolonged sufferers of more severe and disabling pain. Possible reasons suggested for this prolonged exposure to more severe and disabling pain, could be that older adults have a slower rate of recovery from injury and tend to have greater co-morbidities (Bernfort, Gerdle, Rahmqvist, Husberg, & Levin, 2015; Fejer, & Leboeuf-Yde, 2012; Helme, & Gibson, 1999). Furthermore, a study by Makris et al. (2014) identified age related factors such as, frailty and a reduction in social support could impact on the severity of pain experienced. In another situation, a study by Saastamoinen, Leino-Arjas, Laaksonen, and Lahelma (2005) reported that older adults with lower socio-economic differences were more likely to experience more chronic and disabling pain. The experience of chronic pain in this population group is truly multidimensional and the impacts of aging can further complicate the presentation of chronic pain.

Experiences of chronic pain

There is a large body of qualitative research focusing on understanding the experience of living with pain. However, this research is predominantly focused on understanding the experiences of living with CLBP. A greater focus on a single body area has been criticised for a lack of generalisation in understanding the full picture of chronic pain conditions. In order to provide a fuller picture and understanding of chronic pain conditions, Toye et al. (2013) suggest that research is needed to understand the experiences of living with other chronic musculoskeletal conditions.

There is research evidence to suggest that pain sufferers of other chronic musculoskeletal pain conditions affecting different body sites also endure the same negative aspects of pain as CLBP sufferers. In particular, a study by MacNeela, Doyle, O'Gorman, Ruane, and McGuire (2015) found that individuals living with other chronic pain conditions were just as likely to suffer from the same threat to their self-identity, as individuals living with CLBP. Whilst, Crowe et al. (2017) conducted a qualitative meta-synthesis of experiences of chronic pain across conditions, and reported that participants described similarities in chronic pain experiences across different conditions.

There is growing interest in understanding chronic pain among older adults, with a growing body of qualitative research on understanding the experiences and impact of chronic pain in older adults (Makris et al., 2015; Makris et al., 2017; Stensland, & Sanders, 2018a, b; Willman, Petzall, Ostberg, & Hall-Lord, 2013). Current research evidence suggests older adults living with chronic pain are expected to endure similar negative effects as identified by their younger counterparts. These negative effects include attacks on the sense of self identity, ongoing need to legitimise pain and restrictions to function (Makris et al., 2017; Stensland, & Sanders, 2018a). Although, older adults are reported to endure similar negative effects of pain, the meaning of these experiences can differ and be complicated by various factors that are associated with aging. These may include, higher rates of co-morbidities, poly-pharmacy, and a reduction in their social support networks (Makris et al., 2017). All of these factors can have an impact on the way pain is experienced by an older adult, and therefore need to be taken into account when working with older adults who are living with chronic pain.

Despite current research on the experience of chronic pain, what appears to be lacking, is research that is solely focused on the management of chronic pain in older adults. The majority of larger qualitative reviews conducted focus on understanding the experience of chronic pain, rather than its management, and these studies included younger or middle aged participants with a lack of older adults aged 65 and over (Bunzli, Watkins, Smith, Schmutz, & O'Sullivan, 2013; Crowe et al., 2017; Froud et al., 2014; MacNeela et al., 2015; Snelgrove, & Liossi, 2013). In particular, available research for the oldest group of adults aged 80 and above who require residential care (Willman et al., 2013). The impact of chronic pain may be more significant among this group of adults, as they may experience more severe and debilitating pain and are higher users of medical resources.

The impacts of chronic pain

Chronic pain is considered to be more than just a sensory experience that occurs within the nervous system. Not only can pain occur with or without biological changes, but also the experience of pain has been reported to be influenced by psychological factors (Fordyce et al., 1968; Melzack, & Wall, 1956), cultural, social boundaries that one adheres to (Morris, 1991), historical events and experiences that the individual has encountered (Morris, 1991; Morley, 2008). The impact of chronic pain is reported to have an all-encompassing impact on an older adult's life (Makris et al., 2014; Stensland, & Sanders, 2018 a, b) and also their younger counterparts (Froud et al., 2014; Smith et al., 2001; Turk, Swanson, & Tunks, 2008; Ojala et al., 2015). A study by Willman et al. (2013) reported the negative consequences of chronic pain, which could have profound effects on an older adult's physical, psychological and social function.

The experience of pain can be unrelenting for an older adult and the impacts of living with chronic pain are well documented in research. Not only can chronic pain affect the physical and social functions, it has also been shown to impact on emotional well being (Ojala et al., 2015), employment, relationships and is shown to be associated with a high level of disability (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Smith et al., 2001; Vellucci, 2012) and a reduced quality of life (QoL). The impact of chronic pain can also have extreme financial and well-being costs for the

pain sufferer. Stensland, and Sanders (2018 a, b) felt a deterioration in function could then have a trickling effect on the individual's sense of identity.

Self-identity

The impact of chronic pain on the individual's sense of self is well supported in the literature, although the majority of researches conducted on self-identity are from younger and middle aged adults (Smith, & Osborn, 2007; Snelgrove, & Liossi, 2013; Osborn, & Smith, 2006). This threat to self-identity is also reported to occur in older adults (Stensland, & Sanders, 2018a). The threat to self-identity is thought to be related to the all-encompassing impact of chronic pain and the reduction in function.

The threat to self-identity has been referred to differently in the literature, with Smith, and Osborn (2007) describing this threat as an assault on the self. Whilst, Bowman (1994) and Snelgrove, and Liossi (2009) spoke of the impacts and changes that living with chronic pain can have on personal identity. While Bunzli et al. (2013) referred to the threat on self as a biographical suspension, where the traumatic demands of pain can leave the self in three stages of suspension: a suspension of wellness, suspension of self and finally a suspension of the future.

There are various explanations that may account for the impact chronic pain has on self-identity. A possible explanation could be associated with a distortion in the manner information is processed. Pincus, and Morley (2001) offered a framework called the Enmeshment Theory to understand the interaction between pain and self and the way illness influences these two areas. The Enmeshment Theory refers to pain, illness and self as schemes. These schemes are thought to exist in the individual and are interconnected; when one aspect is affected it will have a cascade effect on the other schemes. Due to the interconnection of these schemes, any negative beliefs held by the individual about their illness and pain, can have an impact on the perception of their self-identity.

The impact of chronic pain on self-identity could also be associated with the unrelenting nature of pain. Individuals living with chronic pain are recognised to be sufferers who are unable to escape these experiences. The inability to escape the presence of pain is reported to cause chaos and threaten the very essence of the individual's sense of self (Aldrich, & Eccleston, 2000; Eccleston, & Crombez, 1999). The

individual is required to continuously endure the threat of pain and over time MacNeela et al. (2015) believe that this threat will have a significant impact on the individual's sense of identity. Chronic pain is essentially a non-life threatening condition, but due to its unrelenting nature it can significantly impact on the individual's ability to function and their sense of self-identity.

The impact on self-identity is recognised to have a detrimental impact on the individual's ability to function. Osborn, and Smith (2006) consider a threat to an individual's sense of identity is central to maintaining the negative experiences associated with chronic pain. These negative experiences and further deterioration in self-identity are expected to continue with prolonged exposure to pain (Smith, & Osborn, 2007, Osborn, & Smith, 1998). The experience of living in constant pain can be exhausting for the individual, as the individual is required to constantly attend to the demands of the pain, but at the same time finding some balance and normality with the pain.

The unrelenting nature of chronic pain is said to consume the individual's needs and attention, and Vlaeyen, Morley, and Crombez (2016) refer to this as the competitive nature of chronic pain. The competitive nature of chronic pain can drive the individual's need to find answers (Aldrich, & Eccleston, 2000). This drive can become unhealthy for some chronic pain sufferers who are unable to find a cure and have a continual desire to be pain free. Overtime the competitive nature of pain, along with the ongoing demand for attention and monitoring of symptoms, will eventually become disruptive and interfere with the individual's ability to function. These disruptive changes will ultimately have an impact on the individual's QoL and slow erosion on one's sense of identity.

The unpredictable nature of pain could also contribute to deterioration in self-identity as described by pain sufferers. According to MacNeela et al. (2015), deterioration in self-identity was considered to be associated with the unpredictable and uncontrollable nature of living with chronic pain. The unpredictable nature of pain can often leave the individual feeling despondent, especially when hard-earned positive gains can be easily taken away during an episode of increased pain (Hayes, Strosahl, & Wilson, 1999, 2012). This sense of failure and ongoing frustration with pain can result in a slow degradation of one's self-identity.

The invisibility of pain is another factor to consider when understanding the impacts of chronic pain on self-identity. The experience of pain is subjective and its symptoms are essentially invisible to others. This invisibility can often lead to misunderstanding by others, and questions around the legitimacy of pain. The pain sufferer's constant fear of being scrutinised and judged by society is reported to have profound effect on the individual's self-identity (Harding, Parsons, Rahman, & Underwood, 2005; Morley, 2008; Smith, & Osborn, 2007). To prove the legitimacy of their pain, pain sufferers are required to maintain their current pain behaviours and uphold an image that they are in pain.

For some pain sufferers, the invisibility of pain can also have a different impact and cause them to retract further into the invisibility of pain. The experiences of pain can only ever be understood through the manner in which the pain sufferer moves, functions and behaves within a social context (Harding et al., 2005; Morley, 2008; Morris, 1991). Society has certain expectations on how an individual with pain should move and behave. Due to the fear of being further scrutinised by society, Osborn, and Rodman (2010) suggest some individuals living with pain will be more likely to retract into this invisibility, and portray an image that outwardly they are functioning successfully. The experience of pain is very much an individualistic experience, as some individuals will retract further into the invisibility, whilst others will continue to portray an image of a self that remains in pain.

The experience of chronic pain can be further complicated by the idea that different aspects of self can co-exist, and that a separation of self can occur with chronic pain. Not only is there a disruption to self-identity, but there can also be dissonance between the old and new self (Smith, & Osborn, 2007). Frank (1995) suggests that different forms of selves can exist during chronic illnesses and that the different aspects of selves can co-exist. However, finding a new self that the individual is happy with can be difficult (Osborn, & Smith, 2006). The difficulty in accepting a new self that remains in pain becomes problematic, especially when the pain sufferer attempts to move forward with their pain.

The individual's inability to accept the new self and the continual desire for the pre-pain self, can impact on the individual's ability to move forward. A study by Bunzli et al. (2013) refers to this as a life placed on hold, and the individual is forced to

continue to live their life in a suspended manner, with the inability to move forward or backwards. This obsession of wanting to get back to the pre-pain self, along with an inability to accept a new self in pain, presents a binding dilemma for chronic pain sufferers. This dilemma can serve as a continuous drive for cure seeking and further assault on the sense of self.

Emergence of the painful body - Fragmentation of self and body

When describing the experiences of living with chronic pain, pain sufferers also referred to the emergence of a painful body and a change in narratives. During chronic illnesses, Frank (1995) reports that the narratives of the painful body become salient and there is a sense of dualism between the mind and body. Crowe et al. (2010) sum up this fragmented relationship with their use of a metaphor, listening to the body and talking to self. The authors suggest when living with chronic pain, the pain sufferer reports of a separation between the self and body. Where the mind is willing to do things, but is restricted by the painful body, and during periods of increased pain the narratives of the body become more important. No matter how much you will yourself to move, the pain sufferer will eventually succumb to the painful body.

Osborn, and Smith (2006) suggest the development of a painful body was a result of the continuous attention and demands of living with chronic pain. This constant monitoring and rechecking of symptoms was also reported by Hayes et al. (1999, 2012) to have an impact on the spontaneity and freedom that the pain free body once had. Hayes suggests that in the presence of pain, the body's ability to move will be restricted and movement's will now become carefully planned and closely monitored. In particular, movements or tasks that are deemed to aggravate the pain will become feared and avoided. This avoidant behaviour could lead individuals to place further emphasis and attention to the narratives of the painful body.

Frank (1995) highlighted the importance of the painful body in the expression of chronic illness behaviours. The author spoke about the role of the body as a storyteller, where the body is able to provide a platform for the individual to tell a story. It is thought that individuals living with chronic illnesses will utilise the body to tell a new story. A story that only includes narratives from the painful body and narratives from the once heathy body will become irrelevant.

Individuals living with chronic pain can often have difficulties finding a narrative that is congruent and understood by others who are not in pain. The individual's inability to express a narrative that is comprehensible to others could be related to what Lavie-Ajayi, Almong, and Krumer-Nevo (2012) refer to as a narrative distress. The authors described an internal conflict that can occur within individuals living in chronic pain. The narrative distress refers to the struggles of the pain sufferer, where in one aspect the pain sufferer is required to endure and acknowledge the realness of their pain experiences, yet in another aspect, the legitimacy of these vivid pain experiences is scrutinised due to the invisible nature of their pain.

The impact of chronic pain on self–identity is significant, and the ongoing strain on the individual's sense of self is reported to influence the individual's ability to live with their pain. From a clinical perspective, this will have a significant bearing on the success of pain management programs and any therapeutic approach used will need to address the disruptions to self-identity. A review conducted by Williams (2000) reports that for any therapeutic gains to occur, disruptions to the body and self-identity will need to be addressed. Therefore, individuals living with chronic pain will need a therapeutic approach that addresses the disruptions to self-identity, and assist with the development of a new narrative that is viable and cohesive to accepting a new self with pain.

The concept of acceptance is recognised to have an important role in assisting the individual's ability to re-conceptualise and make sense of the disruptions caused by pain (McCracken, & Eccleston, 2003). The psychotherapeutic model of acceptance commitment therapy (ACT) could provide a more meaningful framework for pain sufferers to view their pain and self-identity. Smith, and Osborn (2007) suggest that ACT can assist the individual to conceptualise their own understanding of pain. By making adaptations to the way pain is understood, this may facilitate the development of new strategies to enable the pain sufferer to co-exist harmoniously with pain, and to build a new self that is coherent and valued.

The costs of chronic pain

Chronic pain is a common experience among older adults, yet the costs of living with chronic pain in this population group are inaccurately reflected. Possible reasons for this under reporting may be attributed to the fact that older adults have greater co-morbidities, higher resistance to asking for help and are underrepresented in chronic pain research (Magnusson, & Fennell, 2011; Sofaer et al., 2005). A study by Stensland, and Sanders (2018b) reported the under representation of older adults living with chronic pain is especially noticeable among the oldest group of adults who reside in residential homes. According to Bernfort et al. (2015), in order to accurately reflect the true costs and impacts of chronic pain among the elderly population, more research is warranted, especially among groups of older adults living with severe pain and reside in residential care.

The ubiquitous nature of chronic pain is identified to have a global impact. Historically, chronic pain was recognised as a Western society condition (Blyth et al., 2001), but now it is a condition that can affect all populations and ethnic groups, regardless of age and gender (Goldberg, & McGee, 2011; Tsang et al., 2008). In Western society, Fayaz et al. (2016) estimate 28 million adults living in the United Kingdom will experience chronic pain. In New Zealand, it is estimated that 1 in 6 adults will report experiencing chronic pain (Blyth et al., 2001). The prevalence of chronic pain is also on the rise for non-Western societies. In Japan, it is estimated that 15.4% of the population will report experiencing chronic pain (Nakamura, Toyama, Nishiwaki, & Ushida, 2011). Furthermore, Moradi-Lakenh et al. (2017) estimates the rate of individuals living with chronic pain in Eastern Mediterranean regions is expected to grow faster than the rest of the world. Chronic pain is fast becoming a worldwide phenomenon and a condition that is not isolated to one particular age, gender or population group.

The cost of chronic pain can have profound impacts on the economy and health system, especially in terms of loss of wages and costs of medical interventions (Bernfort et al., 2015; Turk et al., 2011; Walsh et al., 2008). The impact of a loss of wages was significantly noticeable when chronic pain occurred in middle aged adults. Dionne et al. (2006) found a high cost of chronic pain was associated with a high incidence rate of chronic pain among middle-aged adults. This group of adults was

considered to be the most productive with work and earnings. Therefore, the inability to work because of their pain will have significant impacts for the individual, their families and contributions to society.

The cost of living with chronic pain can have a significant impact on health care. Older adults are considered to have lived longer with their pain and are exposed to more chronic and disabling pain (Dionne et al., 2006; Fejer, & Leboeuf-Yde, 2012; Saastamoinen et al., 2005). This prolonged exposure can have significant impacts, especially for an older adult who is already dealing with other health related problems. All these factors can have a cascade effect on an already over stretched health system. The cost of managing chronic pain conditions among older adults presents a challenge, as there are multiple factors that can influence the presentation of pain among older adults. Therefore, isolating the cost of chronic musculoskeletal pain from other chronic illnesses will be difficult, as often these chronic illnesses can cause pain.

Management of chronic pain

Despite the commonality of chronic pain and research in this area, it is a condition that continues to be a challenge to treat. For some sufferers, there continues to be a lack of effective diagnostic and treatment options (Nakamura et al., 2011; Ojala et al., 2015; Turk et al., 2011; Vowles, & Thompson, 2011). This leaves individuals to simply learn to endure the daily challenges of pain and trying to co-exist (Gatchel, & Okifuji, 2006; Smith, & Osborn, 2007). Chronic pain is a condition that is essentially unique to the individual and can have profound impacts on their ability to function. Due to its complexities, management of chronic pain needs to be multimodal, and Turk et al. (2008) suggest that no singular approach can be effective in the management of chronic pain.

Presently there are no cures for chronic pain. Treatment methods for chronic pain are vast and these can include exercise therapy, manual therapy, medication, injections, surgery and cognitive and behavioural based therapies. Exercise therapy and physiotherapy is considered to be the most commonly used approach to conservatively manage the symptoms of pain (Godfrey et al., 2012, van Middelkoop et al., 2010). Other common approaches for treatment of chronic pain are the use of opioids and spinal surgery, both of these methods are reported to be on the rise

(Okifuji, & Turk, 2015). Despite the large range of available treatment options, there continues to be a lack of consensus on the most appropriate and effective treatment for the management of chronic pain (Turk et al., 2008; Turk et al., 2011).

There is a growing recognition on the use of a broader psychosocial approach to the management of chronic pain conditions. According to Gatchel, Peng, Peters, Fuchs, and Turks (2007), chronic pain is best managed under the biopsychosocial model of care. The biopsychosocial model of care includes many therapies that can be utilised to assist with the management of chronic pain conditions, including psychological approaches like cognitive behavioural therapy (CBT). This is one approach that is commonly used in the management of chronic pain conditions, especially LBP (Morley, Eccleston, & Williams, 1999; Williams, Eccleston, & Morley, 2012).

Assessment process

Management of chronic pain in the older adult can be a challenging process, and the management of chronic pain has been criticised to be inadequate, especially among older adults (Abdulla et al., 2013; Herr, 2011; Schofield, 2016). Herr (2011) believes a possible reason for this could be attributed to the lack of comprehensive pain assessment conducted on an older adult who presents with pain complaints. Furthermore, Hadjistavropaulos et al. (2007) outlined several reasons why pain assessment on an older adult may be challenging and that these reasons were shown to be specific to the older population. These factors include, frailty, high co-morbidity rates, certain beliefs about pain and medication, sensory and cognitive impairment and stoicism. These factors can all impact on the medical practitioner's ability to perform a comprehensive assessment of an older adult's pain complaints.

In another situation, the lack of comprehensive pain assessments conducted could also be attributed to the under reporting of chronic pain among older adults. Studies by Clarke et al. (2014) and Makris et al. (2015) highlighted the challenges in the management of chronic pain in older adults, especially among groups that do not seek medical help for the fear of being a burden on society. The under reporting of chronic pain among older adults and the lack of a comprehensive pain assessment, will ultimately have an impact on the effective management of chronic pain.

Time availability has been highlighted as a possible factor that can restrict the clinician's ability to perform a comprehensive pain assessment. Due to the high rates of co-morbidities among older adults, assessment of their pain complaints can often be time consuming and complicated. Conducting a comprehensive assessment within the time restraints set in a clinical setting can be challenging, as the time available to perform these lengthy assessments are luxuries that are rarely available in health centres (Hadjistavropaulos et al., 2007; Hochberg et al., 2012).

Other factors that can lead to an inadequate assessment of pain among older adults are the lack of specific assessments designed for an older adult. A study by Herr (2011) suggests that pain assessment of an older adult represents a unique challenge, and current assessment measures that are used may not account for changes such as sensory and cognitive changes. These changes can impact on the assessment process, and clinicians need to adapt the assessment process to suit the older adult that is present in the clinic.

There are clinical guidelines that are available for the assessment and management of chronic pain in the older adults (Abdulla et al., 2013; Hadjistavropoulos et al., 2007) and guidelines on management of osteoarthritis of the hand, hip and knee (Hochberg et al., 2012). Despite this availability, McGuire, Nicholas, Asghari, Wood, and Main (2014) felt these clinical guidelines were poorly applied into a clinical setting. Hadjistavropoulos et al. (2007) suggest possible reasons that may account for the poor application of these guidelines into clinical practice could be associated with time restraints, availability of specialists and funding. The first step to providing effective management strategies for chronic pain in an older adult is to obtain a comprehensive assessment of their pain. Without a comprehensive assessment, older adults are being penalised for the inadequate care that they are receiving.

Management process

The management of chronic pain in the older adult favours heavily on the use of pharmacological therapies, rather than non-pharmacological therapies (Reid et al., 2015). A greater emphasis on the use of medication to treat chronic pain continues despite evidence from Hochberg et al. (2012) who strongly recommend the use of

exercise therapy, and moderately support the use of psychotherapy interventions in the management of osteoarthritic pain. The underutilisation of non-pharmacological therapies in the management of pain in older adults is slowly being acknowledged, in particular with McGuire et al. (2014) who highlighted the lack of consideration that was given to the use of non-pharmacological therapies in the management of chronic pain among older adults.

The reasons to account for the underutilisation of non-pharmacological therapies are unclear. The lack of use appears to be illogical due to possible risk factors that are associated with some medications. A study by Keefe, Porter, Somers, Shelby, and Wren (2013) highlighted the limitations of pharmacotherapy and provided further support towards the use of psychosocial interventions in the management of chronic pain among older adults. While Hadjistavropaulos et al. (2007) also noted the challenges of using pharmacological managements in the management of chronic pain among older adults. Due to these concerns, a greater emphasis should be placed on the use of non-pharmacological therapies, as they are safer, less invasive and potentially have fewer side effects.

The lack of non-pharmacological therapies used in the management of chronic pain among older adults could be attributed to their age. A study by Macfarlane et al. (2012) found age determined the type of pain management interventions used, and older adults were less likely to be referred for physiotherapy, exercise therapy, or to a specialist. Macfarlane felt possible reasons for this lack of referral may be attributed to previous negative experiences or preconceptions that the older adult or their referring clinician may have towards these therapies. The notion that age can influence the type of therapy offered is of interest and requires further exploration.

At times, regardless of all the best efforts from clinicians and the various treatments used in the management of chronic pain, some individuals may never be free from their pain and are required to find ways to live and self-manage their pain. In the presence of unsuccessful attempts to be pain free, Schofield et al. (2016) felt that self-management is a viable option in the management of chronic pain in the older adult population. While Nicholas et al. (2013) also support the use of self-management programs, such as CBT and exercise therapy in older adults living with chronic pain. Although there has been an increased interest in understanding the impact of chronic

pain among older adults, more work is warranted to understand the treatment of chronic pain in older adults, in particular the use of non-pharmacological interventions like psychological based therapies (McGuire et al., 2014; Reid et al., 2015; Schofield, 2016).

Psychological Management

The use of psychological based therapies has been shown to be effective in the management of chronic pain in the elderly population. However, the majority of this research is focused on the use of CBT (Scott, Daly, Yu, & McCracken, 2017), and CBT is considered to be the most commonly used and shown to be an effective approach in the management of chronic pain (Keefe et al., 2013; Nicholas et al., 2013). Despite the common use of CBT in clinical settings, it does have its shortfalls and may not be suited for every chronic pain sufferer (Williams et al., 2012).

Another psychotherapy approach that is gaining traction in the management of chronic pain among the elderly population is ACT. The therapeutic approach of ACT takes roots from the pragmatic philosophy of Functional Contextualism (FC) and it stems from the Psychological Flexibility (PF) model, which recognises the flexibility and inflexibility of human functioning (Hayes, Pistorello, & Levin, 2012a; Hayes et al., 2012). The components of the PF model are reported to include the components of acceptance, defusion, self as context, committed action, values and attention to the present moment (Hayes et al., 2012a; McCracken, & Morley, 2014). The term PF has been defined by Wetherell et al. (2011) as the individual's ability to adapt their behaviour to the situation, and the aim of ACT is reported by Hayes et al. (2012a) and Scott et al. (2017) to improve the individual's PF. ACT is reported to achieve this through its strong focus on goals and values attainment, rather than on the elimination of pain (Wetherell et al., 2011; Scott et al., 2017).

ACT also draws on the theory of language; the relational frame theory (RFT) (Hayes et al., 2012a; McCracken, 2011). Therefore, the fundamental position of ACT recognises the importance of context and language in understanding human behaviour. The theory outlines that as human beings, we exist in this world and our ability to make sense of the world comes from the interactions that is encountered on a daily basis. The meaning of these interactions is derived from the context in which

the interaction occurs in and the language that is used. Therefore, the meaning of that particular interaction will be influenced by factors such as language, current and historical events, cultural, and social factors (Frank, 1995; Hayes et al., 2012a; McCracken, 2011; Morris, 1991). All these factors are considered to be inseparable and imperative to the meanings and beliefs that individuals use to understand the world they exist in.

The PF model also recognises the inflexibilities of human behaviour. Hayes et al. (2012a) refer to this inability to change as the psychological inflexibility of human function. The authors suggest that at an early age individuals learn to develop certain belief and values systems, and the thoughts and feelings underlying these beliefs are considered to be so engrained into the individual's belief system that they become inflexible and cannot be unlearnt (Hayes et al., 1999, 2012). Applying this to chronic pain, the experiences of pain is considered by Hayes et al. (2012a) to be normal occurrences. The perception of these experiences will be determined by the individual's belief and value systems, which are predetermined and cannot be unlearnt. This inflexibility of human function can serve to drive the belief that pain is an abnormal sensation and an experience that needs to be abolished.

The approach of ACT recognises and acknowledges this inflexibility to change and does not attempt to stop or eliminate these pain symptoms. Hayes et al. (2012a) suggest that ACT requires the individual to remain in the present moment and experience their pain symptoms without any resistance. Hayes felt that the willingness to experience pain with an open-minded manner would allow new strategies to develop, and enable the individual to cope with the unwanted thoughts and feelings associated with pain. Over time, the hope is for these new strategies to dampen the negative effects of pain, whilst allowing the individual to function with reduced interference from their pain.

Despite all the best efforts of therapy, the individual may still have pain that they need to learn to live with. Incorporating the process of acceptance will be an important aspect in the individual's pain management program. The ability to accept pain will require the individual to place the onus of pain management back onto themselves. This can be achieved by relinquishing the need to continue with

unproductive strategies, and to adapt more sustainable approaches to co-exist with the pain.

The concept of acceptance

Freud first mentioned the term acceptance in 1926 (Risdon, Eccleston, Crombez, & McCracken, 2003). Since then acceptance has been defined in various forms and can have different meanings. The different meanings of acceptance would be dependent on the viewpoint that is adapted by the individual. Morris (1991) and McCracken (1999) referenced acceptance as an attitude change that is adapted by the individual. While Hayes et al. (1999, 2012) consider acceptance to be an active process for change from the status quo. Although acceptance is defined differently, there are commonalities between these definitions. The common factor in acceptance is that it requires the individual to make an active change in the way they view their pain experiences. This active change requires the individual to actively disengage from utilising ineffective therapeutic approaches to control the pain, what Hayes et al. (2012) refer to as a shift from the status quo.

There are different meanings of acceptance that are offered, from the perspectives of a chronic pain sufferer; the interpretation of the term acceptance may differ from the conceptualised definition. The constant exposure to pain may lead the pain sufferer to view pain more negatively and consider acceptance as a begrudged necessity for living. A study by Jacobson, and Christensen (1996) found that individuals, who perceive a lack of choice, were more likely to view acceptance more negatively and view acceptance as a sign of resignation or giving into the pain. The meaning of acceptance can differ greatly for individuals living in pain, especially when they are unable to escape from its unrelenting presence.

For some individuals living with chronic pain, the meaning of acceptance could also be medically influenced. Due to the chronicity of pain, some pain sufferers would have had greater exposure to medical narratives. A study by Biguet et al. (2016) reported that exposure to medical narratives can medically bias the pain sufferer's understanding of acceptance. For an older adult living in pain, acceptance of pain may simply be adopting the more dominant medical dialogue and resigning to the assumption that pain is part of aging. Frank (1995) referred to the dominance of the

medical narratives and that these narratives can often dominate and replace the individual's own narratives.

Acceptance is one component of the PF model that has been shown to play an important role in the management of chronic pain. McCracken (1998) applied the concept of acceptance to chronic pain management, and defined acceptance as a willingness to live alongside the pain, without the need to challenge or resist these personal experiences. The act of experiencing pain without resistance is hoped to enable individuals to participate in value-orientated activities, rather than focusing on unproductive ways to eliminate the pain (McCracken, 1998; McCracken, & Eccleston, 2003; McCracken, & Morley, 2014). The role of acceptance has an important part to play in the management of chronic pain, as the act of accepting requires the individual to co-exist with pain, rather than to waste valuable energy to abolish it.

From a clinical perspective, it is imperative to acknowledge the complexities of acceptance, and that the meaning of acceptance will differ depending on the viewpoint in which acceptance is understood. In order to provide a clinically meaningful framework for the management of chronic pain in older adults, the misconceptions of acceptance need to be addressed. By recognising that different meaning of acceptance can occur simultaneously, the aim would be to address these differences and identify ways to facilitate the process of acceptance within each individual.

Factors that facilitate and hinder the process of acceptance

The individual's ability to accept their pain experience is recognised as a precursor to learning to live with their pain (Sofaer et al., 2011). There are various factors that has been identified to facilitate the process of acceptance amongst pain sufferers and some of these factors include receiving a diagnosis (Kostova, Caiata-Zufferey, & Schulz, 2014; Sheedy, McLean, Jacobs, & Sanderson, 2017), relinquishing the need to find a cure and viewing acceptance not as a sign of failure (Risdon et al., 2003; Toye et al., 2013), integrating the painful body (Toye et al., 2013) and cultural influence (Kleinman, 1978; Woolf, & Plfeger, 2003).

Role of diagnosis

Receiving a diagnosis for the cause of the pain is an important factor in facilitating acceptance. Sheedy et al. (2017) found receiving a diagnosis represented a turning a point in the individual's recovery and assisted the individual's ability to move forward with their pain. A study by Kostova et al. (2014) demonstrated a positive relationship between diagnosis and acceptance rates in individuals living with Rheumatoid Arthritis (RA). The importance of diagnosis was further reflected in situations when there was an absence of a diagnosis or an explanation for the pain. Research evidence suggests that in the absence of a diagnosis, doubt can be cast on the legitimacy of pain and hinder the process of acceptance (Bunzli et al., 2013; MacNeela et al., 2015; Osborn, & Smith, 2006). The continual need to prove the legitimacy of pain can result in the individual's resistance to accepting their pain.

The speed in which a diagnosis is provided was another important facilitator of acceptance. The time it takes to receive a diagnosis is also important. Biguet et al. (2016) reported that a delay in receiving a diagnosis could also hinder the process of acceptance, and limit the individual's ability to positively adjust to the required changes. Furthermore, Kostova et al. (2014) found that individuals, who received an earlier diagnosis for their pain condition, demonstrated greater acceptance when compared to individuals who received a late diagnosis. Not only is a diagnosis important in facilitating the process of acceptance, but also the speed in which this occurs is also important in the management of chronic pain.

The importance of diagnosis in facilitating acceptance is recognised in younger and middle aged adults, however this appears to differ for an older adult living with pain. Research has shown older adults to place less importance on receiving a diagnosis for their pain, when compared to their younger counterparts (Gignac et al., 2006; Sofaer et al., 2005). Possible reasons for this could be related to other significant life events that may be occurring for the older adult. These events may include loss of spouse or independence, higher levels of co-morbidities and disability (Helme, & Gibson, 1999). When faced with other life adversities, the importance of chronic pain may differ, especially when faced with a terminal illness, as the threat to mortality becomes more imminent.

Despite placing less emphasis on the role of receiving a diagnosis, older adults living with chronic pain have shown to have a higher rate of acceptance than their younger counterparts. There are a number of possible explanations to account for this and they are: the common belief pain is part of aging (Risdon et al., 2003), utilising the biomedical model to understand their pain (Clarke et al., 2014; Collis, & Waterfield, 2014), normalisation of pain, and high rates of co-morbidities (Abdulla et al., 2013).

Society holds a common belief that pain is age related, and that pain is part of the wear and tear process that occurs with aging (Grime, Richardson, & Ong, 2010). According to Sanders, Donovan, and Dieppe (2002), an older adult's ability to view pain as part of aging was considered to be a coping mechanism that was developed to demonstrate the individual is aging successfully despite the pain. Understanding pain as part of aging will enable the individual to normalise their experience of pain. Adapting this view will serve to reduce the threat of pain and consider it as a normal occurrence of aging.

Research also suggests an individual's ability to accept ongoing pain will be dependent on the individual's perception of their pain. An older adult's ability to normalise their pain experience and to acknowledge the commonality of pain amongst their peers, will allow the threat of the pain to be reduced. A study by Sanders et al. (2002) considered a perceived low level of threat from the pain to be an important precursor to acceptance. Another study by Collis, and Waterfield (2014) found older adults who perceived pain to be non-threatening were able to live successfully with pain. Chronic pain is fundamentally a condition that threatens the individual's morbidity and identity, rather than on mortality (Aldrich, & Eccleston, 2000; Eccleston, & Crombez, 1999; Osborne, & Smith, 1998). Therefore, normalising the experience of pain as part of aging can be a coping strategy developed by older adults to protect themselves against the threats of pain.

By normalising their pain, the older adult is reported to favour the use of the biomedical model when attempting to understand their pain (Clarke et al., 2014; Collis, & Waterfield, 2014). A greater emphasis on the biomedical model could be related to what Makris et al. (2014) refer to as a development of a mechanistic view to understanding pain. Older adults who adopt this view were shown to be more likely to understand their pain as having a physical or mechanical cause. Understanding pain

through a mechanistic lens will favour the use of the biomedical model with its focus on cause and disease management. This mechanistic view will help to confirm the assumption that pain is related to the structural changes that occur during the aging process.

A sole focus on utilising the biomedical model is in direct contrast to the recommended best practice for the management of chronic pain. It remains uncertain as to why a biomedical focus would facilitate greater acceptance of pain in the older adult, as a biomedical focus with its narrow focus on disease and cure is reported to hinder acceptance in younger adults (McCracken, Carson, Eccleston, & Keefe, 2004; Snelgrove, & Liossi, 2009). There are differences that exist between an older adult and their younger counterpart's experiences of chronic pain and its management. To understand these differences, further research with a focus on understanding the experiences and management among older adults is warranted.

Relinquishing the need for a cure and changes to the understanding of acceptance

The ability to relinquish the ongoing need to find a cure was another factor identified to influence the process of acceptance (Vlaeyen et al., 2016). To accept a life with pain requires the individual to forgo the continuous use of unproductive and costly interventions in the management of pain. Hayes et al. (1999, 2012) describe this as a shift from status quo and considered it to be a pre-requisite to acceptance. Whilst, Toye et al. (2013) refer to this as realising that there is no cure and letting go of unproductive methods to manage the pain. To accept a life with pain, the individual is required to discontinue the need to continue with unproductive methods to abolish pain and renounce hope of finding a cure.

The meaning of acceptance is reported to differ between individuals, and the understanding of acceptance is dependent on the stance in which the individual views their pain experiences. Risdon et al. (2003) suggest that how an individual defines or understands the concept of acceptance will have a bearing on their rate of acceptance. The concept of acceptance can often be viewed negatively by the pain sufferer and differs from its conceptualised meaning. Conceptually the process of acceptance is considered to be an active process that requires great strength from the pain sufferer; where the pain sufferer is required to have the willingness to stay in the presence of

their pain, and experience that private experience wholly without any challenge (Hayes et al., 2012). To adopt the process of acceptance, the pain sufferer is required to alter the way they understand pain and make meaningful cognitive and behavioural changes.

Integrate the painful body

The ability to integrate the painful body was another factor that was recognised to facilitate the process of acceptance. Individuals living with chronic pain are recognised to be sufferers who continuously endure threats to their personal identity (Bowman, 1994; Bunzli et a., 2013; MacNeela et al., 2015; Smith, & Osborn, 2007; Snelgrove, & Liossi, 2009). Risdon et al. (2003) suggest successful adjustments to acceptance will require a change in the individual's identity and accepting a new self with pain. The pain sufferer's inability to accept the new self with pain, and the continual desire to get back to the pre-pain self can hinder the process of acceptance. The constant struggle to adapt to a new life with a body in pain requires tremendous energy from the individual to resist the ongoing desire to get back to the pre-pain self.

Influence of culture

The role of culture can also have an impact on the prevalence and prognosis of chronic pain (Woolf, & Pfleger, 2003). Research suggests that the way illness is perceived is culturally diverse and Kleiman (1978) suggest that different cultures use different explanatory models of care to interpret and treat their illnesses. Individuals that take on the more dominant biomedical model to categorise their pain, will be more likely to seek and adhere to Western medical explanations and diagnosis for their pain. The role of culture has an important role to play on the development of chronic pain beliefs and the expression of pain behaviours. From a clinical perspective, Magnusson and Fennell (2011) suggest it is imperative to understand the role of culture on pain beliefs and the expression of behaviour, when assessing and managing individuals living with chronic pain.

Acceptance is a complex concept and there are concerns this concept is being misunderstood (Biguet et al., 2016). McCracken (1998) acknowledges the complexities of acceptance and considers the concept to be more than just engaging in activities as

a way to reduce pain. According to Hayes et al. (2012) the process of acceptance is considered to be an active process that requires the pain sufferer to make meaningful and lasting changes to the way they view and manage their pain. It is not enough to verbalise willingness to change, the individual is required to actively make meaningful cognitive and behavioural changes to the way pain is managed.

Is acceptance helpful?

Individuals living with chronic pain have been shown to have the potential to change and improve their QoL. A high degree of acceptance has also been found to associate positively with greater QoL (Leadely et al., 2013; Mason, Mathias, & Skevington, 2008). Despite this positive trend, a study by Sofaer et al. (2005) highlighted uncertainties in research pertaining to QoL and acceptance in older adults living with chronic pain. The authors recommend further research is required to understand the relationship between acceptance and QoL, and identify factors that can facilitate an older adult's ability to live successfully with pain.

Individuals who are more accepting of their pain have been shown to have greater positive changes like a reduction in pain levels, improvement in anxiety and depression (Kostova et al., 2014), have less physical and psychological disability, and improved work status (McCracken, 1998; McCracken, & Eccleston, 2003). The process of acceptance has been demonstrated to facilitate positive changes such as assisting with the individual's ability to live with the pain (Hallstam, Stalnacke, Sevense, and Lofgren, 2015; Hayes et al., 2012; McCracken, 1998; McCracken, Spertus, Janeck, Sinclair, & Wetzel, 1999; Toye et al., 2013) and improvement in treatment outcomes (Vowels, McCracken, & Eccleston, 2007). Individuals living with pain have shown to have the potential to change. What is important is what role acceptance has on these changes and how acceptance can be effectively facilitated in a clinical setting, especially in pain sufferers who may be stuck in the management of their pain.

Despite promising research surrounding acceptance and the use of ACT in the management of chronic pain, this evidence is largely from younger or middle aged adults. There are studies on the use of ACT that has included older adult participants (McCracken, Sato, & Taylor, 2013; Wetherell et al., 2011). Criticism around these studies revolves around a number of concerns; firstly, the studies included a low

number of older adult participants. Secondly, there were uncertainties around the percentage of older adults allocated to ACT intervention groups. Thirdly, the inclusion of results from younger or middle aged adults could also cause results to be diluted or skewed. The process of acceptance among older adults living with chronic pain remains unexplored. Further research specifically focused on understanding the impacts of acceptance in older adults living with chronic pain is required.

Despite these pitfalls in research, the overall preliminary support for the use of ACT amongst older adults living with chronic pain is positive (Lunde, & Nordhus, 2009; McCracken, & Jones, 2012; Scott et al., 2017). Wetherell et al. (2016), found age to be a moderating factor in the preference of psychotherapy options, and the use of ACT was more favourable among older adults. These results from the above studies lack generalization, as there remains to be very little research on acceptance-based therapies with older adults 65 and above, and even less on the oldest adults who are over the age of 80.

The under representation of older adults in research and especially the oldest age group could be due to the fact that older adults do not want to be a burden and will often not seek medical assistance (Clarke et al., 2014). Sofaer et al. (2005) suggest reasons such as a lack of financial assistance, and not knowing what resources or services are available are also common barriers for an older adult to seek help for their pain. Current available evidence on the management of older adults living with pain is under represented, and this is especially evident among the oldest group of adults who reside in residential homes.

Little is known about the influence of age on the perception of acceptance (McCracken, & Jones, 2012). Older adults are reported to be more accepting of pain, but this acceptance may be begrudged or out of necessity (Collis, & Waterfield, 2014, Gignac et al., 2006). More research is required to understand the role that aging has and its impact on the relationship between pain and acceptance. The preliminary results on the use of ACT in the older population is supportive, but further work is required to understand the component of acceptance and the role it has on chronic pain management in older adults (Barban, 2016; Scott et al., 2017).

Acceptance is one of the components of the PF model and it has been shown to have an effective role to play in the management of chronic pain. Whilst the majority

of the current evidence is based on younger or middle aged adults living with CLBP, more work is required to focus solely on the older adult, especially the oldest groups of adults. The experience of chronic pain among older adults is unique and challenging. Older adults are expected to endure more complicated and severe pain for longer periods, which can all impact on the presentation of chronic pain. Understanding the experience of chronic pain and the role of acceptance from the perspective of an older adult will provide what Gagliese (2009) describes as a fuller picture towards understanding the experiences of chronic pain and its management.

Summary of Introduction

Chronic pain is a common condition that can affect people of all ages and ethnic backgrounds. It is a condition that is common among older adults, yet at the same time this condition is under represented in research. The experience of chronic pain in the older adult presents a unique and challenging picture, not only are older adults expected to endure their pain experiences for longer, but also these experiences can often be compounded by other co-morbidities and influenced by medical narratives. The role of acceptance is recognised to be an important facilitator in the individual's ability to live with their pain. However, the majority of the current evidence is based around younger and middle-aged adults with little inclusion of older adults. The psychotherapeutic approach of ACT has gained preliminary results to support its use among older adults living with pain, yet older adults are less likely to be referred for non-pharmacological therapies and there continues to be criticisms around the inadequate management of chronic pain among older adults. The process of acceptance in older adults living with chronic pain remains unclear, and warrants further investigation. The purpose of this study is to provide a more in depth exploration of the process of acceptance and the role it has on an older adult's ability to live with their pain.

Chapter two: Methodology

Interpretative Phenomenological Analysis (IPA)

Pain is a subjective experience and Smith, and Osborn (2007) described the experience to be individualistic in nature. It is an experience that is personal to the individual and to make sense of these lived experiences, it needs to be understood from the perspectives of the individual who is living with chronic pain. The Interpretative Phenomenological Analysis (IPA) approach was the chosen method to study this complex phenomenon. IPA was chosen for this study due to its underlying fundamental assumptions of phenomenology, hermeneutics and idiographic. The underlying assumptions of IPA will help to provide an in-depth exploration of the individual's personal lived experiences, and provide an appropriate framework to understand the complexities and ambiguous nature of chronic pain (Smith, & Osborn, 2015).

The approach of IPA draws roots from phenomenology. This current study is concerned with understanding the individual's lived experiences. Human beings are said to be sense-making beings (Hayes et al., 2012) and the generation of these experiences are developed through the daily interactions that the individual has with others and their environment. By utilising the IPA approach, the aim is to provide a detailed in-depth exploration of an individual's account of their pain experiences and to understand the impact of these private experiences on their daily functions.

To align with the assumptions of phenomenology, it is also important to acknowledge that our experiences are shaped by our everyday interactions. In particular, Snelgrove (2016) suggests that an individual's ability to make sense of these interactions can be biased by their backgrounds, beliefs, historical events, language, expectations and assumptions. In order to generate meaning and understanding of these personal experiences from an outsider's perspective, it is imperative to acknowledge the influential role the above factors has on the individual's interpretation of pain and generation of knowledge.

The notion of context is also imperative in generating meaning and understanding of these private pain experiences. Heidegger acknowledged this context as "being in the world" (Snelgrove, 2016, p. 133). The experience of chronic pain is considered to be more than just a biomedical process or reactions involving the

nervous system; it is a subjective experience that is contextually defined (IASP, 2018; Morris, 1991). Therefore, to make sense of these pain experiences, it is important to consider the context in which these experiences occur. The approach of IPA aligns itself to the assumptions of phenomenology, as it attempts to understand the context of pain from the perspective of the pain sufferer.

The approach of IPA also draws from the fundamentals of hermeneutics. It is considered that generation of meaning into what it is like to live with chronic pain will require an interpretative approach from both the observer and the subject (Eatough, & Smith, 2017). This highlights the importance of the relationship between the observer and subject in research. Smith (2004) considers that generation of knowledge is through attempts made by the observer, where the observer is trying to make sense of the subject's experience, whilst at the same time the subject is also trying to make sense of their own personal accounts of pain. Sense making of complex conditions such as chronic pain is achieved through an interpretative approach. This approach requires an active observer to look in and understand these private pain experiences from the perspectives of the pain sufferer.

IPA highlights the important relationship between the observer and subject in research, and recognises the active role of the researcher in this process. Whilst IPA places importance on understanding individual's own experiences, at the same time it acknowledges that the process of research is a dynamic and non-bias free process, and can be complicated by the researcher's own preconceptions and experiences (Smith, & Eatough, 2012). To counteract this, IPA requires the researcher to disclose their own intentions to research and engage in a process of reflective practice (Smith, 2004). The ability to participate in reflective practice requires the researcher to actively examine their own feelings, reactions and motives for research, and how these factors can influence data collection and interpretation.

There are several issues that need to be considered in regards to the current study. Firstly, the researcher is an active participant in the research process. The idea that research is not bias free begins with the researcher, as the researcher will predetermine the topic of interest and questions pertaining to research. Secondly, the researcher is a practicing physiotherapist with an interest in chronic pain; her own preconceptions and previous experiences working with individuals with chronic pain

may influence her thoughts and understanding of pain towards a medical narrative. A stronger bias toward the dominant medical discourse can further disrupt the perceived power imbalance between participants and researcher.

Finally, the researcher was also actively involved with the collection and interpretation of data. Being a clinician and conducting the interviews may influence the responses that participants may provide, such as a greater emphasis towards physiotherapy matters, or that participants may not want to fully disclose their thoughts due to fears of offending the interviewer. The researcher also engaged actively in the process of data analysis, and the undertaking of this process could be influenced by the researcher's previous experiences and preconceptions (Smith, & Eatough, 2012). The researcher's preconceptions or beliefs about chronic pain may have influenced the development of themes, where themes may be skewed towards the researcher's preconceptions, rather than from the pain sufferer's own accounts.

To counteract these issues the researcher was required to disclose her intentions for research, this included disclosing her background as a practising therapist during the recruitment phase. The act of sharing information was suggested by Smith (2004) to reduce the imbalanced relationship between the researcher and participants. The researcher was also required to engage in a process of self-reflection throughout the research process by keeping a diary of accounts and thoughts post interview. Through the process of reflective practice, the researcher will be able to maintain an awareness of her own orientation to research, and how her own experiences and interests could influence data analysis (Smith, 2004, 2007). The researcher's ability to examine her own feelings and thoughts enabled her to be critical of her own thoughts and to stay true to each individual's pain experience.

By aligning itself to the fundamentals of hermeneutics, IPA also recognises the limitations of an interpretative approach to research and calls for an empathetic researcher. To gain richness in data collection Smith, and Eatough (2012) suggest that researchers need to be empathetic in order to get close to the personal experiences. To be an empathetic researcher, the researcher is required to listen and walk alongside the participant. The act of doing this will allow the researcher to get as close as possible to experiencing these private experiences from the pain sufferer's perspective.

The empathetic researcher is also required to remain critical throughout the research process. Smith, and Eatough (2012) believe that the ability to be critical is imperative to the validity of IPA, as it will allow the researcher to distance themselves from the individual's private experiences when required. The ability to distance themselves from the personal experiences of others is important, as it allows the researcher to reflect back on their own thoughts and beliefs, and to make distinctions between their own preconceptions from that of the individual's personal experiences. By undertaking this process, the aim is to remain truthful to the pain sufferer's own experiences.

The approach of IPA draws from the fundamental assumptions of hermeneutics and uses semi-structured interviews to collect data. The open face-to-face approach of semi-structured interviews will enable the researcher an opportunity to be both empathetic and critical at the same time. The interviews were conducted in real time; this allowed the researcher to walk alongside the pain sufferer and experiencing that particular personal experience at the same time. The semi-structured interview process also allows the researcher to be critical as it uses open-ended questions and allowed the individual an opportunity to tell their story. According to Smith, and Eatough (2012), having open-ended questions will enable the researcher to be critical and address any burning issues that may have surfaced through these interviews.

The third fundamental assumption of IPA is its commitment to the idiographic approach, where the focus of research is on having a small sample size. Focusing on a small sample size allows the researcher to perform a detailed examination of each individual's account of his or her personal experiences (Eatough, & Smith, 2017; Smith, & Eatough, 2012). Chronic pain is considered to be a personal experience and Smith, and Osborn (2007) refers to the experience of chronic pain as being individualistic. It is a condition that revolves around the individual, and it is the individual who is trying to make sense of these experiences within their life. To understand this phenomenon and what it is like to live with chronic pain, one needs to understand it from the perspective of the individual living with it.

To fully appreciate the individualistic nature of chronic pain, a qualitative approach like IPA is required (Smith, & Osborn, 2015; Snelgrove, 2016). IPA provides an opportunity for the researcher to understand the lived experiences of chronic pain,

and appreciate the feelings, emotions and personal experiences from the perspective of individuals living with pain. According to Vlaeyen et al. (2016), an understanding of each individual's suffering will enhance our understanding of chronic pain, and assist with the development of individualised treatment options.

The approach of IPA does have limitations. Firstly, the aim of IPA is not to make laws, in particular Clarke, and Iphofen (2007) suggest the main commitment of IPA is towards understanding individual's accounts of living with a certain phenomenon. However, Vlaeyen et al. (2016) felt that by understanding the experiences at an individual level, it is hoped that this understanding could then provide a greater understanding of the condition as a whole. Smith, and Eatough (2012) acknowledge this and suggest a good IPA study has two aspects. In one aspect, it allows entry into the narratives of the pain sufferer's personal world, whilst at the same time offering an opportunity to learn about possible generic themes pertaining to the chronic pain population group.

Secondly, the validity of IPA has been criticised, in particular the generation of results has been criticised as just mere descriptions (Smith, 2011). IPA acknowledges these limitations and highlights the non-bias free approach of research and that the generation of knowledge from a third person's narrative can never be complete (Smith, 2011; Smith, & Osborn, 2015). By accounting for these limitations, IPA requires a reflective and open approach to research. The researcher is required to partake in reflective process by keeping a diary throughout the whole research process, and acknowledge that any interpretative process can never be fully achieved.

The selection of IPA is appropriate to study a condition such as chronic pain, as chronic pain is a condition that is individualistic in nature. The use of IPA can also offer a safe forum for the older adult to talk about their experiences of living with chronic pain, whilst attempting to make sense of these experiences. Through an in-depth exploration of individual experiences, it is hoped that knowledge generated will help to understand the pertinent issues that are relevant to older adults living with chronic pain (Makris et al., 2014; Makris et al., 2015).

Classification of pain

For the purpose of this study, the generic definition of chronic pain is used. There are limitations with using a generic definition as it tends to group together all different types of musculoskeletal pain conditions like back pain, fibromyalgia and neuropathic pain. This makes it difficult to distinguish between each condition and make comparisons between studies. To address the limitations of pain classifications, a task force was set up by the IASP (Treede et al., 2015). The group suggest using a multi-layered parenting classification model that considers chronic pain to be a primary parent with seven groups of different pain groups underneath. This classification system recognises musculoskeletal pain conditions and neuropathic pain conditions as distinct groups of pain conditions, and created a new diagnostic entity of chronic primary pain. The chronic primary pain category is designed to capture pain conditions like widespread pain, fibromyalgia and back pain, which can often be grouped together and hard to classify (Treede et al., 2015).

The new classification system of primary pain condition will be advantageous to assist with capturing the epidemiology of different chronic pain conditions, such as related health costs and development of interventions specific to that pain condition. However, clinically the task required to tease out the complexities between different chronic pain conditions and placing everyone into the right group remains overwhelming.

Grouping individuals into different pain conditions remains to be a difficult feat. The definition of chronic pain is essentially defined as having biological, physical and emotional elements (IASP, 2018). The expression of pain behaviours is determined not only by the biological, but also the psychological, social, contextual and historical events (Fordyce et al., 1968; Melzack, & Wall, 1956). Morris (1991) reports the factors that make up the personal experiences of pain are inseparable, so the task of trying to separate all these factors will become a daunting one.

At present, there is a lack of reference in research for the new classification category of chronic primary pain. Therefore, for the purpose of this study the generic definition of chronic musculoskeletal pain has been chosen, which defines pain that affects the bones, joints, tendons, muscles or soft tissues (Treede et al., 2015) that

have persisted for longer than 3-6 months, and impacts on the individual's wellbeing and ability to function in their daily activities (IASP, 2018; Walsh et al., 2008).

Chapter three: Method

The current study is part of a longitudinal study Talking about Health 2016-2018, the Talking about Health study was conducted by the Central Primary Health Organisation (CPHO) and MidCentral District Health Board to understand how long term conditions are managed at home. Participants living with long-term conditions were recruited from their general practitioner's (GP) practices, and were asked to undertake a comprehensive health assessment (CHA). The information collected from the CHA was then provided to the CPHO, and invitation letters and consent forms were sent out to potential participants to participate in the Talking about Health study. All consent forms were then sent back to a member from the Talking about Health Team, who then sent out questionnaires once consent was obtained.

The Talking about Health study required all participants to be 18 and above with at least one long-term condition. These include conditions such as diabetes, angina and heart failure, respiratory, chronic kidney disease and renal failure. A total of 2730 potential participants were recruited, and 397 of the participants identified themselves to be aged 65 and above. Participants were required to complete an annual questionnaire for a three-year period. Ethics approval for the Talking about Health study was obtained from Northern A Health and Disability Ethics Committee.

Prior to consultations with the Talking about Health Team, the researcher for this current study undertook cultural guidance to assist with any cultural issues that may occur from the research process. After consultation with the cultural advisor was completed, initial consultations with a member from the Talking about Health study was undertaken. After ongoing consultations with the Talking about Health Team, an outline of the current study and development of information package was achieved. This information package included information sheets outlining the purpose of the study (Appendix 1), participants consent form to be contacted (Appendix 2), and a letter introducing the researcher from the Talking about Health Team (Appendix 3).

Once all the information sheets and forms were completed, a member from the Talking about Health team sent a list of 75 eligible participants to the researcher. This list of potential participants formed the sample group for the current study. The participants identified themselves as older adults aged 65 and above, who considered pain as their main problem and consented to be interviewed about their long-term

condition. The list of participants was encrypted with all identifiable personal data removed, and each participant was assigned a number for ease of selection by the researcher. The age of participants ranged from age 68-93 years old, and included both female and male participants.

The researcher of the current study reviewed the list of potential participants and selection of participants was based on the following criteria; adults aged 65 and above, community dwellers and had been living with chronic musculoskeletal pain for at least 1 year or greater. Participants who were post-surgical of greater than 1 year were also eligible for the study. Exclusion criteria were, chronic pain due to cancer, progressive diseases and illness, unstable fractures, or if they were still awaiting further investigations for their pain. Participants that may have been treated by the researcher were also excluded from the study, due to patient-provider relationships.

Participants

On the first round of recruitment, 30 participants (10 male and 20 female) were selected by the researcher to be contacted. All participants identified themselves as European and considered pain to be their primary condition. Participants were excluded if they were prediabetic, living with diabetes, cancer, identified as having mental health psychological disorders, alcoholism, hearing loss and memory problems. After selecting 30 participants, this information was relayed back to a member from the Talking about Health Team, who then sent the recruitment information package to the selected participants on behalf of the researcher. This information package included information sheets, participants consent form to be contacted and an introductory letter on the researcher.

A total of 15 potential participants responded from the first round of recruitment and agreed to be contacted by the researcher. Initial contact was made with all 15 respondents by the researcher, during this initial contact, 13 respondents agreed to be interviewed and voice recorded, while two of the respondents decided not to proceed further and opted out of the study. One participant was still awaiting further investigation for their pain, and the other participant reported they were getting better and declined to continue with the study.

During the second round of recruitment a further 17 potential participants were selected from the original list of 75 potential participants. During this round of recruitment, participants who were prediabetic, or living with diabetes were included. Participants with cancer, alcoholism, memory problems, depression and anxiety were excluded. After selection of the 17 participants was complete, this information was relayed back to the Talking about Health team member, who then sent out the recruitment information package to the 17 participants on behalf of the researcher.

Nine potential participants responded to the second round of recruitment, the researcher made contact with the first seven respondents, this was based on the order in which the responses were received. All seven respondents from the second round of recruitment agreed to be interviewed and voice recorded. The study had a total of 20 participants who provided verbal consent to be interviewed and voice recorded.

Procedures

An information package was sent out to eligible participants, this included an initial letter introducing the researcher, information sheets outlining the purpose of the study and a participant's contact form with a pre-paid envelop attached. Participants who were interested in participating were invited to either phone the researcher on the number provided, or to return the participant's contact form in the pre-paid envelope to the researcher. The researcher then got in touch with potential participants to discuss further.

During the initial phone call with potential participants who agreed to be contacted, the researcher disclosed her interest in the study, her background as a current practicing physiotherapist and interests in chronic pain. The aim and process of the study was also explained to potential participants, along with inclusion and exclusion criteria. Participants were then given time to ask questions pertaining to the research.

Initial verbal consent to participate in this study was obtained during the initial phone call, and a suitable time and meeting location was determined. Interviews were conducted at participant's homes where they felt most comfortable. However, when this was not available, participants were offered an option to meet at the Massey University Campus Psychology Department.

At the first face-to-face meeting and prior to commencing the interview, the researcher went over the aim of the study again with the participant, and reassured all participants that they were allowed to stop the interview at any stage and were not obligated to continue. Participants were encouraged to speak as freely as possible and not to pay too much concern on their use of correct language and grammar. Written consent (Appendix 4) was then obtained from each participant before proceeding to audio recording of the interview. Before starting the interview process, all participants were reassured about confidentiality and that all information gathered would remain anonymous. Participants were given the opportunity to assign a pseudonym of their choice to their interview. All the names provided for the interviews are pseudonyms that the participants have chosen for themselves.

This study used a semi-structured interview approach to collect data. This allowed the information gathering process to be guided, yet remained individualised to the participant. The researcher was guided by a schedule of questions during the interview (Appendix 5). Even though it was guided, participants were also encouraged to talk as freely as possible about their experiences of living with chronic pain, and any individualised concerns were further explored as they presented.

During the interview process, the researcher actively participated in the process of reflective thinking by keeping a diary post interviews. This process of reflection allowed the researcher to consider and write down any pre-existing ideas, experiences, thoughts and feelings post interview. By undertaking this process, the researcher was able to distance her views from that of the participants, and consider herself as an observer who was trying to understand the experience of chronic pain from the perspectives of an older adult, who were also trying to make sense of their own experiences at the same time.

Analysis of the data

The researcher transcribed all interviews verbatim, and all completed transcripts were then returned to each participant to review and make adjustments. Changes to the transcripts were sent back to the researcher in a pre-paid envelope. Out of the 18 transcripts, 16 had corrections to be made. The majority of these changes were related to the use of grammar. One transcript had the majority of the transcript changed with

large deletions of text. Despite the large deletions of text, the researcher felt that the participant's accounts of her experience of living with pain could still contribute to the richness of the study, and was included in data analysis. The changes to the transcripts were amended and participants were provided with the option for this new amended copy of the transcript to be sent back, should they wish to keep a copy. Written consent was gained from all participants for the release of transcripts (Appendix 6).

Two participants dropped out of the study, sadly one participant had passed away by the time her transcript was sent back, and no consent was obtained for the release of transcript. Despite follow up phone calls, the second participant declined to consent for release of transcript and return of transcript. A total of 18 transcripts were analysed for this study. The age of the participants involved in this study ranged from 68-93 years, with a mean age of 77. The duration of living with pain in years, ranged from 2 – 56 years with a mean duration of 26 years. For the majority of the participants, the onset of pain started before the age of 65, and 14 out of the 18 participants in the study, reported the onset of pain to be between 18-60 years old.

Analysis of the data closely followed the four-stage process as outlined by Smith, and Eatough (2007) and Storey (2007). Initially, the researcher carefully read through each transcript, making notes in the left margin about what the participant was saying in their story. The themes were then formulated in the right margin after the second reading of the transcript, and on the third reading, clustering of themes was made. Then a final reading of the transcript was done and superordinate themes were formed. Throughout this process, the researcher actively referred to the reflective diary entries. This process was repeated for each participant, reading and re-reading of the text and analysing it along with reflective notes previously made.

Introduction of participants

Participant One: Cecil

Cecil is a 93-year-old male, who had been living with knee pain for two years since falling and injuring his knee. Cecil had his knee x-rayed and reported that because of his age he was told by his GP that he was not a suitable surgical candidate. Cecil was a fiercely independent individual, and since his knee pain he had noticed that his mobility and function was hugely impacted on, to a point where his movements and outings were carefully planned and monitored to accommodate his knee pain.

Participant Two: Fred

Fred is a 79-year-old male, who had been living with pain for 10-12 years. Fred's situation is complicated, as he also has a history of Parkinson's Disease (PD). For Fred, in the presence of an incurable disease, his musculoskeletal pain did not appear to be as threatening. But its complexities are multiplied, as Fred experienced pain from both conditions, the normal aches and pains and also the secondary pain from his PD. Often symptoms arising from both conditions could be interwoven and could be hard for Fred to distinguish the different aspects of various pains.

Participant Three: Alan

Alan is a 70-year-old male, who had been living with his back pain for 10 years. Alan recalled first being aware of his back pain when he started working on a farm. He had an x-ray of his back, and was told by his GP that he had general degeneration of his back and that this was due to aging, which Alan simply accepted.

Participant Four: Jenny

Jenny is a 76-year-old female, who had been living with ongoing back pain for 56 years. Jenny reported of having a weak spine and that her back "literally collapsed". In the absence of any traumatic event and lack of a conclusive explanation to account for Jenny's ongoing pain, Jenny was left to endure the suffering of her pain and felt a constant need to prove the legitimacy of her pain to everyone. Despite having had four failed back surgeries and various treatment interventions to get rid of the pain, Jenny continues to be in pain. Jenny is trying to live and manage her pain to the best of her ability.

Participant Five: Nan

Nan is a 74-year-old female, who had been living with neck and back pain for 8 years. Nan indicated that there was no specific cause for her pain, initially Nan did not have a diagnosis for her pain and felt that she had to prove the legitimacy of her pain to her doctor. At the end, Nan reported that she was given a diagnosis of arthritis for her pain. Nan felt this diagnosis was meaningless, as she did not understand the medical jargon associated with her diagnosis and remained unclear on the management of her pain.

Participant Six: Chooky

Chooky is a 70-year-old female, who had been living with back pain for 50 plus years. She also had a history of fibromyalgia and life threatening lung conditions. Chooky referred to her lungs as a "petrified forest" and she reported that she had been given a "life sentence" with her lung conditions. Given her failing health, the threat of her musculoskeletal pain complaints was not as imminent and these complaints were superseded by her lung conditions.

Participant Seven: Betsy

Betsy is an 83-year-old female, who had been living with back pain for 55 years. Betsy reported that there was no actual traumatic event to cause her pain, and attributed her pain to physical activities. Betsy painted a bleak future of herself living with pain, as she did not believe that she would ever be without pain, and the only way for her to be without pain was to die.

Participant Eight: Irene

Irene is a 68-year-old female, who had been living with lower back and neck pain for 39 years. Irene sustained neck and back fractures after falling from a flight of stairs. Initially these fractures were undiagnosed and Irene was told to go home and self-manage. After a period of trying to self-manage, she was seen by the doctors at the hospital and was told that her back had "jack knifed". It wasn't until 10 years later that she was told by an orthopaedic surgeon that her lower back was inoperable and she would have to continue to live with it.

Participant Nine: Petronella

Petronella is an 84-year-old female, who had been living with back pain for 30 plus years. Petronella was unable to recall an incident that caused her pain, and attributed her back pain to be related to the physical work of farming. Petronella held a strong view that pain was part of living, and that the experience of pain was a reflection of how she had used her body throughout life.

Participant Ten: Elizabeth

Elizabeth is a 70-year-old female with a history of knee pain for 20 plus years. Elizabeth was unable to recall a particular incident that caused her knee pain, but attributed the onset of her pain to be related to her physical job and a belief that aging had worsened this pain.

Participant Eleven: Frances

Frances is a 74-year-old female, who had been living with right hip pain for 27 years. Despite having the hip operated on, Frances continued to live in post-operative hip pain. With her failing health, Frances began to notice the impact of her pain on her mobility more than ever.

Participant Twelve: Gordon

Gordon is an 83-year-old male with a history of back pain for 30 years. His back pain was a result of the physical work he had done as a farmer. Gordon was referred to an orthopaedic surgeon and was informed that there was only 50% chance that his back could be cured, or he could end up in a wheelchair. Based on the orthopaedic surgeon's recommendations, Gordon decided to give up farming and is currently managing his pain.

Participant Thirteen: Grace

Grace is a 75-year-old female with a history of back pain for 25 years. Grace felt that her back pain was related to her occupation, and described the constant nature of her pain as like an unwanted visitor that was just lurking in the background and waiting for any opportunity to present itself.

Participant Fourteen: Mary

Mary is a 70-year-old female, who had been living with neck and lower back pain for 58 years. Mary cared for her husband who was wheelchair bound for any years, and assumed that the physical work of lifting and caring for her husband had caused

her neck and lower back pain. In the absence of a diagnosis for her lower back pain, Mary was left with a sense of helplessness and struggled to manage her pain on a daily basis.

Participant Fifteen: Anne

Anne is a 76-year-old female who had been living with Rheumatoid arthritis (RA) for 16 years. Anne was able to privately fund her specialist appointments; this ensured a speedy and efficient diagnosis for Anne's pain. Receiving a speedy diagnosis meant that Anne's pain was managed and under control quickly.

Participant Sixteen: Bill

Bill is a 79-year-old male, Bill hurt his lower back when he was 18 and was told he had a "soft spine" by an orthopaedic surgeon and surgery was offered. Bill's mother declined the surgery and since then Bill had been managing his back pain for 61 years. Bill also suffered from shoulder and arm pain since having a stroke. In Bill's situation, the role of diagnosis was extremely important to his ability to live with his pain. Bill considered his back pain to be non-problematic, as he felt that he had a diagnosis and knew what is causing his back pain. However, Bill was finding it hard to manage his shoulder and arm pain, as he felt that he had not received a diagnosis or an explanation from the doctors or specialist.

Participant Seventeen: Olive

Olive is a 78-year-old female and had been living with LBP for 18 years. Olive was unable to recall what caused her initial LBP, but an MRI scan indicated she ruptured a disc and had it operated on. Despite her back operation, Olive continued to experience ongoing pain and was required to live with it on a daily basis.

Participant Eighteen: David

David is a 78-year-old male who had been living with his LBP for 5-6 years. David attributed the cause of his LBP to be related to the physical work he did as a builder. David reported that he had not received a diagnosis for his back, but did recall being told that his pain was due to arthritis. David reported that his doctor has told him that his pain was related to aging, and is now reluctant to seek further medical advice for his pain due to fear of being told his pain is a part of aging.

Chapter Four: Results

Through analysing each participant's account of their lived experience with pain, four themes were identified and labelled as: 1) different aspects to the experience of pain, 2) acceptance, 3) begrudged acceptance and 4) learning to live with pain.

Theme one: Different aspects to the experience of pain

Participants' talked about the contrasting aspects of pain. In one aspect participants described the vivid and realness of their experiences, yet in another aspect this experience remained invisible. Firstly, participants referred to the realness of their pain experiences when they spoke about the unrelenting and competitive nature of pain and the toll it had on their mood, physical and functional abilities. The presence of pain demanded the participant's attention and it was this competitive nature of pain that could impact on the participant's ability to perform their daily functional activities. Secondly, the realness of the pain was contrasted by the invisibility of pain. This presented a unique challenge for the participant, as the participant was required to constantly prove the legitimacy of their pain symptoms.

i) The realness of pain - unrelenting nature of pain

Participants' referred to the realness of pain as they described the unrelenting nature of pain and that they were never without the pain. In Grace's situation, she described her pain as *"always there, just lurking",* referring to the pain to be like an unwanted stranger, who was never too far away and waiting for an opportunity to present itself again. Frances also spoke about the unrelenting nature of her pain and that she was never without it. For example, Frances said, *"I'm in continual pain, I can't get rid of it ... its niggly, its niggling all the time ... it's just there".*

Mood effects

The unrelenting nature of chronic pain had an all-encompassing impact and participants described the negative impacts of pain on their mood, physical and functional states. Participants' described the toll pain had on their mood as they spoke of feeling angry, grumpy and frustrated with their pain. In Bill and Petronella's

interviews, they talked about the inability to escape from their suffering, and as a result this could cause them to be bad tempered and not pleasant to be around.

> *Bill: "It's going to be there ... there is no relief for it. Makes you feel bad tempered ... exacerbated because it is hurting".*
>
> *Petronella: "You ask my daughter or somebody and they will tell you when the pain is bad because I'm so bad tempered, really bad tempered".*

Irene also talked about the unrelenting nature of her pain and the emotional toll this had on her. Irene talked about getting angry at the pain as she was unable to escape these unpleasant experiences for days, and the pain continued regardless of her attempts to abolish the pain. At the end, Irene accepted that the sufferings she had to endure were all part of living in constant pain.

> *Irene: "I get angry because in the end it could be going on for three or four days … the heat is not helping me either and I just can't settle … I think that is part of living with constant pain all the time".*

These negative emotional states could also impact on the participant's ability to relate to others, especially people who were the closest to them. In Irene's interview, she spoke about the mood effects of pain, and these negative experiences were described as having an impact on Irene's ability to interact with others close to her. For example, Irene said,

> *Irene: "Being in constant pain all the time takes its toll on family because you end up being grumpy … I still get grumpy now … takes its toll on your mental stability … I get frustrated, really frustrated, but I really obviously know how other people feel that live in constant pain".*

The competitive nature of pain – physical and functional restrictions

The competitive nature of pain demands the participant's full attention. Participants' talked about the competitive nature of pain when they referred to the physical and functional restrictions that were placed on them by pain. Where physical movements and activities would become closely monitored and re-analysed to reduce

the fear of aggravating the pain. This constant monitoring of pain symptoms now became the new normal, and movements that were once carried out without any thought or preparation were now carefully planned and executed. For example, Cecil spoke of the difficulties he faced with simple physical activities, such as heading out of his house. For Cecil, this task became carefully analysed and planned around his pain.

> *Cecil: "... Some mornings to walk out to the taxi I have to go out the back door, and stepping down those steps is real agony, I never use the front steps unless there is someone there with me, because the back door I've got a rail ... I can lower one leg down, usually put my sore leg down first and then the other one, I do each step separately to get down".*

The competitive nature of pain also had a significant impact on the individual's physical function. For example, Betsy talked about her physical limitations since the onset of her pain, where the presence of pain could stop her from carrying out the most fundamental tasks in life, like her ability to stand or walk. The significant impact pain had on Betsy's mobility was highlighted, as she described her struggles to walk 20 steps without pain.

> *Betsy: "I'm never without pain, not without pain any day ... I suffer pain every day ... I mean I get up now and I won't be able to walk easily, I keep sticks handy ... I can't get up".*
>
> *"I count the steps, there are twenty steps and I would say only five of them are free, the rest are painful".*

Alan also talked about the physical restrictions of his pain, and how he was becoming more careful and selective with the activities that he chose to do. The tasks that Alan chose to perform would be carried out in a slow and meticulous manner to avoid aggravating his pain. This process of monitoring became more automatic and Alan considered this process of monitoring was fast becoming the new normal for him as he said,

> *Alan: "I have deliberately done it for so long it has become instinctive, I won't rush, I'm quite careful where I put my left foot … I'm deliberately or almost instinctively now as to what is that going*

to involve, now I avoid doing things that I know are going to be difficult or potentially painful for me".

"I watch where I put my feet ... don't walk as fast ... I take my time getting down and standing up … What I'll do is I'll put it this way when I do this ... get down on the floor and do it or then get up ... I'm strategically planning what I do ... that is normal for me".

Frances referred to the competitive nature of her pain as she considered living with pain as a battle that she was slowly losing. When describing her experiences, Frances often used the term defeatist to describe the struggles of living with pain. Frances spoke about the physical restrictions that she experienced and that her ability to carry out functional tasks were determined by her pain. When the pain is not so severe Frances has grand plans of getting with her day to day activities, however reality hits when she starts moving, the pain starts to dominate and her mobility is restricted again. For example, Frances said,

Frances: "I don't go too far ahead, I think I better just get through each day. I often lie in bed in the morning and plan, think what I'm going to do for that day … because I'm lying there and I'm not so sore, I'm going to do this and that and when I get out of bed and put my feet on the ground everything changes. I think I can't do that today, I can't push the wheelbarrow anymore, I don't think I will do it, I suppose that's the defeat, defeatist attitude … It's getting the better of me, I'm letting it get the better of me and it is beating me".

ii) The invisible aspect of pain

The contrasting aspect to the realness of pain is its invisibility. The invisible nature of pain can often lead participants to become fearful of being judged and the ongoing need to prove the legitimacy of their pain. In Jenny's account, she talked about the invisibility of her pain and because there was no visible evidence to confirm her pain symptoms, Jenny was reluctant to open up about her pain experiences for fear of being misunderstood by her friends.

Jenny: "I don't talk about it ... it's a very hard thing to explain ... because outwardly you don't show anything, it's all inside".

"... it can't be seen, it's not understood, it makes me loathe to try and say to someone about it and I can't do this today ... they will be scratching their head and think well she looks alright".

Participants' felt the fear of being misunderstood or judged by others who were not in pain was a big part of living in constant pain. For Elizabeth, the most difficult thing for her was the lack of understanding and acceptance that she received from others who were not in pain. Elizabeth felt that she was unable to make firm commitments to her engagements, and due to the invisibility of her pain, Elizabeth's inability to commit drew criticisms from her peers regarding the legitimacy of her pain, as outwardly Elizabeth appeared to be physically able.

Elizabeth: "When people look at me they think there is nothing the matter with her".

"I think other people are worse about it than I am, they just find it hard to accept ... that I can't stand for a long length of time, and I think people find that hard to accept".

Frances spoke about feeling embarrassed with her pain and would try to hide it by retracting further into the invisibility of her pain. Frances achieved this as she attempted to hide her pain symptoms in different ways. Firstly, Frances achieved this by rarely disclosing her condition to her friends and secondly, Frances would restrict her public outings due to the fear of being seen with all of her mobility equipment. For example, Frances said,

Frances: "I don't sort of really talk about my problems ... I probably don't tell people the whole truth ... because I don't like going on about it ... so just sort of brush it off".

"I felt embarrassed, I didn't want to go to town, I didn't want to be seen with the equipment".

The experiences of chronic pain are complex, not only is it a personal experience, but different aspects of this experience can co-exist and become conflicting for the individual. Participants' described the realness of the experiences, as they described the unrelenting and competitiveness nature of pain, which can disrupt and encroach

on all aspects of the participant's life. In another aspect, the realness of these experiences was placed under scrutiny due to the invisible nature of the pain. Participants' living with chronic pain was required to live and cope with the contrasting aspects of pain and a life that was full of interruptions.

Theme Two: Acceptance

Participants' were accepting of their pain, and the theme acceptance was a strong common theme that participants' spoke about in their interviews. Participants' also talked about different approaches that helped to achieve this process. The first approach that participants talked about was the belief that pain was part of living and descriptions of adopting a mechanistic view to the onset of pain. The second approach that facilitated acceptance was receiving recognition from medical professionals regarding the cause of their pain. The third approach that participants described was the reduction in the threat of pain to facilitate the process of acceptance. The fourth approach that some participants described, as being helpful in facilitating the process of acceptance was the role of diagnosis.

i) Pain is part of living

Participants' expressed a belief that pain was part of living, and that pain was part of what you had done in life and the genes that you had inherited. They described how these factors could all contribute to the onset and experience of pain. For example, Bill strongly believed that pain and aging are tightly interwoven and considered the relationship between pain and aging was a part of living.

> *Bill: "It's a trite statement, it is a fact saying pain is part of aging, it is like saying the moon is white or the sky is blue, it's a fact ... As you get older you are going to get those sort of things".*
>
> *"It is part of living ... it's just that sheer physical things are going to go wrong ... that is a fact of life ... there is no use in worrying about it, it's a fact".*

In another example, Petronella made references to the inevitability of her pain and considered the onset of her pain as a matter of when would it occur rather than if it would occur. Petronella made this point during her interview, as she suggested the unavoidable nature of pain would be something that the researcher would experience. For example, Petronella said, *"I've got a lot of aches and pains, got arthritis and all sorts of things … It is what you will have, it's what is going to come to you".*

Petronella provided further support to the idea that pain was a part of living, as she strongly believed that her body was made to be used and she did. To make sense

of this Petronella was able to recall on all the physical work and sporting activities that she once subjected her body to, and believed that as a result of all the physical activities, it was only natural to expect a degree of pain as you grow.

> *Petronella: "Our bodies were made to be used and I used mine in all sorts of silly ways and did all sorts of silly things, I mean I did a lot of sports ... cross country and mountain climbing".*

In the larger scheme of life, the experience of pain was considered to be a consequence of living. In her talk, Petronella considered the experience of pain to be a necessary aspect of life, an experience that happens in life and like any other life adversities, it has a role in making you into the person that you are today. For example, Petronella said *"It's what you are, it's who you are, that's what happens to you as you grow, that's why you develop, you won't be who you are if you didn't have whatever you have".*

Adapting a mechanistic view

Participants' who believed pain was a part of living often described a physical cause to the onset of their pain. This mechanistic view to understanding the cause of their pain was another mechanism that participants referred to when they talked about their acceptance of pain. When referring to a possible cause for the onset of pain, participants often described a physical component as a cause of their pain. The following participants, Betsy, Elizabeth and Gordon all expressed that the cause of their pain was related to the hard physical work that they once did. As a result of all the lifting and physical stress on their body, this had subsequently led to the development of their pain.

> *Betsy: "Many, many acres of gorse and natural brush and it needed clearing ... so I used to work on the hill and I believed that was the start of my pain".*
>
> *Elizabeth: "My lower back, I blame the work I did because I was a care assistant ... you had to lift people and didn't have hoist".*
>
> *Gordon: "Just work, working too hard, the lifting, lifting what I shouldn't be lifting ... you know just wore out and being in sharing all the time, it was quite hard on the back".*

In the absence of an explanation to explain the cause of ongoing pain, the adoption of a mechanistic view to the onset of pain appeared to be the most logical. In Grace's interview, she was unable to think of a single incident that led to the development of her back pain, and attributed the cause of her back pain to the repeated poor postures and positions that she had to adapt to as a teacher.

> *Grace: "I never ever had an injury ... I was a teacher, I believe that was a big part of my ongoing pain, it was that the desk levels were too low, so I spent half my life bending and at the wrong level".*

For Mary, the only cause that she could attribute to the onset of her lower back pain, was from the physical demands of caring for her husband who was wheelchair bound. The heavy manual work of lifting her husband on her own, without any training or assistive equipment had led Mary to injuring her back and hence her ongoing pain.

> *Mary: "Looked after my husband ... sprained my back ... I had to do heavy lifting and help him and everything on my own ...without any training … I had a pretty strenuous life so you can understand why I get pain".*

ii) Confirmed by the medical dialogue

Confirmation by medical professionals that pain was a part of aging was another aspect that facilitated acceptance amongst some of the participants'. Participants' described seeking medical assistance for their pain and were often told by their doctors that their pain was due to arthritis or a result of aging. In Alan's case, he recalled being told by his doctor that his back pain was related to aging and this explanation was further confirmed by medical imaging. As a result, Alan simply accepted his pain as something that occurred with aging.

> *Alan: "I had this problem and they sent me for an x-ray ... said to me, its um general degeneration because you are getting old and I sort of accepted that".*

The influence of the medical narratives had also led Olive to come to accept the conclusion that her pain was a part of aging. Olive expressed her preconceptions of pain and described arthritic pain as common changes that occur among the elderly. Olive's preconceptions of pain were confirmed by her GP and medical investigations.

This led Olive to accept her pain as an arthritic condition that commonly occurred in the elderly. For example, Olive said *"Arthritis is something that older people get ... I think probably the GP has said, it has shown up on some of the x-rays".*

For Chooky, receiving confirmation from her doctor that her pain was due to osteoarthritis or degenerative changes enabled her to accept her pain. The realisation that her pain was never going to go away led Chooky to accept the pain as a part of her.

> *Chooky: "They just class it as ... osteoarthritis its well part of it, and degenerative yes degenerative discs … the doctors will say to you, never going to get rid of it … you just accept it, it is now part of you anyway".*

Medical professionals also frequently acknowledged confirmation that the onset of participant's pain had a mechanical cause. For some participants', being told that the onset of pain was associated with previous physical work helped to reaffirm participant's existing views that their pain had a mechanical cause. In Elizabeth's account of her acceptance process, she recalled being told by her doctor that her back pain was due to the physical work she once did as a health care assistance. This explanation provided by the doctor was able to confirm Elizabeth's preconceptions of her pain, and helped to consolidate her belief that her pain had a physical cause.

> *Elizabeth: "I've mentioned to my GP ... and he said "oh it would be work related" … My lower back pain I blame the work I did because I was a care assistance … you had to lift people, you didn't have hoist … don't forget I was pumping beds up and down you didn't have electric beds".*

Participants who received confirmation that their pain was due to aging or arthritis, was also told by their doctor that there was very little that could be done for the pain. For some participants', being told that nothing could be done for their pain represented a turning point in the management of their pain and the need to accept their situation. For example, in Bill's interview, he talked about receiving confirmation that his pain was related to arthritis and aging. Being told by his doctor that the bone structures were all worn out and that there was nothing medically that could rectify

this. Bill was left with no other choice but to accept his pain and considered his pain as a fact of living.

> *Bill: "I've got arthritis in my hands, you know its age ... he told me there wasn't really stuff all you can do about it, you've got it, and if you are lucky enough you get out of it, and if you're unlucky you have to live with it, in pain for the whole of your life".*
>
> *"I went to my doctor and my neck was hurting ... they did the x-ray and the doctor said "they are worn broken and chipped", the bone people won't do anything about it, because there is nothing they can do, it's just worn out that's the fact".*

The participant's ability to accept the dominant medical narratives was assisted by a strong sense of trust that some participants had in their doctors. Some participants expressed a strong sense of trust in their doctors and viewed them as experts in their care. These participants expressed a strong sense of trust as they referred to the notion that when you seek advice from a specialist or doctor, you should listen to the advice that is given and accept it. In Cecil's accounts of his trust in his doctor, Cecil described his trust as something that was innate to him and that there was a dependency on medical professionals to make decisions on his behalf.

> *Cecil: "I've always had the feeling ... you rely on what your doctor tells you ... not worth going there if you don't listen to what they tell you".*

In Bill's interview, he talked about having a degree of trust in the advice that was given to him by his specialist. Bill expressed a strong regard for medical professionals and strongly believed they are the experts in his care, and any advice given by a specialist should be listened to rather than contested.

> *Bill: "I've always been a believer ... you don't pay a man and bark as well ... you are asking for his recommendation, you should accept it ... basically they are the experts and you should listen to them and not go off on a tangent".*

iii) Pain is non-threatening

Participant's ability to view pain as non-threatening was another factor that facilitated the process of acceptance. Participants' spoke of different strategies that assisted with a reduction in the threat of their pain. The first strategy that participants' spoke about was being exposed to the signs and symptoms of arthritis, the second strategy that some participants described was to normalise their pain symptoms, and the third strategy that some participants described of using was recognising the chronic nature of their pain.

Some participants referred to witnessing family members going through the struggles of living with arthritis and pain. These participants talked about how their previous exposure to others living with pain had helped to reduce the threats of the aches and pains that they were experiencing. Having prior knowledge of these unpleasant experiences was considered by some participants' to be a protective mechanism to the threats of pain. These participants were able to describe knowing what the aches and pain symptoms meant and what to expect.

Both Elizabeth and Frances talked about their expectations of getting arthritis. Both participants were able to reflect back on seeing their mother go through similar pain symptoms as them. Seeing her mother go through the struggles of living with arthritic pain provided Elizabeth with certain expectations that one day she would develop these painful experiences. For example, Elizabeth said,

> *Elizabeth: "I saw my mother suffer with it, so I'm probably going to do exactly the same ... I accepted the fact that because my mum had had arthritis that I'm sorry but I'm going to have it".*
> *"My mother had it ... perhaps I'm going to follow suit ... I think probably before he (doctor) even did those blood tests, in my own mind I knew what the outcome was".*

Frances also suspected that the cause of her pain was due to arthritis before receiving final confirmation from her doctor. Having prior exposure to the signs and symptoms of arthritis, Frances was not surprised when she was finally given the diagnosis of arthritis for her pain. To a certain degree, Frances had an expectation her pain was due to arthritis.

Frances: "My mother had arthritis really badly ... somewhere in my mind I used to think, I might end up like this".

"I knew I had arthritis, I knew it was coming, so I wasn't surprised to hear that".

In Anne's interview, she described her initial exposure to pain when she saw her sister go through the pain symptoms of RA. This exposure to the signs and symptoms of RA had provided Anne with first-hand experience of what RA was like, and helped Anne to be prepared for her diagnosis.

Anne: "As a family, we knew what it looked like ... those night sweats and the flu like symptoms ... the swollen joints, the extreme pain ... I knew pretty well".

In another way, Grace strongly believed genetics had a role in determining the onset of arthritic pain. In her interview, Grace considered a family history of arthritis was a strong predisposing factor for its onset. In this example, Grace referred to the risk of developing arthritis, and that the risk for its development was higher if you had parents who suffered from it. *"... Your genes you know if you've got an arthritic, both arthritic parents, then you are bound to have that pain yourself".*

The second strategy that participants used to reduce the threat of their pain experiences was normalisation of their pain symptoms. In the interviews, some participants were able to normalise their pain symptoms by considering the commonality of pain symptoms among their peers. In the following examples, participants referred to the commonality of arthritis amongst their peers and seeing their spouse go through similar symptoms had helped to reduce the threat of pain. For example, the threat of pain was reduced for Olive as she considered the prevalence of pain complaints amongst her peers.

Olive: "I understand that a very high proportion of old people have osteoarthritis ... my husband has arthritis ... I suppose that is all part of our lives".

Whilst Bill and Alan both referred to the common occurrence of arthritis, as they also acknowledged the commonality of arthritis amongst their spouse.

Bill: "My wife is riddled with arthritis".

Alan: "My wife gets a bit ... again those are some of the things that old people get ... The bottom line is, lots of people I know have slowed right down with aches and pains, this is it ... I'm sure it's entirely due to aging".

David also shared Alan's reference to pain as related to aging. David expressed his understanding of his pain and considered his pain to be an inevitable part of aging. David achieved this as he described the changes with aging and that pain was to be expected as you aged.

David: "... At my age in life now ... I just accepted the fact that ... your body is going to pack up … pain is something that happens, oh that's why I think it's sort of something that develops with old age".

The third strategy used to reduce the threat of pain by some participants', was recognising the chronic nature of pain. In Grace's accounts, she referred to the chronicity of her pain, and due to the length of time she had to endure the pain she was unable to imagine a life without it. The chronicity of pain had allowed Grace to consider her pain as non-threatening to her mortality, and allowed her to contemplate a lesser sinister cause for her pain. For example, Grace said,

Grace: *"I don't know how different it would be if I didn't have pain, I don't know, just accept it ... oh it can't be too bad it's been there all these years and I'm still around, so whatever it is I just think its muscle, a muscle thing".*

The chronicity of Olive's pain had allowed her to come to the conclusion that her pain was not life threatening. This had enabled Olive to view her musculoskeletal pain complaints as a lesser threat to her mortality, and that she needed to continue with living.

Olive: "I mean it's not going to kill me ... so in the meantime I just carry on each day and do the things that I want to do".

The chronicity of some participant's pain had also enabled them to consider their pain condition as like any other chronic illnesses. Considering chronic musculoskeletal pain complaints to be like any other chronic illness was another protective mechanism that participants alluded to when describing their acceptance of pain. For example,

Alan talked about his pain experience, and due to the length of time that he had endured his pain; he now considered his pain to be a part of him, just like other chronic illness that he had to learn to live with. For example, Alan said,

> *Alan: "I've taken it in as part of me ... in the same way as I've taken it as part of me that I'm short sighted and everywhere I go I have to have glasses ... I have taken it in the fact that ... I take my little box with my CPAP machine ... that I've accepted that, that is a condition of my life, the way I live".*

When talking about his pain, Bill also viewed his pain condition as like any other chronic condition that he needed to learn to live with. For example, Bill realised that there was nothing that could be done to change his pain situation. When faced with this prospect, Bill described that he had no other choice but to accept the pain as like any other chronic illness and move on. For example, Bill said,

> *Bill: "It seems it's not going to go away so why worry about it ... I've got diabetes, there is nothing I can do about it, I have to accept it. I've got kidney problems and I have accepted they are a nuisance ... but I can't change it, so get on and accept it and live your life".*

Irene had also accepted her pain to be like any other chronic illness. In her talks, Irene acknowledged the importance of accepting her pain condition as like any other chronic illness. This appeared to be a coping mechanism that Irene had developed in order to continue living her life.

> *Irene: "Accept it and get on with life ... just accept the same if you've got cancer, something you've got to fight, but is the same with any illness ... you've got to be positive ... I've got pain, I'm going to live with it for the rest of my life, it's just like any disability that you've got to live with".*

iv) Receiving a diagnosis

For some participants', receiving a diagnosis was identified as an important factor in facilitating the process of acceptance. Firstly, participants' felt receiving a diagnosis provided a framework for them to learn and manage their pain. Secondly,

the importance of diagnosis in facilitating acceptance was highlighted in situations when there was an absence of diagnosis to explain the presence of pain.

Firstly, participants expressed the importance of a diagnosis in facilitating their understanding of pain and to regain some control of their pain. Participants' felt that by having a diagnosis they had the ability to recognise their limitations, and how far they were able to push themselves. From Irene's accounts, she felt that receiving a diagnosis gave her some background information on her condition. This information was important as it allowed Irene to learn about her condition, her physical capabilities, and her restrictions.

> *Irene: "When I found out the diagnosis I knew how far I could push myself ... you just got to work it out how you feel, your limitations".*

Participants identified that receiving a diagnosis allowed them to have some control over a condition that was considered to be uncontrollable. Having a diagnosis allowed participants to start understanding what they had and how best to manage it. For example, Jenny felt that a diagnosis gave her some control of her pain situation, as she knew what she had and what could be done to manage it.

> *Jenny: "Yes, I do feel I've got a diagnosis, I know what I've got, I know what it is capable of, I know what to avoid, to bring it on".*

Participants' also expressed that, for a diagnosis to be effective, it needed to be provided in a timely manner. Anne referred to the speed in which she saw her specialist and was given a diagnosis for her pain. The speed of her diagnosis was important in getting her pain under control and on a correct pain management pathway.

> *Anne: "Able to see me ... very quickly he got the whole thing under control ... allowed me to live a pretty normal life".*

Secondly, the importance of a diagnosis was emphasised when there was an absence of an explanation to account for the participant's pain. Participants' expressed the impacts of not receiving a diagnosis, such as being stuck in a state of helplessness and continuously trying to make sense of their pain experience. Without a diagnosis, Mary was left in a continual state of trying to make sense of her pain, and a strong reliance on her doctor to provide her with the answers for her pain. Mary described a

sense of helplessness, as she desperately wanted to know the cause of her pain and approaches to improve her coping strategies. Without an explanation to account for her pain, Mary's only strategy to manage her pain was passive. For example, Mary said,

> *Mary: "I want to know why, I like to know why, and what I can do to try and ease it, what exercises are there, I don't know. I'm doing what's best, lying in bed instead of exercising".*

In the absence of a meaningful diagnosis, the uncertainties of living with chronic pain could be enhanced. For example, in Mary's accounts, she talked about her lack of knowledge about her pain, without knowing what was causing her pain, Mary was left fearing the worst and that one day she may become wheelchair bound.

> *Mary: "I'm scared the pain will get worse ... I don't know what is happening, whether I will end up in a wheelchair or not".*

The role of diagnosis in facilitating acceptance was highlighted in Bill's interview as he attempted to make sense of his pain. Bill suffered from both back and shoulder pain. In his talks, Bill felt that he was able to accept and manage his back pain, as he had an acceptable diagnosis for this. However, Bill felt that he had not received a diagnosis or an explanation for his shoulder pain. Without a diagnosis, Bill had started to question the legitimacy of his shoulder pain, as no one could work out the cause of his shoulder pain. In the absence of a diagnosis, Bill was left wanting verification in the form of an x-ray to support and explain the pain he was experiencing.

> *Bill: "The real disadvantage now is my shoulder … it goes through cycles of quite excruciating pain … nobody can work out why I'm in so much pain … I thought somebody would have done an x-ray to find out, if what I'm saying is so or whether there is damage to my shoulder … I've continually asked, "What is wrong with my shoulder?" … Nobody yet has understood the pain in my shoulder".*

Acceptance was a common thread that participants described through their interviews. The process of acceptance was individualised and participants described different approaches of arriving at this conclusion. The different approaches used to achieve acceptance was reflected on by the different explanations that participants offered in their interviews. Firstly, participants described the process of acceptance

was facilitated by their understanding that pain was a part of living and often associated with a mechanical cause. Secondly, these preconceptions were often readily confirmed by the dominant medical narratives, which contributed to the participant's acceptance of pain. Thirdly, reconfirmation from medical narratives were also described by participants to reduce the threat of pain and assisted with the process of acceptance.

Theme three: Acceptance is begrudged

Participants' referred to their acceptance of pain, however there were also threads of resistance to this acceptance. In their interviews, participants provided different examples to support their begrudged acceptance of pain. Firstly, participants' spoke of their resistance when they considered acceptance as a necessity and felt they had no other choice but to accept. Secondly, resistance towards acceptance was reinforced when participants challenged the common assumption that pain was associated with aging. Thirdly, a begrudged acceptance of pain was demonstrated when participants described a strained relationship with their practitioners. Lastly, the final thread of resistance towards acceptance was evident when participants described the temporal nature of acceptance, and that different aspects of acceptance could occur.

i) No choice but to accept

Acceptance of pain was considered to be begrudged when participants expressed they had no other choice but to accept their pain. Participants' described different approaches that allowed them to arrive at this conclusion. The first approach that led participants to believe they had a lack of choice in acceptance was being told by their doctors or specialist that nothing more could be done for their pain, and they needed to learn to live with the pain. The second approach participants described related to the length of time they had to endure their pain, and due to a lack of improvements, participants arrived at a conclusion that they had no choice but to accept. The third approach that participants used to describe the lack of choice, was when they referred to the alternative option of non-acceptance as impractical.

The first approach that participants' spoke about was being told nothing more could be done for their pain. Participants' described the failings of the medical system and expressed that they had no other choice but to accept their pain. The following examples from Chooky and Irene described their journey of arriving at a begrudged acceptance. Chooky recounted her frustrations with the medical system and expressed her anger towards the lack of available treatment and contemplated all the new medical advances that were happening; yet these advances were not available to her.

Chooky: "... He couldn't help me, because there is nothing, nothing they can do ... well we don't want to play with your discs, your back anymore because ... its shot".

"I started getting a bit angry, because why can't they do something, you can see on TV these wonderful things happening and why not me?'"

Receiving the news that nothing could be done for the pain can often be difficult for participants to accept. In Irene's case, she described of being told by her specialist nothing more could be done for her pain. Despite being a strong person she was unable to shield herself from the disappointment of receiving the news that her back was inoperable. In the absence of a cure and the prospects of having to live with an inoperable back, this took a toll on Irene's mental stability. For example, Irene talked about her hopes being taken away and sending her into a state of depression.

Irene: "Up until the proper diagnosis … I thought there was hope … I still had hope, that there could be a back operation, that they could put a rod to straighten my spine … there was no chance and that's just really devastating because you've got so much hope, and that's just your feet have been kicked out underneath".

"... He just said, "I know you've had your hopes up, because nobody else had said anything" ... "are you able to cope with it?" And I said "well I'm a strong person, yeah, I can cope with it", but it doesn't make it any easier, because you go into, you know semi-depression, you don't want to do anything".

In Betsy's interview, her account of her acceptance of pain was a bleak one. Due to a lack of options for the management of her pain, Betsy considered the only plausible option for her to be pain free was to die. The toll of living with the demands of pain must have a slow deterioration on your future outlook. Despite this bleak view on her future, Betsy still held some glimmer of hope that one day her pain may be taken away. But this hope was getting weaker, as she did not believe anything could be done for her.

Betsy: "I'd like it gone, I don't really believe there's much help I can get ... I've got this pain as long as I live, and the only way I'm without pain is to die".

The second approach that led participants to believe they had no other choice but to accept their pain, was when participants referred to the length of time they had to endure their pain. Having to endure the pain for a great length of time, participants described of naturally arriving at a conclusion that their pain was not going to change. For example, David referred to the time it had taken him to come to the conclusion that his pain was here to stay. At the end, David came to the realisation that his pain was not going to change and that his pain would be with him for the rest of his life.

David: "I've had it for quite a few years … probably 5-6 years … Its really after 2014 I think that I started to think to myself you are stuck with this ... Come to recognise it is not going to go away, this is going to be a part of me for the rest of my life".

In Jenny's case, after receiving four failed back surgeries and finally being told by her spinal surgeon that she would always have problems with her back. The passage of time had enabled Jenny to come to a conclusion that her pain would remain as she describes the unlikelihood of her being pain free. For example, Jenny said,

Jenny: "When I came to the final meeting with the surgeon he said "you are always going to have to give into your back, and I doubt very much you'll be able to work again, as you're going to have problems … I can't see how something that has been with you for over 40 years, is suddenly going to disappear, it can't".

Over time, this acceptance becomes begrudged, as participants expressed the resentments to having to endure their pain. For example, both Petronella and Olive adapted a negative view of their acceptance. Both participants' felt that their ability to live with pain was not a simple matter of accepting the pain, but rather considered pain to be something that needed to be put up with or endured.

Petronella: "It isn't that I accept it, I put up with it ... there is no alternative, right so get on with it".

Olive: "I don't see its enjoying ... I have to endure it".

The third approach that participants mentioned was the belief that the alternative option of non-acceptance was unfeasible. Participants felt the option of non-acceptance was counterproductive and had greater negative impact on their state of mind. In Irene's case, the alternative option of non-acceptance was not an option that Irene would consider. Irene recognised there was more to living than pain, by choosing acceptance Irene was able to continue to live her life, rather than a life that remained suspended or in misery.

> *Irene: "If you don't' accept it, you are going to be miserable ... If people don't accept, accept it, they are just going to be miserable, accept what you've got, you still got a life, you can still live, accept it and get on with your life".*
>
> *"Accept what you've got ... you've got to accept it, otherwise you'll be a bitter person for the rest of your life".*

Fred also described his acceptance as out of necessity. Fred felt that the negative implications of non-acceptance significantly outweighed the negative implications of accepting a life with pain. In an example from Fred, he described the negative consequences of non-acceptance and the impact this could have on his family. A sense of being needed by his family allowed Fred to remain grounded and accepted a life with pain, rather than focusing on the alternative option of not accepting.

> *Fred: "There is nothing much that can be done about it ... acceptance by knowing that there is not much other choice except feel sorry for yourself as that won't solve anything".*
>
> *"You feel life is not worth living ... you have to tell yourself that is not the attitude to take ... your grandchildren need you, your children need you, and your partner needs you".*

Other participants felt non-acceptance was an impractical option, as it could lead to miss opportunities. In Bill's interview, he felt that the alternative option of not accepting his pain would have led to a number of missed opportunities. In the following example, Bill highlighted the importance of acceptance, and by accepting his pain Bill was able to continue to live a full and enjoyable life. Bill viewed this choice was his to make and that by being non-accepting, the only person that stood to be affected was himself.

Bill: "If I've let things get me down, and not accept it, I wouldn't have been president of a club, and had two years of a lot of fun … If you don't accept it you are going to be the loser".

ii) Resistance against aging as a cause for pain

Participants' talked about the commonalities of pain with aging, but at the same time there was resistance to the notion that pain was part of aging. This criticism was supported by various explanations that participants' spoke about in their interviews, in particular their belief about the relationship between aging and pain and how this relationship could be blurred. For example, Anne's resistance to this relationship stemmed from her views on pain, and questions whether aging should cause pain. Her questions revolved around the onset of pain and considered pain to be associated with a particular condition rather than aging.

Anne: "Why should it be? ... It is the condition that causes pain, not the age ... I can't see why age should cause pain ... why should age cause pain?"

The relationship between pain and aging is complex, and its causative relationship remains unclear. The relationship between pain and aging can often be blurred, as some of the limitations that participants' talked about may not be solely related to the pain, but rather as a result of aging. For example, Anne talked about the complexity of this relationship and described some of her current limitations as not being solely related to her pain condition, but rather related to her age.

Anne: "... a lot of things that I might be complaining about has nothing what so ever to do with my rheumatoid, it's just old age ... bit of a fuzzy line".

Cecil further challenged the relationship between aging and pain, as he considered age was not a factor in the development of his knee pain. Cecil arrived at this conclusion, as he was able to recall a direct injury that he sustained, which caused his knee pain. Furthermore, Cecil questioned the impact of aging as he reiterates the commonality of pain among younger adults, who are experiencing and complaining of similar symptoms as him. These two observations had led Cecil to resist the idea that pain was a part of aging. For example, Cecil said,

Cecil: "Mainly my knee, I blame that on the fact that I had an accident in July ... Lots I know that are years younger than me, they are complaining of the same complaints that I've got … they moan oh we can't do this, we can't do that, and they have to get somebody to do this".

Participants' who resisted the idea that arthritis was a condition among older adults also challenged the notion that aging caused pain. Arthritis was a common explanation provided to account for participants' pain complaints. Although arthritis is common among the elderly, some participants considered arthritis to be a condition that could occur at any age. Olive acknowledged the commonality of arthritis, and that arthritis was not confined to any particular age group and can occur at any stage in life. A sense of doubt was demonstrated in Olive's talk, as she reflected back on her pain experiences. Because of the short time she had her pain, Olive was led to question whether her pain was directly related to the aging process.

Olive: "There are a lot of young people who have pain as well, there is some arthritis that starts in childhood ... I didn't have it that long ago".

Olive further challenged the relationship between aging and pain, when she referred to the complexities of pain and aging. The complexity of this relationship was demonstrated in Olive's interview, as she recognised the commonalities of arthritis amongst her peers, yet at the same time she was also able to recall that not all her peers suffered from the same fate. These individual differences could further blur the relationship between age and pain, and that the development of chronic pain in the older adult could be multifactorial.

Olive: "I think its multiple factors ... I've got a lot of friends who are old and older. I think a lot of them have got arthritis, but some of them don't and I think gosh you are so spritely".

Mary also challenged the relationship between pain and aging when she compared herself against her peers or adults older than her. Mary made the observation that adults who were older than her were not restricted by pain and were functioning at a higher level than her. Based on these observations of individual

differences between older adults, Mary questioned the idea that pain was a part of aging, as not all individuals who ages suffered the same outcome with pain as her.

> *Mary: "I've seen people older than me getting around the streets as good as gold, and I wish I could do that sometimes".*

iii) Patient and practitioner relationship – seen but not heard

Participants' resistance to acceptance was also demonstrated when participants referred to a relationship breakdown between their practitioners. Participants' identified various threads that contributed to this breakdown. The first thread that participants voiced were around the frustrations of having their pain complaints not listened to. The second thread that contributed to this breakdown could be due to practitioners only getting a glimpse of the participant's pain experiences. The third thread that participants described was the ongoing need to prove the legitimacy of their pain. The fourth thread that participants expressed that contributed to this relationship strain, was around the lack of guidance provided on the management of pain.

The first common thread that participants' spoke about was the dissatisfaction around the lack of acknowledgement of their pain complaints. Some of the participants expressed their dissatisfaction with their doctor when seeking out medical advice about their pain. In particular, this dissatisfaction was evident when participants were told their pain was due to aging and given medication to manage it. In Fred's interview, he voiced his frustration about not being listened to and painted a bleak picture of the health system from the view of an older adult. That once you reach a certain age, the care provided will be determined by your age and finance.

> *Fred: "... Without checking further, they put it down to older age ... but that mightn't be what is causing it ... it could be a virus, it could be all sort of things".*
>
> *"Doctors don't' look very closely at your illness when you are in your late 70's, because there is a certain budget ... help the people who have got families to raise and still have a fair bit of life to go".*
>
> *"With your age, they are not all that keen on allotting time and money towards older people".*

Both Alan and Mary felt that their concerns were not listened to when they described their interactions with their doctor. They both described coming away with very little knowledge or guidance on the cause for their pain and how to manage it.

> *Mary: "I've told the doctors and nurses about it but they did nothing".*

Alan talked about the numerous occasions he raised the issue of his pain to his doctor and that it was getting worse. There was a lack of acknowledgement of Alan's pain complaints and his doctor told him that his pain was part of general degeneration, which Alan begrudgingly accepted because he was 70.

> *Alan: "I did raise the issue of how this is getting a lot worse, which I've done on occasions with the doctor...didn't make any comment ... just put it down to natural degeneration and I accepted it because I'm 70".*

When seeking medical advice, some participants' felt that their concerns were not listened to or taken seriously. These private pain experiences were often minimised and grouped together as common complaints amongst the elderly. For example, Grace talked about the minimisation of her back pain experience by her doctor. Even though there may be common aspects of pain shared by participants', these pain experiences were also personal and individualised. Grace demonstrated a sense that her pain was being minimised when she acknowledged the commonalities of her back pain, yet, at the same time Grace felt these personal pain experiences should be recognised as being unique to her.

> *Grace: "When I was younger and times got really bad, I'd go to the doctors and they would say, "lots of people have sore backs", but yes this is my sore back".*

Some participants made references to the strained relationship between their practitioners, as they described their lack of trust in their doctors. For example, Nan talked about her frustrations around her care and trust in her doctor. Nan's distrust was at the system level, as she considered the whole medical system to be failing her and very little help was offered. This dissatisfaction led Nan to undervalue the doctor service and considered the only help she received was for prescription of medications to treat her pain.

Nan: "There's no real help, I think the whole GP system is kind of falling apart ... I haven't been told anything ... the doctors are there to just say here is a prescription ... He just prescribed me anti-inflammatories and that was the end of it".

In his interview, David also described a strained relationship with his doctor. In the following example, David described a lack of attention and assistance provided in the care of his pain. In the end, David's experience of not being heard led him to arrive at a conclusion that his pain was not that serious and begrudgingly accepted his pain. David continued to live with his pain and considered his pain as not serious enough to warrant any further medical attention.

David: "I've been to doctors about it, but they don't seem to do much about it, you know it's just one of those things that's not serious enough... you just live with it ... it's not worth paying $40 bucks to go to the doctors".

Medical practitioners only ever get a glimpse

Participants' felt that the private experiences of pain could never be fully understood by an outsider. This limitation could contribute to the breakdown in the patient and practitioner relationship. In the interviews, participants' felt that doctors or specialists only ever got a glimpse of what it was like to live with their pain. An example from Anne depicted this; Anne felt her specialist would never get a true and complete picture of her pain, as he only ever saw her when she was at her best. For example, Anne said,

Anne: "He's always very delighted with my state ... he's always pleased, but between visits I can have pain ... or very swollen hands ... he usually sees me when I'm just about on holiday".

In another way, Bill felt that his doctor's understanding of his shoulder pain could never be fully understood. Bill described his pain experience as something that was personal to him and it was his body that was experiencing the pain. Due to this, Bill felt that his doctor's ability to understand his pain was only as good as his own understanding and ability to articulate these experiences to his doctor.

Bill: "Nobody yet has understood the pain in my shoulder ... it could be the way I explain it ... they are not my body with the pain".

Legitimacy of the pain

Pain is a subjective experience that is invisible to others. This invisibility can lead to misunderstandings and constant scrutiny from others not in pain. The constant need to provide legitimacy for the pain can also lead participants to resist acceptance of their pain. In Jenny's situation, she reported that her back "literally collapsed", and in the absence of a clear traumatic event or medical explanation to account for her back pain, Jenny felt that the legitimacy of her back pain was under constant scrutiny. In the following example provided by Jenny, she talked about her fear of being judged and labelled as a malingerer or a hypochondriac, especially when there was nothing conclusive to account for the pain she was experiencing.

Jenny: "I can't be a person that is a malingerer and yet this is what they are saying, that there is nothing wrong with her ... I broke down".

"I did go through quite a bad period, where I definitely did get the feeling that they thought I was a hypochondriac".

Bill also expressed his concerns about the legitimacy of his shoulder pain post stroke. In his talk, Bill was struggling to understand and manage his shoulder pain. Bill felt that his shoulder pain had not been fully assessed and that health practitioners were unable to identify a cause for his shoulder pain. Due to a lack of understanding of his shoulder pain, Bill felt that every time he mentioned his pain, the legitimacy of his shoulder pain was being questioned.

Bill: "Nobody's really come up and said let's look at this shoulder and find out what is wrong with it, or what isn't wrong with it ... I do get the feeling sometimes, they think I'm crying wolf".

The legitimacy of Nan's pain was also placed under review when seeking assistance for her pain. From Nan's accounts, seeking out medical attention was an activity that was not done lightly. For her to ask for help to manage her pain indicated the seriousness of her pain and that attention was required. When this obvious

distress was not recognised by her doctor, Nan came away feeling undervalued and not heard. For example, Nan said,

> *Nan: "I was in agony, I mean for me that, that is saying something, and he poked and prodded and then looked at me and said "I suppose I better send you for an x-ray", I mean I was too miserable to say something ... that's no way to treat a patient".*
> *"I mean he was testing it and I was wincing, it was obvious, and I haven't been to him complaining about anything before ... there's something wrong with the system".*

Lack of advice given

All participants talked about the lack of advice or guidelines given to help manage their pain. The meaningfulness of the diagnosis was dependent on its delivery, and the use of medical jargon often influenced the participant's ability to understand what was said. In Nan's interview, she talked about receiving a diagnosis for her pain, but felt this diagnosis was meaningless, as she was unable to understand all the medical jargon. Nan felt there was little help given to assist her to understand her diagnosis and she was left to search for answers without success.

> *Nan: "... you've got bone spurs in the top, the whole top part of your spine ... I don't really even quite know what bone spurs are ... I've asked, but they go hmm ... you can look it up, but is all medical language it's not quite what I understand".*

In another situation, Grace was also left without any explanation for her pain and felt there was no real help offered. Despite having had an x-ray done and seeking assistance from other medical professionals, Grace was still left without an explanation for her pain.

> *Grace: "I've had x-rays because of the pain, I don't know what it is ... people don't know, backs are tricky things ... could be a manner of different things ... I've been to an osteopath ... physiotherapist, I've been to a doctor and it makes no difference, none of them ever knew".*

A lack of practical advice given on the management of pain could also impact on the usefulness of a diagnosis. The majority of participants reported that they were given a diagnosis of arthritis to account for their pain complaints. Despite receiving a diagnosis, some participants were left without the next step post diagnosis. Participants' felt that there was very little advice given on how to manage their pain, especially around practical advice to manage their pain. An example from Chooky expanded further on the lack of assistance she was given after receiving her diagnosis. From her previous experiences of living with pain, Chooky knew what a diagnosis of arthritis meant, and felt the diagnosis given offered very little practical advice to help manage her pain. Chooky felt receiving practical advice on how to manage her pain would be more beneficial, than receiving a diagnosis that her pain was related to arthritic changes.

> *Chooky: "There was no real help ... nobody's really said much about it ... pain is different, everybody feels it differently … I was given a book to read, that was it ... I know this, all this really. I know all this through arthritis you know, I knew it, so why did I need a book to tell me what I already knew ... it didn't say what you could do, it just told you what has happened".*

The importance of advice given post diagnosis was highlighted in participants' interviews. Participants' identified that any advice given needed to be personalised and specific to the painful body area being treated. An example from Irene's interview expressed her concerns that advice given to manage her back was too generalised. Irene felt that there was a lack of advice given to help her manage the other parts of her back that were also in pain. For Irene, there needed to be more focused and individualised treatment strategies to address different painful body areas.

> *Irene: "A lot of the back pain things that they advise you on is sometimes not specific ... everything is just normalised for back pain, there should be stuff for how to cope with the back up between the shoulder blades ... I was never told how to cope with this".*

"There should be things specifically, not just generalised ... you do need specific things for different parts of your back, don't just generalise".

A lack of advice provided by medical professionals could also be associated with the difficulties in obtaining information from the doctors or specialists. The difficulties in information sharing could impact on the perceived power imbalance between the patient and their practitioner. For example, David talked about an imbalance of power and the willingness to share information. He felt that people who were more knowledgeable were less likely to come forward with the information, and that at times he had to gather the information himself.

David: "I don't know it's, people don't want to, or willing to give you advice especially those that got knowledge about things … certain information that you have to dig for, it doesn't come readily, and I've found the doctor I have we gotten along … but then there are other ones that are really snappy and this, that and other things".

In Anne's interview, she also referred to the lack of advice that she had received from her specialist. The lack of advice and support received meant that it was up to Anne to figure out the best way to manage her pain and function. For example, Anne said, *"I want to say none, no, don't think that anybody has ever ... certainty the specialist doesn't, he leaves it all to me really."*

When there was a lack of advice provided by the doctor or specialist on the management of the participant's pain, participants often took matters into their own hands. They were proactive in searching for the information and used forums such as the internet, joining arthritis groups and attending courses to gather information. In the following examples, participants talked about their abilities to be proactive in gathering information to understand their condition. An account from Nan indicated her ability to find information and learn what she could about her condition to assist her management of pain.

Nan: "I'm quite capable of finding information for myself ... just what I read or find out from the arthritis society".

Anne also felt that she was more than capable of searching for information to help her manage her pain. Anne attributed her capabilities to searching for information as a contributing factor to the lack of advice she received from her doctor.

> *Anne: "I'm not someone who sits around and waits for somebody to do something ... I don't want to say no I've not received any advice, but I can't think from whom. I'm sure the GP would probably give me advice if she felt I wasn't self-motivated".*

iv) Temporality of acceptance

The temporality of acceptance was another sub theme that offered support to participants' resistance of acceptance. Participants' referred to the temporality of acceptance and that participants could exist between the two states of acceptance or non-acceptance at the same time. The most common factor that participants identified as having an impact on the temporality of acceptance was during periods of increased pain.

Cecil referred to the temporality of his acceptance as he attempted to make sense of his pain. Cecil initially accepted his pain; this acceptance was facilitated by medical confirmation that because of his age there was little that could be done for his knee pain. During episodes of increasing pain, Cecil developed a sense of regret and quickly shifted from a state of accepting, to not accepting and wished that he had taken the risk to fix his knee.

> *Cecil: "At my age, I wouldn't be able to cope with the pain of the operation ... I accepted that at that stage, ah not with the pain I have been having at times now, I think I should had taken the risk, but you don't know at that time … With the pain this week ... I sure wish I had the knee operation".*

An example from Alan's interview also indicated the temporality of his acceptance, as he described the ongoing shift between accepting and non-accepting. Alan initially accepted his pain as a part of natural degeneration with aging. The fragility of Alan's acceptance was demonstrated during periods of increased pain and Alan shifted to a state of non-acceptance and wanted his pain to be alleviated.

Alan: "Only had an x-ray done … that's one thing that I'm going to sort of challenge them on, is there something positively that can be done … which will give me some relief".

In another way, Alan demonstrated his resistance to accepting his pain as he spoke about wanting his pain to be further investigated. Alan described of wanting to take a more assertive approach when speaking to his doctor, this approach would allow Alan to be in control of his care. Taking a more assertive approach would also lead Alan to move away from the status quo of being a passive patient and take control of his own health care.

Alan: "I would go and see my doctor and say "look this is the situation ... what I want you to do is, first of all I ask him to have me x-rayed again to make sure he knows exactly what the problem is, and then put me onto some kind of specialist or someone like that".

An example from Alan demonstrated the ongoing conflict between acceptance and non-acceptance of his pain. Alan was aware that the final outcome for him was to accept his pain; despite this awareness Alan continued to resist the notion of having to accept his pain. Alan's resistance to acceptance was evident as he talked about his fears and regrets of not exhausting all possible treatment options for his pain. This fear of regret continued to fuel the temporality of Alan's acceptance and reinforced his need to search for answers.

Alan: "I think what's going to happen is I just have to accept that's the way it is ... but I do want a surgeon to have a look at it about now, because I don't want to get to that stage and someone says to me ... we could have done x, y and z ... what a pity you didn't come and see us five years ago".

Participants' who experienced a change in their pain symptoms commonly referred to temporality of acceptance. During this period of pain fluctuation, participants' first thoughts were to see their doctor and get something done. The process of acceptance was changeable and the temporal nature of acceptance was demonstrated in the following examples. These participants' spoke of initially accepting their pain, yet during periods of change in their pain symptoms, participants'

acceptance was placed under scrutiny, as they shifted towards a state of non-acceptance and cure seeking.

> *Nan: "I don't know what I'll do if I have worse pain, I would obviously have to go and beat up somebody and say "look you've got to do something about this".*
>
> *Elizabeth: "If I had to I would go to my doctor and say I think we need ... you don't have to learn to live with severe pain because you can do something about it and I would. I would make an appointment with the GP".*
>
> *David: "I have toiled with the idea of going up for an x-ray ...I had that thought going through my mind just to see if there, what it was ... seeing it was few years now I was told it was probably arthritis. If it's getting worse I would book into the hospital for an x-ray of my back to see what's going on it there".*

Acceptance can exist in different forms and it was a theme that was commonly expressed by participants'. Yet at the same time this resistance can be challenged and begrudged. Participants' resistance towards their acceptance was evident as they provided different explanations to support this. A common explanation that participants provided was viewing the concept of acceptance as out of necessity, where participants had no other choice but to accept. Other explanations that participants provided include the following, resistance against aging as the cause of pain, which could lead to a relational strain between their practitioners and resulted in a begrudged acceptance.

Theme four: Learning to live with the pain

Participants' talked about different aspects of acceptance that could occur simultaneously. Despite this ongoing conflict, participants recognised the importance of finding strategies to co-exist with their pain. Participants' spoke about different strategies that enabled them to live with their pain. The first strategy that participants described was a change in attitude to understanding their pain. Participants' recognised this strategy was a prerequisite to allowing them to learn to live with their pain. The second strategy that participants described of using to enable them to live with the pain, was to make behavioural adjustments to their daily physical activities. The third strategy that participants referred to was the importance of remaining physically active in order to co-exist with pain.

i) Attitude change

Some participants considered that a change in attitude in their understanding of pain was an important facilitator of acceptance. These participants regarded a change in attitude was a turning point in their ability to accept the pain. Bill and Jenny talked about their process of acceptance, which was preceded by an attitude change to the way they viewed their pain and situation. Both participants' felt that having the right attitude was an important prerequisite to accepting and learning to live with the pain. For example, Bill and Jenny said,

> *Bill: "... that's the attitude I have to life ... you get on with it ... that's the best thing you can do … My attitude is that if you can't change it, you have to accept it".*
>
> *Jenny: "My whole attitude changed, it is my problem, I have to deal with it, I have to live with it".*

Adopting a positive attitude was also important to Irene's acceptance of her pain. Despite her ongoing pain, Irene felt that in order to continue living her life, she needed to remain positive, rather than be distracted by the negative aspects of pain. Irene referred to the need to be positive in order to stay on top of her pain.

Irene: "You've got to have a positive attitude, you can't sit down, and say oh well, that's me I'm not going to do this and I can't do that, its positivity, stay on top of your pain".

In Grace's interview, she referred to the importance of adopting the right attitude in life when managing her pain. In accepting her pain, Grace talked about focusing on the positive aspects of life rather than the negativities of pain. More importantly, this was a choice that Grace had made, as she referred to the use of "my" when talking about her back pain. Recognising that she had this option must have been empowering, especially in the presence of uncertainties when living with persistent pain.

> *Grace: "You can moan and grizzle and think poor me, poor me ... or you can live a life as full as you want it to be and that was my choice".*

ii) Behavioural adjustments

Making behavioural adjustments to the way daily activities were carried out was a common strategy that participants utilised. These adjustments enabled participants to live with their pain, and various strategies were employed to achieve this. The strategies mentioned in participants' talks were, using distractions, changing the way tasks were performed, pacing, knowing their limitations and saving energy for valued activities.

The majority of participants described of employing the use of distractions to help them manage their pain. By using distractions, participants were able to take the focus away from their pain, which allowed them to continue with their daily activities. In Cecil's interview, he talked about using distractions to help him manage his pain. Cecil recognised the unrelenting nature of his pain and by channelling his energy towards performing more valued activities, Cecil was able to continue to live his life.

> *Cecil: "If you ignore it, it won't go away admittedly, if you concentrate on doing something else, you tend to forget it, you keep living your daily life".*

Performing enjoyable activities was the most common distraction technique that participants talked about in their management of pain. By partaking in these valued activities, participants were able to take their minds away from their pain. These valued activities also provided participants with enjoyment and reprieve from the unrelenting nature of pain. The following examples demonstrated some of the

distraction strategies that participants had used in their management of pain. An example from Irene indicated the importance of performing valued activities to help her cope and live with her pain.

> *Irene: "Doing things that I want to do, going through finding different photos ... getting out ... sitting down making things ... doing something I like because it takes my mind of the pain".*
>
> *"Doing something that takes your mind off it, and that's how I cope, even if I sit down and do puzzles".*

In Olive's case, partaking in enjoyable activities and keeping herself distracted was a coping mechanism that she had identified to assist with her ability to live alongside her pain. For example, Olive said,

> *Olive: "I try to keep myself occupied ... I do a lot of knitting ... concentrating on something and doing something you enjoy, you don't notice it too much ... try and keep yourself occupied, keep your mind occupied".*
>
> *"…Try to concentrate on other things … it fades into the background, especially when you are doing things that you enjoy".*

In her interview, Frances talked about immersing herself in activities she enjoyed and this took her focus away from her pain. *"That's when I pick up a crossword or get myself lost or pick up something to read ... get lost in something else and not think about your pain ... it does work for me".*

Other strategies that participants described when learning to live with pain, were learning from previous experiences, and making adjustments based on these experiences. Learning from previous experiences allowed participants to listen to their body and use strategies like pacing when managing their pain. From David's accounts, he was able to use the knowledge previously learnt about his pain to help him to manage his pain. By listening to his body, David was able to change his body positions on a regular basis to alter his pain. This allowed David to cope and live with his pain at a manageable level.

> *David: "You experiment and just work through what you are doing and you find ways to live with it … Having a break and sitting down*

and having a coffee and talking ... bit of a jiggle and moving around and that sort of thing helps"

"... I found I can cope ... you would just sit down for quarter of an hour and do something else ... different position, sit, standing up, pushing and bending over".

Planning out your day was another behavioural strategy that participants used to cope with their pain. Formulating a plan for the day was a helpful coping mechanism, as it allowed participants to determine what they could or could not do, and how to spend their energy wisely through the day. For example, in Olive's interview she found that planning out her day assisted her to manage her pain more effectively. This simple task allowed Olive to spread her energy throughout the day, and plan how to utilise her energy levels more wisely with the pain.

Olive: "... Configure that into your day so what you are going to do and how much, because the pain will affect what you want to do ... you've got to pace yourself".

Another strategy that participants described to assist with their ability to live with their pain was to know your own limitations. Realising what can or cannot be done was a vital tool for participants' when living with their pain. This awareness allowed participants to utilise strategies like pacing or breaking tasks down to more achievable sizes. For Anne, she was able to utilise a number of strategies that assisted her to live with her pain, strategies such as waiting for the right time, breaking tasks down and accepting that it was ok if she did not manage to complete all tasks.

Anne: "...Employ various techniques such as not over doing it ... wait for the right day ... reduce and do things like, do something on the day when you feel you are capable of doing it".

"I don't ever do all the house work in one day ... do the bathrooms today and then I might do something else tomorrow".

iii) Remain physically active

Participants' talked about the importance of remaining physically active when living with pain. Exercise therapy appeared to be an easy activity that participants did to help them manage their pain. Whilst participants identified that performing

exercises did not take their pain away, it enabled them to cope and live with their pain. In an example from Grace, she talked about the limitations of exercises in abolishing her pain, but in another sense Grace spoke about the benefits of exercising and how these benefits allowed her to manage her pain more effectively.

> *Grace: "Doesn't help, it doesn't take the pain away, but I think it probably makes me more able to cope with it … because I'm fitter and stronger"*
>
> *"Activities designed to help, they actually never helped, but what I did notice was that I gained strength and balance".*

Participants' often had the best intentions to remain active and fit, but these intentions were often short lived and hard to maintain. Participants' talked about the difficulties with maintaining their physical activities, and this was due to a number of issues like motivation, a lack of support to keep going and a fear of increasing their pain. For example, Olive talked about the benefits of being physically active, but this was difficult to initiate as she lacked the motivation and support to achieve this.

> *Olive: "Keeping moving is one of the best things you can do for yourself and sometimes that can be incredibly hard to get off your bottom and do something."*
>
> *"Having someone over see you do it and having the company to do it, they are the two big factors".*

In Nan's interview, she also recognised the importance of moving and exercising, as Nan talked about her experience with continuing her physical exercises. Due to a lack of support and motivation, Nan was unable to continue with her gym or walking. Although Nan's best intentions were to remain active to help her manage her pain, this remains difficult for her to achieve. For example, Nan said,

> *Nan: "…Trying to be more positive and get the exercise … will try and go to the gym but they don't have any support for older people … we can try walking just around our street … we've said that a lot, we've never done it, because we've got used to not doing it".*

For David, the fear of increasing his pain with exercising coupled with a lack of coping strategies to manage his pain were two factors that kept David from exercising.

David reported of being stuck in a continuous cycle of wanting to exercise but was unable to because of his pain. David was struggling to find solutions where he could continue to exercise, whilst keeping his pain at a manageable level. For example, David said, *"The best thing is to keep walking, keep moving … I wondered whether if I went to the gym … if I push too much then my hips go … then I give it a break … I don't do as much walking like I used to do because it just gets to a stage where if I push, it will be painful".*

Despite the different aspects of acceptance and the changeability of acceptance, participants considered acceptance to be an imperative process in allowing them to learn to live with their pain. Participants' recognised that despite the pain, they still had a life to live, which served as a strong motivator for participants to learn to co-exist with their pain. Participants' talked about employing various strategies to enable them to live alongside their pain, the main strategies participants described were: an attitude change towards the way pain is understood, making behavioural adjustments to their daily activities and to remain physically active.

Chapter Five: Discussion

Chronic pain in the older adult (65 and above) is both prevalent and inadequately managed. Understanding how older adults manage to live with chronic musculoskeletal pain may provide insight into how people manage chronic pain in everyday life. In the current study, interviews with older adults dealing with chronic musculoskeletal pain provided insight into the understanding of what it means to live with pain. From the participants' interviews, four common themes were identified: 1) different aspects to the experience of pain, 2) acceptance, 3) begrudged acceptance and 4) learning to live with the pain. Participants recognised the important aspects of acceptance in allowing them to co-exist with their pain. Yet at the same time they were also critical about the diagnosis and management of their pain. This led participants to resist the notion of accepting their pain and begrudge acceptance. The ongoing struggle between accepting and not accepting pain indicates the dynamic and complex nature of acceptance, and that there are different aspects to this process.

Acceptance of pain – protective strategies

This current study found older adults to be accepting of their pain. Each participant described various strategies that assisted him or her in accepting their pain. Some of the protective strategies that participants identified included a shared understanding that pain was part of living, belief that pain had a mechanical cause, the chronicity of their pain, and previous exposure to the experience of pain.

One of the protective strategies that participants' spoke of was a shared common belief that pain was a natural part of living. Participants' described their pain as a result of what they did and how they used their body to carry out day to day activities. A study by Risdon et al. (2002) suggested older individuals shared a common belief that pain was a natural part of living. While other studies by Cabak et al. (2015) and Gignac et al. (2006) acknowledged the high rates of acceptance among older adults living with chronic pain. The authors suggested the high rate of acceptance among older adults could be related to their perception of chronic pain. In the current study, acknowledging pain as part of living was thought to serve as a protective mechanism against the threats of chronic pain and allowed participants to co-exist harmoniously with their pain.

Participants' acceptance of pain was facilitated when there was a perceived mechanical cause to explain their pain. Participants' often described of adopting a mechanistic view as they attempted to make sense of their pain. This view enabled participants to attribute the cause of their pain to be associated with the physical work they had previously done. A study by Makris et al. (2014) suggested that adopting a mechanistic view to the cause of pain was considered to be part of the coping mechanisms that an older adult had developed to co-exist with pain. Participants' in the current study had provided evidence to suggest that adopting this view had facilitated the process of acceptance in the management of pain.

The participant's ability to adopt a mechanical cause to pain could also be attributed to their bias towards the use of the biomedical model. The biomedical model is reported to focus on disease and cure (Snelgrove, & Liossi, 2009) and Clarke et al. (2014) found older adults favoured the use of the biomedical model to understand their pain. Despite criticisms from Holloway et al. (2000) on the inadequacies of the biomedical model to understanding the context and meaning of pain, older adults appear to favour this approach. The use of the biomedical model aligns well with the participant's preconception of their pain and allowed them to focus on the physical aspect of pain.

A greater emphasis on a physical cause to explain pain could be part of the different strategies that participants had developed to normalise the experience of pain and facilitate acceptance. The ability to normalise the experience of pain has been suggested by Sanders et al. (2002) to be an important coping mechanism to reduce the threat of pain on the individual's self-identity. A reduction in the threat of pain was also shown by Collis, and Waterfield (2014) as a mediating factor in the older adult's ability to live successfully with their pain. Adopting a mechanical view to pain had reduced the potential threat of pain and facilitated the process of acceptance among participants' in the current study.

The chronicity of pain also enabled some participants to come to a level of acceptance. Participants' described arriving at a state of acceptance after enduring their pain for a lengthy period of time. Due to a lack of change in the nature of pain, participants considered the threat of pain on mortality was low and spoke of arriving

at a degree of acceptance. The condition chronic pain is reported to be non-life threatening (Aldrich, & Eccleston, 2000; Eccleston, & Crombez, 1999; Osborne, & Smith, 1998), and over time the perceived threat to the individual's mortality was considered by Sanders et al. (2002) to become less and facilitated the process of acceptance.

From a clinical perspective, the notion that time can influence the process of acceptance could be clinically useful. The concept of time has an important role when a diagnosis of chronic pain is considered. A diagnosis of chronic pain is only considered after the individual has experienced persistent pain for a period of 3-6 months since the initial onset (IASP, 2018; Walsh et al., 2008). It is uncertain what role time has in the facilitation of acceptance, further research is warranted. In particular, more work is required to determine whether the process of acceptance is simply a result of time and participants naturally arrive at acceptance, or could the process of acceptance be facilitated to improve the management of pain.

The chronic exposure to pain has led some participants to accept their musculoskeletal pain as like any other chronic illness that needed to be self-managed. A study by Makris et al. (2014) found that older adults, who perceived their pain condition to be chronic and unlikely to change, were able to normalise their pain and reduce the threat of pain. Normalising the experience of chronic pain as like any other chronic illness could be protective mechanisms participants' in the current study has developed to reduce the threat of pain, and allowing them to live alongside the pain.

The process of acceptance was also reported to occur once all effective interventions had been exhausted. Participants' recall trying different attempts to abolish their pain, but despite these attempts, their pain remained and participants were left with no other option but to accept their pain. A systematic review conducted by Froud et al. (2014) found participants only considered acceptance of pain once all available treatments were exhausted. A study by Toye et al. (2013) provided further support and reported that participants' living with pain were only able to move forward once they considered there was no cure for their pain. In the absence of effective treatments, participants' in the study expressed that this was a turning point in their journey with pain, and a realisation that they needed to learn to live with the pain.

The temporal stage of acceptance – fluctuations between acceptance and non-acceptance

The shift between acceptance and non-acceptance provided insight into the struggles of living with constant pain. Participants' described moving easily between accepting and not accepting their pain, and that these two states could co-exist simultaneously. Bunzli et al. (2013) provided support for this fluctuation in acceptance and felt that this resistance to acceptance was most likely to occur during episodes of increased pain. It is evident that during times of uncertainty, doubts can occur and lead participants to challenge their own understanding of pain and question their decision to accept. Participants' identified fluctuations between acceptance could be determined by factors such as: the availability of treatment options to manage pain, the difficulties in maintaining acceptance and individual's belief systems.

Availability of treatment options

The unpredictable and episodic nature of chronic pain can often make the process of acceptance a difficult journey to achieve. For some chronic pain sufferers, the process of acceptance may never be reached, and the individual may be stuck in a state of searching for answers to their pain. An important situation where the changeability of acceptance occurs is when participants perceived there to be a lack of options in the management of pain. In particular, Collis, and Wakefield (2014) suggested that chronic pain sufferers, who perceived a lack of choice in their management of pain, would eventually arrive at a begrudged acceptance. In the current study, in the absence of perceived choice for treatment, participants referred to the changeability of acceptance in their interviews and frustrations towards the failures of the medical system. The clinical importance of this changeability in acceptance is to recognise what factors contribute to the fluctuation in acceptance and what strategies can be developed to reduce these episodes.

Participants' described their frustrations with a lack of choice in the management of pain and that acceptance was simply out of necessity. A study by Bowman (1991) interviewed participants' attending pain management centres and found that participant's acceptance of pain was only out of despair. Whilst Holloway et al. (2000), referred to a begrudged acceptance as a participant's way of being

accommodating of pain. Participants' in the current study acknowledged the importance of acceptance in enabling them to co-exist with their pain, but in the absence of effective treatment options, this acceptance may be out of necessity and considered to be an experience that is endured and difficult to maintain.

The difficulties in maintaining acceptance –factors that contribute to the temporality of acceptance

The participant's ability to maintain acceptance can often be disrupted by the stability of their pain. The maintenance of acceptance is often challenged when there is a fluctuation in pain severity. Participants' expressed their ability to maintain their acceptance when the experience of pain was perceived to be stable, and did not interfere with their ability to function. However, during times of uncertainty and changes in pain severity, participants described a sense of helplessness and doubt on prior decisions to accept pain. Moseley, and Butler (2015) referred to the unpredictable nature of chronic pain, and suggest these uncertainties and fluctuations in pain symptoms could make chronic pain difficult to live with. A study by Holloway (2000) also referred to the difficulties in maintaining the state of acceptance and described the constant adjustments pain sufferers had to make to their daily activities in order to co-exist with pain.

Participants' spoke of their struggles to maintain acceptance. This was often influenced by the notion that acceptance of pain does not necessarily lead to the extinction of pain. Despite all the attempts participants described of using to abolish their pain, it was never successful and participants were always left with a degree of pain. The focus of acceptance is not to extinguish pain but rather as Hayes et al. (1999, 2012) states, the aim of acceptance is for individuals to experience their pain in a non-judgemental manner. The ultimate outcome of acceptance would be for the individual to co-exist with their pain rather than focus on the methods to abolish their pain. Overtime it is hoped that the intrusiveness of these pain experiences will reduce and allow the individual to function to the best of their abilities. Participants' misconception of acceptance could influence their ability to view acceptance as being useful, further work is warranted to address participants' understanding of acceptance.

The participant's ability to maintain acceptance may also be impacted by the negative feelings and thoughts that are associated with pain. Hayes et al. (1999, 2012) reported that the individual's perception of pain could be determined by prior feelings, thoughts and emotions that may be associated with the experience of pain. Hayes felt these emotions are learnt from an early age and become ingrained into the individual's belief system. Pincus, and Morley (2001) refer to these systems as schemes that are interrelated and can bias the individual's perception of their pain, self and illness. These belief systems are recognised to be rigid and cannot be eliminated, they can only be subdued to a level where it does not impede the individual's ability to function (Hayes et al., 2012a; Hayes et al., 1999, 2012).

The subdued negative feelings and thoughts associated with pain are reported to be never too far from the surface and can come rushing back during times of uncertainty (Hayes et al., 1999, 2012; Frank, 1995). Participants' in the current study described the constant presence of pain and referred to pain as an unwanted visitor that was lurking in the background waiting for an opportunity to present itself. Frank, (1995) described the constant presence of the negative feelings and thoughts associated with living with a chronic illness, and reported that during times of uncertainties or worsening of symptoms, these negative feelings or thoughts could come flooding back to the surface and challenge the individual's ability to live with the condition. Due to the inability to fully abolish the negative feelings or thoughts that are linked to pain, the process of acceptance can never be complete.

The constant presence of pain can be taxing for participants'. Participants' referred to the impact of pain as they spoke about the ongoing disruptions to their physical, emotional and social function. These disruptions faced by participants were also described by studies conducted by Makris et al. (2014) and Stensland, and Sanders (2018 a, b). The studies indicated that the impact of living with chronic pain was thought to infiltrate every aspect of an older adult's life. Living in constant pain can take a toll on the participant's ability to function, not only do they need to manage and adapt to the changes that come with aging, but they are also required to make adjustments and accommodate the constant disruptions of living with persistent pain.

Constant disruptions in life are considered to be normal events in life, and Willman et al. (2013) recognised pain disruptions as normal occurrences when living in

constant pain. The participant's inability to recover from these daily pain disruptions could be related to the competitive nature of pain. Participants' referred to the competitive nature of pain as they described the unrelenting nature of pain, and considered living with pain to be a constant battle they had to endure. A study by Aldrich, and Eccleston (2000) referred to the competitive nature of pain and that living with pain demanded the individual's full attention. The competitiveness of pain was also referred to by Stensland, and Sanders (2018b), the authors described the constant demands of pain, and that to live with pain the individual was required to constantly adapt to the fluctuations in pain symptoms and severity.

Participants' ability to maintain the state of acceptance could also be influenced by their inability to accept the new self in pain. Participants' resistance to accepting the new self in pain was acknowledged when they described their concerns about living with a self that remains in pain. In particular, participants talked about the regrets and fears of being physically incapacitated, should they accept a life in pain. Bunzli et al. (2013) referred to this inability to move forward with pain as a biological suspension or a life placed on hold, where the individual is suspended in a state of uncertainty. Studies by Bowman (1994) and Snelgrove, and Liossi (2009) referred to this biological suspension of self as a personal attack on self-identity; where pain sufferers are constantly subjected to the disruptions and threats to their identity, yet they lacked the tools to resolve this conflict and move forward.

The fragility of acceptance was another factor that could provide further support towards a participant's ability to maintain the state of acceptance. Participants' highlighted the fragility of their acceptance especially during fluctuation of pain, where their thoughts quickly turned into doubts of whether they should accept their pain.
Hayes et al. (2012) referred to the fragility of acceptance and considered that the new beginning of acceptance could easily be disrupted. Frank (1995) used the metaphor of a freshly healed scab to symbolise the fragility of this new beginning. During times of uncertainty or worsening of pain, the subdued negative feelings and thoughts associated with pain would come flooding back, and cause participants to question their acceptance of pain.

The fragility of this new beginning was further tested when participants were left to deal with the ongoing frustrations and disappointments of living with chronic

pain. The unpredictability of pain can often leave participants' feeling disappointed, especially when satisfaction from hard earned functional gains are easily taken away. Participants' described this as a sense of being defeated by the pain, which can leave them in a state of despair and questioning whether they should accept a self that remains in pain. MacNeela et al. (2015) acknowledge the continuous struggles of pain sufferers. Not only do pain sufferers need to accept a new self in pain, but they are constantly required to adapt to the disappointments and frustrations of living with pain.

Begrudged acceptance

Participants' provided different explanations to demonstrate their resistance to acceptance. Firstly, participants described a begrudged acceptance as they spoke of their resistance towards accepting age as a cause for their pain. Secondly participants described that a strained relationship between their practitioners could also lead to begrudged acceptance. Participants' often referred to a strained relationship between their practitioners when there was a perceived lack of understanding from their doctor, and a constant need to demonstrate the legitimacy of their pain.

The complexities of aging on pain and acceptance

The process of aging is complex and participants described different aspects to pain and aging. To facilitate their acceptance of pain some participants considered pain as part of aging, while other participants described resistance towards accepting aging as a cause of pain and questioned why aging should cause pain. Research evidence suggests older adults are more accepting of their pain and a study by Makris et al. (2014) found older adults demonstrated a strong belief that their pain was a result of aging, and considered pain as an inevitable part of aging. This shared common belief that pain is part of aging was considered by Sanders et al. (2002) to be a coping mechanism that some older adults has developed in order to live with their pain.

Medical professionals, who shared and acknowledged the commonality of pain with aging, also facilitated participants' acceptance of aging as a cause of pain. Receiving medical confirmation that pain was part of aging may be a logical explanation for participant's who already perceives pain to be related to aging.

Acceptance of this explanation may be facilitated by the notion that participants' favour the use of the biomedical model to understand their pain. Makris et al. (2014) found older adults favoured the use of the biomedical model, by aligning their thinking towards the more dominant medical narratives; older adults were able to accept their pain as part of aging.

From a pathophysiological perspective, the presence of pain with aging appears to be a logical explanation. A study conducted by Hadjipavlou et al. (2008) referred to the structural changes that occur in the body with aging, and considered these changes to be normal occurrences that could contribute to the cause of pain. However, Hadjipavlou felt caution should be adhered to when using age as a diagnostic label for an older adult's pain complaints. The individual may experience pain with aging, but the development of chronic pain may not eventuate. The development of pain is complex and other factors such as mechanical and genetic factors need to be considered before attributing age as the primary cause of pain.

While other participants' felt receiving medical confirmation that their pain was a part of aging, hindered their ability to accept. A study by Makris et al. (2015) found ageist statements from medical narratives to act as potential barriers to participant's acceptance and reduced health seeking behaviour for their pain. Participants' in the study spoke of their resistance towards acceptance as they described a lack of trust in their doctors to understand their pain complaints and often felt their pain complaints were not listened to. These participants reported reluctance towards seeking further medical attention for fear of being told their pain complaints were age related. Statements about age can be commonly used within the medical realm. Medical professionals need to take care when using these statements, as they can influence the participant's health seeking behaviour and management of pain.

In another situation, ageist statements from medical professionals can also minimise the experience of pain and hinder the process of acceptance. In the current study, after receiving confirmation that pain was age related, participants reported feeling frustrated and dissatisfied that their pain complaints were not heard. This dissatisfaction was evident when participants felt these individual experiences were commonly grouped together as common symptoms among older adults. A study by Makris et al. (2014) on the experience of pain among older adults, reported ageist

comments from medical narratives could also minimise an older adults experience of pain. The assumption that pain is part of aging remains unclear; Gagliese (2009) reports this assumption as untested and that more work is warranted to understand the role of aging and pain. Chronic pain is a complex condition that does not occur in isolation. Attributing age as the main explanation to account for the participant's pain complaint remains inadequate.

Participants' resistance to aging as a cause of pain could also be associated with the terminology that was used to explain their pain. Resistance to acceptance of pain as part of aging was evident when participants described their frustrations towards the use of aging or degeneration to account for their pain. Participants' felt these terms offered very little meaning and did not provide any assistance in the management of pain. A study by Bunzli et al. (2013) highlighted the importance of having a meaningful diagnosis and reported that in the absence of a meaningful explanation to understand the complexities of chronic pain, individuals were often left in a state of uncertainty about the nature of their pain. The usefulness of degeneration as a diagnosis was also criticised by Hadjipavlou et al. (2008). Hadjipavlou felt the term degeneration was not an appropriate diagnostic label, as it only refers to the underlying process that is occurring with age. It does not account for other potential factors that may be causing pain such as mechanical or genetic factors. Participants' in the current study questioned the meaningfulness of aging and degeneration to describe their pain. This resistance identifies the need for a meaningful diagnosis that is pitched at a level that participants' can understand.

The importance of a diagnosis was recognised in the literature to be an important facilitator for acceptance. However, for some participants' this was not the case. There is research evidence to suggest that receiving a diagnosis was not considered to be as pertinent for an older adult as compared to their younger counterparts (Gignac et al., 2006; Sofaer et al., 2005). Reasons to account for a reduced emphasis on receiving a diagnosis could be associated with the fact that older adults have more stressors to contend with, such as dealing with their failing health and other negative aspects of aging like loss of a spouse, and a reduction in social networking (Helme, & Gibson, 1999). Given these concerns, some participants' in the current study placed less emphasis on receiving a diagnosis, as they felt that a

diagnosis only provided them with background information. Participants' identified that receiving practical advice and information on how to manage and cope with their pain was more pertinent and useful.

The label chronic pain is commonly assigned to describe persistent pain complaints, this label can offer very little meaning for participants'. This term chronic pain can often be vague and confusing for individuals living in pain. The confusing aspect with this label is that a diagnosis of chronic pain can be given in the absence of any acute tissue damage (IASP, 2018). A diagnosis of chronic pain is only given when the following has been ruled out, such as a lack of response to medical interventions, the length of time since onset, and the exclusion of other organic causes that may be causing the pain (MacNeela et al., 2015; Smith, & Osborn, 2007). The suggestions that ongoing pain can occur in the absence of physical injury can be a difficult concept to accept, especially for participants' that has a strong mechanistic bias to the cause of their pain.

Chronic pain is complex and the aspect of aging can further complicate the presence of pain in an older adult. Participants' described different aspects of aging and mentioned that aging could be both a facilitator and hindrance to the process of acceptance. Facilitation of acceptance was achieved as participants accepted the natural process of pain as a part of aging, which was often confirmed by medical narratives. However, receiving confirmation that pain is part of aging was also reported by some participants to hinder their acceptance and led to a begrudged acceptance. Participants' resistance against the use of aging as an explanation to account for pain was evident in their talks. This resistance was demonstrated by participants' who questioned the meaningfulness of ageist statements to account for their pain complaints, and placed less emphasis on receiving a diagnosis.

A strained relationship between patient and practitioner

A cohesive patient and practitioner relationship is recognised to be imperative in the success of chronic pain management. Makris et al. (2015) highlighted the importance of this relationship, and suggested that a positive relationship between patient and practitioner is required to enhance an older adult's engagement in their care and management of pain. A break down in this relationship could lead individuals

to resist the idea of accepting their pain. Participants' spoke of a begrudged acceptance when there was a perceived relational strain between their practitioners. Participants' were able to identify common factors that contributed to the strain on this relationship and they included frustrations with not being heard, minimisation of pain symptoms, a continual need to demonstrate the legitimacy of their pain and inadequate management options. These factors led some participants to lose faith in their health practitioners and impacted on their health seeking behaviour.

A strained relationship between patients and practitioners was often demonstrated when participants perceived their pain complaints to be unheard. A study by Clarke et al. (2014) where older adults were interviewed found that their pain complaints were often not listened to. The lack of acknowledgement of the pain sufferer's narratives could be associated with the dominance of the medical narratives. The dominance of the medical narratives has been reported to render the pain sufferers own narratives to a point where they are incomprehensible and become irrelevant. Frank (1995) provided evidence of this, as he used the term narrative surrender to describe the dominance of the medical narratives, which takes over and causes the individuals to abandon their own narratives. Accepting the medical narratives that pain is a result of aging can leave some participants without a meaningful framework to understand their pain, and frustrations of not being listened to.

Participants' also expressed their resistance against acceptance when they perceived a lack of understanding from health professionals. Participants' felt that their pain complaints were never fully understood by their practitioners, and that practitioners only ever got a glimpse of what it was like to be in pain. The practitioner is considered to be the third person trying to understand and make sense of the pain sufferer's pain experiences. Stensland, and Sanders (2018b) suggest a full understanding of an individual's pain experience can only ever be partially achieved. From a research perspective, Eatough, and Smith (2017) considered that the understanding and generation of knowledge from a third person could never be full. To reduce this gap and to get closer to the pain experience, the researcher is required to understand the experience at the same time as the pain sufferer, who is also trying to make sense of these experiences. The meaning of pain could never be fully

understood by an outsider, the aim would be to walk alongside the participant and understand the experience of pain from their perspective, and make them the experts of their pain.

To generate meaningful understanding of pain experiences, Smith, and Eatough (2012) call for an empathetic and critical researcher. This concept would be clinically relevant and could be applied into a clinical setting to improve the cohesiveness of the patient and practitioner relationship. Participants' spoke about their frustrations of having a practitioner that did not listen to their pain complaints. This can leave participants' questioning their trust in their doctors and the medical service received. A study by Stensland, and Sanders (2018b) recognised the importance of patient centred care in the management of chronic pain in the elderly population, and that an empathetic clinician was recognised to be an important aspect to this care. Adopting an empathetic approach would allow practitioners to get closer to the participant's experience, and reduce participant's frustrations with the medical system.

Although an empathic practitioner is required to facilitate a cohesive patient and practitioner relationship, at the same time Smith, and Eatough (2012) highlighted the importance of being critical and having the ability to distance one's experience from that of the pain sufferer. The ability to be critical would also allow the practitioner to distance themselves from the individual's experiences. By acknowledging his or her own pre-conceptions that can prejudice the patient's experience of pain, the practitioner is able to take a closer step towards understanding the experience of the pain from the perspective of the pain sufferer.

Minimisation of pain symptoms

The minimisation of pain symptoms by medical professionals could also lead to a begrudged acceptance. Participants' provided examples of their personal pain experiences being acknowledged as common symptoms among the elderly. Participants' described their frustrations towards this minimisation of pain symptoms, and attempted to take some control back of their pain experiences by personifying these pain experiences. Evidence of this was demonstrated when participants used phrases like "my pain" and "it's my body" to describe and personify their experiences of pain. Makris et al. (2014) referred to the importance of control in the management

of pain, and reported older adults who perceived greater control of their pain, demonstrated more effective coping and adaptive behaviours. The experience of chronic pain may have elements that are commonly shared by other chronic pain sufferers. Despite this, participants continued to acknowledge the individualistic nature of pain, as they attempted to personify their own pain experiences.

Legitimacy of pain

The invisible nature of pain also led participants to describe an ongoing need to verify the legitimacy of their pain. The need to prove pain legitimacy was another factor that participants identified to impact on their acceptance of pain. Chronic pain is considered to be a subjective and unique experience to the individual (Smith, & Osborn, 2007). This unique experience can be difficult for others who are not in pain to grasp, especially when pain symptoms are invisible. Frustrations with the ongoing need to prove the legitimacy of pain was evident in the study, as participants described a sense of being seen but not heard from their doctors, and fears of being judged by others not in pain. The legitimacy of pain is compounded by the invisible nature of pain, where participants' feel a continuous need to seek medical assistance to verify the realness of their pain experiences and to abolish their pain.

The invisible nature of pain can cause further strain on the relationship between patient and practitioners. Participants' described two aspects to their pain experience; in one aspect participants described the realness and unrelenting nature of pain. Whilst in another aspect these private experiences remained invisible and participants often reframed from expressing their true feelings to others, due to the fear of being misunderstood. A study by Lavie-Ajayi et al. (2012) recognised these two different aspects of pain experiences that can occur and referred to this contrast in pain experiences as a narrative distress, which can occur in older adults living with pain.

This internal struggle within the individual can present as a cognitive dissonance, where acknowledging the presence of pain requires the pain sufferer to accept a self that is broken and a continual need to prove the legitimacy of pain (Lavie-Ajayi et al., 2012). Yet acceptance of ongoing pain may also result in further retraction into the invisibility of pain (Osborn, & Rodman, 2010) and portray an image that outwardly there is nothing wrong. Some participants' in the study describe of retracting into the

invisibility of their pain as they reframed from truly expressing their experiences and struggles with pain. This appeared to be a protective mechanism that participants had developed to reduce the fear of being misunderstood and scrutinised by others not in pain. Living with chronic pain can be a lonely experience for some participants', especially for those who are fearful of being judged and scrutinised by others not in pain.

As a researcher and a clinician, I experienced this first hand when I questioned the legitimacy of participant's pain experiences. Due to my own preconceptions of chronic pain, I found myself questioning the legitimacy of some of the participants' pain experiences. At this point, I realised that as a clinician and a researcher, I needed to step back and distance myself from these private experiences and understand it from the participant's perspective. To understand what it was like to live with such vivid yet invisible experiences, and having these experiences constantly scrutinised by others, must be demeaning for the participant.

Inadequate management options

There is a growing interest in understanding the experience of chronic pain among older adults, with a rich qualitative research based evidence to support the impacts of chronic pain from an older adult's perspective (Makris et al., 2014; Makris et al., 2015; Makris et al., 2017; Stensland & Sanders, 2018 a, b), and a larger qualitative meta-synthesis study conducted by Crowe et al., (2017). Despite an increased interest in understanding the experience of chronic pain in older adults, the management of older adults living with chronic pain remains insufficient.

In the current study, when seeking medical assistance, participants were often told by their doctors or specialists that their pain was related to aging, and were given pain medication to manage their pain. Practitioner's readiness to prescribe medication often left participants' in a dissatisfied state and a resistance towards having to take pills to manage their pain. The clinical guidelines on the management of chronic pain heavily focus on the use of pharmacological therapies (Abdulla et al., 2013; Hadjistavropoulos et al., 2007; Hochberg et al., 2012;). Older adults are reported to be at risk of being over medicated and given their reduced tolerance to medication side effects, the use of non-pharmacological therapies should be considered. Participants'

identified a lack of available medical interventions to manage chronic pain and can often result in frustration and resistance towards acceptance.

The lack of pain treatment options available for an older adult can also be related to the inadequate assessment of an older adult's pain complaints. In a review conducted by Hajistavropoulos et al. (2007), the authors suggest assessment of older adults with pain complaints were often poorly assessed. Participants' in the study described of an inadequate assessment of their pain complaints and report their pain complaints was often attributed to age related. In the absence of a comprehensive pain assessment, formulating an effective management of participant's pain would be significantly impacted.

A study by McGuire et al. (2014) suggests potential reasons to account for the lack of application of assessment guidelines into a clinical setting could be: the length of time it is required to conduct a comprehensive assessment and the lack of specialists to carry out these assessments. From a clinical perspective, the time required to conduct a comprehensive pain assessment can be difficult for most clinics with their busy schedules and time restrictions. According to Makris et al. (2014) more work is required to develop and refine the assessment process to capture the unique challenges that older adults may face when living with chronic pain. The above factors could all have an impact on the transferability of clinical guidelines into clinical settings.

A begrudged acceptance could be due to the restrictions placed on the type of interventions that were available to manage pain in an older adult. Participants' spoke of the frustrations with the lack of available treatment options when they reached a certain age group. Participants' were often prescribed medication to manage their pain, rather than being referred for other non-pharmacological services. It is uncertain as to the reason for this, but a study by Macfarlane et al. (2012) where older adults were interviewed, found the type of interventions offered in the management of pain were determined by age. The authors found older adults were more likely to be offered pharmacological therapies, rather than non-pharmacological interventions like psychological and exercise based therapies. Age as a mediating factor in the type of treatment offered to manage pain in the older adult, was another factor that resulted

in participant's dissatisfaction with the medical service and a begrudged acceptance of their pain.

Learn to live with pain – the importance of acceptance

Despite the ongoing conflict for the struggles between acceptance and non-acceptance, participants also acknowledged the importance of acceptance in allowing them to co-exist with pain and to continue living their life. The importance of acceptance to enabling participants to live with their pain was also recognised by Bowman (1991) and Holloway (2000). While, Toye et al. (2013) used the term moving forward to describe the individual's ability to carry on despite the struggles of pain. Although participants' in the study did not use the words moving forward, they did describe the process of moving forward when they talked about learning to live with their pain. To achieve this, participants described various strategies that enabled them to live with their pain.

The most common strategy described by participants to assist with their ability to live with their pain was to make cognitive and behavioural adjustments to the manner in which pain was viewed and managed. The easiest way to achieve these changes that participants' spoke about was to make attitude changes to the way pain was viewed and understood. Morris (1991) and McCracken (1999) recognised the importance of acceptance and referred to acceptance as being an attitude change. However, Hayes et al. (1999, 2012) recognises the process of acceptance to be more than just an attitude change and acknowledged acceptance to be an active process that requires the participant to make cognitive and behavioural changes to the way pain is understood and managed (Hayes et al., 1999, 2012; McCracken, 1998).

Participants' also recognised the importance of acceptance in allowing them to continue to live their life. A study by Sofaer et al. (2005) provided further support towards acceptance in facilitating participants' ability to learn to live with pain, and recognised acceptance to be the first step in allowing the pain sufferer to make adaptations to live with the pain. Once acceptance was achieved, the next step participants' in the study talked about was making behavioural adjustments in their physical movements, their environment and the way physical activities were carried out. The need to make behavioural adjustments was also recognised by Snelgrove, and

Liossi (2013) to be an important facilitator of acceptance. The authors considered behavioural adjustments to be part of an essential part of an individual's pain coping mechanisms. Despite the negative aspects of pain and the struggles between the two aspects of acceptance, participants' in the study still recognised the importance of acceptance in allowing them to continue to live their life.

Participants' also spoke of the importance of physical activities to assist with their ability to live with pain. Exercise therapy is considered to be a common approach to conservatively manage chronic pain (Godfrey et al., 2012; Snelgrove, & Liossi, 2013; van Middelkoop et al., 2010). Participants' in the study felt that exercising and keeping general good physical health was an important aspect in their pain management regime. Participants' described different ways of achieving this and a common way was to join a gym or exercise group. However, in the absence of professional guidance, regular follow-ups and ongoing costs, participants often found it difficult to continue with exercise therapy. Exercise therapy is a non-invasive approach that participants identified as an important aspect in their management of pain. Further research is warranted to address the barriers that could restrict a participant's ability to partake in exercise therapy.

Limitations of the study

There are limitations with this preliminary study. Firstly, this study is based on a specific population group that consisted of European male and female participants' who are community dwellers. Unfortunately, the list of participants' that was provided for recruitment only consisted of participants from European backgrounds. Inclusion of participants from other ethnic groups would have added to the richness of data collected, as Morris (1991) highlighted the important role of culture on the experience of pain. Participants' that were recruited for this study were also part of an existing longitudinal study; this was problematic as Snelgrove (2014) suggests repeated collection of data from the same group of participants' can result in participants becoming sensitised to the process of research.

Secondly, the majority of participants reported onset of their pain occurred during middle age. Given the participants' age, 65 and over, there were concerns over memory and cognitive problems associated with aging and their ability to correctly

account for these experiences over time. Due to the nature of qualitative study, participants are required to recount these experiences from a retrospective manner. Over time these memories may have been distorted and not a true reflection of the experiences that have occurred in the past.

Thirdly, the researcher is a current practicing physiotherapist with an interest in chronic pain. Smith, and Eatough (2012) described an imbalance in power can occur during the process of research, where the researcher is seen to be in a privileged position. The researcher in this study conducted both the interviews and analysed the data. In one aspect, this closeness to the data was a necessary approach as the researcher was attempting to understand the experience of pain from the perspectives of the individual living with pain. However, on the other hand this closeness was also criticised, as the researchers own preconceptions and experiences could bias and influence participants' responses to the questions asked. To reduce this power imbalance, the researcher fully disclosed her interests in chronic pain and her experiences working with individuals living with pain.

Throughout the process, it was imperative to remain true to the participant's own experiences. The researcher achieved this by partaking in regular reflective practice of keeping diary entries throughout the research process. The researcher was also able to refer back to these entries when analysing the data, this process allowed the researcher to acknowledge any preconceptions that may interfere with data analysis. There were times where the researcher needed to distance her views and preconceptions from that of the participants'. A particular diary entry indicated the researcher's thoughts that challenged participant's legitimacy of pain. Upon further reflection, the researcher was able to park these thoughts and consider the difficulties pain sufferers must endure on a daily basis.

The results of this study are preliminary and unable to be generalised to other older adults living with chronic pain, especially older adults who reside in residential homes. The study did not include older adults who resided in residential homes, these individuals are often most vulnerable and potentially have greater failing health and pain. The lack of research on older adults who reside in residential homes is recognised, and to gain a fuller picture of the effects of chronic pain in older adults,

Willman et al. (2013) suggest further work is warranted on older adults who reside in residential homes.

Implications for practice

Participants' recognised the importance of a cohesive relationship with their doctor in the management of chronic pain. Further work is required to understand this relationship and what can be done to facilitate a more cohesive working relationship. A possible way this can be achieved may be to explore the understanding of pain from the perspectives of medical professionals working with older adults. Performing interviews with medical professionals and understanding the difficulties faced with managing older adults with chronic pain, could provide further insight into identifying the limitations and barriers of chronic pain management in the elderly.

Chronic pain in the older adult presents a unique and challenging experience. The assessment process of pain complaints from an older adult has been criticised and often these pain complaints are simply put down as being age related (Hadjipavlou et al., 2008). The current assessment guidelines have been criticised for its length and the time required, and the lack of test specificity to the elderly population. These factors may reduce the transferability of these guidelines into clinical practice. Further research is required to understand the barriers that may be restricting comprehensive pain assessments being carried out.

A comprehensive assessment of pain is imperative in the implementation of a pain management program. The treatment of chronic pain in older adults is reported to be inadequate (Abdulla et al., 2013; Herr, 2011; Schofield, 2016). Possible reasons for this could be an inadequate assessment of pain, and that management of pain in an older adult represents a unique challenge due to various factors like frailty, high co-morbidities, high use of medication, reduction in mobility, loss of spouse and many more. Some of these factors can also cause pain themselves and further complicate the picture of musculoskeletal pain. Further research is warranted to address the inadequacies in assessment and management of older adults living with chronic musculoskeletal pain.

The role of ACT

When faced with the prospect of living with incurable pain, the use of ACT may be appropriate with its focus on finding different strategies to co-exist with the pain, rather than to abolish the pain (Hayes et al., 2012a, Hayes et al., 1999, 2012). Preliminary results indicate the use of ACT in older adults living with chronic pain to be positive. However, further larger quantitative studies are required to explore the clinical usefulness of ACT in the management of chronic pain among older adults.

Despite research indicating the use of psychological therapies to be efficacious in the management of pain, these therapies continue to be underutilised in the elderly population (Hochberg et al., 2012; Reid et al., 2015). Participants' in the study did not mention the use of psychological therapies in their management of pain. The reasons to account for the underutilisation of psychological services among this current group of participants are unclear. A study by McGuire et al. (2014) suggests previous preconceptions and experiences held by pain sufferers and practitioners towards the use of psychological therapies, could limit the use of psychological services. Further research is warranted to understand the barriers that may be impacting on the use of psychological therapies amongst older adults living with chronic pain.

There continues to be a lack of research that is solely focused on the process of acceptance in older adults living with chronic pain. The majority of research conducted in this area includes a combination of young, middle aged and older adults, with small numbers of older adults represented in the study (Wetherell et al., 2011; Wetherell et al., 2016). Schofield (2016) also felt that applying results from studies that included adults of different ages would likely minimise the experience of pain and not be a true reflection of the impact of chronic pain among older adults. At present, only two studies were found that solely focused on the use of ACT in older adults (McCracken et al., 2013; Scott et al., 2017). The results of these studies are positive but are only preliminary, further larger quantitative research is required to determine the effectiveness of ACT in the elderly population.

Participants' spoke of the importance of acceptance in allowing them to co-exist with their pain and continue to live their life. The component of acceptance was considered by McCracken (2011) to be the most commonly researched, and has been identified to facilitate the following changes: a greater change in the management of

chronic pain (McCracken, Vowels, & Eccleston, 2005), an improvement in functioning and mental health (Scott et al., 2017) and improvements in acceptance with the use of CBT (Vowles et al., 2007). Despite this current support for acceptance in chronic pain management, research from Lunde, and Nordhus (2009) and Wetherell et al. (2011) challenges the support for acceptance and suggests that the component of values may have a greater role to play in the management of pain. Due to these inconsistencies in research, Wetherell et al. (2011) calls for further research to identify which components of the PF model would be best suited to specific individual characteristics.

The management of chronic pain in older adults can be impacted by the temporal nature of acceptance. Participants' described moving easily between the stages of acceptance and non-acceptance. To address this temporality, follow up sessions would be appropriate to provide a continuity of care and sustainability of acceptance. In particular, Lunde, and Nordhus (2009) recommended the use of booster sessions to prevent relapses. The use of booster sessions may lessen the changeability of acceptance and the fluctuation between acceptance and non-acceptance. Further research is warranted to assess the merit of booster sessions on the stability of acceptance.

Conclusion

The common theme of acceptance was described through participants' interviews, yet at the same time this acceptance could be begrudged. Participants' provided various explanations of this resistance towards acceptance, such as acceptance out of necessity, resistance towards aging as a cause of pain, and a strained relationship with their practitioners. The fluctuations in acceptance are thought to represent the temporal nature of acceptance, and are considered to be part of the coping mechanisms that an older adult has developed to adapt to the unpredictable nature of chronic pain. Despite the internal struggles between the different aspects of acceptance, participants also recognised the importance of acceptance in allowing them to continue to live their life. In the end, participants were able to accept their pain and described using different strategies to live with their pain. More in depth qualitative and future quantitative research would be beneficial to address the different aspects of acceptance and management of chronic pain among

older adults. This work should focus on how acceptance can be facilitated to ensure its sustainability, and to reduce the temporality of acceptance and the occurrence of a begrudged acceptance.

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Appendix One: Participant information sheet

The experiences of older adults living with chronic pain: a qualitative study.

PARTICIPANT INFORMATION SHEET

My name is Laura Ng. I am a practicing physiotherapist and a student enrolled to complete my master's thesis in psychology at Massey University. I am inviting you to take part in my research project on understanding how people manage living with chronic pain that is non-cancerous and affects the bone(s), joints, tendons or muscles. I am interested in what pain means to you and the role of acceptance in your ability to self-manage.

I am inviting both women and men aged 65 and over, who have been living with chronic pain for at least 1 year or greater to participate in this study. By focusing on chronic musculoskeletal pain in the older adult, I am hoping to gain a fuller understanding of how people manage chronic pain conditions in everyday life.

Chronic pain and the older adult?

Chronic pain is defined as pain that exceeds the expected time that takes tissue to heal, and pain that has been present for a period longer than 3-6 months. There are different types of pain that individuals may suffer from and the term chronic pain has been used to encompass the different types of pain.

Chronic pain has no age barrier, it can affect people of all ages. Chronic musculoskeletal pain is considered to be common amongst older adults. The four most common musculoskeletal conditions are: osteoarthritis, rheumatoid arthritis, osteoporosis and low back pain. I am interested in discussing the ways in which people manage their pain, and understand their ability to "move forward" with the pain and achieve goals that are important to them.

What does the study involve?

You are invited to discuss with me the everyday challenges and experiences of living with chronic musculoskeletal pain. It is important to be aware that this study does not offer any treatment.

The interview should last between 1 and 2 hours, and this will be conducted at a time and location that is most suited to you. The interviews will be voice recorded and all interviews will be transcribed by myself. You have the right as the participant to request that the voice recorder be turned off at any point throughout the interview. All transcriptions from the interview will be given back to you to check the information if you wish. You are under no obligation to read the transcript, and if I do not receive it back after two weeks then I will assume that you are happy with it. At the end of transcription, you also have the option to have your audio recordings returned to you or they will be destroyed.

The information obtained from the interviews will form the basis of the research and will be included in a written report. A summary report of the findings from this study will be provided back to each participant, and to the Central PHO and MidCentral District Health Board. The information will be written anonymously, so that it would not be possible for you to be identified. No names or family names will be used in the report.

Confidentiality of identity will be strictly preserved, as all the material collected will be kept confidentially and separately from any other identifiable data in a secure location. The information collected will be available to myself, my supervisor Professor Christine Stephens and the Talking about Heath study team. Upon completion of the written report, all information and data collected from this study will be stored along with the rest of the Talking about Health data.

Your rights:

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question,
- Withdraw from the study at any given point prior to the analysis of the data,
- Ask any questions about the study at any time during participation,
- Provide information on the understanding that your name will not be used unless you give permission to the researcher,
- Access to a summary of the project findings when it is complete.

Please consider this information carefully before deciding whether you would like to participate or not to participate. Should you have any questions or would like further information regarding this research, please do not hesitate to contact me or my supervisor on;

Laura Ng
Phone: [redacted]
Email: [redacted]

Christine Stephens
0800 100 134
c.v.stephens@massey.ac.nz

Should you wish to participate you have the option of either:

1) **Calling or texting me on the cell number 022 064 7478 and I can call back to discuss your interest in participation and to arrange an interview.**

OR

2) **Please complete the response form enclosed and return it in the free post envelope provided (note you do not need to use a stamp). I will phone you to discuss your interest in participation and to arrange an interview.**

Thank you for your time.

Regards

Laura

Appendix Two: Participant contact information form

The experiences of older adults living with chronic pain: a qualitative study.

PARTICIPANT CONTACT INFORMATION FORM

Name:
Address:
Phone number:
Time that is most suitable to be contacted to discuss the interview:
Please return this form in the prepaid envelope should you wish to participate in the study.

Appendix Three: Introductory letter for researcher

TALKING ABOUT HEALTH: Long term conditions study 2016-2018

Interviews 2017

Dear

The time has come for us to organise interviews with the people who indicated they would be prepared to talk to one of the Talking about Health study team about how they manage their long-term conditions at home. Firstly, we would like to thank you for agreeing to be interviewed. We were overwhelmed by the number of people who offered to be interviewed and as we don't have enough people on our study team to talk to everyone we have enlarged our team so that we can accommodate more people.

We are specifically contacting you because you indicated that you have chronic pain and we have a Masters student at Massey who is interested in learning more about how people with unrelieved pain manage their lives. She is keen to talk to people who have had pain for at least a year that is not due to cancer but involves bones, muscles or tendons. Examples include osteoarthritis, rheumatoid arthritis, osteoporosis and lower back pain. Laura is a qualified physiotherapist who is now studying Psychology and we have included an information sheet about her topic to help you decide if you are eligible and would like to take part in her research.

The information you provide her with would be written up as her Master's thesis and could also be added to the information we have collected from other Talking about Health study participants.

To maintain your privacy, Laura does not have your name or contact information and is therefore unable to contact you. So if you are willing to talk to her please return the form she has provided and she will get back to you. Alternatively you can call her on [redacted].

Best wishes

Claire Budge

On behalf of the Talking about Health study team

MidCentral District Health Board

Te Pae Hauora o Ruahine o Tararua

Appendix Four: Participant consent form

The experiences of older adults living with chronic pain: a qualitative study.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the information sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

(Please tick)

	Yes	No
1. I agree to the interview being sound recorded.		
2. I wish to have my recordings returned to me.		
3. I agree to participate in this study under the conditions set out in the Information Sheet.		
4. I agree to allow the researcher (Laura Ng) to have access to the information provided in the Talking about Health questionnaire results.		

Signature: ..... **Date:** .....

Full Name – printed .....

Appendix Five: Interview schedule

The experience of older adults living with chronic pain: a qualitative study.

INTERVIEW SCHEDULE

A semi-structured interview using the following questions will be used to guide discussions and to ensure that all necessary information is obtained.

1. **Tell me about your pain.**
    a. Could you describe how your pain started?
    b. How long have you had the pain?
2. **Has the cause of your pain been diagnosed (Yes or No)?**

    If yes

    a. Who provided this diagnosis?
    b. When did you receive this diagnosis?
    c. What does it mean to have a diagnosis?

    If no

    d. How do you feel about not having a cause for your pain?
    e. How has this impacted on your ability to manage your pain?
    f. Do you think there is an explanation for your pain?
3. **From your own words, can you tell me what is your understanding of the pain?**
    a. Does this differ from what you have been told?
    b. What do you think is going on?
    c. What do you consider to be “normal” pain or “abnormal” pain?
4. **How do you manage your pain?**
    a. What are the main challenges that you face in caring for yourself?
    b. Does financial and availability of support affect how you look after yourself?
    c. How do you feel about getting support from other people?
    d. Are you part of a support group? Tell me about that
5. **What advice has been given to you about the management of your condition?**

a. How do you feel about the advice that has been given?

b. Has the advice given been useful?

c. Is there anything that you would change?

6. **What are your thoughts/views towards living with the pain, and have these views changed over time?**

    a. Has your life changed since the onset of pain and how has this changed?

    b. How does this make you feel?

    c. Do you think that getting older has affected your pain at all?

7. **How do you see your future with this pain?**

    a. Has your view of your pain changed over time?

    b. Do you think that your pain will be part of your life from now on?

        -What processes or strategies have led you to accept that your pain is part of your life?

        -What are your hopes for the future?

    c. What do you consider to be normal aging pain and not normal aging pain?

    d. What are your thoughts towards living with the pain when you are experiencing a flare up?

8. **If you could provide advice to someone living with chronic musculoskeletal pain, what would you say?**

    a. If you could go back to your younger self, from what you know now about your pain, would you change anything?

Appendix Six: Authority for the release of transcripts

The experiences of older adults living with chronic pain: A qualitative study.

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: ..... **Date:** .....

Full Name - printed .....