

***Empowering South Asian Women  
to Effectively Manage Chronic  
Pain: A Multi-Phase Study***

*Sukhvinder Biring*

*School of Health, Education, Policing,  
and Science*

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## Abstract

South Asian women (SAW) are one of the groups that are more likely to be affected by chronic pain. However, they continue to remain underrepresented in research, resulting in a lack of understanding about their needs, experiences, and how they manage their condition. These insights are essential for delivering holistic and culturally sensitive care, as ethnicity and sex influence both pain perception and behaviour. The overarching aim of this research was to gain a better understanding of SAW's experiences of living with chronic pain and to explore ways that could potentially improve health outcomes. This project adopted a predominantly qualitative approach consisting of one study with three different components. Phase one involved conducting a meta-synthesis to gain a collective and comprehensive understanding of women's lived experiences of chronic pain and identify gaps in our knowledge about SAW's experiences. The second phase involved conducting qualitative interviews to address the gaps identified from the review. The third component, an action research study, was divided into three separate stages. The initial stage, through focus groups, explored the key challenges that SAW living with chronic pain face as well as potential solutions. The second stage involved using this data to develop an intervention and resource, and the third stage evaluated them. SAW aged between twenty-four and seventy-eight years, experiencing chronic pain, from the UK were recruited using a combination of snowball and purposive sampling for the second and third phases. The qualitative data were analysed inductively using reflexive thematic analysis. Analysis of the fifty-six studies in phase one provided a deeper understanding of the impact of pain on women's lives, the numerous losses they experienced, and their path to seeking solace

and self-empowerment. The second phase identified themes relating to SAW's experiences of chronic pain, its impact, their needs, and coping strategies. Three key themes were identified during the final evaluation stage: Resource Design and Content, Effects, and Continued Engagement. Participants' mean scores on the Warwick-Edinburgh Mental Well-being Scale were collected before and after the intervention. Statistical analysis showed a significant improvement of approximately ten points in mean post-intervention scores ( $p \leq .001$ ). The themes generated from the analysis of data at each stage are discussed in relation to psychological theories and research on pain management. The contributions and implications of each research phase, the limitations, guidelines for those supporting women living with pain, and suggestions for future research are also stated.

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## Declaration

I affirm that this thesis is the result of my own research and work and has not been previously submitted for any degree or qualification. All contributions made by others have been acknowledged. Where elements of this thesis were developed collaboratively, this has been explicitly stated.

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## Abbreviations

Abbreviation	Unabbreviated Term
ANS	Autonomic Nervous System
ACC	Anterior Cingulate Cortex
CIP	Congenital Insensitivity to Pain
DLPFC	Dorsolateral Prefrontal Cortex
HCP	Health Care Provider
IASP	International Association for the Study of Pain
NICE	National Institute for Health and Care Excellence
PAR	Participatory Action Research
PLP	Phantom Limb Pain
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RTA	Reflexive Thematic Analysis
SAW	South Asian Women
TPB	Theory of Planned Behaviour
WHO	World Health Organization

## Chapter One: Introduction

### Chapter Overview

Chronic pain is a global public health concern. It is the most prevalent disease worldwide, leading to substantial disability and tremendous socioeconomic costs (Nijs et al., 2021; Parks, 2020). This chapter aims to review the theories and relevant literature on chronic pain, define key terms pertaining to pain, and discuss how our understanding of pain has evolved. It aims to provide insight into the complex, multidimensional nature of pain and the various factors that can influence how it is experienced and that also need to be considered when assisting individuals to manage their pain. The chapter will provide a detailed rationale for this study and finish by presenting the research aims, questions, and an overview of the thesis.

### **The Motivation Behind Conducting Research on the Topic of Pain**

Several factors influenced the decision to investigate the topic of pain. It is a fascinating and intriguing subject due to its complexity. However, this study was more than just academic interest and curiosity. A concerning rise in opioid prescribing in the UK, despite their limited efficacy for persistent pain, underscores the need to explore alternative, more effective pain management strategies. Furthermore, the profound impact pain has on individuals' lives cannot be ignored. Chronic pain touches the lives of millions of individuals worldwide, profoundly affecting their daily lives, their ability to function, their quality of life, and their overall well-being (Community Research and Development Information Service, 2020; NHS England and NHS Improvement South West, 2020).

The following quote from the International Association for the Study of Pain (IASP) captures the essence of why exploring pain in women is crucial. 'Every day millions of women around the world suffer from chronic pain but many remain untreated'. The IASP states that several factors may contribute to the ongoing barriers to treatment, including insufficient 'acceptance or understanding of the biological differences between men and women' that can influence pain perception (IASP, 2021). Additionally, economic and political obstacles persist in many countries, 'leaving millions of women living in pain without proper treatment' (IASP, 2021). It highlights the need for targeted research on women and chronic pain to improve understanding and treatment. Consequently, this study's exploration of pain was about learning from those who endure it and striving to use this knowledge to ensure more effective, personalised care for women and to explore novel ways to ease their pain.

## Review of the Literature on Pain

### **The Concept of Pain**

In a broader context, medical science divides pain into three different types: nociceptive, neuropathic, and nociplastic (Hunt, 2023; Mears & Mears, 2023). These categories can be further classified based on the duration of pain: acute pain (short-term pain that typically results from an injury or surgical procedure) and chronic pain (pain that persists for longer than three months after tissue damage has healed; Bonica, 1991; Kerns et al., 2011; Raja et al., 2020). Acute pain is the body's immediate response to a harmful stimulus and is often categorised as nociceptive pain, which is the first category of pain that will be described.

Nociceptive pain refers to pain that arises from the activation of nociceptive fibres, which serve as the body's innate sensors for potential harm (Nijs et al., 2021). This type of pain is typically associated with acute tissue trauma or injuries to muscles, ligaments, or tendons. It is frequently sharp, intense, and localised, making its source simpler to identify. Pain medication can be effective for this type of pain, mitigating the effects of an injury as they exert an effect on the nociceptive system. This pain serves a protective function and usually resolves quickly as the underlying cause is addressed (Fitzcharles et al., 2021; Hunt, 2023; Raja et al., 2020). Once the cause of acute pain has been identified, eliminated, and healing has occurred, the pain will often cease (Cleveland Clinic, 2022).

Neuropathic pain, the second category, arises as a consequence of nerve damage, which can occur during surgical procedures involving nerve severance as well as in cases of nervous system trauma or disease, such as spinal cord lesions, multiple sclerosis, or diabetes (Hunt, 2023). Additionally, neuropathic pain can manifest as a result of nerve damage caused by substance addiction. Pharmaceutical interventions have the potential to alleviate symptoms, although they may not always yield long-term benefits (Hunt, 2023).

Finally, the third type, nociplastic pain, arises due to altered nociception without convincing evidence of tissue damage activating peripheral nociceptors or a somatosensory system disease or lesion (Nijs et al., 2021). It is pain that is not directly related to ongoing tissue damage or inflammation, as is the case with nociceptive pain, nor is it caused by damage in the nervous system, as in neuropathic pain. Instead, nociplastic pain is believed to result from changes in

the way the nervous system processes pain signals, and it lasts longer than three months (Fitzcharles et al., 2021; Hunt, 2023; Nijs et al., 2021).

### **Early Theories on Pain**

Pain has long been a subject of fascination and debate in the realms of religion, science, and philosophy (dating back to Aristotle, 384–322 BCE). As knowledge in the field of pain has increased, so have theories about the concept. Our understanding has evolved from viewing pain as a mystical and supernatural idea to a multidisciplinary scientific field. This advancement has transformed pain management approaches, and a greater understanding of pain continues to enhance them (Bonica, 1991; Cervero, 2012; Lyman, 2021). Devising interventions requires an understanding of these changes, as well as the role of pain and factors that can influence how it is experienced (Parks, 2020); a brief overview is provided below.

Early humans appeared to understand the pain that resulted from most injuries, and their methods for alleviating it included massaging the affected area and exposure to heat from the sun or cold water from the lakes (Bonica, 1991). However, what was less well understood was pain caused by internal illnesses. The painful effects of diseases were attributed to the intrusion of mystical fluids, malevolent spirits, or pain demons in the body. The treatment methods aimed to ward off, appease, or frighten away these demons using various objects (Bonica, 1991).

Ancient Greek physicians, such as Hippocrates and Galen, however, believed that an imbalance of bodily fluids, or humours (phlegm, blood, black bile, and yellow bile), caused disease and pain (Hajar, 2012). Pain was often

thought to result from an excess of black bile or from inflammation due to an imbalance of the other humours.

Ancient Egyptians and Indians believed that pain originated in the heart. The philosopher Plato (427-347 B.C.E.) similarly posited that pain was an emotional experience residing in the soul, which he associated with the heart. He argued that pain and pleasure, despite being opposing sensations, were intertwined and originated from the heart as expressions of the soul (Bonica, 1991). Aristotle (384-322 B.C.E.) also recognised that pain and pleasure influenced human behaviour and stated that humans selected what was pleasant and avoided what was painful (Lyman, 2021). He regarded pain as one of the driving forces behind human behaviour, a 'passion of the soul' (Cervero, 2012). Aristotle believed that the heart was the centre of sensory perception and the most crucial organ in the body. Like Plato, Aristotle argued that pain was felt in the heart, and this Aristotelian concept and his philosophical framework continued to dominate during the middle ages (Bonica, 1991).

As time progressed, understanding about the origins and causes of pain shifted from evil spirits to notions of sin and pain as a form of punishment inflicted by a displeased deity. Consequently, priests were called upon, and they used a combination of prayer and natural remedies. The use of analgesic agents derived from plants was prevalent across various cultures, with notable mentions of the poppy and hemp plants (Bonica, 1991). Headaches and aching joints were treated with aromatic herbs like lavender and sage. A concoction of henbane and hemlock was applied to sore joints (Hajar, 2012).

However, the concept of the sensory heart was beginning to be challenged by some scientists (Bonica, 1991). New theories were being put

forward, and a shift in the centre of sensory perception from the heart to the brain began with René Descartes (1596-1650), a prominent philosopher and scientist. Researchers in the field of pain began shifting their attention to pain's beneficial role in protecting the body from harm (Bonica, 1991; Cervero, 2012).

### **Unpleasant but Vital: Pain as a Protector**

Descartes (1596-1650) was among the first writers to elucidate the protective role of pain. Through his work, he made significant contributions to our understanding of pain and how the nervous system responds to potential injury. He described how pain protected the body from harm in the seventeenth century (Cervero, 2012; Descartes et al., 1664, as cited in Moayedi & Davis, 2013). Descartes stated that an actual or potentially harmful event activated sensory nerves in the body. Once activated, they then transmitted this event-related information to the brain, prompting an appropriate action to be taken to avert further harm.

Similarly, Sherrington (1906) adopted this perspective in his explanation of the role of pain and emphasised its protective nature. He defined pain as 'the psychical adjunct of a protective reflex' (Sherrington, 1906, p. 252). Later, Sherrington (1906) introduced the term 'nociception' to describe the neural processes involved, from the occurrence of a harmful event to the initiation of a protective reflex action ('adapted reactions'; Sherrington, 1906, p. 235).

Both Descartes and Sherrington offered thorough descriptions of the protective function of pain, and modern texts still use Descartes' model to explain the role of nociceptive pain, and his work has been very influential in pain research (Cervero, 2012). Descartes explained how pain protects the body,



using the example of thermal stimulation: when an individual's foot comes into contact with a hot object, a warning signal is sent to the nervous system to initiate a motor response to minimise potential harm. The nervous system, composed of the central (the brain and spinal cord) and peripheral nervous systems (including nerves extending outside the brain and spinal cord; Queensland Brain Institute, 2022), evaluates the appropriate action. As a result, a protective reflex action is triggered, causing the affected body part to retract from the hot object (Cervero, 2012; Descartes et al., 1664, as cited in Moayed & Davis, 2013; Sherrington, 1906).

This is an example of how somatic nociceptive pain (originating from the skin and/or deeper tissues) protects the body. However, nociceptive pain can in various situations emanate from some internal organs (visceral nociceptive pain), but the role of pain is still to protect. An example of this would be severe abdominal pain providing a warning of a possible impending medical emergency: a ruptured appendix (Prescott & Ratté, 2017). Similarly, severe chest pain could signal a possible myocardial infarction. However, the initial pain frequently begins elsewhere. Visceral pain in these situations is known as 'referred' pain (when pain is initially felt somewhere other than where damage has occurred or is happening; Ambron, 2022).

Thus, when the brain determines there is sufficient evidence to believe danger exists, it produces pain as a warning (Moseley et al., 2022; Parks 2020). In such cases, pain does serve as a warning mechanism, motivates individuals to alter their behaviour to protect themselves, and teaches them to be cautious in the future when faced with similar situations (Lyman, 2021). Eccleston (2011) stated that pain's principal function was to serve as an alarm, prompting

individuals to put aside all other concerns or goals in order to concentrate solely on easing or escaping the source of their pain (Eccleston & Crombez, 1999).

Acute pain has a distinct evolutionary and life-sustaining function, drawing attention to the presence of real or potential tissue damage and motivating the organism to distance itself from the source of pain (Tompkins et al., 2017). Without this protective mechanism, it is easy to understand how simple everyday activities could become dangerous and how potentially life-threatening situations could go unnoticed.

### **Congenital Insensitivity to Pain**

This vulnerability can be observed in individuals living with a rare condition that inhibits their ability to perceive physical pain: congenital insensitivity to pain (CIP; MedlinePlus, 2022). This inability to perceive pain can lead to a variety of injuries that may not have occurred, or would have been less severe, if individuals had felt pain. The pain would have warned them of the potential for injury and the seriousness of a situation. CIP can have a detrimental effect on the lives of individuals living with the condition. Over time, these injuries may lead to other health problems, which could also affect life expectancy (MedlinePlus, 2022). Individuals that live with this condition can sustain serious, even life-threatening injuries and not be aware of them. In some cases, it is only after their death that this is revealed.

Pain's vital role in warning and protecting individuals from harm is evident in these cases. The Cartesian model of pain and the idea that pain signals are transmitted (from the affected site) to the brain in order to protect individuals from harm are valid (for certain situations), and they have influenced many

others in the field of pain (Cervero, 2012). They led to the development of other theories, namely the specificity theory of pain (Von Frey, 1895, as cited in PainScale, 2022), which proposed the existence of specific pathways that carry pain signals and a specific system and area in the brain for perceiving pain: the pain centre (PainScale, 2022). This was later challenged (discussed below), but this early research in pain did demonstrate the significance of acute pain (sudden, short-term pain with an underlying cause) and how it functions to protect individuals.

### **The Complexity of Pain**

However, even with sudden, short-term pain, there is more going on than tissue damage and protection. The brain can also create acute pain when there is no actual injury, and it modulates the overall pain experience. In a notable case reported by researchers (Fisher et al., 1995) in the 1990s, a young man was admitted to a hospital complaining of excruciating pain caused by a nail that had supposedly pierced his foot through his boot. He was administered powerful opioids due to the severe agony he claimed to be in. However, upon removing his boot, it was discovered that the nail had not actually penetrated any part of his foot; it had slipped between his toes, leaving his foot completely unharmed (Fisher et al., 1995; Lyman, 2021). In this case, there could have been no pain signal from his uninjured foot; there was no tissue damage, yet he still experienced pain. It is also noteworthy that observers of such a situation might themselves experience both the sensory and emotional components of pain (clutching their feet or even looking away). Research suggests that observing another person in pain activates many parts of the observer's brain that are involved with the actual sensation of pain (Lamm et al., 2011; Lyman, 2021).

Furthermore, pain can be experienced due to somatisation: the process where emotional or psychological distress is expressed through physical symptoms.

A closely related concept to this is psychosomatic, which refers to the relationship between the mind and the body in which psychological factors, such as emotions, thoughts, and stress, can influence physical health and well-being. In essence, psychosomatic conditions are those in which mental and emotional factors play a significant role in the development, progression, or exacerbation of physical symptoms or diseases (Barsky & Klerman, 1983; Eich et al., 2023). The pain experienced by individuals who are grieving can be classified as a form of psychosomatic pain (Ambron, 2022).

Another condition falling under the psychosomatic umbrella is conversion disorder. Individuals with conversion disorder may experience neurological symptoms, such as paralysis, numbness, or convulsions, for which no identifiable neurological cause can be identified. These symptoms are thought to result from psychological stress or trauma (Cleveland Clinic, 2022a; Peeling & Muzio, 2023). Psychosomatic conditions are real, as is the pain that individuals report experiencing, and they can cause significant distress and impairment in individuals' lives. They require a comprehensive approach to diagnosis and treatment that addresses both the physical and psychological aspects of the condition.

Early research in the field of pain could not explain such occurrences. Consequently, the early theories have been criticised for offering a very limited account of the whole range of pain mechanisms. They ignore and fail to explain the many forms of pain that are unrelated to protective reflexes or that are not

completely consistent with a concept that sees pain as a warning system and having a dedicated path (Cervero, 2012). This includes phantom limb pain (PLP), the experience of pain in a part of the body that no longer exists. PLP is not protecting the body in any way. There is no protective justification for this pain being experienced in a part of the body that is not there, and there is no tissue from which an individual could be receiving pain signals. It has been argued that this focus on pain's protective purpose has overshadowed the fact that pain is much more than just a warning system designed to protect individuals from harm (Cervero, 2012).

The above models of pain also do not explain why pain categorised as chronic persists. Later research in the field of pain began acknowledging the complex nature of pain and that it did not always serve to protect individuals from harm. There was also acknowledgement of the importance of the brain in pain with the development of general anaesthesia (Bonica, 1991; Lyman, 2021).

### **Pain and the Brain**

Phantom limb pain has demonstrated that there is no specific pain pathway and that nerves are not needed for pain, just the brain. Pain is generated by the brain (Lyman, 2021; Wager, 2020). Pain arising due to somatisation is also indicative of this. Likewise, this is also demonstrated with surgical procedures and general anaesthesia: tissue damage and injury still occur, but pain is never produced when the brain is not involved in the process and the transmission of pain signals to the brain is blocked (Lyman, 2021).

Individuals with pain asymbolia, a condition where pain is perceived without the associated suffering, underscore the brain's involvement in pain

processing. This condition results from damage to specific brain regions responsible for emotions. Consequently, those with pain asymbolia may feel some level of pain but do not experience the typical unpleasantness associated with it, although some individuals may experience the unpleasantness without being able to describe the pain itself. It illustrates the complex interplay between sensory perception and emotional processing in the brain (Bain, 2014). This highlights that pain is not merely a sensation or emotion but a unique amalgamation of sensory input, emotions, and cognitive processes (Lyman, 2021; Wager, 2020).

Furthermore, the brain can activate and deactivate pain depending on individual circumstances and what it deems crucial for an individual's survival. This can be seen in incidents where injured individuals, who should have been in excruciating pain, manage to accomplish seemingly impossible feats when faced with life-threatening situations (Parks, 2020). The context in which pain occurs can substantially influence how individuals perceive and respond to it. A person engaged in combat may not react to pain in the same manner as someone who sustains a sprain while jogging. The context in which pain occurs is extremely important and will impact the level of pain individuals experience (Hunt, 2023).

In life-threatening situations, the body's primary focus is on survival. The brain can modulate the perception of pain to prioritise immediate survival needs (Parks, 2020). This is often referred to as the 'fight or flight' response, where the body's stress response system is activated, and pain perception may be temporarily diminished or altered. The release of stress hormones like

adrenaline can dampen pain perception, allowing individuals to carry out essential actions without being overwhelmed by pain (Hunt, 2023; Parks, 2020).

### **The Gate Control Theory**

The Gate Control Theory (Melzack & Wall, 1965) was the first model to fully appreciate the value of additional psychosocial elements playing a role in how pain is experienced and in explaining its variability (Cleveland Clinic, 2022b; Melzack & Wall, 1996). It proposed the idea of the existence of a neurological gating system located in the dorsal horn of the spinal cord that allowed the perception of pain to be modified. According to the theory, biological and psychosocial factors influence this gating mechanism, with some factors 'opening' the gates (e.g., anxiety and focusing on pain) and others 'closing' them (e.g., optimism, distraction, and relaxation). When the latter occurs, less information about injuries and related issues may be returned to the brain by the spinal cord. Consequently, the nerve signals that would normally lead to pain are greatly reduced (Parks, 2020).

Ultimately, the gates determine whether the pain signals reach the brain and how strong they are if they do. This theory was ground-breaking in that it explained why tissue damage did not always immediately equate to pain and how the experience of pain could be dialled up or down by the brain (Cleveland Clinic, 2022b; Melzack & Wall, 1996). It also offered the first modern explanation of how pain is produced and modulated, and it led to the neuromatrix theory. It introduced the importance of psychological theory in understanding pain and formed the basis for the biopsychosocial model of pain. However, it still failed to explain PLP (Rodham, 2019).

## **The Neuromatrix Theory**

The neuromatrix theory of pain (Melzack, 2001), on the other hand, helped to address the challenges of explaining PLP. It was developed in response to understanding it and persistent pain. The neuromatrix theory proposes that pain occurs due to the output of nerve impulse patterns generated by a widely distributed neural network in the brain (neurosignature) as opposed to direct sensory input from a physiological cause (Melzack, 2001). Patterns of nerve impulses could be triggered by a painful stimulus (e.g., an injury or an illness). However, they could also be triggered by other factors, like those that would also influence the gating mechanism.

Each person has a unique neuromatrix that is produced through genetics and modified over time by sensory experience and memory, and it impacts how pain is experienced (Melzack, 2001). It is then these unique inputs that activate the network of neurons in the brain that create the perception of pain. This theory acknowledged that cognitive states could influence pain perception and numerous brain regions can be involved in creating pain (Lyman, 2021). This includes areas involved with fear and threat, as well as an individual's thoughts, beliefs, expectations, and memories.

Pain is an integral component of individuals' memories (Cervero, 2012), and all these factors could influence how it is experienced. The theory helped to explain the occurrence of PLP and chronic pain that exist in the absence of a specific painful stimulus. It posited that pain is the product of the neural network in the brain rather than direct sensory input. This theory accounts for the wide variability in pain experiences and the influence of genetics, stress, and prior



experiences. According to the neuromatrix theory, PLP is experienced due to abnormal patterns of activity (neurosignatures) occurring in the brain (PainScale, 2022a). It is also now understood that components of the matrix can be deliberately manipulated to regulate pain (Ambron, 2022).

Modern theories of pain perception recognise the intricate interplay of sensory, cognitive, emotional, and psychological factors in the experience of pain. They take into account the role of the central nervous system in processing pain signals and emphasise the importance of a multidimensional approach to understanding pain. As knowledge about pain has increased, the way in which pain is defined has also changed.

### **A New Definition of Pain**

Pain was defined by the IASP in 1979 as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage' (Raja et al., 2020, p. 13). This was widely accepted and remained unchanged for over forty years. This definition also challenged the linear biomedical approach (discussed below) taken to treat individuals presenting with pain, as it acknowledged that factors other than nociception may have contributed to an individual experiencing pain. From the perspective of those living with pain without an identifiable injury and feeling challenged by others regarding the legitimacy of their condition (Åsbring & Närvänen, 2002), the IASP definition provided hope and lends credence to their experiences (Cervero, 2012).

In recent years, however, there have been calls for the definition of pain to be re-evaluated due to advances in research and understanding of pain.

Experts in the field of pain deliberated (from 2018 to 2020) on whether this definition should be retained or revised, and they agreed on the latter. The definition of pain was revised in 2020 and is defined by the IASP (2020) as ‘an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage’ (Raja et al., 2020, p. 14).

From this definition, it can be seen Aristotle’s views on pain have had a deep and lasting influence on Western philosophy. He acknowledged the emotional dimension of pain which the IASP definition also refers to (Cervero, 2012; Neilson, 2016). This new definition acknowledges that an inability to describe pain does not mean that it is not being experienced (verbal expression is not necessary for the experience of pain to be valid). It was also accepted that any individual reporting an experience of pain should be acknowledged and appreciated as such (even if the cause is not easily identifiable). The revised definition of pain by the IASP (2020) is valid for both acute and chronic pain.

### **The Stigma and Enigma of Chronic Pain**

Chronic pain is often non-specific; there is often no evidence of tissue damage or pathology to explain the pain experience (Nijs et al., 2021). As chronic pain can be experienced in the absence of tissue damage or any other pathophysiological cause(s) (Crofford, 2015; Eccleston & Crombez, 1999; IASP, 2020), it is challenging to treat. Numerous individuals experience chronic pain with no clear indication of a physical injury.

It is a complex phenomenon. Few sensory experiences can transition as dramatically from a defensive reaction to a perceived curse (Cervero, 2012). It has been stated that about twenty-five percent of individuals who experience

acute pain following an injury are also likely to have this progress to chronic pain. This tends to happen due to the nervous system's sensitivity remaining high long after an injury has healed. Consequently, there are individuals who have sustained wounds that ought to have healed, but their pain continues (Parks, 2020). Overprotection is often the root cause of chronic pain (in such cases); an oversensitive central nervous system can trigger pain. The nerves from a previously injured part of the body will keep sending signals and updates to the brain. Consequently, even after the injury has started to heal, almost any activity can trigger the alarm system in the brain, and pain will be produced (Parks, 2020).

Chronic pain is a unique condition involving the body and mind: thoughts, emotions, behaviours, stress, and life experiences all play a role in how even a slight injury can progress into chronic pain (Parks, 2020). It is now acknowledged that the combination of psychological, physiological, and social factors influence pain sensation (Adams et al., 2006; Gatchel, 2004; Mills et al., 2019; Painscale, 2022). All these factors not only make it an extremely complex condition but also one that is often misunderstood and stigmatised (Parks, 2020).

The growing opioid epidemic (mentioned below) has further exacerbated the stigma associated with having an invisible ailment (Hudspith, 2018, as cited in Collier, 2018). This stigma and living with chronic pain can cause stress, and stress can cause or exacerbate pain, creating a vicious cycle. The uncertainty that accompanies living with chronic pain, a disease that affects every aspect of one's life, often results in individuals frequently encountering feelings of stress,

anxiety, frustration, and sadness, which can all amplify pain (Ambron, 2022; Schubiner & Betzold, 2015).

### **Unlocking the Mind-Body Connection: Emotions, Stress, and Pain**

Sarno (2018), a prominent American physician and author, emerged as a pioneer in the realm of mind-body medicine, particularly in relation to chronic conditions, and has assisted countless individuals through his work (Schubiner & Betzold, 2015). He became well-known for his work on the mind-body connection in relation to chronic pain. He proposed the theory that many chronic pain conditions, particularly back pain, could be caused by psychological factors such as repressed emotions, psychological stress, and unresolved conflicts (referred to as Tension Myositis Syndrome/Tension Myoneural Syndrome; Sarno, 2018; Schubiner & Betzold, 2015). This stress can increase the perception of pain.

Stress is not merely an unpleasant mental state; it has profound implications for physical and mental health and pain management. It has been explained that when a discrepancy is perceived by an individual between the physical or psychological demands of a specific situation and the resources of his or her biological, psychological, or social systems, stress arises (Sarafino, 2012). When individuals encounter stressors, whether they are physical, psychological, or emotional, their bodies' fight-or-flight responses are triggered. When these responses are activated, stress hormones are released, primarily adrenaline and cortisol, preparing individuals to confront or flee from perceived threats. While this response is vital in acute situations, chronic stress keeps individuals' stress response systems in a constant state of activation. Over

time, this can have detrimental effects on their health (Ambron, 2022; Schubiner & Betzold, 2015).

The neurobiological mechanisms of the brain explain how stress and negative emotions can manifest as physical pain (Schubiner & Betzold, 2015). Emotions and memories, particularly those processed by the amygdala, play a crucial role in this process. The amygdala plays a central role in processing emotions, especially those related to fear, anxiety, and threat detection, and it helps initiate the fight-or-flight response. Emotions such as anxiety or anger can influence the autonomic nervous system (ANS), which regulates physiological processes including heart rate, digestion, and muscle tension. This interplay can contribute to chronic pain conditions, such as back pain (Schubiner & Betzold, 2015).

Furthermore, after the ANS has been activated, it will stimulate the immune system and cause inflammation and, consequently, pain (Ambron, 2022). The ANS affects various bodily functions, including blood circulation, heart function, and the gastrointestinal system, resulting in symptoms that vary among individuals. ANS activation can cause pain, tingling, numbness, burning sensations, dizziness, irritable bowel and bladder syndromes, cardiovascular changes, migraines, fatigue, and depression. This pain stems from activated nerve pathways, a hallmark of mind-body syndrome, rather than from tissue damage or physical disease (Schubiner & Betzold, 2015).

Besides the amygdala and the ANS, the anterior cingulate cortex (ACC) also influences pain perception. Emotional responses can enhance ACC activity, intensifying pain. The ACC is activated by emotions like worry, fear, resentment,

and frustration. MRI scans show that ACC activation significantly increases pain perception and inhibits the dorsolateral prefrontal cortex (DLPFC ), which typically reduces pain perception (Schubiner & Betzold, 2015). Moreover, persistent stress causes an increase in cytokine levels (small proteins that are essential for regulating the growth and activity of immune system cells, and various other cells, including blood cells; American Cancer Society, 2022). An increase in cytokine levels increases inflammation, causes the activation of the pain matrix's affective components, and affects the way pain is experienced (Ambron, 2022).

### **The Science of Neuroplasticity**

It has also been stated that individuals have the ability to alter how the brain functions. There has been a lot of research on neuroplasticity (the brain's ability to keep changing structurally and functionally in response to life experiences; Doidge, 2007; Klingberg, 2010; Merzenich, 2013; Schwartz & Begley, 2003; Tatta & Moday, 2021; Wager, 2020), and evidence does show that individuals have the power to alter pain perception in the body by changing their thoughts and consciously 'rewiring their brain' (Tatta & Moday, 2021).

Some authors also argue that there is a learning component to pain (Cordier & Diers, 2018; Moseley, 2017). However, Quintner and Griffiths (2020) emphasise the importance of distinguishing between sensation and perception when discussing the human experience of pain. They contend that the former cannot be 'unlearned,' as is sometimes suggested, but pain perception can be modified (Quintner & Griffiths, 2020). They have expressed this view in their critique of an infographic by Moseley (2017) that explains how pain functions

and implies that it is 'learned'. Quintner and Griffiths (2020) argue that this is misleading. As it has been discussed, the sensation of pain serves as a warning signal to the body, signalling potential harm or danger. This rapid and automatic response is essential for survival and protection, and it would be problematic and challenging to 'unlearn'.

However, Moseley (2017) has done an admirable job of simplifying a complex subject for the intended audience (the general population living with pain). In the context of chronic pain, various factors contribute to how individuals perceive and manage their pain. Learning effective pain management techniques, such as relaxation exercises, mindfulness, or cognitive-behavioural strategies, can modify how individuals perceive and cope with pain (Ambron, 2022). Therefore, while the basic sensation of pain (nociception) is innate and not learned, the overall experience of pain (including its intensity, duration, and impact on daily life) can be shaped by psychological, social, and learned factors. This distinction is important in understanding how to effectively manage and treat pain conditions.

### **The Power of Distraction**

According to the self-directed neuroplasticity theory, the brain's functioning can alter based on where individuals direct their attention (Schwartz & Begley, 2003). Thus, if individuals focus on their pain, they will give these neural pathways greater power to develop. The opposite would occur if they focused on something other than their pain. These claims are backed by the successful application of numerous distraction strategies for reducing the experience of pain in adults and children (distraction analgesia; PainScale,

2022b; Schreiber et al., 2014). Distract strategies (which include engaging with nature, listening to music, and colouring) are aimed at distracting individuals from negative thoughts, and they have been shown to be effective for managing emotions (Mansell et al., 2020; Tabibnia, 2020).

Ambron (2022) states that dwelling on pain only makes it worse. However, knowing that people are not generally very good at multitasking and cannot effectively concentrate on more than one sensation at a time can be helpful in trying to manage pain (Ambron, 2022). It can then be reduced by focusing attention on another sensation. Music and pleasing images are powerful distractors (Ambron, 2022). Distraction is found to reduce activation in many areas of the pain matrix (Bantick et al., 2002).

Viewing natural scenery has been shown to increase pain tolerance (Diette et al., 2003), resulting in patients requiring less pain medication (Ulrich, 1984), and reduce anxiety and pain intensity (Miller et al., 1992; Ulrich et al., 1991). In addition to music therapy (Aldridge, 1993; Trauger-Querry & Haghighi, 1999; Whipple & Glynn, 1992), mindfulness (the act of intentionally and nonjudgmentally directing one's attention to the present moment; Ambron, 2022; Kabat-Zinn, 1990), expressive writing (Graham et al., 2008), and engagement in art have been found to be helpful for managing pain. The latter has been reported to reduce pain perception, anxiety, and stress, resulting in an increase in the quality of people's lives (Solan, 2018).

Overall, pain is clearly immensely complex, with numerous factors influencing its occurrence, duration, and the intensity with which it is experienced. This is also the reason why physical pathology is not usually



proportionate to the severity of pain and disability (Keefe et al., 2004). Physical markers, in fact, are extremely poor predictors of pain complaints (Eccleston, 2011a).

### **Chronic Pain: A Global Public Health Concern**

Chronic pain is regarded as a major public health problem that has both high personal and societal costs (Breivik et al., 2006; Dueñas et al., 2016; Yong et al., 2022). Chronic pain is often associated with having a negative impact on the physical, psychological, and social well-being of an individual. Furthermore, it often has a negative influence on an individual's quality of life, and it has been linked to a variety of physical and mental conditions. It is also the most prevalent disease worldwide (Cervero, 2012; Nijs et al., 2021). It is estimated that approximately one hundred million people are living with chronic pain in Europe (Community Research and Development Information Service, 2020). The prevalence of chronic pain in the UK is indeterminate, but it has been estimated to affect approximately one-third to a half of the population (Fayaz et al., 2016).

Globally, estimates suggest that over one and a half billion individuals are living with chronic pain (Goldberg & McGee, 2011; IASP, 2021). It is estimated that women account for seventy percent of this figure (Kiesel, 2017). These estimates are also anticipated to increase in line with an ageing population and due to increased reporting of musculoskeletal pain associated with long COVID (Geddes, 2021; Khoja et al., 2022). Women are also significantly more likely than men to experience long COVID (Schnirring, 2022). Thus, the increases will most likely be greater in women.

### **The Opioid Epidemic**

Opioids are frequently employed for the treatment of pain, and the last three decades have witnessed a catastrophic increase in opioid prescriptions, deaths from opioid overdoses, and no reduction in overall reported pain levels or disability (Kolodny et al., 2015; Parks, 2020). The opioid epidemic in the US has been a significant public health crisis for several decades (Kolodny et al., 2015; Parks, 2020). It can be traced to the excessive prescribing of opioid painkillers in the 1990s and early 2000s. Pharmaceutical companies vigorously promoted prescription opioids as safe and effective for chronic pain management, resulting in a substantial increase in opioid prescriptions (Dyer, 2022; Jones et al., 2018; Kolodny et al., 2015).

Influenced by misleading information from pharmaceutical companies, physicians began prescribing opioids more frequently. Patients were falsely assured that these medications were non-addictive or posed a low risk of addiction (Dyer, 2022; Marks, 2020). Many individuals who were prescribed opioids for legitimate medical reasons developed a dependence on them and, in some cases, addiction. The latter is notoriously difficult to overcome, prompting some individuals to seek illicit sources of drugs once their prescriptions have run out. As the availability of prescription opioids decreased, some individuals turned to heroin, which is cheaper and more accessible (Dyer, 2022; Jones et al., 2018; Kolodny et al., 2015). As a consequence, heroin use increased, contributing to overdose deaths.

The emergence of synthetic opioids like fentanyl, which are extremely potent and frequently mixed with other substances like heroin and cocaine, exacerbated the opioid crisis. Fentanyl's synthetic nature affords precise control of its chemical composition, potency, and effects. However, this also renders it

more susceptible to misuse and abuse when it is created or acquired illegally (Jones et al., 2018; Klobucista & Ferragamo, 2023; National Institute on Drug Abuse, 2023). The production of fentanyl through illegal means has played a major role in the opioid crisis, leading to an increase in overdoses and fatalities related to opioids. This is primarily due to the drug's extreme strength and the difficulties in regulating its dosage outside of medical settings. Due to the potency of these substances, there has been a significant increase in overdose deaths (Dyer, 2022; Jones et al., 2018; Kolodny et al., 2015; National Institute on Drug Abuse, 2023). Additionally, the increasing presence of nitazenes, a class of highly potent synthetic opioids (not approved for medical use), is also exacerbating the opioid epidemic. Their supply in the illicit market increases the risk of fatal overdoses, leading to a rise in the number of deaths among users (Pergolizzi et al., 2023).

Opioids also have many other side effects: they can alter blood pressure, cause damage to the kidneys and liver, alter brain chemistry, destabilise the mood, and have a negative impact on memory and cognition (Parks, 2020). Using opioids for chronic non-cancer pain has been associated with a higher risk of myocardial infarction, fractures, and death (Montgomery et al., 2023). Moreover, prolonged use, misuse, and use without medical supervision can result in opioid dependence. Furthermore, because of the effects of opioids on the region of the brain that regulates breathing, opioid usage can result in death, as can an overdose (World Health Organization [WHO], 2023).

Several countries, however, have continued to witness an increase in the number of prescriptions for these drugs. Between 1998 and 2018, opioid prescriptions in the UK more than doubled (NHS England and NHS

Improvement South West, 2020). This surge has recently been described as an opioid epidemic in the UK, albeit not as severe as that in the US (NHS England and NHS Improvement South West, 2020). Opioids can be beneficial for acute pain; however, there is little evidence to support opioids as being beneficial for long-term pain (NICE, 2019; Parks, 2020). Furthermore, women have been reported to be at a higher risk for opioid misuse (across all age groups; Koons et al., 2018).

Thus, exploring different ways of managing pain is important in the current opioid epidemic so that alternative, effective options can be offered to individuals for pain management (with reduced drug use). As chronic pain is a multidimensional phenomenon, in order to effectively manage it, biological, psychological, and sociocultural elements would need to be considered (Adams et al., 2006; Love-Jones, 2019). With chronic pain, relying on a biological approach (biomedical model) frequently fails (Parks, 2020).

### **The Biomedical, Biopsychosocial, and Biopsychosocial-Spiritual Models**

The biomedical model of illness took a reductionist view of health by only considering biological factors in health (Engel, 1977). By ignoring psychological or social aspects of illness, the biomedical approach failed to explain the multifaceted experience of chronic pain. As knowledge and understanding of health and pain have progressed, there has been a shift from this simple dualistic biomedical model that viewed the mind and body as separate entities to a more complex one that takes biological, psychological, and social factors and their influence on health and illness into account: the biopsychosocial model (Gatchel et al., 2007; Rodham, 2019).

It is worth noting that Descartes (1596–1650) is often referred to as the prominent proponent of mind-body dualism when discussing the strict biological approach. However, according to Neilson (2016), these perspectives underestimate his contributions. The author acknowledged the complexity of pain within his otherwise dichotomous perspective, recognising the intricate nature of pain through his statement that his mind and body were 'closely conjoined' (Neilson, 2016). Cervero (2012) also stated that there was a slight acknowledgement by Descartes that emotions might influence pain perception when he stated that an identical action could be pleasant in times of happiness but disagreeable in times of sadness (Cervero, 2012).

Currently, the biopsychosocial approach is considered the most useful for understanding the complexities of chronic pain and managing it (Gatchel et al., 2007; Parks, 2020; Roditi & Robinson, 2011). Many argue that this model should include a spiritual dimension, and a biopsychosocial-spiritual and culturally sensitive approach is required for treating patients (Burton & Shaw, 2015; Lasch, 2000; Morrison & Bennett, 2016; Sulmasy, 2002).

### **Spirituality, Coping, and Inner Strength**

Globally, spirituality is recognised as a significant factor in addressing various questions pertaining to both well-being and contentment (Gaur & Sharma, 2014). Spirituality is unique to each individual. An individual's spirit helps them understand who they are, their purpose, and the reason they are here. Spirituality provides a means to find inner calm and peace, enabling people to navigate the challenges that life presents (Gaur & Sharma, 2014).

Uslu-Sahan et al. (2023) state that spirituality and religion are closely linked in Muslim societies, and both notions provide frameworks for individuals

to interpret the meaning, purpose, and values of their lives. They state that spirituality and religion are traditionally thought to be synergistic in nations where Muslims constitute the majority of the population (Uslu-Sahan et al., 2023). They conducted interviews with fourteen Muslim women to gain thorough insights and improve knowledge of the spiritual experiences of Muslim women with gynaecological cancer in Turkey. Their study found that nearly all of the participants reported that engaging in religious and spiritual activities associated with Islamic beliefs, such as praying, greatly assisted them in feeling relieved, relaxed, and rejuvenated, as well as enabling them to cope with any side effects that might arise during the course of their treatment. The majority of participants reported adopting hobbies as a means of coping with the adverse effects of the disease, either during its progression or by continuing activities that brought them solace prior to being diagnosed with cancer. Various participants mentioned finding therapeutic value in activities such as painting, gardening, knitting, reading books, and going for walks.

Spirituality has also been found to be a factor that helps lessen the negative effects of a child's illness on carers and contributes to carers' mental well-being. This finding emphasises the need for frontline healthcare personnel to recognise and incorporate spirituality as a coping technique. It emphasises the significance of consistently asking about spiritual coping during screenings or evaluations and then making accommodations to strengthen spiritual practices, thus contributing to a holistic and supportive care management system for both the patient and their family (Chong et al., 2023).

Benson et al. (2010), when discussing spirituality, faith, and culture, make an important point, stating: What may appear as 'passive fatalism to some' could

also represent a profound source of 'strength, courage, and wisdom' that has supported individuals throughout the numerous challenges they may have encountered (p. 6). They state that for HCPs to gain a deeper understanding of a particular culture, it is essential that they remain open to learning from those within that culture.

Shahid et al. (2020) provide valuable insights into the concept of 'fatalism'. They state that classic fatalism refers to the belief that events are predetermined, regardless of one's actions, and studies have shown that this belief is linked to higher levels of depression and a tendency to feel less in control of one's life. This perspective suggests that events are predetermined, and individual actions may not significantly impact outcomes. People with high classic fatalism might feel their efforts are futile in influencing their fate.

In Shahid et al.'s (2020) study, they proposed another concept: active fatalism. They stated that this involves believing in a predetermined future but also believing that individuals have a role in making that future happen. This variation acknowledges a predetermined future but also emphasises personal agency and responsibility in shaping that future. Individuals with active fatalism believe they play a role in bringing about the destined future. They hypothesised that active fatalism would be linked to lower levels of depression, a greater sense of control, and healthier coping skills. To test this, they gathered data from an online survey of religious participants. Their results supported the existence of multiple facets of fatalism. They stated that passive fatalism, which aligned with traditional definitions of fatalism, demonstrated a positive and significant correlation with depression, negative coping, and an external locus of control. Conversely, active fatalism exhibited a significant and positive

correlation with the utilisation of positive coping strategies, while displaying a negative correlation with depression symptoms and an external locus of control (Shahid et al., 2020).

Spirituality is important as it is central to the lives of many individuals. Research suggests a majority of patients (ninety percent) see themselves as both religious and spiritual, often using these terms interchangeably (Taylor et al., 2013). Spirituality and/or religion serve as vital coping mechanisms for individuals with chronic conditions. Recognising and addressing the spiritual and religious needs of patients is essential for a comprehensive approach to managing chronic pain. Furthermore, ninety-five percent of patients want their health care providers to address their spiritual needs (Taylor et al., 2013).

It has also been argued that 'spirituality has paramount importance for high standard medical training and clinical practice' (Saad et al., 2017, p. 5). There is, however, disagreement on how spirituality is defined. It has been argued that rather than focusing on defining spirituality, researchers should concentrate on how patients define the term themselves (Taylor et al., 2013).

Many authors have acknowledged the importance of incorporating a spiritual component to the biopsychosocial model. Many endorse the expansion of the medical paradigm to incorporate a biopsychosocial-spiritual framework (McKee & Chappel, 1992; Siddall et al., 2015; Sulmasy, 2002). Spirituality and religiosity are acknowledged as crucial resources for coping with chronic diseases and serious illnesses, providing patients with a sense of peace, meaning, and purpose. Addressing spiritual needs through a holistic, patient-centred approach can lead to improved health outcomes (Büssing & Koenig, 2010; Glover-Graf et al., 2007; Ross, 1995). The universal human needs for



peace, health, and social support are especially significant for patients experiencing chronic conditions (Büssing & Koenig, 2010; Büssing et al., 2010).

Chronic pain is a condition involving the central nervous system where the structure and function of the nerves change in a way that perpetuates the pain. Spiritual practices can bring positivity that rewires the brain and its connections, leading to a more positive outlook on managing pain. When people think positively and balance their thoughts about pain, it can reduce social isolation, catastrophic thinking, and anxiety related to pain (Salgaonkar et al., 2021). On the other hand, negative thoughts can fuel fear and a cycle of inactivity. These negative thoughts, emotions, expectations, and memories can create additional sources of chronic pain (Salgaonkar et al., 2021). Clinical interventions that enhance a sense of meaning and purpose in life can help chronic pain patients overcome the negative thoughts associated with pain, thereby alleviating symptoms (Salgaonkar et al., 2021).

Overall, it has been argued that there is already sufficient evidence to support the incorporation of spiritual aspects into medical education (McKee & Chappel, 1992), and recognising the spiritual dimension of pain is essential to a comprehensive approach to chronic pain management (Salgaonkar et al., 2021). The table below (Table 1.1) outlines each dimension of a biopsychosocial-spiritual model of pain along with examples of factors within each dimension.

**Table 1.1: Biological, Psychological, Social, and Spiritual Factors that can Influence the Experience of Pain**

Dimension	Factors that can influence the experience of pain
Biological	Sex

	Physical health, injury/tissue damage
	Age
	Hormones
<b>Psychological</b>	Mental health (e.g., depression, anxiety)
	Knowledge, thoughts, and beliefs
	Coping strategies
	Stress
<b>Social</b>	Family relationships (e.g., support networks)
	Social support (e.g., friends, community)
	Socioeconomic status (e.g., income, education)
	Culture
<b>Spiritual</b>	Personal beliefs (e.g., religion, belief in a higher power)
	Sense of purpose (e.g., life goals, meaning)
	Connection to nature (e.g., eco-spirituality)
	Mindfulness and meditation practices

There are many psychosocial factors found to influence the experience of pain, and these include anxiety, stress, depression, self-efficacy, thoughts, socioeconomic/employment status, culture, loneliness, discrimination, and HCP bias (Anxiety & Depression Association of America, 2021; de Heer et al., 2014; Lyman, 2021; Maly & Vallerand, 2018; Mills et al., 2019; Painscale, 2022; Tatta & Moday, 2021). These factors influence how the nervous system responds to injury, danger, and healing (Tatta & Moday, 2021). Effective management of chronic pain requires careful consideration of all these factors (Adams et al., 2006; Alhowimel et al., 2018; Miró et al., 2009; Rodham, 2019), as they

contribute to the chronicity of pain (Kerns et al., 2011). The gradual shift away from the biological model has resulted in the introduction of biopsychosocial treatments such as cognitive behavioural therapy (CBT), mindfulness-based stress reduction, and fear-avoidance methods in the management of chronic pain (Meints & Edwards, 2018; Turner et al., 2007).

Despite this introduction, the quality of health care that individuals receive for chronic and musculoskeletal (MSK) pain has been reported as suboptimal, and it has also been reported that psychological and social elements are still being ignored in the management of chronic pain (Lim et al., 2019; Lin et al., 2018; Ng et al., 2021; Parks, 2020). Patients with chronic pain in the UK report not being very satisfied with the support they receive from HCPs for their pain (Arthritis & Musculoskeletal Alliance, 2019; Gordon et al., 2017).

### **Persistent Problems**

It has been stated that despite numerous disciplines having dedicated considerable academic resources and humanitarian enthusiasm to the study of pain, the number of people expressing their suffering remains as high as ever (Bourke, 2014; Parks, 2020). The clinical practice guidelines for common MSK pain conditions were reported to be poor. Another issue that has been highlighted is the overuse of opioids. A failure to provide patients with education and guidance about their condition has also been identified (Gordon et al., 2017; Lim et al., 2019; Lin et al., 2018; Parks, 2020; Vakil et al., 2023).

Additionally, a recent systematic review conducted by Basnet et al. (2023) investigated online information on chronic pain in Nepal, Australia, and Mexico with regards to three areas: credibility, readability, and accuracy. The authors

concluded that there was a need for international improvements in chronic pain online resources in all three aspects. Enhancing these aspects globally is crucial to better support the effective management of chronic pain (Basnet et al., 2023).

At present, the ever-increasing number of people with serious chronic illnesses encounter numerous hurdles in managing their condition, and medical care often does not meet their needs for information, effective clinical management, and psychological support (Gordon et al., 2017; Lim et al., 2019; Lin et al., 2018; Ng et al., 2021; Parks, 2020; Vakil et al., 2023; Wagner et al., 2001). It has been argued that this may be due to the demands of chronic illness patients not being met by a system built primarily for acute conditions (Wagner et al., 2001). However, to improve health outcomes, a thorough understanding of the group's needs, attitudes, challenges, and beliefs is required (Lucas et al., 2013).

## **Women and Chronic Pain**

'For many people their sex and gender are the same. . .[and they will] just respond "male" or "female" as appropriate' (Office for National Statistics [ONS], 2019, p. 4), and the terms are often used interchangeably. This study focuses on women's experiences (adult females) and will include SAW over the age of eighteen. To avoid repetition and ensure clarity, the terms 'women' and 'men' in this document refer specifically to adult females and adult males, respectively. This project includes adult individuals (18+) whose sex assigned at birth and gender identity are both female.

It is estimated that seventy percent of people living with chronic pain are women (Kiesel, 2017). Interestingly, they are less likely to receive adequate treatment (Kiesel, 2017). As mentioned above, many factors impact how individuals experience living with persistent pain (Love-Jones, 2019). Sex is an important factor in differentiating illness experiences (Criado Perez, 2019; Mills et al., 2019). Pain research reveals that females are more sensitive to the perception of pain than males and report higher levels, longer durations, and more frequent occurrences of it. Additionally, they experience more pain-related conditions (Bartley & Fillingim, 2013; Fillingim & Maixner, 1995; Fillingim et al., 2009; Keogh et al., 2005; Koons et al., 2018; Mills et al., 2019; Miyazaki & Yamamoto, 2009; Pieretti et al., 2016; Riley et al., 1998).

Furthermore, women are disproportionately affected by several chronic painful conditions, including fibromyalgia (which causes widespread pain), migraines, and temporomandibular (jaw joint) disorders (Hurley & Adams, 2008; Pieretti et al., 2016; Versus Arthritis, 2021). Women are also more frequently affected by MSK conditions, such as arthritis, which impact the joints, bones, muscles, and spine (Arman et al., 2020; Versus Arthritis, 2021). They also tend to live longer lives (age is a factor related to chronic pain; Mills et al., 2019) and are more likely to develop osteoporosis and joint inflammation (Pieretti et al., 2016), all of which contribute to pain. It has also been reported that women are more likely to experience high-impact chronic pain (severe disabling pain) than men of a similar age (Versus Arthritis, 2021). Individuals experiencing radicular symptoms report a negative effect on nearly all areas of their lives, including the presence of suicidal thoughts (Ryan & Roberts, 2019). Therefore, it is crucial to

consider the mental health implications of MSK disorders and the chronic pain that accompanies them (Arman et al., 2020; Ryan & Roberts, 2019).

However, there is also evidence suggesting that men are less likely to report pain than women (Greenspan et al., 2007; Koons et al., 2018), potentially influencing the observed higher prevalence of women affected by pain (Koons et al., 2018). However, findings from a systematic review found that evidence for increased female consultation for two prevalent conditions, headache and back pain, was found to be weak (Hunt et al., 2011).

Overall, pain is more commonly experienced by women than men. This is observed at all ages. Additionally, women are more likely to experience multiple types of pain and chronic conditions (Skuladottir & Halldorsdottir, 2011). Managing women's health requires a specifically tailored approach. From childhood to old age, females may experience various physiological processes and health-related events that are exclusive to them (e.g., menstruation, pregnancy, and menopause) and a number of sex-specific health issues. To provide effective health care and enhance the well-being of women as a whole, it is essential to acknowledge their experiences and needs.

### **The Data Gender Gap**

Data is essentially information that can originate from a variety of sources, such as statistics and/or human experience (Criado Perez, 2019). Nonetheless, if decisions are to be made based on this information, it must be gathered from both men and women, and their distinctions must be acknowledged. However, this is not the case, and there is an urgent need to resolve the 'gender data gap' (Criado Perez, 2019). Furthermore, Criado Perez

(2019) argues that data is virtually non-existent for women of colour, those with disabilities, and women from working-class backgrounds.

Women seem to be largely excluded from health-related research, and this can have serious consequences: there are differences in the way drugs are metabolised by the body, for example, and prescribing gender-neutral dosages puts women at risk of an overdose (Criado Perez, 2019; Schiebinger, 2003). This was echoed recently in an article by Plevkova et al. (2020). It was stated that there is a lot of evidence that sex bias in research is to blame for things like treatments that work well for men but not for women. Furthermore, the number of adverse effects reported by women is also higher because certain drugs were made and tested only on male participants.

### **The Rationale for Selecting South Asian Women (SAW)**

The need to focus on the diverse health needs of women from various ethnic groups is also being acknowledged (Schiebinger, 2003). SAW were selected for this study as they are underrepresented in research. There is a lack of recent qualitative research that explores chronic pain in SAW. Recent research has explored SA's thoughts about pain and pain management (Burton et al., 2019) and the lived experiences of five English-speaking SA individuals (Singh et al., 2018). A recent study conducted in the UK explored the perception of pain with SAW living in the UK, aged between forty and seventy-five years (Holt & Waterfield, 2018). However, the focus was not on chronic pain management, and the women were not required to be living with any pain (some were not). Furthermore, the authors used small group interviews, and one-to-one interviews could provide deeper insights on a topic of interest (Barbour, 2018).

Additionally, SAW are more likely to be living with chronic pain due to them being at a greater risk of having certain other chronic conditions (e.g., diabetes) and low physical activity (PA) levels (Diabetes UK, 2023). PA levels of South Asians (SA) living in the UK are consistently below those of the general population, a trend that develops early in life (Bhatnagar et al., 2016; Jepson et al., 2012). In this group, PA is the lowest among SAW. Research suggests that they engage in far less PA and that some barriers prevent them from doing so (Johnson, 2000; Lip et al., 1996; Public Health England [PHE], 2018; Sriskantharajah & Kai, 2007).

Inactivity increases the risk of developing chronic conditions like diabetes, but it can also exacerbate pain perception (Anderson & Durstine, 2019; Lima et al., 2017). In their narrative review of chronic pain and its epidemiology and associated factors, Mills et al. (2019) found, among other factors, gender, ethnicity and cultural background, and physical activity as factors associated with the development of chronic pain.

There has also been evidence pointing to the disproportionate number of ethnic minority groups impacted by the COVID-19 pandemic (Institute of Health Equity & The Health Foundation, 2020; Otu et al., 2020). As previously stated, COVID causes additional challenges in terms of pain; hence, treatments focused on these groups are required. Older SAW are also an at-risk group for suicide (Mental Health Foundation, 2021), and as they would also be more likely to be living with chronic pain, research that could provide further insights that could help improve their health outcomes and well-being is needed.

### **Why Research Could Be Lacking on SAW with Chronic Pain**



There are many reasons that may have led SAW to be excluded from research: language barriers, not being present in healthcare settings where recruitment is taking place, and cultural issues (Shah, 2004). Women who may have difficulty understanding or communicating in English may feel less comfortable participating in research, feel that they are not able to express their experiences well, or do not know the terminology or words to use to describe their experiences, as most research is conducted in English. The use of translators during research may not solve this problem because building rapport is essential.

There have also been problems reported with researchers using translators (Chiu & Knight, 1999; discussed in Chapter Two), and there is also the issue of confidentiality and how individuals would feel about this. It has been argued (although referring to healthcare settings) that individuals would feel more at ease and communicate freely in language-concordant encounters as opposed to language-discordant encounters (Chaufan et al., 2016; Molina & Kasper, 2019).

Furthermore, due to access to research participants also needing to be negotiated in accordance with cultural norms and restrictions, this can also cause difficulties in recruitment. A female interviewer, for example, may be accepted where a male interviewer may not be (Shah, 2004). Cultural norms and constraints will also influence recruitment and retention, and these need to be acknowledged (Basit, 2013; Shah, 2004). However, research indicates that minority ethnic groups are generally open to participating in studies if the research is relevant to them and their community and if they receive a

considerate approach along with detailed information about what their involvement entails (Redwood & Gill, 2013).

## **Ethnicity and Pain**

### ***Terminology***

Ethnicity is a complex and multifaceted concept that refers to an individual or group's cultural identity, which is frequently characterised by shared cultural characteristics, heritage, language, religion, customs, and sometimes a sense of shared history or ancestry. Ethnicity is distinct from race, which is primarily determined by physical and genetic characteristics. The term 'ethnicity' was considered appropriate for this research (given the importance of biopsychosocial factors), as it comprises not just race but also psychosocial and cultural characteristics, all of which are inextricably linked to one's identification as a member of a specific group (Campbell & Edwards, 2012; Edwards et al., 2001).

According to PHE (2018), terminology relating to ethnic groups varies, needs to be refined, and frequently entails broad groupings being used. SAs in the UK, however, are widely recognised as persons of Pakistani, Indian, and Bangladeshi descent (Diabetes UK, 2023; 2024; Iqbal, 2023). The study will include women (in the UK) who identify as SA.

### **Unnecessary Pain**

Lyman asserts that unnecessary pain accompanies social injustice (Lyman, 2021), and there are numerous individuals and groups whose pain is exacerbated by social injustice (two of which are women and ethnic minorities; Lyman, 2021). Decades of research indicate that an individual's ethnicity may

influence their experience of chronic pain and the treatment for it (Bull et al., 2023). It is suggested that there are ethnic inequalities at every level of the healthcare system, including with the patient (genetic predispositions to developing certain conditions), the practitioner (implicit biases that can have a negative impact on interactions with patients from minority groups), and the system itself (access to care; Green et al., 2003; Wheeler & Bryant, 2017).

Black patients are less likely to receive medication for their pain than White patients (Meghani et al., 2012; Singhal et al., 2016). This is also true for Black children (Goyal et al., 2015; Lyman, 2021). This has also been found with Hispanic patients compared to non-Hispanic White individuals, and these distinctions remained evident even after controlling for factors such as gender, primary language, injury severity, and substance abuse (Anderson et al., 2009).

According to a review conducted by Anderson et al. (2009), these inequalities were observed in the provision of pain care in various settings and for various kinds of pain (acute, chronic, cancer, and palliative) throughout a person's life. The study revealed that minority populations received lower-quality pain care compared to non-Hispanic Whites. Moreover, African American individuals and women with chest pain were prescribed fewer medications aimed at alleviating pain and addressing related cardiovascular risk factors compared to the White patients and men (Anderson et al., 2009).

Studies have found that there are biases and false beliefs about an individual's ethnicity among health professionals and medical students (Druckman et al., 2018; Hoffman et al., 2016). Hoffman et al. (2016) found in their study that approximately half of the White medical students and residents in their sample ( $n = 418$ ) shared false beliefs based on ethnicity. Additionally,

those who expressed agreement with these ideas tended to perceive the pain of Black patients as less severe when compared to White patients and provided less precise treatment recommendations. Conversely, participants who did not subscribe to these false beliefs tended to rate the pain of Black patients as more severe but did not exhibit any bias in their treatment recommendations. The authors concluded that such findings indicate that individuals with some level of medical training uphold and potentially rely on inaccurate beliefs about biological distinctions between Black and White individuals when making medical judgments. Reliance on these beliefs could contribute to disparities in the assessment and treatment of pain among racial groups.

The relationship and importance of the relationship between pain, culture, and ethnicity was explored and highlighted over fifty years ago (Zborowski, 1952; Zola, 1966). Zborowski (1952) noted that immigrants in the US seemed to adopt the host culture with regards to most behaviours and attitudes. However, this did not seem to occur in relation to pain. He stated that the further an individual is 'from the immigrant generation the more American is his behavior'. However, attitudes toward pain seem to persist to a large extent, even among third-generation members (p. 27).

Findings from more recent research exploring the occurrence of pain in different ethnic groups and between males and females show more variability in the presentation of pain among women across the life span and in different ethnic racial groups (Parmelee et al., 2012; Plesh et al., 2011). Women experienced higher levels of pain and slightly greater disability compared to men. Additionally, African Americans reported more disability and slightly higher levels of pain in comparison to non-Hispanic Whites (Parmelee et al.,

2012). Furthermore, African American patients exhibit a lower level of ischemic pain tolerance (experimental pain) than Caucasian patients (Edwards et al., 2001). Similar disparities were found among older individuals in Singapore from a national survey; where those of Malay descent reported less severe pain than Chinese participants, while Indian participants reported greater pain severity compared to both Malay and Chinese participants (Campbell & Edwards, 2012).

There is also a difference in the pain behaviours reported by different racial and ethnic minority groups, with more self-care behaviours being reported by Caucasians than Hispanic and African Americans (Hastie et al., 2005). Higher numbers of individuals in the latter groups were also found to have prayed to reduce their pain than those in the former. The researchers stated that these pain-based behaviours could be based on cultural influences that may have been acquired fairly early in life.

While the studies discussed above were U.S.-based, similar findings have also been reported in the UK. A study in the UK compared the experience of pain and coping strategies adopted by individuals of SA and African-Caribbean origin (Rogers & Allison, 2004). Widespread pain was reported more commonly by both groups than in a general population sample from the same area. Individuals in the former group, however, were found to be less likely to adopt individual coping strategies and instead tended to emphasise fragility and paralysis of the body. There was also a reluctance to acknowledge symptoms of depression, and home remedies were selected by older individuals from both groups (Rogers & Allison, 2004).

Another study conducted in the UK with SA males found that they exhibited lower heat pain thresholds and reported higher pain levels when compared to matched White British males (Watson et al., 2005). Research in the UK has also found that MSK pain is reported to be higher in some ethnic minorities than in Caucasians (Allison et al., 2002).

In the US, variations in how individuals respond to interventions have also been reported (Merry et al., 2011; Siedlecki, 2009). Siedlecki (2009) investigated how individuals from different racial backgrounds responded to music in a sample of adults dealing with chronic pain. In the post-test analysis, both music groups, regardless of race, reported a reduction in both pain and depression compared to the control group. However, the statistical significance of this difference was observed only within the Caucasian music group, whereas it did not reach statistical significance in the African American group.

A similar finding was reported by Merry et al. (2011). Their study aimed to assess ethnic group variations in pain-related outcomes after receiving multidisciplinary chronic pain treatment. They used a pre- and post-treatment assessment approach to examine how ethnicity influenced changes in pain-related factors following a four-week multidisciplinary pain treatment program. Results indicated that following the completion of the multidisciplinary treatment, both White and African American patients experienced reductions in interferences related to pain and depressive symptoms. However, only White patients also reported decreased pain severity. It has been argued that these findings suggest that certain non-pharmacological treatments may be formulated and administered in a manner that is more likely to be advantageous for non-Hispanic White individuals compared to others. Customising these

treatments to align with different cultural backgrounds has been recommended (Campbell & Edwards, 2012).

There is also variation in the way individuals from different ethnic groups metabolise important drugs, and differences in how clinically effective they are, and variations in the side effect profiles (Burroughs et al., 2002). In a study investigating biological variations, researchers investigated the connection between plasma oxytocin (OT) levels and pain sensitivity in both African American and non-Hispanic White women. The results of the study revealed a significant difference in pain tolerance between African American women and non-Hispanic White women. The former group of women exhibited significantly lower pain tolerance across tasks and lower levels of plasma oxytocin compared to the latter group. Importantly, the lower oxytocin levels among African American women were found to contribute significantly to the ethnic disparities observed in their responses to experimental pain. The authors concluded that the low levels could be one of several biological factors contributing to the heightened sensitivity to experimental ischemic pain, as well as the increased prevalence of certain types of clinical pain among African Americans when compared to White individuals (Grewen et al., 2008).

Knowledge and self-efficacy also seem to vary between different ethnic groups. Lucas et al. (2013) reviewed studies on SA's beliefs and knowledge on adopting a healthy lifestyle and concluded that 'Concepts such as self-efficacy or empowerment. . . may not be readily applicable to South Asians'. They state that the emphasis on individuals managing their own health is challenging because it demands significant motivation and prioritisation of health. This becomes

difficult when the benefits of engaging in health-related behaviours are not clear and long-term health is not a top priority for individuals.

However, it has been argued that it is important to highlight that cultural beliefs and other health-related attitudes may not always be the cause of non-participation in medical examinations, maintaining an unhealthy lifestyle, and delayed seeking of professional aid. Additional issues, such as insufficient knowledge regarding symptoms and treatments, may hold equal significance (Dein, 2004).

As discussed above, for self-efficacy and empowerment, an individual also needs to have knowledge to feel confident that they can alter an outcome. Greenhalgh et al. (2015), from their qualitative study exploring how social and cultural factors influenced the behaviour of SAW with diabetes in pregnancy, found that there were a lot of misconceptions about their condition among this group, and they were not fully aware of health behaviours that could be beneficial and those that were not. Dein (2004) reported a notable absence of understanding about cancer, particularly among non-English speakers and the elderly. Such findings have led others to call for more effective community-based interventions for such individuals, such as the provision of bilingual interpreters and health education materials that are sensitive to cultural differences.

These studies underscore the significance of considering ethnicity in pain management. They shed light on the existence of disparities in pain assessment and treatment based on ethnic backgrounds. Reports of cancer pain undertreatment are also troubling, but it is even more concerning that studies show patients from minority groups are at an even higher risk of receiving



inadequate pain management for this. If cultural factors are not considered, the care provided may be ineffective or even harmful (Cleeland et al., 1997; Lasch, 2000).

A substantial portion of the research on ethnicity and pain has been conducted in the US and highlights that African Americans, in contrast to non-Hispanic Whites, experience a greater burden of pain and the difficulties associated with it (Campbell & Edwards, 2012). However, as previously discussed, documentation of ethnic disparities is also occurring in other countries. In the UK, minority ethnic groups often experience poorer health outcomes compared to the general population, with chronic pain affecting certain minority groups disproportionately (Leach et al., 2023; Parliamentary Office of Science and Technology, 2007). Factors such as cultural beliefs, health care provider biases, and perceptions of discrimination can contribute to differential pain experiences and outcomes among various ethnic groups. Obstacles hindering the achievement of optimal pain management for racial and ethnic minority patients encompass a range of factors involving the patients themselves, HCPs, and the healthcare system (Green et al., 2003; Leach et al., 2023; Parliamentary Office of Science and Technology, 2007).

Patient-related barriers may encompass variations in pain thresholds and tolerances among different racial and ethnic groups, genetic factors, and attitudes and beliefs related to pain. Provider-related obstacles often stem from a lack of knowledge and training in pain treatment, insufficient assessment and management of pain, as well as preconceived beliefs and expectations concerning minority patients (Green et al., 2003; Parliamentary Office of Science and Technology, 2007).

Understanding how cultural and ethnic backgrounds influence pain perception, expression, and treatment can lead to more effective and patient-centred care, as culture shapes how people perceive and communicate their pain. Some cultures may encourage open expression of pain; others emphasise stoicism and restraint. Additionally, patients' cultural and ethnic backgrounds can influence their preferences for treatment and their beliefs about pain management. Some individuals may favour non-pharmacological methods, traditional remedies, or alternative therapies over medication (Anderson et al., 2009; Green et al., 2003). Recognising and respecting cultural diversity are essential aspects of delivering patient-centred care.

Other authors have also argued that there is an urgent need for research committed to identifying, understanding, and reducing inequalities in health care (Institute of Health Equity and The Health Foundation, 2020; PHE, 2018; Wheeler & Bryant, 2017). According to research, some individuals worry that incorporating ethnicity may add an additional layer of complexity to their work, but addressing this issue is important (PHE, 2018).

### Aims of the Present Study and the Research Questions

The overarching goal of this research was to gain a better understanding of women's, specifically SAW's, experiences with chronic pain and explore options that could potentially improve health outcomes. The research objectives and questions for each of the three phases of the present study are listed below.

#### **Phase One**

This phase aimed to gain a collective understanding of women's experiences of living with chronic pain and identify gaps in the literature on SAW.

**Research Question:**

What are women's experiences of living with chronic pain?

**Phase Two**

This phase sought to gain insight into SAW's experiences of living with and managing chronic pain, the impact on their well-being, and how well the healthcare system addresses their needs, including the application of the biopsychosocial model.

**Research Questions:**

What are SAW's experiences of living with and managing chronic pain, and how do these experiences impact their well-being and daily lives?

What coping strategies do they use?

How have SAW found their experience with the healthcare system in managing their pain and well-being, particularly in terms of addressing their needs, applying the biopsychosocial model, and the level of information provided to them?

**Phase Three**

An action research project to address the concerns raised in Phase Two in order to empower women to live well with chronic pain.

**Stage One Objectives**

To identify the key challenges faced by SAW living with chronic pain and understand what improvements they would like to see.

**Stage Two Objectives**

To gather ideas from SAW on the design of a resource and co-create a resource/intervention to help manage their pain.

### **Stage Three Objectives**

To evaluate the effectiveness of the designed intervention/resource based on SAW's feedback and changes in their self-reported Warwick-Edinburgh Mental Well-being Scale (WEMWBS) pre- and post- intervention scores.

### **Research Questions:**

What are the key challenges faced by SAW living with chronic pain, and what improvements do they seek?

How do SAW envision the design of resources to help manage their pain?

What are the perceptions of SAW regarding the effectiveness of the co-created intervention/resource?

Does participation in the intervention result in a statistically significant improvement in the well-being of the participants as measured by the Warwick-Edinburgh Mental Well-being Scale (WEMWBS)?

### **Impact and Potential Value**

The findings of the present study could be used to inform the planning of future interventions to help manage chronic pain and improve patient experience and outcomes. They could also be used to plan for larger-scale studies. The findings highlight the needs of an underrepresented group and could help to reduce the health inequalities that have been highlighted by the Race Disparity Audit (PHE, 2018), and research by the Institute of Health Equity

and The Health Foundation (2020). It would also address the current gap in literature that exists in this area and could help individuals manage their pain more effectively with reduced drug use.

## Chapter Summary

This chapter has discussed the development of our understanding of pain. It was frequently attributed to supernatural forces, deities, or evil entities as divine punishment or malevolence in ancient times. Since then, it has been accepted as an integral part of the human experience, serving as a warning signal for potential harm and a motivator for necessary actions to safeguard and preserve health. It is also extremely complex: an amalgamation of sensory input, emotions, and cognitive processes. The various theories, dimensions, and factors that influence how pain is experienced have been addressed.

Understanding the multidimensional nature of pain is crucial in order to provide effective treatment and support. It sheds light on the power of individuals and HCPs to help ease it. Pain, in all its forms, is a reminder of our vulnerability as humans and underscores the importance of addressing and alleviating suffering whenever possible. Furthermore, recognising the complexities of pain may help foster empathy and compassion among individuals who may never have personally experienced it. A rationale for the present study has been provided, the three different phases explained, and the research aims and questions stated. The subsequent chapter, the methodology chapter, explains the research paradigm and provides justification for the data collection methods for each phase of the study. Further chapters to follow within this thesis include a meta-synthesis (Chapter Three), study component two (Chapter Four), study component three (Chapters Five, Six, and Seven), a general discussion of the

findings, suggestions for future research, recommendations, and a conclusion (Chapter Eight).

### Chapter Overview

The previous chapter provided an overview of the relevant literature on pain, defined theories, and discussed the complex, multidimensional nature of pain. SAW continue to remain underrepresented in pain research. The present project aims to address this gap by exploring, analysing, and reporting on their experiences, needs, and challenges. To achieve this in a comprehensive manner, it is important to consider the research paradigm and provide a rationale for the various approaches selected. This chapter aims to provide an overview of the studies conducted, the research paradigm, and the methodological considerations of this project. It will discuss the researcher's ontological and epistemological stance, provide a more detailed description of the approaches and data collection methods employed, as well as the rationale for the decisions made throughout all three phases of the project. The final section of the chapter will address the issues surrounding validity, quality, and ethics.

### Overview of the Studies

The devastating effects of chronic pain on those living with it as well as the tremendous societal costs have been discussed. Chronic pain affects approximately twenty percent of adults in Europe and impacts every aspect of their lives, including work, relationships, and physical and mental health (Hadi et al., 2019; Nijs et al., 2021). Thus, effectively managing it is crucial.

The overarching aim of this research was to gain a better understanding of women's and specifically SAW's experiences of living with chronic pain and explore options that could potentially improve health outcomes. This project adopted a predominantly qualitative approach and consisted of three different

phases. In Phase One, a meta-synthesis was conducted to obtain a collective and comprehensive understanding of women's lived experiences of chronic pain and identify gaps in our knowledge of SAW who live with it. The second component involved conducting qualitative interviews to gain insights into SAW's experiences with pain, address the gaps identified from the review, and explore the themes generated. The third component, an action research study, used focus groups to explore ways of addressing the concerns raised in Phase Two, co-create an intervention and resource, and evaluate them.

### Research Paradigm and Methodological Considerations

In the field of research, three main paradigms are recognised: quantitative research, qualitative research, and mixed-methods research. The mixed-methods approach combines elements from both the quantitative and qualitative paradigms within a single study or a series of related studies (Gunasekare, 2015; Rapport & Braithwaite, 2018). These paradigms are often associated with different philosophical perspectives: positivists are typically linked to the first paradigm, interpretivists to the second, and pragmatists to the third (Curry & Nunez-Smith, 2015; Giddings & Grant, 2006).

The researcher's views align with the ideas of pragmatism in relation to research methodology. Pragmatism places a strong emphasis on the research question and the approaches and methods that effectively address it (Parvaiz et al., 2016). Thus, a pragmatic researcher may choose to conduct quantitative, qualitative, or mixed research depending on the needs of their research (Maarouf, 2019). Some research situations will lend themselves to quantification, while others will lend themselves to a qualitative approach (Babbie, 2012), and some to both. The researcher's choice of research methods was determined by



the research questions (Coolican, 2014; Morgan, 1997), and the methods selected were those that were considered 'most effective' in addressing the study's aims (Kaushik & Walsh, 2019).

### **Pragmatism, Ontology, and Epistemology**

Charles Peirce, William James, and John Dewey are regarded as establishing the first wave of pragmatism, often referred to as classical pragmatism (Kelly & Cordeiro, 2020). Pragmatism is a philosophical approach to research that is not tied to any one theory about reality, and it encourages pluralism and eclecticism (Johnson & Onwuegbuzie, 2004). Pragmatists believe that research can avoid unnecessary metaphysical debates about the nature of truth and reality and focus on practicality and real-world issues (Kelly & Cordeiro, 2020). In this way, pragmatism provides researchers with the freedom to conduct research using the methods best suited to answering the research questions.

However, pragmatism has been criticised by some for not paying attention to metaphysical issues (Maarouf, 2019; Morgan, 2014). It has also been argued that pragmatism has engendered an anti-philosophical attitude that avoids discussing these issues of reality (Hathcoat & Meixner, 2017). Numerous researchers have argued that the ontological issue in pragmatism has received insufficient attention from scholars and it should not be ignored. Furthermore, it has been stated that merely stating that a pragmatic researcher employs both quantitative and qualitative ontological positions is a significant flaw that impedes pragmatism's development into a coherent framework (Maarouf, 2019). As a result, and given that a comprehensive approach to research necessitates that researchers address three fundamental components in a research paradigm: epistemology (the ways of knowing and learning about the

world), ontology (beliefs about the nature of reality), and methodology (the chosen research approach; Denzin & Lincoln, 2008; Guba et al., 1994; Ormston et al., 2014), these will be discussed.

There are nuanced epistemological and ontological perspectives within quantitative and qualitative research; positivists generally obtain knowledge through a deductive approach, whereas interpretivists employ an inductive one (Ormston et al., 2014). Positivists also hold the ontological stance that there exists a single objective reality that can be accurately observed and measured. In contrast, the qualitative approach asserts an ontological view that there are multiple realities or truths, depending on how they are constructed or interpreted. Consequently, positivists tend to emphasise quantitative research methods such as experiments and surveys with closed-ended questions. In contrast, interpretivism focuses on qualitative research methods like semi-structured interviews and focus groups, as well as small, purposeful sampling to gain insights into the phenomenon under study (Campbell et al., 2020; Ormston et al., 2014). The researcher's views fall somewhere in the middle of these philosophical positions. They align with critical realism and the approach taken by Maxwell (2012): ontological realism and epistemological constructivism.

Maxwell's explicit objective was to develop a form of realism that would be acceptable to constructivist thinkers (Willis, 2022). Consequently, he adopts a stance of ontological realism, which acknowledges the existence of a real world independently of any perceptions, theories, or constructions. However, he also emphasises that any comprehension of this world is a product of specific perspectives and incorporates elements of constructivism (Willis, 2022).

Constructivism is the middle ground between there only being an objective reality to everything being relative and the belief that reality is the result of human intelligence interacting with real-world experience. It is argued that we have accepted constructivism the moment we include human mental activity in the process of knowing reality (Elkind, 2005; Schwandt, 1994). Others also claim that all scientists are epistemological constructivists and relativists (Shadish et al., 2002).

The researcher shares these views and those argued by Elkind (2005), who argues that the acceptance of certain information is contingent upon social agreement regarding the nature of reality rather than being solely based on an objective manner of viewing reality. He further asserts that finding a constructivist who refutes the existence of a world that is outside of individual experiences would be difficult. Furthermore, if everything was relative then there would not be any shared commonalities; however, constructivists acknowledge these (Elkind, 2005). This constructivist approach also appears to be accepted by pragmatists, as according to pragmatism, knowledge is 'both constructed and based on the reality of the world we experience and live in' (Johnson & Onwuegbuzie, 2004, p. 18).

This is the stance taken by the researcher: the view that there can be a shared reality, but it can only be known through the human mind (Schwandt, 1994). It is felt that this idea of a shared reality also aligns with the purpose of the present study and social science research. Social research aims primarily to identify consistent patterns in social behaviour (Babbie, 2012). Through these patterns of social regularity, researchers aim to describe and understand social reality. It is also accepted that any exceptions to social regularities do not mean

that they are not 'real'; if some cases do not fit the general pattern (Babbie, 2012). Some of this was observed and discussed in the previous chapter (CIP and pain asymbolia). Some individuals do not experience pain, but this does not negate the existence of pain for others, nor does it invalidate the truth of their own pain-free experiences. Pain is just not constructed in their mind or experienced as it is by others.

### **Qualitative Methodology**

Having covered two of the dimensions of a research paradigm: ontology and epistemology, this section will now consider the final component: methodology. Qualitative research aims to generate a rich, detailed, and textual explanation or understanding of the phenomenon being studied. Qualitative health psychology research highlights the diversity of lived experiences, empowers patients, and makes an impact by presenting their perspectives (Gough & Deatrack, 2015). Thus, this approach was deemed appropriate for the study's overarching aim. A qualitative approach was selected to gain a more comprehensive understanding of women's experiences of living with chronic pain. The experience of pain would have been difficult to capture using quantitative methods, but experiences can be explored in detail using qualitative methods (Hennink et al., 2011; Willerton, 2010). Furthermore, qualitative research methods are useful for exploratory research on topics where there is little research and with underrepresented groups (Engel & Schutt, 2013). This is another reason a qualitative approach was adopted. It permits the researcher to examine in detail the experiences of individuals by employing a particular set of qualitative research methods (Hennink et al., 2011). The research question and objectives of each phase of the study influenced the selection of these methods (Coolican, 2014; Hennink et al., 2011; Howitt, 2016).

## **Qualitative Research Methods**

In the first phase, a meta-synthesis was undertaken. For the subsequent phases, interviews were chosen as the data collection method for Phase Two, and focus groups were selected for Phase Three. The latter phase consisted of an action research project utilising a coaching approach. The rationales for the approach(es) taken and the data collection methods employed at each phase are discussed below.

### **Phase One: Meta-synthesis**

A meta-synthesis (an interpretive integration of qualitative findings involving inductive analysis and synthesis; Finfgeld, 2003; Sandelowski & Barroso, 2007) is frequently utilised for synthesising findings from qualitative studies (Finfgeld, 2003; Sandelowski & Barroso, 2007). Similar steps are taken to conduct one of these reviews (Finfgeld, 2003; Sandelowski & Barroso, 2007): conceiving the focus of the study, selecting a research question, searching for sources, retrieval of the sources, review and appraisal of these sources, analysis, and presentation of the results. The rigorous methodology employed in a meta-synthesis, such as systematic searching, data extraction, and synthesis, enhances the validity and reliability of research findings. This strengthens the evidence base for informed and effective decision-making (Petticrew & Roberts, 2005).

Moreover, meta-syntheses hold significant importance in health research as they can offer a comprehensive understanding of complex health issues (as chronic pain is). According to Petticrew and Roberts (2005), systematic reviews also help practitioners deal with the 'overload' of information that is available to them. Systematic reviews synthesise information and provide HCPs with a reliable overview of the research literature. They evaluate and synthesise the

findings and implications of vast amounts of research and enable HCPs to make informed decisions and consequently improve health outcomes for patients (Petticrew & Roberts, 2005).

In summary, meta-syntheses provide a framework for examining research from various angles, enabling a holistic perspective that goes beyond isolated findings. It is a method for unifying knowledge, deepening understanding, and generating new perspectives. In patient-centred research, they can unearth valuable insights into the experiences, preferences, and needs of individuals dealing with complex health conditions and inform policy decisions, health guidelines, and future research directions. Based on this and the aims of Phase One of the study, it was decided that a meta-synthesis would be most suitable. It could provide the in-depth understanding that this research sought and identify gaps in the literature on women and pain. This would also ensure that future research efforts are directed towards the areas and groups that are found to be most overlooked.

Furthermore, a meta-synthesis would allow common themes, comparisons, and differences based on sex to be identified and provide deeper insights than what would be gained from a single study on chronic pain (Erwin et al., 2011). It would also help to contribute new knowledge to the existing pain literature. Contributing to ongoing discussion on the topic could also encourage research in the field where gaps are identified and could help to improve healthcare delivery and patient outcomes for women living with pain.

## **Phase Two: Interviews**

Qualitative interviews have a long history in the social sciences and are a powerful research method for gaining insight into topics of interest to

researchers. Qualitative interviews are a key method for exploring how participants understand and experience their world. They offer a unique window into the lives of the participants, who are able to describe their experiences in their own words (Kvale, 2007). Thus, they were deemed most suitable for gaining insight into women's experiences of living with pain.

In-depth, semi-structured interviews were selected. Unlike structured interviews, in which the researcher strictly adheres to the interview guide or list of questions, semi-structured interviews allow participants and the researcher to explore additional areas of interest raised during the interview (Braun & Clarke, 2013; Shaw & Holland, 2014). The freedom that semi-structured interviews afford both the researcher, and the participants is their principal advantage (Braun & Clarke, 2013). They provide for easier exploration of areas of interest than other, more structured methods of data collection (Braun & Clarke, 2013) and permit exploration of topics that the researcher may have overlooked (Willig, 2013). Additionally, participants, not simply the researcher, have the ability to influence the direction of the interview (Bryman, 2004; May, 1997). Moreover, an immediate confirmation of the interviewer's interpretation can be obtained by asking the participant if the interviewer fully understood the participant's statement (Kvale, 2007).

All these reasons influenced the decision to conduct semi-structured interviews in Phase Two (Coolican, 2014). It was also felt that the topic being investigated may be too sensitive to explore in a group setting and that one-on-one interviews would be most appropriate (Barbour, 2018). By engaging in one-to-one interviews, participants would be provided with a safe and confidential space to share their personal experiences and perspectives. The researcher was

committed to encouraging and listening to the voices of the participants throughout the project.

### **Phase Three: Action Research**

This phase involved co-creating a resource and intervention for SAW living with chronic pain. Whereas other research may just make recommendations, action researchers collaborate with participants (co-researchers) to find practical solutions to challenges and problems that they face in their daily lives.

### **What is Action Research?**

It has been argued that defining action research is difficult due to its nature as a research approach rather than a specific method. It is characterised by its flexibility and the possibility of employing different methods rather than adhering to a predetermined set. Action research has been undertaken in various healthcare environments, and its frequently ambiguous scope is acknowledged (Deery, 2005; Smith et al., 2017). It involves investigating real-life issues that have an impact on individuals' lives, their well-being, and exploring solutions (Stringer & Ortiz Aragón, 2021). It is a dynamic approach that empowers individuals and communities to tackle real-world problems while adding to broader knowledge. Key principles include active participant involvement, a cyclical process of planning and reflection, a focus on context-specific issues, and close collaboration between researchers and co-researchers (Stringer & Ortiz Aragón, 2021).

The research process 'includes three major steps: LOOK : Gathering and generating information ( data ) THINK : Analyzing and interpreting the data ACT : Taking action based on that analysis' (Stringer & Ortiz Aragón, 2021, p. 41).



Data collection in the 'look' phase helps to fully understand the problem. The goal is to collect relevant and accurate information about the problem. The data collected is then used to generate information and insights about the problem. This information helps in developing a clear picture of the situation and the factors contributing to the problem. Data analysis in the 'think' stage involves organising, coding, and categorising the data to identify patterns, trends, and relationships. In the 'act' stage, a plan for action is developed based on the analysis of data and the identified solutions. This plan outlines specific steps, responsibilities, and resources required for implementing changes or improvements.

After implementing the planned actions, the process of action research does not stop. It involves continuous evaluation and monitoring of the changes to assess their effectiveness. If further improvements are needed or if new issues arise, the process repeats by returning to the 'look' stage. This cyclical nature allows for ongoing learning and adaptation (Pipon-Young et al., 2011; Stringer & Ortiz Aragón, 2021). It prioritises the specific needs and contexts of the participants. This ensures that interventions and solutions are tailored to the unique challenges faced by the group and generates practical knowledge (Stringer & Ortiz Aragón, 2021). Action research is a powerful approach that bridges the gap between theory and practice. It empowers individuals and communities to address real-world challenges effectively (Pipon-Young et al., 2011; Stringer & Ortiz Aragón, 2021).

The lack of structure in action research makes it difficult to foresee what participants are agreeing to. However, during each phase participants were reminded that their participation was voluntary and that they were free to

withdraw at any stage, and they were reminded of the importance of ensuring confidentiality (Deery, 2005).

### **The Rationale for Action Research**

Participatory action research (PAR) serves as a powerful approach to understanding and reducing health disparities, ultimately creating a more equitable and effective healthcare system (Olshansky et al., 2005). According to Olshansky et al. (2005), if healthcare is considered a fundamental right, but only a few have access to high-quality healthcare services, a state of disparity and inequity arises. Conducting research that identifies the problem without offering remedies, although a starting point, is insufficient. PAR involves both identifying and recording specific issues, as well as actively engaging in efforts to address and resolve these issues. This approach is gaining increased recognition for its capacity to successfully tackle issues associated with health inequalities (Olshansky et al., 2005). It encompasses collaboration and partnership with individuals, who are typically thought of as research participants in a study. There is a strong emphasis on change, and actions taken are based on the data (Olshansky et al., 2005; Pipon-Young et al., 2011; Stringer & Ortiz Aragón, 2021).

This approach was adopted as the goals of action research aligned with the aims of Phase Three of the study: empowering women to effectively manage chronic pain and enhance their well-being. Furthermore, as previously stated (Chapter One), the biopsychosocial model of health has been in existence for several decades, but empirical evidence suggests that its effective implementation in the domain of pain management, specifically pertaining to women, is lacking. Despite ongoing recommendations emphasising its

importance, there seem to be few improvements in the quality of care that patients living with chronic pain receive, and a change is required (Gordon et al., 2017; Lim et al., 2019; Parks, 2020). Research may also be perceived as exploitative by certain groups, providing them with little benefit. In contrast, participatory research may help to ensure that research findings address real needs and are actually used (Green & Mercer, 2001).

Garwick and Auger (2003) state that there is a history of outside researchers exploiting American Indian communities with studies that often did not benefit and sometimes harmed them. They stated that PAR ensures communities have a voice throughout the research process. Additionally, they note that PAR aligns well with core aspects of Indian culture, including the high value placed on respectful listening (Garwick & Auger, 2003).

Furthermore, PAR was found to be an effective approach to empowering SAW in a study conducted in Canada (Choudhry et al., 2002). The study's goal was to investigate SA immigrant women's health promotion challenges and to aid in the development of empowering knowledge and self-understanding about health-promoting activities. The study concluded that PAR empowered participants in creating and sharing knowledge.

Thus, it can be seen that although HCPs are in a privileged position to be able to improve health outcomes for individuals and making recommendations is important, researchers, with their expertise, can also play a crucial role in this and alleviate suffering, as can family and friends. Consequently, in response to the challenges identified in Phases One and Two, the decision was made to undertake an action research study, with participants from Phase Two

participating as co-researchers, aiming to tackle the challenges they face more effectively.

Action research also operates on the idea that individuals with lived experiences of issues being researched and examined are experts and should be included in determining how to effectively address them (Pipon-Young et al., 2011; Stringer & Ortiz Aragón, 2021). This also aligned with the views of the researcher. It was determined that focus groups (taking a coaching approach) would be the most effective method of data collection for exploring the proposed questions and objectives of the action research phase (Coolican, 2014).

### **What Are Focus Groups, and What Should Be Considered Before Conducting Them?**

Focus groups are considered to be an important qualitative research method and have become popular in health sciences research (Duggleby, 2005). 'A focus group is a sort of collective interview, directed by the researcher (moderator), that exploits the interactive potential of the situation in order to generate rich data' (Howitt, 2016, p. 88). It is viewed as a group discussion (Braun & Clarke, 2013; Krueger, 1994). Research with focus groups often entails planning and executing a number of small-group discussions and then analysing the data collected using various qualitative methods (Wilkinson, 1998).

Focus groups are a remarkably versatile research tool in that they can be adapted to collect data on virtually any subject in a variety of settings. The discussions can be quite broad or more specific, as well as highly or loosely structured. This adaptability makes focus groups a valuable tool and explains

their popularity. They are a scientifically sound method for generating ideas (Stewart et al., 2007) and useful for participants to discuss perceptions and opinions (Krueger & Casey, 2000).

Moreover, the focus group setting allows for more spontaneous responses and allows participants to discuss problems and offer potential solutions (Butler, 1996; Duggleby, 2005; Onwuegbuzie et al., 2009). In addition, a large amount of data can be collected in a short amount of time (Braun & Clarke, 2013), and a variety of perspectives can be expressed and obtained in a single session (Howitt, 2016).

There are numerous guides on conducting focus groups (Barbour, 2018; Barbour & Kitzinger, 1999; Krueger & Casey, 2000). Morgan (1997) advises, when considering the use of focus groups, to ask oneself about the level of engagement and ease with which participants would discuss the issue of interest. Within the context of a focus group, visual stimuli or other activities may be used to elicit responses and provide a foundation for discussion. They can be used as a stand-alone method (Barbour, 2018). They last about an hour or two (Morgan, 1997), and there can be a single group meeting or multiple meetings (Onwuegbuzie et al., 2009). It has also been stated that a single focus group can provide sufficient data to answer the research questions of a study (Stewart & Shamdasani, 1990; Stewart et al., 2007). The likelihood of finding new information will not necessarily increase with the number of groups, but extending the focus group session length may be helpful (Fern, 2001). On the recommended number of participants, anywhere from three to six is preferred by some; others suggest the optimal number being between four and eight

(Barbour & Kitzinger, 1999; Kitzinger, 1994;1995). However, more than six participants may discourage disclosure (Willig, 2013).

The focus group data analysis method, like any other qualitative research method, is determined by the researcher's methodological approach, which reflects the study's specific aim (Duggleby, 2005). It is essentially the same as analysing any other qualitative data (Kitzinger, 1995). Traditional qualitative analysis techniques are used to analyse this data. Typically, this involves conducting either content analysis or thematic analysis (Wilkinson, 1998).

### **The Challenges Associated with Focus Groups**

Group rapport and group composition are important for participants to feel at ease and express their opinions (Krueger & Casey, 2000). The group's homogeneity and level of acquaintance should be considered. If the participants are strangers, establishing rapport may take some time. It could be argued, however, that members may contribute more freely due to their anonymity. However, recruiting strangers is more difficult than recruiting members of established groups. Some individuals may also feel anxious about speaking in front of others. It is also possible for vociferous members to dominate the group, resulting in data that does not accurately represent the group. Furthermore, focus groups can produce challenging group dynamics that can be distressing to individual participants. They may also not be suitable for sensitive topics (Barbour, 2018; Howitt, 2016; Krueger & Casey, 2000; Sim & Waterfield, 2019; Willig, 2013).

However, the presence of shared demographics, cultural backgrounds, and experiences among group members can contribute to a heightened sense of comfort (Fallon & Brown, 2002; Rodriguez et al., 2011). Many authors have

noted that collecting data through focus groups works best when participants 'share similar social identities and experiences and are in a comfortable environment' (Rodriguez et al., 2011, p. 409). It has been argued that it can be extremely beneficial 'to ensure that focus group members are characterized by a shared culture, especially where ethnic minority groups are concerned' (Fallon & Brown, 2002, p. 206).

The female participants in the present study shared some characteristics, and it was noted that some of them were already acquainted with each other, which was perceived as a benefit in terms of rapport. It was also felt that the women may feel more comfortable and confident in the group setting due to this (Fallon & Brown, 2002; Rodriguez et al., 2011). Additionally, the groups were organised in accordance with the participants' preferences, reflecting their individual comfort levels. Moreover, the topics to be discussed were not regarded as too sensitive. Focus groups are optimal when the research being conducted is not excessively sensitive and the dynamics of group interaction can generate substantial insights pertinent to the research objectives (Barbour, 2018; Willig, 2013). 'By design, constructivist focus groups allow participants and researchers to co-create knowledge together' (Rodriguez et al., 2011, p. 402).

The focus group does, however, also raise ethical concerns that are not present in other data collection methods; the open nature of focus groups means that ensuring anonymity and confidentiality can be difficult (Howitt, 2016; Sim & Waterfield, 2019). The researcher explained that complete confidentiality cannot be guaranteed in this situation, but participants were advised of using a pseudonym if the group contained participants not known to them (Roller &

Lavrakas, 2015). The participants were notified that any information disclosed during the focus groups must be kept confidential and the privacy of the participants must be respected.

### **Rationale for Selecting Focus Groups**

The concept underlying the focus group method is that group processes can help individuals explore and clarify their perspectives in ways that would be more difficult to achieve in individual interviews (Kitzinger, 1994). The interactive discussion among participants has the potential to reveal 'dimensions of understanding that often remain untapped' with other methods (Kitzinger, 1995, p. 299-300). This is the main advantage of using focus groups as a method of data collection in qualitative research, and it was also the reason that they were selected. In addition, focus groups are useful as an exploratory tool when looking at an understudied area. They are really useful in the early stages of research for generating new ideas that participants believe are important (Kitzinger, 1995; Krueger & Casey, 2000). As a result, this method was deemed the most appropriate to explore the development/use of an intervention in Phase Three. It was felt that through focus groups, the researcher could gain insight into the collective wisdom of SAW living with chronic pain. Furthermore, that they could generate information and insights and bring richness and depth to our research that other methods could not (Kitzinger, 1995; Morgan, 1997).

### **Rationale for Adopting a Coaching Approach**

The implementation of a coaching approach was motivated by its emphasis on placing the individual at the centre of their own growth and development. Instead of providing solutions, coaching facilitates the process by which individuals are empowered to discover their own insights, recognise their



unique strengths, and establish goals that align with their own values and aspirations (Maini et al., 2020; Starr, 2012; Whitmore, 2001). Health coaching has recently become popular due to its effectiveness in addressing various behaviours and the self-management of illnesses in a cost-efficient way (Butterworth et al., 2007).

Findings from a systematic review of thirteen studies aimed at describing the impact of health coaching on adult patients living with chronic diseases suggest that health coaching yields favourable effects on patients' physiological, behavioural, and psychological well-being, as well as on their social interactions. Notably, statistically significant results demonstrated enhanced weight management, increased engagement in physical activity, and improved physical and mental health statuses. The authors concluded that health coaching contributes to the better management of chronic diseases. They stated that health coaching emerges as an efficacious approach to patient education, motivating individuals, leveraging a patient's willingness to modify their lifestyle, and supporting home-based self-care (Kivelä et al., 2014).

Health coaching also takes individual motivations into account, is person-centred, and has the potential to promote healthy behaviours and address chronic disease risk factors (McGlynn et al., 2022). Taking a coaching approach 'invites the patient to set and make explicit their own agenda from the outset, enabling them to take ownership of this' (Rogers & Maini, 2016, p. 36). Furthermore, using a coaching approach can enhance individuals' health literacy and the likelihood of genuine empowerment (Rogers & Maini, 2016). It raises self-awareness and allows choices to be identified by patients, who then can find their own solutions (Rogers & Maini, 2016). It is 'underpinned by

research showing that human beings function best when we make and live with the results of our own decisions' (Rogers & Maini, 2016, p. 40). It provides patients with skills and leads to less dependency and patients feeling unable to 'self-manage' on their own. This has been a concern and weakness of self-management interventions (Rodham, 2018).

### **Powerful Questions and Homework**

The coach helps to guide individuals to come up with solutions and make their own decisions through powerful questions. They can lead to creative insights and bring about change (Vogt et al., 2003). A powerful question possesses the ability to spark the listener's curiosity, prompting reflective and thought-provoking conversations. In essence, a powerful question is a catalyst for a dynamic and meaningful exchange; it evokes further questions and can create a lasting impact on those engaged in the dialogue (Vogt et al., 2003). The focus group's prompt sheet was devised to include these.

Homework is also an important aspect of coaching. In coaching, homework refers to tasks, assignments, or actions that a coach assigns to a client to be completed between coaching sessions. The purpose of homework is to support the individual's progress and promote the application of insights gained during coaching sessions. Assigning homework also fosters a sense of accountability. Individuals are more likely to be committed to their development when they have specific tasks to complete and report back on. Homework may involve self-reflection exercises, journaling, or other activities that encourage clients to deepen their understanding of themselves and their motivations (Valcour, 2015; Waller, 2018). This was included prior to the first session, after it, and after each session thereafter.

Taking a coaching approach also aligns with Self-Determination Theory (SDT), which posits that individuals are most motivated and fulfilled when they experience autonomy, competence, and relatedness (Deci & Ryan, 1985). In coaching, the aim is to empower individuals by fostering their sense of control, enhancing their skills, and building supportive relationships, thereby promoting intrinsic motivation and personal growth.

Overall, coaching plays a crucial role in promoting behavioural change. It helps individuals identify their goals, create a plan, and take actionable steps towards achieving them. It is tailored to the individual's unique needs and circumstances, making it highly personalised and effective (Starr, 2012; Whitmore, 2001).

### **Embracing a Coaching Approach with the GROW Model**

The researcher chose to employ the GROW model (in Phase Three). The focus group questions were framed around the GROW model (Appendix Thirteen). GROW is an acronym for Goal (this is where the individual and coach define a clear, specific, and achievable goal), Reality (in this stage, the individual and coach explore the current reality or situation), Options (the individual and coach brainstorm and evaluate various strategies and actions to bridge the gap between the current reality and the desired goal), and Will or Way Forward (in the final stage, the individual commits to a specific plan of action; Whitmore, 2001). Individuals outline the steps they will take and identify potential obstacles and solutions.

GROW is a well-established, extremely popular, and widely recognised coaching framework. It can be used in conversations and meetings to unlock possibilities (Performance Consultants, 2023). It offers a clear and structured

pathway for individuals to define their goals, assess their current reality, explore a spectrum of options, and commit to a plan of action. The GROW model is widely used in coaching, mentoring, and personal development settings because of its simplicity and effectiveness (Miller, 2020; Performance Consultants, 2023).

The GROW model was used for devising the prompt sheet that was used during the focus groups to generate creative solutions, set goals, and explore solutions for the key challenges identified. It aligns seamlessly with the coaching philosophy of empowering individuals to find their own solutions and take ownership of their development. Through this model, we were able to collaboratively explore goals, navigate the complexities of the women's current reality, co-create innovative options, and devise an action plan. The purpose was to tap into the collective wisdom of the participants and generate ideas that could benefit the group.

### **The Theory of Planned Behaviour**

It has been stated that there is no clear evidence to support one intervention development approach over another. However, experts propose using multiple ways that are adaptive to different scenarios in order to strengthen outcomes and increase intervention development (O'Cathain et al., 2019). It is felt that the GROW model is similar to another popular model. The GROW model is conceptually similar to the Theory of Planned Behaviour (TPB). The latter is a widely used social-psychological model for predicting and explaining human behaviour (Ajzen, 2002, 2011; Armitage & Conner, 2001; Chater & Cook, 2014; Han & Stoel, 2017; Zhao et al., 2019).

Ajzen's (2002) TPB is an extension of the Theory of Reasoned Action (TRA). It posits that human behaviour is determined by intentions, which, in turn, are influenced by three factors: attitudes towards the behaviour, subjective norms, and perceived behavioural control. Attitudes reflect an individual's positive or negative assessment of engaging in a specific behaviour. Positive attitudes often lead to a higher likelihood of intending to perform the behaviour (Ajzen, 2002; Chater & Cook, 2014). Subjective norms pertain to the perceived social pressure or expectations of others regarding a specific behaviour (the approval or disapproval of significant others). Perceived behavioural control refers to an individual's assessment of how easy or difficult it is to engage in a specific behaviour (Ajzen, 2002; Chater & Cook, 2014).

Both models focus on goal setting and behaviour change. TPB's emphasis is on intentions, and GROW's emphasis is on goals. Assessing the current situation and understanding the reality of the individual in GROW is quite similar to the TPB's perceived behavioural control. The options phase in GROW, where individuals evaluate different strategies, taking into account personal beliefs and social influences, relates to the TPB's concept of subjective norms. According to the TPB, intentions are a key factor in predicting whether an individual will engage in a behaviour. It aligns with the GROW model's emphasis on setting clear goals and taking clear actions (will) to achieve them. This further reinforced the decision to go forward with this approach in Phase Three. Also, a great deal of evidence supports the notion that optimising lifestyle behaviours is a key factor in the prevention and management of chronic diseases (Linden et al., 2010).

### **Inclusion Criteria and Justification (Phases Two and Three)**

Women in the UK with chronic pain who are over the age of eighteen and self-identify as SA were recruited through purposive and snowball sampling (from the researcher's contacts and the contacts of recruited participants). These sampling methods are often employed by researchers when they are seeking particular types of participants. Furthermore, they allow researchers to increase participant variation and obtain a diverse range of perspectives, thereby allowing for a deeper understanding of the research topic (Denscombe, 2017; Patton, 1990). Snowball sampling is also an effective method for recruiting hard-to-reach, underrepresented groups in health research (Sadler et al., 2010).

Children, people with learning disabilities, and individuals who did not meet the above inclusion criteria were to be excluded.

### **Data Saturation and Information Power**

The concept of saturation is one guiding concept in deciding sample size in qualitative studies. Data saturation is stated to occur when no new information is obtained through data analysis, causing researchers to consider terminating data gathering (Faulkner & Trotter, 2017; Morse, 2015). There are also guidelines provided on the number of participants to recruit to reach this point of data saturation. Guest et al. (2006) suggest that twelve interviews should be sufficient to understand the shared experiences of a group of relatively homogeneous individuals.

However, it has also been argued that researchers are always likely to discover something new in their data, which can happen with additional recruitment and increased engagement with the data. There is also always the possibility of coming back to a dataset after some time and discovering new

themes, and it has been argued that in the real world, it is better to stick to what could be described as a 'good enough' (Barbour, 2018). The authors (Braun & Clarke, 2022), whose framework is being used for analysing data in this project also do not strongly support the idea of saturation and instead point to an alternative concept of information power (Braun & Clarke, 2022).

The concept of 'information power' can assist researchers in determining an appropriate sample size for qualitative studies (Malterud et al., 2016). According to information power, the more information the sample provides that is relevant to the actual study, the fewer participants are required (Malterud et al., 2016). 'The greater the amount of useable data obtained from each person (as number of interviews and so forth), the fewer the number of participants' (Morse, 2000, p. 4). This may also assist researchers who may otherwise develop interview studies on a quantitative basis: the more interviews conducted, the more scientific the study (Kvale, 2007). These principles were used to guide sample size, and it was agreed that information power would be used as a guide to determine when to end recruiting participants (when it is felt that enough data has been acquired to address the research questions).

## Data Analysis

The researcher's approach, the type of data being collected, the method of data collection, and the research questions and aims were all considered when selecting the optimal data analysis method.

## Reflexive Thematic Analysis

In all three phases, Braun and Clarke's six-step process for thematic analysis was followed (Braun & Clarke, 2013; 2022). Braun and Clarke (2022)

provide a well-defined framework for analysing data. This framework has been used in a variety of research projects, and it can be implemented within any of the principal ontological and epistemological frameworks that underpin qualitative research (Braun & Clarke, 2006; 2022).

Thematic analysis can also be used to answer most types of research questions that qualitative researchers may be interested in. It is useful for exploring participants' experiences, and it can highlight patterns across the entire data set (Braun & Clarke, 2006; Clarke & Braun, 2015). This approach was compatible with the research aims and theoretical underpinnings, and it provided a clear framework for the analysis of complex datasets.

### **The Process of RTA**

Braun and Clarke's RTA approach 'involves a six-phase process' and these phases are discussed below (Braun & Clarke, 2022).

#### **Familiarisation**

The first phase entails becoming deeply familiar with the dataset's content through immersion. This entails reading and re-reading the collected data (as well as listening to the recordings) and taking notes on any analytic ideas or insights that arise. This stage also included translating the recordings. Translation is a complex process that requires not only fluency in another language but also careful attention to context (Esposito, 2001). This is particularly important when there are no English words for some concepts that may arise. Also, due to the fact that the structures of some languages are so dissimilar, a literal translation would result in grammatically incorrect English (Barbour, 2018; Twinn, 1997).



This complexity in translating research documents was observed by Chiu and Knight (1999). In their research on women's experiences with breast and cervical screening, Chiu and Knight (1999) relied on interpreters to facilitate groups in languages other than English. This highlighted the extent to which interpreters were altering the meaning of questions and, as a result, affecting the content of the data generated. Chiu's bilingualism provided insights that would have otherwise gone unnoticed (Barbour, 2018).

## **Coding**

This phase includes working systematically and meticulously through the dataset, identifying data segments that appear potentially relevant or meaningful to the research question(s), and assigning them meaningful and analytical descriptions (code labels).

## **Generating Initial Themes**

During this phase, shared patterns of meaning across the dataset are identified. Clusters of codes that appear to share a central idea and may provide a meaningful answer to the research question(s) are compiled ('themes are constructed by the researcher'; Braun & Clarke, p. 35). Thematic maps were created to aid in theme formulation, theme exploration, and the development of new themes.

## **Developing and Reviewing Themes**

The potential themes generated in phase three are reviewed in this phase. This involves determining whether or not the provisional themes make sense in relation to the coded extracts as well as the entire dataset. Provisional

candidate themes can then be refined, combined, and discarded as deemed appropriate.

### **Refining, Defining, and Naming Themes**

In this phase, succinct, descriptive names are generated for each theme. This phase may also involve additional development if the refining process indicates so.

### **Writing Up**

This phase entails combining the researcher's analytic narrative with compelling data extracts selected from the dataset and producing a report of the research findings (Braun & Clarke, 2022).

### **Reflexivity in Research**

Reflexivity in research is a fundamental approach that involves researchers critically examining their own biases, values, and perspectives throughout the research process. It acknowledges that researchers are not neutral observers but active participants in shaping the research process (Gough, 2003; Maso, 2003). It serves as a valuable tool for qualitative researchers, enabling them to cultivate a critical perspective when assessing how the research context and researcher subjectivity influence various aspects of the research process, including project design, data collection, analysis, and presentation of the findings (Gough, 2003).

Reflexivity efforts may focus on a specific phase of the research or be integrated throughout the entire research process. Reflexivity can be enhanced by engaging in discussions with colleagues or research participants or by engaging in regular solitary reflections, which can be documented in a research

journal or diary (Gough, 2003). These reflections may encompass personal thoughts and emotions triggered during interviews and other research activities. This introspection helps in identifying and addressing biases. There is no unanimous consensus on the definition and application of reflexivity in qualitative research. Different researchers will take different approaches to reflexivity, guided by their theoretical perspectives and definitions, and these will inform their unique approaches to how this is conducted (Gough, 2003). However, at its core, reflexivity implies that researchers should transparently acknowledge their individuality and how it influences the research process (Gough, 2003).

Understanding one's positionality is a crucial step towards minimising subjectivity (Maso, 2003). Researchers bear the responsibility of producing an analysis that can be utilised to support a particular worldview, all while acknowledging their role in shaping the research narrative (Gough, 2003).

### **Strategies Utilised in the Present Study**

There were various reflexivity strategies employed in the research. One of which was maintaining a reflexive journal. This journal served as a valuable tool for tracking changes in perspective. The second was peer debriefings (collaborative discussions among research team members on the preliminary themes and early analysis). These helped refine and finalise theme names, with one theme undergoing several revisions (discussed in Chapter 5). They can offer valuable insights and feedback on potential biases and assumptions. Member checking was also used in Phases Two and Three with the aim of ensuring that the data reflected the voice of the women in the study. Member checking involved reviewing the findings with participants after the analysis, allowing

them to provide feedback and confirm the accuracy of the interpretations. This approach was taken to ensure that the findings accurately reflected their experiences. By embracing reflexivity, the researcher aimed to contribute to knowledge lacking in the field of pain and enhance the quality, transparency, and ethical conduct of research by acknowledging and addressing the potential influence of the researcher's subjectivity on the research outcomes. It was hoped that by doing so, the participants' voices would be presented accurately.

### **Reflexivity and Positioning the Researcher**

As discussed, reflexivity also involves the examination of the ways in which the identity of the researcher can impact the research process (Basit, 2013). The researcher can gain illuminating insights into the social world of the researched by sharing the gender, ethnicity, and language of the research participants while respecting the boundaries that must not be crossed (Basit, 2013; Shah, 2004). It has also been argued that a shared cultural identity is also less threatening, and that the researcher is aware of taboos and thus avoids a breakdown in the researcher's relationships with the participants (Shah, 2004). With all of these factors considered, it was hoped that the researcher's position would prove beneficial to the research.

### **Reflexivity and Positionality Statement**

In conducting this research, I have carefully considered my positionality and its implications for the study, particularly in the context of PAR. My background, values, and some of my research skills have played a role in shaping both the research process and its outcomes. As a female researcher who shares the same language and cultural background as the participants, I felt

I was able to establish a strong rapport and foster trust with the participants. This connection was crucial for facilitating open and honest communication, allowing participants to feel understood and respected. It was also felt that my ability to communicate, explain, and provide written information about the research in the language potential participants were fluent in, combined with my sensitivity to cultural norms, contributed to creating a supportive environment that facilitated rich data collection. It also meant that individuals from different generations could be involved.

Despite these shared attributes, I am acutely aware of my position as an outsider concerning the lived experience of chronic pain. I do not have personal experience with it, which can present a potential gap in understanding. To ensure participants' views were accurately presented, a reflexive approach was adopted. This involved actively working to gain an insider perspective by listening closely to participants' experiences and reflecting on their narratives throughout the research process. Participants were made clear of my position and theirs as experts on their experiences. The aim was to ensure that the data truly reflected their voices and perspectives and empowered participants to shape the research outcomes and interventions.

Furthermore, the potential for my position to influence participants' feedback, especially when evaluating the resource and intervention, was an important consideration. Participants may have been inclined to provide positive feedback. To mitigate this, deliberate efforts were made to foster an environment where critical feedback was welcomed and valued. Participants were encouraged to share both positive and critical reflections on the resource

and intervention, ensuring that their evaluations were as honest and constructive as possible.

Moreover, the intervention and resource were co-created, and participants were equal contributors, so it was also felt that they could be honest. Throughout the research, the goal was to engage participants meaningfully and ensure that they felt empowered in the process. By involving them in the co-creation of the intervention and encouraging their active participation, the study aimed to balance any perceived power dynamics and make the research process as collaborative as possible.

This approach was intended to enhance the validity of the data and ensure that the interventions were truly reflective of participants' needs and preferences. In summary, my positionality as a female researcher with cultural and linguistic alignment with participants, combined with my awareness of my outsider status regarding chronic pain, has been central to shaping the research process. By acknowledging and addressing these aspects, I have strived to ensure that the research was conducted with respect, transparency, and a genuine commitment to capturing the participants' voices accurately and meaningfully.

### **Validity and Quality**

There were various guidelines followed in devising and conducting the research and analysis to enhance validity and quality. In the social sciences, the former refers to whether a method explores what it claims to investigate (Arksey & Knight, 1999; Kvale, 2007). For the latter, the total quality framework (TQF) proposed by Roller and Lavrakas (2015) provides a foundation for the development of skills required for the implementation of high-quality qualitative

research designs. Their framework offers researchers a flexible way to focus on quality issues, consider bias in their approach and how it can be mitigated, and maximise the quality of their research. Integral to this framework are four dimensions: credibility (the trustworthiness of the research outcomes), analysability (the completeness and accuracy of the analysis; verification at this stage can be accomplished through peer debriefings, a reflexive journal, and triangulation), transparency (complete disclosure of the design and research process in the final report and the degree to which a reader is able to evaluate the study and its transferability to other contexts), and usefulness (advancing knowledge; Roller & Lavrakas, 2015). These four components are considered crucial in assisting researchers in assessing their choice of qualitative methods and guiding them through the design process of qualitative research. It is a valuable framework for researchers planning, conducting, interpreting a qualitative research study, and consumers of the study (Roller & Lavrakas, 2015).

There are also other useful guidelines in terms of quality. It has been stated that there are two complementary aspects to research quality: 'methodological and reporting quality' (Harrison et al., 2017, p. 359). The former refers to the design and execution of the research, while the latter refers to the quality of the reporting of the study. This is frequently evaluated based on whether a reader could replicate the study. Four criteria are commonly used to evaluate the methodological quality of qualitative research: credibility (how well the methodology is explained, whether it is appropriate for the research aims, and whether a justification is provided; Guba et al., 1994; Stenfors et al., 2020), dependability (the detail to which the procedural steps of the research process were described for replication), confirmability (whether there is a clear

relationship between the data and the findings reported), and transferability (the degree to which the findings can be transferred to other groups; Gray, 2018; Guba et al., 1994). All the studies were planned with these guidelines in mind, and the recommended strategies were used during the data collection/ analysis and reporting stage (peer debriefings, instructor triangulation, a reflexive journal, and member checking). The data analysis phase is described in detail, and maps generated during this stage are also included.

It is also important to note that these strategies are not without criticism. As some researchers argue, dependability or external reliability (replicability of research) in qualitative research is also questionable due to the impossibility of recreating the exact same situation at another point in time (LeCompte & Goetz, 1982). It has also been suggested that stating that research team members agree on what they observe from data analysis (internal reliability) is incompatible with the principles of qualitative research. Having a second researcher check to see if the themes are 'correct' and true goes against the induction process. It has been argued that the researcher involved in conducting the interviews acquires more knowledge than a second researcher, who may simply be 'checking'. Thus, expecting another researcher to have the same insight as the primary researcher is unrealistic and may be counterproductive (LeCompte & Goetz, 1982).

Therefore, although it is acknowledged that qualitative research and triangulation are inherently interpretive, it has been argued that this does not preclude researchers from pursuing rigour in these research processes and striving for this (Farmer et al., 2006). Thus, all the research strategies mentioned above were incorporated into the research process. The data analysis process



was reviewed through peer debriefings. 'This exercise can help identify possible biases or areas of subjectivity that. . .may have been introduced into the analysis' (Roller & Lavrakas, 2015, p. 92). Member checking was also undertaken, and this can strengthen internal validity in qualitative research (whether the researcher's observations and the findings are a good match). Moreover, by continually reflecting and taking an inductive approach, researchers can try to ensure that the findings remain as close to the views stated by the participants (Kvale, 2007).

## Ethics

There was considerable consideration of the ethical responsibilities that come with collecting personal stories and facilitating group discussions. The paramount importance of ethics in research is encapsulated in its role as a safeguard for the rights and dignity of research participants. The principles of informed consent, privacy, and confidentiality ensure that individuals who contribute to research are treated with respect and autonomy. This not only preserves their well-being but also fosters trust in the research process, encouraging participation and the pursuit of knowledge. Ethical considerations are of paramount importance in health research to ensure the well-being and rights of participants and maintain the integrity of the research process (Kvale, 2007).

According to Kvale (2007), ethical considerations should be taken into account at seven separate stages of research. To begin, during the thematising stage, which involves creating research questions and clarifying the issue under examination, the study's objective should extend beyond obtaining knowledge, taking into account the potential improvement of the human situation under consideration. Obtaining informed consent, preserving participant anonymity,

and considering the potential consequences of the research on participants are all ethical considerations that must be addressed during the designing stage.

Moving on to the interview stage, it is important to consider how the interviewees may be affected by the interaction during the interview. Protecting the confidentiality of interview participants is critical during the transcription stage, and precise data transcription is required to maintain the accuracy of respondents' comments. The level of interview analysis poses ethical considerations during the analysis stage. The depth to which interviews can be analysed should be stated. The verification stage entails conveying knowledge as accurately as possible (Kvale, 2007). This was mentioned earlier in terms of validity and research quality. Finally, in the reporting stage, the confidentiality and implications of the published report for participants need to be considered.

These guidelines were used for planning the studies in Phases Two and Three, and ethical approval was sought from the University of Staffordshire's Ethics Committee (Appendix One [B]). All studies adhered to the code of ethics of the British Psychological Society (BPS), and all data was stored in accordance with university guidelines. Consent, both informed and ongoing, was obtained. Participants were informed of the purpose of the study, potential risks and benefits, and their right to withdraw from the study without providing a reason. Personal information about participants was kept confidential.

Additionally, participants were advised about the option of using a pseudonym when participating in focus groups. No deception was employed at any point during the research. Participants were provided with a debriefing session after the interviews to explain the study's purpose and address any queries or concerns. The researcher ensured that participation was voluntary,

and all data was handled and stored carefully. The transcripts were only made available to other researchers after anonymisation.

## Chapter Summary

This chapter has provided an overview of the study and the three different phases. It delved into the realms of action research and explored the power and potential of focus groups and using the GROW model. These intertwined approaches served as the foundation of this study's holistic approach to empowering women to live well with chronic pain. The justification for each dimension of the research paradigm for each phase of the study has been provided. Rationales have been provided for the sampling methods and the approaches taken to analyse the data. The detailed descriptions of how the data was collected and analysed are provided in Chapters Three (for Phase One), Four (for Phase Two), and Chapter Five (for Phase Three). General quality, validity, and ethical issues have also been addressed in this chapter. The following chapter will cover Phase One, presenting the findings along with a discussion of these results and their implications.

## Chapter Three: Women's Experiences of Living with Chronic Pain: A Qualitative Meta-Synthesis

### Chapter Overview

The previous chapter covered the research paradigm and provided a detailed examination of the research and analysis methods. This chapter focusses on the first phase of the study: a meta-synthesis aimed at developing a collective and comprehensive understanding of women's experiences of living with chronic pain. Through this approach, existing qualitative research is systematically reviewed, synthesised, and interpreted to form a cohesive narrative. By integrating findings from multiple studies, the chapter aimed to provide a holistic overview of how women describe their lived experiences with chronic pain. Chapter One presented a detailed review of the literature on pain. To avoid repetition, a summary of the key points will be provided in the introduction.

### Introduction

Chronic pain is defined as pain that persists for longer than three months despite medication or treatment (NHS Inform, 2022). One hundred million people are estimated to be living with chronic pain in Europe, which significantly impacts their quality of life (Community Research and Development Information Service, 2020). Of these individuals, it is estimated that seventy percent are women (Kiesel, 2017). Biopsychosocial factors shape how individuals experience living with persistent pain (Adams et al., 2006; Love-Jones, 2019). One of these factors is the sex of an individual, which is a key variable in differentiating illness prevalence and experiences: females are more likely to report or experience persistent pain than males (Mills et al., 2019), and

they are more likely to experience high-impact chronic pain (severe, disabling pain) than males of a similar age (Versus Arthritis, 2021). They also experience more pain-related conditions, report higher levels of pain, longer durations of pain, and experience it occurring more frequently (Fillingim & Maixner, 1995; Fillingim et al., 2009; Hallin, 2003; Keogh et al., 2005; Koons et al., 2018; Mills et al., 2019; Miyazaki & Yamamoto, 2009; Pieretti et al., 2016; Unruh, 1996).

There are also differences between how men and women experience medical care, and women are treated differently when it comes to pain (Bostick et al., 2018; Hoffmann & Tarzian, 2001; Lyman, 2021; Samulowitz et al., 2018; Werner & Malterud, 2003). Women have reported that they are not believed or taken seriously by others, and their pain is more likely than men's to be attributed to psychological factors (Driscoll et al., 2018; Hoffmann & Tarzian, 2001; Kempner, 2014; Newton et al., 2013; Roberto & Reynolds, 2002; Samulowitz et al., 2018; Werner & Malterud, 2003). They are also more likely to be prescribed sedatives and anti-anxiety medications than pain medications (Billock, 2018; Calderone, 1990; Koons et al., 2018) and experience ill health and disability for a significantly greater period of their lives (Department of Health and Social Care, 2021).

A more comprehensive and refined understanding of women's experiences with chronic pain is therefore required to address health inequalities in this area. This understanding is crucial for designing chronic pain interventions that are sensitive to women's needs, grounded in their lived experiences, and tailored accordingly. To the best of the researcher's knowledge, no systematic qualitative synthesis has been conducted that

exclusively explores women's experiences of living with chronic pain, and one that is not restricted to a particular condition.

Qualitative syntheses have been identified that focus on a specific condition and that explore the experiences of men and women (Crowe et al., 2017; MacNeela et al., 2015; Toye et al., 2013). Toye et al. (2013) and MacNeela et al. (2015) conducted meta-ethnographies of patients' experiences of chronic non-malignant MSK pain and chronic low back pain, respectively. In conducting a meta-synthesis of people's experiences of living with chronic pain across conditions (from the years 2000 to 2015), Crowe et al. (2017) identified five themes: 'the body as obstacle, invisible but real, disrupted sense of self, unpredictability, and keeping going' (Crowe et al., 2017). However, as mentioned above, exploring experiences that are unique to men and women is also important. Thus, this review aimed to systematically analyse qualitative findings on women's experiences with chronic pain to gain a more thorough and nuanced understanding.

## Methods

### Design

Meta-synthesis involves the interpretive integration of qualitative findings (Sandelowski & Barroso, 2007) and is frequently used for reviewing findings from qualitative studies (Finfgeld, 2003; Sandelowski & Barroso, 2007). The approach allows common themes, comparisons, and differences based on sex to be identified, providing deeper insights than would be gained from a single empirical study (Erwin et al., 2011). The meta-synthesis followed seven procedural steps: formulating the research question, developing the search strategy, conducting a comprehensive search and review of studies, extracting

data and appraising the included studies using the 14-item NICE quality appraisal checklist for qualitative studies (Bradbury, 2018; NICE, 2012), performing inductive thematic data analysis and synthesising findings to address the review question, presenting the findings, and assessing validity and confidence in the findings using the GRADE-CERQual approach (Grading of Recommendations Assessment, Development and Evaluation-Confidence in the Evidence from Reviews of Qualitative research; Lewin et al., 2018). The review protocol was registered in the International Prospective Register of Systematic Reviews (registration number: CRD42022331582).

### **Development of a search strategy**

The search was pre-planned and designed to capture as many studies as possible; a librarian was also consulted during this development stage. Search terms concerning the participants, topic, what was being evaluated, and the research methodology were considered, as well as a timeframe.

### **Search Strategy**

Initial scoping of the literature and the SPIDER tool (Cooke et al., 2012) were used to formulate the search strategy and the research question guiding this meta-synthesis: What are women's experiences of living with chronic pain? The sample sought consisted of women with chronic pain lasting more than three months that was unrelated to terminal illness or cancer (the phenomenon of interest). This meta-synthesis aimed to examine qualitative findings from any study that employed qualitative data collection methods (design). Qualitative data can provide insights into what this review sought to evaluate: women's experiences (daily life, perceptions, views, attitudes, health care, pain

management, physical, social, and psychological impact). Mixed methods and qualitative studies (research types) were to be screened.

The following electronic databases were searched in May and June 2022 (from inception to the search date): PubMed Central, the Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus), the Health Research Premium Collection, Web of Science, ScienceDirect, and PsycINFO. Searches were conducted using Boolean operators to combine terms. Citation searches were also undertaken. Figure 3.1 provides an overview of the study screening and selection process.

### **Search Terms**

The following search terms, Boolean operators, and truncated terms were used: (women OR female OR gender) AND ("chronic pain") AND (qualitative OR "mixed methods" OR interview\* OR "focus groups" OR explor\*) AND (experience\* OR impact OR Perception OR view\* OR attitude\*) NOT cancer. The researcher conducted searches in May and June 2022; all were restricted to abstracts, and some databases allowed further filtration, which was utilised (stated below):

PsycINFO (filter applied to show all journals), CINAHL Plus (search restricted to journals), and the ScienceDirect search had to be adjusted to meet the search requirements: (women OR female OR gender) AND ("chronic pain") AND (qualitative OR "mixed methods" OR interviews) AND (experiences) NOT cancer.

### **Eligibility Criteria**

To be included in the review, studies had to: (1) be primary research using qualitative or mixed methods; (2) focus on the experiences of females



(aged over eighteen years) living with chronic pain (excluding those with cancer and terminal conditions); and (3) be reported in the English language in journals. There was no restriction on geographical region or setting. Studies were excluded if they focused on male experiences only, focused on pain with a malignant cause, or were literature reviews.

### **Selection Process**

Zotero was used to record the search process and identify and remove duplicate articles. The researcher screened all titles and abstracts against the eligibility criteria and repeated this process with full texts. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) diagram was used to show the number of articles identified, included, and excluded (Figure 3.1).

There were a total of 4,253 records identified from the six database searches (Figure 3.1). Zotero was used to remove duplicates ( $n = 2,180$ ). The titles and abstracts of the remaining articles ( $n = 2,073$ ) were screened against the inclusion criteria. Articles not meeting the inclusion criteria were excluded ( $n = 1,964$ ). Of the one hundred and eighteen full articles sought for retrieval, a hundred and nine were retrieved and read in full. Fifty-six studies were included in the review, and fifty-three were excluded (not qualitative/primary studies:  $n = 5$ ; full articles not in English:  $n = 5$ ; studies not focusing on women's experiences of living with chronic pain:  $n = 43$ ).

### **Quality Appraisal**

Quality was assessed independently by the researcher using the 14-item National Institute of Clinical Excellence (NICE) quality appraisal checklist for qualitative studies (NICE, 2012), and a sample was independently evaluated by

PK. As there is no gold standard appraisal tool or any agreement on the value or approach to quality appraisal (Majid & Vanstone, 2018), this tool was selected as it is comprehensive and provides a guide to overall assessment. The questions are also designed in such a way that they can cover a wide range of qualitative research methods. According to the checklist, studies should be rated as '++' if all or most of the criteria have been met, '+' if some of the criteria have been met (but where it is unlikely to affect the conclusion), and '-' if few or no items on the checklist have been met (NICE, 2012).

Validity and confidence in the review findings were assessed using the GRADE-CERQual approach (Lewin et al., 2018). The GRADE-CERQual approach consists of four components: methodological limitations, coherence (a measure of how clear and well supported the data from the primary studies and a review finding are: consistency across studies), adequacy of data (a measure of how rich and well supported a review finding is by the included studies), and relevance (how well the evidence from the primary studies fits into the context of the review question; Lewin et al., 2018). The first component was assessed using the NICE checklist.

### **Data Extraction**

A standardised data extraction sheet was used to extract the following: research title, author, date, country, aims, sample size, participant details (ethnicity, condition, age range of women), data collection method, data analysis method, summary of key findings/themes, and report the NICE checklist rating. All data from the included studies under the headings abstract, results or findings, discussion, and conclusion were regarded as data.

### **Data Analysis and Synthesis of Findings**

There is no one method or technique for qualitative meta-synthesis. A flexible and creative approach is encouraged; one which does not violate philosophical foundations and methodological assumptions, is systematic, and is suited to the question of the project undertaken (Sandelowski & Barroso, 2007). Inductive RTA (Braun & Clarke, 2006, 2022; Crowe et al., 2017; Leake et al., 2021) was deemed appropriate for the aims of the review, and it was adopted to analyse and synthesise the findings as this method can be used with a variety of qualitative paradigmatic approaches (Braun & Clarke, 2006, 2022; Kiger & Varpio, 2020).

All data from the included studies under the headings abstract, results or findings, discussion, and conclusion were regarded as data and analysed. Inductive RTA (Braun & Clarke, 2006, 2022) began with data familiarisation (reading the above-mentioned text and highlighting the themes/participant quotes). Codes were then assigned to any part of the data that appeared potentially relevant to the review question or focused on any aspect of the experience of living with chronic pain. These codes were then refined as this process was repeated several times. The next stage involved developing themes from the finalised codes. Thematic maps (Appendix One [A] ) were generated to assist with theme development, exploring the relationship between themes, and developing final themes. These initial themes were then reviewed and analysed (through re-engagement with the data), and new final themes were generated. Some themes were grouped together at this stage and renamed, as some themes were so closely related and often discussed together in the studies. The themes were examined and discussed collaboratively. For the write-up and to help with the GRADE-CERQual evaluation, the excerpts of data that gave the

best examples of the themes were selected. A narrative account of the results with quotations taken from the included studies was produced.

## Results

### Study Characteristics

The 56 studies included in the review were published between the years 1994 and 2022 and were conducted in fifteen countries: Australia ( $n = 2$ ), Belgium ( $n = 1$ ), Brazil ( $n = 2$ ), Canada ( $n = 5$ ), Chile ( $n = 1$ ), Denmark ( $n = 1$ ), England ( $n = 2$ ), Iceland ( $n = 1$ ), Korea ( $n = 1$ ), New Zealand ( $n = 1$ ), Norway ( $n = 9$ ), Portugal ( $n = 1$ ), South Africa ( $n = 1$ ), Sweden ( $n = 16$ ), and the United States ( $n = 12$ ). Twenty studies focused on chronic pain in general, while others focused on specific conditions: fibromyalgia ( $n = 15$ ), chronic neck pain ( $n = 1$ ), chronic low back/back pain ( $n = 4$ ), rheumatoid arthritis ( $n = 1$ ), osteoarthritis ( $n = 1$ ), MSK pain ( $n = 4$ ), interstitial cystitis/bladder pain syndrome ( $n = 1$ ), pelvic girdle pain ( $n = 1$ ), endometriosis and chronic pelvic pain ( $n = 1$ ), chronic pelvic pain ( $n = 2$ ), chronic widespread pain ( $n = 2$ ), chronic muscular pain ( $n = 2$ ), myofascial pain syndrome and fibromyalgia ( $n = 1$ ). The twenty studies that focused on chronic pain in general included women with a range of conditions: lupus, multiple sclerosis, Ehlers-Danlos syndrome, irritable bowel syndrome, migraines, repetitive strain injury, and phantom limb pain. However, in some of these studies, the number of women with each condition was not always clear.

Various data collection methods (interviews ( $n = 51$ ), focus groups ( $n = 9$ ), observations ( $n = 6$ ), written narratives/use of art ( $n = 5$ ), reflective photo voice ( $n = 1$ ), fieldwork ( $n = 1$ ) and approaches were utilized: Phenomenology ( $n = 13$ ), Thematic Analysis ( $n = 11$ ), Content Analysis ( $n = 9$ ), Grounded Theory ( $n = 12$ ), Interpretive Design/Description ( $n = 2$ ), Narrative Analysis ( $n = 1$ ),

Phenomenological Discourse Analysis ( $n = 1$ ), Feminist Methods ( $n = 1$ ), Interpretive Phenomenological Analysis ( $n = 3$ ), Hermeneutic Phenomenology (Gadamerian Hermeneutics) ( $n = 2$ ), and Framework Analysis ( $n = 1$ ).

The sample size of the studies included in this review ranged from three to fifty-eight women. The total number of women from the fifty-six studies was seven hundred and eighty-nine. The ages of the participants ranged from eighteen to eighty-one years. The ethnicity of the participants was not identified in several studies (see Table 3.2 for details).

### **Study Quality**

Following an evaluation of the included studies' methodological limitations, thirty-eight were rated as '++' (all or most of the criteria of the checklist had been met) and eighteen as '+' (some of the criteria had been met but it was deemed unlikely to affect the conclusion; see Table 3.5). Most studies were found to be methodologically sound, indicating high confidence in their findings. Key aspects assessed included study design, data collection methods, and analytical rigour. Where studies often fell short was in adequately reporting the context and characteristics of the participants, particularly in relation to ethnicity. Additionally, the role of the researcher was often not clearly defined, particularly concerning the relationship between the researcher and participants.

Overall, the evaluation of the included studies revealed that they were methodologically sound with only a few minor concerns, further strengthening confidence in the findings of the meta-synthesis: they are based on rigorous, well-conducted research. This solid foundation reinforces confidence in the

synthesis's implications and how effectively they represent women's experiences with pain.

## **Themes**

Four themes were generated following thematic analysis: 1) Life Revolving around Pain and Multiple Responsibilities, 2) Countless Losses (and their Consequences), 3) Lack of Understanding (Delegitimising and Disempowering Encounters), and 4) Solace and Self-Empowerment. The confidence in the first theme was evaluated as moderate; the remaining were rated as high (see Table 3.3 GRADE-CERQual Evaluation).

### **Life Revolving around Pain and Multiple Responsibilities**

Women in the studies expressed that their lives revolved around their pain and that they also had numerous other responsibilities to deal with: 'The pain takes over. . .there is nothing except pain and work' (Hallberg & Carlsson, 1998). The latter consisted of employment outside the home, housekeeping, shopping, parenting, and care responsibilities. Parenting and pain were described as a 'dual burden' for mothers living with chronic pain. A participant stated that 'looking after her children was the hardest part of pain' (Evans & de Souza, 2008). Women were also mostly responsible for housework (even if they were in pain and unable to work outside the home; Richardson, 2005).

Women spoke of how each day was dictated by their pain: 'You can't just do anything you want. You've now got this little thing called severe back pain constantly holding you in check' (White & Seibold, 2008). Another stated, 'In any situation. . .my back comes first. . .Every situation you can possibly think of, that's what my back stops me from doing' (Evans & de Souza, 2008). Women often expressed taking it 'one day at a time' (Hallberg & Carlsson, 1998) and not being

able to plan for the future: 'I can't make a commitment of any sort for the next day. That bothers me. I don't know where it's [pain] going to be' (Roberto & Reynolds, 2002). Another participant stated, 'My life actually revolves around my pain most of the time. . .it is something I've had to come to terms with and live with' (White & Seibold, 2008). Younger and older women felt this restrictive nature of pain controlling their lives, as well as an inability to plan for the future and participate fully in life.

The confidence in this theme was evaluated as moderate. Of the fifty-six studies included in this review, thirty-nine contributed to this theme (see Tables 3.3 ,3.4, and Appendix One [A], Document Two). There were very few minor concerns regarding methodological limitations. The theme was evaluated as richly described across twenty-seven studies and represented across fourteen of the fifteen countries identified in the review.

### **Countless Losses (and their Consequences)**

Women living with chronic pain experienced many losses as a result of their pain/condition: loss of work, identity, a routine, structure to their day, relationships, self-esteem, a sense of control, their ability to function in life, their former lives, selves, roles, loss of hope, future dreams, and a life they had hoped for (Gullacksen & Lidbeck, 2004). A participant described some of the changes she had experienced: 'The pain has stolen from me the roles of mother, wife, friend, and work colleague' (Dysvik et al., 2013). Another participant described the loss of her work and her identity: 'I had to quit working and that was just incredibly horrible for me because my identity has always been very tied up with my profession' (Howell, 1994), and another participant described the impact on

everyday life: 'You can't go shopping or go for a walk with the baby in a pram' (Knutsen et al., 2022).

The loss of the life they had hoped for was also experienced and expressed: 'I'm only 50 and I should be doing this that and the other cos they say life begins at 40 but I can't and I s'pose it does bother me, it's frustrating that people of my own age are. . .and you feel as if you can't' (Osborn & Smith, 1998). The loss of functioning, control and relationships echoed across the studies. A woman stated that she found it extremely challenging to 'not to be in control of myself' (Knutsen et al., 2022). These losses were accompanied by negative feelings, beliefs, and painful emotions: grief, loneliness, sorrow, anguish, anxiety, and sadness: 'You want to be able to do what you were able to before—it creates a lot of anxiety and grief' (Arman et al., 2020).

Forty-five studies contributed to this theme (see Tables 3.3, 3.4, and Appendix One [A], Document Two). There were very few minor concerns regarding methodological limitations. The theme was found to be comprehensively described in thirty-three studies. It was identified across thirteen of the fifteen nations identified in the present review, and confidence in this theme was evaluated as high.

### **Lack of Understanding: Delegitimising and Disempowering Encounters**

Women reported how they felt that others did not understand their conditions, predicaments, or the challenges that they faced. They stated that this was due to their pain not being visible (both physically and clinically): 'They don't understand it [chronic pain] because they don't see it. I used to give a lot of explanation, but now I can't be bothered anymore. There are very few people who understand it' (Wuytack & Miller, 2011). Women stated that they



experienced stigmatisation from others and from health care professionals (HCPs) because of this lack of understanding and visibility. Women across the studies reported feeling 'dismissed,' 'rejected,' 'disbelieved,' and 'ignored' by HCPs. Participants also felt that many HCPs lacked an understanding of the complexity of chronic pain. Women reported being met with disbelief and discouragement. A woman spoke of how her neurologist dismissed her condition (fibromyalgia): 'There are believers and non-believers, and I am a nonbeliever, so we're not going to talk about that' (Wuytack & Miller, 2011). This was also echoed by another participant: 'The rheumatologist that I saw knew what fibromyalgia was, but he didn't believe in it' (Reibel & Pearson, 2017). Another participant stated that 'unless you have a huge gaping wound or something that they can see, it's really hard to be treated for pain' (Campbell et al., 2022; see also Werner & Malterud, 2003). Furthermore, some of the women felt that they also lacked knowledge about their condition because of their HCP's lack of knowledge and the incorrect information provided to them. Women also felt that their pain was trivialised and not taken seriously: 'It's just not taken seriously [chronic pain]. I think it's very difficult for women to be heard' (Bostick et al., 2018). Other women were told to 'go home and take two aspirins' or that the pain was in their minds (Roberto & Reynolds, 2002).

Women had expectations and hopes when seeking health care (Müllersdorf et al., 2011). However, very few women reported leaving a consultation feeling hopeful, empowered, and validated. Many women left with all their hopes of a diagnosis and effective treatment destroyed. A woman recalled being told by a neurosurgeon that there was nothing wrong with her and that 'Nobody can fix you. Everybody has a bit of pain in life and you better

just get used to it' (Howell, 1994), and another participant left being told, 'You've got no pain. . .there's nothing showing up on this X-ray. . .there's nothing wrong with you!' (Wade & Shantall, 2003), and one woman was told there was nothing else that could be done for her (Arman et al., 2020).

The present theme was found to be comprehensively described in thirty-three of the forty-eight contributing studies. There were only minor concerns regarding methodological limitations. The theme was identified across fourteen countries identified in the present review, and confidence in it was evaluated as high.

### **Solace and Self-Empowerment**

Many of the women in this study were seeking self-empowerment and were trying to self-manage, ease their pain, and make their lives as comfortable as they could. Some women sought comfort and solace in religion, and others gained strength from a belief in a 'higher force' (Gonzalez et al., 2015), organisations, and support groups: 'I get more help from them [support staff] than I do [laughs] with the doctors I go to seek help from' (Allen et al., 2015). They were actively seeking knowledge about their condition, and some had researched extensively: 'You have to become your own doctor, I swear. You've got the three years medical school, but you don't have the certificate hanging on your wall' (Campbell et al., 2022).

Participants used various coping strategies (mainly distraction), took up new hobbies as a way of regaining a purpose in life, and engaged in meaningful activities (volunteering and helping others; Hwang et al., 2004; Wuytack & Miller, 2011). Many women continued on their quest for self-empowerment, and they remained hopeful: 'I don't rely on anybody. This is absolutely my lone

battle against the disease. I have to overcome it by myself' (Hwang et al., 2004); they did not want to be a 'burden' to others (Horment-Lara et al., 2022). They also sought advice from the internet and social media and turned to 'God for strength' (Mellado et al., 2020; Molin et al., 2022), which helped them to also remain hopeful.

This theme was acknowledged across fourteen countries identified in the present review, and confidence in it was evaluated as high. There were only minor methodological concerns, and the theme was comprehensively described across thirty-one of the forty-three contributing studies (Tables 3.3 and 3.4).

## Discussion

This meta-synthesis aimed to explore, evaluate, and analyse women's experiences of living with chronic pain. Findings indicate that the lives of these women revolved around pain and managing multiple responsibilities; their lives were filled with countless losses (which also impacted their psychological well-being), involved experiencing a lack of understanding from others and delegitimising and disempowering encounters, and as a result, their journey was one of seeking solace and self-empowerment to manage their pain. The first theme was evaluated as having moderate confidence. There was high confidence in the evidence of the remaining three themes.

Thirty-nine studies contributed to the first theme. Participants described how their pain was ever-present and how each day was dictated by their pain. Many women referred to pain as something that was 'there all the time,' 'consistent' in their lives, and 'steals' their ability to fully participate in life. Pain significantly shaped their daily experiences and decisions, making it 'difficult to disengage from'; there was a persistent preoccupation with pain (Barnes et al.,

2021; Hallberg & Carlsson, 2000; Howell, 1994; Kirkham et al., 2015; White & Seibold, 2008). Women also had to manage employment outside the home, housekeeping, shopping, parenting, and care responsibilities. These were often considered women's responsibilities. Some women did report receiving help from their family, but again, this indicated it was still their responsibility but for which they were being helped (Söderberg & Lundman, 2001). Domestic work is a strongly gendered activity, with women shouldering a greater share of household responsibilities compared to men (Harryson et al., 2012). This has implications for the support provided to assist women living with chronic pain (Arman et al., 2020). Frustration, annoyance, and depression owing to the limitations imposed by their conditions was also apparent, and some women were choosing to withdraw from social situations. They did not wish to be a 'burden socially' and frequently declined social invitations (Evans & de Souza, 2008).

This is closely linked to the second theme, countless losses (and their consequences). As women withdrew, it led to them experiencing social isolation: 'In the last two years, I have had no social contact' (Mellado et al., 2020). Other women also reported loss of relationships and experiencing loneliness. It is important to address the latter, as loneliness undermines psychological well-being, and has been connected to various mental health problems, suicide, addiction, and depression (Russell et al., 1984). Loneliness is both physically and emotionally painful and it is a form of stress (Hainer, 2012). This can exacerbate pain, and stress also decreases an individual's tolerance for pain (Ahmad & Zakaria, 2015; Lang, 2020; Melzack, 2001). Thus, pain management interventions should be devised to address both. Support groups

were found to be beneficial for women experiencing chronic pain in this review (Allen et al., 2015).

Significant losses were also reported with the loss of employment. Women expressed sadness at losing their job and being unable to work. Some referred to this loss as being associated with their identity. Job loss profoundly impacts psychological well-being (The Mental Health Foundation, 2021). It can cause immense stress and anxiety, impact the self-concept, and cause depression. All of which also physiologically strain the body (British Psychological Society, 2019; Climent-Rodríguez et al., 2019; Guindon & Smith, 2002; Jahoda, 1982; Jahoda et al., 2017; Paul & Moser, 2009) and further exacerbate pain. Loss of work has been described as 'one of the most painful and traumatic events' an individual can experience (Climent-Rodríguez et al., 2019) and one that involves them going through a process of grieving (Climent-Rodríguez et al., 2019; Guindon & Smith, 2002). Individuals may display symptoms similar to those experienced by people affected by a crime: shock, fear, and depression (Guindon & Smith, 2002). It has been stated that it is the loss of latent benefits (social contacts, a time structure, and regular activity) associated with work that results in poorer psychological well-being (Jahoda et al., 2017).

The six factors in Ryff's (1989) model of psychological well-being (self-acceptance, personal growth, purpose in life, environmental mastery, autonomy, and positive relations with others) were all impacted by the losses associated with chronic pain. The studies demonstrated the detrimental effect of chronic pain on psychological well-being. Individuals who witness previous losses of

former self-images without concurrently developing equally valuable new ones ultimately suffer (Charmaz, 1983).

Interventions need to provide a means of replacing some of these latent benefits and other losses. Some of the women in this review had already acknowledged this and had started to take up new hobbies as a way of regaining a purpose in life and engaging in meaningful activities (volunteering and helping others; Hwang et al., 2004; Wuytack & Miller, 2011). Others in a similar situation should also be supported and encouraged to do the same. This theme, evident across forty-five studies, was evaluated as one of high confidence.

The third theme, lack of understanding (delegitimising and disempowering encounters), was also assessed as having high confidence. Women reported a lack of understanding from others as well as HCPs and not being believed. Howell (1994) asserted almost thirty years ago that validation was a significant factor in how women experience pain. However, this has not been addressed, and women continue to needlessly suffer and be met with doubt and disbelief. Women felt that their pain was stigmatised and trivialised. The research indicates that overall, the HCP response is gendered: women's pain is often dismissed (Billock, 2018; Hoffmann & Tarzian, 2001; Samulowitz et al., 2018; Werner & Malterud, 2003; Wuytack & Miller, 2011). HCPs approached women with a general disregard for or disbelief in their experience of pain, as if they were 'making it up' and being told that it was all in their head and to go 'to mental health' (Driscoll et al., 2018). Moreover, women felt that this was due to a lack of understanding regarding chronic pain (from both professionals and laypeople) as well as its invisibility (both physically and clinically). Stigmatisation

can adversely impact both the physical and mental health of individuals (Seele, 2017) living with chronic pain.

Chronic pain is a condition that is poorly understood and cannot be objectively validated and measured. It has been stated that the stigmatisation potential of such conditions can increase because of this (Åsbring & Närvänen, 2002). 'Compassion fatigue' among HCPs and the decline of empathy during medical education has been highlighted, the consequences of which are stigmatisation and blame (Carr, 2016). Improving the public's and HCP's understanding of chronic pain by educating them about women's experiences with chronic pain could be the key to raising awareness, compassion, and reducing stigma (Nehrke et al., 2017; Stenhoff et al., 2015), especially for HCPs.

Women in the included studies were also dissatisfied with the quality and lack of information provided to them; this is especially important as communication and access to information are essential for empowering individuals to manage their condition (Molin et al., 2022). The former is even more crucial in the case of chronic conditions, as individuals must not only deal with a range of distressing symptoms but also learn to adjust to new and more restricted lifestyles (Gullacksen & Lidbeck, 2004). Not providing women with information also undermines self-efficacy (the belief in one's ability to succeed in a given situation; Bandura, 1982). This is crucial for self-management because an individual's sense of it influences his/her behaviour, motivation, and how one approaches goals and health-related challenges (Paterick et al., 2017). It is an important factor in coping with pain and impacts both motivation and behaviour (Firth et al., 2019). HCPs should be empowering women by providing them with helpful information and encouragement (Skuladottir & Halldorsdottir, 2011).

These findings also highlight the necessity of considering chronic pain management interventions within a biopsychosocial framework (Adams et al., 2006).

Confidence in the final theme, solace and self-empowerment, was rated as high. Women were actively seeking information and using various strategies to manage their pain. Some sought comfort in religion, and others were using distraction strategies. Distraction strategies (which include engaging with nature, listening to music, and colouring) were aimed at distracting individuals from negative thoughts, and they have been demonstrated to be effective in managing emotions (Mansell et al., 2020; Tabibnia, 2020). Hence, these should be encouraged, and women should be provided with quality resources so they can continue on their quest for achieving self-empowerment.

### **Limitations**

The search strategy was planned to capture as many studies as possible. However, this was limited to studies published in English and in journals. Thus, the experiences of non-English speaking women (that were not translated) and those not appearing in journals were not analysed. There were also some studies that were not accessible. However, a large number of the studies sought were retrieved. Also, due to the interpretive nature of this analysis, multiple interpretations are possible. However, adopting a reflexive approach aimed to ensure that the interpretation closely reflected and was grounded in the data (Braun & Clarke, 2022; Buetow, 2019; Dodgson, 2019). The iterative nature of the analysis involved revisiting the data and themes across studies for continuous refinement and deeper understanding. Peer debriefings further examined these themes, honouring the complexities of the participants' lived



experiences, with the aim of ensuring the interpretations were anchored in the original findings.

Women recommended a variety of distraction strategies, and larger-scale quantitative studies could examine how effective these are for women living with chronic pain. Ethnicity is also an important factor in differentiating illness experiences, and only one study was identified that compared and contrasted the experiences of women based on this (Pryma, 2017). Other studies (Mustafa et al., 2020; Nortvedt et al., 2016; Nyen & Tveit, 2018) highlighted how the stressful lives of immigrant women, along with cultural expectations to prioritise others' needs, limited time for rest or medical care, and language barriers, intensified their pain experiences. This underscores the need to explore the unique needs of women from diverse backgrounds and cultures and develop appropriate, accessible pain self-management solutions, which future research could explore. Some individuals may also face barriers related to technology use and access. The needs, challenges, and experiences of these individuals are also important areas to explore.

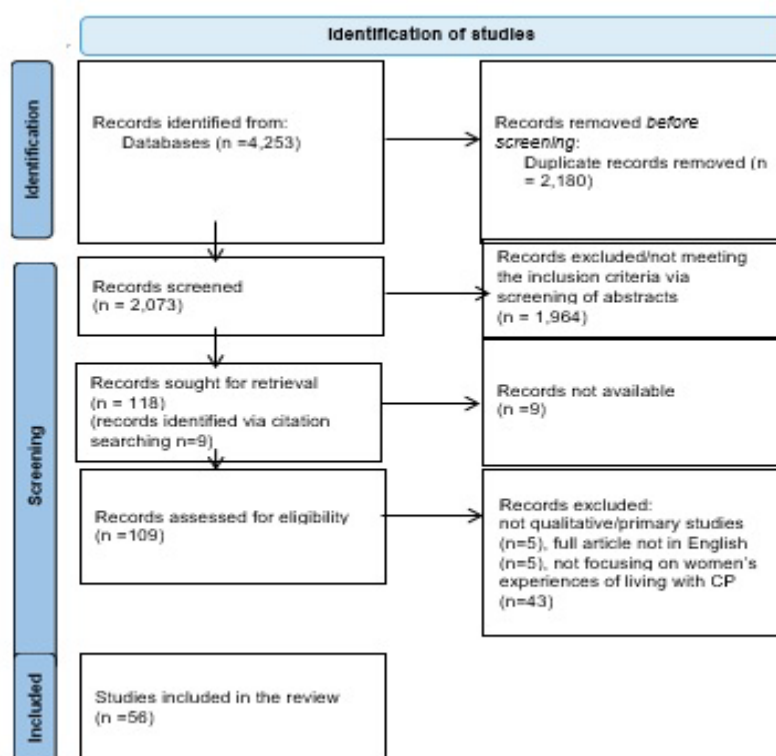
## Conclusion

This meta-synthesis presents a new, more comprehensive, and integrated analysis of women's experiences of living with chronic pain. These findings suggest that comparable patterns run through the lives of women who experience chronic pain across a wide range of age groups, regions, and conditions. The findings reveal the dominance and influence of chronic pain in women's lives. It should thus be considered a clinical priority. Furthermore, an effort should be made to mitigate the existential losses experienced. The issue of women not being believed calls for HCPs to engage more seriously with them

and may indicate a need for educational interventions on chronic pain for HCPs. If an individual claims to be experiencing pain, then this should be acknowledged as such (IASP, 2020). Moreover, the findings have demonstrated that women are developing their own coping strategies at the individual and community levels; these must serve as one of the foundations for chronic pain management. Women's experiences and needs should be considered in their treatment and care, in devising interventions, and in order to empower these women to live well with their conditions (Olshansky et al., 2005).

The studies included in this review demonstrated the power and influence of others on women's experiences of pain. HCPs have the power to influence the length and severity of women's pain. Medicine can be both a supportive institution that addresses or alleviates numerous problems and, at the same time, a restrictive one that may create or worsen other challenges (Howell, 1994; Williams, 2004). HCPs are still guilty of stigmatising women, resulting in denial of treatment (Lyman, 2021; Seele, 2017). To not acknowledge an individual's account of their pain is to destroy all hope of managing it; if they are not believed, then they cannot be helped. Pain is a subjective experience; there is no gold-standard test or measurement for it. Moreover, individuals might show their suffering in a variety of ways. It would thus be unethical to acknowledge the suffering of one person or group while ignoring the suffering of another. Furthermore, not all women may possess the mindset, amount of motivation, self-efficacy, and resilience necessary to transform these bad experiences into a desire for empowerment. Thus, HCPs need to be mindful of the power of their words and their positions.

Figure 3.1: PRISMA diagram: The Search and Screening Process



(Adapted From: Page et al. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. <http://www.prisma-statement.org>)

Table 3.1: Numbered List of Studies Included in the Review

1. Ahlsen et al. (2014). (Un)doing gender in a rehabilitation context: A narrative analysis of gender and self in stories of chronic muscle pain.
2. Allen et al. (2015). Exploring the experience of chronic pain among female survival sex workers: A qualitative study.
3. Arman et al. (2020). Women's lived experiences of chronic pain: Faces of gendered suffering.
4. Barnes et al. (2021). Exploring the emotional experiences of young women with chronic pain: The potential role of self-compassion.
5. Bostick et al. (2018). Pain assessment recommendations for women, made by women: A mixed methods study.
6. Campbell et al. (2022). Women's experiences of navigating chronic pain within the context of living with an episodic disability.

7. Campeau (2018). Adaptive frameworks of chronic pain: Daily remakings of pain and care at a Somali refugee women's health centre.
8. Dickson and Kim (2003). Reconstructing a meaning of pain: Older Korean American women's experiences with the pain of osteoarthritis.
9. Driscoll et al. (2018). Patient experiences navigating chronic pain management in an integrated health care system: A qualitative investigation of women and men.
10. Dysvik et al. (2013). A narrative approach to explore grief experiences and treatment adherence in people with chronic pain after participation in a pain-management program: A 6-year follow-up study.
11. Evans and de Souza (2008). Dealing with chronic pain: Giving voice to the experiences of mothers with chronic pain and their children.
12. Gonzalez et al. (2015). Life history of women with fibromyalgia: Beyond the illness.
13. Gullacksen and Lidbeck (2004). The life adjustment process in chronic pain: Psychosocial assessment and clinical implications.
14. Hallberg and Carlsson (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia: In-depth interviews with twenty-two female patients.
15. Hallberg and Carlsson (2000). Coping with fibromyalgia: A qualitative study.
16. Horment-Lara et al. (2022). "I don't want to be a burden": A qualitative study of the beliefs of women with chronic low back pain in relation to their painful experience.
17. Howell (1994). A theoretical model for caring for women with chronic non-malignant pain (CNP).
18. Hwang et al. (2004). Lived experience of Korean women suffering from rheumatoid arthritis: A phenomenological approach.
19. Juuso et al. (2011). Living with a double burden: Meanings of pain for women with fibromyalgia.
20. Juuso et al. (2014). Meanings of being received and met by others as experienced by women with fibromyalgia.
21. Juuso et al. (2016). The workplace experiences of women with fibromyalgia.
22. Kanter et al. (2017). Important role of physicians in addressing psychological aspects of interstitial cystitis/bladder pain syndrome (IC/BPS): A qualitative analysis.

23. Kengen Traska et al. (2012). Strategies used for managing symptoms by women with fibromyalgia.
24. Kirkham et al. (2015). Painting pain: An interpretative phenomenological analysis of representations of living with chronic pain.
25. Knutsen et al. (2022). 'The sofa is my base in daily life': The experience of long-term, pelvic girdle pain after giving birth.
26. Lehti et al. (2017). Walking down 'Via Dolorosa' from primary health care to the specialty pain clinic—Patient and professional perceptions of inequity in rehabilitation of chronic pain.
27. Löfgren et al. (2006). 'A constant struggle': Successful strategies of women in work despite fibromyalgia.
28. Mellado et al. (2016). Social isolation in women with endometriosis and chronic pelvic pain.
29. Mellado et al. (2020). Daily life attitudes of women with moderate or severe chronic pelvic pain: A qualitative study.
30. Michaëlis et al. (2015). Quality of life and coping strategies among immigrant women living with pain in Denmark: A qualitative study.
31. Molin et al. (2021). Grieving over the past and struggling forward—A qualitative study of women's experiences of chronic pain one year after childbirth.
32. Molin et al. (2022). Disempowering women: A mixed methods study exploring informational support about pain persisting after childbirth and its consequences.
33. Monsivais (2013). Decreasing the stigma burden of chronic pain.
34. Müllersdorf et al. (2011). The magnitude of reciprocity in chronic pain management: Experiences of dispersed ethnic populations of Muslim women.
35. Mustafa et al. (2020). The lived experiences of chronic pain among immigrant Indian-Canadian women: A phenomenological analysis.
36. Nortvedt et al. (2015). Caught in suffering bodies: A qualitative study of immigrant women on long-term sick leave in Norway.
37. Nortvedt et al. (2016). A lonely life: A qualitative study of immigrant women on long-term sick leave in Norway.
38. Nyen and Tveit (2018). Symptoms without disease: Exploring experiences of non-Western immigrant women living with chronic pain.

39. Osborn and Smith (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis.
40. Peppard et al. (2022). The lived experience of military women with chronic pain: A phenomenological study.
41. Pryma (2017). "Even my sister says I'm acting like a crazy to get a check": Race, gender, and moral boundary-work in women's claims of disabling chronic pain.
42. Råheim and Håland (2006). Lived experience of chronic pain and fibromyalgia: Women's stories from daily life.
43. Reibel and Pearson (2017). Beyond the pain: A look into the experiences of women living with fibromyalgia.
44. Richardson (2005). Establishing the (extra)ordinary in chronic widespread pain.
45. Roberto and Reynolds (2002). Older women's experiences with chronic pain: Daily challenges and self-care practices.
46. Schaefer (1995). Struggling to maintain balance: A study of women living with fibromyalgia.
47. Skuladottir and Halldorsdottir (2011). The quest for well-being: Self-identified needs of women in chronic pain.
48. Söderberg and Lundman (2001). Transitions experienced by women with fibromyalgia.
49. Söderberg et al. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia.
50. Wade and Shantall (2003). The meaning of chronic pain: A phenomenological analysis.
51. Werner and Malterud (2003). It is hard work behaving as a credible patient: Encounters between women with chronic pain and their doctors.
52. Werner et al. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain.
53. Westergården et al. (2021). 'Moving between living in the shadow of pain and living a life with the pain in the shadows': Women's experiences of daily life with chronic widespread pain: A qualitative study.
54. White and Seibold (2008). Walk a mile in my shoes: An auto-ethnographic study.
55. Wuytack and Miller (2011). The lived experience of fibromyalgia in female patients: A phenomenological study.

56. Zander et al. (2013). Struggling for sense of control: Everyday life with chronic pain for women of the Iraqi diaspora in Sweden.

Table 3.2: Overview of Included Studies in the Review

Study title, author, date, and (country)	Aims of the study	Details of female participants (ethnicity, condition, age range of women)  Sample Size (women)	Data collection method/Analysis method	Key findings/themes
<b>1.Ahlsen et al. (2014). (Un)doing gender in a rehabilitation context: A narrative analysis of gender and self in stories of chronic muscle pain. (Norway)</b>	Exploration of gender in the self-told stories of men and women undergoing rehabilitation for chronic pain.	6 Norwegian Women with Chronic Neck Pain 28-50 years	Interviews Narrative Analysis	The evolving self through rehabilitation: women's stories tended to develop from "chaos", towards a quest narrative with a more autonomous self. Their stories displayed selves that were actively trying to transcend their former identity and life conditions, in which their pain was embedded.
<b>2. Allen et al. (2015). Exploring the experience of chronic pain among female Survival Sex Workers: a qualitative study. (Canada)</b>	To understand the experience of chronic pain among female Survival Sex Workers (and address the gap in literature on chronic pain experience in this group) in Vancouver's downtown east side	11 females with chronic pain Age 42- 56 years  Six women identified as Aboriginal and five as Caucasian	In-depth semi-structured interviews  Thematic Analysis	1.Communication understanding chronic pain (subjectivity and diversity in descriptions) communicating with others: not being heard 2. Cures Use of various substances to numb the pain 3.Systemic barriers multiple systemic barriers were described by women in managing their chronic pain (including judgment (stigma) and poverty). 4.Stressors (adverse



				experiences in life/lack of family support). 5.Support: peer support groups were vital
<b>3.Arman et al. (2020). Women's Lived Experiences of Chronic Pain: Faces of Gendered Suffering. (Sweden)</b>	To understand the lived experience of women with chronic pain (from a caring science and gender perspective).	21 women with Chronic pain 20-61 years	Semi-structured interviews  Hermeneutic Phenomenology (Gadamerian Hermeneutics)	1.Living an Overwhelming Life in Loneliness 2. Taking Care of Others Without Yourself Being Cared For 3. Keep Going and a "Knackered" Body 4. Understanding Suffering in the Light of Their Own Lives
<b>4.Barnes et al. (2021). Exploring the emotional experiences of young women with chronic pain: The potential role of self-compassion. (Canada)</b>	Exploration of the emotional experiences of women with chronic pain and the role of self-compassion	Seven women with chronic pain that was not related to another health condition or related to a diagnosed pain condition Age 19-34 years All Canadian and white (one also self-identified as indigenous)	Narrative Inquiry Focus groups Reflective photo voice One-to-one semi-structured interviews Holistic-content analysis	1.The Emotional Challenges of Chronic Pain 2. The Journey to Self-Awareness 3. The Transition to a Self-Compassionate Mind-set
<b>5.Bostick et al. (2018). Pain Assessment Recommendations for Women, Made by Women: A Mixed Methods Study. (Canada)</b>	To Qualitatively explain unique features of women's pain experiences	10 women living with chronic (non-cancer) pain 24-63 years	Semi-structured (phone) interviews (qualitative phase) Content Analysis	Qualitative findings 1.Stigmatisation (not being listened to; Pain is more than a number and Social roles & norms).
<b>6.Campbell et al. (2022). Women's experiences of navigating chronic pain within</b>	To explore the experience of chronic pain for	30 women Age 20-62 years	Semi-structured interviews Interpretive description	Navigating and responding to the healthcare system The power of being

**the context of living with an episodic disability.  
(Canada)**

women living with episodic disabilities.

living with chronic pain and an episodic disability (Lupus, Multiple Sclerosis, Fibromyalgia, Ehlers -Danlos syndrome, Rheumatoid arthritis, and irritable bowel syndrome)

dismissed  
Dis(respecting) medical advice  
Seeking personalized care in an unpersonal system.  
The "cost" of well-being.  
Seeking the essentials of living beyond healthcare

**7.Campeau (2018). Adaptive frameworks of chronic pain: Daily remakings of pain and care at a Somali refugee women's health centre.  
(United States)**

To understand Somali women's use of informal and formal networks of healthcare

12 Somali women living with chronic pain (headaches n= 5, Lupus n=2, auto-immune disease n= 2, post-traumatic stress disorder & Endometriosis n=1, Chronic pelvic and back pain n= 1, and Rheumatoid arthritis and heart disease, n= 1)  
  
Interviews (n=12) and Focus groups (n=8), participant observation (12 women with pain and 3 health educators)

Ethnographic study:  
  
Interviews, Focus groups, and Participant observations  
  
Grounded Theory

Four frameworks identified:  
  
1.Pain as a symptom of exile (lost home linked to bygone health)  
2. Pain and the strength to bear pain as issues of faith (faith as a coping strategy for all the participants)  
3. Medicine as powerful, curative and fluid  
4. Medical discrimination and exclusion.

**8. Dickson and Kim (2003). Reconstructing a meaning of pain: older Korean American women's experiences with the pain of osteoarthritis.  
(United States)**

To gain a deeper understanding of older Korean American women's experiences of chronic osteoarthritic pain

Women (n=7) with Osteoarthritis  
  
Age 63- 80 years  
  
Korean American

Interviews  
  
Grounded Theory

Women came to perceive their pain as a component of aging rather than as a symptom of disease.  
  
Five stage process of constructing meaning of pain:  
Suffering with pain  
Struggling to remove pain  
Stumbling along with pain  
Striving to reduce pain

<p><b>9. Driscoll et al. (2018). Patient Experiences Navigating Chronic Pain Management in an Integrated Health Care System: A Qualitative Investigation of Women and Men.</b></p> <p><b>(United States)</b></p>	<p>To describe perceptions of managing pain in an integrated health care system and to explore gender differences</p>	<p>Women (n=22) with chronic pain</p> <p>Average age 55.2 years</p> <p>64% White</p>	<p>Focus groups</p> <p>Grounded Theory</p>	<p>Managing and tolerating pain</p> <p>1. just keep plugging</p> <p>a. always a reacquaintance process</p> <p>b. so many hoops</p> <p>c. to medicate or not.</p> <p>A distinct theme, "the challenges of being female," reflected women's perceptions of stigma and bias</p>
<p><b>10. Dysvik et al. (2013). A narrative approach to explore grief experiences and treatment adherence in people with chronic pain after participation in a pain-management program: A 6-year follow-up study.</b></p> <p><b>(Norway)</b></p>	<p>To explore grief caused by chronic pain and treatment adherence, and how these experiences are integrated into ongoing life stories.</p>	<p>Five women living chronic pain caused by different musculoskeletal disorders</p> <p>Age 41-66 years</p>	<p>Narrative inquiry (image/written narratives)</p> <p>Narrative Analysis</p>	<p>Experiences of grief over time were commonly associated with chronic pain. The participants' past experiences reflected their grief at having to abandon jobs and social networks and revealed loneliness and despair.</p> <p>Adaptation, and hope for the future had been established.</p>
<p><b>11. Evans and de Souza (2008). Dealing with chronic pain: Giving voice to the experiences of mothers with chronic pain and their children.</b></p> <p><b>(New Zealand)</b></p>	<p>Exploration of the impact of chronic pain on mothers and their children (from a gains and losses theory and the strengths perspective).</p>	<p>16 mothers with chronic pain</p> <p>Age 27-45 years</p> <p>(Lupus n=1, arthritis n=1, polycystic ovary syndrome n=1, migraine n=2, repetitive strain injury n=2, spinal pain n=9)</p> <p>All White sample</p>	<p>Open-ended semi-structured interviews</p> <p>Framework (deductive) Analysis</p>	<p>Pain formed a substantial part of the participants' lives. Every facet of life was impacted by pain. Positive and negative aspects of pain were identified (pain as a burden and focus on blessings). Parenting was observed as a two-way interaction.</p>

**12. Gonzalez et al. (2015). Life History of Women with Fibromyalgia: Beyond the Illness. (Portugal)**

To explore the life history of women with fibromyalgia that had experienced a critical or very stressful life event before the onset of the syndrome

10 women with fibromyalgia  
Ages 29-59 years

Interviews  
  
Interpretative Phenomenological Analysis

1.Struggle, 2. focus on adversities,3. positive overlaps the negative, 4. scars of an unhappy childhood, 5. help others, 6. perfectionism and desire to achieve, 7. unsatisfactory present, 8. perception of injustice, and 9. keep feelings inside.

**13. Gullacksen and Lidbeck (2004). The life adjustment process in chronic pain: psychosocial assessment and clinical implications. (Sweden)**

To explore the subjective experience/life adjustment processes of women diagnosed with chronic musculoskeletal pain

18 women (11 with myofascial pain syndrome and 7 with fibromyalgia.  
Age 23 -55 years

Interviews  
Inductive thematic analysis (phenomenological framework)

A proposed model for life adjustment Three stages of the life adjustment process:  
1. Prelude, struggling to restore life, self-deception, confirmation, and acknowledgement  
2.Working through, sorrow and loss, losing oneself, leaving the role of being sick, defining the problems, finding solutions, picture of the future affects coping.  
3.Establishing a new course of life. After the three stages, the work of maintaining the adjustment reached is continuous.

**14. Hallberg and Carlsson (1998). Psychosocial vulnerability and maintaining forces related to fibromyalgia.**

To describe women's experiences of living with Fibromyalgia, their beliefs

22 women with Fibromyalgia  
Age 22-60 years

Open-ended in-depth interviews  
  
Grounded Theory

Main findings  
Psychosocial vulnerability (with subcategories: traumatic life history, over-compensatory

**In-depth interviews with twenty-two female patients. (Sweden)**

about the pain and its origin, and how pain impacts family and social life.

To broaden the understanding of what it means to the women to be living with Fibromyalgia

perseverance, pessimistic life view, and unsatisfying work situation, which contribute to the development of CP) and maintaining forces (three subcategories: professional care, pain benefits, and family support, which contribute to the persistence and chronicity of the pain symptoms).

**15. Hallberg and Carlsson (2000). Coping with fibromyalgia: A qualitative study. (Sweden)**

To describe women's experiences of living with chronic pain (diagnosed with fibromyalgia) and how they manage their situation

22 women with Fibromyalgia  
Age 22-60 years

Open-ended in-depth interviews  
Grounded theory

Core concept: preoccupied with pain  
Three categories: subjective pain language diversified pain coping pain communication.

**16. Horment-Lara et al. (2022). "I don't want to be a burden" A qualitative study of the beliefs of women with chronic low back pain in relation to their painful experience. (Chile)**

To explore the beliefs of women with non-specific chronic low back pain (regarding the nature of their symptoms, fears associated with pain, expectations for recovery, family, social and work-related

10 women with non-specific chronic low back pain  
Age 43 -76 years

semi-structured interviews  
  
Thematic (deductive) analysis

1. Beliefs regarding the nature of pain  
2. Fears associated with the experience of pain  
3. Expectations of recovery  
4. Behavioral outcomes originating from beliefs: social life and self-efficacy

	limitations, and perceived self-efficacy)			
<b>17. Howell (1994). A theoretical model for caring for women with chronic non-malignant pain (CNP). (United States)</b>	To uncover the underlying processes in the experience of living with CNP from women's perspectives and explain these processes.	19 women living with chronic pain (low back pain, phantom limb pain, fibromyalgia, arthritis, and migraine headaches) Age 21-76 years (Details on ethnicity provided for fourteen participants: 11 Caucasian, 2 Hispanic, and 1 Black)	In-depth Interviews Participant observation Critical incident health diaries  Grounded Theory	Theory to explain women's healthy progression through the experience of living with CNP (three phases): 1.The pain takes over 2.Filling my life with new hope (some women did not progress to this healthy phase but progressed to illness: 'filling my life with pain and despair'). Progression is influenced by patterns of validating (others/doctors). 3.Fulfilling my life with pain
<b>18. Hwang et al. (2004). Lived experience of Korean women suffering from rheumatoid arthritis: a phenomenological approach (Korea)</b>	To explore and describe the illness experience of women with Rheumatoid arthritis in Korea	5 women with Rheumatoid arthritis 34-61 years	Interviews Phenomenology	1.severe pain 2. self-esteem 3. negative feelings 4. reflect the past life 5. concentrate on recovery from disease 6. a comfortable mind in pain 7. support of family and others 8. new life
<b>19. Juuso et al. (2011). Living with a double burden: Meanings of pain for women with fibromyalgia. (Sweden)</b>	To elucidate the meanings of pain for women with Fibromyalgia	15 women with Fibromyalgia Age 38-64 years	Interviews Phenomenology	1.Experiencing an unwilling body and 2. Experiencing a good life despite all.  Pain dominated daily life, but the women found ways to manage and control it. They experienced disbelief/not being taken seriously and found relief through distraction.

**20. Juuso et al. (2014). Meanings of Being Received and Met by Others as Experienced by Women with Fibromyalgia. (Sweden)**

To elucidate meanings of being received and met by others as experienced by women with FM

9 women with fibromyalgia  
Age 40-65 years

Interviews  
  
Phenomenology

1.being seen as a malingerer 2. being acknowledged Meanings of being received and met by others, as experienced by women with FM, was seen as a movement between the two perspectives. When women were acknowledged, their feelings of security and trust increased. However, the women could not rely on this because others received and met them in such an unpredictable manner.

**21. Juuso et al. (2016). The Workplace Experiences of Women with Fibromyalgia. (Sweden)**

To explore experiences of the workplace of women living with Fibromyalgia

15 women  
Age 38 - 64 years

In-depth interviews  
  
Hermeneutic Phenomenology (Gadamerian Hermeneutics)

1.The body as an obstacle to working (women wished to work but found it exhausting) 2. Accepting the inability to work as before 3. Work meant everything in life 4. A future shaped in vagueness

**22. Kanter et al. (2017). Important role of physicians in addressing psychological aspects of interstitial cystitis/bladder pain syndrome (IC/BPS): A qualitative analysis (United States)**

To explore patients' experience with Interstitial cystitis/bladder pain syndrome symptoms and of their medical care to elicit suggestions to

15 women with Interstitial cystitis/bladder pain syndrome (Mean age 52.6 years)  
  
American Indian/Alaskan Native (n=2), Non-Hispanic Caucasian (n=6), Hispanic (n= 4), Other (n=3)

Focus groups  
  
Grounded Theory

1.IC/BPS is a life-altering, debilitating condition 2. Fear and anxiety from the unrelenting and unpredictable nature of the disease 3. Isolation  
  
Provider impact  
1. Patients wanted to know that all their providers (irrespective of whether they

	improve patient satisfaction with that care			were physicians, nurses, physical therapists, or otherwise) were truly listening to them. 2. Participants desired increased knowledge about their condition and largely preferred to hear about treatment options. 3. Provider expression of hope for improvement of their symptoms was vital.
<b>23. Kengen Traska et al. (2012). Strategies used for managing symptoms by women with fibromyalgia. (United States)</b>	To describe how individuals with fibromyalgia manage their condition and explore the strategies they utilize	8 women with fibromyalgia Age 54 to 81 years Hispanic, n=1 and Caucasian, n=7	Focus group Content Analysis	(1) pacing/planning; (2) focusing on mind, body and spirit/distraction; (3) coping with sensitivity to touch; (4) social support; (5) pushing yourself/putting on a mask; and (6) medications
<b>24. Kirkham et al. (2015). Painting pain: An interpretative phenomenological analysis of representations of living with chronic pain. (England)</b>	To understand women's experiences of living with chronic pain and their conditions through pictorial representations of their chronic pain, alongside their accounts of those images	Seven women living with chronic pain White British Age 36 -52 years	Semi-structured Interviews/illustrations Interpretative Phenomenological Analysis	1. Pain as an object: Sinister, violent, punitive 2. The color of pain: Red and Burning, Black and Brooding  Images showed a movement from the self before pain to the self since the pain had started or pointing to aspirations for the possible relief of pain in the future.



<p><b>25. Knutsen et al. (2022). 'The sofa is my base in daily life': The experience of long-term, pelvic girdle pain after giving birth.</b></p> <p><b>(Norway)</b></p>	<p>To explore how women struggling with long-term pelvic girdle pain after giving birth experienced it and coped in their daily life.</p>	<p>9 Norwegian women with pelvic girdle pain Age 26- 56 years</p>	<p>Semi-structured interviews Phenomenology</p>	<p>1.A life with pain and an unpredictable body 2.An identity as disabled, dependent, and ashamed 3.Recharging on the sofa: adaptation and fighting for dignity and acceptance 4.Striving to live as you wish: isolation and working life</p>
<p><b>26. Lehti et al. (2017). Walking down 'Via Dolorosa' from primary health care to the specialty pain clinic–Patient and professional perceptions of inequity in rehabilitation of chronic pain.</b></p> <p><b>(Sweden)</b></p>	<p>To analyze patient and professional perceptions about (in)equity of care and rehabilitation of chronic pain patients from primary health care to assessment at a specialty rehabilitation clinic.</p>	<p>(sample of women) 5 females living with chronic pain Age for all patients provided: 35-65 years</p>	<p>Focus group and semi-structured interviews  Grounded Theory</p>	<p>one core category, 'walking down Via Dolorosa', and five inter-related categories 'pain – an illness with low status', 'stereotyping thoughts', 'burdened by pain – referrals as a way out', 'assessing and selecting in context' and 'a proper patient, ready to change'.</p>
<p><b>27. Löfgren et al. (2006). 'A constant struggle': Successful strategies of women in work despite fibromyalgia.</b></p> <p><b>(Sweden)</b></p>	<p>To explore and obtain increased knowledge of the strategies used by working women with fibromyalgia regarding control of pain, fatigue and other symptoms.</p>	<p>12 females living with fibromyalgia Age 30-63 years</p>	<p>Diaries and focus groups (n=7) and individual interviews(n=2), diary (n=3) only and FG only (n= 2)  Content analysis and Grounded Theory</p>	<p>The core category 'constant struggle' with eight sub-categories: enjoying life, taking care of oneself, positive thinking, setting limits, using pain as a guide, creative solutions, learning/being knowledgeable and 'walking a tightrope'. A 'grieving process' was a prerequisite for managing the struggle and 'social</p>

<b>28. Mellado et al. (2016). Social isolation in women with endometriosis and chronic pelvic pain (Brazil)</b>	<p>To evaluate the perceptions of women with endometriosis and chronic pelvic pain regarding their social ties</p>	<p>29 females with endometriosis and chronic pelvic pain Age 21–49 years</p>	<p>Focus groups Grounded Theory</p>	<p>support' facilitated the struggle.</p> <ol style="list-style-type: none"> <li>1.Social isolation</li> <li>a. Avoiding intimacy</li> <li>b. isolation from family and friends</li> <li>c. Lack of understanding about the disease</li> <li>d. Resignation</li> </ol>
<b>29. Mellado et al. (2020). Daily life attitudes of women with moderate or severe chronic pelvic pain. A qualitative study. (Brazil)</b>	<p>To understand the attitudes adopted by women with chronic pelvic pain (CPP) to deal with daily life problems caused by their condition</p>	<p>58 females with CPP Age 22 -57 years</p>	<p>Semi-structured interviews (phenomenological study) Thematic Analysis</p>	<p>1) shaping life by pain; 2) isolating from social contact; 3) avoiding sexual relationships; 4) seeking pain relief; 5) seeking positive strategies (these were more frequent in older women).</p>
<b>30. Michaëlis et al. (2015). Quality of life and coping strategies among immigrant women living with pain in Denmark: A qualitative study. (Denmark)</b>	<p>To examine the quality of life and coping strategies among immigrant women living with chronic pain in Denmark.</p>	<p>13 females living with chronic pain. All participants were non-western immigrant women who had migrated to Denmark from Turkey, Iraq, Afghanistan, Somalia, Pakistan, Jordan or Morocco.  Age 33- 63 years</p>	<p>Semi-structured interviews (and observations) Content Analysis</p>	<p>1. Experiences of chronic pain (the negative impact on activities of daily living, altered mental well-being, strained social relations) 2. Coping with chronic pain (altering everyday life, seeking healthcare)</p>
<b>31. Molin et al. (2021). Grieving over the past and struggling forward–A qualitative study of women's experiences of chronic pain one year after childbirth.</b>	<p>To describe women's experiences of chronic pain related to childbirth</p>	<p>20 women experiencing chronic pain Age 25- 43 years</p>	<p>In-depth interviews Content analysis</p>	<p>1."Grieving over the past and struggling forward" a. "Mourning the losses", b. "Struggling with the present" and c. "Managing the future"</p>

<b>(Sweden)</b>	approximately one year after labour			
<b>32. Molin et al. (2022). Disempowering women-a mixed methods study exploring informational support about pain persisting after childbirth and its consequences.</b> <b>(Sweden)</b>	To explore women's experience and thoughts regarding information about chronic pain, and informational support about pain persisting after childbirth and its consequences.	20 women experiencing chronic pain Age 25- 43 years (in-depth sample)	In-depth interviews (qualitative phase) Content analysis	Three categories emerged in the interview data: 1. "Inadequate information ", 2. "Negative consequences (emotional distress)", and 3. "Information needs and requirements"
<b>33.Monsivais (2013). Decreasing the stigma burden of chronic pain.</b> <b>(United States)</b>	To explore stigmatizing experiences shared by Mexican American women living with chronic pain and provide guidelines for reducing stigma.	15 Mexican American women 21-65 years old living with chronic pain	Ethnographic study consisting of semi structured interviews, participant observations, and fieldwork Thematic analysis	1.Role functions and communication within the family (participants were often unable to fulfil role functions within the family because of pain) 2.Role functions and communication within the workplace (women remained silent about the pain in order to maintain their identities as independent, truthful, and hardworking women). To reduce stigma HCPs must understand their own misconceptions about CP.
<b>34. Müllersdorf et al. (2011). The magnitude of reciprocity in chronic pain management:</b>	To examine the experience of living with	Five Females with chronic pain (MSK)	Semi-structured interviews Grounded Theory	1. 'The magnitude of reciprocity' based on a. impact of pain, b. managing

<b>Experiences of dispersed ethnic populations of Muslim women.</b> <b>(Sweden)</b>	musculoskeletal pain and experience of health care among dispersed ethnic populations of Muslim women.	Age 33 – 56 years (dispersed ethnic populations of Muslim women from Iraq in Sweden).		pain and c. facing health care
<b>35. Mustafa et al. (2020). The lived experiences of chronic pain among immigrant Indian-Canadian women: A phenomenological analysis.</b> <b>(Canada)</b>	To explore the lived experiences of chronic pain among immigrant Indian women in Canada.	Thirteen women with chronic musculoskeletal pain Age 34-60 years Indian	Semi-structured interviews  Thematic analysis (informed by van Manen's phenomenology of practice)	1.The body in pain 2. Pain in the context of lived and felt space 3.Pain and Relationships 4. Pain and time.
<b>36. Nortvedt et al. (2015). Caught in suffering bodies: A qualitative study of immigrant women on long-term sick leave in Norway.</b> <b>(Norway)</b>	To explore the issues faced by immigrant women on long-term sick leave due to chronic pain, focusing on their personal perspectives on their daily lives, their bodies and their pain	14 females (immigrants from Asia/Africa) with chronic pain Age 30 to 59 years	participant-observation (n=14) and in-depth interviews (n=11)  Phenomenology	1.Bodies marked by onerous experience (two subthemes: It is in my body and Invisible pain)
<b>37. Nortvedt et al. (2016). A lonely life-A qualitative study of immigrant women on long-term sick leave in Norway.</b> <b>(Norway)</b>	To explore how immigrant women on long-term sick leave in Norway due to chronic pain experience their	14 females (immigrants from Asia/Africa) with chronic pain Age 30 -56 years	Participant observation (n=14) and semi-structured Interviews (n= 11)  Phenomenology	1. A lonely life Shut inside the home and rejected at the workplace

	illness and their relationships at work and in the family			
<b>38. Nyen and Tveit (2018). Symptoms without disease: Exploring experiences of non-Western immigrant women living with chronic pain. (Norway)</b>	The aims of the researchers were to explore the experiences of non-Western immigrant women living with chronic pain in Norway.	9 females (immigrant women from Pakistan, Morocco, Tunisia, Iran, Somalia, and Ethiopia) with chronic pain. Three participants from Pakistan, two from Somalia, and one each from Tunisia, Morocco, Eritrea, and Iran.  Age 31-55 years	Semi-structured interviews  Phenomenology	1. Explaining pain 2. stressful lives 3. Painful Losses
<b>39. Osborn and Smith (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. (England)</b>	To gain insight into the personal experience of chronic benign lower back pain	9 women with chronic back pain  Age 25-55 years	semi-structured interviews  Interpretative Phenomenological Analysis	1. Searching for an explanation 2. Comparing this self with other selves 3. Not being believed and 4. withdrawing from others
<b>40. Peppard et al. (2022). The Lived Experience of Military Women with Chronic Pain: A Phenomenological Study. (United States)</b>	To explore a typical day for military women living with chronic pain by examining the participants' daily life experiences.	Thirteen active duty, retired, or veteran women experiencing chronic pain.  Age 31- 65 years  Ethnicity  Black or African American (n=4), Hispanic or Latino (n=1), Asian-American/Pacific Islander(n=1), White or Caucasian (n=7)	Semi-structured interviews  Phenomenology	1) living with chronic pain is frustrating, persistent, daily, and an hourly struggle; (2) resilience in living with chronic pain is the new normal; (3) mission first and the impact of invisible pain;(4) self-care management and the internal locus of control in using non-pharmacological therapies; (5) pain accepted and managed to improve quality of life; (6)

**41. Pryma (2017). “Even my sister says I’m acting like a crazy to get a check”: Race, gender, and moral boundary-work in women’s claims of disabling chronic pain (United States)**

To explore how the experiences of women with fibromyalgia who seek legitimation for their pain and disability change based on race. Also, how race shapes the moral boundary-work performed by women suffering from disabling chronic pain.

24 females with fibromyalgia  
Age late-twenties to mid-Sixties stated  
Ten identified as Black and/or African-American, three as Latina, one as Asian-American, and ten as White.

Semi-structured Interviews  
Inductive Thematic analysis

coronavirus disease(COVID-19) diminished social interactions; (7) pain of sexual trauma is not reported; and (8) disparities in health care due to self-perception of provider bias as pain is not understood.

There were different types of moral-boundary work performed: the white women interviewed, primarily relied on biomedical evidence when making claims of legitimate disability; Black respondents often referenced trauma, abuse and discrimination, in addition to their diagnoses, to signal their deservingness of aid. All women described at least one instance of where the legitimacy of their pain was doubted.

**42. Råheim and Håland (2006). Lived Experience of Chronic Pain and Fibromyalgia: Women’s Stories From Daily Life. (Norway)**

To describe and understand women's lived experience of chronic pain and fibromyalgia

12 women with Fibromyalgia  
Age 34-51 years  
White

Life-form interviews  
Phenomenology

Three typologies  
1. At the will of the treacherous body-powerlessness (Morning–The Prison of the Body, Forenoon and Afternoon Needs) Against the Body and Giving Up, Evening–Endless Pain, Feeling Useless and in Despair; Important Relations–Lack of Recognition and Support)

**43. Reibel and Pearson (2017).  
Beyond the Pain: A Look into  
the Experiences of Women  
Living with Fibromyalgia  
(United States)**

To gain an understanding of the lived experiences of women with fibromyalgia

3 females with fibromyalgia

In-depth interviews  
(phenomenological study)  
Thematic Analysis

2.Struggling to escape the treacherous body-ambivalence (Morning–The Body “Threatens to Take Full Control”, Forenoon and Afternoon–Fighting With or Against the Body, Evening–Overwhelmed by Pain and Feeling Desperate; Important Relations–Recognition but Difficulty in Communicating Needs)  
3.Caring for the treacherous body-coping (Morning–Persuading an Unwilling Body, Forenoon and Afternoon–Forget About the Body on the Background of Taking Care, Evening–Pain, but Still Coping; Important Relations–Mutuality and Dialogue).

1.There is nothing we can do for you, 2. We’ve got to find something, 3. I feel like I’m going crazy, 4. losing, 5.the best day, and 6. hope: I can do this.

**44. Richardson (2005).  
Establishing the (extra)ordinary  
in chronic widespread pain.  
(Australia)**

To illustrate the ways in which the invisible, subjective and everyday nature of chronic pain leads to sufferers

6 females with chronic widespread pain  
Age 51-88 years

Interviews  
Interpretive design

1.‘They’re called bludgers’: delegitimation of the pain 2. Extraordinary stories: legitimating chronic pain

	experiencing delegitimation of their condition.			
<b>45. Roberto and Reynolds (2002). Older women's experiences with chronic pain: Daily challenges and self-care practices (United States)</b>	To understand the influence of chronic pain on older women's lives	20 Females living with chronic pain  Age 48- 86 years	Focus groups (n=20)  In-depth interviews (n=8)  Thematic Analysis	1. Pain has personal and shared meaning  2. Beliefs about pain are reinforced by societal stereotypes and the reactions of others 3. Formal interventions and informal coping strategies often are used in tandem to manage pain 4. living with chronic pain requires changes in daily activities and routines 5. Pain influences interactions with family members and friends 6. pain challenges one's sense of self
<b>46. Schaefer (1995). Struggling to maintain balance: a study of women living with fibromyalgia. (United States)</b>	To describe the experiences of women living with fibromyalgia.	36 Women with fibromyalgia  Age range and ethnicity not identified	In-depth interviews (n=36) Follow up interviews (n=6)  A combination of Grounded theory and feminist methods	1. Struggling to maintain a balance Within this process includes recalling perceived normalcy, searching for a diagnosis, finding out, and moving on. Several women's stories indicated that they gave up the struggle to maintain a balance: 'relinquishing the struggle'.



**47. Skuladottir and Halldorsdottir (2011). The quest for well-being: self-identified needs of women in chronic pain. (Iceland)**

To study the self-reported needs of women in chronic pain

5 women with chronic Pain  
Age 36-53 years

in-depth interviews  
Phenomenology (the Vancouver School)

Three major quests: quest to learn to live with pain by making it tolerable and a quest to find support from someone who cares, professional support, and the need to be connected to others. Also, a quest for normalcy by trying to avoid the sick role and maintain a sense of dignity. The overriding theme in all the three major quests is the quest for well-being: physical, mental, emotional and social.

**48. Söderberg and Lundman (2001). Transitions experienced by women with fibromyalgia. (Sweden)**

To illuminate the transitions experienced by women with Fibromyalgia

25 women with Fibromyalgia  
Age 35- 60 years

Interviews  
Content Analysis

Transitions occur in different areas of the women's life—in daily life pattern, in working life, in social life, in family life—but participants expressed the view that they were learning to live with the changes. Fibromyalgia as choreographer of activities/relationships

**49. Söderberg et al. (1999). Struggling for dignity: The meaning of women's experiences of living with fibromyalgia. (Sweden)**

To explore the meaning of women's experiences of living with fibromyalgia

14 women with Fibromyalgia  
Age 35-50 years

Interviews  
Phenomenology

Loss of freedom  
Threat to integrity  
A struggle to achieve relief and understanding

**50. Wade and Shantall (2003).  
The meaning of chronic pain: A  
phenomenological analysis.  
(South Africa)**

To provide a  
description of  
the life-world of  
people with  
chronic low back  
pain

Three females, who had  
experienced unrelieved,  
continuous  
chronic low back pain

Interview  
  
Phenomenology

Chronic pain is persistent,  
giving it quality that is  
particularly difficult to  
endure.  
Pain Takes Over Your Life  
Chronic Pain Causes  
Interpersonal Difficulties  
One is Alone  
Chronic Pain Creates a  
Bleak Future  
Coping with Chronic Pain  
Finding Meaning in  
Suffering

**51. Werner and Malterud  
(2003). It is hard work  
behaving as a credible patient:  
Encounters between women  
with chronic pain and their  
doctors.  
(Norway)**

To explore  
women chronic  
pain patients'  
consultation  
experiences with  
their doctors and  
'work' done by  
the patients to  
be believed,  
understood, and  
taken seriously

10 women with chronic  
muscular pain  
Age 26-58 years  
Norwegian and one Asian  
immigrant

Semi-structured in-depth  
interviews  
  
Phenomenology

The women patients'  
accounts indicated hard  
work to make the symptoms  
socially visible, real, and  
physical when consulting a  
doctor. Their efforts reflect a  
subtle balance not to  
appear too healthy or too  
sick.

**52. Werner et al. (2004). 'I am  
not the kind of woman who  
complains of everything':  
illness stories on self and  
shame in women with chronic  
pain.**

To explore  
issues of self and  
shame in illness  
accounts from  
women with  
chronic pain

10 women with chronic  
muscular pain  
Age 26-58 years  
Norwegian and one Asian  
immigrant

In-depth Interviews  
Phenomenological  
discourse analysis

Stories told about (positive)  
strength of the women living  
with pain and the (negative)  
illness talk of others. Talk of  
coping and credibility.

(Norway)

**53. Westergården et al. (2021). 'Moving between living in the shadow of pain and living a life with the pain in the shadows' - women's experiences of daily life with chronic widespread pain: A qualitative study.**

(Sweden)

To explore women's experiences of the impact of living with CWP on daily life.

19 women with chronic widespread pain (CWP)  
Age 45-67 years

Interviews  
Content analysis

Moving between living in the shadow of pain and living a life with the pain in the shadows:  
1) living with invisible challenges (feeling neglected as a person and feeling lonely among other people) 2) struggling with limitations (moving between ability and inability, stress and worries, and being dependent on others)  
3) encountering daily life with varying degrees of flexibility (standing still and giving up, moving back and forth by adapting and striving forward with resistance)

**54. White and Seibold (2008). Walk a mile in my shoes: An auto-ethnographic study.**

(Australia)

To uncover and understand the reality of living with chronic, intractable, non-malignant back pain from individuals living with it.

5 females with chronic back pain  
Age 32- 44 years

Auto-ethnographic study  
Interviews and Journaling  
Thematic analysis

Key Themes:  
Loss of control, speaking into the void (the frustration experienced by participants when they felt they were not being listened to or heard by HCPs), body image disruption, attempting to find meaning and mourning the loss (loss of relationships), putting on a mask, being stigmatised and everyone knows best.

**55. Wuytack and Miller (2011). The lived experience of**

To gain a better understanding of

6 females with Fibromyalgia

semi-structured interviews (phenomenological study)

Fibromyalgia pervaded all aspects of life. It impacted

<b>fibromyalgia in female patients, a phenomenological study.</b> <b>(Belgium)</b>	the subjective experience of fibromyalgia, focusing on the personal, occupational and social impact of the condition on patients' lives.	Age 36 -66 years	Thematic analysis	on the participants' 1) Occupation 2) personal life 3) Views about the future 4) Interaction, communication and expression
<b>56. Zander et al. (2013). Struggling for sense of control: Everyday life with chronic pain for women of the Iraqi diaspora in Sweden</b> <b>(Sweden)</b>	To understand the specific needs of women living with chronic pain from the Iraqi diaspora in Sweden	11 females 40-64 years of age (table), with chronic musculoskeletal pain	Semi-structured interviews Grounded theory	1.Living as a migrant 2. The changing pain 3. Efforts to control pain 4. Mediating resources  The women's everyday life was characterized by a struggle for a sense of control. The struggle was multidimensional and influenced by their situation in life together with their unpredictable pain.

Table 3.3: GRADE-CERQual Evaluation

<b>Finding</b>	<b>Studies Contributing to Each Theme</b>	<b>Assessment of Methodological Limitations</b>	<b>Assessment of Relevance</b>	<b>Assessment of Coherence (1)</b>	<b>Adequacy</b>	<b>Overall Assessment/explanation</b>
<b>Life Revolving around Pain and Multiple Responsibilities</b> Across the studies, women consistently reported that their lives were	39 contributing studies*: 1, 2, 3, 4, 5, 6, 8, 10, 11, 13, 14, 15, 16, 17, 18, 19, 21, 24, 25, 27, 29, 30, 31, 35, 36, 37,39, 40, 42, 44, 45, 47, 48, 50, 52, 53, 54, 55, 56	No/minor concerns (all studies were rated as '++/+' in this review	No/minor concerns in relation to the review question. All women over the age of eighteen, living with chronic pain in any setting was specified in the	Minor/moderate concerns about coherence	Moderate concerns  Findings evaluated as rich across twenty-seven studies. Thirty-nine contributing studies	Moderate confidence due to moderate concerns on coherence/adequacy (described richly across 27/39 studies)

profoundly shaped by the dual burden of chronic pain and multiple responsibilities. Pain emerged as a central determinant, governing their capacity to engage in or abstain from various activities. For some, the demands of their responsibilities not only heightened their sense of strain but also exacerbated their physical discomfort, creating a cyclical relationship wherein their obligations exacerbated their pain.

**Countless Losses (and their Consequences)**

Many women described enduring a multitude of losses, including their physical functionality, sleep, confidence, sense of self, future aspirations, dreams, goals, employment opportunities, and personal

Contributing 45 studies\*: 2, 3, 6, 8, 10, 11, 13, 14, 16, 17, 18, 19, 20,21, 22, 24, 25, 27,28, 29, 30, 31, 32, 33, 34, 35, 36,37, 38, 39, 41, 42, 43, 44, 45, 46, 48, 49, 50, 51, 52, 53, 54, 55, 56

No/minor concerns

review question. All the studies satisfied these criteria. Various chronic pain conditions/countries represented (14 countries; Portugal not included)

No/minor concerns (as above)  
Countries represented: 13 (not included: Portugal and Iceland)

No/Minor concerns

No/Minor concerns  
Findings evaluated as rich across 33 studies.  
Forty-five contributing studies

High confidence due to no/minor concerns across all four domains

relationships. These profound losses significantly impacted their psychological well-being, deepening the challenges they faced and underscoring the pervasive effects of pain/the losses on various aspects of their lives.

**Lack of Understanding: Delegitimising and Disempowering Encounters**

Many women reported feeling misunderstood by those around them, including HCPs. They described experiencing various disempowering interactions and expressed frustration at the lack of adequate information and guidance provided to help them manage their pain effectively. These challenges contributed to a sense of isolation and hindered their

48 studies contributing\*: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 17, 18, 19, 20, 22, 23, 25, 26, 28, 30, 31, 32, 33, 34, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 52, 53, 54, 55

No/minor concerns

As above  
Countries represented: 14 (not included: Chile)

No/Minor concerns

No/minor concerns  
Findings evaluated as rich across 33/48 studies

High confidence due to no/minor concerns across all four domains. However, the experience of women from different ethnic backgrounds may amplify the intensity of feeling misunderstood due to factors such as language differences, cultural stigma, or experiences of bias (discussed in the thesis).

ability to navigate their condition with confidence.

**Solace and Self-Empowerment**  
Many women, after receiving limited information, sought solace and self-empowerment by actively seeking help and information elsewhere. They engaged in support groups and took proactive steps to better understand and manage their situations, striving to regain a sense of control over their lives.

43 studies contributing\*: 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 15, 16, 17, 18, 19, 22, 23, 24, 25, 26, 27, 29, 31, 32, 34, 39, 40, 42, 43, 44, 45, 46, 47, 48, 49, 50, 51, 54, 55, 56

No/minor concerns

No/minor concerns in relation to the review question. 14 countries represented (Denmark not included)

No/Minor concerns

No/minor concerns Findings evaluated as rich across 31/43 studies

High confidence due to no/minor concerns across all four domains. As mentioned above, seeking solace could take culturally specific forms/traditional practices.

\*List of studies (with their identifying numbers) can be found in Table 3.2

(1) Coherence (a measure of how clear and well supported the data from the primary studies and a review finding are: consistency across studies), adequacy of data (a measure of how rich and well supported a review finding is by the included studies), and relevance (how well the evidence from the primary studies fits into the context of the review question).

Table 3.4: Studies Contributing to Each Theme \*

Study Authors (Date)	Life Revolving around Pain and Multiple Responsibilities	Countless Losses (and their consequences)	Lack of Understanding: Delegitimising and Disempowering Encounters	Seeking Solace and Self-empowerment
1. Ahlsen et al. (2014)	X		X	x
2. Allen et al. (2015)	X	x	X	x
3. Arman et al. (2019)	X	x	X	x
4. Barnes et al. (2021)	X		X	x

5. Bostick et al. (2018)	X		X	x
6. Campbell et al. (2022)	X	x	X	x
7. Campeau (2018)			X	x
8. Dickson and Kim (2003)	X	x	X	x
9. Driscoll et al. (2018)			X	x
10. Dysvik et al. (2013)	X	x	X	x
11. Evans and de Souza (2008)	X	x	X	x
12. Gonzalez et al. (2015)			X	x
13. Gullacksen and Lidbeck (2004)	X	x	X	x
14. Hallberg and Carlsson (1998)	X	x	x	
15. Hallberg and Carlsson (2000)	X			x
16. Horment-Lara et al. (2022)	X	x		x
17. Howell (1994)	X	x	x	x
18. Hwang et al. (2004)	X	x	x	x
19. Juuso et al. (2011)	X	x	x	x
20. Juuso et al. (2014)		x	x	
21. Juuso et al. (2016)	X	x		
22. Kanter et al. (2017)		x	x	x
23. Kengen Traska et al. (2012)			x	x
24. Kirkham et al. (2015)	X	x		x
25. Knutsen et al. (2022)	X	x	x	x
26. Lehti et al. (2017)			x	x
27. Löfgren et al. (2006)	X	x		x
28. Mellado et al. (2016)		x	x	
29. Mellado et al. (2020)	X	x		x
30. Michaëlis et al. (2015)	X	x	x	
31. Molin et al. (2021)	X	x	x	x
32. Molin et al. (2022)		x	x	x



33. Monsivais (2013)		x		x	
34. Müllersdorf et al. (2011)		x		x	x
35. Mustafa et al. (2020)	X	x			
36. Nortvedt et al. (2015)	X	x		x	
37. Nortvedt et al. (2016)	X	x		x	
38. Nyen and Tveit (2018)		x		x	
39. Osborn and Smith (1998)	X	x		x	x
40. Peppard et al. (2022)	X			x	x
41. Pryma (2017)		x		x	
42. Råheim and Håland (2006)	X	x		x	x
43. Reibel and Pearson (2017)		x		x	x
44. Richardson (2005)	X	x		x	x
45. Roberto and Reynolds (2002)	X	x		x	x
46. Schaefer (1995)		x		x	x
47. Skuladottir and Halldorsdottir (2011)	X			x	x
48. Söderberg and Lundman (2001)	X	x		x	x
49. Söderberg et al. (1999)		x		x	x
50. Wade and Shantall (2003)	X	x		x	x
51. Werner and Malterud (2003)		x		x	x
52. Werner et al. (2004)	X	x		x	
53. Westergården et al. (2021)	X	x		x	
54. White and Seibold (2008)	X	x		x	x
55. Wuytack and Miller (2011)	X	x		x	x
56. Zander et al. (2013)	X	x			x

*\*Table created by AB*

Table 3.5: Methodological Quality Appraisal of the Included Studies Using the NICE (2012) Checklist

Study Authors	NICE Guidelines Checklist Numbers/Overall Assessment (OA) rating														
(Date)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	OA
Ahlsten et al. (2014)	++	++	+	++	++	+	+	++	+	+	++	++	++	-	+
Allen et al. (2015)	++	++	+	++	+	+	++	+	+	++	+	++	++	++	+
Arman et al. (2020)	++	++	++	++	+	++	++	++	++	++	++	++	++	++	++
Barnes et al. (2021)	++	++	++	++	++	++	++	+	+	++	++	++	+	++	++
Bostick et al. (2018)	++	++	+	+	+	+	++	++	++	++	++	++	++	++	++
Campbell et al. (2022)	++	++	++	++	+	+	++	+	+	+	++	++	+	++	+
Campeau (2018)	++	++	+	+	+	++	+	++	++	+	++	++	+	++	+
Dickson and Kim (2003)	++	++	+	++	+	+	+	++	++	++	++	++	+	++	++
Driscoll et al. (2018)	++	++	++	++	+	+	++	++	++	++	++	++	++	++	++
Dysvik et al. (2013)	++	++	++	++	++	+	++	++	++	++	++	+	++	++	++
Evans and de Souza (2008)	++	++	+	+	-	++	+	+	+	+	+	++	+	++	+
Gonzalez et al. (2015)	++	++	+	++	++	+	+	++	+	+	++	++	++	++	++
Gullacksen and	++	++	+	++	+	+	+	+	++	+	++	++	++	++	+

Lidbeck (2004)															
Hallberg and Carlsson (1998)	++	++	+	++	+	+	+	++	++	+	++	++	+	++	+
Hallberg and Carlsson (2000)	++	++	++	++	+	+	+	++	++	+	++	++	++	+	++
Horment- Lara et al. (2022)	++	++	++	++	+	++	++	++	++	++	++	++	++	++	++
Howell (1994)	++	++	++	+	+	++	++	++	++	++	++	++	+	+	++
Hwang et al. (2004)	++	++	+	++	+	+	+	++	++	++	++	++	++	+	++
Juuso et al. (2011)	++	++	+	++	+	+	+	++	+	++	++	++	++	++	++
Juuso et al. (2014)	++	++	+	++	+	+	+	++	+	++	++	++	++	++	++
Juuso et al. (2016)	++	++	++	++	+	++	+	++	++	+	++	++	+	++	++
Kanter et al. (2017)	++	++	+	++	+	++	+	+	++	++	++	++	++	++	++
Kengen Traska et al. (2012)	++	++	+	++	+	+	++	+	++	++	++	++	++	++	++
Kirkham et al. (2015)	++	++	++	++	+	++	++	++	++	+	++	++	+	++	++
Knutsen et al. (2022)	++	++	+	++	++	+	++	++	++	++	++	++	+	++	++
Lehti et al. (2017)	++	++	++	++	++	+	++	+	++	++	++	++	++	++	++
Löfgren et al. (2006)	++	++	++	+	+	++	++	+	+	++	+	++	+	++	+
Mellado et al. (2016)	++	++	++	++	+	++	++	++	++	++	++	++	++	++	++
Mellado	++	++	+	++	+	+	+	++	++	++	++	++	++	++	++

et al. (2020)															
Michaëlis et al. (2015)	++	++	++	++	+	+	++	++	++	++	++	++	++	++	++
Molin et al. (2021)	++	++	++	++	++	++	++	++	++	++	++	++	++	+	++
Molin et al. (2022)	++	++	++	++	+	++	++	++	++	++	++	++	++	++	++
Monsivais (2013)	++	++	+	+	+	+	++	+	+	+	++	++	+	+	+
Müllersdorf et al. (2011)	++	++	++	++	+	+	+	++	+	++	++	++	++	+	++
Mustafa et al. (2020)	++	++	++	++	+	++	+	+	++	++	++	++	++	++	++
Nortvedt et al. (2015)	++	++	+	++	+	++	++	+	+	++	++	++	+	++	++
Nortvedt et al. (2016)	++	++	+	++	+	+	++	+	+	++	++	++	++	++	++
Nyen and Tveit (2018)	++	++	++	++	+	+	+	+	++	++	++	++	++	++	++
Osborn and Smith (1998)	++	++	+	++	+	+	+	++	++	++	++	++	++	+	+
Peppard et al. (2022)	++	++	+	++	+	+	++	++	++	+	++	++	++	++	++
Pryma (2017)	++	++	+	++	+	++	+	+	++	+	+	++	+	++	+
Råheim and Håland (2006)	++	++	++	++	+	++	+	++	++	++	++	++	++	+	++

Reibel and Pearson (2017)	++	++	++	++	++	+	++	+	++	++	++	++	++	++	++
Richardson (2005)	++	++	++	++	+	+	+	-	++	+	++	++	+	++	+
Roberto and Reynolds (2002)	++	++	++	++	+	+	++	+	++	++	++	++	+	-	++
Schaefer (1995)	++	++	+	++	++	-	++	+	+	++	++	++	+	+	+
Skuladottir and Halldorsdottir (2011)	++	++	++	++	+	+	+	++	++	++	++	++	+	++	++
Söderberg and Lundman (2001)_	++	++	+	++	+	+	+	+	++	++	++	++	+	++	+
Söderberg et al. (1999)	++	++	+	++	+	+	++	++	++	++	++	++	+	++	++
Wade and Shantall (2003)	++	++	+	++	+	+	+	+	++	+	++	++	+	+	+
Werner and Malterud (2003)	++	++	+	++	+	+	+	++	++	+	++	++	++	-	+
Werner et al. (2004)	++	++	+	++	+	+	+	+	+	+	+	+	+	-	+
Westergården et al. (2021)	++	++	+	++	+	+	+	++	++	++	++	++	++	++	++
White and Seibold (2008)	++	++	++	++	+	+	+	+	+	+	++	++	+	++	+
Wuytack and Miller	++	++	+	++	+	+	+	++	++	+	++	++	++	++	++

(2011)

Zander et al. (2013)    ++    ++    +    ++    +    ++    ++    ++    +    ++    +    ++    ++    ++    ++

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The NICE (2012) Checklist:

Appraisal key: (++) = Appropriate/Sufficient, (-) = Insufficient, (+) = Not Sure/Mixed

1. Is a qualitative approach appropriate? (Appropriate (++) , Inappropriate (-) , Not sure (+)
2. Is the study clear in what it seeks to do? (Clear (++) , Unclear (-) , Mixed (+)
3. How defensible/rigorous is the research design/methodology? (Defensible (++) , Indefensible (-) , Not sure (+)
4. How well was the data collection carried out? (Appropriately (++) , Inappropriately (-) , Not sure/inadequately reported (+)
5. Is the role of the researcher clearly described? (Clearly described (++) , Unclear (+) , Not described (-)
6. Is the context clearly described? (Clear (++) , Unclear (-) , Not sure (+)
7. Were the methods reliable? (Reliable (++) , Unreliable (-) , Not sure (+)
8. Is the data analysis sufficiently rigorous? (Rigorous (++) , Not rigorous (-) , Not sure/not reported (+)
9. Is the data 'rich'? (Rich (++) , Poor (-) , Not sure/not reported (+)
10. Is the analysis reliable? (Reliable (++) , Unreliable (-) , Not sure/not reported (+))
11. Are the findings convincing? (Convincing (++) , Not convincing (-) , Not sure (+)
12. Are the findings relevant to the aims of the study? (Relevant (++) , Irrelevant (-) , Partially relevant (+)
13. Is there adequate discussion of any limitations encountered (conclusions)? Adequate (++) , Inadequate (-) , Not sure (+)?
14. How clear and coherent is the reporting of ethics? Clear (++) , Unclear (-) , Not sure (+)

### Overall assessment (OA)

As far as can be ascertained from the paper, how well was the study conducted?

- ++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.
- + Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
- Few or no checklist criteria have been fulfilled, and the conclusions are likely or very likely to alter (NICE, 2012).

## Chapter Summary

This chapter has provided a comprehensive understanding of women's experiences of living with chronic pain. It summarised the impact of chronic pain on women, highlighting its profound effects across various age groups, regions, and conditions. It emphasised that addressing chronic pain should be a clinical priority and recognised the existential challenges faced by women. The chapter raised concerns about HCP's inadequate acknowledgement of women's pain experiences and advocates for heightened awareness and education on chronic pain. It stressed the importance of validating women's experiences and tailoring treatment to their specific needs. Additionally, it highlighted the need to explore the pain experiences of women from diverse backgrounds. The chapter also discussed how HCPs can positively or negatively influence women's experiences with pain and addressed issues such as stigmatisation and treatment denial. The chapter underscored the subjective nature of pain and the necessity of addressing it with empathy. Finally, the chapter highlighted the need for HCPs to be mindful of their influence and role in supporting women with chronic pain. The next chapter will provide an in-depth understanding of SAW's experiences with chronic pain.

## Chapter Four: South Asian Women's Experiences with Chronic Pain

### Chapter Overview

The previous chapter discussed the first phase of this project, which sought to gain a comprehensive understanding of women's experiences of living with chronic pain, identify what is known about SAW's experiences, and identify gaps in our understanding. Several of the included studies did not provide sufficient data on ethnicity, and none specifically addressed SAW's experiences of managing pain, the coping strategies they use, or their health care experiences. As a result, our understanding of SAW's experiences remains unclear. This chapter presents Phase Two, a study that aimed to provide a more detailed understanding of these experiences. Since ethnicity can affect pain experiences, it is important to explore other cultural perspectives. This chapter explores SAW's experiences with chronic pain, provides an introduction to the study, details the participants, outlines the methods used, and presents and discusses the findings. It will also discuss the study's limitations and implications, provide suggestions for future research, and finish with a conclusion.

### Introduction

Chronic pain is a complex phenomenon, and its occurrence and experience can be influenced by various biopsychosocial factors (Crofford, 2015; IASP, 2020). The ethnicity and sex of an individual are two factors that can influence the development and experience of chronic pain, and they are the focus of this study. The literature review in Chapter One presents decades of research indicating that an individual's ethnicity may influence both their experience of chronic pain and the treatment they receive (Allison et al., 2002; Bull et al., 2023; Goyal et al., 2015; Lyman, 2021; Meghani et al., 2012; Rogers &



Allison, 2004; Singhal et al., 2016; Zborowski, 1952; Zola, 1966). Researchers have also noted disparities in pain management strategies among different ethnic groups (Hastie et al., 2005; Rogers & Allison, 2004).

As previously discussed, chronic pain is more common in women. The meta-synthesis (Chapter Three) revealed that women also often endure pain while managing multiple responsibilities and encounter dismissive or invalidating interactions (Campbell et al., 2022; Hallberg & Carlsson, 1998; Richardson, 2005; Roberto & Reynolds, 2002; Wuytack & Miller, 2011). These factors contribute to a compounded challenge in effectively managing women's pain.

These findings highlight the significant role of ethnicity and sex in shaping pain perception, behaviour, and management. The reviewed literature also reveals a gap in research on SAW, emphasising the importance of investigating this area in order to develop effective pain management interventions.

A study (Mustafa et al., 2020) in Canada examined the experiences of chronic pain among immigrant Indian women. Thirteen women participated in the research. The authors noted that the collectivist nature of Indian culture places pressure on women to prioritise family responsibilities above their own health. Despite recognising the toll this workload took on their health, the participants continued to shoulder these responsibilities. This cycle of self-neglect and overwork contributed to the worsening of their chronic pain over time (Mustafa et al., 2020). Women felt that they often neglected themselves due to their gender roles and responsibilities. The participants also discussed

the challenges of pain management, including a lack of time and the cultural expectation to prioritise the needs of others. Consequently, their pain was becoming increasingly intense over time. This situation is deeply concerning and underscores the urgent need to explore pain self-management options that are culturally appropriate and accessible. It also highlights the need to raise awareness among these women about the importance of managing their pain for their overall health and well-being.

Other research in the UK has explored SA's thoughts about pain and pain management (Burton et al., 2019) and the lived experiences of five English-speaking SA individuals (two of whom were women) contrasted with five white British participants (Singh et al., 2018). The latter study reported disruptions to cultural-religious well-being and a lack of community understanding of their conditions. Both groups showed a shift from relying on HCPs to adopting more active coping strategies, such as seeking online resources and increasing physical and social activities.

However, those without English proficiency in the UK should also be acknowledged. Language barriers pose challenges for non-English speakers (Patel et al., 2009). Research with eighteen general practitioners exploring their perceptions of the service needs of SA patients with chronic pain in the UK acknowledged the difficulties and limited resources available for non-English-speaking SA patients, as well as situations where translators are inappropriate (e.g., counselling) and three-way conversations are not optimal (Patel et al., 2009). The lived experiences and needs of these individuals, however, have received little attention. It is important to explore these experiences, as SAW are more likely to be living with chronic pain (Bhatnagar et al., 2016; Diabetes UK,

2023; Jepson et al., 2012), and older SAW (who also may not speak English fluently) constitute a vulnerable demographic for suicide (Mental Health Foundation, 2021). This necessitates further research that could yield insights to enhance their health outcomes and overall well-being. Future research is needed to provide a more comprehensive understanding of SAW's chronic pain experiences, the coping strategies they use, and how they manage their pain.

The present study aims to explore chronic pain in SAW in order to gain a better understanding of their experiences, the impact of these experiences, and how they manage their pain. It sought to address the following research questions: What are SAW's experiences of living with and managing chronic pain, and how do these experiences impact them? What coping strategies do they use? How have SAW found their experience with the healthcare system in managing their pain and well-being, particularly in terms of addressing their needs, applying the biopsychosocial model, and the level of information provided to them? An understanding of these issues is vital to ensuring that chronic pain interventions are culturally appropriate, based on women's lived experiences, and tailored to their specific needs.

## Methods

The philosophical approach of this qualitative research study adhered to critical realism: ontological realism, epistemological constructivism, and induction to analyse the data (Maxwell, 2012; see Chapter Two for a detailed discussion). An inductive, data-driven approach was taken to ensure the findings remained close to the participants' reported experiences without any imposed constraints (Harding, 2019), and a qualitative methodological approach was deemed most appropriate for the present study's aims (Coolican, 2014; Hennink

et al., 2011), since experiences are difficult to capture using quantitative methods.

In the present study, fourteen in-depth, semi-structured, one-to-one phone interviews were conducted. It was determined that this data collection method would be the most appropriate in light of the study's objectives (Coolican, 2014; Kvale, 2007). It was also felt that participants may have found it difficult to share and discuss their feelings on the sensitive issues addressed in this study in a group setting (Barbour, 2018).

In line with guidance on determining sample size and the point at which additional data collection is deemed unnecessary (Guest et al., 2006), it was anticipated that approximately twelve participants would be sufficient. This guidance and the concept of 'information power' were to be used to assist the researcher in determining an appropriate sample size (Malterud et al., 2016). This concept is based on aiming to achieve a level of analysis that is meaningful and valuable for the specific research goals and was viewed as a more pragmatic approach to qualitative research (Barbour, 2018; Malterud et al., 2016). It was determined that by the tenth interview, sufficient rich data had been collected to provide insight into the research questions.

However, due to the limited existing research on this group and the interest of additional potential participants, a total of fourteen interviews were conducted. All the data collected contributed to the findings and was analysed using inductive RTA (Braun & Clarke, 2022). Ethical approval for the present study was obtained from Staffordshire University's Ethics Committee in February 2023 (Appendix One [B]).

## **Recruitment**

Purposive and snowball sampling methods were selected based on the main aim of gaining insight into SAW's experiences with chronic pain. These methods enable a variety of perspectives to be gained, allowing for a deeper understanding of the research topic, and are often used when specific types of participants are sought (Braun & Clarke, 2006; Denscombe, 2017; Patton, 1990). Snowball sampling is also a successful strategy for recruiting difficult-to-reach underrepresented groups in health research (Sadler et al., 2010).

The researcher sought female participants in the UK who were over the age of eighteen, self-identified as SA, and living with chronic pain (not related to cancer or terminal conditions). Participants with learning disabilities, cognitive impairments that would hinder participation, or mental health conditions and those who did not meet the inclusion criteria outlined above were to be excluded from the study.

## **Reflexivity**

As the interviewer and primary analyst approaching the topic of pain from an academic perspective and without personal experience, a reflexive approach (peer debriefings, use of a reflexive journal) was adopted throughout the research process to ensure a deeper understanding of participants' experiences. Fostering a collaborative relationship with participants, acknowledging the expertise they bring to the conversation about their own lives, member checking, and taking a reflexive approach aimed to ensure that the findings presented in this study were grounded in the voices and experiences of the participants (Braun & Clarke, 2022; Gough, 2003; Olshansky et al., 2005).

## Procedure

Six potential interviewees were put in touch with the first author through the first author's contacts. Four potential participants who were known to the researcher through work in the community were approached directly and instructed to contact the researcher if they wished to take part, and four more were recruited through snowball sampling. The researcher's contact details, and participant information sheets (Appendix Two) were provided. Interviews with potential participants were scheduled over the phone, and their language preference and mode of interview (audio or video) were noted. Information about participation was also reviewed to ensure that the women understood it, met the criteria for participation, and had a chance to discuss any concerns or questions they might have. Individuals interested in the research were provided with demographic questionnaires (Appendix Three), debriefing sheets (Appendix Four), and consent forms (Appendix Five). All fourteen participants chose to complete the demographic questionnaire on the day of the interview. The questionnaires sought to provide background information about the participants. Furthermore, given that various factors can also have an effect on the experience of pain, the information was to be used to contextualise the findings. Arrangements were made to ensure the consent forms were returned to the researcher prior to the interviews. The participants were requested to have their demographics and debriefing sheets with them on the day of the interview. For participant convenience, interviews were conducted remotely, from the home(s) of the first author and the participants, rather than in person.

Phone interviews were conducted between February and April of 2023. The women were reminded that the interview would be audio recorded and

that their data would remain anonymous (the participants were assigned numbers from one to fourteen). In addition, they were informed that they could terminate the interview at any time, request a break, withdraw their data (at any time up to two weeks after the interview), and decline to respond to any questions they did not feel comfortable answering. It was made clear to the participants at the start of the interview that the focus of the research was on their experiences and that there were no right or wrong answers. The interviews were conducted using an interview guide (Appendix Six), and a digital audio recording device was used to record the phone conversation (on loudspeaker). Each interview lasted approximately forty-five minutes. Throughout the interviews, the researcher took notes, documenting the key points from the participants' statements. Following the interview was a short (approximately five-minute) debriefing session. The purpose of the study was restated; the women were given contact information for available support services (if needed), and they were asked if they would like to go over the findings in a short phone conversation after the data had been analysed. Synthesised member checking was conducted, and seven participants engaged in a short (approximately five minute) one-on-one phone conversation in April 2023 with the researcher to discuss the results and conclusion of the study (Slettebø, 2021). The key themes were retained.

The researcher conducted, recorded, and transcribed all the interviews. Interviews conducted in English, or a combination of English and Hindi/Punjabi were transcribed verbatim, but those conducted almost entirely in Punjabi (n = 6) were translated contextually by the researcher (Esposito, 2001). A literal translation is not always possible (Barbour, 2018; Twinn, 1998) with a language

like Punjabi, as it would alter the meaning of some of what was actually said. The use of a process journal, notes, and maps ensured continuous reflection and a reflexive approach throughout the study (Buetow, 2019), minimising the author's opinions and beliefs from influencing the collection and analysis of data.

### **Study Sample**

Fourteen female (Indian,  $n = 11$ , Pakistani,  $n = 2$ , and Bangladeshi,  $n = 1$ ) participants were recruited, between the ages of twenty-four and seventy-eight ( $M = 52$ ,  $SD = 18.17$ ); six women were married, three were single, one was separated, and four were widowed. Three were graduates, one a postgraduate, eight women reported high school (six attended in India and two in the UK) as their highest level of education, and two reported attending primary school in India. Three participants reported English as their first language, and five women stated that they were not able to access resources online. The shortest period reported of experiencing chronic pain was one year; the longest period was fifteen years ( $M = 6.43$ ). Two women reported having shoulder pain, one pelvic pain, three back pain, one neck and back pain, another neck and abdominal pain, two experiencing abdominal pain, three experiencing knee pain, two of whom had osteoarthritis, and another participant also reported osteoarthritis but having pain in the hands and wrists. All women reported their pain ranging from four to six (nagging to distressing) on the visual analogue scale. This is a continuous scale that allows individuals to rate their pain by indicating a point along a line. The line's endpoints are labelled with opposing descriptions of pain: 'no pain' on one end and 'worst pain imaginable' on the other (Operative Neurosurgery, 2016). The participants were asked to



determine a point on the line that represented their perception of their level of pain at the time (from zero to ten).

(Table 1 in Appendix Seven contains additional information about the participants.)

## **Analysis**

RTA was used to inductively analyse the data (the data guided coding and theme development). Themes were identified and reported at the semantic and latent levels (Braun & Clarke, 2022). This approach was selected due to its flexibility and suitability for the study's aims. This is a powerful method often used for gaining an in-depth understanding of experiences (Braun & Clarke, 2022; Kiger & Varpio, 2020).

Analysis of the interview data was conducted according to the guidelines and six phases provided by Braun and Clarke (2022): familiarising oneself with the dataset, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the written analytic report. After each interview, the data were transcribed (some were also translated). The accuracy of the transcriptions was verified through self-checking, and the recordings were re-listened to. The notes taken during the interview were also compared, and any initial thoughts of the researcher or insights were noted. This immersion facilitated greater comprehension and familiarity with the data. By the tenth interview, it appeared that the same issues were being highlighted and that there was a great deal of data to address the research questions. The combined data from these ten interviews was analysed, and aspects that appeared potentially relevant to the research questions the study sought to address were highlighted and assigned meaningful descriptions (e.g.,

biomedical care: analgesics and surgery, coping mechanisms, reliance on religion). Some codes that appeared to identify the same idea and that it was felt could be grouped together were then combined (e.g., psychological/physical impact). Initial themes were generated from these that identified the shared patterns across the dataset, and an initial map was generated to assist with data analysis. The map aided theme review and development. The visual representation facilitates easier identification of patterns and relationships in the data. Some themes were also combined (e.g., physically and psychologically damaging losses, coping in the midst of darkness), and the remaining four interviews were analysed in the same manner up to the coding stage. Similar codes were being assigned. The review of all interview codes and preliminary themes was repeated. Another thematic map (Appendix Eight) and peer debriefings assisted with refining and finalising theme names for the entire dataset (Appendix Nine). Relevant data extracts were selected from the dataset, and a report of the research was produced. Participants' (P) quotes are presented in italics below.

## Results

Four key themes were developed following RTA of the data: 1) Life Shaped by Pain, Duty, and Responsibilities; 2) Physically and Psychologically Damaging Losses; 3) A Lack of Understanding: Unmet Needs; and 4) Coping in the Midst of Darkness.

### **Life Shaped by Pain, Duty, and Responsibilities**

The first theme was particularly strong and prevalent across the majority of the interviews. The women's accounts indicated that their lives were shaped

by pain, fulfilling their responsibilities, and adhering to a strong sense of duty. Most women in the study discussed how their lives revolved around their pain and balancing multiple responsibilities. It was frequently stated that the participants' pain dictated the course of their day, requiring them to plan accordingly:

*When my pain is bad then I cannot do anything at all. . .My body is under the control of my pain at these times (P1)*

*Well, I need to plan everything with my condition in mind. . .The constant planning around it is also tiring. . .it [pain] impacts every aspect of my life, from my routines to what I can and can't do to what I wear sometimes (P2)*

It was evident from the participants' accounts that these women bore the primary responsibility for household chores. They shared narratives where they struggle with pain, carry significant burdens, and navigate their lives guided by a strong sense of obligation. The response provided by participant three when asked to describe a typical day encapsulates this theme, as does an account shared by interviewee eleven. The former response also emphasises the constant struggle to balance responsibilities and the physical pain that the women endure:

*Well, that depends on how my pain is, If it not too bad, then I can wake up early and try and get all the house chores completed slowly. . .This suits me because this means that if my pain gets worse in the middle of the day then I can take some medication and rest. If the pain is bad, then my work piles up. . .it just builds up for me, as my husband does not really cook or do anything around the house. (P3)*

*even with pain, we [women] have the extra work in the house; the men don't, and neither do they worry about it (P11)*

A strong commitment to fulfil their responsibilities could be seen. Even though many women were in pain, they still took care of and had responsibilities towards others. These included their in-laws, their husbands, and, in some cases, children and grandchildren. Many participants daily routines involved household chores, shopping, cooking, and caring for older family members, all while managing their pain. A subset of the participants also continued to work outside the home:

*The cleaning sometimes has to wait. . .I have the children's dinner to prepare, and for my husband and my mother-in-law. It gets hard with my back pain. . .I was so tired. I took leave from work for a bit so I could try and take it a bit easy as my back at this point was killing me. But being at home just meant I was then. . .doing more housework. . .it was not like I could get rest, so then it was just better for my mental health to be at work. At least I got to speak to different people, get out of the house (P5)*

Participant ten, who was also concurrently managing her pain and employment, expounded on her many responsibilities, some of which she felt were greater for women in her community:

*I have my children to look after and drop to school and collect. I also have my husband's tea and dinner. . .the housework too. . .there are so many expectations placed on us women and I think it is worse for our women as we have bigger families and then bigger responsibilities. . .I was cooking and looking after everyone in the home and that was my children, my*

*husband, my mother and father-in-law, and my husband's brother. The cooking and housework never finished, and I had so much pressure and tension then.*

Their experiences underscore the enormous burden these women with chronic pain bear, as well as their responsibilities to their extended families.

### **Physically and Psychologically Damaging Losses**

This theme highlights the losses that the participants experienced due to their pain: loss of employment, a routine, social contact, future certainty and a sense of control, functioning ability, future dreams, power, the life they had hoped for, sleep, and the ability to participate in activities that they enjoyed. These losses triggered negative emotions and pain. All of them were viewed as having a deleterious impact on the women, and a variety of emotions were expressed. These are illustrated through the accounts provided by participants one and fourteen in response to the question regarding the changes they had encountered as a result of living with chronic pain:

*I have left my work as I cannot do that work anymore, and that broke my heart as it gets hard to pass the time with boring tasks and then I was also getting out of the house, walking more. . .I had a good routine that I was never bored or feeling lonely. . .you always had something to talk about.*  
(P1)

*It takes away your power, and the ability to do things you enjoy. I used to love playing hockey, so for me, it really started affecting my mood in a big way. I was starting to get pretty frustrated and down.* (P14)

The loss of the life they envisioned for themselves was also observed in their accounts. Participants reflected on the loss of the life they desired; this loss was evident across numerous interviews:

*I am not living life to the full though or how I would like, and that is the sad situation I am in at the moment (P2)*

*I do sometimes wish I could spontaneously just phone a friend and do stuff like going climbing, kayaking, going on long bike rides. I miss that and being in nature and camping and stuff. That obviously does take a toll on you mentally (P6)*

*I thought then I would be able to enjoy my retirement, but when that time came, my pain started (P7)*

Furthermore, as the participants' futures were uncertain, the loss of control and power increased their anxiety and frustration:

*I worry about what will happen in the future (P1)*

Another participant reflected on the ongoing anxiety about her health and its potential impact on life decisions. The participants' health was frequently at the forefront of their concerns and anxieties:

*there is always worry at the back of your mind about how your health may deteriorate, and having children and things like that do worry me as I am getting older (P6)*

The constant anxiety about deteriorating health and its implications underscores the significant impact that health uncertainties had on their well-being and future outlook.

## **Lack of Understanding: Unmet Needs**

This theme pertains to a dual deficiency in understanding: a failure to grasp and understand the nature of chronic pain, coupled with a lack of empathic understanding. The women themselves lacked the former. Others in their lives and HCPs, on the other hand, appeared to be lacking both. There was a lack of information and guidance provided by the participants' GPs and other HCPs; the participants felt their information and pain management needs were not met, and the focus instead was on analgesics and surgery. Many women reported that they were told by their GPs and hospital doctors that other than pain medication and surgery, there was little that could be done for them:

*They just said that back pain is really common and there is not a lot that can be done for it. (P5)*

*other than pushing for surgery or medicine, doctors never have anything else to say and will just say we cannot do anything (P11)*

A participant mentioned she received no information on managing stress even when it was discussed; others also received no guidance or signposting for their anxiety or sleep problems. Every participant (except one who received some exercises in a format she could not understand) stated that they were provided with no information on managing their condition and available support options:

*I never received any information or advice other than to take painkillers when the pain is bad. (P2)*

*I have never received any information, or even leaflets, or even details of where I can get proper advice by my back doctors (P5)*

The women received disempowering biomedical care: they were not offered any solutions or information beyond pain medication. The women felt that the doctors did not understand the detrimental effects that pain can have on their mental well-being and the quality of their lives. One participant mentioned that they also did not understand the responsibilities and lives of SAW:

*I do not think the doctors at the hospital understand how destructive this is on my life in general and my mental health. (P2)*

*the doctors really do not understand how much pain can destroy the quality of your life. . .they do not understand how it is living in our community and our duties to the wider family (P9)*

The women wanted to be provided with some guidance on managing their pain. The women expressed a desire for a more comprehensive approach, one that transcends conventional medical interventions and considers their well-being and makes life more bearable:

*I also think these [pain management strategies] are things doctors should also tell us about, as any little thing that gives someone in pain a bit of peace is important. (P1)*

Participant nine echoed the sentiments of numerous women regarding their needs and the guidance and advice they desired from HCPs:



*I would like all doctors to understand how back pain can destroy a person's quality of life and their mental health. I would then expect them to help us to improve both these things. They should be sharing all information with us and teaching us about our condition so that we are not worrying endlessly about our future. . . Why are they not offering tips on easing pain, and why am I and people like me desperately asking around?* (P9)

Some women acknowledged that their limited language and technological skills contributed to their lack of understanding:

*I know it is my problem that I cannot understand English well, and maybe if I could, I would not be suffering now.* (P3)

However, among those that could understand English and access online resources, a few felt that these resources did not enhance their understanding:

*It is true that you can find pretty much anything on the internet, but it is hard to know what actually works or helps. Some of it is also hard to make sense of and just confusing, and that is if you have the time and patience to go through everything, and I think most of us with pain don't.* (P14)

Overall, participants felt that their information needs were not met; they wanted strategies and tips on pain management as well as information in a format they could understand. It was also stated that for important appointments, a translator should be made available in case a patient cannot be accompanied by someone who can explain procedures:

*but I do think that at important appointments that doctors should try to get someone who can speak in the language of the patient (P3)*

The lack of empathic understanding was perceived by most of the participants from colleagues, employers, family, partners, and HCPs:

*My husband's family just seem to get annoyed, and they even would say things like, Oh, your pain never stops, or how long is this going to go on for? and just things like this (P10)*

*I realise that people that do not have pain like me will never understand. .if even educated doctors treat me with little care for my pain, then why should I expect other people to be more understanding or show compassion? (P1)*

The participants' accounts demonstrate their frustration of being misunderstood and judged by those who do not grasp the extent of their struggles.

### **Coping in the Midst of Darkness**

Coping in the midst of darkness consisted of two subthemes: spirituality and religion, and the collaborative pursuit of non-medical interventions for managing pain. Religion and spirituality emerged as integral components of coping mechanisms in the lives of these women living with chronic pain, a journey they described as one of darkness, using words such as 'a dark place', 'dark clouds', 'darkness', and 'a dark and gloomy place'. Amidst the darkness, the women relied on their faith. In their stories, it was evident that religion and spirituality held significant importance in their lives as a source of hope and

comfort. They had strong faith and trust in God, a higher power, and demonstrated a strong reliance on their religion and spirituality in general. The women had not lost hope, and their strong faith appeared to strengthen it:

*Oh, religion is so important to me, and I think I could not have kept going like I do if I did not believe that God is helping me out of this darkness.*

*We have a saying that there may be a delay until we are out of darkness, but we will never be kept here permanently if we have faith in God. (P1)*

*I do spend a few minutes speaking to God, you know, just hoping someone may be looking out for me. If I do not believe this, then the future is pretty bleak and I would be lost in a dark and gloomy place, worse than now as now I still have hope. You hear it so many times don't you, about hope being the last thing that goes (P5)*

The importance of religion and spirituality in assisting the participants to cope with chronic pain was evident in the narratives of all the participants. The women navigated the challenges of living with chronic pain by drawing strength from spirituality and religion. The former and latter were viewed as being similar to some:

*I think it is important to believe in something to allow you to cope in life, so both [discussing religion and spirituality] things are important, and they are very much related. . .you can say they are the same. . .if we lose faith, then we have nothing, and for me, it is important to believe that God is helping me to function daily (P3)*

Additionally, all participants mentioned trialling non-medical interventions. Having only been prescribed painkillers for their pain, the

participants turned to the collective knowledge of others. In their pursuit of relief from pain, they explored non-medical methods often recommended by others that extended beyond conventional medicine. These served as important sources of comfort and coping for these women as they navigated the challenges of living with chronic pain. Participants reported that they would try things recommended by others to help with pain management, and they would also share these tips with others, and a few had also been recommended herbalists by friends. This collaborative approach included the sharing of tips such as the use of heating/massage devices, soothing teas, therapeutic oils, supplements, and stretching:

*I use heat. I have a machine I purchased. . .as my friend also had used it and said it was good. (P1)*

*I also try and make my own oils at home, that some of my friends have told me about. (P3)*

*My mother sends me recipes for teas and ingredients that we understand are good for pain. (P10)*

## Discussion

The study's findings highlight the complexities of living with chronic pain for SAW. The participants gave detailed accounts of their experiences with chronic pain and its effects on their well-being. The women's lives were shaped by pain, multiple responsibilities, and a strong sense of duty. They experienced many losses that negatively impacted their mental and physical health. Many felt that the impact of their pain was not understood by their HCPs and that their information needs were not met. They were provided with no information about

their pain or how to manage it, and many of them were relying on spirituality, religion, and non-medical interventions recommended by others to help them traverse a journey that they described as being one of darkness.

The first theme, life shaped by pain, a strong sense of duty, and multiple responsibilities, was observed across the data. The women planned their days with their conditions and pain in mind, and pain shaped the course of their day. Other studies have also reported findings emphasising the limiting nature of pain (Evans & de Souza, 2008; Roberto & Reynolds, 2002; White & Seibold, 2008). However, a strong sense of duty was also detected in the present study. Despite their pain, the women appeared to prioritise their responsibilities and care for their extended families, including in-laws. Their strong sense of duty and their commitment to fulfilling these duties were evident, but this seemed to be at the expense of their own well-being, aligning with findings reported by Mustafa et al. (2020). Very few women spoke of engaging in hobbies or other interests of their own. The demands of their roles took precedence over their well-being.

It is important to highlight that while the meta-synthesis also captured the theme of multiple responsibilities, the interviews with SAW highlighted how cultural expectations and a sense of duty uniquely amplified these responsibilities. This also aligns with the findings of Mustafa et al. (2020). This amplification can also be viewed as a source of additional stress, potentially exacerbating their experience of pain. In the Mustafa et al. (2020) study, participants identified stress from their responsibilities as a contributing factor to chronic pain. This commitment and a sense of duty echo a collectivist culture where women actively contribute to the well-being of their children and

extended families (Kawamura, 2012; Mustafa et al., 2020). The study revealed that the participants were managing numerous responsibilities, with some women also juggling employment commitments beyond their household duties, which were viewed as being primarily the responsibility of the women.

It has been stated that 'Most Asian cultures are collectivistic in nature' (Kawamura, 2012, p. 95). The SA culture, with its collectivist orientation, emphasises the importance of family welfare, encompassing not only immediate family members but also grandparents, aunts, uncles, and cousins. In SA culture, placing utmost importance on familial duties and loyalty, alongside a commitment to self-sacrifice, is a prevailing characteristic (Choudhry et al., 2002; Masood et al., 2015; Mustafa et al., 2020; Shariff, 2009). South Asians are often perceived as being socialised to prioritise family needs over individual ones, with women bearing much of this responsibility (Masood et al., 2009). In this culture, the expectations placed on women often encompass broader familial responsibilities. These expectations can persist and influence their roles within the family even when they have relocated to another country (Masood et al., 2009; Shariff, 2009). Holt and Waterfield (2018) also reported on the increased daily demands of SAW and cultural expectations. The women in their study reported putting others before themselves, feeling compelled to prioritise family and household responsibilities over their own needs, even when they were in pain or exhausted.

It is important to recognise that individual experiences and choices may vary widely and that individuals within these cultures may approach and interpret these expectations differently, and not every woman will conform to these traditional roles. However, many of the women in the present study were

responsible for caregiving, looking after in-laws, and managing domestic tasks such as cooking and cleaning.

Similar findings were reported in another PAR study where focus groups were used with SA immigrant women in Canada (Choudhry et al., 2002). The participants consistently expressed prioritising their family's needs over their own. The women in the study were also found to be responsible for the housework and caring for family members. The authors stated that conventional health promotion programs did not adequately consider the specific circumstances of SAW (Choudhry et al., 2002).

Evidence of this first theme and of life revolving around pain and work has been reported in various studies, and it was women who were predominantly responsible for household chores while also caring for their children and other members of the family (Evans & de Souza, 2008; Hallberg & Carlsson, 1998; Richardson, 2005). Women often experience pain and face numerous obligations that play a central role in their lives. Some women in the present study had to leave work due to their pain. However, the responsibilities at home did not appear to diminish, and this has also been reported by other researchers (Richardson, 2005). A few participants reported employing someone to assist with these duties, and others wished that they could afford to hire someone to help them. This also indicated that these responsibilities were assigned to the women (Söderberg & Lundman, 2001).

Domestic work is a strongly gendered activity, with women having more responsibility (Harryson et al., 2012). Other research has also reported household and maternal responsibilities dominating the lives of SAW.

Researchers reported that domestic duties appeared to be the sole responsibility of these women (Greenhalgh et al., 2015). Moreover, the concept of 'women in the middle' (Brody, 1981), which refers to women who are in the middle from a generational perspective and in terms of managing multiple responsibilities, which include balancing care for their children and parents/in-law, and the difficulty of managing multiple obligations simultaneously, applied to some of these women. As well as the increased obligations associated with collectivist cultures and extended families in general.

This has implications for the support provided to SAW living with chronic pain and should be recognised. Despite their pain, these women continued to fulfil their perceived responsibilities, like housework, cooking, and caring for others. A sense of duty that often led to the sacrifice of their own comfort. The combined weight of these responsibilities, coupled with the additional burden of pain, represents a considerable source of stress.

The women's accounts revealed that they faced a multitude of stressors they could not evade (household chores, work obligations, and physical pain). Consequently, HCPs need to take these into account and take a more holistic and contextualised approach to pain management and SAW. Stress management is extremely important as there is a close relationship between stress and pain perception (Ahmad & Zakaria, 2015; Lang, 2020): stress can exacerbate the symptoms of a condition, which can in turn increase stress levels. Stress also decreases a person's pain threshold (Lang, 2020) and can aggravate chronic pain and certain long-term conditions (Maté, 2019; Melzack, 2001).



Chronic stress (the prolonged activation of stress mechanisms when an individual is exposed to unavoidable stressors) is destructive and can cause lasting damage (Maté, 2019). This damage results from the biological responses and the elevation of hormones triggered by stress. High levels of cortisol, as seen in people who are constantly stressed, are unhealthy. Levels of cortisol that are chronically elevated are destructive to tissue. Moreover, elevated levels of adrenalin over a prolonged period of time both increase blood pressure and cause damage to the heart (Maté, 2019).

The second theme, physically and psychologically damaging losses, was observed for all the women in the study. Chronic pain meant the women faced many losses that spanned physical, emotional, social, and aspirational dimensions: loss of work, autonomy, future certainty, the life that the women had hoped for, participating in the activities that they enjoyed, work contacts, and sleep. Through the women's accounts, these losses revealed a profound connection with psychological responses such as worry, anxiety, and a prevailing low mood. These are factors that inherently lead to more stress (Hainer, 2012; Maté, 2019), and stress exacerbates pain.

Many of these losses have also been reported in other studies (Dysvik et al., 2013; Howell, 1994; Knutsen et al., 2022; Osborn & Smith, 1998). The present study revealed that the most frequently reported issues related to employment, control, functioning ability, relationships, sleep, and autonomy. The women in the present study expressed the losses associated with employment (social interaction, routine, and purpose) and sadness at not being able to maintain their jobs outside the home. One participant mentioned that it 'broke her heart', not being able to work.

It has been stated that job loss profoundly impacts psychological well-being (Guindon & Smith, 2002; Jahoda et al., 2017). The benefits of employment and the effects of its loss on an individual's well-being are well documented. Job loss can cause immense stress, anxiety, and depression (British Psychological Society, 2019; Climent-Rodríguez et al., 2019; Guindon & Smith, 2002; Jahoda, 1982; Jahoda et al., 2017; Newman & Bland, 2007; Paul & Moser, 2009), all of which further exacerbate pain. It has been stated that it is the loss of latent benefits (a time structure, routine, and regular activity: 'basic psychological needs'; Jahoda et al., 2017) associated with work that results in poorer psychological well-being. Some of these were mentioned by the participants, and maintaining employment was also identified as a potential protective factor against worsening psychological well-being in the present study.

Women shared how work provided meaning, motivation, and crucial social contacts. Some women also highlighted that the cessation of work, while seemingly a relief from external pressures, paradoxically increased the pressure to perform tasks at home. These tasks are potentially less meaningful and motivating to them, and they expressed a sentiment that working provided a sense of purpose, meaning, and crucial social contacts that were missed when absent from the workforce. This represents a distinct advancement in our understanding of SAW's experiences. This revelation underscores the potential harm of prematurely ending work and advocates for strategies that retain women in employment (if they desire), recognising the positive impact on their overall well-being.

Individuals' conditions should be accommodated so that they can continue working, if possible and if desired. Participant six described how special equipment and flexible work schedules enabled her to continue working despite experiencing pain. Other interventions should aim to provide this and a means of replacing some of the losses reported. A sense of purpose is important for psychological well-being, and the focus should be on retaining it (Jahoda et al., 2017). Support groups have also been reported to be beneficial for women experiencing persistent pain (Allen et al., 2015).

The third theme, lack of understanding: unmet needs, was observed on two levels: not understanding chronic pain and lack of empathic understanding. The former was displayed by the women themselves, whereas others in their lives and HCPs that they encountered appeared to be lacking understanding on both levels. Although the women did not understand their condition and how to manage it themselves, many of them had discerned that their pain levels were not consistent and were often fluctuating. Furthermore, they had observed that some factors, such as poor sleep were making their pain worse, and sleep is important to address (Walker, 2018).

These findings are in line with both the Gate Control and Neuromatrix theories of pain (Melzack, 2001; Melzack & Wall, 1965). The former purports that multiple factors can influence the gating mechanism that regulates pain, while the latter acknowledges that these same factors can also trigger nerve impulse patterns, resulting in the experience of pain. Both theories acknowledge the importance of physiological and psychological influences on pain perception and underscore the need to consider pain management in a biopsychosocial context.

However, the findings of the present study revealed that the women did not experience this in their healthcare. Instead, the findings suggested that there was a lack of understanding from HCPs and others in understanding chronic pain, the impact of it, and empathic understanding. Their narratives suggest that the current healthcare paradigm does not align with the needs of these women and falls short of a biopsychosocial approach. A holistic and personalised healthcare model is crucial; one that not only addresses the physical aspects of pain but also comprehensively embraces the psychological, social, and spiritual factors. Many participants felt that their HCPs failed to understand the severity of their pain and its impact on their quality of life and well-being. Older and more recent research has found that women's pain is often dismissed (Campbell et al., 2022; Howell, 1994; Roberto & Reynolds, 2002; Samulowitz et al., 2018; Wuytack & Miller, 2011).

The present study's findings also share some commonalities with those reported by Singh et al. (2018): a perceived lack of understanding from the community and a participant's pain interfering with her 'perceived female role', which included housework and cooking. Their study, however, also found that chronic low back pain had a detrimental effect on the cultural and religious well-being of 'Punjabi participants', as it consistently hindered their ability to engage in meditation. This was not reported by the participants in the present study. Their study did mention difficulties of 'sitting in the temple' under this theme. It may be that amidst the COVID-19 pandemic, with places of worship closed, women may have discovered alternative ways to engage in prayer and rituals within their own homes. These new methods may not involve sitting on the floor,

as is often the case in SA places of worship, and they may have enabled them to maintain their religious practices during times of pain.

It has also been argued that individuals tend to depend more on intrinsic religious practices, like private prayer, rather than extrinsic religious activities, such as attending a place of worship, as a means of coping with challenges so this may also explain these differences (Alfano et al., 2023). Additionally, there were no reports of reliance on HCPs or a shift toward seeking resources online. This present study's sample, however, consisted of some women who could not access online resources and had limited English language skills. As a result, their ability to access and understand online resources was also limited. However, among individuals who were able to access resources and understand English well, a few stated that there was so much information out there that they were not sure what to believe and that some of it was 'confusing'.

How well an individual understands the information that may be available to them and whether they can access it are all important factors to consider when developing resources tailored to patients' needs. Furthermore, another participant stated that 'time and patience' were required to go through everything online, and she felt that this was something many people with chronic pain did not have. It could also be seen why this may be particularly challenging for these women with all of their responsibilities (Mustafa et al., 2020).

Similar to the findings of Greenhalgh et al. (2015), the present study found that SAW lacked knowledge and information. Participants stated that they would have benefited from information provided by their GPs or doctors at the

hospital on their condition and how they could manage it in a format that they could understand. Although this is recommended standard care, many of these findings have also been reported in a recent systematic review (Vakil et al., 2023). The review sought to investigate the perspectives of first-generation SA migrants residing in high-income Western countries regarding their experiences with patient-centred care while living with chronic diseases (Vakil et al., 2023). The authors found that many patients expressed a preference for written communication in their own language(s). However, healthcare services often provided printed materials only in the language of the participants' Western countries of residence. Moreover, even when participants received printed materials in their preferred language, these resources were not really beneficial. This was due to the fact that the concepts presented in formal written language were not suitable for individuals lacking expertise and possessing limited literacy in their native language. Furthermore, many SA patients conveyed dissatisfaction with the doctor-patient relationship, citing culturally insensitive advice, language barriers, time constraints during consultations, and an unapproachable demeanour exhibited by the doctors. When patients expressed concerns, they were either discouraged from voicing them or they were overlooked by their doctors. Certain participants reported that when they sought information about their chronic diseases, doctors primarily emphasised adherence to prescribed medication and, in some instances, implied that the requested information was unnecessary (Vakil et al., 2023).

However, the range of health conditions investigated in this review was limited, with most papers focusing on cardiovascular disease or diabetes. Furthermore, some research provided insufficient demographic data to

establish eligibility for inclusion, potentially leading to the omission of certain useful studies from the review (Vakil et al., 2023).

Other literature, however, does highlight similar findings in relation to pain too (Gordon et al., 2017; Lim et al., 2019; Lin et al., 2018; Parks, 2020). Moreover, a lack of understanding and awareness of the cultural needs of SA Sikhs and Muslims with life-limiting illnesses in Scotland was found to be prevalent among HCPs too (Worth et al., 2009). It is acknowledged that patients may not always be seen by HCPs who share a similar background or language. This underscores the importance of providing quality resources that patients can understand.

Another participant in the present study also expressed concern that there was a great deal of inaccurate information online and that better resources should be made available. Findings from a systematic review investigating perceived health information needs related to low back pain also reported that individuals with low back pain desired clear information on treatment options, prognosis, and self-management strategies, provided in a language that they could understand (Lim et al., 2019). Additionally, a recent systematic review conducted by Basnet et al. (2023) investigated online information on chronic pain in Nepal, Australia, and Mexico with regards to three areas: credibility, readability, and accuracy. The authors concluded that there was a need for international improvements in chronic pain online resources in all three aspects.

Overall, the women's narratives in the present study suggest that the current healthcare paradigm does not align with the needs of these women and falls short of a biopsychosocial approach. The limited options of analgesics and

surgery provided to the majority of women indicated that the complexity of pain was not understood. There are other alternatives for managing pain that could be explored: relaxation therapies provide individuals with a variety of tools (deep breathing and mindfulness) that are beneficial for decreasing muscle tension, daily pain, and managing pain more independently. Distraction strategies have also been demonstrated to be effective in managing emotions (Ambron, 2020; Mansell et al., 2020; Tabibnia, 2020). The denial of such options, as well as a lack of information, prolongs women's pain and undermines their self-efficacy, which is crucial for self-management and an important factor in coping as it influences behaviour, motivation, and how individuals approach health-related challenges (Firth et al., 2019; Paterick et al., 2017). This study has highlighted the urgent need to provide women living with chronic pain with guidance during their 'darkest moments'.

Research has also highlighted 'compassion fatigue' among HCPs and the decline of empathy (Carr, 2016). Improving the public's and HCP's understanding of chronic pain and giving them the chance to experience what it is like for women who live with it may serve as a crucial strategy for raising awareness and empathy (Nehrke et al., 2017; Stenhoff et al., 2015). Increasing awareness and understanding among HCPs is important, and they should be empowering women living with chronic pain by providing them with helpful information and encouragement (Skuladottir & Halldorsdottir, 2011). Having access to information is essential for empowering individuals to manage their condition (Molin et al., 2022; Williams, 2004).

Furthermore, although the tremendous opportunity to improve access to services for pain and mental health through the use of digital health tools is



acknowledged, the digital skills and literacy levels of the intended audiences must be considered. Not everyone has access to online services and resources, and even those who do may lack the skills necessary to understand the material.

The fourth theme, coping in the midst of darkness, with spirituality and religion providing hope and comfort, the latter also being obtained through non-medical interventions, was shared by all of the women. This also reflects the findings of other researchers (Holt & Waterfield, 2018; Rogers & Allison, 2004). Holt and Waterfield's (2018) study reported the use of heat, massage, and 'Indian remedies'.

The participants' descriptions indicated that their pain was not only intense and overwhelming, but also cast a shadow over their lives. Their descriptions conveyed the emotional and psychological burden of chronic pain, highlighting the importance of considering the holistic impact of chronic pain on individuals. In Kirkham et al.'s (2015) study (Chapter Three), participants also provided similar descriptions when describing their pain, likening it to 'darkness,' 'blackness,' and a 'black thundercloud' that is ever-present.

The participants reported using religious and spiritual coping strategies to manage their pain and help them navigate through this 'darkness' (prayer and hope; Wachholtz et al., 2007). Other research also indicates (Glover-Graf et al., 2007; Keefe et al., 2001) that patients dealing with chronic pain often rely on religion and spirituality to cope (Chapter One).

A recent qualitative study involving fifteen women with cervical cancer found that participating in religious activities, particularly prayer, was crucial in helping them manage their pain and providing strength (Hobenu & Naab,

2023). Moreover, the strength and comfort provided by religion and spirituality to SAW have also been reported in other studies (Bottorff et al., 1998; Gurm et al., 2008). Additionally, other research has provided evidence that demonstrates a positive correlation between religion and spirituality and well-being (Feuille & Pargament, 2015).

Other research also indicates that individuals often turn to religion during challenging times, and its power is amplified during such periods. Existing literature suggests that the emergence of COVID-19 resulted in a rise in individuals resorting to prayer for strength and protection. Bentzen (2021) noted that in March 2020, during the initial stages of the coronavirus pandemic in Europe, there was a significant increase in Google searches related to prayer, reaching the highest levels ever recorded; surpassing all other religious occasions that often involve prayer, such as Easter, Christmas, and Ramadan (Bentzen, 2021).

Alfano et al. (2023) provided additional evidence supporting a comparable pattern in Italy. Bentzen (2021) argues that this pattern is a worldwide occurrence, indicating that when faced with uncertainty and hardship, people often turn to religion for explanation and comfort (Alfano, 2023).

Another recent study aimed to investigate the relationship between religion and the self-management of type 2 diabetes (T2D) in Muslim participants in the US. It found that religion helped participants cope, provided hope, strength, and motivation to self-manage their condition (Alramadhan et

al., 2023). Similar findings were reported by Singh et al. (2012) in their study with twelve SA participants.

Another recent systematic review explored the connection between spirituality or religiosity and quality of life, mortality, and cardiovascular outcomes in patients with heart failure. Despite the considerable heterogeneity in participant populations, variations in the definitions of spirituality and religiosity, and differences in interventions among the included studies, a consistent finding emerged. Across all studies, positive associations with the examined outcomes and religiosity and spirituality were identified. The authors stated that the dimension of spirituality/religiosity, often overlooked in conventional medical practices, has the potential to enhance the well-being of patients with heart failure and is something HCPs should be aware of (Cilona et al., 2023).

However, religion and spirituality can be adaptive or maladaptive. The latter occurs when individuals fail to maintain any power and surrender it all to a higher power; the former would be a state in which an individual still maintains a sense of responsibility and self-efficacy while also feeling supported by their higher power (Dedeli & Kaptan, 2013). The participants in the present study reported relying on spirituality and religion while simultaneously experimenting with alternative approaches for comfort.

Research also indicates that negative spiritually based thoughts (viewing suffering as retribution from God and feeling abandoned by God in desperate times) are associated with heightened sensitivity to pain, whereas positive thoughts (in which one looks to a higher power for strength, support, and

solace) are associated with the opposite (Bush et al., 1999; Rippentrop et al., 2005). The women in this study were displaying the latter, and they should be supported by HCPs to continue using spirituality and religion to promote adaptive coping. Moreover, spiritual support should be provided, if necessary, by a chaplain or other members of various places of worship (Hasenfratz et al., 2021; Sulmasy, 2002; Tait & Miller, 2007).

Spirituality and religion's influence on pain management is consistent with the Gate Control and Neuromatrix theories of pain (Melzack, 1999; Melzack & Wall, 1965). Spirituality and religion can be perceived as another strategy for coping with pain that can also influence an individual's response to it (Wachholtz et al., 2007) and pain perception (Rippentrop et al., 2005; Wachholtz et al., 2007). Research also indicates that spirituality is important to many patients, and the majority of chronic pain patients wish for spiritual aspects to be considered in their care (Hasenfratz et al., 2021; Sulmasy, 2002).

Many authors, patients, and studies acknowledge the benefits of religion and spirituality for improving health outcomes, as well as reduced utilisation of healthcare services and advocate for a biopsychosocial-spiritual model in medicine (Büssing & Koenig, 2010; Glover-Graf et al., 2007; McKee & Chappel, 1992; Ross, 1995; Siddall et al., 2015; Sulmasy, 2002; Taylor et al., 2013; Uslu-Sahan et al., 2023). Consequently, HCPs should be more cognizant of the significance of spirituality and religion in assisting and supporting individuals experiencing pain (Dedeli & Kaptan, 2013).

The present study sheds light on SAW's experiences with chronic pain. It represents a significant step towards addressing the current paucity of

qualitative research in this field. The sample of SAW in the present study varied in terms of education level, pain duration, work status, and length of time in the UK. They did, however, share comparable experiences with chronic pain. The findings have various ramifications for the management of chronic pain in SAW. The significance of the biopsychosocial-spiritual model of health has been demonstrated in the context of chronic pain. The findings have underscored the necessity of incorporating chronic pain management interventions within a biopsychosocial-spiritual framework for individuals who rely on spiritual practices to help manage their pain (Hasenfratz et al., 2021; Sulmasy, 2002). Spirituality is crucial for high-quality clinical practice and medical training (Saad et al., 2017). Sleep, support for women, self-efficacy and empowerment, stress management, spirituality and religion, and distraction strategies have all been identified as key aspects to include in pain management plans.

However, the study's limitations should be considered when interpreting the findings. The majority of the participants ( $n = 11$ ) were Indian, and all except one reported their financial situation as comfortable or very comfortable. Economic status is another factor that can also influence the experience of pain. Furthermore, interviews were conducted over the telephone, so there were no visual cues to facilitate rapport-building and response interpretation (Arksey & Knight, 1999). However, it was felt that the researcher's similar background to the participants, being female, and being able to communicate with the participants in their preferred language, aided in establishing good rapport and collecting rich data (Shah, 2004).

Translation can also be quite complex, and interpreters can alter the meaning of queries, thereby altering the content of the generated data (Chiu &

Knight, 1999). It is hoped that the researcher's understanding of the study and multilingualism/biliteracy also contributed to the collection of rich data. It also enabled interviews with women of various educational levels, generations, and language abilities to be conducted.

On the basis of the existing literature, considerably more in-depth research on the experiences of SAW with chronic pain is required. Researchers could examine various pain management techniques (e.g., mindfulness, relaxation, and diversion), as well as ways in which the community, chaplains, or religious groups could be of assistance. Throughout the interviews, a wide range of emotions and feelings were expressed, ranging from frustration, anxiety, sadness, tension, and loneliness. Interventions to improve some of these need to be explored. Future research could explore these and the experiences of women from different SA groups and different economic backgrounds. These may also provide additional insight.

## Conclusion

This study aimed to gain a deeper understanding of SAW's experience with chronic pain. The participants, whose lives were shaped by pain, multiple responsibilities, and a strong sense of duty, experienced many physically and psychologically damaging losses. There was a lack of understanding among the women, others, and HCPs. Participants reported that their information needs were not met, and spirituality and religion were extremely important to them.

Optimal care for women living with chronic pain involves an integration of strategies that not only target the physical aspects but also address the psychological and spiritual dimensions. An approach that recognises the

interconnectedness of physical and mental health and acknowledges that improvements in one realm can positively influence the other. Acknowledging and respecting the importance of religious and spiritual beliefs is essential for delivering a holistic, patient-centred approach to pain management. It is important to engage the population, empowering them to devise solutions that address their needs (Whitmore, 2001). This not only enhances the effectiveness of interventions but also equips individuals with a more comprehensive toolkit for managing their pain and promoting overall well-being (Benson et al., 2010; Shahid et al., 2020). HCPs should consider implementing a biopsychosocial-spiritual model of care and educating and empowering women. Similar studies could provide additional insights and be used to inform the design of culturally sensitive pain management plans and interventions that are tailored to the needs of SAW. The findings of this study may be useful for HCPs, policymakers, women with chronic pain, and those who support them.

## Chapter Summary

The underrepresentation of SAW in pain research has resulted in a lack of understanding regarding their experiences of living with and managing chronic pain. The qualitative study described in this chapter aimed to explore and contribute to understanding these experiences. Four main themes were identified: life shaped by pain, multiple responsibilities, and a sense of duty, physically and psychologically damaging losses, a lack of understanding: unmet needs, and coping in the midst of darkness. Additionally, it has highlighted the importance of religion and spirituality. This chapter has discussed these themes in relation to psychological theories and research on chronic pain. The study's

limitations, implications, suggestions for future research, and a conclusion were also provided. The next chapter describes Phase Three of this project.



## Chapter Five: Phase Three, Stage One

### Chapter Overview

The previous chapter detailed the project's second phase, a qualitative study that explored SAW's experience of chronic pain. The identified themes highlighted the psychological effects of living with chronic pain and the struggles these women face in managing their pain. In the third phase of the research, we aimed to systematically address key concerns and develop targeted solutions that could potentially improve health outcomes for the participants. Phase Three was divided into three stages: 1) focus group discussions to identify key concerns and explore potential solutions, 2) co-creation of an intervention and resource, and 3) evaluation of the co-created interventions. This chapter focusses on Stage One, which involved the conduct and analysis of the focus groups.

### Introduction

The findings of the study mentioned in the preceding chapter revealed that SAW living with chronic pain reported experiencing low moods, language barriers, and many losses, and they believed that HCPs were not doing enough to support them to manage their pain, particularly regarding the provision of information.

Low literacy levels, language and communication barriers, and a shortage of translated resources were reported in another study in the UK exploring medicine use and concerns among SAs and Middle Eastern participants (Alhomoud et al., 2015). The study highlighted the danger of insufficient provision of necessary information for patients: it can result in patients making harmful decisions. The study found that when participants were unable to

acquire or get adequate information from doctors owing to low literacy levels, language barriers, a lack of interpreters, or other reasons, some handled their own treatment and made active decisions without seeking information from other sources. The authors provided a concerning example where a participant stated that she had never been advised that cholesterol tablets must be used for the rest of her life as a secondary prevention of cardiovascular disease; therefore, she voluntarily chose to discontinue her medication (Alhomoud et al., 2015).

Lack of access to information was also reported by Bangladeshi participants with diabetes in another study in the UK (Choudhury et al., 2009). Furthermore, a lack of understanding and awareness of the cultural needs of SA Sikhs and Muslims with life-limiting illnesses in the UK was found to be prevalent among HCPs too (Worth et al., 2009).

Gordon et al.'s (2017) qualitative study with fifty-four chronic pain patients in Scotland, which aimed to identify probable barriers that may hinder the implementation and use of self-management strategies, found that some patients believed that discussions about self-management were either delayed or completely absent. The emotional toll of pain was significant, and patients frequently felt that HCPs did not provide adequate support; they felt unsupported. Establishing effective communication and fostering positive relationships were occasionally difficult. Patients frequently identified 'improved listening' as the primary quality they sought from HCPs, and one of the challenges with self-management mentioned by patients was the lack of access to resources. Many patients felt they received minimal self-management support

from their HCPs. Additionally, patients believed that their HCPs frequently offered prescriptions as the only option to manage their pain.

Other literature on pain management also offers comparable conclusions (IASP, 2021; Lim et al., 2019; Lin et al., 2018; Lyman, 2021; Parks, 2020). Patients with pain often feel they must defend their experience and highlight active listening by clinicians as crucial for a strong patient-clinician relationship (Kang et al., 2023). Effective communication helps individuals with chronic pain feel heard, validated, and supported, improving their quality of life despite ongoing pain. The NICE guidelines emphasise the importance of a collaborative and supportive relationship in managing chronic pain (Kang et al., 2023). Moreover, a comprehensive review of thirty-three studies found that person-centred treatment, including shared decision-making and guided problem-solving, is crucial for long-term self-management of chronic pain (Devan et al., 2018).

In light of the existing literature and the findings from Phase Two, the present phase sought to work collaboratively with SAW to identify key challenges, explore potential solutions, develop an intervention based on these findings, and evaluate it. This study also aimed to address the gap in literature on the cultural needs and key challenges faced by SAW living with chronic pain and factors that could improve their well-being and pain management.

Furthermore, it is well documented that prescriptions for opioids are increasing in the UK, despite evidence suggesting that they are not beneficial for chronic pain (NHS England and NHS Improvement South West, 2020; NICE, 2019; Parks, 2020). Therefore, it is necessary to explore alternative and more effective approaches for managing persistent pain for this cohort. Moreover,

having discussed and seen the impact chronic pain has on these women's lives and their well-being, developing solutions that empower them to effectively manage their pain and well-being is essential (Breivik et al., 2006; Dueñas et al., 2016; Nijs et al., 2021; Yong et al., 2022).

The overarching aim of this action research study was to explore options to empower SAW to effectively self-manage their pain and well-being. The first stage of this study aimed to identify the key concerns and challenges that women living with chronic pain would like addressed and to explore what could be helpful to address these and enable women to live well with pain through focus groups.

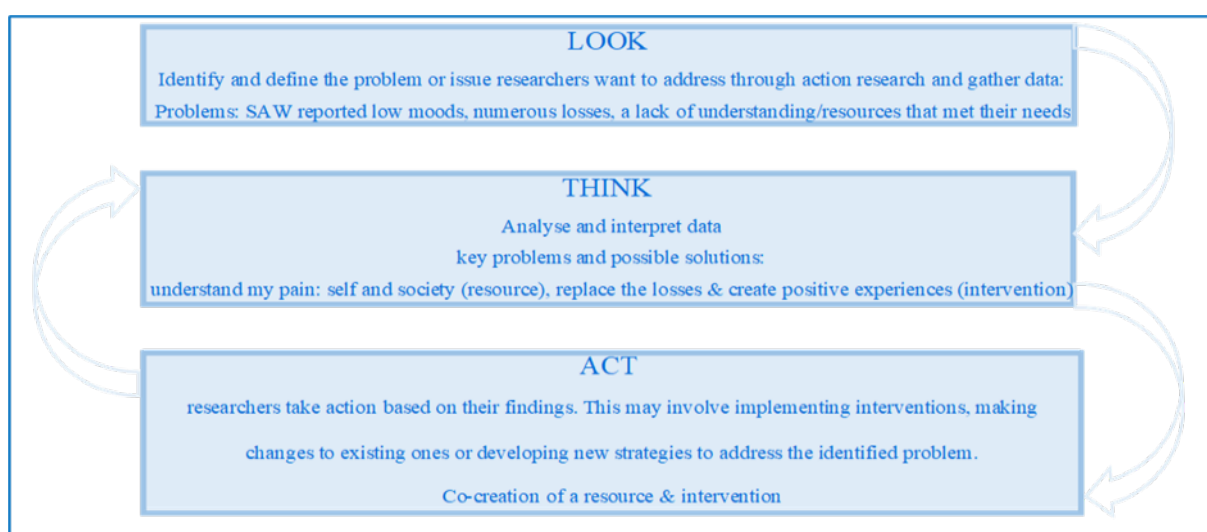
As quantitative methods cannot convey the complexities of human experiences, qualitative methodology was deemed most suitable for the research aims of this study (Howitt, 2016; Willerton, 2010). The research question to be addressed through focus groups was: What are the key challenges faced by SAW living with chronic pain, and what potential solutions could help address them?

## Methods

This action research study used focus groups to identify SAW's key challenges and explore potential solutions. Action researchers work collaboratively with participants (co-researchers) to achieve practical solutions to issues and problems they experience in their everyday lives; it seeks to improve their well-being (Stringer & Ortiz Aragón, 2021). This approach was selected due to it aligning most closely with the project's aims. Additionally, focus groups were deemed the most appropriate data collection method due to their ability

to generate rich data and allow participants to discuss problems and offer potential solutions (Butler, 1996; Duggleby, 2005; Onwuegbuzie et al., 2009). Moreover, the interactive nature of focus groups often reveals nuanced dimensions of understanding that other research methods may not fully capture (Kitzinger, 1994, 1995). This interactive environment is valuable in the present phase as it could encourage the exchange of ideas and the exploration of diverse viewpoints, which could lead to the discovery of novel strategies or approaches to managing pain that may not be evident in individual interviews.

The approach to action research described by Stringer and Ortiz Aragón (2021) was followed, which includes three major steps, and they are presented in the diagram below (Figure 5.1). In the 'looking' phase, participants underwent individual interviews to share their experiences of living with chronic pain (reported in the previous chapter). The present stage focused on discussing these and identifying the key concerns and challenges and exploring strategies for mitigating them (thinking) through focus group discussions. This chapter will discuss Stage One and describe the steps taken during this stage. Ethical approval forms for the present study can be found in Appendix One [B].



**Figure 5.1: Process of Steps Taken in This Study**

## **Study sample**

Sixteen females (Indian,  $n = 14$ , Pakistani,  $n = 2$ ) between the ages of thirty and seventy-eight years ( $M = 56.63$ ,  $SD = 16.71$ ) participated in the present study; nine women were married, two were single, one was separated, and four were widowed. Two were graduates, one a postgraduate, ten women reported high school (seven attended in India and three in the UK) as their highest level of education, and three reported attending primary school in India. Two participants reported English as their first language, and eight women stated that they were not able to access health resources online. The shortest period reported of experiencing chronic pain was one year; the longest period was fifteen years ( $M = 6.50$ ). Three women reported having shoulder pain, four back pain, one neck pain, one neck and back pain, another neck and abdominal pain, two experiencing abdominal pain, three experiencing knee pain, two of whom had osteoarthritis, and another participant also reported osteoarthritis but having pain in the hands and wrists. All women reported their pain ranging from four to six (nagging to distressing) on the visual analogue scale. This is a continuous scale that allows individuals to rate their pain by indicating a point along a line. The line's endpoints are labelled with opposing descriptions of pain: 'no pain' on one end and 'worst pain imaginable' on the other (Operative Neurosurgery, 2016).

Table 2 in Appendix Ten provides further information on the participants.

## **Materials**

A participant information sheet (Appendix Eleven) was provided to participants by the method they had specified (email, post, etc.). Consent forms (Appendix Twelve) were signed and returned to the researcher before the

commencement of the focus groups. During the focus groups, a prompt sheet (Appendix Thirteen) was used to guide the discussion and presented questions in alignment with the GROW model (Whitmore, 2001) in order to identify key challenges, explore options, and empower participants (this has been discussed in detail in Chapter Two).

### **Procedure**

Thirteen participants who were part of an earlier study and had consented to being contacted regarding future research and three others who had expressed interest contacted the researcher wishing to participate in the present study after having viewed the participant information sheets. All participants had filled out a demographic questionnaire, with some having done so as part of a previous study and others before the focus groups. The consent forms were also completed and returned prior to the focus groups (in person or electronically). The participants were notified that their participation in the study was optional and that they were free to withdraw at any point without needing to provide a reason for doing so. The participants were reminded to maintain strict confidentiality regarding any information disclosed by fellow participants in the group and to let the researcher know if they wished to take a break. They were assured of anonymity with respect to any personal information disclosed to the researcher.

A brief, self-administered questionnaire for each participant supplemented the focus groups. However, the data collected will be used for a subsequent stage of this investigation and will be reported in Stage Three (Chapter Seven in this report). The researcher then opened the conversation by restating the prior study's findings and stating that the goal of the discussion

was to collectively identify the issues most important to the participants, explore potential approaches to addressing them, and formulate a course of action to address the key challenges and assist participants in managing their pain and well-being. The questions were framed around the GROW model, which not only facilitates structured discussion but also encourages participants to come up with their own solutions (Whitmore, 1992).

Three focus groups were conducted in December 2023, two with six participants and one with four (in line with guidelines on ideal group size; Kitzinger, 1995). The focus groups were arranged on days, times, and locations that were convenient for all the participants in each group. Two were conducted in person (in the homes of two participants) and one online. At the end of each focus group, the researcher provided a quick overview of key concerns and potential solutions that were raised during the discussion from the researcher's notes. This was done to allow additional reflection, verification, and clarification and to give participants the opportunity to contribute anything further they may have wished to (Collins & Nicolson, 2002). Each focus group lasted approximately an hour, and the researcher facilitated, recorded, translated (where necessary), and transcribed all group discussions.

The transcription of the focus group conducted in English was completed verbatim; focus groups conducted almost exclusively in Punjabi were contextually translated ( $n = 2$ ; Esposito, 2001). This is to ensure that what was actually stated by the participants was retained (Barbour, 2018; Twinn, 1997). A literal translation can cause the meanings of some of what was actually said to be altered. For example, translating 'they do nothing' verbatim would result in 'they something no do' in English. The discussions finished with a five-minute



debriefing session. The goal of the study was restated; participants were given contact information for support services that they may wish to use (if necessary). The participants were contacted by phone to go over the synthesised findings in December. RTA was used for inductively analysing the data (Braun & Clarke, 2022).

## **Analysis**

Analysis of the focus group data was conducted by the researcher according to the guidelines and six phases provided by Braun and Clarke (2022). RTA is effective for investigating unexplored subjects and can address a majority of qualitative research questions (Braun & Clarke, 2022; Clarke & Braun, 2015). The philosophical foundations of this qualitative study adhered to a critical realist ontology, appreciating the complexity and context of the social world of the participants and their experience of pain (Maxwell, 2012; Ormston et al., 2014). An inductive epistemological stance guided the thematic analysis of the data, emphasising a process that captures the richness and complexity of the participants' experiences without predetermined assumptions (Kvale, 2007). Themes were identified and reported both at the semantic and latent levels (Braun & Clarke, 2022).

The researcher (who also translated two transcripts) transcribed the data following each focus group. The accuracy of the transcriptions was verified through self-checking, and the recordings were re-listened to. This immersion served to enhance understanding and familiarity with the data. The individual group data and then the combined data from the three discussions were analysed with a focus on aspects deemed potentially relevant to the study's objectives. These aspects were identified and labelled with meaningful codes on

each transcript, such as 'joy and happiness,' 'pain-free moments,' and 'mourning loss.' Similar codes were combined where they encapsulated the same idea resulting in codes like 'the need to talk', 'safe space', 'active listening' and 'not judged,' combined into the broader concept of 'holding space.'

From these initial codes, themes were generated to reveal shared patterns across the dataset. Key themes were discerned at both the semantic and latent levels. The themes were again reviewed and developed. For instance, the theme originally capturing the comforting nature of the discussion setting (comforting environment) was merged with the concept of holding space, resulting in the final theme: 'Holding Space: Sharing, Safety, and Solace.' The review of all the codes and preliminary themes was repeated, and a thematic map shows the final themes (Appendix Fourteen). Peer debriefings (collaborative discussions among research team members on the preliminary themes/analysis) assisted with refining and finalising theme names. The discussions also helped analyse how the themes were connected. One theme, 'building back the losses and creating positive experiences,' was changed to 're-(creating) the losses and positive experiences' and then to 'restoring the losses and creating positive experiences'. The change was made after a team member found the original phrasing unclear and felt it did not immediately convey the intended meaning. This was revised again, as the second theme appeared to suggest duplicating loss, and the final one better captured the intended meaning of reclaiming the losses. Pertinent data extracts were carefully selected from the dataset, and a research report was compiled to present the findings of the study. Examples and quotes from the data are provided to support the researcher's interpretation.

## Reflexivity

As a researcher, the importance of establishing a robust foundation for reflexivity was acknowledged: recognising the researcher's influence on the study while remaining mindful of being an outsider to the direct experience of chronic pain. Throughout the discussions, notes were made to document the crucial elements that were being discussed and exchanged. Several of these served as the foundation for the early codes that subsequently developed into meaningful themes. For example, 'the need to talk', 'safe space', and 'non-judgemental listening,' were combined into the broader concept of 'holding space.' Good rapport was already established through the process of conducting interviews in Phase Two. Furthermore, keeping a reflective journal ensured that the researcher's initial thoughts were documented in an effort to reduce the influence of assumptions and ensure an accurate representation of the participants' viewpoints.

It was felt that the absence of the researcher's personal familiarity with chronic pain did not hinder the pursuit of understanding the key challenges these women face. There was a commitment to bridging the gap between the researcher's understanding of the struggles of living with chronic pain as an outsider and the challenges faced by the participants by seeking feedback on the researcher's summary at the end of each focus group and the findings after analysis of the data. A reflexive approach ensured that the narratives were analysed with openness and a genuine eagerness to understand the participants' journeys.

## Results

Three themes were developed following inductive reflexive thematic analysis: 1) Holding Space: Sharing, Safety, and Solace; 2) Understand My Pain: Self and Society; and 3) Restoring the Losses and Creating Positive Experiences.

### **Holding Space: Sharing, Safety, and Solace**

The primary emphasis of this theme is the importance of space to be held for these women and the therapeutic benefit gained by these women from candid conversations concerning their struggles and experiences of pain in a safe, non-judgmental setting. They needed a forum to openly discuss their experiences without fear of judgment. The focus groups themselves incorporated a cathartic element for these women. The women described how a weight had been lifted. The participants expressed relief in finding a compassionate space where they could openly and candidly share their stories. This freedom from judgement appeared to provide solace, lifting a burden they often carried in silence:

*I found the interview [speaking about the previous study] so helpful to me, like a heavy burden was lifted from my shoulders. I felt lighter [laughs] but today it is like multiple burdens have been lifted (FG1)*

Being listened to and feeling heard was incredibly beneficial and significant to the women. Engaging in this process alongside others who had undergone similar experiences appeared to be even more impactful:

*You are right. . .This has been really nice too, to share your pain and where everyone listens. . .there is no one saying this is wrong. . .we all know our pain (FG1)*

This comment also suggests that their usual interactions may be judgmental or lack understanding. However, when they are with others who share their experiences, their pain is legitimised and validated. A participant from a different focus group stated the importance of dialogue and a safe setting where mutual understanding reassures participants that they are not alone in their challenges. The participants' accounts emphasised the importance of a secure environment where they could openly share their experiences, as they felt that expressing how they were feeling at home could be regarded as complaining:

*Everyone here understands what pain feels like; we can talk openly, I can't at home as it would be seen as me complaining. Everyone knows how it feels, and no one listens and makes you feel like you are overexaggerating*  
(FG3)

The above quote explicitly highlights how the home environment may not offer the support they need, emphasising the importance of finding a supportive community outside of it. Another participant felt this lack of understanding also applied to the workplace:

*Yes, it would be seen as complaining in any other environment. . .home or work (FG3)*

The focus group discussions themselves revealed a distinct therapeutic quality, as members provided reassurance and support to one another while also validating each other's experiences, as the exchange below between two participants in group three captures:

*I really started thinking it was a me problem (FG3)*

*Hey, don't think that, it is not a problem with you; we are all in the same boat. . .we understand (FG3)*

The impact of mutual encouragement, shared tips, and validation among participants could clearly be seen. Many participants were empathetic and offered validations to others, highlighting how a supportive group can provide the understanding and recognition that might be missing from their home and work environment. The dialogues within the first group also encapsulated the essence of this support, underscoring the significance of attentive listening and genuine empathy. A participant in this group shared how she wished that HCPs and others could emulate the empathetic atmosphere of the focus group, recounting instances of leaving medical appointments in tears:

*I wanted to say thank you [pause] thank you to you all. . .for listening. I wish doctors and other people could listen like this. I know the number of times I left my surgery in tears (FG1)*

This poignant admission also sheds light on the unmet need for compassionate and attentive listening from others and those in healthcare settings. During the discussions, the appreciation that the participants felt for the kind words offered by other participants was also apparent. It appeared that their high regard for sincere compassion stemmed from the rarity with which they encountered it, both in their interactions with medical professionals and in their encounters with others. This sentiment was echoed across all focus groups. Participants emphasised that such compassionate dialogue was a departure from their usual interactions with others, where understanding was often lacking. The shared understanding and compassion went beyond the limitations of their immediate surroundings and healthcare encounters:

*This is the first time in my life that anyone has actually listened and understood my pain (FG2)*

*I said this after my interview [speaking about Phase Two] (FG2)*

An exchange between group one participants about being able to share their pain and attentive listening emphasises the significance of these simple yet powerful acts. The power of listening was evident in the exchange where a participant expressed how the act of sharing one's struggles could, in itself, alleviate pain. The participant felt that a person's pain is diminished when someone listens and understands, underscoring the importance of empathetic listening and support:

*This is one small thing everyone should really be able to do for someone:  
listen to someone's pain (FG1)*

*a person's pain is eased when someone gives time to listen and understand. . . Sometimes all you want is for someone to listen and to have someone to share your pain (FG1)*

The dialogue further unfolded, with participants extending support beyond the group setting:

*Now the weather is cold, but when the weather is better, I can help you.  
We can go to the garden centre together (FG1)*

The very act of women gathering had sparked the initiation of relationships and the establishment of support networks. Their shared experiences and understanding established a foundation for mutual empathy and collaboration. This gathering not only validated their individual experiences but also initiated discussions that could lead to the development of solutions.

The focus groups not only uncovered valuable insights into the experiences of these women but also shed light on the power of having space held, sharing stories, and peer support within these group settings to provide some solace to the participants.

### **'Understand My Pain': Self and Society**

There was a dual desire for self-understanding and a societal understanding of pain. The women were seeking comprehension both personally and in a broader social context. It was apparent that they desired acknowledgement and comprehension of pain on both levels. They expressed a need for others to understand the depth of their pain and the challenges associated with living with it:

*I need others to understand what our pain is and how difficult it makes life, and it is not just us complaining about nothing. . .I need to understand what I can do to help make things easier for me (FG3)*

[all participants talk at once] *yes, yes, same here (FG3)*

*I mean only if we know what we can do, can we do something (FG2)*

The use of 'our pain' instead of 'my pain' during the discussion is notable, potentially indicating a collective sense of understanding and solidarity among the participants. Implicit in this theme is also the idea that understanding pain can have a broader impact, fostering empathy and compassion in society. The shared belief in the focus groups was that by shedding light on the participants' struggles, they can cultivate empathy and compassion in others, establishing a pathway for mutual understanding and support:



*If other people understand, then they will have more sympathy for people in similar positions like us too (FG3)*

*When people ask what is wrong and I say yet nothing has been found on x-rays they seem to think it is not very serious. I want them to know that there are people like us, and it is hard for us. . .when they understand this, I think people will care more (FG1)*

*People can help when they understand the burden of this pain (FG2)*

Participants in all groups expressed a deep-seated desire for others to understand their experiences. This further emphasises the importance of establishing a safe and non-judgmental environment where individuals can freely express their feelings and experiences and receive validation. Participants in group one identified the facilitator's understanding of their pain as a source of compassion. There was a shared belief that information from credible sources, given in a simple, understandable manner, might inspire compassion in all. The quotes below reveal the desire for a resource for participants to use as a reference and to share with their friends and family. All participants revealed a shared desire for something that may assist in managing their pain while also enabling them to articulate their pain and struggles to others. They also felt that this resource would validate their pain. There was a need for their pain to be understood:

*You [facilitator] understand pain that is why you believe us, have compassion, and are willing to listen. If other people have this understanding, they will also be like you, I think. They will know it is a medical problem where people need help (FG1)*

The participants proposed suggestions that could aid others in understanding their pain:

*I think if people can see it written down...then people believe it more. I think it strengthens our experiences and difficulties. We can then also defend ourselves better when people dismiss and invalidate your feelings*  
(FG3)

The desire for an informative resource was expressed across the groups. Participants' exchanges in the first group also emphasised this need and the rationale behind it:

*I would like this written down for me so I can show other people and remind myself I am not mad* (FG1)

*I think we all would like to know how we can make our pain less* (FG1)

*You know I have seen some books at the hospital, I can't read them but some words I can, they are for cancer, and I think something like that for us but what we can read. As people know about cancer and there are those books that tell people about it, so everyone knows so something like that for us* (FG1)

The participants all agreed on something 'written down. . .in a leaflet or booklet type format'.

### **Restoring the Losses and Creating Positive Experiences**

Participants also expressed a deep sense of loss, missing aspects of their lives such as employment, daily walks, and enjoyable activities, a majority of which had been lost due to the onset of pain. Reflecting on the losses, they appeared to have further deteriorated their mood and exacerbated their pain:

*I miss the walks to work. I have put on weight since leaving. I think the walk cleared my mind and my mood used to be a bit better then (FG1)*

*I miss talking with other colleagues during tea breaks, you got to laugh a bit in the day even with pain and that helped my mood (FG1)*

*I miss the joy in life that pain takes. . .I would not say I am in a good place (FG3)*

The discussions also emphasised how household duties and pain consumed the participants' time, leading to the neglect of other activities and moments that brought joy:

*I miss the good things pain has taken, and I feel what is left is just housework which never seems to finish or then pain (FG1)*

*After the pain started, I felt quite sad I just feel I had no time for anything as the work at home was taking me double the time (FG3)*

Many of the participants' accounts highlighted how chronic pain had become a significant barrier in their lives, impacting their ability to engage in activities they enjoy and affecting their overall quality of life. The participants expressed a sense of loss for the enjoyable aspects of life that pain had taken away from them. The quote below reflects a common sentiment among participants: women in their community prioritise the needs of others over their own well-being. This was also discussed in the previous study. The women's accounts implied a societal expectation or cultural norm that prioritises fulfilling caregiving roles for family members or others in the community over self-care:

*You are right. . .we need to do more of these little things that make us happy (FG1)*

*I do not know the last time I did anything for me, for my happiness (FG1)*

*I think in our community, the women make time for everyone else but themselves (FG2)*

*I am missing things that make life fun. . . I am existing, not really living, and everything feels like a chore (FG3)*

The last quote above captures the broader impact of chronic pain on participants' overall quality of life. It reflects a profound sense of loss and frustration with the inability to fully engage in activities that bring joy and fulfilment. Instead of living a full and enjoyable life, participants describe feeling trapped in a cycle of pain and daily chores, which appear to contribute to a sense of existence rather than active living. These quotes collectively underscore the multifaceted challenges faced by individuals living with chronic pain, highlighting not only the physical limitations but also the emotional and social impacts. They emphasise the need for holistic support and interventions that address both pain management and quality of life restoration, as well as the importance of prioritising the well-being of individuals experiencing chronic pain. The participants unanimously expressed the power of joy and happiness in mitigating their pain. Pain-free moments were associated with experiences that brought joy and happiness. They found it was engaging in activities that brought them joy, which led to them forgetting their pain, emphasising the reciprocal relationship between mood and pain perception. It became evident that a harmonious state of mind played a crucial role in alleviating the physical and emotional toll of pain for the participants:

*When I am at weddings or other nice functions, which is not often,*

*I forget my pain (FG1)*

*When I am doing something, I enjoy, I forget the pain. I was showing my grandson how to make paper boats last weekend. We used to do this at school and the evening went so fast that I forgot all about my pain (FG1)*

As the conversations evolved, the potential of embracing activities that participants had enjoyed, fostering connections with others, and actively engaging in and replacing the losses they had endured became apparent:

*I enjoyed my walk today. I have usually not had reasons to go out. I should walk more (FG1)*

*I miss talking with other colleagues. . .so this has been very nice (FG1)*

*I have felt no pain sitting with you sisters today. I enjoyed this (FG2)*

*I think this is true for us all (FG2)*

[agreement among all members of the group]

*I think I need to start making an effort. . .this is not how I thought my life would be (FG3)*

Upon the facilitator 's request for the participants to reflect on past activities that brought them joy, the participants recollected numerous experiences from their childhood:

*Crochet. . .knitting. . .telling stories (FG1)*

*Singing and playing cards (FG2)*

*Reading. . .art. . .music. . .Painting. . .Papier-mâché (FG3)*

Memories of school days filled with origami, card games, singing, walks, and tea parties arose in their collective reflections, reinforcing the potential of these for creating moments of joy. It was becoming clear that there was a potential avenue towards improving the participants' well-being by enriching

their lives with joyful moments, which could help diminish their experiences of pain or at the very least provide more pain-free moments as well as a distraction. A participant's statement effectively encapsulates the significance of this:

*Small happiness enters your life, and it takes away a bit of your pain. There is less room for pain but when sadness comes and pushes away happiness, it makes more space for pain (FG1)*

## Discussion

The main aim of this stage of the project was to identify and explore solutions to address the concerns most important to the participants. It became evident that they had been left to navigate their pain largely on their own. They believed that their understanding of chronic pain, including the causes and variables that can exacerbate or alleviate it, was limited, as was their ability to manage negative emotions. Participants expressed frustrations with the lack of understanding, both from others and themselves, as well as a lack of resources, particularly in their preferred languages. They also expressed a strong desire for increased awareness and understanding of their condition and highlighted the value they found in coming together, sharing experiences, and simply engaging in conversation. During the session, participants were asked to reflect on moments when they experienced relief from pain or were least aware of it. These 'pain-free' moments were consistently associated with activities that brought them joy and fulfilment.

The first theme revealed how candid conversations not only offered solace but also fostered validation, empathy, and support through the collective sharing of participants' personal experiences. The theme underscores the significance of establishing a safe space, and holding space for SAW with

chronic pain. A safe space where women can freely express themselves, feel respected, understood, and heard, and find comfort in sharing their stories.

Safety in this context includes emotional and psychological safety, fostering an atmosphere where individuals feel secure enough to express themselves authentically without fear of criticism or judgement. These participants reported that they had rarely experienced being listened to, feeling understood, or having their pain experiences validated. The women spoke of how much of a weight had been lifted after being able to speak openly with others who understood their struggles. There is a need to hold space for these women where they can experience this comfort of being heard and understood. The focus groups seemed to alleviate a considerable burden, and the women greatly appreciated the kind words offered by fellow participants. It appeared that this appreciation stemmed from the rarity with which they encountered such positive communication, both in their interactions with medical professionals and in their encounters with others. It has been reported that the manner in which HCPs communicated was of utmost significance to SAW, as it either opened the door to continue communicating or closed it (Singh-Carlson et al., 2010).

The researcher felt that a supportive group environment, such as a women's circle, would provide women with the essential validation they need. This setting would allow them to share their stories and self-help strategies for pain management, engage in activities that bring them joy, and add religious/spiritual activities, potentially improving their overall well-being and fostering mutual personal development. Additionally, it would offer a space between them and their problems to reflect (Helgeson et al., 2000; Uchino,

2004; Yalom & Leszcz, 2005). Other studies have found that a significant number of SAW endure their struggles in silence, closely monitored by their own community, and are expected to uphold cultural norms and gender expectations (Gurm et al., 2008).

In a different study, researchers conducted in-depth interviews to assess the experiences and opinions of British SA mothers regarding the feasibility and acceptability of a culturally tailored intervention for postnatal depression. Almost all participants expressed appreciation and support for the group-based intervention. They believed that the group provided a valuable opportunity for sharing information and discussing solutions to their challenges from various perspectives. The mothers perceived the group as the sole platform where they could freely express their emotions and feelings in a secure environment, a luxury they often did not have within their own families. Positive changes in attitudes, behaviour, and self-confidence were reported (Masood et al., 2015).

This underscores the value of creating a safe and supportive environment where individuals can openly express their emotions and experiences without fear of judgement. Positive attitudes may lead to greater acceptance, resilience, and optimism. These changes can impact how individuals tackle issues and make health decisions. They may adopt healthier coping mechanisms or take proactive efforts to improve their conditions (Helgeson et al., 2000; Uchino, 2004; Yalom & Leszcz, 2005). This can lead to improved self-care behaviours and an overall higher quality of life. This also has implications in other areas of health, such as mental health support groups. Providing a secure platform for individuals to share their challenges and successes can similarly lead to positive outcomes. When people feel heard, understood, and supported, it can enhance



their resilience, motivation for self-care, and adherence to treatment plans (Helgeson et al., 2000; Uchino, 2004; Yalom & Leszcz, 2005).

Community-based self-management programmes are a promising approach to tackle the high occurrence of chronic diseases among migrant communities. Interventions can be modified to include a deeper comprehension of different cultures and cater to the specific requirements of the intended community (Sidhu et al., 2014). Sidhu et al. (2014) conducted a systematic review and found that self-management interventions led by non-professionals and customised for minority ethnic groups led to significant improvements in self-efficacy, self-perceived health problems, pain, and fatigue in the short to medium term. By fostering collaborations where lay advisors are trained and supervised by professionals, can ensure that the support provided is both culturally sensitive and medically sound (Sidhu et al., 2014).

Structured, group-oriented, psycho-educational self-management interventions are formulated to assist individuals with long-term conditions (LTCs) in handling their day-to-day lives. The Stanford Model, which comprises weekly group workshops in primary care and community settings for roughly six weeks, is the foundation for many Chronic Disease Self-Management Programmes (CDSMP). The intervention is conducted by laypersons with LTC training who are also affected by LTC (Lorig et al., 1999; Sidhu et al., 2014).

According to Lorig et al. (1999), CDSMPs are thought to be low-cost treatments that lower the use of healthcare. Despite being standardised courses, CDSMPs have undergone numerous modifications to better serve the needs of target communities in terms of health. A few examples of adaptations are adding different behavioural change theories and methodologies, altering the

course's content, the person teaching it, or its location (Sidhu et al., 2014).

Overall, support groups are present in various health disciplines, and numerous studies acknowledge their significant impact on individuals' identity, self-esteem, coping abilities, and social integration (Heijnders & Van Der Meij, 2006).

The second theme underscored the dual necessity for both the participants and others to understand the participants' pain. They sought understanding about the absence of structural issues, why so many HCPs appear to provide no help other than pills, and were eager to acquire knowledge that could be compiled into a resource. Their hope was that such a resource could contribute to increased compassion and empathy, not only for themselves but also for others facing similar challenges. There was also an element of needing their pain validated by others. The collective desire was not only self-understanding, management, but also a wish to convey this knowledge to others. The participants emphasised that they believed if others understood their pain, they would be more likely to exhibit compassion.

They also wanted something designed for easy comprehension to serve as a personal reference and a tool for informing others. There was a focus on clarity, to enable individuals to manage their pain effectively while providing a shareable guide to foster understanding and compassion within their communities. It reflects not only an individual journey to understand and manage pain but also a collective endeavour to create a more compassionate and informed society.

Substantiating this perspective: recent research supports the notion that individuals exposed to information about Chronic Fatigue Syndrome (CFS) through participation in a related research project exhibited fewer stigmatising

attitudes compared to those engaged in projects unrelated to CFS (Nehrke et al., 2017). A participant in the present study had stated that as her x-rays revealed nothing structurally wrong with her that she felt her pain was not taken seriously. The current findings align with the conclusions presented by Åsbring and Närvänen (2002), who, in their research on women with CFS and fibromyalgia, discovered that these women experienced challenges from others regarding the legitimacy of their health conditions (which often lacked visible signs). Consequently, increasing public understanding of persistent pain may serve as crucial elements in heightening awareness and mitigating stigma. The participants unanimously expressed the need for greater awareness, education, and understanding of those in their immediate surroundings. They felt a shareable resource would provide this.

Pain education is important for pain management (Cosio & Lin, 2018). Providing accurate and comprehensible information is crucial for empowering patients to cope independently. Insufficient information can hinder the ability to manage, make decisions, and intensify feelings of uncertainty (Asbury & Walshe, 2005). 'Patient information is fundamental to effective, patient-centred, quality care. . .empowering them to self-manage their conditions. . .have a better understanding of their health or illness ' (Nagpaul, 2021).

A study conducted in the UK found that literate British Pakistani women with type 2 diabetes who received one-on-one health education from a link worker utilising pictorial cards as a visual aid improved both their knowledge and glycaemic control levels (Hawthorne, 2001). It was concluded that illiterate women performed less well, and health educators should consider more innovative approaches to meet the needs of these women.

Another study conducted in the UK discovered that health education interventions boosted the uptake of cervical cytology testing among Asian women who had never been screened (McAvoy & Raza, 1991). Furthermore, according to a review conducted by Barlow et al. (2002), self-management programmes are helpful in enhancing knowledge, symptom management, usage of self-management behaviours, and self-efficacy, as well as promoting positive medical outcomes. It is argued that concise, uncomplicated, culturally sensitive, and linguistically (in Punjabi, Mandarin, and Cantonese) suitable interventions can enhance the acquisition of knowledge (Poureslami et al., 2012).

The third theme underscored the significance of recovering from the losses the women faced due to their pain and the importance of creating positive experiences. Participants expressed a profound sense of loss, missing elements of their lives such as employment, daily walks, and enjoyable activities. The women spoke of many losses that pain had also taken away from them: structure, routine, socialising, purpose, and their walk to work. Good routines are important for individuals' well-being; there is comfort and security in the predictability and structure provided by routines (Jahoda et al., 2017). It is felt that a women's circle would also help build back and restore some of these losses and manage the tension and anxiety reported by these women.

In the UK, ethnic minority women of SA descent have a high frequency of depression (Chaudhry et al., 2009; Gater et al., 2009; Weich et al., 2004), as well as higher rates of suicide and parasuicide (Chaudhry et al., 2009). Research in the US and Canada also reports similar findings: older adults in SA communities, particularly women, experience an unequal burden of psychosocial stress within

the community. Factors such as abuse and neglect, social isolation, and acculturative stress are indicators predictive of depression among older SA adults (Jonnalagadda & Diwan, 2005; Karasz et al., 2019; Lai & Surood, 2008).

Authors in the UK (Chaudhry et al., 2009) created and tested a culturally adapted social group intervention for depressed Pakistani women, which included trips to various locations, a psychoeducation session, and a session on exercise. The objective of the study was to mitigate the intensity of depressive symptoms in these chronically depressed women by involving them in a sequence of communal activities, offering social assistance, mental and physical health education, and providing respite from their distressing surroundings. The researchers found the intervention beneficial for these women. Engaging in conversations with other women was found to have a therapeutic effect as was also found in the present study. Their study found that during the final session, the women expressed a sense of sadness as the groups were coming to a close. However, women's circles are something participants can eventually run on their own. This also leads to less dependency and participants feeling unable to 'self-manage' on their own. This has been a concern and weakness of self-management interventions (Rodham, 2018).

The discussions in the present study also highlighted how household responsibilities and pain consumed the participants' time, causing neglect of hobbies and joyous moments. Participants unanimously emphasised the therapeutic power of joy and happiness in alleviating their pain. Pain-free moments were linked to engaging in activities that brought them joy, underscoring the reciprocal relationship between mood and pain perception. As the conversations progressed, actively seeking replacements for

these losses emerged as a focal point. The potential of embracing hobbies, engaging in walks, creating positive experiences, and fostering connections with others was recognised. Additionally, among the experiences shared in the focus groups were moments of laughter and reflection on neglected interests like origami, knitting, and playing cards. These activities had been neglected due to the obligations of marriage, the prioritisation of household responsibilities, and pain. It is important to focus on creating moments of joy, as the women had reported low moods.

Other research suggests that SAW lack awareness of health risks, hold varying beliefs about self-care, face language barriers, endure significant stress from isolation, prioritise their family's needs, and have limited time to focus on their own health (Choudhry et al., 2002; Mustafa et al., 2020). Incorporating activities that they would enjoy would also help in lifting their mood. These would also provide a meaningful escape from the mundanity of life, as reported by the participants. They would provide a break from their daily routine, often dominated by household chores, a sense of duty, and the weight of persistent pain. Within this supportive environment, women would be able to experience moments of relief, shared understanding, and the chance to concentrate on positive experiences that bring joy, allowing them to transcend their usual responsibilities and pain. Research has found that engaging in a hobby in later years has been associated with a decrease in depressive symptoms as well as an increase in self-reported health, happiness, and overall life satisfaction (Mak et al., 2023).

This is also in line with guidelines provided by the NHS on improving mental well-being through evidence-based strategies. These 'five steps to

mental wellbeing' provide evidence-based strategies to enhance mental health and overall wellbeing. The first step emphasises the significance of connecting with others, fostering positive relationships that contribute to a sense of belonging and self-worth. The second step encourages physical activity, not just for physical health but for its positive impact on mental wellbeing. The third step emphasises the importance of learning new skills to enhance self-confidence, purpose, and social connections. Practical tips include trying out new recipes, taking on new responsibilities at work, and engaging in hobbies that challenge and fulfil. The fourth step involves giving to others, with research indicating that acts of kindness contribute to a sense of reward, purpose, and connection. The fifth and final step advocates for mindfulness, encouraging individuals to pay attention to the present moment, fostering an enhanced appreciation for life and a positive approach to challenges (NHS, 2024).

Moreover, there is evidence that the incorporation of the joyful activities reported by the participants can improve overall well-being. Anxiety, depression, and feelings of isolation can be alleviated through craft. Art can also have a positive impact on one's mental health (Bone et al., 2023; Crafts Council, 2020). A report by the All-Party Parliamentary Group on Arts, Health, and Wellbeing (2017) states that the major challenges faced by health and social care can be addressed through the arts: chronic conditions, loneliness, an ageing population, health inequalities, and mental health. Furthermore, the arts can help save money in the health service. The importance of art therapy for health, mental health, and pain management is acknowledged by others (Bloem et al., 2018; Solan, 2018). Bloem et al. (2018) argue that art can take care of a mind 'tormented' by anxiety and 'see a critical need for healthcare to shift from

treating symptoms or signs towards focusing on people with individual needs and preferences' (p. 2).

The literature indicates that offering patient-centred care, characterised by appropriateness, emotional and physical support, timely accessibility, and delivery with respect for patients' needs, preferences, and beliefs has the potential to enhance patient satisfaction with clinical care, foster better relationships with HCPs, and improve the self-management of chronic diseases (Lin et al., 2020; Rathert et al., 2013; Vakil et al., 2023). This underscores the importance of culturally tailored healthcare provision (Dein, 2004; Napier et al., 2014; Shoiab et al., 2016; Vakil et al., 2023).

The proposition of a women's circle also aligns well with both Carl Rogers' (2014) person-centred approach and a biopsychosocial-spiritual model. Rogers (2014), a pioneering figure in humanistic psychology, developed person-centred therapy, an approach that places the individual at the core of the therapeutic process. There are three fundamental principles underlying this approach: unconditional positive regard (accepting and valuing individuals without judgement), empathy (the therapist's ability to understand and share the client's subjective experience), and congruence (the therapist's authenticity and transparency in the therapeutic relationship).

Person-centred therapy is grounded in the belief in the inherent potential for growth and self-actualisation within each individual. In a person-centred approach, empowerment comes from allowing individuals to take an active role in their own growth and decision-making. It emphasises the creation of a safe, empathetic, and non-judgmental space wherein clients can freely explore their thoughts, emotions, and experiences (Rogers, 2014). While the focus of these



principles is on their use in a counselling and therapeutic context, the fundamental principles remain significant for individuals with chronic pain. Such an approach is especially important in the management of chronic diseases, where effective care must be coordinated by taking individual circumstances into account and where the patient's understanding of the disease is critical to day-to-day control and avoiding and minimising long-term complications (Nagpaul, 2021; Sidhu et al., 2014).

Only by listening to people's stories about their needs and circumstances and devising treatment plans accordingly can health professionals help them manage their disease effectively (Coulter & Oldham, 2016; Picker Institute, 2021; Rhodes et al., 2003). Person-centred care views patients as equal partners in the healing process. When people are treated in this manner, they are not merely viewed as disease 'victims' or as 'passive recipients of care', but rather as individuals with the capacity and potential to control and improve their own health (Coulter & Oldham, 2016, p. 114; Picker Institute, 2021). Since the majority of individuals want to take care of themselves, the health system ought to be designed to give them the information, abilities, and self-assurance necessary to do so. It has been argued that experts frequently underestimate the degree to which patients can assume accountability for their own well-being (Coulter & Oldham, 2016).

### **Addressing Patient-Centred Outcomes in Chronic Pain Management**

It has also been stated that standard outcome measures may not fully reflect what individuals with chronic pain truly value. Patients often emphasise the importance of other outcomes, such as improving sleep and fatigue and increasing their overall enjoyment of life. Current clinical treatments often fall

short here, highlighting the need to better understand the personal experiences of people living with chronic pain and the importance of focussing on patient-centred care (Themelis & Tang, 2023).

According to Themelis & Tang (2023), psychological interventions for chronic pain have improved over time but often focus mainly on managing pain symptoms rather than addressing outcomes that are important to individuals living with pain. To advance the field, they state that it is essential to prioritise the values and preferences of people with chronic pain, involving them in outcome selection and focussing on what matters most to them. This approach includes understanding how pain affects a person's identity and finding ways to help them rebuild or renew their sense of self. Treatment goals should align with individual priorities. Their review advocates for pain management strategies that reflect individual priorities and realities.

In alignment with both the social communication model of pain and the misdirected problem-solving model (Craig, 2009; Eccleston & Crombez, 2007), Themelis & Tang (2023) highlight the importance of addressing broader influences on chronic pain. The social communication model emphasises how social factors (such as the role of carers, healthcare dynamics, and biases) shape a patient's pain experience. Meanwhile, the misdirected problem-solving model suggests that chronic pain may become disconnected from the initial injury over time. Rather than endlessly attempting to resolve the pain itself, treatment should focus on helping individuals pursue meaningful, valued goals. This approach underscores the need for adjusting chronic pain management strategies to address the wider impacts on a person's life, not just the original cause of pain (Themelis & Tang, 2023).

Based on the needs and preferences identified in the current study, it is clear that an informative resource and structured sessions, such as a women's circle, could be highly beneficial. These circles would provide a space for women to share their experiences, engage in hobbies, learn from each other, and receive validation and support. This is particularly relevant, as these women have seldom encountered such opportunities in their lives with regard to their pain. By creating a supportive environment for women to share their experiences, concerns, and self-management tips, the circle would help promote empowerment. The women's circle would provide an opportunity for women to connect, share, and support each other in a community that fosters personal growth and understanding.

Encouraging women to manage their illness and pursue activities that bring them joy allows for autonomy, purpose, and self-directed growth. By incorporating these elements into the intervention, it is hoped to create a therapeutic and empowering environment that aligns with the biopsychosocial-spiritual model and a person-centred approach. It places trust in the participants' capacity for growth, acknowledging that each person possesses the resources needed to navigate their own journey. Secondly, it creates an environment characterised by mutual respect and active listening (empathy and positive regard). It values participants' unique perspectives, emotions, and potential, which is required when assisting individuals with chronic pain (Coulter & Oldham, 2016; Rogers, 2014).

### **Limitations and Future Research**

It has been stated that participants in focus groups may exhibit more socially desirable attitudes or viewpoints than the participants' actual beliefs

(Acocella, 2012; Howitt, 2016). However, research suggests that social desirability bias is often higher in one-to-one interviews than in focus groups, offering some reassurance about the reliability of group dynamics. Several researchers have observed that group discussions, in contrast to interviews, elicit a greater expression of socially undesirable opinions. In a focus group study of AIDS patients' partners, for example, the researchers discovered more furious and emotional statements regarding their treatment by the medical establishment than are often reported in individual interviews (Geis et al., 1986; Wilkinson, 1998).

Similarly, researchers discovered that women whose babies are born healthy are often reticent to express unhappiness with delivery techniques and procedures in one-on-one interviews. In contrast, the supportive environment of other women discussing their labour experiences in focus groups increases women's ability to be critical about their experiences (DiMatteo et al., 1993).

According to many focus group researchers, when participants in research have shared experiences, especially ones that are painful or emotionally intense, such as a stigmatising illness or a sudden bereavement, they tend to provide a lot of specific information about those aspects of their lives. This is especially true when their contributions are supported, and their concerns are acknowledged by other members of the group (Zeller, 1993). Also, due to the participants' existing familiarity, they may have felt comfortable expressing their thoughts openly. It was also felt that the established rapport among participants and mutual respect fostered openness and allowed all individuals a chance to contribute.

Furthermore, the study addressed concerns regarding researcher influence by implementing a reflexive approach, which involved maintaining a reflexive journal. Also, employing the GROW model aided in keeping the researcher focused on acquiring information and suggestions proposed by the participants themselves.

The insights gathered from focus group data can serve as a valuable foundation for informing and designing future interventions. Participants needs, levels of literacy, preferences, and learning styles should be acknowledged when devising these. Participants should also be encouraged to set personal goals, reflect on their progress, and celebrate their achievements during the intervention. A sense of accomplishment promotes motivation, and there is an element of accountability. All of these factors help to increase self-efficacy, adherence, and confidence (Stringer & Ortiz Aragón, 2021; Whitmore, 1992).

Interventions should also be produced in collaboration with participants to ensure the creation of a comprehensive resource that addresses the unique challenges faced by the participants (Deery, 2005; Stringer & Ortiz Aragón, 2021; Whitmore, 1992). Their input enhances the potential for designing interventions that are contextually relevant, resonant with the target audience, and more likely to yield positive outcomes. Future research could also explore the feasibility, acceptability, and effectiveness of these interventions.

The findings of the present study may be beneficial to those assisting SAW living with chronic pain or enhancing their well-being. By capturing the perspectives and experiences of the participants, the focus group findings of the present study provide a rich understanding of the challenges and needs of this cohort.

## Conclusion

The focus groups revealed a need for the women to understand their pain, for others to understand it, and a resource that reinforces this and validates their pain and serves as a tool to foster greater compassion and understanding from those around them. They expressed a desire to share this resource with family and friends who they felt also struggled to understand their pain experiences and felt that it would raise both awareness and compassion. They also hoped that it would help them manage their pain and conversations about their condition with confidence and clarity. There was discussion of a 'book or something' and others spoke of resources (booklets) they had seen for other conditions and suggested something similar.

Moreover, it became clear that the group setting itself may function as a powerful means of offering emotional support to the participants. The exchanges unveiled a supportive space in which participants provided mutual support, helpful advice, offered encouragement, and validated each other's experiences. The strong and natural support system was clearly evident, and it is felt that creating a specialised women's circle may be quite advantageous for these women.

The reported losses that pain had caused led to low mood, loneliness, and a lack of participation in activities that the participants had enjoyed. Thus, a safe space that could allow them to share their stories, explore a variety of concerns, incorporate interests that they once enjoyed, and navigate the challenges they face was identified as inherently beneficial. The ultimate goal would be to create moments of joy, introducing a sense of balance into their lives that often revolved around the demands of daily chores, persistent pain,

and an unwavering sense of duty to others. These women have not received adequate support or resources from HCPs and are in need of self-management tips. Within the group, they can collaboratively explore strategies, share their experiences, and reclaim important aspects missing from their lives, such as establishing routines, finding structure, and rediscovering purpose. Additionally, a women's circle could help foster hope, kindness, peace of mind, and joy, creating a supportive space for shared moments of positivity and understanding. This approach would not only provide support but also encourage active participation, self-reflection, and the pursuit of joy, all of which could contribute to fostering agency and enhancing overall well-being by empowering women to take an active role in managing the challenges they face.

### Chapter Summary

This chapter has presented Stage One of Phase Three. This stage involved collaborating with the participants to identify key challenges and explore possible solutions for managing their pain and well-being. Participants reported finding the group setting helpful and expressed a desire for a resource. They stated that they would appreciate having written tips on pain management and expressed that they would enjoy engaging in activities they liked, as these activities also helped alleviate their pain. The second stage involved proposing the idea of a women's circle and collaboratively developing an intervention along with a pain management resource. The next chapter discusses this co-creation process.

## Chapter Six: Phase Three, Stage Two

### Chapter Overview

The previous chapter detailed the first stage of this project's third phase. The focus groups explored key challenges and ideas about what works or would help participants manage their pain and well-being and how they can actively work towards achieving more favourable outcomes. Through the focus group discussions, participants appeared increasingly motivated to pursue change and develop effective strategies to improve their situation. The current chapter focusses on the second stage, which involved the co-creation of an intervention and a resource to help address the primary challenges highlighted in the previous one.

### Introduction

The first stage of this three-stage study aimed to explore solutions to address the concerns most important to the participants. They felt they had a limited understanding of chronic pain and struggled to manage negative emotions. They expressed frustration over a lack of awareness from others and insufficient resources to meet their needs. Participants expressed interest in a tailored resource (booklet) to address their specific needs. They also expressed a desire to share this resource with their family and friends, who they believed also struggled to understand their pain experiences, with the hope that it would raise both awareness and compassion. They also hoped that it would help them manage conversations about their condition with confidence and clarity.

Additionally, during the first stage session, participants were asked to reflect on moments when they experienced relief from pain or were least aware of it. These 'pain-free' moments were consistently associated with activities that



brought them joy and fulfilment. The idea of a women's circle was identified as a potential solution to enhance participants' well-being. This was also proposed to the participants. The data analysis (from the previous stage) led to the conclusion that restoring some of the losses experienced by the participants due to pain (such as routines, meaningful activities, and social interactions) and creating positive experiences could enhance the participants' overall well-being. These findings guided the collaborative planning and development of a comprehensive resource and intervention tailored to the unique needs of the participating SAW.

### **Co-creating a Pain Self-Management Resource for SAW**

The steps below will outline the collaborative process of developing this resource and intervention, the use and application of the DISCERN (2024) tool, and the current literature, all with the aim of enabling SAW to effectively manage their pain and well-being and live well with chronic pain.

As this was an ongoing study, the ethical processes and methodological rationales will not be repeated here (these have been described in the previous chapter). However, a quick overview of the methodology, procedures, and data analysis will be provided. The results and discussion sections are presented together. The justification for patient education is based on the principle that patients have a right to receive information and be informed about their health (and the participants felt they were not), and that it is important for them to be able to manage their condition. Furthermore, professional guidelines outline this, and it benefits patients, health services, and society (Fernsler & Cannon, 1991; Nagpaul, 2021).

However, in a hierarchical setting, the creation of these materials is often led by clinicians and, at times, researchers, who are perceived as the only ones with the necessary knowledge. This can result in the exclusion of patient involvement, occasionally leading to materials that are inappropriate rather than person-centred (Smith et al., 2017). In contrast, involving patients as co-designers is productive and aligns with the principles of person-centred care (Smith et al., 2017).

## Methods

The study aimed to explore the SAW's key ideas, recommendations, preferences, and requirements for a resource aimed at addressing self-management of pain and their well-being through focus groups. The goal of the present stage was to use this data for the creation of a resource tailored to their needs and allow them to contribute to the contents and put forward their ideas on how the resource should be presented. The research sought to answer: What are SAW's key ideas, recommendations, requirements, and preferences for a booklet on chronic pain? Another objective of the research was to propose the idea of a women's circle and collaboratively plan an intervention (if this was also desired).

## Procedure

Three focus groups were conducted in January and February of 2024, two with six participants and one with four. The participants were all reminded of the audio recording of the discussions and that their participation was voluntary, that they were free to withdraw from the discussions, and that their data would remain anonymous. The focus groups were arranged on days, times, and locations that were convenient for all the participants in each group. Two were

conducted in person (in the homes of two participants) and one online. Each focus group lasted approximately forty-five minutes, and the researcher facilitated, recorded, translated (where necessary), and transcribed all group discussions.

During the focus groups, a prompt sheet (Appendix Fifteen) was used to guide the discussion. The participants that had access to the internet and were able to provide examples of resources that they liked were asked to do so (Appendix Sixteen), and those that did not were asked to comment on these and share their preferences and requirements for the resource. Participants were also asked to share their experiences and insights on effective self-management strategies.

These focus groups were also used to discuss the implications of the findings of the previous focus groups. Participants had been asked during that stage to note moments (the week or so prior) when they experienced the least or no pain, and they frequently reported that these pain-free periods coincided with engaging in enjoyable activities and those that made them happy. The possibility of engaging in such activities was discussed, and the proposal of a women's circle was put forward to the participants, where they would be able to engage in the activities that they enjoyed. Questions were framed using the COM-B model (Michie et al., 2014; see Appendix Fifteen) to ensure that the concept of a women's circle appealed to all participants, that they had access to necessary resources (or that they could be provided), and that the activities would be suitable and enjoyable for everyone involved.

The COM-B model of behaviour change posits that the manifestation of a behaviour (B) is contingent upon a person's physical and psychological

capability (C), as well as the availability of an opportunity (O) to enact the behaviour (B), in addition to the individual's motivation or desire to engage in the behaviour (M). Questions framed around capability included asking if they were comfortable and confident enough to engage in their selected activities. The opportunity component examines the external factors that facilitate or hinder behaviour (resources and environment). Questions framed around this component included asking the participants if they had the necessary materials and space to engage in these activities and if they required help organising the circles. The motivation component delves into the cognitive and emotional drivers behind behaviour. Participants were asked to select activities that they enjoyed and if they had any personal goals or aspirations that they would like to pursue within the context of the women's circle.

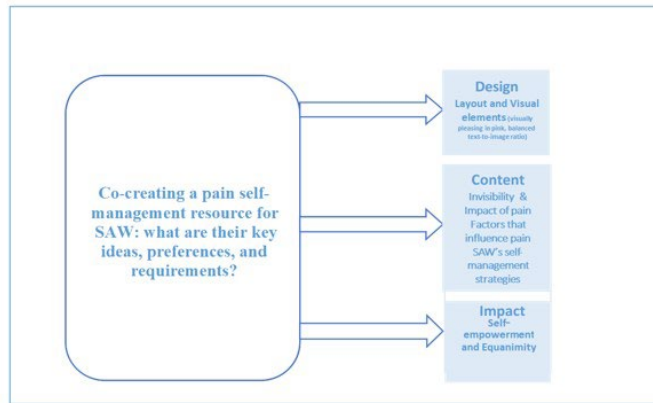
## **Analysis**

The transcription of the focus group conducted in English was completed verbatim; focus groups conducted almost exclusively in Punjabi were contextually translated (n = 2; Esposito, 2001). RTA (consisting of six steps) was used for inductively analysing the data (Braun & Clarke, 2022). Data familiarity was achieved through the processes of translating, transcribing, re-reading, and reviewing transcripts for accuracy. After this, individual group data and then the combined data from the three discussions were analysed with a focus on aspects deemed potentially relevant to the study's objectives to design a resource that meets SAW's needs. These aspects were identified and labelled with codes on each transcript, such as 'visual appeal', 'equal space for images', 'preference for pink', and 'non-white background'. These were combined under 'Design: layout and visual elements', with the subthemes 'visually pleasing in

pink' and 'balanced text-to-image ratio' reflecting their preferences. All themes were again reviewed, and some were developed. For example, 'the impact of pain' and 'visually and medically invisible' were combined under 'Content: impact and invisibility of pain'. The review of all the codes and preliminary themes was repeated.

## Results and Discussion

Three key themes were developed: 1) Design: Layout and Visual Elements; 2) Content; and 3) Impact (self-empowerment and equanimity). A thematic map (Figure 6.1) is provided below with the three key themes and subthemes that were developed. Participants expressed preferences for visual elements and a specific layout. They preferred a pink colour scheme, images that reflect the accompanying text, and a balance between text and pictures. Content-wise, self-management strategies and raising awareness on the invisibility and impact of pain and factors influencing it were to be included. Participants envisioned the resource as a tool for empowering them to manage their pain and well-being independently.



*Figure 6.1: Thematic Map of the Requirements and Needs of SAW that need to be Addressed in the Pain Self-Management Resource*

**Design: Layout and Visual Elements** (*balanced text-to-image ratio, visually pleasing in pink*)

This theme highlights the significance of visual elements like colour and imagery, together with a layout style that balances text and visual elements as expressed by the participants. The participants placed great importance on the design of the resource. They desired a visually pleasing resource with a focus on a pink colour scheme ('like a light rose pink'), a non-white background, and nice images. All participants expressed a preference for the resource to be presented in light colours and pastel shades, with pink being particularly favoured by the majority. They described these colour choices as calming, uplifting, and soothing:

*I really like pink; it is a very calming colour that can lift your mood too.*

(FG1)

*I like light colours, light pink, peachy colour, purple* (FG2)

*I find pink quite soothing* (FG3)

Conversely, they disliked 'white blank backgrounds', which they found to be depressing:

*I could not stand some text books, I needed coloured ones with pictures and stuff, just hated the white blank background. I liked yellow pages rather than white in those days (FG3)*

*I know what you mean about white, it is just depressing (FG3)*

Participants spoke of the layout and arrangement of the various elements within the booklet's pages. Participants preferred a mix of text and images on a page:

*The way this is printed is good with pictures and writing*

*[commenting on a resource] (FG1)*

*I liked the half and half thing going on here [discussing a resource with a combination of written text and images] (FG3)*

*I like the layout [commenting on another resource] again I guess it is the some pictures and some text mix (FG3)*

They felt the combination of images and text presented was 'a good idea', preferred a balanced text-to-image ratio ('half and half'), and wanted something they could 'flick through' that looked 'nice, simple, and colourful and not depressing'. They specifically mentioned a preference for images that complemented or illustrated the written text, as they found the material easier to understand and engage with. Some believed that, with their level of education, the presence of images would increase understanding:

*we are not very educated and when we were at school it was pictures that helped us (FG2)*

*some pictures speak themselves and you know what the message is (FG2)*

*I also liked [speaking about a resource] how some pictures show emotions, and you do not even need that much writing (FG3)*

Some participants recalled this preference stemming from their school years, where textbooks with appealing images were more enjoyable to read:

*I can't really just look at just text, I need images. . . I have always been like that even at school. I needed books to look nice for me to even pick them up and nice books would only be the ones I would read again (FG3)*

This preference for visually stimulating content among the participants suggests a collective inclination towards visual learning styles (Pashler et al., 2008). Patient resources that are primarily text-based may not be as accessible or engaging for them. The use of images that complemented or illustrated the written text was thus an important factor to aid in understanding. This preference also suggests that participants may find it challenging to understand and retain information presented solely through text. Based on these findings, the researcher aimed to ensure that the resource was visually pleasing, incorporated nice shades of pink or pastels, selected images that effectively conveyed the message of the accompanying text, avoided using white, and aimed to achieve a balance between written content and visual elements to enhance readability and engagement, with half of the space dedicated to text and the other half to images, wherever possible.

## **Content**

*Invisibility and impact of pain, factors that influence pain, SAW's self-management strategies*

This theme pertains to the informational content of the resource.

Participants shared insights on pets, sleeping and massage devices, and the importance of prayer, mindfulness techniques, and relaxation exercises. They



highlighted the significance of raising awareness about the invisibility and impact of pain and its influencing factors. They wanted to increase their knowledge of the latter and others' understanding of the impact of chronic pain, highlighting its profound effect on daily life and the individuals living with it:

*they will only have compassion if they understand how much it affects someone (FG2)*

*I just wanted to add the bit on making others aware of how bad this is for us (FG3)*

They wanted to raise awareness that, although it may be medically invisible on x-rays and scans, its impact and experience are profound. They wanted the impact and 'burden of pain' to be understood, and that the absence of visible damage on imaging tests did not discount the presence of pain:

*I want them to know that the x-ray does not show how serious the pain problem is, and it is very serious. They need to know that the x-ray can be misleading (FG1)*

*People need to understand that just because nothing comes up on the scan does not mean we are lying (FG2)*

*we do not really have anything showing on the outside and no medical backing for people to still understand its. . .existence (FG3)*

They also reported that they did not feel confident about their knowledge of factors that could influence pain:

*I do not think we know things we might be doing to make our pain worse (FG2)*

*Agree and any other things that can make it better (FG2)*

*to know. . .things I might be doing that is making it worse (FG3)*

Participants went on to share their personal tips and experiences during the co-creation process. Each of them shared something that helped improve their pain or their well-being. Simple stretches, walking, religion and spirituality, along with engaging in activities that bring joy and breathing exercises that were reported to be helpful, were demonstrated and have been included in the resource. One significant aspect mentioned was the influence of having pets around the house. The importance of spending quality time with pets was emphasised, highlighting how pets can become crucial companions with whom individuals can share their thoughts and feelings. One participant expressed how their dog knows when she is feeling sad and actively tries to bring her happiness. Another participant echoed this sentiment:

*dogs know when you are sad and our dog understands and tries to make me happy, you can get so much love from a dog (FG2)*

*my dog is so important. I feel I have someone I can talk to (FG1)*

Beyond the companionship of pets, participants also shared various tips and techniques they found helpful for managing pain. One participant mentioned using a relaxation device that plays soothing sounds, aiding in better sleep quality:

*It is a device that you basically just plug in, and it plays relaxing sounds, and it really helps me sleep (FG3)*

Another suggestion was to drink turmeric in hot coconut milk as a remedy for pain and improved sleep:

*Drinking turmeric in hot coconut milk also helps with pain and to sleep better (FG2)*

Additionally, flaxseeds were recommended for their anti-inflammatory properties, with one individual adding them to warm water to alleviate pain and inflammation:

*Flaxseeds help with pain and inflammation, and I add a spoon in warm water (FG2)*

Moreover, the importance of physical activity, particularly walking, was highlighted as beneficial for mental well-being. Participants noted that adhering to their New Year's resolution to walk more had a positive impact on their mental clarity and mood:

*Our New Year's resolution, to walk more really does help you feel a bit better, clears the mind (FG3)*

Participants also emphasised the importance of being around supportive and uplifting individuals, as well as engaging in pleasant surroundings and activities:

*You get to see beautiful flowers when the weather is good and trees, and all the colours even when the weather is not good is nice. It can make you happy and it is very calming. (FG2)*

*For me it is being around nice people and things, I think that is so important, like we mentioned last time that is probably why we liked this [group] (FG3)*

They also expressed an appreciation for the shared tips and the new things that they were learning from one another. They emphasised that knowing

that strategies have been tried and tested by others who can relate to their circumstances can make individuals more likely to implement them in their own lives:

*If it helps someone else like me then I know it might help me. (FG2)*

*I will always try it then too (FG2)*

*These will [shared tips] hold more weight for me as I know they are from real people and not people just trying to take advantage of your weakness. (FG3)*

Based on these findings, the aim was to offer clear and accessible information about chronic pain (to raise awareness of its impact and invisibility, factors that can influence it, and self-management strategies shared by all the groups), provide translations, and ensure the resource meets the needs of SAW in relation to the design discussed above. Furthermore, as the women had been left without any additional support other than pain medication, the aim was to create something where peer support would be encouraged to reduce isolation and promote coping skills that align with their cultural beliefs and values.

## **Impact**

### *Self-empowerment and equanimity*

This theme focuses on the participants' desired hopes and expectations for how they hoped that the resource would benefit them. A sense of empowerment and equanimity was emphasised (the previous study already highlighted the need to raise awareness and understanding among others in their broader social circles, including family members and friends). There was a shared desire to take control of their well-being, be in a 'better place mentally', and find 'some peace' and 'calmness', contentment, and freedom from 'negative

emotions' amidst the challenges of managing their condition. They wanted their shared tips combined so that they could refer to them daily and were striving for 'more good days than bad':

*I just want to know what else others are doing and that I can do myself to be comfortable and content and get me to a better place mentally too and things I might be doing that is making it [pain] worse. (FG3)*

*I agree on the better place mentally and I just want to add a place of comfort without all the negative emotions, and hope. . .with all the things we are learning from each other to be summarised in one place (FG3)*

*Yeah so, we are able to live better than we have been. . .with this [pain] (FG3)*

There was agreement among all members of the group. Participants in the other groups also expressed this desire to take an active role in managing their condition and improving their knowledge and well-being:

*If all these tips are written down for us in one place, we have something to remind us, to follow (FG1)*

*We can use them every day and be able to find some peace. (FG1)*

Overall, this theme highlights SAW's desire for a resource that empowers them to actively engage in managing their health, enhance their understanding of their condition, and enhance their mental well-being. This desire for empowerment also aligns with the findings from Phase One. Previous research suggests that providing written health information can enhance patient knowledge and satisfaction. It enables patients to retain and revisit information as needed, empowering them to take responsibility for their own care (Coteur et

al., 2022; Hoffmann & Worrall, 2004; Leake et al., 2021; Smith et al., 2017).

However, patient education resources are frequently inaccessible for individuals with low levels of health literacy (Coteur et al., 2022; Smith et al., 2017; Vakil et al., 2023). The resource creation steps below will detail how the resource was designed to ensure it met the needs and requirements of the participants.

### **Planning the Intervention**

After informing the participants that the findings from the previous stage suggested a women's circle could be beneficial, they were asked if this was something they would be interested in, and they indicated that they were. They were also assured of support in planning them. The discussions then focused on the activities they would like to engage in during the sessions, along with their location and timing. Participants spoke of making things for others and those in need, aligning with their religious beliefs of charitable giving and finding happiness in helping others:

*Helping someone by doing something that you like and who needs it is very nice. I feel I am living in line with the teachings of our Guru jis. That makes you feel better too. (FG1)*

Others expressed how they loved art and would create something that they could 'display around the home when it is finished'. The participants planned activities for the upcoming weeks of the women's circles. They selected activities to incorporate with each member contributing their ideas and preferences. Their input on meeting times, locations, and activities ensured the circles aligned with their needs and preferences. This collaborative and facilitative approach allowed the creation of an environment that encouraged self-empowerment while still offering the necessary support and guidance. The

goal was to empower participants to actively engage in their own well-being and to foster a sense of autonomy within the group. Regular follow-up calls allowed any questions or concerns participants may have to be addressed and provide additional support or resources as needed. The intervention plans included a diverse range of weekly activities, including cooking sessions and eating together; origami; tea, cakes, and playing cards or other games; colouring; and knitting or crocheting projects. The younger group members decided to incorporate activities such as reading and having book club meetings, cooking together, painting, and engaging in diamond art. Participants then went on to engage in women's circles, meeting for two hours each week over an initial period of six weeks (see below).

The intervention was planned for six weeks based on the consideration that intervention length varies widely across studies. In alignment with existing research on popular self-management interventions for chronic conditions, a six-week duration was deemed appropriate (Lorig et al., 2006). The researcher felt that six weeks may provide adequate time for participants to learn and incorporate these strategies into their daily routines. However, if necessary, there were opportunities to adjust or extend the duration to better meet participant needs. A schedule was planned for five weeks that catered to everyone's interests and needs. The diagrams below (Figures 6.2, 6.3, and 6.4) show what was agreed upon. Each group created their own women's circles and planned activities for them. It was decided that the activities would be reviewed, and future activities planned accordingly. For the sixth week, the participants decided to repeat activities conducted in week two.



Figure 6.2: Plan of Weekly Activities for Group One



Figure 6.3: Plan of Weekly Activities for Group Three

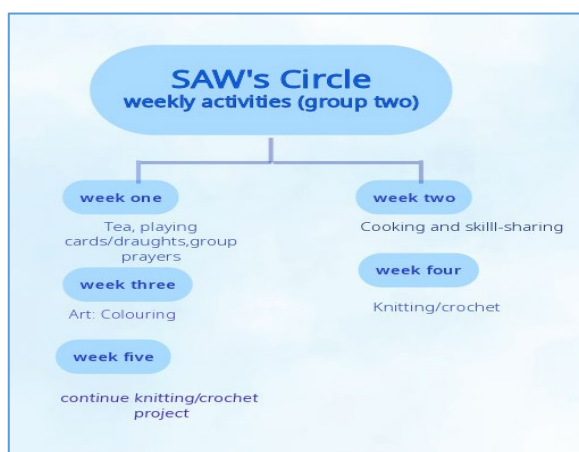


Figure 6.4: Plan of Weekly Activities for Group Two

## Resource Creation

The steps involved in creating the booklet are described below. The co-creation process involved compiling participants' preferences and needs, as well as integrating key findings and following guidelines from relevant research literature and health organisations. This combined approach aimed to ensure that the information provided was grounded in reliable knowledge, offering participants the most effective strategies for managing chronic pain.



Teaching people about pain is a popular approach to helping individuals living with persistent pain and an important aspect of recovery. However, little is known about what patients find most valuable to learn about pain (Leake et al., 2021). To explore this, Leake et al. (2021) conducted an online survey consisting of open-ended and closed questions. This was distributed to participants who had received pain education for their persistent pain and noticed improvements after it. For the open-ended questions, RTA was used to identify common themes regarding what the participants most valued learning about. For the close-ended questions, the authors looked at the frequency of responses. From the responses of 97 participants, the authors identified three main themes from the open-ended questions. The first was that pain did not indicate physical damage. Participants emphasised the importance of letting go of the belief that pain always meant something was physically wrong. The second was the influence of thoughts, emotions, and experiences on pain. Participants highlighted acknowledging the role of various factors, beyond just physical ones, in affecting their pain experience. The third was the ability to retrain the body's overprotective pain system. Participants recognised the possibility of reducing pain by retraining it to respond more accurately. The responses to the close-ended questions confirmed that these themes represented concepts most valued by participants. These authors concluded that the findings provide valuable insights that can help tailor pain education to better meet the needs of patients (Leake et al., 2021).

These insights were incorporated into the resource as well as the guidelines provided in other studies on factors to consider when creating patient resources. These studies have found that the written materials given to

patients is often too advanced for most of the intended readers. Studies have shown that creating an effective patient information requires several key qualities: the information must be unbiased, it should be tailored to meet the patient's needs, and the language should be simple and easy to understand. Additionally, the sentences should be concise and not too long (Adepu & Swamy, 2012; Coteur et al., 2022; Hoffmann & Worrall, 2004).

Furthermore, Griffin et al. (2003) also reviewed the literature on factors that are important to consider when providing effective written health information and provided an overview of the factors that need to be considered when creating or evaluating them. Effective patient education resources require providing appropriate information in a format tailored to the patient's learning needs and style. The design and layout of written materials can be a significant factor in whether an individual will be motivated to read them. Information that is relevant to the patient's life makes them more inclined to comprehend and remember it (Griffin et al., 2003; Hoffmann & Worrall, 2004). Resource creators should consider the reading skills of the patient and present information in a simple manner, with subheadings being quite effective. Illustrations should be recognisable to the patients and effectively convey an idea or a passage of text. It is also important to include the patients for whom the resources are being prepared, from the design phase to the evaluation stage (Griffin et al., 2003). Similarly, other authors have reviewed the literature on written health information to identify factors that are important for creating effective resources and report similar findings (Hoffmann & Worrall, 2004).

These guidelines have been followed, and the resource incorporates insights and perspectives from SAW living with pain. Phase Two provided

insights into the women's experiences and the impact of these experiences. These have also been included in the resource, as well as the findings from the present phase and pain literature. The content is shaped by the participants' needs, reflecting their struggles, self-management advice, and experiences.

### **A Framework to Guide the Resource Creation Process**

When considering procedural aspects, the DISCERN (2024) criteria emphasise identifying pertinent needs, conducting extensive consultations with the target audience, utilising evidence-based approaches, and conducting evaluations (Asbury & Walshe, 2005). The DISCERN health literacy tool was used to create the resource for SAW. It was felt that the DISCERN criteria would allow the researcher to create and offer high-quality, reliable, and clear health information resources suited to participants' specific needs. The DISCERN tool was selected and used in this study as it is a readily available assessment tool intended to be used by health consumers with no need for formal training (Bailey et al., 2013).

The DISCERN (2024) instrument was developed by a panel of experts to assess the quality of health information. These criteria aim to determine the quality of written information on treatment options from various sources, including the NHS, charities, self-help groups, the pharmaceutical industry, and other patient health information providers (Asbury & Walshe, 2005). It is a validated tool used to assess the quality of written information on treatment choices for various health problems. It provides a structured approach for evaluating the reliability and credibility of health information, particularly regarding treatment choices. There are sixteen points to address, and the evaluator scores each item from one to five. A score of five should be assigned

if the answer to the question indicates that the quality criterion has been fully met. A score between two and four should be assigned if the publication being evaluated partially meets the criterion. The specific score within this range depends on the extent of observed shortcomings. A score of one should be assigned if the answer to the question indicates that the quality criterion has not been met at all (DISCERN, 2024).

**Applying the DISCERN Tool to the Resource on Self-Management Strategies for SAW Living with Chronic Pain**

According to the DISCERN tool (2024), a high-quality publication about treatment (self-management in this case) choices should: have explicit aims; achieve these aims; be relevant to consumers; make sources and dates of information explicit; be balanced and unbiased; list additional sources of information; refer to areas of uncertainty; and describe how each treatment (strategy) works and the risks and benefits. Additionally, it should explain what would happen without treatment, describe the effects of treatment choices on overall quality of life, make it clear that there may be more than one possible treatment choice, and provide support for shared decision-making (DISCERN, 2024). The resource's design incorporated and adhered to this framework and the guidelines discussed. Below are the steps taken in creating the pain self-management booklet (Table 6.1) and where the supporting information for each DISCERN item can be found in the resource (Table 6.2). The researcher reviewed the work against the criteria.

*Table 6.1: Steps Taken in Creating a Pain Management Resource*

Creating the Resource on Pain Management	
Planning and Research	
Defining resource aims and objectives.	

Offer clear and accessible information about chronic pain, factors that can influence it, and self-management (non-medication-based) strategies tailored to the specific needs, leaning styles, interests, preferences, lifestyle choices, and experiences of SAW, focusing on overall well-being. The aim was to co-create a comprehensive resource to manage pain and low mood reported in Phase One and based on the input from the participants.

To provide translations and ensure the resource is accessible to SAW (their literacy level/learning preferences).

Conduct research on pain management strategies recommended by the NHS/NICE guidelines. Try and locate if there are resources that meet SAW's needs (none located)

Draft the content structure (using the DISCERN tool below)/Incorporate three core concepts (Leake et al., 2021)

#### Content Development

Ensure the written content is clear, concise, and easy to understand.

Create an initial draft of the resource.

#### Design and Layout (from Stage Two of Phase Three)

Develop a design concept for how the information will be presented, considering a balance of text and visuals.

Select or create images that enhance understanding and engagement.

Work on the layout to create a visually appealing and reader-friendly document.

Use a pink/pastel theme

#### Review and Revision

Share the draft with PK/AB

Gather feedback and make necessary revisions to both content and design.

Review and revise (as needed)

#### Evaluation

Table 6.2: Application of the DISCERN Tool on the Creation of a Resource for Managing Chronic Pain

DISCERN ITEM and supporting statement	Where it can be found in the resource:
1. <b>Clear aims (Question 1):</b> The content aims to increase understanding of chronic pain, its impact, and offer practical strategies (non-medication-based) for self-managing chronic pain, focusing on overall well-being.	In the introduction (P. 2)
2. <b>Achieving aims (Question 2):</b> Chronic pain is explained, its impact, and factors that can influence it. The tips presented provide a range of strategies for managing the complexities of chronic pain, covering various aspects of well-being.	Throughout the booklet but each strategy is addressed separately from p. 10 onwards and general tips and further support provided towards the end.  Throughout the booklet
3. <b>Relevance (Question 3):</b>	Questions 3 and 4:
4. Resource dates are provided.	The publication date is provided at the back.
5. The strategies mentioned are hoped to be practical/realistic and the booklet covers questions readers may ask.	Reference list (at the end of the booklet)
6. <b>Sources of information (Question 4):</b> The publication date is provided at the back.	Acknowledgements Image credits all provided
7. <b>Clarity of date of publication/sources (Question 5):</b> Dates provided	Back of the cover/reference list (Date)

<p>8. <b>Balanced and unbiased information (Question 6):</b> Reference list and acknowledgement indicate various sources were used and tips offered by individuals living with chronic pain themselves.</p> <p>9. <b>Details of additional support (Question 7):</b> details of organisations/websites provided</p> <p>10. <b>Acknowledgement of areas of uncertainty (Question 8):</b> It is essential for each individual to explore and adapt these methods based on their individual needs and preferences (p. 27). <b>Description of how each strategy works (Question 9):</b> Each strategy is accompanied by an explanation of why it is beneficial for managing chronic pain.</p> <p>11. <b>Description of benefits (Question 10):</b> The resource describes the benefits of each strategy, aligning with the aim of enhancing overall well-being.</p> <p>12. <b>Description of risks (Question 11):</b> Risk of sudden withdrawal from painkillers is highlighted, as is the importance of ensuring no spices interact with any medication, and safety during walking and stretches are highlighted.</p> <p>13. <b>Description of no treatment scenario (Question 12):</b> Without proper management, pain can lead to a decline in health and mental well-being.</p> <p>14. <b>Impact on Quality of Life (Question 13):</b> The content considers how strategies affect overall health and well-being.</p> <p>15. <b>Clear on more than one option (Question 14):</b> Various strategies provided</p> <p>16. <b>Support for shared decision-making (Question 15):</b> The resource advises seeking support from friends, family, or support groups, and provides details of organisations. It also mentions things to check with HCPs (exercise/medication and seek HCPs that understand</p>	<p>The input is from various sources and those with lived experiences also contributed to this production. Throughout the booklet</p> <p>At the end of the booklet</p> <p>Importance of exploration (p. 27) and taking a holistic approach. This is included under each strategy provided.</p> <p>This is included under each strategy provided.</p> <p>This is included under each strategy provided.</p> <p>Section on painkillers, walking, stretches, and other tips</p> <p>The introduction states that without proper management, pain can lead to a decline in health and mental well-being.</p> <p>Throughout the book</p> <p>Various strategies are provided throughout the booklet</p>
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<p>their concerns and taking a holistic approach</p> <p>17. <b>Overall score (question 16):</b> Guidelines for rating the question (DISCERN, 2024):  <b>High (5):</b> the publication received a high rating (4 or above) on most questions. A high overall quality rating signifies that the publication is of 'good' quality, making it a valuable and suitable source of information regarding treatment options (with minimal flaws).  <b>Moderate (3):</b> the publication showed both high and low ratings on a comparable number of questions, or most questions were rated in the mid-range (3). A moderate overall quality rating means the publication is of 'fair' quality; it serves as a useful source of information about treatment options but has some limitations. Additional information or support would certainly be necessary.  <b>Low (1):</b> the publication received a low rating (2 or below) on most questions. A low overall quality rating indicates the publication is of 'poor' quality, featuring significant shortcomings and lacking usefulness as a source of information on treatment choices. It is unlikely to provide any benefit and should not be used (DISCERN, 2024).</p>	
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## Conclusion

A women's circle (intervention) was proposed, accepted, and co-created to potentially assist participants in regaining some of the losses they had suffered as a result of being unable to work and/or due to pain: socialising, structure, routine, validation and compassion, getting out of the house, and conversing over tea or coffee breaks. Furthermore, because religion and

spirituality were significant to the participants, the proposed intervention would enable them to include activities that addressed these dimensions.

The participants expressed their wishes for a booklet, and this was co-created with them. It reflected participants' preferences by using shades of pink or pastels and carefully selecting images that complemented the text, effectively conveying its message. It avoided the use of white and aimed to balance written content with visuals to enhance readability and engagement, dedicating roughly half the space to text and the other half to images whenever possible.

### Chapter Summary

This chapter has described the second stage of this three-stage study. It involved collecting data to help create a pain self-management booklet for the participating SAW and plan for a women's circle intervention. The planning process has been discussed, as have the relevant literature and guidelines that were followed in the co-creation process. The next chapter discusses the third and final stage of this study, which aimed to evaluate both the resource (Appendix Twenty) and the intervention.



## Chapter Seven: Phase Three, Stage Three

### Chapter Overview

The previous chapter presented Stage Two of the third phase of this project. It involved the researcher working collaboratively with SAW living with chronic pain to co-create a pain management resource (a booklet on living well with chronic pain; see Appendix Twenty) and an intervention (weekly women's circles) targeting the challenges identified in the findings of Stage One. Participants engaged in women's circles, meeting for two hours each week over a period of six weeks. Activities within the circles were tailored to the interests and preferences of all participants in each group and were selected by the participants themselves. The present chapter presents an evaluation of the co-created intervention and resource.

### Introduction

The overarching aim of this three-stage action research study was to empower SAW to self-manage their pain and well-being. SAW participants had previously only been offered medication and had been left largely to manage their pain and well-being on their own. In response to this, an intervention and resource aimed at aiding women in managing their pain and well-being were created collaboratively with them (as discussed in the preceding chapters). The final stage focused on evaluating them.

#### **Objectives of Stage Three:**

To explore the experiences of women participating in women's circles and any perceived changes in their health, well-being, and lives.

To explore their opinions of the resource

To assess if there had been any statistically significant changes in the participants' mean Warwick and Edinburgh Mental Well-being Scale (WEMWBS) pre- and post-intervention scores.

### Stage Three Research Questions

How have individuals found their experience of participating in the women's circles, and what changes (if any) have they experienced in their daily lives, health, and well-being?

What are the women's opinions of the resource?

The quantitative phase posed the research question: Does participation in women's circles result in a statistically significant improvement in the well-being of the participants as measured by the Warwick-Edinburgh Mental Well-being Scale (WEMWBS)?

Results are expected to contribute to the understanding of any potential benefits of women's circles on the overall well-being of SAW living with chronic pain, make any modifications to the resource, provide insights into the intervention and resource creation process, and offer guidance based on these findings.

### **Hypotheses**

To address the quantitative phase research question, the following hypotheses were proposed:

( $H_0$ ): There is no significant difference in wellbeing, as measured by the WEMWBS, before and after participation in the women's circles (intervention).

( $H_1$ ): There is a significant difference in wellbeing, as measured by the WEMWBS, before and after participation in the women's circles (intervention).

### **Design**

The present study followed an action research approach. During the present, final stage, quantitative and qualitative data were collected. This approach reflects a convergent design, wherein both qualitative and quantitative data were collected and combined during the analysis and interpretation stage (Fetters et al., 2013). This design enables the collection of comprehensive data and provides a thorough understanding of the research topic (NIH Office of Behavioral and Social Sciences, 2018). For the quantitative element of the research, a quasi-experimental within-subjects pre-post design was employed. The independent variable (IV) was participation in the women's circles intervention, with levels 'pre-intervention' and 'post-intervention' after six weeks. The dependent variable (DV) was wellbeing, as measured by the WEMWBS. Three focus groups were conducted (described in detail below), and participants' WEMWBS post-intervention scores were obtained to determine if there was a notable change from the pre-intervention scores. The qualitative data was thematically analysed (Braun & Clarke, 2022).

### **Sample**

Sixteen SAW with chronic pain took part in the study following recruitment in the first stage of the project (see Chapter Five). The women's ages ranged from thirty to seventy-eight years ( $M=56.63$ ,  $SD=17.25$ ); all were residing in the UK.

### **Procedure**

The final qualitative stage of this third phase of the study involved conducting three focus groups to evaluate the resource and intervention. In March and April 2024, three focus groups were conducted, consisting of two groups with six participants each and one group with four individuals. Due to the continuous nature of this project, the rationale for conducting the focus groups and analysing them thematically will not be repeated (please refer to the detailed explanations provided in Chapter Two). Participants were all reminded about the audio recording of the conversations and were reminded that their involvement was voluntary and assured of confidentiality. The focus groups were scheduled at times, dates, and locations that were convenient for all participants in each group. All discussions took place in person, in the homes of three participants. The duration of each focus group was approximately forty-five minutes, which the researcher facilitated, recorded, and later translated (if needed) and transcribed.

A prompt sheet was used to guide the discussions (Appendix Seventeen), and notes were also taken. Participants were asked to share their experiences and opinions about the resource and the women's circles. The transcription of the focus group conducted in English was carried out verbatim; focus groups conducted almost exclusively in Punjabi were contextually translated ( $n = 2$ ). In addition, participants completed the WEMWBS (Appendix Eighteen) to determine if there was a notable change from the pre-intervention scores.

### **Measures/Instruments**

The WEMWBS is a widely used tool for assessing mental well-being. It has been extensively employed across a wide range of research settings and voluntary sectors to assess the effectiveness of interventions or pilots in

enhancing well-being (Blodgett et al., 2022). It has demonstrated good reliability and validity across diverse populations and contexts. The scale consists of fourteen positively worded items that cover different aspects of mental well-being. Respondents rate the extent to which they have felt a certain way in the past two weeks on a scale ranging from one (none of the time) to five (all of the time). Items include statements like, 'I've been feeling useful' and 'I've been feeling relaxed.' The total score can range from 14 to 70, with higher scores indicating higher levels of well-being (Kevern & Hill, 2015; Stewart-Brown et al., 2009).

## Data Analysis

### **Quantitative Data Analysis**

#### ***Data Diagnostics:***

A total post-intervention well-being score was obtained for each participant. A pre-intervention well-being score for each participant was obtained as part of the previous study (Chapter Five). Examination of the distribution of these differences through Q-Q plots and histograms indicated a normal distribution, which was further confirmed by both the Kolmogorov-Smirnov and Shapiro-Wilk tests of normality (Appendix Nineteen).

### **Analytic strategy**

To investigate whether there had been a significant difference between the mean pre- and post-intervention scores ( $H_1$ ), a paired-samples  $t$ -test was conducted in SPSS. The mean differences between the three groups were also explored.

### **Qualitative Data Analysis**

RTA (Braun & Clarke, 2022), as described above (Stage One), was used for inductively analysing the data. Data familiarity was achieved through the processes of translating, transcribing, re-reading, and reviewing transcripts for accuracy. After this, individual group data and then the combined data from the three discussions were analysed with a focus on aspects deemed potentially relevant to the study's objectives to evaluate the resource (Appendix Twenty) and SAW's experiences of participating in the women's circles. These aspects were identified and labelled with codes on each transcript, such as 'easy to understand', 'addresses everything', 'raises awareness', 'thorough', and 'accessible'. These were combined under content: 'comprehensive and comprehensible'. All themes were again reviewed, and this theme became a subtheme under the main theme of resource design and content. The review of all the codes and preliminary themes was repeated.

The qualitative component allowed for in-depth exploration of participants' experiences and perceptions to gain a comprehensive understanding of the intervention's impact. Member checking entailed reviewing the identified themes with each group during their subsequent meetings, lasting around ten minutes per group, during which no changes were made to the themes.

## Results

### **Quantitative Findings**

The analysis of the quantitative data, revealed an increase in participants' mean WEMWBS post-intervention scores from the baseline values, indicating an improvement in well-being following the intervention. The pre-intervention WEMWBS scores ( $M = 38.31$ ,  $SD = 3.55$ ) increased on average by approximately

ten points (95% CI [7.61, 12.76]) post-intervention at the six-week mark ( $M = 48.50$ ,  $SD = 3.93$ ). A paired samples  $t$ -test revealed this increase was significant ( $t(15) = 8.43$ ,  $p < .001$ , two-tailed;  $d = 2.11$ , indicating a large effect (Cohen, 1992; Lakens, 2013).

The pre- and post-intervention mean scores within each group were also compared to determine the intervention's effectiveness across groups. Group one experienced an increase of approximately eleven points, group two saw an increase of ten points, and group three's mean scores increased by approximately nine points. The bar charts below (Figures 7.1 and 7.2) provide a visual representation of these scores and show how well-being has improved for all groups and the aggregated group improvements. The categorical interpretations provided by the Warwick Medical School (2023) also provide additional context. A majority of participants' (81.25%) average pre-intervention scores fell within the low well-being category (scores  $\leq 42$ ). Only three out of sixteen participants (18.75%) scored within the range of moderate well-being (scores greater than 42 but lower than 60). However, by the end of the intervention, all participants' scores had increased, falling in the moderate well-being range, which is a promising outcome.

There is still room for further improvement (eleven participants' scores were below the average scores for women in the population, and nine were below the lower boundary: 50.3 (95% CI [49.7-50.8]); Stewart-Brown et al., 2008). Overall, the findings suggest that women's circles had a positive impact on participants' mental well-being, as supported by the qualitative data, which offer deeper insights into the effects of engaging in these circles. The qualitative

exploration provided insight into the reasons behind the improvements in well-being.

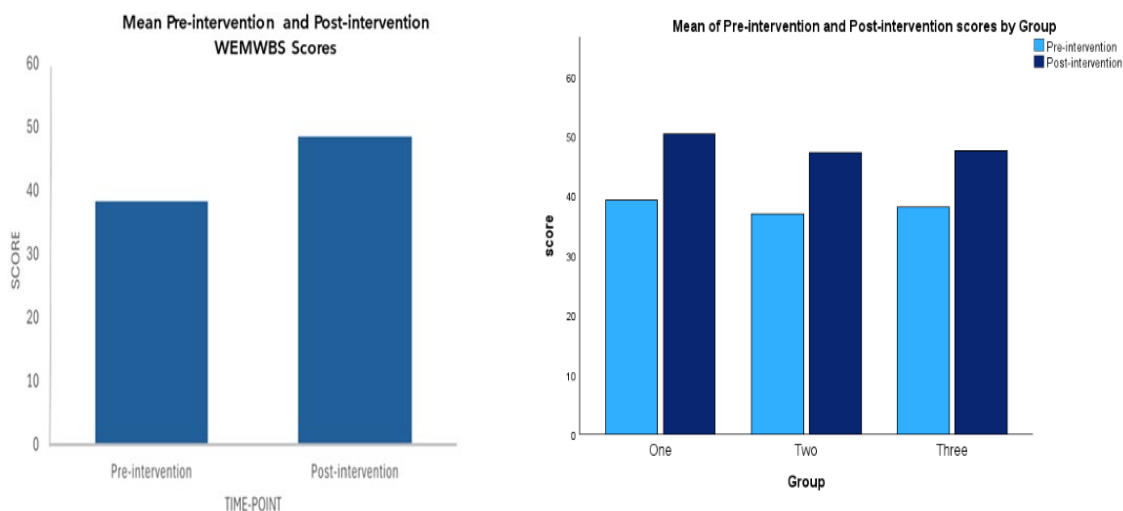


Figure 7.1: Mean pre- and post-intervention WEMWBS scores    Figure 7.2: Group Mean pre- and post-intervention WEMWBS scores

## Qualitative Findings

Three key themes were developed following RTA: 1) Resource Design and Content, 2) Effects, and 3) Continued Engagement. A thematic map (Figure 7.3) is provided below with the three key themes and eight subthemes generated.



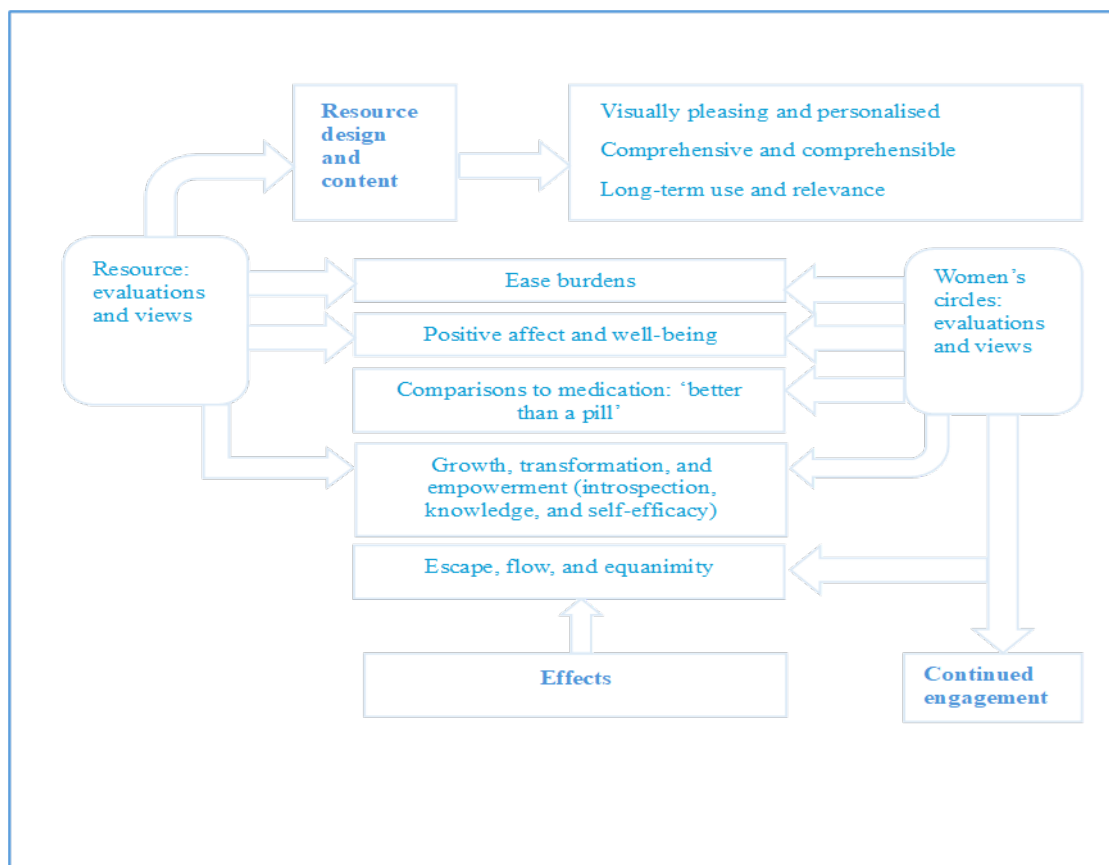


Figure 7.3: Final Thematic Map

## Resource Design and Content

In evaluating the resource, all the participants expressed overwhelming satisfaction with both the design and content. This theme was evident across all the groups. Participants expressed admiration for the aesthetics of the resource. They found the resource visually pleasing, describing it as 'pretty', 'nice to look at', 'stunning', and 'beautiful':

*I loved it and thought it was so beautiful (FG3)*

*It is so nice to look at and read (FG2)*

Furthermore, participants believed that the resource was effectively tailored to their needs. They viewed the resource as a 'great little guide' to managing their pain and well-being, containing information that addressed their concerns and incorporated strategies of interest and relevance to them:

*It contains everything that we wanted (FG2)*

*I love that it is everything we said we wanted, needed, and so  
much nicer than I thought it would be (FG3)*

Additionally, participants felt that the resource was presented in exactly the way they had desired:

*It really is exactly like we were describing and how we wanted (FG1)*

*the look of it [resource] in terms of what we said is like wow (FG3)*

A participant in one of the groups made comparisons of the co-created booklet to the other resources that were provided by the participants, with her expressing preference for the booklet:

*I think it looks so much prettier than any of the ones we offered (FG3)*

Another participant shared that the resource exceeded her expectations. Her comments and those of other participants indicated a high level of satisfaction and appreciation for the resource's design:

*it really looks so much better than I imagined (FG3)*

*everything looks so nice (FG2)*

### **Comprehensive and Comprehensible**

Participants reported that they valued the resource's comprehensiveness and clarity, finding it easy to understand. They appreciated that everything they needed was summarised in one place, making it a comprehensive yet accessible guide to managing their pain and well-being. Moreover, all of the participants stated that their specific needs were addressed, and they felt it was well-written and easy to understand:

*The way it is written is great, I mean you can understand everything, and it is actually nice to read (FG3)*

*not sciency sciency or hard to understand at all (FG3)*

*I liked that everything is explained in a way that we can understand (FG1)*

This theme was strong across the groups, with all participants in each focus group commenting on how everything in the resource was explained in a clear and concise manner. Moreover, they felt that it addressed all the points they raised and desired. The resource was referred to as a 'mini manual', providing a comprehensive summary of the information they required and pain management strategies:

*such a good job in putting everything together*

*and in a way that is so easy to follow and understand. . .a mini manual (FG3)*

*everything we wanted. . .is in this (FG1)*

Furthermore, they noted that the resource effectively conveyed the impact of pain, allowing others to understand their experiences. Participants felt it effectively conveyed the impact of pain on individuals' lives:

*It presents an accurate picture of what it is like living with pain and I think people reading it would understand the difficulties we face. (FG3)*

*I think anyone reading this will now understand how hard it is for us and others like us. (FG1)*

Participants also appreciated that the resource included explanations of how each strategy works:

*I really liked. . .how it explains how each thing helps you so you*

*know why you are doing what you are doing (FG1)*

*liked that the benefits of each exercise are given (FG3)*

### **Long-term Relevance and Use**

Another theme that was identified consistently across the groups was the emphasis on the resource's long-term utility. The participants perceived the resource as one that would remain useful, continue to meet their needs, and engage them over time. They all shared that all of the strategies could be implemented by people of all ages and throughout their lives. Overall, it was viewed as a valuable tool that could support their health and well-being over the long term, implementing a lifelong approach to managing pain and well-being. They also appreciated the practical nature of the information provided and its applicability to various contexts throughout their lives:

*have addressed things that apply to all ages, and I know everything in here would be useful to me now as it would ten or twenty years from now (FG3)*

*we can all do every single thing. . .easy to do at least one thing a day (FG2)*

Furthermore, participants felt that the resource was designed in a way that promotes engagement and long-term use. They felt that the aesthetic qualities of the resource made it engaging to use:

*It is such an easy read, and it just looks so nice too. I have been flicking through it pretty much every day since I got it and making sure I am doing something. . .I pick one thing that I will do the next*

day (FG3)

*I really like the pictures, and they remind and encourage me to  
continue with the new things I am doing (FG1)*

### **Effects**

The main theme of effects refers to the diverse changes and experiences reported by the participants from engaging in the women's circles and with the resource. Some findings were applicable to both the resource and the intervention, while others were only relevant to one of them. The thematic map above (Figure 7.3) visually represents this, and the findings further elaborate on this distinction. The initial subtheme of alleviating burdens pertained to both the resource and the intervention.

### **Ease(d) Burdens**

This theme echoed across the groups and referred to how the participants felt that both the circles and the resource had lifted many burdens. Participants expressed that they had both eased numerous burdens they faced: the weight of disbelief, lack of understanding, the frustration of not being taken seriously, the burden of stressful days, and of having to explain their pain. There was a sense of relief or liberation from burdensome thoughts and emotions. One participant shared a particularly moving reflection:

*my world had started becoming really heavy for me, the pain of feeling  
like you are not important, mad, no one wants to listen, no one has time,  
no one cares or understands. I just wanted someone's understanding. . . I  
feel a lot of weight has been lifted from me through speaking with  
everyone and this [resource] did that too, I feel better knowing I was right,  
pain does not stay the same all the time or only occur if something is*

*visible on a scan, other people just never understood but I was not wrong*  
(FG1)

The reflection revealed a clear relief from the burdens of disbelief and a lack of understanding. The act of voicing and having her experiences acknowledged and reaffirmed in the circles and by the resource appeared to provide the participant with a sense of validation and acknowledgement of her struggles, easing burdens and providing her with some comfort in the midst of scepticism and a lack of understanding. Another participant from a different group shared a similar view:

*We all understand what each of us is going through and we can support each other and that is not something any of us have had before. . .that is a big weight that gets lifted from your shoulders. . .that we all carried alone*  
(FG3)

Another participant emphasised the importance of not only receiving understanding but also receiving some help, 'a little boost' which served as a catalyst to propel them out of the dark place that they felt they were in:

*I agree it does lift this massive weight from your shoulders, but we also really needed like some help, any help, a little boost to help you get moving from the dark, depressing place we were stuck in. . .they both take a huge weight from you* (FG3)

There was agreement in the group, and other participants also felt the resource would ease the burden of explaining their condition to others:

*I do feel this will help so much in taking the pressure of explaining my situation. . .before I would try only for no one to still get it* (FG3)

*I used to worry so much about all the questions people would ask me and then think I am lying or making excuses because my scans were normal and I am so happy this explains this (FG1)*

By alleviating the burden of explanation and providing a means for their experiences to be understood and validated, this theme links to the next one on the experience of positive emotions and moods from engagement with the resource and in the circles.

### **Positive Affect and Well-Being**

Positive moods, emotions, and thoughts about participating in the circle were expressed by all the participants. They also expressed positive emotions and moods like happiness, joy, and gratitude while engaging with the resource. Participants conveyed their appreciation and gratitude for the resource, as well as for the tips and support offered by fellow participants. They appreciated the effort that all group members had put into creating something beneficial for them and expressed genuine gratitude for the presentation of the finished resource:

*I feel so thankful. . .see how many things everyone has shared to try and help everyone (FG1)*

*I feel so happy when I see this. . .all this for us, for me (FG2)*

*we all were saying how we really appreciate the extra effort and personal touch. . .It really is a joy just to look at (FG3)*

Positive affect and well-being was identified as a prominent theme across the focus groups in relation to participation in the circles too. Participants frequently mentioned feelings of happiness and joy and emphasised the positive influence of the supportive atmosphere within the circles. Participating

in women's circles and engaging in activities that they found enjoyable offered them a sense of joy and fulfilment:

*If I had to think of one word to describe how I find coming to the circles and basically doing all the things we love, I would say joyful (FG3)*

*they have brought happiness to my life, and you are doing things you like and doing something that matters to you (FG1)*

*They have taken much sadness and loneliness from my life (FG2)*

The circles went beyond merely providing opportunities for enjoyable activities: they served as nurturing spaces where participants felt supported and encountered displays of compassion and kindness. The statements by the participants below capture the essence of the supportive atmosphere within the group:

*I have had so much support since I started this, and everyone is so kind. (FG1)*

*The best part is how we all support one another, and you feel genuine compassion and kindness. (FG3)*

*You do feel everyone wants to make sure you are happy. (FG1)*

The cultivation of kindness, compassion, and empathy appeared to foster a sense of belonging and emotional validation among participants, contributing to their overall well-being:

*You stop feeling all alone in your struggle (FG1)*

*You feel everyone hears you, gets you (FG3)*

These were the sentiments of many within the groups, highlighting the significance of the circles as spaces not only for validation, support, joy, and



companionship but also for experiencing genuine acts of kindness and compassion. Participants also expressed leaving the circles feeling 'energised', 'lighter', 'recharged', and 'relaxed', after participating in the circles:

*I always leave feeling happy, relaxed, and just more lighter (FG1)*

*you just feel more positive, energised (FG3)*

Additionally, some participants reported how they felt 'less tension'.

Furthermore, for many participants who had given up work due to pain, the circles filled a void left by this: loss of routine, social interactions, and a sense of purpose. They appreciated the opportunity to reconnect with others and engage in meaningful activities that they enjoyed. As one participant reflected,

*I now have a better routine as I feel better in myself and when you feel better you can do more things. . . I am doing things that I like and make me happy, and I get to speak with nice people. I did not have this in my life (FG1)*

*I like the new routine we have and how we sit together and have tea and do and learn new things. (FG2)*

All the participants' comments demonstrated how the circles provided social connection and meaningful engagement in their lives.

### ***Escape, Flow, and Equanimity***

Another prominent theme was the escape from household chores and other obligations that the circles provided. The participants reported experiencing a state of flow and equanimity, describing a loss of awareness of time, feeling a 'sense of peace', and being less impacted by 'annoying stuff'. The escape theme was expressed by a majority of the participants. They spoke of

how the circles provided a 'break' from usual chores, a 'change' from tasks that did not really fulfil them or bring them a sense of purpose or happiness:

*I really look forward to these group meetings, it makes a change from boring housework. (FG1)*

*work around the house does not require much thinking and it is not really something I would say I really like doing but it has to be done, the things we do now we enjoy, you learn new things, you have to use your brain (FG2)*

Participants spoke not only of an escape from their daily chores but also a mental escape from their worries and pain:

*You tend to forget about your problems and worries (FG3)*

*life was just work. . .worrying about pain. . .boring chores, and this is a much-needed break for us (FG3)*

*forget about my problems, sadness, and pain (FG1)*

Participants also described their experience as deeply immersive and rewarding, with many expressing sentiments such as 'time flies by', 'you lose track of time', and 'the meetings go so fast', and 'you don't know where the time goes', indicating the presence of a flow state:

*We all know time flies by when you are having fun and it does here, but this is different from that, it is like it is over before you know it, you get that deep into it. . .that you don't even realise (FG3)*

*the meetings go so fast. . .you don't know where the time goes (FG1)*

Participants also expressed a sense of calm, a 'sense of peace', and better able to manage their emotions and stress. They felt that they were less impacted by negative emotions:

*You find yourself not stressing about petty things so much as you have better things going on and to look forward to. (FG3)*

*I just think you are less affected by negative stuff and pain when you are more positive and feeling good about life. (FG3)*

These responses indicated that participants experienced emotional upliftment, mental calmness, emotional balance, and a reduction in stress levels following their participation in the circles. By providing a space for individuals to escape from the monotony of their daily lives and worries, these circles not only offered moments of respite but also facilitated the rediscovery of joy and happiness and left the participants better able to manage their emotions and stress.

### ***Comparisons to Medication: 'Better than a Pill'***

Another prominent theme that is also linked to the previous two themes was that the participants felt that the intervention was more effective than taking medication for pain. When participants were asked about whether they would recommend the circles for managing pain and well-being, all participants stated that they would. Many felt that they were much better than their alternative: medication. Participants felt that the intervention was superior to pain medication mainly because of the intervention's greater and longer-lasting effects. They spoke of how the positive moods and emotions appeared to last long after the circles ended. One participant highlighted the transient nature of medication's effects, noting that while pills may provide short-term, immediate

relief, the underlying issues often persist, and individuals quickly revert to their previous state:

*I would definitely recommend it [the intervention]. For most of us, all we were told was to take some pills, and like we said, they never really helped. This is better than a pill, as the improvements last longer. With a pill, you really are back to feeling exactly the same in no time, and the other changes we just spoke about, that pills can't give you (FG3)*

This was the view of many of the participants. The participants' sentiments regarding the intervention's superiority over medication for pain management echoed throughout the group discussions. A participant in another group also highlighted the fleeting nature of medication's effects:

*Medicines are not very good, if they did work, it did not last long you were back to feeling like you were after an hour, but when you leave here you feel better for many days not just an hour. (FG1)*

Further reinforcing this sentiment and the dread and anticipation of pain returning after taking painkillers, another participant stated,

*but with pills, it [pain] was still always on my mind. Even when you take a painkiller, there was this horrible feeling of knowing it [pain] will come back pretty soon (FG3)*

Participants in all groups seemed to make comparisons to medication when they were asked if they would recommend the circles for managing pain and well-being. The sentiment below encapsulates the participants' inclination to endorse the intervention over traditional medication for its unique benefits:

*this has given me things that no medicine could, some happiness, peace of mind, a long break from pain (FG2)*

### **Growth, Empowerment, and Transformation**

This subtheme delves into the transformative effects, personal development and empowerment experienced by participants, covering introspection, and increases in knowledge and self-efficacy. There was evidence of transformations in their understanding, as participants reported gaining insights into various aspects of self-care and pain management strategies from other participants. They also noted enhancements in their self-efficacy and feeling more confident in their ability to manage their pain and overall well-being effectively. They reported changes occurring within themselves, their understanding, and their lives. In another moving disclosure during the discussions, a participant described how she had experienced a lack of autonomy in significant life decisions. She reflected on how decisions about her education, her marriage, and even her move to the UK were made for her, leaving her feeling lost and her life shaped by others' expectations. However, she spoke of a profound shift since participating in the circles, and her comments below capture moments of transformation and growth:

*This is the first time in my life I feel I am putting myself first, and I have made decisions for myself that are good for me. . .before everyone else decided what was good for me and what was not, my parents decided going to college would not be good for me, others decided on my marriage. . .where I should be living. . .I live my life now like I want to be living and doing things that are good for me (FG1)*

She reported making decisions and plans that were consistent with her own goals and well-being. All participants reported significant changes in their overall approach to life. They reported experiencing shifts in their perspectives and priorities, as well as newfound clarity, autonomy, and direction in their lives. They were exploring their passions, and many participants expressed optimism about the future and felt that they were 'climbing higher up out of the dark place' they initially reported finding themselves in:

*I am living a life I was not living a few months ago (FG1)*

*I used to just go through the motions. . .work and household chores. . .but now, I make time for things that make me happy and matter to me. I've learned the importance of self-care and prioritising things that make me happy for helping with my pain (FG3)*

Participants felt that they had gained valuable knowledge to better manage their pain and well-being. There was evidence of transformations in their understanding. Participants reported significant changes in their understanding of pain and their abilities to manage it. There was indication of an increased awareness regarding the holistic approach necessary for managing their pain and well-being:

*I have become much more knowledgeable on pain and mental health which I really did not know were connected and it makes sense to me as I had basically thrown away my lifebelt by stopping so many things but at the time you don't really think they will help you. I think I needed to see how important these things are for my pain, and I really do feel I am in a better position to help myself and becoming a better version of myself and improving my life (FG3)*

*I know so much more than I did when we first spoke (FG1)*

The focus groups and circles served as a catalyst for change, empowering participants to take control of aspects of their lives and well-being. These changes indicate a transformative process where individuals have developed, both personally and in their management of their pain and well-being. Through shared learning and mutual support, participants gained a sense of empowerment, feeling more confident and capable in managing their pain and well-being and making positive changes in their lives. Many participants spoke of profound changes since participating in the women's circles. Several alterations were documented, including a shift in perspective, changes in confidence levels, a transition from a 'dark place' to a more illuminated one, a transformation in thinking, and a cessation of being consumed by pain:

*All I used to do was think about all the work I had to do and pain; this is not what my life is like now. I feel the quality of my life is much better and it is not all about pain and sadness. (FG1)*

*I am not in the dark place I was last year (FG3)*

### **Continued Engagement**

Linking to the theme of growth and transformative effects, participants reported continued engagement in the intervention, driven by their acknowledgement of its benefits to their health and well-being. This theme was strong and expressed across all the groups. It encompasses the participant's commitment to remaining actively involved in the women's circles and managing their pain and well-being. All participants expressed a desire to continue attending the circles and engaging in similar activities in the future,

further demonstrating their commitment to sustaining the positive outcomes derived from their participation:

*I will definitely keep continuing with them and making more changes*  
(FG3)

*These small changes are making big improvements in my life. . .and I hope we all can continue meeting like this* (FG1)

There was agreement in all the groups to continue meeting and their statements encapsulate the participants' commitment to ongoing involvement in the women's circles. Another participant reflected on the effects of participating in the circles, expressing a wish that she had initiated such involvement earlier in life:

*I wish I had started something like this earlier in my life. I wasted so much time feeling sad and worrying about my pain. I will not be going back there, and I think we all want to keep meeting* (FG3)

Participants also reported that they had started making changes and incorporating new strategies that they had learned from the circles and resource into their daily routines:

*I went and bought the machine to help with sleep* (FG3)

*We all spend more time with Jadu [dog] and walking more* (FG2)

These statements demonstrate the participants' proactive approach to prioritising their well-being by continuing to engage in supportive and beneficial practices. These women have faced tremendous challenges, yet their collective path exemplifies courage and resilience. They have exhibited an ongoing dedication to self-improvement, recognising and addressing their own



challenges and areas they had neglected. Their full participation in the circles demonstrates a conscious and proactive effort to make positive changes in their lives. They recognised instances where their decisions were unhelpful and utilised introspection and an ongoing effort to amend them. In a collaborative environment, these women have found solace and inspiration in each other's stories. By their own admission, these women described their journeys as one of darkness at the beginning, but all reported being in a 'better place' in the present moment in time.

## Discussion

The present, final stage of this PAR study involved evaluating the resource and participants' experiences of participating in the women's circles for two hours each week over a period of six weeks. This stage of the study sought to offer a comprehensive understanding of how the intervention influenced participants' well-being through the convergence of quantitative and qualitative findings. The investigation delved into not only the statistical changes in well-being scores but also the deeper personal and social transformations reported by participants.

Focus groups explored participants' opinions of the intervention and the resource. They believed that the resource adequately addressed all the points they had raised and aligned with their desired outcome. They perceived the resource to be comprehensive, a 'mini manual', and easy to understand. They reported that their knowledge of factors influencing their pain became clearer as a result of the resource. Moreover, their confidence in their ability to manage their pain had increased. They were satisfied with how well it fulfilled their

requirements. They also felt that it had a more appealing appearance than they had anticipated.

Regarding their involvement in the circles, individuals experienced feelings of joy and happiness. They also perceived time passing quickly and forgetting about their concerns. One participant expressed feeling like a completely different person, while another felt that she was becoming an improved version of herself. Furthermore, a participant shared that she was now pursuing her own passions instead of adhering to the expectations of others. Many participants expressed experiencing a feeling of upliftment, along with other positive emotions and moods. There was evidence of personal growth and other transformative outcomes.

Participants frequently expressed that they were becoming much more 'knowledgeable,' which in turn placed them in a stronger position to 'help' themselves. They emphasised that they now knew 'so much more' than they did before, demonstrating a profound shift in their understanding and capabilities. This growing knowledge and self-efficacy were accompanied by an improvement in their quality of life and well-being, shifting the focus away from constant 'pain,' 'darkness,' and 'sadness.'

Much of this action phase has been about participants identifying key concerns and exploring solutions together with the researcher. Through introspection, participants identified their needs and priorities, gaining clarity on what is important to them. They recognised their neglect of hobbies and self-care, prompting them to acknowledge the necessity for personal changes. They appeared to have experienced increased autonomy as they gained confidence in making decisions, free from external pressures or constraints.

As participants gained confidence in making decisions independently, they began to recognise the importance of prioritising their own needs and desires, often for the 'first time' in their lives. Statements like 'putting myself first,' and 'making time for things that make me happy,' and living life 'like I want to be living' indicate a conscious effort to create space in their lives for activities or pursuits that bring them joy and fulfilment. It represents a shift from living reactively (constantly responding to the needs and demands of others) to living proactively (where they take intentional steps to create a life that is personally satisfying). Overall, there was evidence of a profound personal transformation, where these individuals were more actively involved in making choices that reflected their true selves and aspirations, as opposed to previously, where 'everyone else decided what was good for me and what was not' or what others expected.

Observing the participants over time, from the first phase to the present discussions, the changes were visible, from the way they behaved to the way they saw life. Where there were generally low moods, participants now appeared happier and more optimistic about the future. They had developed deeper connections and supportive relationships, fostering a sense of belonging. Participants perceived their journey as initially one of darkness, but now many shared that they were progressing away from this. They reported that they were living a different life to what they had been before engaging in the circles. All participants highly recommended the intervention and emphasised its superior and more enduring effects in comparison to medication.

Evaluation through focus groups revealed participants' high satisfaction with the resource and perceived effectiveness of the intervention. An increase in

average scores on the WEMWBS following the intervention was significant, further supporting the intervention's beneficial effects on participants' well-being. The findings support other literature highlighting the importance of patient-centred care, characterised by appropriateness, emotional and physical support, and delivery with respect for patients' needs, beliefs, and preferences, to enhance patient satisfaction and improve chronic disease self-management (Gordon et al., 2017; Lim et al., 2019; Lin et al., 2020; Parks, 2020; Rathert et al., 2013; Vakil et al., 2023; Wagner et al., 2001).

Previous research suggests that heightened perceived social support can alleviate pain severity and reduce negative mood in patients dealing with chronic pain (Cohen & Wills, 1985; Feldman et al., 1999). The current study's findings also align with previous research emphasising the positive effects of participating in crafts and enjoyable activities on mental well-being. Art engagement and art-based interventions have been acknowledged for their role in pain management and mental health improvement, including reducing pain perception, anxiety, tension, and stress, as well as promoting relaxation and enhancing overall well-being (Blodgett et al., 2022; Bloem et al., 2018; Bobby, 2022; Crafts Council, 2020; Curry & Kasser, 2005; Dresler & Perera, 2019; Mak et al., 2023; Martin et al., 2018; Sandmire et al., 2012; Solan, 2018). Activities like knitting have also been found to elevate serotonin levels. Knitting can serve as a means of coping, promoting feelings of calmness and a sense of accomplishment, for individuals with chronic pain. It can awaken dormant emotions of anticipation, pride, excitement, and happiness (Corkhill et al., 2014).

Managing stress and anxiety in individuals living with chronic pain is really important, as they both exacerbate it (Ambron, 2022). Engaging in activities that

promote relaxation, enjoyment, and distraction can help mitigate excessive hypothalamic activation in response to stress, worry, or anger (leading to a lower release of stress hormones). Art and craft-based interventions, along with engaging in enjoyable activities, represent practical and cost-effective strategies for managing pain and enhancing well-being. These approaches provide individuals with creative, enjoyable outlets to manage pain, stress, and improve mental health (Crafts Council, 2020).

By promoting access to such interventions, broader societal well-being initiatives can be advanced. This is required and timely in the current opioid epidemic. The arts are recognised as valuable in addressing major health and social care challenges, including ageing, chronic conditions, loneliness, health inequalities, and mental health, potentially saving costs in the healthcare system (All-Party Parliamentary Group on Arts, Health, and Wellbeing, 2017).

The present study also underscores the importance of acknowledging patients'/participants' unique perspectives and expertise, validating their pain, and the necessity of actively listening to and learning from them. When others fail to understand or take their experiences seriously, many individuals express feelings of frustration and hopelessness. Validating their experiences by showing understanding and seriousness is important (Coulter & Oldham, 2016; Picker Institute, 2021; Rhodes et al., 2003; Rogers, 2014). Neglecting to acknowledge individuals' pain and the challenges they face can have a detrimental effect on their self-concept (their perception of themselves, which is influenced by their experiences and interactions with others), as reported by the participants.

In contrast, engaging in active listening (fully concentrating, understanding, and responding) can be viewed as an act of 'rehumanising' (restoring their sense of worth and dignity), as it acknowledges and respects their experiences, emotions, and perspectives (Rogers, 2014). Without this acknowledgement, individuals experience a sense of disregard for their struggles. It also signals a lack of urgency or desire to alleviate their pain, thereby eroding any sense of hope for improvement. Without the ability to think that things could improve, individuals may find themselves trapped in a distressing existence, as many of these participants described. By adopting an empathetic approach, it also helps to alleviate the burden that comes with being dismissed.

However, to bring about significant changes and empower individuals, it is not enough to simply listen and understand. While empathy and compassion lay the groundwork, they alone are not sufficient for facilitating change. Accountability, setting goals, and motivation are also critical components (Deci & Ryan, 1985; Starr, 2012; Whitmore, 2001). By delving into what truly motivates participants and identifying their interests and passions, involving them in goal setting, intervention planning, and decision-making processes can help foster a sense of ownership and accountability, increasing the likelihood of sustained participation and commitment (Maini et al., 2020; Starr, 2012; Whitmore, 2001). Participants feel not only accountable to themselves but also to the collective effort and the support network around them. This not only empowers individuals but also fosters a sense of ownership over their journey towards change (Starr, 2012; Whitmore, 2001).

Moreover, when individuals engage in activities that they find enjoyable or intrinsically motivating, their commitment to those activities tends to be stronger. Intrinsic motivation arises from internal factors such as enjoyment, interest, or personal satisfaction rather than external rewards or pressures (Deci & Ryan, 1985). Also, when individuals feel a sense of choice and control over their actions (autonomy), feel competent in what they are doing, and experience meaningful connections with others (relatedness), they are more likely to engage in activities. Finally, when individuals are supported in satisfying these needs, they are more likely to experience greater well-being and optimal functioning (self-determination theory; Deci & Ryan, 1985).

Thus, by selecting activities that participants find enjoyable and feel competent completing, allowing them to make choices (autonomy), and fostering a supportive environment (relatedness), their commitment to the intervention can be reinforced even further. Participants' capability and motivation (for the proposed intervention/activities) were evaluated by structuring questions based on the COM-B model during Stage Two (Michie et al., 2011). The collaborative approach employed in this study, along with the discussed elements, has the potential to spark a process that brings about beneficial changes (Starr, 2012; Whitmore, 2001).

Furthermore, by equipping participants with the skills to identify problems and develop solutions, it enhances their self-efficacy and coping abilities (Rogers & Maini, 2016; Starr, 2012; Whitmore, 2001). It is felt that this focus on skill-building and the provision of coping strategies and information represents a significant strength of the intervention. Participants not only benefit

from immediate support but also acquire knowledge and valuable skills to navigate future challenges independently.

Communication and access to information are essential for empowering individuals to manage their condition (Molin et al., 2022; Skuladottir & Halldorsdottir, 2011). Participants are not relying on the researcher; rather, they are actively taking steps to improve their lives and manage their pain. The present intervention and resource aimed to prioritise empowering participants with the skills necessary for sustainable self-management beyond the scope of the intervention itself (Rodham, 2018). This approach also acknowledges the multidimensional nature of pain and human motivation and fosters a supportive and empowering environment conducive to personal growth and well-being (Starr, 2012; Whitmore, 2001).

Furthermore, the convergence of quantitative and qualitative data in the present study offers a comprehensive understanding and preliminary evidence of the intervention's positive influence on participants' mood, emotions, and social interactions, providing valuable insights for future research and practice.

### **Limitations and Future Research**

However, there are also limitations to consider: the use of non-random sampling methods and potential biases stemming from social desirability in this research. The sampling methods selected in the study, however, were deemed most appropriate for reaching an underrepresented group and the research aims (Nortvedt et al., 2016). Furthermore, efforts were made to establish a trusting relationship between all group members and the facilitator, with the aim of creating an environment where participants felt comfortable being open and honest. It should also be noted that while positive group rapport and dynamics



(as clearly evident among the group members) can contribute to beneficial outcomes, the results observed in this study may vary in contexts where group rapport and interpersonal dynamics are less favourable (Willig, 2013).

This underscores the importance of considering group composition when organising groups and recognising the potential influence of group cohesion and participant rapport on intervention outcomes (Krueger, 1994). The researcher intentionally organised groups so that participants would feel comfortable and able to understand each other and speak openly in the language that they were comfortable communicating in.

Future research employing random sampling methods and including a control group could further elucidate the broader applicability of the intervention's effects. Additionally, researchers may wish to explore or test the intervention in different groups or contexts. It is also important to consider the influence of other potential confounding variables. For example, participants reported adopting additional positive behaviours, such as increased physical activity and efforts to improve sleep quality during the research period. These external factors could potentially contribute to the observed improvements in well-being.

However, the qualitative findings shed light on the distinct role of the intervention itself. Participants consistently highlighted feelings of support, happiness, experiences of kindness and compassion, and a state of flow, relaxation, and equanimity that was specifically attributed to their participation in the circles. This suggests that despite the presence of potential confounding variables, the unique benefits derived from the intervention remained prominent. Participants expressed anticipation for future circle sessions and

described experiencing lasting effects, underscoring the significance of the intervention in enhancing well-being.

Moreover, while the intervention itself played a central role, participants also noted the significance of various discussions and interactions that took place during the focus groups and planning sessions. Participants actively engaged in dialogue, often generating their own solutions, and recognising aspects of their well-being that had been previously overlooked. In this way, the focus group sessions served not only as a platform for sharing experiences but also as a catalyst for personal reflection and growth, underscoring the dynamic role of participant interactions in fostering change.

## Conclusion

The successful co-creation of a resource that participants valued, along with the establishment and planning of women's circles that were also found to be beneficial, demonstrates the importance of PAR. This collaborative approach not only empowered participants but also ensured that the intervention and resource were tailored to their needs and preferences, leading to greater engagement, self-reported satisfaction, and effectiveness. This approach is also important for providing personalised support tailored to patients' needs. Both researchers and HCPs are uniquely positioned to potentially make positive impacts on individuals' lives, and the adoption of methods enhancing patient-centred care is recommended.

Furthermore, the spontaneous suggestions made by participants and the insights uncovered during the discussions demonstrate the power of qualitative research in general, not only in deeply understanding human experiences but also in fostering growth and positive change. The insights gained from the

present study provide valuable direction for expanding and evaluating the current intervention or developing new interventions for managing chronic pain and mental well-being. More studies like the present one are required to address the underrepresentation of various groups and ensure their perspectives are adequately reflected.

## Chapter Summary

This chapter presented Stage Three of the third phase of this project. Participants shared their experiences and opinions of the resource and intervention. Three main themes were identified following inductive RTA: Resource Content and Design, Effects, and Continued Engagement. Participants' mean scores on the Warwick-Edinburgh Mental Well-being Scale were collected before and after the intervention. Statistical analysis showed a significant improvement of approximately ten points in mean post-intervention scores, which indicated a large effect. In addition to these findings, the limitations, implications of the research, and suggestions for future research were also discussed. The next chapter will offer a discussion and conclusion of all three phases of the project: the meta-synthesis, interviews, and PAR study.

## Chapter Eight: General Discussion

### Chapter Overview

The previous chapter discussed the final stage of the third phase of this project. This chapter will summarise the key findings from all three research phases. The overarching aim of the project and each of its phases will be restated. The primary findings will be discussed, as will the contributions of each research phase to the existing literature. An overview of the project's strengths and limitations, implications, contributions, recommendations, a conclusion, and suggestions for future research will also be provided. The chapter will finish with a final summary.

### Discussion

The aim of this project has always been about learning from women who live with chronic pain and using this understanding, and insights gained from the research to explore ways to potentially bring some relief or improvement to their situation. As previously noted in Chapter One, there has been an increase in opioid prescriptions in the UK, despite evidence suggesting limited benefits for chronic pain management. Moreover, opioids carry risks of addiction and significant side effects (NHS England and NHS Improvement South West, 2020; WHO, 2023). Thus, there is a need to investigate non-medication-based approaches to pain management. This can only be achieved by understanding the needs and challenges of individuals living with pain and exploring and testing various approaches with them.

SAW's underrepresentation in pain research continues to hinder our understanding of their needs, experiences, and challenges in living with and managing chronic pain. These insights are necessary for holistic, culturally

sensitive care, as an individual's ethnicity and sex can influence both pain perception and behaviour (Fillingim & Maixner, 1995; Fillingim et al., 2009; Hastie et al., 2005; Keogh et al., 2005; Koons et al., 2018; Mills et al., 2019; Miyazaki & Yamamoto, 2009; Parmelee et al., 2012; Pieretti et al., 2016; Rogers & Allison, 2004; Zborowski, 1952; Zola, 1966).

This project aimed to address this gap in understanding through three phases. The first phase involved conducting a meta-synthesis. The aim was to gain a collective and comprehensive understanding of women's lived experiences with chronic pain and identify gaps in our knowledge about SAW's experiences with it. By systematically reviewing existing studies, it was possible to identify areas where research about SAW's pain experiences was missing, required attention, or was unclear. Furthermore, the insights gained from this review were critical for identifying and formulating relevant and meaningful research questions about SAW's pain experiences, as well as guiding the other studies. This approach ensured that the project was grounded in existing literature, enabling it to explore previously unexplored aspects and address some of the identified gaps. It also adds to the existing scholarly discourse and provides a new, more comprehensive, and integrated examination of women's experiences with chronic pain.

This meta-synthesis identified common themes and gaps in the literature by synthesising findings from fifty-six studies, particularly noting the limited focus on SAW's experiences. Consequently, the experiences and needs of SAW remained unclear. On the basis of the existing literature, considerably more in-depth research on the experiences of SAW with chronic pain was required.

The meta-synthesis, however, identified several common themes in women's experiences. Women in the studies described their lives as being dominated by their pain while also having to manage numerous other responsibilities (Hallberg & Carlsson, 1998). These additional duties included employment outside the home, housekeeping, shopping, and parenting. Many women also expressed that their pain dictated their daily lives. They often referred to pain as something that was 'there all the time' and that 'stole' their ability to fully participate in life. It significantly shaped their daily experiences and decisions, making it 'difficult to disengage from' (Barnes et al., 2021; Hallberg & Carlsson, 2000; Howell, 1994; Kirkham et al., 2015; White & Seibold, 2008).

Another significant theme was the numerous losses associated with pain (Dysvik et al., 2013; Gullacksen & Lidbeck, 2004; Howell, 1994; Knutsen et al., 2022; Nyen & Tveit, 2018; Osborn & Smith, 1998), reported in the studies, and the lack of understanding (disempowering and delegitimising encounters) the women experienced mainly from HCPs (Bostick et al., 2018; Reibel & Pearson, 2017; Werner & Malterud, 2003; Wuytack & Miller, 2011).

Howell (1994) emphasised that validation significantly influences women's pain experiences almost thirty years ago. Despite this, the meta-synthesis revealed women still face unnecessary suffering, often being met with doubt and disbelief. Research shows HCPs tend to dismiss women's pain, stigmatising and trivialising their experiences (Billock, 2018; Hintz, 2023; Hoffmann & Tarzian, 2001; Lyman, 2021; Samulowitz et al., 2018; Werner & Malterud, 2003; Wuytack & Miller, 2011). Women often feel their pain is treated

as imaginary, being told it is 'all in their head' and being advised to seek help from mental health services (Driscoll et al., 2018).

Numerous studies have documented the frustration and isolation felt by patients due to a lack of understanding, disbelief, and lack of interest and commitment from HCPs (Campbell et al., 2022; Campeau, 2018; Driscoll et al., 2018; Hallberg & Carlsson, 1998; Kanter et al., 2017; Werner & Malterud, 2003; Wuytack & Miller, 2011).

In Campeau's (2018) study, participants described their experiences with the healthcare system as receiving 'the scraps of medical care'. This stark expression indicates a profound sense of neglect and inadequate care, prompting patients to seek alternative forms of treatment. The reliance on complementary medicine, faith rituals, and homoeopathic treatments appeared due to a lack of accessible and effective conventional medical care, pushing participants to more accessible approaches (Campeau, 2018). This shift underscores the desperation and resourcefulness of patients trying to manage their pain in the absence of sufficient medical support.

This was observed in many studies (with one of the themes in our meta-synthesis being seeking solace and self-empowerment). The meta-synthesis revealed that many women sought solace and empowerment through various means. They took proactive steps to educate themselves about their condition, actively seeking out information and resources (Allen et al., 2015; Campbell et al., 2022; Dickson & Kim, 2003; Hwang et al., 2004; Molin et al., 2022).

Neglecting to acknowledge an individual's account of their pain is to negate all prospects of managing it; if they are not believed, they cannot be assisted. It shatters any hope of improvement. Pain is inherently subjective,

devoid of a universally accepted gold-standard test or measurement for it. Furthermore, expressions of pain may vary widely among individuals, making it extremely unethical to selectively validate the pain of certain individuals or groups over others. These issues highlight the need for HCPs to engage more seriously with women with chronic pain and indicate a need for educational interventions on chronic pain for HCPs.

Furthermore, the lack of information provided to women living with chronic pain undermines women's self-efficacy, which is crucial for self-management and coping with pain (Bandura, 1982; Firth et al., 2019; Paterick et al., 2017). To empower women to effectively manage their pain, HCPs need to provide the necessary support and information (Molin et al., 2022; Skuladottir & Halldorsdottir, 2011).

These findings allowed the project to identify specific areas where existing research was lacking and provided a foundation for further investigation. The demographic data from Phase One revealed that there is a significant cultural and ethnic representation issue. The studies did not adequately explore SAW's coping mechanisms, how they manage their pain, or their experiences of the healthcare system. There was a noticeable lack of research on the interactions between SAW and HCPs, as well as factors that may impact the quality of pain management care provided to this group. The underrepresentation of women of colour has been acknowledged by other researchers (Campeau, 2018; Criado Perez, 2019; Kempner, 2017). Campeau's (2018) study in the review focussing on pain in Somali women was conducted in response to observations that a significant portion of social science research on chronic pain focuses predominantly on White women (Kempner, 2017). It has



been stated that samples consisting mainly of White, middle-class women yield incomplete results, highlighting the need for more diverse research samples in studies on chronic pain (Kempner, 2017). The review underscored the limited insight into SAW's experiences with chronic pain, and the second phase was undertaken to shed more light on the experiences of these women.

The project's second phase involved conducting in-depth interviews with SAW living with chronic pain. The dedication to capturing participants' personal experiences in Phase Two through semi-structured, one-to-one interviews, combined with an inductive approach, allowed for a deeper understanding of these experiences and their impact. These interviews highlighted the women's priorities for their immediate and often extended families, their sense of duty, the lack of understanding they reported from others, including HCPs, and the importance of religion and spirituality in providing strength and comfort. These women also reported many losses that they experienced due to pain. These losses spanned physical, emotional, social, and aspirational dimensions: loss of work, future certainty, the life that they had hoped for, participating in the activities that they enjoyed, socialising with colleagues, and sleep.

The present study found that autonomy, enjoyment, relationships, sleep, and employment were the most frequently reported issues. It has been stated that it is the loss of latent benefits associated with work that results in poorer psychological well-being (Jahoda et al., 2017). Pain took away many of these aspects from the women's lives. Interventions need to provide a means of replacing some of these latent benefits and other losses. The importance of structure, routine, and purpose in managing chronic pain was discussed. Establishing a daily routine and engaging in purposeful activities can help

individuals cope with the latent losses caused by pain. This approach can provide a sense of normalcy and control, countering the disruptions caused by chronic pain.

Despite their loss and pain, the women continued to prioritise their responsibilities and care for their extended families, including their in-laws. Their dedication seemed to come at the expense of their comfort. Very few women talked about engaging in hobbies or other interests of their own. Their perceived roles' demands took precedence over their own well-being. Similar findings on SAW have been reported by other authors (Choudhry et al., 2002; Gurm et al., 2008; Holt & Waterfield, 2018; Masood et al., 2015; Mustafa et al., 2020; Shariff, 2009).

The authors in another action research study (Choudhry et al., 2002) found that participants consistently prioritised their family's needs and societal expectations over their own. The authors stated that 'selflessness' and 'self-sacrifice' were firmly embedded in the mindset of South Asians. The women in their study were heavily 'involved in caring for grandchildren and housework', leaving little personal time for their own health. Moreover, those in nuclear families lacked assistance and support with chores, which further limited their ability to engage in health-promoting activities. These were very similar to the findings reported by SAW in Phase Two. The theme of duty and multiple responsibilities was prominent among the participants.

For SAW, these obligations were not just additional responsibilities but core elements of their social role, often leading them to prioritise the well-being of others at the expense of their own health and self-care. This nuanced understanding is crucial because, while the meta-synthesis captured the general

theme of multiple responsibilities, the interviews with SAW highlighted how these responsibilities are uniquely amplified by cultural expectations. This was also reported by Mustafa et al. (2020). This amplification can also be seen as a source of additional stress, potentially exacerbating their experience of pain. In Mustafa et al.'s (2020) study, participants identified stress from their responsibilities as a contributing factor to chronic pain.

Furthermore, in contrast to the meta-synthesis findings, the interviews with SAW revealed that many of these women lacked access to online resources, with some unable to read English, while others found the available information confusing. Their limited digital literacy and language barrier hindered them from seeking the same empowerment sources as the women in the broader studies. This emphasises the need for culturally and linguistically tailored resources to better assist SAW in managing their pain.

The participants in Phase Two also spoke about the importance of religion and spirituality in providing strength and comfort while navigating a journey they described as one of 'darkness', using words such as 'a dark place', 'dark clouds', 'darkness', and 'a dark and gloomy place'. In Kirkham et al.'s (2015) study, which included seven White female participants, the researchers explored women's experiences of living with chronic pain through pictorial representations and accompanying accounts. They also noted that pain was often referenced as a darkness. Their participants also provided similar descriptions when describing their pain, likening it to 'darkness,' 'blackness,' and a 'black thundercloud' that is ever-present.

Amidst the darkness, the women in Phase Two relied on their faith and spoke of the importance of religion and spirituality. Many authors, patients, and

studies acknowledge the benefits of religion and spirituality for improving health outcomes, as well as reduced utilisation of healthcare services, and advocate for a biopsychosocial-spiritual model in medicine (Büssing & Koenig, 2010; Glover-Graf et al., 2007; McKee & Chappel, 1992; Ross, 1995; Siddall et al., 2015; Sulmasy, 2002; Taylor et al., 2013; Uslu-Sahan et al., 2023).

Consequently, HCPs should be more cognizant of the significance of spirituality and religion in assisting and supporting individuals experiencing pain (Dedeli & Kaptan, 2013).

Additionally, all participants reported trying non-medical interventions. After being prescribed only painkillers, they sought advice from others and explored non-medical methods (teas, oils, and devices) recommended by them. In their search for pain relief, these alternative approaches became important sources of comfort and coping.

It was felt that the pain management strategies SAW were using (teas, oils) were often quick, low-cost, and easily integrated into their daily routines, allowing them to fulfil their obligations to others without significantly disrupting their responsibilities. Unlike self-care and management activities that might require dedicated time and attention (attending support groups/physical activity). It appeared as a way to manage pain quietly and efficiently, without drawing attention to their own needs or burdens.

The SAW participants also expressed a desire for their GPs or hospital doctors to provide them with information (that they could understand) about their condition and its management (which they had not received). Although this is recommended standard care, many of these findings have also been reported in other studies. Research has highlighted that medical care often fails to meet

individuals' needs for adequate information, effective clinical management, and psychological support (Alhomoud et al., 2015; Gordon et al., 2017; Lim et al., 2019; Lin et al., 2018; Molin et al., 2022; Ng et al., 2021; Parks, 2020; Vakil et al., 2023; Wagner et al., 2001).

The participants in the present study echoed similar sentiments, feeling that their pain was not understood and that they were largely left to manage it on their own. The studies in Phases One and Two revealed how this lack of understanding and support can lead to feelings of isolation, hopelessness, and frustration. Leaving patients to navigate their pain without adequate guidance can intensify their discomfort and challenges.

Overall, Phase Two's key findings revealed that participants had largely been left on their own to manage their pain and well-being. Many felt that their HCPs failed to understand their pain's impact and did not meet their information needs. Many of them were relying on spirituality, religion, and non-medical interventions from others to help them traverse a journey that they described as being one of darkness. Their descriptions indicated that their pain was not only intense and overwhelming but also cast a shadow over their lives. Moreover, they conveyed the emotional and psychological burden of chronic pain, highlighting the importance of considering the holistic impact of chronic pain on individuals.

Many participants faced barriers such as language and limited access to online health resources, which left them without vital information and support. Providing information is important and offers numerous benefits: empowering patients to make informed choices and take responsibility for their health, as well as enhancing compliance with treatment methods and recommendations

(Fernsler & Cannon, 1991; Nagpaul, 2021). The insights gained from this phase provided valuable direction for the third phase.

The third component (a PAR study) was also divided into three separate stages. The first stage of this study explored the key challenges that women with chronic pain face, which they felt were most important to them to address, as well as potential solutions. The second stage involved using this data to co-create an intervention and resource, and the third stage evaluated them.

During the first stage, through active listening and facilitated discussions, a variety of concerns and challenges were reported by the participants, and factors were identified that could help mitigate them. Three themes were identified following inductive RTA (identifying patterns in the data without pre-existing coding frameworks) in Stage One: Holding Space: Sharing, Safety, and Solace; 'Understand My Pain': Self and Society; and Restoring the Losses and Creating Positive Experiences. The first theme highlighted the critical importance of creating a judgement-free space where the women could share their experiences, receive validation, and experience the compassion and understanding often lacking in their lives. The second theme emphasised the need for the women to understand their own pain and for others to do the same and the desire for a more accurate portrayal of their experiences. The third theme captured the need to reclaim what pain had taken from the participants and create new, positive experiences that were often associated with little or no pain. During this stage, a women's circle where participants could speak openly, share stories and pain management strategies, and engage in activities that they enjoyed doing was identified as a possible solution. Participants also explicitly expressed their desire for a booklet on managing pain during this stage.

The second stage involved exploring if a women's circle would be something that the participants would like to explore, with the underlying rationale that participants reported experiencing less pain when they were engaged in activities that brought them joy and being with supportive peers was something they appreciated. Also, it was felt that this intervention could also allow participants to regain the losses experienced as a result of being unable to work and/or being in pain: socialising, structure, routine, getting out of the house, and conversations during tea or coffee breaks. Furthermore, given that religion and spirituality were important to the participants, the proposed intervention would allow them to incorporate activities to address these dimensions. The idea was welcomed by the participants.

The second stage then included planning for activities in the women's circles and the contents of the resource with the participants. During this stage, participants emphasised their preference for a visually appealing resource with a pink theme, aiming for simplicity and the inclusion of self-management strategies recommended by fellow participants. They preferred an equal balance of pictures and text. They wished for others to understand their condition better as well as the challenges they experienced. They also wanted more knowledge on factors that could influence pain. Insights and strategies shared by participants were collected for inclusion. A resource was created: a booklet on living well with chronic pain (the steps of this creation process have been outlined in Chapter Six).

The co-created booklet incorporated various strategies and recommendations from participants for managing chronic pain. It underscored the necessity of validation, reminding readers that the struggles of those with

chronic pain are profound and warrant understanding (Howell, 1994). It emphasised self-care as essential for overall well-being. The resource outlined key strategies such as distraction, physical activity, and incorporated a spiritual dimension. Key points included using distraction through hobbies to provide relief and purpose (Ambron, 2022; Wuytack & Miller, 2011), as well as the role of social connections in offering support. Expressive arts, like painting and knitting, were suggested as therapeutic outlets. Regular exercise, gentle movements like stretching or yoga, were recommended to alleviate physical tension and enhance well-being (NHS, 2021).

Additionally, the booklet discussed the significance of faith and spirituality in coping with pain, noting that spiritual beliefs can provide strength and resilience. Nurturing spiritual well-being helps individuals find meaning, purpose, hope, and comfort during difficult times (Dedeli & Kaptan, 2013; NHS, 2021, 2024; Sulmasy, 2002).

The participants also planned sessions for the intervention (women's circles), which included origami, knitting, group prayers, and art. The intervention was based on the rationale that engaging in joyful activities was associated with pain-free moments, and incorporating these activities could therefore help participants manage their pain and reduce its dominance in their lives. Also, as the women had reported low moods, the intervention would be incorporating some of the recommended 'five steps to mental wellbeing' by the NHS (2024), which outline evidence-based strategies to enhance mental well-being (connecting with others, physical activity, learning new skills, giving to others, and mindfulness; NHS, 2024). The intervention adopted a comprehensive biopsychosocial-spiritual approach by identifying the primary



factors impacting women's well-being, which were primarily the psychological effects of significant losses due to pain.

An integral part of the third phase was the use of focus groups, which provided a forum for these women to share their stories and experiences in a supportive environment. The power of focus groups lies in their ability to generate insight that other methods may fail to (Kitzinger, 1995). The involvement of participants was a significant strength of this project. Actively involving participants in the research process ensured that their perspectives, needs, and experiences shaped the creation of the intervention and the resource. The findings from these discussions were invaluable in developing an intervention and resource that were reported to be relevant and effective. By co-creating the intervention and resource with the women themselves, the project ensured that the solutions were directly relevant to their needs and contexts.

Ethically, maintaining participant continuity was crucial, as participants expressed a clear need for ongoing support. PAR research focuses on using findings to take action that improves participants' circumstances. By using the same sample throughout the study, the research ensured depth, consistency, and meaningful engagement. Participants were active contributors to the intervention's development and evaluation, making continuity vital to preserving this dynamic. This continuity, combined with the rapport already established, provided a richer understanding and an opportunity to observe how participants responded to interventions throughout the stages.

The project also took a novel approach and used the GROW model (Whitmore, 2001) to frame questions to assist participants in identifying their goals, challenges, and needs, as well as exploring potential solutions. An

innovative approach was required with a commitment to developing interventions that considered the emotional, social, and spiritual dimensions of chronic pain. The women's circles were created with all these dimensions in mind. The six-week intervention was carefully designed and planned with the participants. They looked forward to their meetings, where vulnerability was met with the kindness and empathy they seldom experienced elsewhere. In a warm and understanding atmosphere, the women engaged in activities that brought them joy and a sense of calm: playing cards, solving riddles, conversing over tea, group prayers, origami, and crafting.

Three key themes were identified during the final evaluation stage of the resource and intervention: Resource Design and Content, Effects, and Continued Engagement. Participants reported that they found the resource visually pleasing and exactly as they desired, with many stating that it exceeded their expectations. They expressed satisfaction with the resource's comprehensiveness and clarity, as well as its long-term relevance and utility. They also highlighted the effects of the intervention and resource, which included five subthemes: easing burdens, positive affect and well-being, escape, flow, and equanimity, and growth, transformation and empowerment. They also described the intervention as more effective than medication (fifth subtheme) due to its lasting effects on pain and overall well-being. Participants' mean WEMWBS post-intervention scores increased from the baseline values. Statistical analysis showed a significant improvement of approximately ten points in the mean post-intervention scores ( $p \leq .001$ ).

The impact of the co-created intervention and resource on the participants' lives and well-being was reported to be overwhelmingly positive,

with many describing a transition from a state of darkness to one of light. Prior to this intervention, these women had received little support beyond pain medication and had not received any validation of their pain and its impact.

The most impactful aspect of this project was the action research study. Actively involving the participants in the research process and the co-creation of a resource/intervention was a transformative experience. It not only ensured that the solutions were tailored to their specific needs but also empowered the women by validating their experiences and contributions. This approach reinforced the importance of collaboration and inclusivity in research, highlighting the potential for meaningful change when participants are actively engaged.

The women's circle empowered these women by providing a sense of purpose and joy in their lives. It fostered connections that extended beyond the circle, promoting ongoing support. The last session with the researcher concluded with a sense of continuity. The women left equipped with skills for self-management, were provided resources for ongoing support, and reported continuing to incorporate strategies in their daily lives. The circles became a testament to the transformative power of shared experiences, understanding, action research, and the unwavering spirit of women supporting women in their pursuit of improved well-being and empowerment.

### Contextual Considerations and Broader Implications

The findings from this project contribute valuable insights to SAW's chronic pain experiences, providing a deeper understanding of the impact of these experiences, their needs and challenges, pain management strategies, and addressing gaps identified in the existing literature. This project also

detailed the procedure for collaboratively developing an intervention and a resource (Chapter Six) and presented their evaluation findings. Through these studies, we have gained a deeper understanding of how chronic pain affects various aspects of individuals' lives, including psychological, emotional, spiritual, and social dimensions.

It is hoped that this comprehensive insight has paved the way for more targeted and effective interventions. A notable contribution to knowledge is the co-creation of a resource and intervention specifically tailored for SAW living with chronic pain. This resource was designed not only to address their pain management needs but also to be culturally sensitive and relevant to them. The findings from these studies have highlighted several barriers that SAW face, particularly in accessing and understanding health information.

Multifaceted barriers such as language difficulties, limited IT skills, internet accessibility, and information presentation prevented participants from understanding and accessing health information. As a result, all participants struggled to find and/or understand the health information they required, which hinders effective pain management and overall well-being.

The development process for both the intervention and the resource itself is another key contribution to knowledge. We incorporated a comprehensive biopsychosocial-spiritual approach, addressing multiple dimensions of pain experience and management. Furthermore, we acknowledged the importance of involving SAW throughout all stages of the resource and intervention development process (Pipon-Young et al., 2011; Stringer & Ortiz Aragón, 2021). By engaging SAW as active collaborators, we ensured that the developed tools were relevant and meaningful to them. We

meticulously designed the booklet and intervention to reflect the perspectives, needs, preferences, and experiences of the participants.

### **The Importance of PAR**

The gap between scientific research and its practical application in healthcare appears significant in the field of pain management. Another pressing issue is the underrepresentation of certain groups in research. Although there has been some progress in inclusivity, a substantial gap remains, preventing a complete understanding of health across different communities (Kempner, 2017). The inclusion of diverse perspectives in research not only brings about new insights and innovations but also acknowledges that different communities possess unique experiences, knowledge, and perspectives that can contribute to the development of more effective interventions/policies.

PAR is particularly valuable because it centres the voices and experiences of those who are directly impacted by the issue at hand, leading to more relevant and impactful outcomes. Action research facilitates the translation of research findings into practical applications (Olshansky et al., 2005; Pilon-Young et al., 2011; Stringer & Ortiz Aragón, 2021). Given the current strain on the NHS, it is more crucial than ever to collaborate with patients on both the prevention, education, and self-management of chronic diseases. While private healthcare is an option, those most in need are often the least likely to be able to access it.

This approach, however, comes with challenges, particularly in relation to ethics applications due to its unstructured and evolving nature. The GROW model helped address the amorphous nature of action research and provided a clear, structured framework to guide the research process. The GROW model is

known for its practical and action-oriented nature (Miller, 2020; Whitmore, 2001). Using this model in the focus group aligns with a solution-focused approach to better management of pain and well-being. Participants can not only share their concerns but also actively contribute to generating ideas and strategies for positive change.

This was evident by participants expanding their circles to include contacts they felt may benefit. They shared their experiences with other women in the community, sparking considerable interest among them. Many expressed a desire to join the participants and spoke of others who they felt might be interested. This illustrated the importance of self-empowerment and self-management. The project was always about empowering women to rely on their own abilities and resources rather than others who may not understand their experiences or the impact of them. They left with reporting enhanced self-efficacy and confidence in their abilities to manage their pain and well-being.

Our intervention focused on creating purpose, nurturing spiritual well-being, aligning with participants' personal goals, addressing their losses, and building social connections. This approach closely aligns with Lyman's (2021) idea that effectively managing pain involves treating the whole person. Themelis and Tang (2023) also suggested exploring goals and outcomes that mattered to the patients. We aimed to help participants restore and reclaim their sense of self and purpose. We addressed the numerous losses experienced by individuals living with pain, which can erode aspects of their self-concept and identity. Our intervention was about recovering the aspects of life that gave them purpose and meaning. Through this holistic approach, participants experienced profound transformations. Lyman (2021) also noted that simple

things can have profound effects, and we saw firsthand how powerful and transformative this approach could be. The intervention further emphasised the value of his views.

This research highlights the transformative potential of acknowledging and addressing the unique experiences of underrepresented groups. Empowering individuals through research and tailored interventions not only can improve their well-being but also contributes to the ongoing effort to create more equitable and effective healthcare practices.

### **Summary of the Project's Contributions and Implications**

The project highlighted the all-encompassing nature of chronic pain. The pervasive influence of chronic pain on both the mind and body underscores the urgent need to treat it as a clinical priority. The meta-synthesis conducted in the initial phase of the research offers a valuable contribution to knowledge by providing a comprehensive overview of women's experiences with chronic pain. This synthesis not only enriches our understanding of women's experiences with chronic pain, but it also paves the way for future research by identifying critical areas needing further exploration. It lays the foundations for future research by identifying gaps and proposing areas for further investigation.

The qualitative interviews in Phase Two make another important contribution. They provide rich, detailed insights into the experiences of SAW living with chronic pain. This primary data offers a deep understanding of their unique experiences, challenges, and needs.

The use of the GROW model in Phase Three was important in facilitating goal-setting and problem-solving among participants. This is an innovative use

of the model in this field and adds a valuable methodological contribution to the literature. Moreover, the project acknowledged the significant role that religious beliefs and the spiritual dimension play in many individuals' lives, as advocated by others in the field (discussed in Chapters One and Four). For some, religion is not just a source of strength but a reliable companion in their journey, offering strength and resilience that is so often needed when living with a chronic disease. Consequently, the adoption of a biopsychosocial-spiritual approach in designing the intervention also represents a significant advancement in pain management strategies.

The present project integrated physical, psychological, social, cultural, and spiritual dimensions. The co-creation and planning process honoured the complexities of pain by adopting this biopsychosocial-spiritual approach. The co-creation of a culturally tailored resource for chronic pain, including the development of an intervention (women's circle) aimed at restoring the losses and creating positive experiences that pain took away from the participants' lives and including interactive activities, is also a notable contribution.

This practical application of the research findings, which directly benefit the participants, sets a precedent and provides a model for how interventions and resources can be designed and implemented in a culturally sensitive manner with SAW living with chronic pain. The reporting of the co-creation process and evaluation is also novel with SAW. The study provides a template for others wishing to develop culturally sensitive interventions and can be adapted to other settings or populations.

The action research approach demonstrated how research findings and psychological theory can be applied to design practical interventions. It bridges



the gap between theoretical knowledge and practical application to address everyday challenges and improve participants’ well-being. These contributions not only advance our understanding but also offer practical solutions that can potentially improve the quality of life of individuals living with chronic pain. The steps taken during the creation and evaluation stages provide a useful template for others to follow. In this manner, the study contributes to both academic knowledge and to developing practical solutions. This is particularly vital in light of the current opioid epidemic, which underscores the inadequacy of existing solutions. It highlights the need to explore and implement alternative approaches to pain management. It is essential for researchers and HCPs to continue adopting such personalised approaches to improve patient care and develop policies that ensure equitable access to high-quality pain management services and resources. By integrating these insights into practice and policy, we can work towards more inclusive, effective, and compassionate care.

Table 8.1: Summary of Key Contributions and Implications

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<b>Meta-synthesis</b>
Presents a collective and comprehensive overview of women’s experiences with chronic pain and identifies gaps and areas for further research.
<b>Insights into SAW's Chronic Pain Experiences Study</b>
Provides a deeper understanding of the impact, needs, challenges, and pain management strategies of SAW, addressing gaps in existing literature.
<b>Co-Creation of Culturally Tailored Resource &amp; Intervention</b>
Co-creation of a resource and intervention addressing SAW's pain management needs, ensuring cultural sensitivity and relevance.
<b>Identification of Barriers to Healthcare Access</b>
Highlighted challenges such as IT skills, internet accessibility, and health information presentation that hinder effective pain management.

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### **Biopsychosocial-Spiritual Approach**

Integration of physical, psychological, social, and spiritual dimensions in pain management, emphasising holistic care.

### **Participatory Action Research (PAR) Approach with SAW with Chronic Pain**

Engaged SAW as active collaborators, ensuring interventions were relevant, empowering, and impactful.

### **Application of the GROW Model**

Used as a structured framework to facilitate goal-setting, problem-solving, and solution-focused discussions in pain management. The questions were framed around the GROW model (see Appendix Thirteen). For example, when exploring goals, participants were asked, 'What do you find most difficult about living with chronic pain, and what areas would you like to change?'

### **Bridging Research and Practical Application**

Demonstrated how research findings can be applied to develop practical, community-driven interventions.

### **Contribution to Healthcare Policy and Practice**

Advocates for PAR, inclusive and personalised approaches to pain management, providing a template for future interventions.

### **Future Research and Expansion**

Highlights areas for further exploration, including different pain management techniques, and expanded evaluation of interventions

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## **Moving Forward**

While this study effectively identified needs and developed targeted interventions, further research is needed to explore their broader applicability. Future studies could assess how these interventions might be adapted for other SAW living with chronic pain, considering factors such as socioeconomic status, healthcare access, religion and spirituality, language preferences, and community-specific factors. Testing these interventions with diverse groups

would help evaluate their relevance to different groups, allowing for necessary adjustments.

Additionally, researchers could investigate various pain management approaches (such as mindfulness, relaxation, art, and diversion) and explore the role of community support, chaplains, and religious groups in providing assistance. The study highlighted a wide range of emotions expressed by participants, including frustration, anxiety, sadness, tension, and loneliness. Future research should examine how interventions can be tailored to address these emotional aspects and improve overall well-being. Understanding the experiences of women from different South Asian groups and economic backgrounds may offer further insights into refining these approaches.

Ensuring that interventions are developed in collaboration with participants is also crucial for creating a comprehensive and contextually relevant resource. Co-designing interventions with those affected enhances their resonance with the target audience and increases the likelihood of positive outcomes (Deery, 2005; Stringer & Ortiz Aragón, 2021; Whitmore, 1992). Future research could evaluate the feasibility, acceptability, and effectiveness of these interventions in practice.

Methodologically, employing random sampling techniques and including a control group in future studies could provide stronger evidence for the intervention's broader applicability. Testing the intervention across different groups and contexts would further validate its effectiveness. Additionally, a more in-depth evaluation of the developed resource may help assess how it is perceived by others and identify areas for improvement.

By addressing these areas, future research can build on the foundation of this study, ensuring that interventions are refined, expanded, and adapted to support a wider population of SAW experiencing chronic pain.

### **Limitations**

However, the limitations of this project should also be considered when interpreting the findings. The search strategy in Phase One aimed to capture as many studies as possible but was restricted to English-language journal articles. Consequently, the experiences of non-English-speaking women whose accounts were not translated, or studies not published in journals were not analysed. Additionally, unfulfilled requests prevented the acquisition of a few studies. The interpretive nature of the analysis also allows for multiple interpretations; however, adopting a reflexive approach (peer debriefings and journaling; Buetow, 2019; Dodgson, 2019) helped to ensure that the focus remained solely on the current data.

Furthermore, Phase Two interviews took place over the telephone, which lacked visual cues for rapport-building and response interpretation (Arksey & Knight, 1999). However, it was felt that the first author's similar background, being the same sex as the participants, and communicating in their preferred language helped establish good rapport and collect rich data (Shah, 2004; see also Reflexivity and Positionality Statement; Chapter Two).

Moving on to the issue of the use of non-random sampling methods and potential social desirability biases. The sampling methods chosen were deemed most appropriate for reaching an underrepresented group and achieving the research aims, and enabling the selection of 'information rich cases' (Nortvedt et al., 2016).

Using a single sample across successive stages of this PAR study has limitations. One potential issue is that the repeated involvement of the same participants may create response biases due to growing familiarity with the researcher, potentially influencing how participants respond or interact in later stages. While acknowledging the potential for participants to provide socially desirable responses (Acocella, 2012; Howitt, 2016), efforts were made to mitigate this. Member checking, taking a reflexive approach, and establishing an environment conducive to openness and respect were key strategies in overcoming potential biases. These methods aimed to ensure that participants felt comfortable expressing their authentic views, allowing for more honest and accurate data collection despite their growing familiarity with the researcher.

The establishment of trust and rapport facilitated open communication, while a reflexive approach allowed for a deeper understanding of participants' experiences. By actively involving participants in the co-creation of interventions and encouraging honest feedback, the researcher aimed to empower them and balance any perceived power dynamics. It was felt that this collaborative approach not only enhanced the validity of the data but also ensured that the outcomes were reflective of the participants' true needs and preferences. Ultimately, the commitment to respect, transparency, and collaboration has been pivotal in capturing the authentic voices of the participants throughout the research. The establishment of rapport and mutual respect within the group was believed to foster an environment conducive to openness and honesty, where participants felt at ease expressing their views candidly. Furthermore, participants were prompted to engage in discussions regarding both favourable and unfavourable elements of the intervention and resource. Additionally, the

intervention was designed through collaborative efforts, where participants were active contributors. It was felt that by doing so, participants would feel empowered to provide genuine feedback, including any aspects they were dissatisfied with.

It is also important to consider other potential confounding variables in the third phase of the present study, such as participants adopting additional positive behaviours like increased physical activity and efforts to improve sleep quality. These factors could have contributed to the observed improvements in well-being. However, the qualitative findings provide insight into the distinct role of the intervention itself.

Participants consistently noted feelings of support, happiness, kindness, compassion, relaxation, and equanimity specifically attributed to their participation in the circles. Despite potential confounding variables, the unique benefits of the intervention remained prominent. Participants conveyed their eagerness for upcoming circle sessions and reported lasting effects, highlighting the importance of the intervention in improving well-being.

## Conclusion

In conclusion, this project has been a deeply enriching experience. It has reinforced the importance of giving voice to underrepresented groups and the value of participatory approaches in research. Qualitative research allowed a deeper understanding of the complex experiences of women with chronic pain to be gained and to help develop interventions that can improve their quality of life and well-being.

The opportunity to assist with creating something that can help alleviate someone's pain and the challenges they face was incredibly rewarding. As was

the opportunity to support women who had been enduring chronic pain without adequate resources or validation. The positive feedback from the women, who described their transition from a place of darkness to one of light, reinforced the power of qualitative research and adopting an action research approach and its potential to create meaningful change. This project contributes to the existing body of knowledge by providing insight into SAW's experiences with chronic pain and managing it, a group whose experiences have received little attention in previous studies. It provides a deeper understanding of their needs and challenges. This project also described the process of co-creating a culturally appropriate holistic intervention and a resource for managing pain that adopted a biopsychosocial-spiritual approach. Also presented are the participants' experiences with them.

These findings can be used for expanding and evaluating the current intervention or developing new interventions for managing chronic pain and mental well-being. Researchers may also wish to explore the intervention in different groups or contexts. Future research employing random sampling methods and incorporating a control group could provide a clearer understanding of the intervention's broader applicability. Researchers could also examine various pain management techniques (e.g., mindfulness, relaxation, and diversion), as well as ways in which the community, chaplains, or religious groups could be of assistance. The participants also expressed a wide range of emotions and feelings, including frustration, anxiety, sadness, tension, and loneliness. Interventions to improve some of these could also be explored. More studies like the present one are required to address the underrepresentation of various groups and ensure that their perspectives are

adequately reflected. Additionally, a more in-depth evaluation of the resource may be beneficial to understand how it is perceived by others.

Our intervention's success reemphasises the importance of treating the whole person and confirms that simple, holistic approaches can lead to profound and transformative changes in individuals' lives (Lyman, 2021). Researchers and HCPs can positively impact individuals' lives and improve health outcomes, and the adoption of methods that can achieve this is recommended. Ongoing research is needed to better understand the experiences of chronic pain patients and to develop policies that ensure equitable access to high-quality pain management services. The project's findings may be useful for HCPs, researchers, policymakers, women with chronic pain, and those who support them.

### Reflective Summary

Throughout this project, I have gained valuable insights into women's experiences with pain, particularly the gap between research and its real-world application. Despite longstanding knowledge of the biological, social, and psychological factors influencing pain, the research indicates that a predominantly biomedical approach still dominates chronic pain clinical practice, with meaningful progress in implementing a holistic approach remaining limited. There is still a significant gap in the actual implementation of biopsychosocial approaches. For decades, researchers have emphasised the need for patient-centred, multidisciplinary care; yet research indicates that little has changed in practice. This disconnect highlights the urgent need for a more holistic approach; one that treats the whole person and prioritises the aspects



most relevant to individuals living with chronic pain. There is a pressing need to bridge the gap between research and action in chronic pain management.

It has been discussed that, while making recommendations is important, it is not enough. This project has reinforced the idea that we, as researchers, are uniquely positioned to take action and make a change. PAR and other patient-centred approaches offer a way to bridge the gap between research and real-world impact. Reflecting on this approach has heightened my awareness of how research can and should lead to tangible improvements in people's lives. By working collaboratively with those experiencing chronic pain, research becomes more meaningful and ethical, ensuring that findings translate into practical solutions rather than remaining purely academic.

Additionally, this research has highlighted a significant issue regarding cultural and ethnic representation in the literature on women's experiences with chronic pain. Furthermore, this project has deepened my understanding of chronic pain as an issue that demands a biopsychosocial-spiritual approach. It has also reinforced the need for empathy, advocacy, and inclusive healthcare policies. Moving forward, more research should focus on culturally tailored interventions, patient empowerment, and addressing the biopsychosocial and spiritual aspects of chronic pain. Above all, this project has emphasised the importance of listening to those with lived experiences and valuing their voices in shaping future pain management strategies. Meaningful change in the understanding and treatment of chronic pain can be achieved more effectively by moving beyond recommendations and into action.

One of the most transformative aspects of this experience has been witnessing the power of qualitative research and action research firsthand.

These methodologies not only deepen our understanding of lived experiences but also foster meaningful change for both participants and researchers. The GROW model played a crucial role in shaping the PAR study by providing a clear, structured framework for the research process. This model facilitated the identification of goals, the reality of participants' experiences, the exploration of options, and the final steps of establishing a way forward. By applying the GROW model, the research process became more focused and manageable, ensuring that each stage of the study was aligned with the objectives of the participants. Additionally, the GROW model was instrumental in the process of applying for ethical approval. It helped address the amorphous nature of action research and provided a clear outline indicating at which point data collection would stop and move on to the next stage. This journey has reinforced the importance of generating knowledge and equally analysing, reflecting, and applying theory to develop impactful interventions. It has also highlighted the need to enhance the quality of patient resources to better support and empower individuals. This experience has strengthened my commitment to PAR and patient-centred care.

## Chapter Summary

This chapter provided an overview of the key findings from all three phases of the research project. It discussed these key findings and the implications of the research. An overview of the limitations, strengths, and the contributions each phase makes to the literature was also provided. Additionally, recommendations for future research were outlined. This chapter also reflected on the broader implications of the study, showcasing the potential of qualitative research methods to drive meaningful change. It advocates for

them and for future research to continue exploring diverse populations and refining interventions to address emerging needs. It also highlighted the transformative impact of PAR. It serves as a testament to the potential of this approach to foster empowerment and advance understanding, ultimately contributing to better health outcomes and more inclusive practices. The project provides a foundation for ongoing improvement and innovation in pain management for SAW.

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## Appendices

### Appendix One (A): Thematic Maps and Supporting Quotes and Extracts

#### Document One: Thematic Maps

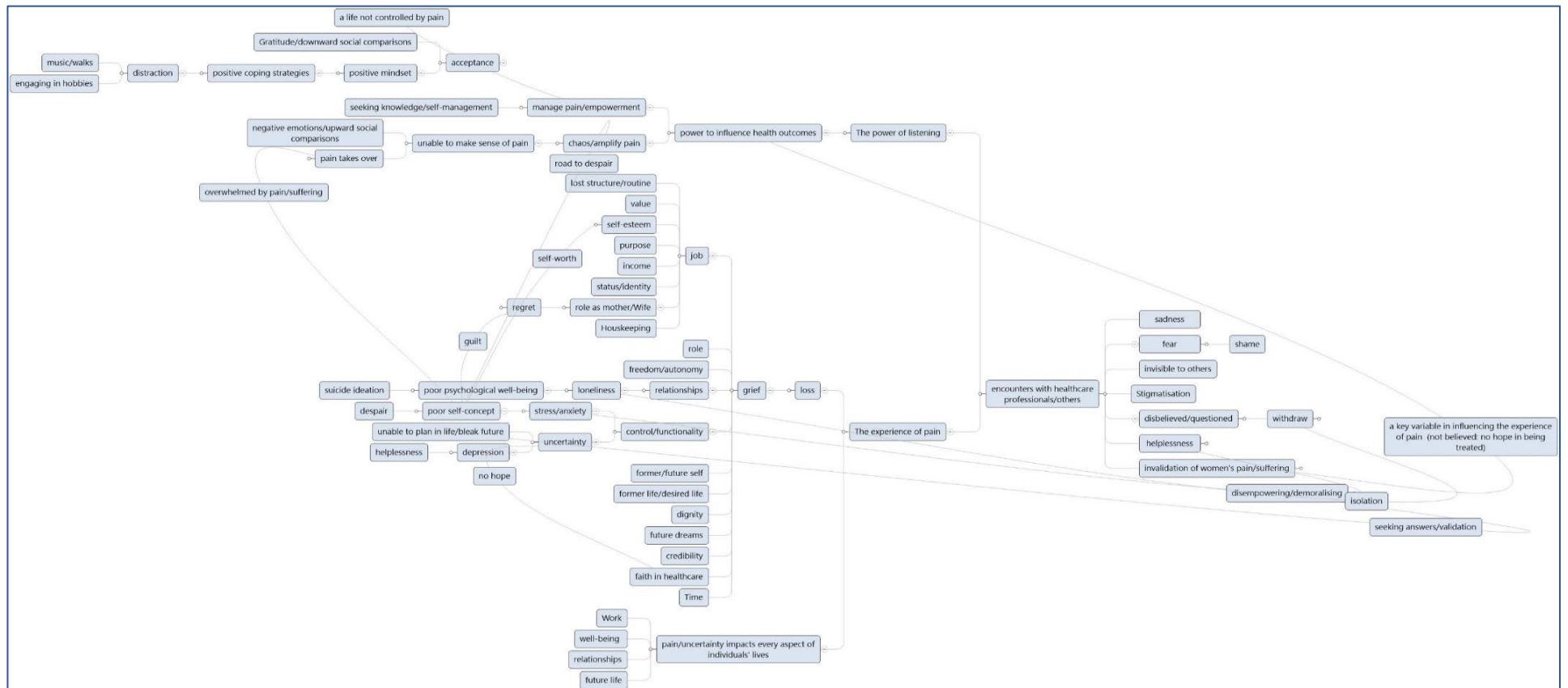


Figure 1 Initial thematic map

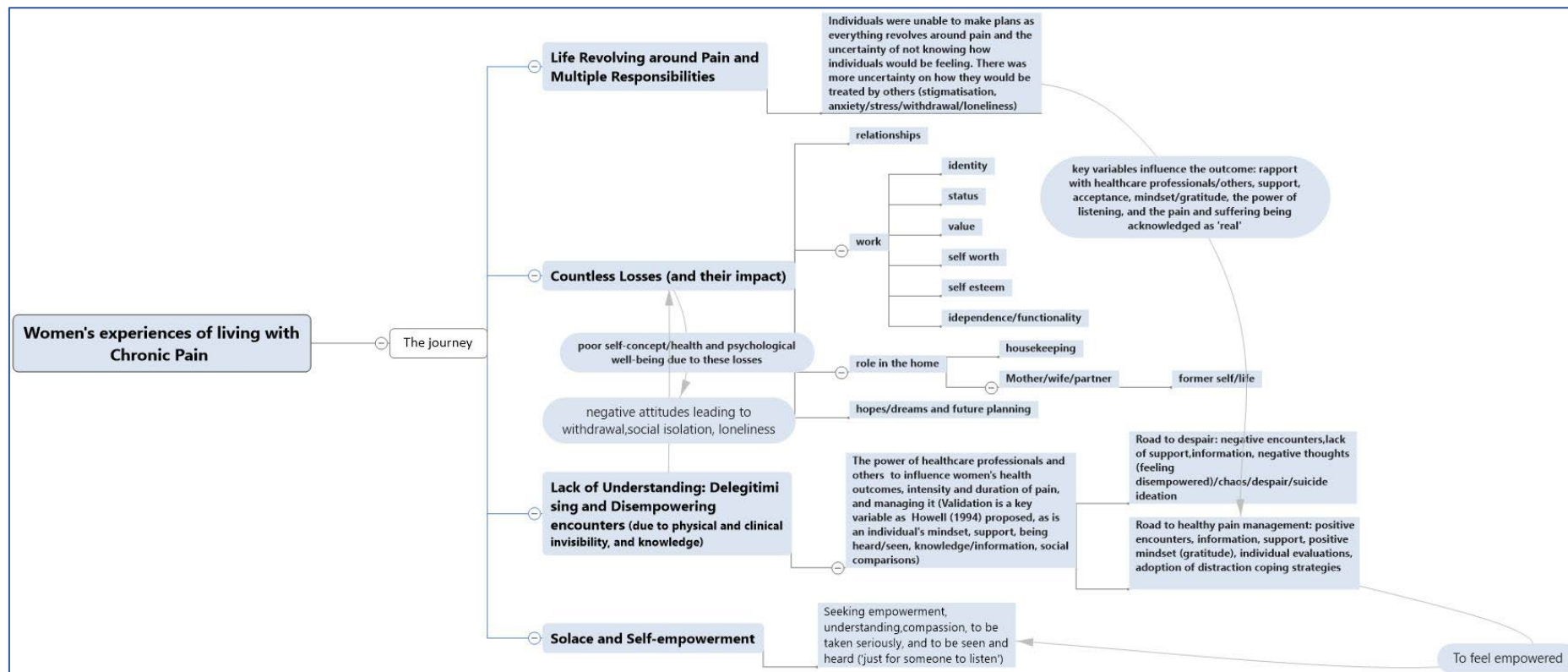


Figure 2 Final thematic Map

## Document Two: Table of Supporting Quotes and Extracts

**Table 1 Supporting Quotes and Extracts from Included Studies**

Study Author s (Date)	Life Revolving around Pain and Multiple Responsibilities	Countless Losses (and their consequences)	Lack of Understanding: Delegitimising and Disempowering Encounters Quotes/findings	Seeking Solace and Self-empowerment  Quotes/finding
Ahlсен et al. (2014)	Striving to manage pain and being aware of it I kept going.		'Nobody listened to me – nobody, neither the doctor nor my husband, so the situation gradually became very tense. I did not want to talk about it'.	Their stories tended to develop from “chaos”, towards a quest narrative with a more autonomous self. seeking control from chaos Linda’s story emphasizes the arrival of a renewed self, one that is more independent from medicine, and more autonomous than it had been in the past.
Allen et al. (2015)	Seeking help for pain	Lost hope in the healthcare system  “Ever since my hospital experiences, I’m traumatized now. You try and get me into a hospital, I ain’t going until I’m almost on my death bed”.  Lack of family support identified as a stressor	Communication was a key theme Women repeatedly described their experiences of being “ignored” and of feeling “rejected” . Multiple systemic barriers were described by women in managing their chronic pain including judgment (stigma) and poverty. They felt judged for being from a certain area and from a certain ethnic background. Experience feeling rejected by the healthcare system. I don’t wanna go back through not being listened to again, do you know what I mean there, right? . . . If you can reject it first before somebody rejects you, it’s easier to shut it down. It’s that wall you put up, right? You know, people think they’re all scum down here, but you know what, that’s - they didn’t start here. You know, this is just a place they ended up	Despite feelings of rejection, the women interviewed had found strength in solidarity, in peer-to-peer support groups and empowering partnerships with each other. Women specifically spoke about PACE Society staff and their empowerment and advocacy roles in a peer-to-peer setting.  “I always felt honored about who I am, you know, and validated and supported and I get more help from them than I do [laughs] with the doctors I go to seek help from.”
Arman et al. (2020)	Everyday life was described as a struggle, filled with demands and unpleasant chores: “Everyday things you have to do: shopping, cleaning, washing—everything.” Everything’s just difficult it’s not a life worth living in any way Sometimes all the pain and stiffness is really extreme. women emphasised focusing on carrying the load of their environment: caring for their children or close relatives, the family, the home, and their work. “I think I’ve done too much. I’ve sorted out the food, the house, the kids, largely by myself and then I’ve been working full-time.	grieving loss “You want to be able to do what you were able to before—it creates a lot of anxiety and grief “.  “Sometimes all the pain and stiffness is really extreme, but it might just be that the depression is the main thing”. Loss of Hope: “there’s nothing more I can do for you right now”.  Loss of relationships The women spoke of relationships deteriorating over the years. I’ve felt so incredibly lonely the whole time	Lack of understanding from others Suicide mentioned by some women I felt like I didn’t want to live anymore, it was so ...it’s not a life worth living in any way. Everything’s just difficult When they did seek medical help, they did not feel recognised, listened to: ‘they haven’t understood that I don’t feel well’. They felt left alone with their invisible health problems, when in health care encounters it was more or less directly expressed that “there’s nothing more I can do for you right now”. Women experienced emotional loneliness. I’ve never been able to talk to my husband. I don’t have anyone in my family I’ve been able to talk to.	Desperately seeking balance in their lives

	Women were caring for their children or close relatives, the family, the home, and had their work to deal with.		I've not been able to raise all of this with my friends because they don't really understand. So, I've felt so incredibly lonely the whole time.	
Barnes et al. (2021)	Speaking of pain as 'consistent' in life. 'The pain never seems to go away. The cycle has repeated itself once again; I went to sleep last night hoping that when I woke up this morning my pain would be gone.		Participants felt others did not understand: It's too hard to try and explain to her how I really feel; she never really understands, and I doubt she ever will (speaking about her mother).	Gratitude and hearing inspiring stories: Hearing his story really puts 'things into perspective when there [are] people that are in significantly more chronic pain and they are not letting it stop them'. Adopting a positive mindset I am inspired by our guest lecturer's determination and positive perspective. As I continue to listen, I feel less alone and very self-aware. I begin to feel grateful and incredibly lucky for the body I do have.
Bostick et al. (2018)	I think women tend to put up with a lot of pain and do things even when they're in pain because, like, they're providers. . .I know a lot of women have a lot more pressure at home right, with children and jobs, and expectations' (indicates a lack of support too)		Stigmatisation theme' I did feel dismissed... Maybe that was because I was female, maybe that was because I was emotional about it in, like, in explaining'. 'It's just not taken seriously (speaking of chronic pain). I think it's very difficult for women to be heard'. Participants felt that many HCP are not equipped with an adequate understanding of the unique aspects of women's pain. This lack of understanding included both women-specific issues and a general understanding of the complexities of pain and manifested as stigmatisation.	Wanted HCPs to have sufficient knowledge of pain to help them.
Campbell et al. (2022)	'Sometimes, it can be a giant mess and it becomes a struggle—you're not just struggling to deal with the chronic pain and the illness and the disease and the takedown and the comorbidities and the constant information, you have to become your own doctor'.	Loss of their energy/time The constant need to qualify and explain how pain was being experienced to new or disbelieving health-care providers was common and exhausting for women.	'...unless you have a huge gaping wound or something that they can see, it's really hard to be treated for pain'. Overwhelmingly, women experienced gendered treatment within the healthcare system and reported that they were frequently dismissed by their healthcare providers, most often physicians. It's easier to put the onus on the patient and say, "well we couldn't find anything wrong with you"	All participants sought out HCPs who were effective communicators and had compassionate attributes. Women seeking more information/research you have to become your own doctor, I swear. You've got the three years medical school, but you don't have the certificate hanging on your wall.'
Campeau (2018)			Medical discrimination and exclusion. 'When discussing their medical interactions, Participants described medicine as an institution less accessible to them because of their skin colour, clothing, accents or insurance. Many participants felt they received 'the scraps of medical care.'	Nine participants said they prayed, and eight elaborated that they prayed by reading verses of the Koran. "It's the only way I can sleep", Nimo explained. "When I wake up with pain, or with my anxiety", Muna said, "I read verses of the Koran. It's like meditation".
Dickson and Kim (2003)	Suffering with pain Being concerned with pain Felt persistent pain	Worrying about losing self-control Loss of functional abilities (Felt they were viewed as a burden by their children and spouses (self-stigma)	Lack of understanding from others (one participant spoke of her children)	Women were striving to reduce pain/Manage pain. Seeking alternative treatments to try and manage pain that their doctors had not been able to help with. Women tried to control their pain



Driscoll et al. (2018)			A distinct theme, "the challenges of being female," reflected women's perceptions of stigma and bias. Many perceived that providers approached them with a general disregard or disbelief about their pain, as if they were "making it up" or "he says it's all in your head. Go to mental health". Often prescribed an antidepressant. The women felt that they felt they were not adequately informed about how the medication would be helpful. They felt some interventions were not designed for women but men.	Women often wanted to find ways to manage their pain without medication. Women also felt that women-centered pain programs would be both encouraging and validating.
Dysvik et al. (2013)	The pain does not allow participants to participate fully in their roles.	The pain has stolen from me the roles of mother, wife, friend, and work colleague. Experiences of grief over time were commonly associated with chronic pain. The participants' past experiences reflected their grief at having to abandon jobs and social networks and revealed loneliness and despair. Lost self-esteem	Lack of understanding from others. Frustration and despair at the lack of their own understanding	There are stories of personal development and strength.
Evans and de Souza (2008)	'In any situation...my back comes first. Every situation you can possibly think of, that's what my back stops me from doing'. Theme: pain as a burden. Parenting responsibilities and pain described as a "dual burden". One participant commented that looking after her children was 'the hardest part of pain'.	'Not being able to do the things I used to. Because no one understands I feel like escaping. Sometimes I just feel like leaving. I've had enough. Some days I just can't do anything. And it drains you-physically and emotionally'. Lost friends. Lost opportunities for engaging in activities. They did not wish to be a 'burden socially' and frequently declined social outings.	'I've lost friends because they haven't understood. I think society and people out there do judge you. They can't see anything physical, so they don't believe you've got anything wrong with you'.	Focussing on blessings. Compassion and care for others (friendship groups). Education and learning (researching their condition provided the women with a sense of empowerment). Positive coping strategies and appreciating the small things.
Gonzalez et al. (2015)			Several women mentioned the lack of understanding other people have toward fibromyalgia, not valuing their symptoms and sometimes not believing that they really feel bad, in pain and incapable of working and fulfil their obligations. People still do not understand how we feel. Sometimes the pain and the fatigue are the worst but other times what hurts the most is to know what some people think about us.	Searching for self-enhancement. Learning to appreciate the small things. Appreciating the positive things in their life. A belief that future will bring happiness; the belief in protection from a "higher" force.
Gullacksen and Lidbeck (2004)	The women described how previously natural things like shopping, sitting in the car, receiving guests or running the household no longer could be accomplished automatically	"A gigantic mourning". They missed the kind of life they were used to. Some of them hid their sorrow by withdrawing while others gave voice to it. Losing oneself. The women described how previously natural things like shopping, sitting in the car, receiving guests or running the household no longer could be accomplished automatically.	Many of the women had the experience of being disbelieved when they sought medical treatment, and that their troubles were neglected or regarded as a sign of mental or social problems. They protested desperately: "I know my body well enough, and I am honest enough and capable of understanding that this isn't something in my head, this is something that has happened to my body," The situation was described not as insulting and a threat	Women valued information. Information about pain and increasing knowledge was important for coping with chronic illness and negative consequences.

			to the person's own reason. The doubts of the surrounding world were exhausting. Women felt rejected by the health care system, sometimes also by relatives and employers: this added to their suffering and stigmatisation.	
Hallberg and Carlsson (1998)	A majority of the women, older as well as younger, had no plans or expectations for the future because pain 'takes over'. 'It feels as if life is over', and 'Future? There is no future for me. It feels as if life is over. I live one day at a time'. The pain seemed to demand most, or almost all, of the women's energy, attention, and interest. For many women, pain seemed to be their whole life: 'The pain takes over all of you, there is nothing except pain and work'.	Loss of a life they had planned, lost hopes and dreams This is absolutely not the life I expected to live', 'I really hope that something will happen to change my life', and 'It is impossible to do the things I wanted to do most of all, for example, becoming a professional dancer'. A majority of the women had no plans or expectations for the future: 'I have no longer any zest for life', 'It feels as if life is over', and 'Future? There is no future for me. It feels as if life is over. I live one day at a time'.	All women described their perception of other individuals' doubts as to the reality of their pain and suffering. These distrusting attitudes were expressed explicitly or implicitly by people in general, and also by health care professionals 'I have mobility in my body, and it seems that if you are mobile then you cannot be in pain'. 'Nobody understands this disease. . .and nobody cares	
Hallberg and Carlsson (2000)	Pain is continuously present and affects every aspect of life. Life seems to be guided by the pain Women were preoccupied with their pain. There is a continuous awareness of and coping with the pain. Pain tends to interrupt normal life, demands attention and is difficult to disengage from.			Various coping strategies were being used
Horment-Lara et al. (2022)	Participants described maladaptive beliefs about pain, leading to fearful attitudes and low expectations for recovery. These beliefs seemed to perpetuate pain and stopped them participating fully in life( limit engagement in daily tasks and meaningful activities).	loss of work/being productive		Their current beliefs were maladaptive; however, they did wish to be able to be productive and not 'burden' anyone.
Howell (1994)	Life revolves around pain Pain takes over 'pain is my life' You want to crawl into a black hole...and not come out-except pain is in the hole with you. There is no escape'. 'stealing my life away' Pain stretches out in the future like a vulture	Loss and grieving process 'I had to quit working and that was just incredibly horrible for me because my identity has always been very tied up with my profession.' Losing the desired life In phase 1 counting the losses in mentioned as a subprocess: Losing physical abilities, former life, work, role in the family, friends, spiritual life, independence. 'Losing your mind' and doubting your own pain. Pain stealing my life	Others doubted the reality of their pain (self-doubt was mentioned too). A woman recalled being told by a neurosurgeon that there was nothing wrong with her and 'Nobody can fix you. Everybody has a bit of pain in life and you better just get used to it'.  'We are treated as if we were pesky little flies that won't leave our doctors alone. I want to shout and tell them, 'HEY, LOOK AT ME. I EXIST!!!' The medical profession make you feel 'degraded and less than human because you need them. No wonder chronic pain sufferers are either severely depressed and/or suicidal'.	Filling my life with new hope Women were seeking ways to maximise their pain management efforts and well-being
Hwang et al. (2004)	Female patients have more difficulties	Participants were in bitter tears of remorse over their past life.	'I never talk about my disease, but sometimes I feel so sad nobody understands my pain''	Attempt to overcome the disease by Themselves

	than male patients, because they still have responsibility for housework and childcare, even though they are patients.	<p>“When I was young, I worked hard for my family. I didn’t take care of myself. I feel empty now.”</p> <p>Loss of physical strength</p> <p>Missing past healthy life</p>	<p>“I don’t rely on anybody. This is absolutely my lone battle against the disease. I have to overcome it by myself.”</p> <p>Participants stated that they attempted almost all methods that were considered effective treatments, including various folk remedies.</p> <p>“I do anything if they are effective to cure rheumatism.”</p> <p>Try almost every effective treatment</p> <p>Rely on religion</p> <p>“I was very powerless a few months before.</p> <p>“Sometimes I serviced hospice care as a volunteer in church. I contribute to social benefit, and also, I am identified by my value.”</p> <p>“I have never given up what I want, because of the disease. Further, I always try to do what I want”.</p>	
Jusso et al. (2011)	<p>Housekeeping and shopping despite their pain ever-present pain.</p> <p>Women described how they had to wait for their body to catch up with their ideas.</p> <p>Times of increased pain further limited daily life</p> <p>They were never totally pain free as pain was always present.</p> <p>Pain dominated life</p>	Loss of functional capabilities	<p>They said that they were not listened to or taken seriously regarding their invisible pain.</p> <p>“Others can't understand what they can't see.” Women with FM described how they had repeatedly been disbelieved by HCPs. Not even their family understood their experience of pain.</p> <p>I was mocked at work when I had a hard day and had a lot of pain under my feet. It's like walking on glass actually and I had taken with me a paper about the pain so I could explain and then she came [the boss] and saw the paper and mocked me about it and that's why I've backed off and I don't want to tell anyone about the pain.</p>	<p>They found meaning in helping others who were in a worse situation than themselves.</p> <p>keep on going quite a lot...and I think this is mostly because I have to distract myself from the pain in some way....If I do something else and think of something else then I don't think on, well when something is fun, then you forget [the pain] for a while.</p> <p>Seeking ways to ‘forget’ the pain</p> <p>Positive mindset</p> <p>“The only way to survive is actually to be optimistic and try to make the best of everything.”</p> <p>I have had it for such a long time so I will probably have to live with it [the pain]. It has to be like this and I usually say that there are others who are worse off.</p>
Jusso et al. (2014)		Lost credibility	<p>Being disbelieved. Women with FM described that they had been met and received with distrust, because FM is an invisible illness with an unclear etiology.</p> <p>Women with FM described that when seeking help from health care personnel, they felt they were not listened to or taken seriously.</p> <p>A similar view was expressed about the work environment.</p> <p>Women with FM described the lack of understanding from within their family, as well.</p>	
Jusso et al. (2016)	<p>You keep on going the whole day at work and are totally exhausted when you come home, but it's actually then that everything starts. You have to manage the evening, also’.</p> <p>Pain did not allow them to continue to work</p>	<p>Loss of former work role</p> <p>Value/self esteem</p> <p>Losing full working capacity</p>		

Kanter et al. (2017)		Loss of relationships	Lack of understanding from family members/friends Lack of understanding from healthcare providers This emergent concept of isolation stemmed from a lack of understanding from family, friends, employers, and providers. Focus group discussion commonly revolved around comments that family members did not understand what it was like to live with the condition: 'They don't really understand'. Many patients talked about providers who did not understand or believe in their condition, which added to the significant loneliness and isolation.	Participants desired increased knowledge about their condition and largely preferred to hear about treatment options.  Information about their condition was important to manage it. During initial visits, patients wished to acquire knowledge about IC/PBS and requested information of potential causes and alternatives to treating it.
Kengen Traska et al. (2012)			Lack of understanding from others	Attending support groups Talking and listening to others in order to help them deal with their condition. Distraction strategies They mentioned meditation and listening to music or white noise as helpful –either done daily or following a stressor.
Kirkham et al. (2015)	To me it's just like a big thundercloud, black thundercloud. It's there all the time, but some-times you don't notice it, until it actually starts to rain	The self before pain and the present self		Aspirations for the possible relief of pain in the future
Knutson et al. (2022)	What the women were able to do varied according to the pain. The women described how one day's ups and downs were not necessarily the same the next day. Everyday life influenced and partly governed by pain and disability. A life with pain was unexpected. A significant focus in their lives was related to expectations about women, especially concerning domestic work. They described feeling a great responsibility to create a respectable and tidy home.	Loss of control What I find most challenging is not to be in control of myself. Loss of capabilities You can't go shopping or go for a walk with the baby in a pram. I have lost many friends	The women found it challenging that that their pain was invisible, and that people did not understand their situation. The women experienced limited knowledge and interest among health professionals, .Some had to abandon friends because they did not respect or understand their challenges.	Women still expressed a strong hope and belief that their condition would improve
Lehti et al. (2017)			Women felt that they struggled to be 'a proper patient' who had status and were respected. They struggled to be believed and there was a lack of understanding from HCPs: Sometimes when you go to see a doctor, you have make-up on and have fixed your hair. They say that you look very good. How can you have as much pain as you say? It does not seem to be so Not taken seriously	Patients tried to manage their own pain and were continuing to try and appear like 'a good patient' to be taken seriously it is important to fit into the norm of a proper patient by not looking too good (i.e. healthy) or too bad (i.e. ill).
Löfgren et al. (2006)	The participants had to endure the situation, knowing that it would probably last for the rest of their lives	Regret for the parts of life that no longer could be lived. They reached a turning point through grieving and accepting the situation.		Seeking empowerment by action orientated strategies learning everything there is to know about Fibromyalgia. They were reading extensively and discussed issues with others. It helped them find new ways to cope and encouraged them in thinking about their pain as not dangerous

Mellado et al. (2016)		Loss of relationships Participants spoke of how relationships had ended. “My engagement ended in 2001, since then I have been alone”	Lack of understanding about their condition also demonstrated by participants. Additionally, there were some misconceptions about the condition too. “Endometriosis is an infection, one thing I have and never heal”. “My relatives always avoid my company. No one understands me”	
Mellado et al. (2020)	“Sometimes I am good, and suddenly I start feeling pain again. The pain commands my life.” “... the pain is the cause of everything in my life”.	Women described progressive physical and psychological limitations, followed by loss of autonomy. Loss of relationships In the last two years, I have had no social contact. I have no friends.		Positive attitudes in face of the adversities of the pain, in general, led to the perception of improvement in the quality of life. It was also frequent the reference for finding comfort in religious faith “It is usually the job that helps me to forget the pain.” “But I don't let myself get down because of that. I live today. I don't let the pain get me down. "I ask God for strength,
Michaëlis et al. (2015)	The longstanding pain controlled the women, forcing them to adjust their lives.  Women were responsible for household chores such as cooking, cleaning, hoovering and shopping; however, only one received home help. Sole responsibility:  “House cleaning, I cannot do, and my house is dirty, but I have to do without a lot of things because I cannot carry it off”. The women struggled with maintaining motherhood roles and responsibilities despite the experience of chronic pain.	Loss of work, income, social connections I cannot work because of my pain, it affects my financial circumstances, and it affects me socially Loss of social relations Loss of control	HCP encounters: women felt that they not being listened to or taken seriously, and this was viewed as hindering their attempts of gaining a sense of control.	
Molin et al. (2021)	Pain meant that the women had to make many adjustments as well as reprioritise	Grieving theme Loss of former self The women could not recognise themselves as the persons they used to be and found it difficult to reconcile themselves: I don't like who I have become'. They were also mourning that they were restricted in their social relationships and unable to pick up their child, go swimming with them, and engage fully with their child. The women felt that they did not live up to the role model of a mother.	Some women also experienced being met with distrust and scepticism.  No one can believe that I am in so much pain. So, I think it's hard even for my family, they do not understand.	The women constantly struggled with the pain but, despite that had hopes for improved health in the future.
Molin et al. (2022)		Loss of autonomy/control Loss of confidence in themselves One woman reported that she started to doubt her own experiences to the degree that she thought that the pain was in her	There was a lack of understanding among the women themselves about their condition and they stated that this was due to inadequate, insufficient, and incorrect information being provided by HCPs. Access to information is essential	Many women sought information from other sources. They often asked acquaintances and friends for advice or sought information on the internet. Several women found groups on Facebook where they

	imagination. It is almost as if you think you are imagining it.	to achieving patients' empowerment	met women with similar problems. In these groups, the women often received acknowledgement, which made them feel less isolated and alone. Almost all women expressed the need and desire for more information about persistent pain after childbirth. The women said that the information should be preferably written, as a brochure or book, which they could read when appropriate and which they could return to if necessary. Something in the form of a slim book.
Monsivais (2013)	Loss of functioning Loss of former roles	Participants in this study were subject to stigmatization primarily related to the invisibility of pain. "I think my family thought I was faking it and I started feeling like I better not even tell anybody because I feel like I'm faking it".	
Müllersdorf et al. (2011)	Loss of capabilities	Not being properly examined, or offered optimal treatment, not being believed or understood, were all seen as signs of dismissal within health care.	Seeking help Participants in the study had hopes and expectations when they sought health care.
Mustafa et al. (2020)	<p>Women had to balance traditional household responsibilities of family labour and care alongside employment outside the home, exacerbating pain.</p> <p>Women spoke a great deal about the physical strains put on their bodies through a never-ending workload since their arrival in Canada.</p> <p>Housework—such as errands, taking care of children, cleaning, and cooking for their families—was highlighted as their sole responsibility because they were women.</p> <p>Women identified family stress associated with their responsibilities and duties as another reason pain became chronic in their lives. They also indicated that due to their gender roles, most of their lives were spent prioritizing the needs of others, especially their husbands and children. They felt that they often neglected themselves.</p> <p>Women were also overwhelmed by work. They spoke of being entirely responsible for the household as well as working outside the home.</p> <p>Women were expected to drive children to and from school and extracurricular activities, as well as take care of the elders who often lived with them in a joint family setting.</p> <p>Chores were considered mandatory</p>	Women expressed the losses of leaving their homeland, one of which was a loss of domestic help.	

Nortvedt et al. (2015)	Pain meant withdrawing from employment uncertainty and insecurity about their pain and their challenging lives at home and at the workplace.	Loss of willpower, control, hope Loss of being able to return to work 'loss of life energy'	Women suffered because they did not understand their pain. They experienced discriminative attitudes among colleagues and employers at their workplaces, which worsened their suffering. The women in this study had experienced being rejected and mistrusted, and in general not being taken seriously, by their general practitioners.
Nortvedt et al. (2016)	Women could not prioritise their need for rest and recuperation in their homes because of high demands in caring for their families, taking on economic responsibilities and dealing with violent or sick spouses.	Loss of functional capabilities	<p>Their employers lacked sufficient knowledge of painful chronic diseases and hardly made efforts to include these women into the work community or help make the workplace suited for their needs. One woman described how she felt rejected and humiliated by her boss when she asked for suitable work tasks at the primary school: One day he [the boss] told me that maybe I should start thinking about changing primary schools if I couldn't work here. They experienced lack of understanding from their work colleagues.</p> <p>Being excluded or not feeling valued by colleagues, employers or even by family members rendered their daily lives humiliating and lonely. Another example was a woman who even after explaining to her boss about work tasks that provoked pain, she was still assigned heavy duties and unsuitable work. Therefore, she felt that she was poorly and unfairly treated: ... no consideration was given to how I could carry out my tasks. I didn't get any help from the management or colleagues. They never even took that into consideration. The women expressed that they experienced attitudes like trivializing, condemnation and indifference from their workmates.</p>
Nyen and Tveit (2018)		Painful Losses (lost homeland, relations, dreams)	Many of their stories recounted frustrating and unsatisfactory encounters with health personnel
Osborn and Smith (1998)	Not being able to engage fully in life due to pain I'm only 50 and I should be doing this that and the other cos they say life begins at 40 but I can't and I s'pose it does bother me, it's frustrating that people of my own age are you can see them flying their kite and you feel as if you can't.  Pain stopped my life completely	Loss of past self Alice grieved for her personality; she wanted to be the 'old Alice', the Alice who could exercise regularly to keep her weight. I used to be right bubbly and lively and you know, but it's, that's gone, and even my mum says that I've changed,	<p>Lack of understanding The participants felt a continual need to justify their pain as 'real', that is not in any way psychogenic which was synonymous with 'mad or bad': It's quite embarrassing because its nor something that you can see and I do feel guilty, I know that my back really does hurt and I'm not making it up and I feel sort of angry that I can't do it and I think well I wish I could</p> <p>Gratitude I felt sorry for myself, and then I saw somebody else in a wheelchair so you know, I'm not quite as bad as that. This comparison with others who were more unfortunate was intended or considered as a strategy for enhancing self-esteem</p>

		<p>just prove to them that my back really is bad and that I really must not do it, because if I do I put myself back week.</p> <p>Participants dissatisfied with their own understanding of pain.</p>	
Peppard et al. (2022)	<p>Preoccupied with pain</p> <p>A constant internal battle, managing pain is done or experienced on an ongoing, daily basis.</p>	<p>disparities in health care due to self-perception of provider bias as pain is not understood.</p> <p>Women not being treated fairly compared to men</p> <p>I've seen the difference on active duty, and I see the difference now. My husband gets better health</p>	<p>I've learned to live with it. Tough it out and it becomes your new normal, being in pain."</p> <p>"I try to maintain a positive attitude, develop coping strategies</p> <p>I have to learn how to still be a full-time mom.</p>
Pryma (2017)	Loss of work/careers	<p>Most women interviewed reported interactions with doctors who did not believe that fibromyalgia was a real disorder</p> <p>"I know it's considered the invisible disease, but I'm visible, and this is what I have."</p> <p>Not being believed by others and the HCPs</p> <p>Black women consistently offered vivid descriptions of feeling as though their pain was invisible to others because of their race.</p> <p>Stigma</p> <p>shared stigmas, across race, reported by the women. They could all describe at least one instance in which someone doubted the legitimacy of their pain or disability. Carlie, a middle-aged, working class, white woman explained the challenges of convincing her family that her fibromyalgia was truly disabling:</p> <p>I just tell them like why I would give up the career that I wanted to do for all of my life. . .like why I would quit that if it wasn't real? Why would I go from making like three or four thousand a month to making thirteen hundred if it wasn't real? Like I try to explain to them and tell them I don't like being like this.</p> <p>One woman speaking of her doctor:</p> <p>'I don't think he believes it exists (Fibromyalgia) for any woman, but I believe if I had been a white woman, he would have gone, and, you know, done things quicker'.</p> <p>Welfare Stigma</p> <p>They say that I'm acting. . .even my sister says that I'm 'acting like a crazy so I can get a check.' And she spreads this around that I'm a hypochondriac and I'm just nagging. . .and she don't know that that's so far from the truth, but coming from a family member, it hurts even more than it does from a stranger</p>	



Råheim and Håland (2006)	The Body “Threatens to Take Full Control”, Agnete feels alone in taking care of her children. She and the baby have been ill several times since the baby was born. She has no energy left for her older child, which is very hard for her. Her husband regularly leaves early and works late and does not take part in the practical care of their children. At the heart of this experience is a feeling of being at the will of a treacherous body and left alone in never-ending pain.	Loss of control	Lack of understanding for the family	I have decided to make it. I will not break down. I feel strong.” But it is a struggle.’  We (woman speaking about her husband) have solved it by talking about it. That is easier for me, so he just had to listen. Long nights talking, because it was important that he should understand my situation.
Reibel and Pearson (2017)		Loss of hopes unemployment deterioration of relationships with spouses and family	<p>“There is nothing I can do for you. If I can’t prescribe you medication, there is nothing I can do for you. The rheumatologist that I saw knew what fibromyalgia was, but he didn’t believe in it. The experience of living with FM was one of being dismissed by the medical community. My doctors didn’t believe me, my family didn’t believe me, and my friends were not there for me. I had no support. I even lost my husband (divorce).</p> <p>My husband would say, “You are crazy,” and he would even say I was lazy.          “You know the doctors can’t find anything wrong with you, all your tests are coming back normal, maybe it is in your head, and you need to see a psychologist.”          The stigmatization was clearly expressed by each. Physicians and significant others had tried to assign labels of crazy and lazy to these women.</p>	<p>When he (doctor) saw the support group bracelet on my arm, he said, “Where did you get this? ” I said, “From the fibromyalgia support group.” I said, “I have found other people like me, this is real, I don’t care what you say.” From here on out I found another doctor.</p> <p>The power of listening          HCPs who demonstrated concern for their well-being and willingness to actively listen to their health concerns. These specific interactions proved to be monumental in their lives.</p> <p>She [HCP] said, “I’m going to get you some help.” This was such a relief. I said, “Whatever you say, I’ll do it.” She could say “You need to go to the edge of the river and kneel down and pray,” and I’d do it. She saved my life. I thank God, she saved my life</p>
Richardson (2005)	Responsibility for housework (even if women were in pain and not able to work outside the home) was mainly on women.	Losing credibility	Lack of understanding from others due to their condition being invisible I mean I had more sympathy from people when I had this tumour because I had a scar and bandage; that was visible. I’ve got this scar down my back that no-one sees and, you know, people think I’ve got a ‘backache’: ‘Oh yes, you’re whinging again’. So, I don’t talk about it.	Utilising coping strategies – what do you call them? – a shoulder bag type thing, I used to put in my cleaning, anything I wanted and hobble around with that, so you find ways of managing things. You don’t have a choice; you just have to do it.
Robertson and Reynolds (2002)	The unpredictable nature of chronic pain had an effect on the events women could plan for the day. “I can’t make a commitment of any sort for the next day. That bothers me. I don’t know where it’s [pain] going to be.”	I think my personality has changed a lot. I’m a different type of personality because of pain. I do not think I’m as cheerful a person or as enjoyable to be around as I might once have been because I always had fun, you know.	One woman suffering from multiple pain sites related that a nurse told her “Tough! Go home. We can’t give you any more medicine.” Some women believed physicians trivialized their pain by simply telling them to “go home and take two aspirins” or by suggesting that the pain was “in my mind.” Still others expressed a frustration with the way “old age” was looked upon	Gratitude/positive mindset As a widow with no children and no acknowledgment of having any close friends, Vera had adopted a philosophical outlook on her pain: When you hear someone else’s problems, they are always worse.

	<p>I get irritated because, for one thing, mine isn't constant and so I never know when I can make plans to do anything.</p> <p>Chronic pain influenced all aspects of the women's lives, and all aspects of life influenced the women's ability to respond to and manage their pain</p>		<p>by some in the medical profession. As one woman said, "I think they [doctors] think after you are 80 you should prepare to die. They don't encourage you to try to live."</p> <p>It was difficult not being believed and they felt people could understand what it was like to live with pain.</p>	<p>Be thankful you have got your own</p> <p>Women were sharing strategies with friends that were also living with pain to help manage it</p> <p>The women developed their own regimens for dealing with the pain such as applying salves to the pain area, seeking homeopathic treatments, and using heating pads.</p> <p>Distraction strategies</p> <p>One woman shared that she tried to "keep myself busy and try to keep my mind off of it as much as I can. That seems to help me deal with it."</p> <p>Other women listened to music, meditated, or used breathing exercises. The women also used prayer as a way of coping with the pain. One woman said "I have to work it out between me and God . . . He's heard me every night: 'Please just let me get up in the morning:'.</p>
Schaefer (1995)		<p>Mournful of past life</p> <p>'My husband left me because he could not deal with the disease'.</p>	'The doctor just didn't believe me'	<p>Searching for answers</p> <p>Women continued to seek help. Moving on involves finding meaning, living day by day, creating a safe environment, and transcending the illness.</p>
Skuladottir and Halldorsson (2011)	<p>The women were used to doing the housework, it used to be their role</p> <p>Some were also obliged to do the housework because no-one else did.</p>		<p>More disbelief and being misunderstood by others: 'Well, you can work, you are not that bad'. They don't realize what it takes to be able to cope.</p>	<p>If you are determined to live a satisfying life, you have to find a new purpose. Have something else to do (participant)</p> <p>There are two options, to give up and be depressed or to try to live a good life with this.</p>
Söderberg and Lundman (2001)	<p>Women described having problems with housework</p> <p>"One can never plan to do anything . . . instead you are day-by-day, and you have to see how it goes."</p>	<p>Transitions in Social Life.</p> <p>You lose your social contacts.</p> <p>Some of the women expressed sadness at having to leave their jobs, and a sense of being placed outside the world, and they felt that they were less valuable: I felt it was very difficult, it was like losing something of myself . . . my identity. . . . It was as if I'm nothing anymore in principle. I can't be what I was before . . . it's hard.</p>	<p>Speaking of husbands</p> <p>it's a little bit hard for him to understand this, I don't think he understands really how difficult it is for me sometimes.</p> <p>Lack of understanding led to feelings of alienation</p>	<p>It's clear that you are hoping, and you must never give up hope, it's the last thing you give up, hope. You hope all the time that something will happen'.</p>
Söderberg et al. (1999)		<p>Credibility/dignity</p> <p>Loss of confidence (self-doubt)</p>	<p>Women felt that they were not believed when they were seeking help</p> <p>Not taken seriously/laughed at</p> <p>Lack of knowledge about FM and negative attitude of society.</p> <p>They did not feel that they were respected as human beings</p> <p>'If you do not look like a sick person, you cannot be sick'.</p>	<p>They had a need to understand their condition.</p> <p>Wanted to be able to defend themselves and increase awareness</p> <p>Women felt that disseminating knowledge about their condition would allow them to defend themselves. It is important to spread a positive attitude and to dissolve prejudice.</p> <p>Disbelief caused pain.</p>

			<p>Not being believed made them question themselves</p> <p>They experienced lack of understanding and a negative attitude from HCP, family, friends, and colleagues.</p> <p>They felt the lack of understanding was because it is not easy to understand what one has not experienced.</p> <p>The study revealed a lack of knowledge about FM in society and among HCP.</p>	<p>‘...all those around you should know what it means...more information is needed...so they can understand better.’</p>
Wade and Shantal (2003)	Pain Takes Over Your Life	Loss of former life/self control	<p>A participant’s doctor refused to acknowledge the validity of her complaint, causing her to lose a disability claim: You’ve got no power and you’ve got no proof. . . What do you do? He says to you “You’ve got no pain...there’s nothing showing up on this X-ray. Lady, do you want to be sick, or do you want to be better?” “No, no I want to be better.” “Well then, there’s nothing wrong with you!”</p> <p>Judgements from HCPs/significant others</p>	<p>Praying</p> <p>Participants emphasised that it is vital to retain hope, because losing hope may lead to one being overwhelmed by pain and even to suicide.</p> <p>Valued information about their condition</p> <p>Participants highlighted the importance of education and knowledge and of the mind in dealing with pain.</p>
Werner and Malterud (2003)		hope	<p>Negative encounters with HCPs</p> <p>Some mentioned, when consulting HCPs being “tested”, “checked”, or “assessed” for mental rather than somatic factors.</p> <p>“hard work being a credible patient”</p>	<p>Seeking empowerment</p> <p>continuously having to “take the initiative”, persevere, be stubborn, and spend all their strength on struggling, quarrelling, and asserting themselves during consultations, some of them still pointed out that they would not give up.</p>
Werner et al. (2004)	It is difficult to accept that I can’t do everything that I want to do	Loss of former self/capabilities	<p>Not believed by HCPs</p> <p>Met with scepticism and distrust</p>	
Wester gården et al. (2021)	<p>The women either allow the pain to overshadow their daily life, adapting their lives to the pain, or resisting the pain to determine the terms of daily life.</p> <p>Pain...affects one’s whole situation, concentration, and general disposition”</p> <p>Participants with CWP felt that the pain affected their possibilities of carrying out daily activities, such as household chores, gardening, or duties related to work</p>	Lost friends/a social life functionality	<p>Their condition was often not taken seriously because the pain was not visible</p> <p>Stigmatisation</p> <p>The ignorance of the public regarding the pain-affected daily life to such an extent that most participants started to withdraw</p> <p>They felt neglected as a person and feeling lonely among other people</p>	
White and Seibold (2008)	<p>‘My life actually revolves around my pain most of the time’. I can assure you this is not the way I want it, but it is something I’ve had to come to terms with and live with’.</p> <p>‘You can’t just do anything you want. You’ve now got this little thing called severe back pain constantly holding you in check.’</p>	<p>Loss of mobility, loss of roles, financial security, and a partner and friends.</p> <p>I am now divorced. I don’t blame my former partner who had met and married someone who no longer exists.</p>	<p>‘You’ll have to fake a smile. Of course, when people see you doing this, more often than not they’ll think you’re a fraud and a malingerer, leaving you feel judged and stigmatised’.</p>	Trying to do ‘my best’

Wuytack & Miller (2011)	The unpredictability of their symptoms obliged them to live on a day-to-day basis making it difficult to plan.	<p>Lost identity/work role</p> <p>Friends</p> <p>They don't understand it because they don't see it. I used to give a lot of explanation, but now I can't be bothered anymore. There are very few people who understand it.'</p> <p>My husband at the time my symptoms started showed really no understanding whatsoever. . .we divorced'.</p>	<p>lack of understanding and social acceptance of fibromyalgia</p> <p>'All the women had experienced disbelief, denial and lack of commitment and interest. Participant 4 had an experience which was typical of the latter: 'At the start of my complaints I visited a neurologist who had frankly said:</p> <p>"There are believers and non-believers, and I am a nonbeliever, so we're not going to talk about that." That really closed a door for me.' Most said to have had so many negative encounters, that they were utterly grateful to those health practitioners who had shown respect and understanding.</p>	Some had taken on new hobbies as a way to regain some purpose in life.
Zander et al. (2013)	Pain destroyed life; it limited the women's everyday activities and possibilities to have fun, and it created a negative atmosphere	Loss of work/roles/mobility		Seeking comfort in religion

## Appendix One (B): Ethical Approval Forms

### Document One: Ethical Approval for Phase Two



School of Health, Science and Wellbeing

#### ETHICAL APPROVAL FEEDBACK

<b>Researcher name:</b>	Sukhvinder Biring
<b>Title of Study:</b>	SU_22_076 'Exploration of South Asian Women's experiences of living with chronic pain, their well-being, health care, and pain management.'
<b>Award Pathway:</b>	PGR
<b>Status of approval:</b>	Approved

Your project ***proposal has been approved*** by the Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal. This approval is only valid for as long as you are registered as a student at the University. You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

The Ethics Committee wish you well with your research.

**Signed:**

**Date: 20.02.2023**

Dr. Edward Tolhurst  
Ethics Co-ordinator for Health



## School of Health, Science and Wellbeing

### ETHICAL APPROVAL FEEDBACK

<b>Researcher name:</b>	Sukhvinder Biring
<b>Title of Study:</b>	SU_22_357: <i>Self-management of chronic pain for South Asian Women</i>
<b>Status of approval:</b>	Approved

Thank you for addressing the committee's comments. Your research proposal has now been approved by the Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal. This approval is only valid for as long as you are registered as a student at the University.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

**Signed:**

**Date: 16.11.2023**

Dr Edward Tolhurst

Ethics Co-ordinator for Health

## **Participant Information Sheet**

### **Exploration of South Asian Women's experiences of living with**

### **chronic pain, their well-being, health care, and pain management**



My name is Sukhvinder, and I would like to invite you to take part in this study, which is being undertaken as part fulfilment of a PhD in Health Studies, under the supervision of Dr Amy Burton, Dr Lynn Dunwoody, and Professor Peter Kevern. The study aims to explore the experiences of South Asian women living with chronic pain. Before you decide whether to participate, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully. and please feel free to ask the researcher if there is anything that is unclear or if you would like more information.

Thank you for taking the time to read this

#### **Why is the research being conducted?**

South Asian women (SAW) are more likely to be affected by chronic pain/certain conditions. However, there is a lack of recent research that explores chronic pain in SAW. Consequently, they remain underrepresented in health research and there is a lack of knowledge about their needs, experiences of living with chronic pain and the healthcare system, and how they manage their condition. This is important as ethnicity and culture are factors which can influence both pain perception and behaviour. Thus, a greater understanding of SAW's needs is required if holistic, culturally sensitive care is to be provided. This study aims to gain deeper insight into the experiences of SAW living with chronic pain.

#### **Why have I been invited to take part?**

You meet the inclusion criteria: a South Asian Woman, aged eighteen years or above, living in the UK, and managing chronic pain. The definition of chronic pain used in this study is any pain which carries on for longer than twelve weeks, despite medication or treatment. The research requires individuals to meet this criterion.

#### **Do I have to take part and what is involved?**

You are under no obligation to take part, but if you decide to, you will be asked to participate in a one-to-one interview with the researcher, to discuss your experiences of living with chronic pain, the healthcare system, and pain management. The interview can be conducted on the phone or as an online video call (whichever you prefer). However, this will only be audio recorded. You will also be asked to sign a consent form, complete a short demographics questionnaire, and email this to me (post/arrange to have it collected), prior to the interview. I will then arrange a time for the interview that is suitable for you. The demographic information can also be collected at the start of the interview if you prefer.

It is important to note that there are no right or wrong answers to my questions, I am seeking to gain a deeper understanding of your experiences. The interview will be audio recorded and should take no longer than forty-five minutes of your time. All data will be stored securely

and remain anonymous. The audio recording will be destroyed after it has been transcribed. The data and findings will be written up as part of my thesis, but all information will be anonymous.

You will also have the option to participate in any follow-up activities that explore the findings of the present study and possible future interventions, actions, and recommendations.

**Are there any risks to taking part?**

The risks are very minimal, but I appreciate that it may be upsetting talking about your experience/condition. You may stop the interview at any time and skip any questions you do not wish to answer. I have also provided a helpline number and some websites for information that you may find of use.

**Are there any benefits to taking part?**

There are no direct benefits for participating in the research study, however, it is hoped that your participation will provide insights about SAW's experiences of living with chronic pain, managing it, and their needs. These findings will be used to explore possible future interventions/actions of how pain management could be improved for SAW.

**Will taking part in this study be kept confidential?**

All information we collect from you will be stored securely and anonymised. This means that your name and any other identifying information you share during the interviews will be removed. Quotes from your responses to the questions may be included within final reports of the findings, however, you will not be able to be identified from the quotes used. This study complies with the General Data Protection Regulations 2018. Staffordshire University is the managing organisation for this study. The data will be stored securely for ten years, after which it will be destroyed by the researcher. Anonymised data will not be able to be erased from outputs (e.g., PhD thesis, articles), and if published in academic journals, it may be made available permanently, in a repository, if required. You can choose to not permit this but still take part in the study.

However, if a situation arises in which a disclosure may reveal that you or someone you know is at risk of harm, I will be required to notify the appropriate health/emergency services.

**What if I change my mind about participation?**

Your participation is voluntary, and you are under no obligation to participate. If you agree to take part and then decide before or during the interview that you want to withdraw from the study, just let me know (by e-mailing me before the interview or by letting me know during it). You can withdraw your data up to two weeks after the completion of your interview by contacting me via email/phone.

**What will happen to the results of this study?**

The results of this study will be used in the writing of my PhD thesis (this may involve other publications, such as academic journal articles). The results will also be used to inform the next stage of the study, and this may involve the design of an intervention or exploring how chronic pain management could be improved for SAW.

**What happens next if I do decide to take part?**

You can contact the researcher via email ([sukhvinder.biring@research.staffs.ac.uk](mailto:sukhvinder.biring@research.staffs.ac.uk)), and if



you wish to take part, a copy of the consent form, demographics questionnaire, and other relevant information will be emailed/provided to you. I can also collect the demographic information at the start of the interview if you prefer.

**Who has reviewed this study?**

The study has been reviewed and approved by the Staffordshire University Ethics Committee.

**Further information and contact details**

Should you require any further information, please feel free to contact the researcher (sukhvinder.biring@research.staffs.ac.uk), the research supervisors, Dr Amy Burton (amy.burton@staffs.ac.uk), Dr Lynn Dunwoody (l.dunwoody@ulster.ac.uk), Professor Peter Kevern (P.kevern@staffs.ac.uk), and the Chair of Health and Social Care Research Ethics Committee, Dr Edward Tolhurst (e.tolhurst@staffs.ac.uk).

**What if any issues arise during my participation?**

If any concerns or issues arise throughout the study, please contact myself, my supervisors, or the chair of the ethics committee, by using the contact details provided

**Help and Information about Chronic pain and well-being**

Healthtalk.org is run by the Dipex charity and they help people by providing useful information and links to organisations on chronic pain (and other conditions). Others can share their experiences if they wish to. Many individuals have shared their stories, to try and increase knowledge and understanding of what people may/can experience and expect, when living with a particular condition, and help others to feel less alone. More information and support can be gained via their website at address below.

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

Pain UK is a charity that also has information that you may find helpful. Please find their website address below.

<https://painuk.org/help-and-support/>

The Mental Health Foundation and Mind are both great charities, based in the United Kingdom. They provides support and resources on mental health and well-being, and their websites can be accessed at the addresses below.

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

Mind also offer an information line, and you can reach this service at the number below:  
0300 123 3393

**Thank you**



### ਭਾਗੀਦਾਰ ਜਾਣਕਾਰੀ ਸ਼ੀਟ

ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ, ਉਨ੍ਹਾਂ ਦੀ ਤੰਦਰੁਸਤੀ, ਸਿਹਤ ਸੰਭਾਲ, ਅਤੇ ਦਰਦ ਪ੍ਰਬੰਧਨ ਦੇ ਨਾਲ ਰਹਿਣ ਦੇ ਅਨੁਭਵਾਂ ਦੀ ਖੋਜ/ਅਧਿਐਨ/ਰਿਸਰਚ

ਮੇਰਾ ਨਾਮ ਸੁਖਵਿੰਦਰ ਬਿਰਿੰਗ ਹੈ, ਅਤੇ ਮੈਂ ਤੁਹਾਨੂੰ ਇਸ ਰਿਸਰਚ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਾ ਦੇਣਾ ਚਾਹਾਂਗੀ, ਜੋ ਕਿ ਡਾਕਟਰ ਐਮੀ ਬਰਟਨ, ਡਾਕਟਰ ਲਿਨ ਡਨਵੁੱਡੀ ਅਤੇ ਪ੍ਰੋਫੈਸਰ ਪੀਟਰ ਕੇਵਰਨ ਦੀ ਨਿਗਰਾਨੀ ਹੇਠ ਹੈਲਥ ਸਟੱਡੀਜ਼ ਵਿੱਚ ਪੀਐਚਡੀ ਦੀ ਇੱਕ ਹਿੱਸੇ ਦੀ ਪੂਰਤੀ ਵਜੋਂ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ। ਅਧਿਐਨ ਦਾ ਉਦੇਸ਼ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਨਾਲ ਰਹਿ ਰਹੀਆਂ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਅਨੁਭਵਾਂ ਦੀ ਪੜਚੋਲ ਕਰਨਾ ਹੈ। ਇਸ ਤੋਂ ਪਹਿਲਾਂ ਕਿ ਤੁਸੀਂ ਇਹ ਫੈਸਲਾ ਕਰੋ ਕਿ ਕੀ ਹਿੱਸਾ ਲੈਣਾ ਹੈ, ਤੁਹਾਡੇ ਲਈ ਇਹ ਸਮਝਣਾ ਮਹੱਤਵਪੂਰਨ ਹੈ ਕਿ ਖੋਜ/ਅਧਿਐਨ ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ ਅਤੇ ਇਸ ਵਿੱਚ ਕੀ ਹੋਵੇਗਾ। ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਬਾਰੇ ਹੋਰ ਜਾਣਨਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਖੋਜਕਰਤਾਵਾਂ/ ਰਿਸਰਚਰ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

### ਇਸ ਨੂੰ ਪੜ੍ਹਨ ਲਈ ਸਮਾਂ ਕੱਢਣ ਲਈ ਤੁਹਾਡਾ ਧੰਨਵਾਦ

ਖੋਜ/ਅਧਿਐਨ/ ਰਿਸਰਚ ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ?

ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਨੂੰ ਲੰਬੇ ਸਮੇਂ ਦਾ ਦਰਦ ਹੁੰਦਾ ਹੈ। ਪਰ ਉਹਨਾਂ ਬਾਰੇ ਬਹੁਤ ਘੱਟ ਖੋਜ/ਅਧਿਐਨ ਹੈ। ਸਾਨੂੰ ਉਹਨਾਂ ਦੀ ਸਹਾਇਤਾ ਕਰਨ ਲਈ ਉਹਨਾਂ ਦੇ ਦਰਦ ਦੇ ਅਨੁਭਵਾਂ ਨੂੰ ਸਮਝਣ ਦੀ ਲੋੜ ਹੈ।

ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕਿਉਂ ਸੱਦਾ ਦਿੱਤਾ ਗਿਆ ਹੈ?

ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਲੋੜਾਂ ਨੂੰ ਪੂਰਾ ਕਰਦੇ ਹੋ: ਇੱਕ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤ, ਅਠਾਰਾਂ ਸਾਲ ਜਾਂ ਇਸ ਤੋਂ ਵੱਧ ਉਮਰ ਦੀ, ਜੂਕੇ ਵਿੱਚ ਰਹਿ ਰਹੀ, ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਨਾਲ। ਇਸ ਪ੍ਰੋਜੈਕਟ ਵਿੱਚ ਹਿੱਸਾ ਲੇਹਨ ਲਈ ਤੁਹਾਨੂੰ ਦਵਾਈ ਜਾਂ ਇਲਾਜ ਦੇ ਬਾਵਜੂਦ ਬਾਰਾਂ ਹਫ਼ਤਿਆਂ ਤੋਂ ਵੱਧ ਸਮੇਂ ਲਈ ਦਰਦ ਹੋਣਾ ਚਾਹੀਦਾ ਹੈ।

ਕੀ ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣਾ ਪਵੇਗਾ ਅਤੇ ਕੀ ਹੋਵੇਗਾ?

ਜੇਕਰ ਤੁਸੀਂ ਨਹੀਂ ਚਾਹੁੰਦੇ ਤਾਂ ਤੁਹਾਨੂੰ ਹਿੱਸਾ ਲੈਣ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ। ਜੇਕਰ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਇੱਕ ਇੰਟਰਵਿਊ ਹੋਵੇਗਾ। ਤੁਹਾਨੂੰ ਇੱਕ ਫਾਰਮ 'ਤੇ ਦਸਤਖਤ ਕਰਨ ਲਈ ਕਿਹਾ ਜਾਵੇਗਾ ਅਤੇ ਤੁਹਾਡੀ ਆਵਾਜ਼ ਰਿਕਾਰਡ ਕੀਤੀ ਜਾਵੇਗੀ। ਕੋਈ ਵੀ ਤੁਹਾਡਾ ਨਾਮ ਨਹੀਂ ਜਾਣੇਗਾ। ਤੁਸੀਂ ਚੁਣ ਸਕਦੇ ਹੋ ਕਿ ਤੁਸੀਂ ਇੰਟਰਵਿਊ ਵਿੱਚ ਕਿਵੇਂ ਭਾਗ ਲੈਣਾ ਹੈ: ਫੋਨ ਜਾਂ ਵੀਡੀਓ। ਕੁਝ ਜਨਸੰਖਿਆ ਸੰਬੰਧੀ ਸਵਾਲ ਨੋਟ ਕੀਤੇ ਜਾਣਗੇ। ਤੁਹਾਡੇ ਇੰਟਰਵਿਊ ਨੂੰ ਟ੍ਰਾਂਸਕ੍ਰਾਈਬ ਕੀਤੇ ਜਾਣ ਤੋਂ ਬਾਅਦ, ਰੀਕੋਡਿੰਗ ਨੂੰ ਮਿਟਾ ਦਿੱਤਾ ਜਾਵੇਗਾ। ਰਿਪੋਰਟਾਂ ਲਿਖਣ ਲਈ ਇੰਟਰਵਿਊ ਡੇਟਾ ਨੂੰ ਸ਼ਾਮਲ ਕੀਤਾ ਜਾਵੇਗਾ ਪਰ ਸਾਰੀ ਜਾਣਕਾਰੀ ਗੁਪਤ ਰੱਖੀ ਜਾਵੇਗੀ। ਇੰਟਰਵਿਊ ਪੰਜਤਾਲੀ ਮਿੰਟਾਂ ਤੋਂ ਵੱਧ ਨਹੀਂ ਹੁਣਾਂ ਚਰੀਦਾ।

ਕੀ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕੋਈ ਰੀਸਕ ਹਨ?

ਇਹ ਸੋਚਿਆ ਜਾਂਦਾ ਹੈ ਕਿ ਕੋਈ ਵੀ ਨਹੀਂ ਹੋਵੇਗਾ। ਪਰ ਜੇਕਰ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਪ੍ਰੈਸ਼ਨੀ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ ਇੰਟਰਵਿਊ ਨੂੰ ਰੋਕ ਸਕਦੇ ਹੋ ਜਾਂ ਬ੍ਰੇਕ ਲੈ ਸਕਦੇ ਹੋ। ਸਹਾਇਤਾ ਸੰਸਥਾਵਾਂ ਦੇ ਕੁਝ ਫੋਨ ਨੰਬਰ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਹਨ।

ਕੀ ਹਿੱਸਾ ਲੈਣ ਦੇ ਕੋਈ ਲਾਭ ਹਨ?

ਕੋਈ ਸਿੱਧਾ ਲਾਭ ਨਹੀਂ ਹੋਵੇਗਾ ਪਰ ਤੁਸੀਂ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੀਆਂ ਲੋੜਾਂ ਨੂੰ ਸਮਝਣ ਵਿੱਚ ਮਦਦ ਕਰ ਰਹੇ ਹੋਵੋਗੇ।

ਕੀ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ?

ਸਾਰਾ ਡਾਟਾ ਅਗਿਆਤ ਅਤੇ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ। ਇਹ ਅਧਿਐਨ ਜਨਰਲ ਡਾਟਾ ਪ੍ਰੋਟੈਕਸ਼ਨ ਰੈਗੂਲੇਸ਼ਨਜ਼ 2018 ਦੀ ਪਾਲਣਾ ਕਰਦਾ ਹੈ। ਸਟੈਫੋਰਡਸ਼ਾਇਰ ਯੂਨੀਵਰਸਿਟੀ ਇਸ ਅਧਿਐਨ ਲਈ ਪ੍ਰਬੰਧਕੀ ਸੰਸਥਾ ਹੈ। ਡੇਟਾ ਨੂੰ ਦਸ ਸਾਲਾਂ ਲਈ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ, ਜਿਸ ਤੋਂ ਬਾਅਦ ਖੋਜਕਰਤਾ ਦੁਆਰਾ ਇਸਨੂੰ ਨਸ਼ਟ ਕਰ ਦਿੱਤਾ ਜਾਵੇਗਾ। ਤੁਸੀਂ ਆਪਣੇ ਡੇਟਾ ਨੂੰ ਆਨਲਾਈਨ ਰਿਪੋਜ਼ਟਰੀ ਵਿੱਚ ਸਟੋਰ ਨਾ ਕਰਨ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ।

ਪਰ, ਜੇ ਤੁਹਾਨੂੰ ਜਾਂ ਤੁਹਾਡੇ ਕਿਸੇ ਜਾਣਕਾਰ ਨੂੰ ਨੁਕਸਾਨ ਹੋਣ ਦਾ ਖਤਰਾ ਹੈ ਤਾਂ ਮੈਨੂੰ ਹਸਪਤਾਲ ਜਾਂ ਡਾਕਟਰ/ਐਂਬੂਲੈਂਸ ਸੇਵਾ ਨੂੰ ਦੱਸਣ ਦੀ ਲੋੜ ਪਵੇਗੀ।

ਜੇਕਰ ਮੈਂ ਭਾਗੀਦਾਰੀ ਬਾਰੇ ਆਪਣਾ ਮਨ ਬਦਲ ਲਵਾਂ ਤਾਂ ਕੀ ਹੋਵੇਗਾ?

ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਹਿੱਸਾ ਲੈਣਾ ਬੰਦ ਕਰ ਸਕਦੇ ਹੋ, ਅਤੇ ਇੰਟਰਵਿਊ ਤੋਂ ਦੋ ਹਫ਼ਤੇ ਬੀਤ ਜਾਣ ਤੋਂ ਪਹਿਲਾਂ। ਤੁਸੀਂ ਇਹ ਈਮੇਲ ਜਾਂ ਫ਼ੋਨ ਰਾਹੀਂ ਕਰ ਸਕਦੇ ਹੋ।

ਇਸ ਅਧਿਐਨ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਕੀ ਹੋਵੇਗਾ?

ਰਿਪੋਰਟਾਂ/ਲੇਖ ਲਿਖਣ ਲਈ ਵਰਤਾਇ ਜਾਣਗੇ। ਜੇਕਰ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਖੋਜਕਰਤਾ ਜਾਂ ਉਸ ਵਿਅਕਤੀ ਨਾਲ ਸੰਪਰਕ ਕਰੋ ਜਿਸਨੇ ਤੁਹਾਨੂੰ ਜਾਣਕਾਰੀ ਦਿੱਤੀ ਹੈ। ਉਹ ਮੈਨੂੰ ਤੁਹਾਡੀ ਜਾਣਕਾਰੀ ਦੇ ਸਕਦੇ ਹਨ ਅਤੇ ਤੁਹਾਨੂੰ ਮੇਰੀ ਜਾਣਕਾਰੀ ਦੇ ਸਕਦੇ ਹਨ। ਜੇ ਤੁਹਾਨੂੰ ਅਧਿਐਨ ਬਾਰੇ ਕੋਈ ਚਿੰਤਾ ਹੈ ਤਾਂ ਮੇਰੇ ਨਾਲ ਜਾਂ ਮੇਰੇ ਸੁਪਰਵਾਈਜ਼ਰਾਂ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

ਕਿਸਨੇ ਇਸ ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਹੈ?

ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਗਈ ਹੈ ਅਤੇ ਸਟੈਫੋਰਡਸ਼ਾਇਰ ਯੂਨੀਵਰਸਿਟੀ ਐਥਿਕਸ ਕਮੇਟੀ ਨੌਂ ਮਨਜ਼ੂਰੀ ਦਿੱਤੀ ਗਈ ਹੈ।

ਹੋਰ ਜਾਣਕਾਰੀ

ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਜਾਣਕਾਰੀ ਦੀ ਲੋੜ ਹੈ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਰੇਸ਼ਰਚਰ/ ਰਿਸਰਚਰ, ਸੁਖਵਿੰਦਰ (sukhvinder.biring@research.staffs.ac.uk), ਰੇਸ਼ਰਚ ਸੁਪਰਵਾਈਜ਼ਰ, ਡਾਕਟਰ ਐਮੀ ਬਰਟਨ (amy.burton@staffs.ac.uk), ਡਾਕਟਰ ਲਿਨ ਡਨਵੁੱਡੀ (l.dunwoody@ulster.ac.uk), ਪ੍ਰੋਫੈਸਰ ਪੀਟਰ ਕੇਵਰਨ (P.kevern@staffs.ac.uk), ਅਤੇ ਐਥਿਕਸ ਕਮੇਟੀ ਦੇ ਮੇਮਬਰ, ਐਡਵਰਡ ਟੋਲਹਰਸਟ (e.tolhurst@staffs.ac.uk) ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

ਵਧੇਰੇ ਜਾਣਕਾਰੀ ਅਤੇ ਸਹਾਇਤਾ

ਹੇਠਾਂ ਦਿੱਤਿਆਂ ਵੈਬਸਾਈਟ ਤੁਹਾਨੂੰ ਕੀਮਤੀ ਲੱਗ ਸਕਦੀਆਂ ਹੈ।

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

ਪੇਨ ਯੂਕੇ ਇੱਕ ਚੈਰਿਟੀ ਹੈ ਜਿਸ ਕੋਲ ਅਜਿਹੀ ਜਾਣਕਾਰੀ ਵੀ ਹੈ ਜੋ ਤੁਹਾਨੂੰ ਮੱਦਤਗਾਰ ਲੱਗ ਸਕਦੀ ਹੈ।

<https://painuk.org/help-and-support/>

ਮੈਂਟਲ ਹੈਲਥ ਫਾਊਂਡੇਸ਼ਨ ਅਤੇ ਮਾਈਂਡ ਦੇਵੋਂ ਵਧੀਆ ਚੈਰਿਟੀ ਹਨ। ਇਹ ਮਾਨਸਿਕ ਸਿਹਤ ਅਤੇ ਤੰਦਰੁਸਤੀ ਲਈ ਸਹਾਇਤਾ ਪ੍ਰਦਾਨ ਕਰਦੇ ਹਨ, ਅਤੇ ਉਹਨਾਂ ਦੀਆਂ ਵੈਬਸਾਈਟਾਂ ਨੂੰ ਹੇਠਾਂ ਦਿੱਤੇ ਪਤੇ 'ਤੇ ਐਕਸੈਸ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

ਤੁਸੀਂ ਹੇਠਾਂ ਦਿੱਤੇ ਨੰਬਰ 'ਤੇ ਇਸ ਸੇਵਾ ਤੱਕ ਪਹੁੰਚ ਸਕਦੇ ਹੋ: 0300 123 3393

ਸਮਾਰੀਟਨਜ਼ (ਜੋ ਤੁਹਾਨੂੰ ਕਿਸੇ ਚਿੰਤਾ ਬਾਰੇ ਕਿਸੇ ਨਾਲ ਗੱਲ ਕਰਨ ਦੀ ਲੋੜ ਹੈ), ਕਿਸੇ ਵੀ ਸਮੇਂ, ਕਿਸੇ ਵੀ ਫ਼ੋਨ ਤੋਂ, 116 123 'ਤੇ ਮੁਫ਼ਤ ਲਈ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

**ਧੰਨਵਾਦ**

### **Demographic Questionnaire**

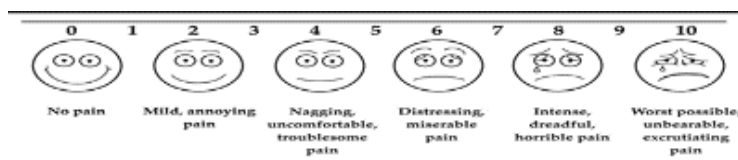
**Please only fill in this questionnaire if you are aged over 18 years, female, living in the UK, from a South Asian background, and living with chronic pain. Should you not wish to answer any question(s), please leave the space blank**

1. What is your age? \_\_\_\_\_
2. Please state your area of residence \_\_\_\_\_
3. Please state the South Asian ethnic group you identify as belonging to and your first language  
\_\_\_\_\_
4. Please state how long you have been living in the UK? \_\_\_\_\_
5. Do you have a religion or faith (if so, please specify)? \_\_\_\_\_
6. Please state your level/highest level of education (e.g., no formal education/ high school/graduate/postgraduate) \_\_\_\_\_
7. Are you able to access the internet and find resources? Yes [ ☐ ], No [ ☐ ] (if not then the reasons for this \_\_\_\_\_)
8. Are you able to read and write in English? (Please tick) No [ ☐ ], at a very basic level [ ☐ ], yes [ ☐ ]
9. Are you able to speak and understand English? No [ ☐ ], at a very basic level [ ☐ ], yes [ ☐ ]
10. Please provide details of your employment status/occupation  
\_\_\_\_\_
11. Please state (on a scale of 1 to 10) how you would describe your financial situation (1= finance sometimes a struggle, 5= financially comfortable 10= financially very comfortable)  
\_\_\_\_\_

Adapted from Adler, N. E., Epel, E. S., Castellazzo, G., & Ickovics, J. R. (2000). Relationship of subjective and objective social status with psychological and physiological functioning: Preliminary data in healthy, White women. *Health Psychology, 19*(6), 586-592. (the MacArthur Scale of Subjective Social Status).

12. Please state your marital status  
\_\_\_\_\_

13. Using the scale below, please state how you would describe your level of pain (please indicate with a number from 1 to 10)



(Scale source: Operative Neurosurgery. (2016). *Visual analogue scale* (VAS).  
)[https://operativeneurosurgery.com/doku.php?id=visual\\_analog\\_scale](https://operativeneurosurgery.com/doku.php?id=visual_analog_scale)

**Thank you**

## Appendix Four: Debrief Sheets

### Debrief Form (Punjabi)

ਡੀਬ੍ਰਿਫ ਫਾਰਮ



ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ, ਉਨ੍ਹਾਂ ਦੀ ਤੰਦਰੁਸਤੀ, ਸਿਹਤ ਸੰਭਾਲ, ਅਤੇ ਦਰਦ ਪ੍ਰਬੰਧਨ ਦੇ ਨਾਲ ਰਹਿਣ ਦੇ ਅਨੁਭਵਾਂ ਦੀ ਖੋਜ/ਅਧਿਐਨ

ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਨੂੰ ਲੰਬੇ ਸਮੇਂ ਦਾ ਦਰਦ ਹੁੰਦਾ ਹੈ। ਪਰ ਉਹਨਾਂ ਬਾਰੇ ਬਹੁਤ ਘੱਟ ਖੋਜ/ਅਧਿਐਨ ਹੈ। ਸਾਨੂੰ ਉਹਨਾਂ ਦੀ ਸਹਾਇਤਾ ਕਰਨ ਲਈ ਉਹਨਾਂ ਦੇ ਦਰਦ ਦੇ ਅਨੁਭਵਾਂ ਨੂੰ ਸਮਝਣ ਦੀ ਲੋੜ ਹੈ। ਤੁਹਾਡੀ ਭਾਗੀਦਾਰੀ ਉਹਨਾਂ ਦੀਆਂ ਲੋੜਾਂ ਅਤੇ ਮੁਸ਼ਕਿਲਾਂ ਨੂੰ ਸਮਝਣ ਵਿੱਚ ਮਦਦ ਕਰੇਗੀ।

ਸਾਰਾ ਡਾਟਾ ਅਗਿਆਤ ਅਤੇ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ। ਇਹ ਅਧਿਐਨ ਜਨਰਲ ਡਾਟਾ ਪ੍ਰੋਟੈਕਸ਼ਨ ਰੈਗੂਲੇਸ਼ਨਜ਼ 2018 ਦੀ ਪਾਲਣਾ ਕਰਦਾ ਹੈ। ਸਟੈਫੋਰਡਸ਼ਾਇਰ ਯੂਨੀਵਰਸਿਟੀ ਇਸ ਅਧਿਐਨ ਲਈ ਪ੍ਰਬੰਧਕੀ ਸੰਸਥਾ ਹੈ। ਡੇਟਾ ਨੂੰ ਦਸ ਸਾਲਾਂ ਲਈ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ, ਜਿਸ ਤੋਂ ਬਾਅਦ ਖੋਜਕਰਤਾ ਦੁਆਰਾ ਇਸਨੂੰ ਨਸ਼ਟ ਕਰ ਦਿੱਤਾ ਜਾਵੇਗਾ। ਤੁਸੀਂ ਆਪਣੇ ਡੇਟਾ ਨੂੰ ਆਨਲਾਈਨ ਰਿਪੋਜ਼ਟਰੀ ਵਿੱਚ ਸਟੋਰ ਨਾ ਕਰਨ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ।

ਇੰਟਰਵਿਊ ਤੋਂ ਦੋ ਹਫ਼ਤੇ ਬੀਤ ਜਾਣ ਤੋਂ ਪਹਿਲਾਂ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣਾ ਬੰਦ ਕਰ ਸਕਦੇ ਹੋ। ਤੁਸੀਂ ਅਪਣਾ ਡੇਟਾ ਨੂੰ ਵਾਪਸ ਲੈ ਸਕਦੇ ਹੋ। ਤੁਸੀਂ ਇਹ ਈਮੇਲ ਜਾਂ ਫੋਨ ਰਾਹੀਂ ਕਰ ਸਕਦੇ ਹੋ।

ਜੇ ਤੁਹਾਨੂੰ ਅਧਿਐਨ ਬਾਰੇ ਕੋਈ ਚਿੰਤਾ ਹੈ ਤਾਂ ਮੇਰੇ ਨਾਲ ਜਾਂ ਮੇਰੇ ਸੁਪਰਵਾਈਜ਼ਰਾਂ ਨਾਲ ਸੰਪਰਕ ਕਰੋ:

ਸੁਖਵਿੰਦਰ (sukhvinder.biring@research.staffs.ac.uk), ਰੇਸ਼ਰਚ ਸੁਪਰਵਾਈਜ਼ਰ, ਡਾਕਟਰ ਐਮੀ ਬਰਟਨ (amy.burton@staffs.ac.uk), ਡਾਕਟਰ ਲਿਨ ਡਨਵੁਡੀ (l.dunwoody@ulster.ac.uk), ਪ੍ਰੋਫੈਸਰ ਪੀਟਰ ਕੇਵਰਨ (P.kevern@staffs.ac.uk),

ਵਧੇਰੇ ਜਾਣਕਾਰੀ ਅਤੇ ਸਹਾਇਤਾ

ਹੇਠਾਂ ਦਿੱਤੀਆਂ ਵੈਬਸਾਈਟ ਤੁਹਾਨੂੰ ਕੀਮਤੀ ਲੱਗ ਸਕਦੀਆਂ ਹਨ।

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

ਪੇਨ ਯੂਕੇ ਇੱਕ ਚੈਰਿਟੀ ਹੈ ਜਿਸ ਕੋਲ ਅਜਿਹੀ ਜਾਣਕਾਰੀ ਵੀ ਹੈ ਜੋ ਤੁਹਾਨੂੰ ਮੱਦਤਗਾਰ ਲੱਗ ਸਕਦੀ ਹੈ।

<https://painuk.org/help-and-support/>

ਮੈਂਟਲ ਹੈਲਥ ਫਾਊਂਡੇਸ਼ਨ ਅਤੇ ਮਾਈਂਡ ਦੇਵੋਂ ਵਧੀਆ ਚੈਰਿਟੀ ਹਨ। ਇਹ ਮਾਨਸਿਕ ਸਿਹਤ ਅਤੇ ਤੰਦਰੁਸਤੀ ਲਈ ਸਹਾਇਤਾ ਪ੍ਰਦਾਨ ਕਰਦੇ ਹਨ, ਅਤੇ ਉਹਨਾਂ ਦੀਆਂ ਵੈਬਸਾਈਟਾਂ ਨੂੰ ਹੇਠਾਂ ਦਿੱਤੇ ਪਤੇ 'ਤੇ ਐਕਸੈਸ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

ਤੁਸੀਂ ਹੇਠਾਂ ਦਿੱਤੇ ਨੰਬਰ 'ਤੇ ਇਸ ਸੇਵਾ ਤੱਕ ਪਹੁੰਚ ਸਕਦੇ ਹੋ: 0300 123 3393

ਸਮਾਰੀਟਨਜ਼ (ਜੋ ਤੁਹਾਨੂੰ ਕਿਸੇ ਚਿੰਤਾ ਬਾਰੇ ਕਿਸੇ ਨਾਲ ਗੱਲ ਕਰਨ ਦੀ ਲੋੜ ਹੈ), ਕਿਸੇ ਵੀ ਸਮੇਂ, ਕਿਸੇ ਵੀ ਫੋਨ ਤੋਂ, 116 123 'ਤੇ ਮੁਫਤ ਲਈ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

ਧੰਨਵਾਦ

## **Debrief Form**



### **Exploration of South Asian Women's experiences of living with chronic pain, their well-being, health care, and pain management**

Name of Researcher: Sukhvinder

#### **Thank you for your time and taking part in this study.**

South Asian women (SAW) remain underrepresented in health research and there is a lack of knowledge about their needs, experiences of living with chronic pain, the healthcare system, and how they manage their condition. This is important as ethnicity and culture are factors which can influence both pain perception and behaviour. Thus, a greater understanding of SAW's needs is required if holistic, culturally sensitive care is to be provided. This qualitative study aimed to explore SAW's experiences of living with chronic pain. Your interview will help to gain a deeper insight in this area. The results will be used to inform the next stage of the study, and this may involve the design an intervention or exploring how chronic pain management could be improved for SAW.

The audio recording of the interview will be deleted once it has been transcribed (turned into a word for word written account of what was said or translated to English). All data will be stored securely and anonymised. The data will be processed and destroyed in accordance with the university policy and the Data Protection Act 2018 (ten years after completion of the study). Anonymised data will not be able to be erased from outputs (e.g., PhD thesis, articles).

Should you wish to contact the researcher, you can do so via email. You may also withdraw your data up to two weeks from the date of the interview via email/phone.

If any concerns or issues arise throughout the study, please contact any of the supervisors on this project: Dr Amy Burton ([amy.burton@staffs.ac.uk](mailto:amy.burton@staffs.ac.uk)), Dr Lynn Dunwoody ([l.dunwoody@ulster.ac.uk](mailto:l.dunwoody@ulster.ac.uk)), Professor Peter Kevern ([P.kevern@staffs.ac.uk](mailto:P.kevern@staffs.ac.uk)), or the Chair of Health and Social Care Research Ethics Committee, Dr Edward Tolhurst ([e.tolhurst@staffs.ac.uk](mailto:e.tolhurst@staffs.ac.uk)).

#### **Help and information about Chronic pain and Well-being**

I have listed a helpline number with websites for you below, should you wish to access them.

Healthtalk.org is run by the Dipex charity and they help people by providing useful information and links to organisations on chronic pain (and other conditions). Others can share their experiences if they wish to. Many individuals have shared their stories, to try and increase knowledge and understanding of what people may experience and expect, when

living with a particular condition, and help others to feel less alone. More information and support can be gained via their website at address below.

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

Pain UK is a charity that also has information that you may find helpful. Please find their website address below.

<https://painuk.org/help-and-support/>

The Mental Health Foundation and Mind are both great charities, based in the United Kingdom. They provides support and resources on mental health and well-being, and their websites can be accessed at the addresses below.

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

Mind also offer an information line, and you can reach this service at the number below:

0300 123 3393

Samaritans (if you urgently need to speak to someone about any problems you are experiencing and need someone to listen) can be contacted free at any time, from any phone, on 116 123.

**Thank you**

## Appendix Five: Consent Forms

### Consent Form (Punjabi)



#### ਇਜਾਜ਼ਤ ਅਤੇ ਸਹਿਮਤੀ ਫਾਰਮ

ਪ੍ਰੋਜੈਕਟ ਦਾ ਸਿਰਲੇਖ: ਸੋਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ, ਉਨ੍ਹਾਂ ਦੀ ਤੰਦਰੁਸਤੀ, ਸਿਹਤ ਸੰਭਾਲ, ਦਰਦ ਪ੍ਰਬੰਧਨ, ਅਤੇ ਦਰਦ ਦੇ ਨਾਲ ਰਹਿਣ ਦੇ ਅਨੁਭਵਾਂ ਦੀ ਖੋਜ/ਅਧਿਐਨ

ਰੋਸ਼ਰਚਰ/ਰਿਸਰਚਰ ਦਾ ਨਾਮ: ਸੁਖਵਿੰਦਰ

ਕਿਰਪਾ ਕਰਕੇ ਟਿਕ ਕਰੋ

ਮੈਨੂੰ ਇਸ ਅਧਿਐਨ ਬਾਰੇ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਦਿੱਤੀ ਗਈ ਹੈ ਅਤੇ ਪੜ੍ਹੀ ਗਈ ਹੈ

ਹਾਂ ☐ ਨਹੀਂ ☐

ਮੈਂ ਸਮਾਜਦੀ ਮੇਰਾ ਇਸ ਪ੍ਰੋਜੈਕਟ ਵਿੱਚ ਭਾਗੀਦਾਰੀ ਸਵੈ-ਇੱਛਤ ਹੈ। ਤੁਸੀਂ ਇੰਟਰਵਿਊ ਤੋਂ ਪਹਿਲਾਂ

ਜਾਂ ਇੰਟਰਵਿਊ ਹੁੰਦੇ ਸਮੇਂ ਹਿੱਸਾ ਲੈਣ ਤੋਂ ਇਨਕਾਰ ਕਰ ਸਕਦੇ ਹੋ। ਇੰਟਰਵਿਊ

ਡੇਟਾ ਵਾਪਸ ਲਿਆ ਜਾ ਸਕਦਾ ਹੈ, ਕਿਸੇ ਕਾਰਨ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ। ਇਹ ਈਮੇਲ ਜਾਂ ਫੋਨ ਰਾਹੀਂ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

ਜੇਕਰ ਇੰਟਰਵਿਊ ਬਾਅਦ ਦੇ ਹਫ਼ਤੇ ਬੀਤ ਗਏ ਹਨ ਫਿਰ ਡੇਟਾ ਵਾਪਸ ਨਹੀਂ ਲਿਆ ਜਾ ਸਕਦਾ ਕਿਉਂਕਿ

ਇਹ ਦੇਰ ਹੋ ਜਾਵੇਗੀ ਅਤੇ ਲਿਖਣਾ ਸ਼ੁਰੂ ਹੋ ਜਾਵੇਗਾ

ਹਾਂ ☐ ਨਹੀਂ ☐

ਮੈਂ ਸਮਾਜਦੀ ਮੇਰਾ ਡੇਟਾ ਸੰਭਾਲ ਕੇ ਰੱਖਿਆ ਜਾਵੇਗਾ।

ਕੋਈ ਮੇਰਾ ਨਾਮ ਨਹੀਂ ਜਾਣੇਗਾ (ਸਿਰਫ ਜੇ ਲੋੜ ਪਾਈ ਕਾਨੂੰਨੀ ਤੌਰ ਤੇ)

ਹਾਂ ☐ ਨਹੀਂ ☐

ਮੈਂ ਆਡੀਓ ਰਿਕਾਰਡਿੰਗ ਦੀ ਇਜਾਜ਼ਤ ਧੀਂਦੀ ਹੈ

ਹਾਂ ☐ ਨਹੀਂ ☐

ਮੈਂ ਉਪਰੋਕਤ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹਾਂ

ਹਾਂ ☐ ਨਹੀਂ ☐

ਜੇਕਰ ਡੇਟਾ ਪ੍ਰਕਾਸ਼ਤ ਕੀਤਾ ਜਾਂਦਾ ਹੈ ਤਾਂ ਮੈਂ ਇਸਨੂੰ ਇੱਕ ਔਨਲਾਈਨ ਰਿਪੋਜ਼ਟਰੀ ਵਿੱਚ ਸਟੋਰ ਕੀਤੇ ਜਾਣ ਲਈ ਇਜਾਜ਼ਤ ਧੀਂਦੀ ਹੈ (ਇਹ ਵਿਕਲਪਿਕ ਹੈ)

ਹਾਂ ☐ ਨਹੀਂ ☐

ਜੇਕਰ ਮੈਨੂੰ ਹੋਰ ਖੋਜ ਲਈ ਲੋੜ ਹੋਵੇ ਤਾਂ ਮੇਰੇ ਨਾਲ ਸੰਪਰਕ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ

ਹਾਂ ☐ ਨਹੀਂ ☐

ਭਾਗੀਦਾਰ ਦਾ ਨਾਮ

ਦਸਤਖਤ

ਤਾਰੀਖ

ਰਿਸਰਚਰ ਦਾ ਨਾਮ

ਦਸਤਖਤ

ਤਾਰੀਖ





## Consent Form

**Project Title: Exploration of South Asian Women's experiences of living with chronic pain, their well-being, health care, and pain management**

Student researcher's name: Sukhvinder

Please tick

I have been given and read the information sheet about this study [ ]

I understand that my participation is voluntary and that I am free to withdraw and withdraw my data at any time prior to or during the interview, without giving a reason and without my rights being affected in any way.

I may also withdraw my data up to two weeks after the completion of the interview via email/phone [ ]

I understand that the researcher will hold all information and data securely and in confidence, all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) [ ]

I agree to the researcher audio recording the interview [ ]

I agree to take part in the above study [ ]

In the case of academic journal publications of the findings, I agree to my data being held permanently in an online repository (optional) Yes [ ] No [ ]

I would be willing to consider participation in a further study and consent to being contacted by the researcher at a later date, using the contact details I have provided for the present study. Yes [ ] No [ ]

Name of Participant

Signature

Date

---

Name of Researcher

Signature

Date

---

## Appendix Six: Interview Guide

### Interview Guide

Can you please provide me with a few details about your condition?

(prompts: When did it start/location/condition? What does it feel like?)

How would you describe a typical day?

How would you describe your mood/feelings on most days of the week? Would you describe them as negative or positive?

When/if you feel low/sad/stressed, how does your pain feel?

When/if you feel happy/joyful/relaxed how does your pain feel?

Do you feel how you are thinking and feeling influences the level of pain you are experiencing?

When you experience pain what helps to improve it?

How do you manage your pain?

What have you found to be most successful in managing pain?

Is there anything that makes your pain feel worse?

What changes have you experienced since living with chronic pain?

Have you experienced any difference in the way people treat you?

Have you discussed your pain with a healthcare professional? If so, what was that experience like?

What information have you had about chronic pain and managing it? Where did this information come from? How helpful did you find this information?

Do you feel your needs have been effectively considered/addressed?

Have you experienced any problems? If so, what improvements (if any) would you wish to see?

How important is religion and/or spirituality to you?

(if it is important then move to the question below)

How important is it for helping you to cope/for strength to deal with chronic pain?

What are your sources of strength/coping?

Is there anything else about your chronic pain experience that we have not yet discussed and that you feel is important for me to know about?

What advice would you give to someone who is experiencing chronic pain?

## Appendix Seven: Participant Information

Table 2 Participant Information

Participant	Age	Area of residence	SA group	First language	Length in the UK (years)	Religion	Highest level of education	Internet access/financial resources: yes/no (reasons)	Read/write in English	Speak/understand English	Employment status	Financial situation*	Condition/length of living with pain (years)	Marital status	Pain level (1-10)
1	57	London	Indian	Punjabi	40	Sikh	High School (India)	No (limited ICT/literacy skills)	Very basic level	Very basic level	Not currently working	5	Shoulder Pain (5)	Married	6
2	46	West Midlands	Indian	English	46 (SB)	Non-religious	Postgraduate	Yes	Yes	Yes	Coordinator	5	Abdominal Pain (1)	Separated	6
3	67	London	Indian	Punjabi	51	Sikh	Primary School (India)	No (limited ICT/literacy skills)	No	Very basic level	Retired	5	Pain in hands/wrists/Osteoarthritis (8)	Married	5
4	24	Hertfordshire	Bangladeshi	English	24 (SB)	Hindu	Graduate	Yes	Yes	Yes	Service Analyst	5	Pelvic Pain (5)	Single	5
5	43	West Midlands	Pakistani	Urdu	33	Muslim	High School	Yes	Yes	Yes	Sales Assistant	5	Back Pain (4)	Married	5
6	31	Berkshire	Indian	Hindi	25	Hindu	Graduate	Yes	Yes	Yes	Accountant	5	Neck/back pain (10)	Single	5

7	75	Berkshire	Indian	Punjabi	57	Sikh	High School (India)	No (limited ICT skills)	Very Basic level	Very Basic level	Retired	10	Neck/Abdominal pain (6)	Widowed	6
8	77	Berkshire	Indian	Punjabi	60	Sikh	Primary School (India)	No (limited ICT/literacy skills)	Very basic level	Very Basic level	Retired	5	Osteoarthritis/knee pain (15)	Widowed	5
9	44	London	Pakistani	Urdu	44 (SB)	Muslim	High School	Yes	Yes	Yes	Homemaker	1	Back pain (4)	Married	5
10	30	West Midlands	Indian	Hindi	12	Hindu	High School (India)	Yes	Yes	Yes	Care Assistant	5	Abdominal Pain (5)	Married	5
11	78	London	Indian	Punjabi	62	Sikh	High School (India)	Yes	Very basic level	Very basic level	Retired	5	Osteoarthritis/knee pain (10)	Married	5
12	67	London	Indian	Punjabi	52	Sikh	High School (India)	Yes	Yes	Yes	Retired	5	Shoulder Pain (8)	Widowed	4
13	57	London	Indian	Punjabi	42	Sikh	High school (India)	No (limited ICT/literacy Skills)	Very basic level	Very basic level	Not currently working	5	Back Pain (3)	Widowed	6
14	32	London	Indian	English	32 (SB)	Hindu	Graduate	Yes	Yes	Yes	Policy Assistant	5	Knee Pain (6)	Single	4

## Appendix Eight: Thematic Maps

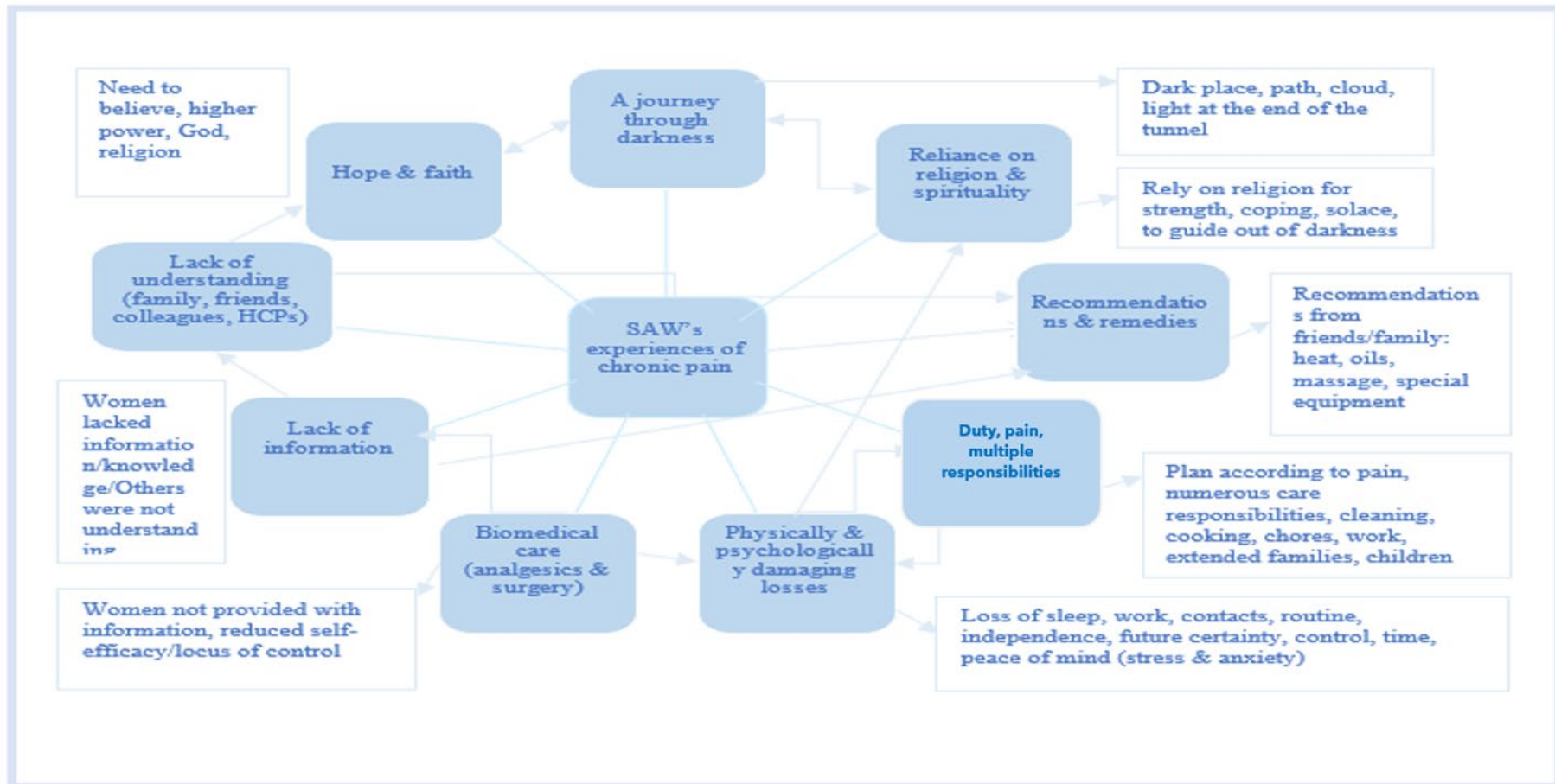


Figure Three Initial thematic map

## Appendix Nine: Final Themes

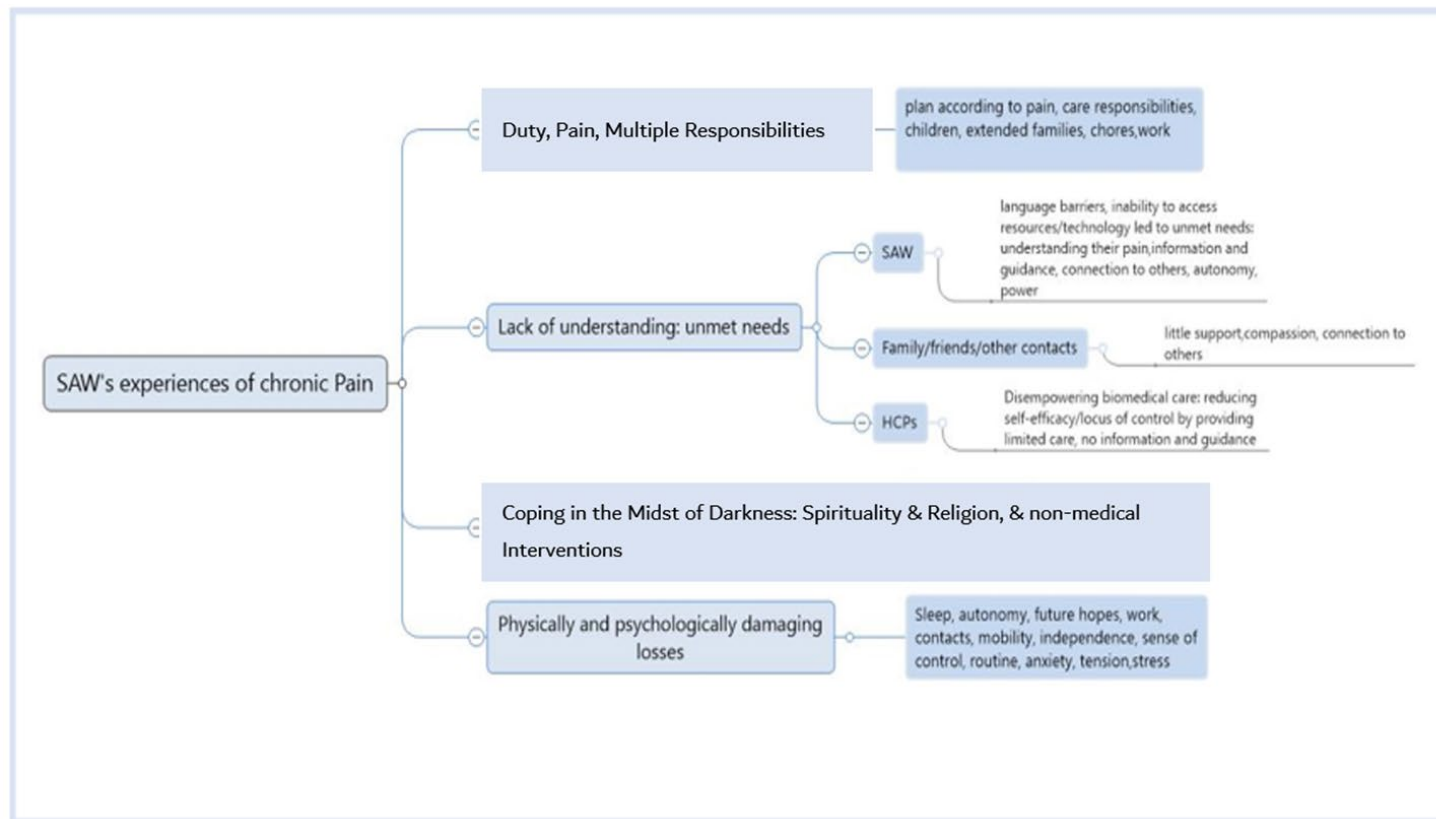


Figure 3 Final thematic map

## Appendix Ten: Participant Information

Table 3 Participant Information

Participant	Age	Area of residence	SA group	First language	Length in the UK (years)	Religion	Highest level of education	Internet access/financial resources: yes/no (reasons)	Read/write in English	Speak/understand English	Employment status	Financial situation*	Condition/length of living with pain (years)	Marital status	Pain level (1-10)
1	57	London	Indian	Punjabi	40	Sikh	High School (India)	No (limited ICT/literacy skills)	Very basic level	Very basic level	Not currently working	5	Shoulder Pain (5)	Married	6
2	46	West Midlands	Indian	English	46 (SB)	Non-religious	Postgraduate	Yes	Yes	Yes	Coordinator	5	Abdominal Pain (1)	Separated	6
3	67	London	Indian	Punjabi	51	Sikh	Primary School (India)	No (limited ICT/literacy skills)	No	Very basic level	Retired	5	Pain in hands/wrists/Osteoarthritis (8)	Married	5
4 (n)	54	London	Indian	Punjabi	40	Sikh	High School (India)	No (limited ICT/literacy skills)	Very basic level	Very basic level	Not currently working	5	Back Pain (5)	Married	5
5	43	West Midlands	Pakistani	Urdu	33	Muslim	High School	Yes	Yes	Yes	Sales Assistant	5	Back Pain (4)	Married	5
6	31	Berkshire	Indian	Hindi	25	Hindu	Graduate	Yes	Yes	Yes	Accountant	5	Neck/back pain (10)	Single	5
7	75	Berkshire	Indian	Punjabi	57	Sikh	High School (India)	No (limited ICT skills)	Very Basic level	Very Basic level	Retired	10	Neck/Abdominal pain (6)	Widowed	6

8	77	Berkshire	Indian	Punjabi	60	Sikh	Primary School (India)	No (limited ICT/literacy skills)	Very basic level	Very Basic level	Retired	5	Osteoarthritis/knee pain (15)	Widowed	5
9	44	London	Pakistani	Urdu	44 (SB)	Muslim	High School	Yes	Yes	Yes	Homemaker	1	Back pain (4)	Married	5
10	30	West Midlands	Indian	Hindi	12	Hindu	High School (India)	Yes	Yes	Yes	Care Assistant	5	Abdominal Pain (5)	Married	5
11	78	London	Indian	Punjabi	62	Sikh	High School (India)	Yes	Very basic level	Very basic level	Retired	5	Osteoarthritis/knee pain (10)	Married	5
12	67	London	Indian	Punjabi	52	Sikh	High School (India)	Yes	Yes	Yes	Retired	5	Shoulder Pain (8)	Widowed	4
13	57	London	Indian	Punjabi	42	Sikh	High school (India)	No (limited ICT/literacy Skills)	Very basic level	Very basic level	Not currently working	5	Back Pain (3)	Widowed	6
14	32	London	Indian	English	32 (SB)	Hindu	Graduate	Yes	Yes	Yes	Policy Assistant	5	Knee Pain (6)	Single	4
15	74	Berkshire	Indian	Punjabi	60	Sikh	High School (India)	No (limited ICT/literacy skills)	Very basic level	Very Basic level	Retired	5	Neck pain (6)	Married	5
16	74	Berkshire	Indian	Punjabi	65	Sikh	Primary School (India)	No (limited ICT/literacy)	Very Basic level	Very Basic level	Retired	5	Shoulder pain (8)	Married	5



## **Participant Information Sheet**

### **Self-management of chronic pain for South Asian Women**



My name is Sukhvinder, and I would like to invite you to take part in this study, which is being undertaken as part fulfilment of a PhD in Health Studies, under the supervision of Dr Amy Burton and Professor Peter Kevern. The study aims to explore some of the difficulties faced by South Asian women living with chronic pain in order to address them. Before you decide whether to participate, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully. and please feel free to ask the researcher if there is anything that is unclear or if you would like more information.

Thank you for taking the time to read this

#### **Why is the research being conducted?**

South Asian women (SAW) are more likely to be affected by chronic pain/certain conditions. Research has revealed that they do not feel that they are provided with information about chronic pain and how they can manage their condition and difficulties associated with it. This study aims to work with SAW living with chronic pain to help empower them to self-manage their condition.

#### **Why have I been invited to take part?**

We believe that you meet the inclusion criteria: a South Asian Woman, aged eighteen years or above, living in the UK, and managing chronic pain. The definition of chronic pain used in this study is any pain which carries on for longer than twelve weeks, despite medication or treatment. The research requires individuals to meet this criterion.

#### **Do I have to take part and what is involved?**

You are under no obligation to take part, but if you decide to, you will be asked to participate in a group discussion with other SAW (approximately four to six women in total) also living with chronic pain, to explore what would be helpful to SAW to live well with chronic pain. This will be conducted in person (at an agreed venue) or as an online video call (whichever you prefer) and should last no more than an hour and a half. Arrangements for tea and snacks will be made for participants attending in person. These will only be audio recorded and not video recorded. You will also be asked to sign a consent form, complete a short questionnaire on your well-being, and email this to me (if you are not attending in person) or bring it with you on the day. A time for the discussions that is suitable for you and the other participants will be arranged. After this data has been analysed (which involves the researcher listening back to the audio recording, transcribing, analysing, and identifying themes that will be discussed with the supervisors), I will then arrange another meeting (in approximately two weeks) to discuss how we can progress forward. This will also be audio-recorded. It is anticipated that there will be approximately three meetings in total, however, your contribution is voluntary, and you are free to withdraw if you no longer wish to participate in future discussions.

All data will be stored securely and remain anonymous. The audio recording will be destroyed after it has been transcribed. The data and findings will be written up as part of my thesis, but all information will be anonymous.

**Are there any risks to taking part?**

There are no risks anticipated. I have also provided a helpline number and some websites for information that you may find of use.

**Are there any benefits to taking part?**

The aim of this research is to help SAW live well with chronic pain. Some research has shown that individuals with chronic pain find it helpful to discuss their experiences and share information about how to manage pain. We hope that there will be some benefit for you from this study.

**Will taking part in this study be kept confidential?**

All information we collect from you will be stored securely and anonymised. This means that your name and any other identifying information you share during the group interviews will be removed. Quotes from your responses to the questions may be included within final reports of the findings, however, you will not be able to be identified from the quotes used. You can choose to not permit this but still take part in the study. You can choose a pseudonym in the group discussions. Participants will be expected to respect the privacy, confidentiality, and views of all the participants. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

The data controller for this project will be Staffordshire University. The university will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the GDPR is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

You have the right to access information held about you. Your right of access can be exercised in accordance with the GDPR. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the Staffordshire University Data Protection Officer. If you wish to lodge a complaint with the Information Commissioner's Office, please visit [www.ico.org.uk](http://www.ico.org.uk). The data will be stored securely for ten years, after which it will be destroyed by the researcher. Anonymised data will not be able to be erased from outputs (e.g., PhD thesis, articles), and if published in academic journals, it may be made available permanently, in a repository, if required. However, if a situation arises in which a disclosure may reveal that you or someone you know is at risk of harm, I will be required to notify the appropriate health/emergency services.

**What if I change my mind about participation?**

Your participation is voluntary, and you are under no obligation to participate. If you agree to take part and then decide before or during the group discussion that you want to withdraw from the study, just let me know (by e-mailing me before the discussion or by letting me know during it). The researcher's email is [sukhvinder.biring@research.staffs.ac.uk](mailto:sukhvinder.biring@research.staffs.ac.uk)

**What will happen to the results of this study?**

The results of this study will be used in the writing of my PhD thesis (this may involve other publications, such as academic journal articles). The results will be used to the design an intervention for SAW living with chronic pain.

**What happens next if I do decide to take part?**

You can contact the researcher by the contact details provided/ via email (sukhvinder.biring@research.staffs.ac.uk), and if you wish to take part, a copy of the consent form, questionnaires, and other relevant information will be emailed/provided to you.

**Who has reviewed this study?**

The study has been reviewed and approved by the Staffordshire University Ethics Committee.

**Further information and contact details**

Should you require any further information, please feel free to contact the researcher (sukhvinder.biring@research.staffs.ac.uk), the research supervisors, Dr Amy Burton (amy.burton@staffs.ac.uk), Professor Peter Kevern (P.kevern@staffs.ac.uk), and the university Ethics Committee, (ethics@staffs.ac.uk).

**What if any issues arise during my participation?**

If any concerns or issues arise throughout the study, please contact myself, my supervisors, or the chair of the ethics committee, by using the contact details provided

**Help and Information about Chronic pain and well-being**

Healthtalk.org is run by the Dipex charity and they help people by providing useful information and links to organisations on chronic pain (and other conditions). Others can share their experiences if they wish to. Many individuals have shared their stories, to try and increase knowledge and understanding of what people may/can experience and expect, when living with a particular condition, and help others to feel less alone. More information and support can be gained via their website at address below.

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

Pain UK is a charity that also has information that you may find helpful. Please find their website address below.

<https://painuk.org/help-and-support/>

The Mental Health Foundation and Mind are both great charities, based in the United Kingdom. They provides support and resources on mental health and well-being, and their websites can be accessed at the addresses below.

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

Mind also offer an information line, and you can reach this service at the number below:

0300 123 3393

Samaritans (if you urgently need to speak to someone about any problems you are

experiencing and need someone to listen) can be contacted free at any time, from any phone, on 116 123.

**Thank you**



### ਭਾਗੀਦਾਰ ਜਾਣਕਾਰੀ ਸ਼ੀਟ

#### ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਦਾ ਸਵੈ-ਪ੍ਰਬੰਧਨ

ਮੇਰਾ ਨਾਮ ਸੁਖਵਿੰਦਰ ਬਿਰਿੰਗ ਹੈ, ਅਤੇ ਮੈਂ ਤੁਹਾਨੂੰ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸੱਦਾ ਦੇਣਾ ਚਾਹਾਂਗੀ, ਜੋ ਕਿ ਡਾਕਟਰ ਐਮੀ ਬਰਟਨ ਅਤੇ ਪ੍ਰੋਫੈਸਰ ਪੀਟਰ ਕੇਵਰਨ ਦੀ ਨਿਗਰਾਨੀ ਹੇਠ ਹੈਲਥ ਸਟੱਡੀਜ਼ ਵਿੱਚ ਪੀਐਚਡੀ ਦੀ ਇੱਕ ਹਿੱਸੇ ਦੀ ਪੂਰਤੀ ਵਜੋਂ ਕੀਤਾ ਜਾ ਰਿਹਾ ਹੈ। ਅਧਿਐਨ ਦਾ ਉਦੇਸ਼ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਨਾਲ ਰਹਿ ਰਹੀਆਂ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੀ ਮੁਸ਼ਕਿਲਾਂ ਦੀ ਪੜਚੋਲ ਕਰਨਾ ਹੈ ਤਾਂ ਜੋ ਉਹਨਾਂ ਨੂੰ ਹੱਲ ਕੀਤਾ ਜਾ ਸਕੇ। ਇਸ ਤੋਂ ਪਹਿਲਾਂ ਕਿ ਤੁਸੀਂ ਇਹ ਫੈਸਲਾ ਕਰੋ ਕਿ ਕੀ ਹਿੱਸਾ ਲੈਣਾ ਹੈ, ਤੁਹਾਡੇ ਲਈ ਇਹ ਸਮਝਣਾ ਮਹੱਤਵਪੂਰਨ ਹੈ ਕਿ ਖੋਜ ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ ਅਤੇ ਇਸ ਵਿੱਚ ਕੀ ਹੋਵੇਗਾ। ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਬਾਰੇ ਹੋਰ ਜਾਣਨਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਖੋਜਕਰਤਾਵਾਂ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

#### ਇਸ ਨੂੰ ਪੜ੍ਹਨ ਲਈ ਸਮਾਂ ਕੱਢਣ ਲਈ ਤੁਹਾਡਾ ਧੰਨਵਾਦ

ਰੇਸਰਚ (ਖੋਜ) ਕਿਉਂ ਕੀਤੀ ਜਾ ਰਹੀ ਹੈ?

ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਨੂੰ ਗੰਭੀਰ ਦਰਦ ਹੁੰਦਾ ਹੈ। ਖੋਜ ਤੋਂ ਪਤਾ ਲੱਗਾ ਹੈ ਕਿ ਔਰਤਾਂ ਨੂੰ ਦਰਦ ਬਾਰੇ ਜਾਣਕਾਰੀ ਨਹੀਂ ਦਿੱਤੀ ਜਾਂਦੀ। ਇਹ ਪ੍ਰੋਜੈਕਟ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਨਾਲ ਕੰਮ ਕਰਨ ਦੀ ਉਮੀਦ ਕਰਦਾ ਹੈ ਤਾਂ ਉਹਨਾਂ ਦੀ ਸਹਾਇਤਾ ਕਰਨ ਲਈ ਉਹਨਾਂ ਦੀ ਮੁਸ਼ਕਿਲਾਂ ਨੂੰ ਸਮਝਣ ਦੀ ਲੋੜ ਹੈ। ਫਿਰ ਅਸੀਂ ਦੇਖ ਸਕਦੇ ਹਾਂ ਕਿ ਉਹਨਾਂ ਲਈ ਕੀ ਮਦਦਗਾਰ ਹੋ ਸਕਦਾ ਹੈ।

ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕਿਉਂ ਸੱਦਾ ਦਿੱਤਾ ਗਿਆ ਹੈ?

ਅਸੀਂ ਸੋਚਦੇ ਹਾਂ ਕਿ ਤੁਸੀਂ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਲੋੜਾਂ ਨੂੰ ਪੂਰਾ ਕਰਦੇ ਹੋ: ਇੱਕ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤ, ਅਠਾਰਾਂ ਸਾਲ ਜਾਂ ਇਸ ਤੋਂ ਵੱਧ ਉਮਰ ਦੀ, ਯੂਕੇ ਵਿੱਚ ਰਹਿ ਰਹੀ, ਗੰਭੀਰ ਦਰਦ ਨਾਲ। ਇਸ ਪ੍ਰੋਜੈਕਟ ਵਿੱਚ ਹਿੱਸਾ ਲੇਹਨ ਲਈ ਤੁਹਾਨੂੰ ਦਵਾਈ ਜਾਂ ਇਲਾਜ ਦੇ ਬਾਵਜੂਦ ਬਾਰਾਂ ਹਫ਼ਤਿਆਂ ਤੋਂ ਵੱਧ ਸਮੇਂ ਲਈ ਦਰਦ ਹੋਣਾ ਚਾਹੀਦਾ ਹੈ।

ਕੀ ਮੈਨੂੰ ਹਿੱਸਾ ਲੈਣਾ ਪਵੇਗਾ ਅਤੇ ਕੀ ਹੋਵੇਗਾ?

ਜੇਕਰ ਤੁਸੀਂ ਨਹੀਂ ਚਾਹੁੰਦੇ ਤਾਂ ਤੁਹਾਨੂੰ ਹਿੱਸਾ ਲੈਣ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ। ਜੇਕਰ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਤਿੰਨ ਜਾਂ ਚਾਰ ਗਰੁੱਪ ਮੀਟਿੰਗਾਂ ਹੋਵੇਗੀਆਂ। ਤੁਹਾਨੂੰ ਇੱਕ ਫਾਰਮ 'ਤੇ ਦਸਤਖਤ ਕਰਨ ਲਈ ਕਿਹਾ ਜਾਵੇਗਾ, ਤੁਹਾਨੂੰ ਦਰਦ ਅਤੇ ਤੁਹਾਡੀ ਤੰਦਰੁਸਤੀ ਬਾਰੇ ਕੁਝ ਸਵਾਲ ਪੁੱਛੇ ਜਾਣਗੇ, ਅਤੇ ਤੁਸੀਂ ਇਸਨੂੰ ਮੈਨੂੰ ਈਮੇਲ ਕਰਸਕਦੇ ਹੋ ਜਾਂ ਗਰੁੱਪ ਮੀਟਿੰਗਾਂ ਵਾਲੇ ਦਿਨ ਇਸਨੂੰ ਆਪਣੇ ਨਾਲ ਲਿਆ ਸਕਦੇ ਹੋ। ਤੁਹਾਡੀ ਆਵਾਜ਼ ਰਿਕਾਰਡ ਕੀਤੀ ਜਾਵੇਗੀ। ਕੋਈ ਵੀ ਤੁਹਾਡਾ ਨਾਮ ਨਹੀਂ ਜਾਣੇਗਾ। ਤੁਸੀਂ ਚੁਣ ਸਕਦੇ ਹੋ ਕਿ ਤੁਸੀਂ ਗਰੁੱਪ ਮੀਟਿੰਗਾਂ ਵਿੱਚ ਕਿਵੇਂ ਭਾਗ ਲੈਣਾ ਹੈ: ਵੀਡੀਓ/ਆਹਮੇ-ਸਾਹਮਣੇ। ਤੁਹਾਡੇ ਰੀਕੋਡਿੰਗ ਨੂੰ ਟ੍ਰਾਂਸਕ੍ਰਾਈਬ ਕੀਤੇ ਜਾਣ ਤੋਂ ਬਾਅਦ, ਰੀਕੋਡਿੰਗ ਨੂੰ ਮਿਟਾ ਦਿੱਤਾ ਜਾਵੇਗਾ। ਰਿਪੋਰਟਾਂ ਲਿਖਣ ਲਈ ਗਰੁੱਪ ਮੀਟਿੰਗਾਂ ਡੇਟਾ ਨੂੰ ਸ਼ਾਮਲ ਕੀਤਾ ਜਾਵੇਗਾ ਪਰ ਸਾਰੀ ਜਾਣਕਾਰੀ ਗੁਪਤ ਰੱਖੀ ਜਾਵੇਗੀ। ਮੀਟਿੰਗਾਂ ਨੌਂ ਮਿੰਟਾਂ ਤੋਂ ਵੱਧ ਨਹੀਂ ਹੁਣਾਂ ਚਲੀਆਂ। ਚਾਹ ਅਤੇ ਸਨੈਕਸ ਦਾ ਪ੍ਰਬੰਧ ਕੀਤਾ ਜਾਵੇਗਾ।

ਕੀ ਹਿੱਸਾ ਲੈਣ ਲਈ ਕੋਈ ਰੀਸਕ ਹਨ?

ਇਹ ਸੋਚਿਆ ਜਾਂਦਾ ਹੈ ਕਿ ਕੋਈ ਵੀ ਨਹੀਂ ਹੋਵੇਗਾ। ਪਰ ਜੇਕਰ ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਪ੍ਰੈਸ਼ਨਰੀ ਮਹਿਸੂਸ ਕਰਦੇ ਹੋ ਤਾਂ ਤੁਸੀਂ ਮੀਟਿੰਗ ਨੂੰ ਛੱਡ ਸਕਦੇ ਹੋ ਜਾਂ ਬ੍ਰੇਕ ਲੈ ਸਕਦੇ ਹੋ। ਸਹਾਇਤਾ ਸੰਸਥਾਵਾਂ ਦੇ ਕੁਝ ਫੋਨ ਨੰਬਰ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਹਨ।

ਕੀ ਹਿੱਸਾ ਲੈਣ ਦੇ ਕੋਈ ਲਾਭ ਹਨ?

ਤੁਸੀਂ ਸੇਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੀਆਂ ਲੋੜਾਂ ਨੂੰ ਸਮਝਣ ਵਿੱਚ ਮੱਦਤ ਕਰ ਰਹੇ ਹੋਵੋਗੇ। ਇਹ ਉਮੀਦ ਕੀਤੀ ਜਾਂਦੀ ਹੈ ਕਿ ਇਹ ਪ੍ਰੋਜੈਕਟ ਔਰਤਾਂ ਨੂੰ ਪਛਾਣੀਆਂ ਗਈਆਂ ਕੁਝ ਮੁਸ਼ਕਿਲਾਂ ਨੂੰ ਦੂਰ ਕਰਨ ਵਿੱਚ ਮੱਦਤ ਕਰ ਸਕਦਾ ਹੈ।

ਕੀ ਇਸ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਨੂੰ ਗੁਪਤ ਰੱਖਿਆ ਜਾਵੇਗਾ?

ਸਾਰਾ ਡਾਟਾ ਅਗਿਆਤ ਅਤੇ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ। ਇਹ ਅਧਿਐਨ ਜਨਰਲ ਡਾਟਾ ਪ੍ਰੋਟੈਕਸ਼ਨ ਰੈਗੂਲੇਸ਼ਨਜ਼ 2018 ਦੀ ਪਾਲਣਾ ਕਰਦਾ ਹੈ। ਸਟੈਫੋਰਡਸ਼ਾਇਰ ਯੂਨੀਵਰਸਿਟੀ ਇਸ ਅਧਿਐਨ ਲਈ ਪ੍ਰਬੰਧਕੀ ਸੰਸਥਾ ਹੈ। ਡੇਟਾ ਨੂੰ ਦਸ ਸਾਲਾਂ ਲਈ ਸੁਰੱਖਿਅਤ ਢੰਗ ਨਾਲ ਸਟੋਰ ਕੀਤਾ ਜਾਵੇਗਾ, ਜਿਸ ਤੋਂ ਬਾਅਦ ਖੋਜਕਰਤਾ ਦੁਆਰਾ ਇਸਨੂੰ ਨਸ਼ਟ ਕਰ ਦਿੱਤਾ ਜਾਵੇਗਾ। ਤੁਸੀਂ ਆਪਣੇ ਡੇਟਾ ਨੂੰ ਆਨਲਾਈਨ ਰਿਪੋਜ਼ਟਰੀ ਵਿੱਚ ਸਟੋਰ ਨਾ ਕਰਨ ਲਈ ਕਹਿ ਸਕਦੇ ਹੋ।

ਪਰ, ਜੇ ਤੁਹਾਨੂੰ ਜਾਂ ਤੁਹਾਡੇ ਕਿਸੇ ਜਾਣਕਾਰ ਨੂੰ ਨੁਕਸਾਨ ਹੋਣ ਦਾ ਖਤਰਾ ਹੈ ਤਾਂ ਮੈਨੂੰ ਹਸਪਤਾਲ ਜਾਂ ਡਾਕਟਰ/ਐਂਬੂਲੈਂਸ ਸੇਵਾ ਨੂੰ ਦੱਸਣ ਦੀ ਲੋੜ ਪਵੇਗੀ।

ਜੇਕਰ ਮੈਂ ਭਾਰੀਦਾਰੀ ਬਾਰੇ ਆਪਣਾ ਮਨ ਬਦਲ ਲਵਾਂ ਤਾਂ ਕੀ ਹੋਵੇਗਾ?

ਤੁਸੀਂ ਕਿਸੇ ਵੀ ਸਮੇਂ ਹਿੱਸਾ ਲੈਣਾ ਬੰਦ ਕਰ ਸਕਦੇ ਹੋ।

ਇਸ ਅਧਿਐਨ ਦੇ ਨਤੀਜਿਆਂ ਦਾ ਕੀ ਹੋਵੇਗਾ?

ਰਿਪੋਰਟਾਂ/ਲੇਖ ਲਿਖਣ ਲਈ ਵਰਤਾਏ ਜਾਣਗੇ। ਜੇਕਰ ਤੁਸੀਂ ਹਿੱਸਾ ਲੈਣਾ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਖੋਜਕਰਤਾ ਜਾਂ ਉਸ ਵਿਅਕਤੀ ਨਾਲ ਸੰਪਰਕ ਕਰੋ ਜਿਸਨੇ ਤੁਹਾਨੂੰ ਜਾਣਕਾਰੀ ਦਿੱਤੀ ਹੈ। ਜੇਕਰ ਤੁਹਾਨੂੰ ਅਧਿਐਨ ਬਾਰੇ ਕੋਈ ਚਿੰਤਾਵਾਂ ਹਨ ਤਾਂ ਮੇਰੇ ਜਾਂ ਸੁਪਰਵਾਈਜ਼ਰਾਂ ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

ਕਿਸਨੇ ਇਸ ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਹੈ?

ਅਧਿਐਨ ਦੀ ਸਮੀਖਿਆ ਕੀਤੀ ਗਈ ਹੈ ਅਤੇ ਸਟੈਫੋਰਡਸ਼ਾਇਰ ਯੂਨੀਵਰਸਿਟੀ ਐਥਿਕਸ ਕਮੇਟੀ ਨੌਂਹ ਮਨਜ਼ੂਰੀ ਦਿੱਤੀ ਗਈ ਹੈ।

ਹੋਰ ਜਾਣਕਾਰੀ

ਜੇਕਰ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਜਾਣਕਾਰੀ ਦੀ ਲੋੜ ਹੈ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਰੇਸ਼ਰਚਰ, ਸੁਖਵਿੰਦਰ

(sukhvinder.biring@research.staffs.ac.uk), ਰੇਸ਼ਰਚ ਸੁਪਰਵਾਈਜ਼ਰ, ਡਾਕਟਰ ਐਮੀ ਬਰਟਨ

(amy.burton@staffs.ac.uk), ਪ੍ਰੋਫੈਸਰ ਪੀਟਰ ਕੇਵਰਨ (P.kevern@staffs.ac.uk), ਅਤੇ ਐਥਿਕਸ ਕਮੇਟੀ

(ethics@staffs.ac.uk) ਨਾਲ ਸੰਪਰਕ ਕਰੋ।

ਵਧੇਰੇ ਜਾਣਕਾਰੀ ਅਤੇ ਸਹਾਇਤਾ

ਹੇਠਾਂ ਦਿੱਤਿਆਂ ਵੈਬਸਾਈਟ ਤੁਹਾਨੂੰ ਕੀਮਤੀ ਲੱਗ ਸਕਦੀਆਂ ਹੈ।

<https://healthtalk.org/chronic-pain/learning-about-pain-management>

ਪੇਨ ਯੂਕੇ ਇੱਕ ਚੈਰਿਟੀ ਹੈ ਜਿਸ ਕੋਲ ਅਜਿਹੀ ਜਾਣਕਾਰੀ ਵੀ ਹੈ ਜੋ ਤੁਹਾਨੂੰ ਮੱਦਤਗਾਰ ਲੱਗ ਸਕਦੀ ਹੈ।

<https://painuk.org/help-and-support/>

ਮੈਂਟਲ ਹੈਲਥ ਫਾਊਂਡੇਸ਼ਨ ਅਤੇ ਮਾਈਂਡ ਦੇਵੋਂ ਵਧੀਆ ਚੈਰਿਟੀ ਹਨ। ਇਹ ਮਾਨਸਿਕ ਸਿਹਤ ਅਤੇ ਤੰਦਰੁਸਤੀ ਲਈ ਸਹਾਇਤਾ ਪ੍ਰਦਾਨ ਕਰਦੇ ਹਨ, ਅਤੇ ਉਹਨਾਂ ਦੀਆਂ ਵੈਬਸਾਈਟਾਂ ਨੂੰ ਹੇਠਾਂ ਦਿੱਤੇ ਪਤੇ 'ਤੇ ਐਕਸੈਸ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

<https://www.mentalhealth.org.uk/>

<https://www.mind.org.uk/>

ਤੁਸੀਂ ਹੇਠਾਂ ਦਿੱਤੇ ਨੰਬਰ 'ਤੇ ਇਸ ਸੇਵਾ ਤੱਕ ਪਹੁੰਚ ਸਕਦੇ ਹੋ:

0300 123 3393

ਸਮਾਰੀਟਨਜ਼ (ਜੋ ਤੁਹਾਨੂੰ ਕਿਸੇ ਚਿੰਤਾ ਬਾਰੇ ਕਿਸੇ ਨਾਲ ਗੱਲ ਕਰਨ ਦੀ ਲੋੜ ਹੈ), ਕਿਸੇ ਵੀ ਸਮੇਂ, ਕਿਸੇ ਵੀ ਫ਼ੋਨ ਤੋਂ, 116 123 'ਤੇ ਮੁਫ਼ਤ ਲਈ ਕੀਤਾ ਜਾ ਸਕਦਾ ਹੈ।

ਧੰਨਵਾਦ

## Consent Form



### Project Title: Self-management of chronic pain for South Asian Women

Student researcher's name: Sukhvinder

Please tick

I have been given and read the information sheet about this study [ ]

I understand that my participation is voluntary and that I am free to withdraw at any point without giving a reason. However, my data cannot be withdrawn as it is part of the group conversation [ ]

I understand that the researcher will hold all information and data securely and in confidence. [ ]

I agree to the researcher audio recording the discussions [ ]

I agree to take part in the above study [ ]

In the case of academic journal publications of the findings, I agree to my data being held permanently in an online repository (optional) Yes [ ] No [ ]

Name of Participant

Signature

Date

---

Name of Researcher

Signature

Date

---

Consent Form in Punjabi

ਇਜਾਜ਼ਤ ਅਤੇ ਸਹਿਮਤੀ ਫਾਰਮ



ਪ੍ਰੋਜੈਕਟ ਦਾ ਸਿਰਲੇਖ: ਸੋਊਥ ਏਸ਼ੀਅਨ ਔਰਤਾਂ ਦੇ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਦਾ ਸਵੈ-ਪ੍ਰਬੰਧਨ  
ਰੇਸ਼ਰਚਰ ਦਾ ਨਾਮ: ਸੁਖਵਿੰਦਰ

ਮੈਨੂੰ ਇਸ ਪ੍ਰੋਜੈਕਟ ਬਾਰੇ ਜਾਣਕਾਰੀ ਸ਼ੀਟ ਦਿੱਤੀ ਗਈ ਹੈ ਅਤੇ ਪੜ੍ਹੀ ਗਈ ਹੈ

ਕਿਰਪਾ ਕਰਕੇ ਟਿਕ ਕਰੋ  
ਹਾਂ [ ] ਨਹੀਂ [ ]

ਮੈਂ ਸਮਾਜਦੀ ਮੇਰਾ ਇਸ ਪ੍ਰੋਜੈਕਟ ਵਿੱਚ ਭਾਗੀਦਾਰੀ ਸਵੈਇੱਛਤ ਹੈ। ਤੁਸੀਂ ਗਰੁੱਪ ਮੀਟਿੰਗਾਂ ਤੋਂ ਪਹਿਲਾਂ  
ਜਾਂ ਹੁੰਦੇ ਸਮਾਇ ਹਿੱਸਾ ਲੈਣ ਤੋਂ ਇਨਕਾਰ ਕਰ ਸਕਦੇ ਹੋ, ਕਿਸੇ ਕਾਰਨ ਦੀ ਲੋੜ ਨਹੀਂ ਹੈ ਪਰ ਤੁਹਾਡੇ ਡੇਟਾ ਨੂੰ  
ਮਿਟਾਇਆ ਨਹੀਂ ਜਾ ਸਕਦਾ ਹੈ

ਹਾਂ [ ] ਨਹੀਂ [ ]

ਮੈਂ ਸਮਾਜਦੀ ਮੇਰਾ ਡੇਟਾ ਸੰਭਾਲ ਕੇ ਰੱਖਿਐ ਜਾਵੇ ਗਾ।  
ਕੋਈ ਮੇਰਾ ਨਾਮ ਨਹੀਂ ਜਾਣੇਗਾ (ਸਿਰਫ ਜੇ ਲੋੜ ਪਾਈ ਕਾਨੂੰਨੀ ਤੌਰ ਤੇ)

ਹਾਂ [ ] ਨਹੀਂ [ ]

ਮੈਂ ਆਡੀਓ ਰਿਕਾਰਡਿੰਗ ਦੀ ਇਜਾਜ਼ਤ ਧੀਂਦੀ ਹੈ

ਹਾਂ [ ] ਨਹੀਂ [ ]

ਮੈਂ ਉਪਰੋਕਤ ਅਧਿਐਨ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣ ਲਈ ਸਹਿਮਤ ਹਾਂ

ਹਾਂ [ ] ਨਹੀਂ [ ]

ਜੇਕਰ ਡੇਟਾ ਪ੍ਰਕਾਸ਼ਿਤ ਕੀਤਾ ਜਾਂਦਾ ਹੈ ਤਾਂ ਮੈਂ ਇਸਨੂੰ ਇੱਕ ਔਨਲਾਈਨ ਰਿਪੋਜ਼ਟਰੀ ਵਿੱਚ ਸਟੋਰ ਕੀਤੇ ਜਾਣ ਲਈ ਇਜਾਜ਼ਤ ਧੀਂਦੀ ਹੈ (ਇਹ  
ਵਿਕਲਪਿਕ ਹੈ)

ਹਾਂ [ ] ਨਹੀਂ [ ]

ਖੋਜਕਰਤਾ ਦਾ ਨਾਮ \_\_\_\_\_

ਭਾਗੀਦਾਰ ਦਾ ਨਾਮ \_\_\_\_\_ ਦਸਤਖਤ \_\_\_\_\_

ਤਾਰੀਖ \_\_\_\_\_

## Appendix Thirteen: Prompt Sheet

### **Focus Group Prompt Sheet**

From the first phase there were many issues highlighted including:



Sleep, anxiety, tension, feelings of sadness, general low mood, little support, lack of understanding from others, and lack of knowledge. The aim of this discussion is that we can together identify the issues most important to us to improve and set goals and explore options on how we can go about addressing these.

Implementing a coaching approach (G (goals)R (reality) O (options)W (way forward/will do) model)

What issues would you like to discuss and/or improve? (goal)

What do you find most difficult about living with chronic pain and what areas would you like to change? (goal)

Which would you like to focus on, and which are most important to you? (goal)

How would you like things to be? (goal)

What are the major challenges that you find stopping you from living well with chronic pain?

I also requested if you could note any moments that you did not experience pain in the week or so prior to this discussion, if we could also discuss what you were doing and how you were feeling during or prior to this time.

Do any of you wish to share your notes relating to these moments during the last week and what you were doing and how you were feeling? When are you not so aware of pain?

Was your pain particularly bad on any day during the week and what were you doing and how they were feeling? When do you most notice your pain?

What have you found that helps you or makes your pain better? (options)

What is working well at the moment? (options)

What have you found to improve things? (options)

What do you think could improve things for you? (options)

(Reality)

On a scale of 1-10 what number are you at in terms of your knowledge of chronic pain as in the reasons of why it can occur and the factors that can make it worse or better?

One being not good at all and ten being excellent. You can write these down and I can collect it at the end if you prefer

On a scale of 1- 10 how confident do you feel at the moment in terms of managing the low mood or feelings of sadness, stated in the interviews?

What number would you like to be at? (goal)

What would you like to know and understand?

How should be go about addressing these and what are the objectives ? What would you like?

What should we do? What ideas do you have ? (Moving forward)

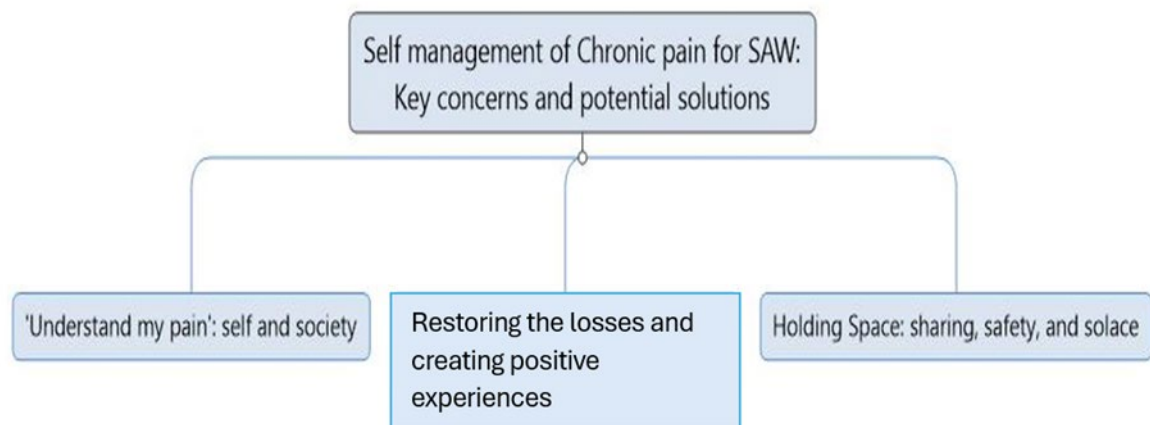
What would be the best way?

What do you think should be our first step?

(my own reflection): Would you say this \_\_\_\_\_ accurately summarises your views?

Is there anything else that anyone would like to add or talk about that we have not discussed?

## Appendix Fourteen: Final Thematic Map



Final Thematic Map

## Appendix Fifteen: Prompt Sheet

Focus Group Prompt Sheet

## Prompt Sheet

Let us discuss a specific example of a resource provided. What aspects do you appreciate about it, and is there anything you dislike or would change?

Do you like how it is presented?

How would you prefer it to be presented?

Do you like the pictures?

Do you like pictures to be included?

Do you like the colours?

what colours do you like?

What about the size of the booklet?

Is there anything about how it is presented that you do not like or feel could be improved?

Reflecting on your own experiences, what tips or advice would you offer to others who may be dealing with similar challenges in pain management? Also, what would you like to include that has been most helpful to you?

What do you hope to gain from this resource for yourself? How do you hope it can help you?

Is there anything else you would like to add or discuss?

## COM- B framed questions:

Capability:

Do you all feel comfortable with engaging in these activities?

Do you all feel confident in your ability to participate in the planned activities?

Opportunity:

Do you have access to the necessary materials and space to engage in these activities?

(resources and environment)

Do you need help organising these meetings/circles? Is there anything I can assist you with in organising or setting up the women's circles?

Are there any particular days or times that work best for you to attend these gatherings? Can you all make this time, and will it be okay with your family circumstances and commitments?

Motivation:

Would you be interested in continuing these meetings and incorporating some of the activities that you all enjoy?

Are there any personal goals or aspirations you would like to pursue within the context of the women's circle?

## Appendix Sixteen: Samples of Resources provided by Participants

Samples can be found at:

<https://www.shropscommunityhealth.nhs.uk/content/doclib/14179.pdf>

<https://www.ouh.nhs.uk/patient-guide/leaflets/files/86568Pcalfstrain.pdf>

<https://www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/having-examinations-and-blood-tests-easy-read>

<https://www.sath.nhs.uk/wp-content/uploads/2020/07/How-you-may-feel-when-someone-dies.pdf>

## Appendix Seventeen: Prompt Sheet

### **Resource/Intervention Focus Group Prompt Sheet**

Having had a chance to view the booklet and read through it, I wanted to discuss your thoughts and opinions about it. What did you think about the presentation, information, and the pictures? What are your opinions after reading it?

Do you feel that we have created what we intended?

Does it meet your expectations?

We discussed during our first meeting that you felt your knowledge about pain and the factors that can influence it was not very good, and you did not feel very confident in managing low moods. Has this changed now? If so, in what ways?

What aspects (if any) did you like and/or which ones (if any) did you find unhelpful or dislike?

Are there any things that are lacking in the resource and that can be improved or included?

Are there any other changes that you would like to see?

Is there anything else that you would like to share about the resource?

### **Intervention evaluation**

Can we discuss your experience of participating in the weekly women's circles? How did you find the experience?

What were your main feelings and emotions experienced when participating in the circles and generally in life now?

Have you noticed any changes in your daily life, health, and well-being? If so, can you please provide examples of any changes?

How content would you say you are with life in general now?

How likely are you to continue participating in these circles?

Would you recommend these circles for managing pain and well-being?

Is there anything else that you would like to share?

## Appendix Eighteen: The Warwick-Edinburgh Mental Well-being Scale

### **WEMWBS**

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) was used in this study. The scale is protected by copyright. For access, please refer to:  
<https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/about/>

### Paired Samples Test

		Paired Differences					Significance		
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		t	df	
					Lower	Upper			One-Sided p Two-Sided p
Pair 1	Post-intervention - Pre-intervention	10.188	4.833	1.208	7.612	12.763	8.431	15	<.001 <.001

### Tests of Normality

Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk			
	Statistic	df	Sig.	Statistic	df	Sig.
Difference	.160	16	.200 <sup>*</sup>	.946	16	.431

\*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

### Report

Group		Pre-intervention	Post-intervention
group 1	Mean	39.33	50.33
	N	6	6
	Std. Deviation	3.266	3.882
	Median	39.00	51.50
	Minimum	35	43
	Maximum	44	53
group 2	Mean	37.00	47.25
	N	4	4
	Std. Deviation	2.944	4.717
	Median	36.50	45.50
	Minimum	34	44
	Maximum	41	54
group 3	Mean	38.17	47.50
	N	6	6
	Std. Deviation	4.401	3.391
	Median	37.50	47.50
	Minimum	33	44
	Maximum	43	53
Total	Mean	38.31	48.50
	N	16	16
	Std. Deviation	3.554	3.933
	Median	38.00	48.50
	Minimum	33	43
	Maximum	44	54



### Paired Samples Effect Sizes

Pair 1	Post-intervention - Pre-intervention	Standardizer <sup>a</sup>	Point Estimate	95% Confidence Interval	
				Lower	Upper
Pair 1	Cohen's d	4.833	2.108	1.204	2.990
	Hedges' correction	5.093	2.000	1.143	2.838

a. The denominator used in estimating the effect sizes.

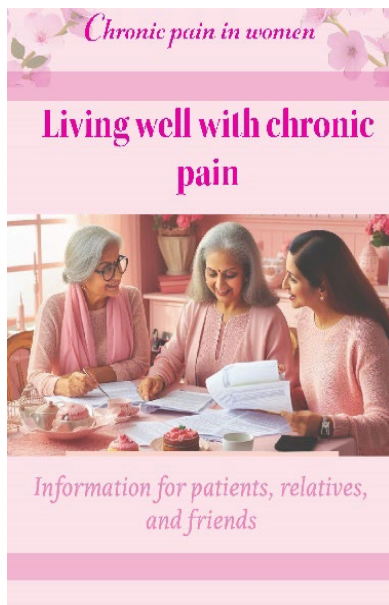
Cohen's d uses the sample standard deviation of the mean difference.

Hedges' correction uses the sample standard deviation of the mean difference, plus a correction factor.

### Report

	Pre-intervention	Post-intervention
Mean	38.31	48.50
N	16	16
Std. Deviation	3.554	3.933
Median	38.00	48.50
Minimum	33	43
Maximum	44	54

## Appendix Twenty: Pain Management Resource



## Introduction

This booklet provides information about chronic pain, challenges experienced by patients living with it, factors that can affect an individual's level of pain, and strategies for managing it. This is not meant to replace consultation between patients and their health care providers. However, it aims to help enhance understanding and well-being and help patients manage their pain with non-medication-based alternatives. Exploring and applying different self-management strategies is key to enhancing overall well-being. Without proper management, pain can lead to a decline in health and mental well-being. Every individual's situation is unique, so finding personalised solutions that work for each individual is key.

### What is pain?

Pain serves as the body's warning system, signalling that something might be wrong or requires attention. Acute (short-term) pain functions like a swift alarm, triggered when we get injured or may get hurt. Special nerves send a message to the brain, prompting us to take immediate action, such as removing our hand from a hot object or resting a sprained ankle. Typically, this type of pain diminishes as the body heals. However, in some cases, even after the healing process, the brain may persist in signalling pain, leading to chronic pain.

### What exactly is chronic pain?

Chronic pain is defined as pain that lasts more than twelve weeks despite medication or treatment.

### How common is chronic pain?

It is the most prevalent disease worldwide, affecting millions of individuals. Chronic pain is more common in women. It is estimated that seventy percent of individuals living with chronic pain are women. However, despite impacting millions collectively, chronic pain can be an isolating experience for individuals, with many struggling to have their experiences fully understood by others.



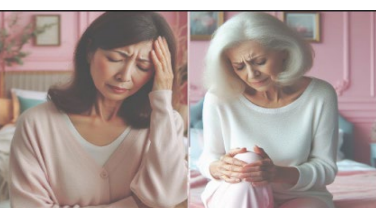
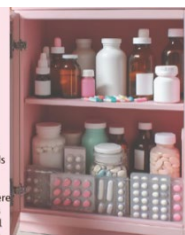
### Why does pain become chronic?

Chronic pain can result from various factors. However, when there is no apparent cause, injury, or damage, chronic pain often stems from a maladaptive pain warning system, mistakenly alerting individuals to a non-existent threat. In such instances, the maladaptive warning system needs to be retrained for more accurate signalling. It is being a bit too protective and needs to learn that there is no threat or injury occurring. Pain is influenced by many factors, which will be covered in this booklet. Addressing these factors through the various self-management strategies mentioned in this booklet can contribute to reshaping the system to respond more adaptively. Almost all pain can be managed and it is important to find medical professionals who understand your concerns and recognise the importance of adopting a holistic approach to managing pain.



### The truth about pain medication for chronic pain

While painkillers may provide temporary relief for acute (short-term) pain, their effectiveness in managing chronic pain is limited. Moreover, pain medication can have side effects, and some can be addictive. It is, however, essential to approach any changes in pain medication carefully and not abruptly stop taking them, as sudden withdrawal can lead to discomfort and other issues. Developing a carefully planned approach to reducing medication, if this is desired, with the guidance of health care providers is essential to minimising potential withdrawal symptoms.



### Beyond the surface: invisible but real

Chronic pain does not always come with visible wounds; there does not have to be evidence of an injury or outward signs, but its impact is profound. Unlike a cast on a broken arm or a visible injury, the absence of physical evidence may lead others to doubt or question the validity of the pain. This invisibility can contribute to scepticism and misunderstanding. The struggles and pain are real, and not acknowledging them can exacerbate the isolation and frustration experienced by those living with chronic pain.

### Will I cause more damage by regular movement?

In cases of acute pain, rest may be advisable to allow the body time to heal from a specific injury or condition. However, when dealing with chronic pain, where there is no evident injury or structural damage, it is important to recognise that using the parts of the body that are painful does not mean you will be causing harm. In fact, appropriate movement and activity can be an integral part of managing chronic pain, contributing to improved function and overall well-being. Engaging in physical activity is beneficial for individuals with other chronic conditions too, but it is important to consult with your doctor to establish safe and appropriate levels of activity.

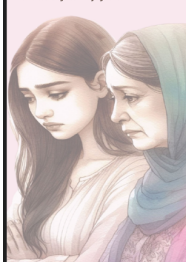
### How can chronic pain affect an individual?

Chronic pain has a profound impact on various aspects of an individual's life and their well-being. Individuals may find it challenging to maintain employment, engage in certain activities, or participate in social events. The constant discomfort and the challenges of managing pain can also take a toll on individuals' mental health. Their overall quality of life can also be substantially diminished as it affects relationships, self-esteem, and the ability to enjoy life.

### Factors that can influence pain

Biological factors such as sex, hormones, psychological factors like stress or anxiety levels, social factors including support networks, and spiritual aspects like personal beliefs can influence both the onset and intensity of pain. An individual's environment, memories, thoughts, emotions, and experiences play crucial roles in how pain is perceived and experienced. Positive emotions and strong support networks can help to mitigate pain. In contrast, negative beliefs, attitudes, and a lack of support, along with factors such as anxiety, grief, anger, and stress, can amplify pain.

Living with chronic pain alone can be a source of stress, as it can affect various aspects of life. When coupled with multiple responsibilities and duties, such as work, caregiving, or household management, the stress can intensify. Juggling these responsibilities without sufficient support or time for self-care can negatively impact health and well-being. Thus, a holistic approach is essential to managing pain effectively. Treatment strategies may include medications, physiotherapy, and lifestyle changes.



### What can relatives and friends do to support patients?

The way forward involves cultivating empathy and understanding the challenges of our friends and family who may be dealing with chronic pain. Listening without judgement, offering support, and validating their feelings can make a profound difference. It is important to remember that even if we may not fully comprehend the depth of someone's pain, our willingness to empathise can contribute significantly to their well-being. Moreover, educating ourselves about the conditions and challenges our loved ones face can strengthen our ability to provide meaningful support.

### The power of listening

Listening to someone in pain can provide significant relief to them, as it can feel like a substantial burden has been lifted. Often, individuals in pain experience a lack of understanding from others, and having someone truly listen and empathise can make them feel heard and supported, lightening the emotional load they may be carrying.

### Acknowledge that pain is a subjective experience

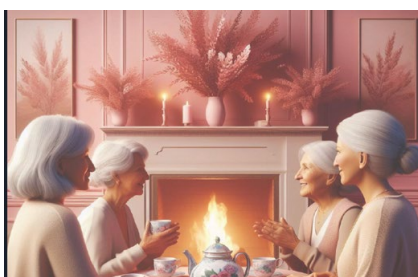
It is essential to acknowledge that pain is a subjective experience, and what matters most is the individual's own description and perception of their pain, and to believe this.

### Small acts of kindness

Sometimes those living with pain may need your help with shopping, cooking, or cleaning, as they often juggle these tasks all by themselves while also managing their pain. If you have time and are able to help, ask them if they need a hand. Your simple act of kindness can make a world of difference to someone in pain who is struggling.

### Flexibility, patience, and an awareness of patient limitations

Chronic pain is notoriously unpredictable, and patients frequently experience fluctuations in their symptoms. Being patient and flexible with plans and activities when their pain is more difficult to manage is often required. Recognise that individuals experiencing pain may find it necessary to decline invitations or alter their activities accordingly. Prevent them from being pushed beyond their capabilities. Ensure that they do make time for activities they enjoy; it is extremely vital for their mental and physical well-being.



### Seeking support

#### Patients sharing experiences

Share your experiences and challenges with someone who understands whether it is a friend, family member, or support group. Connecting with others that understand your pain can help reduce feelings of isolation. They can also allow you to discover solutions that you may not have otherwise considered.

#### Compassionate, candid conversations

Talking to someone who understands can provide emotional support and improve psychological wellbeing, all of which are vital in managing chronic pain.

#### Seeking help

It is entirely appropriate to request help and accept it. Having a strong circle of support is essential for receiving emotional and practical support during difficult times and effectively managing pain.



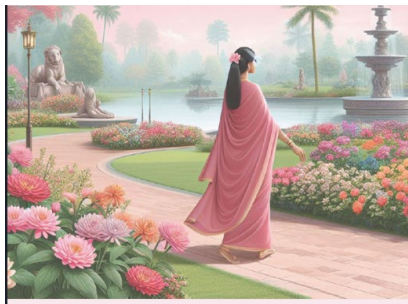


## Physical activity

The positive impact of physical activity on mental health and its potential to mitigate symptoms of depression are widely recognised. Exercise also releases endorphins, which are the body's natural painkillers. Walking is an excellent low-impact form of physical activity, is suitable for individuals of all fitness levels and requires no special equipment or skills.



However, ensure your footwear is comfortable, non-slip, and well-fitting. Incorporating walking into one's daily routine can be an effective way to reduce stress, anxiety and pain, improve sleep, and improve overall health and well-being. Start slowly and gradually increase the duration of your walks as you feel more comfortable. Aim to build up to thirty minutes a day, set achievable goals, and celebrate each milestone as you progress. On days when you would rather not go outside, stationary bikes provide a convenient indoor alternative.



## Mindfulness

There are mindfulness exercises you can attempt while you are walking. Mindfulness requires being fully absorbed and engaged in the current experience, without judgement or distraction, and having appreciation for the richness of the present moment.

## Moving mindfully

Try to concentrate on the sensation of your body moving. If you go for a mindful walk, you may notice the breeze on your skin, the sensation of your feet or hands against different textures on the ground or surrounding surfaces, and the different objects, sounds and smells around you.

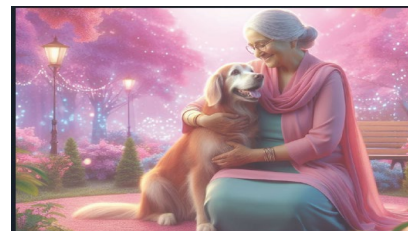
9



## Prayer and spirituality

Prayer and spirituality can help individuals living with chronic pain. They can provide strength, purpose, hope, comfort, and inner peace and can help get individuals through challenging times. Engaging in prayer and connecting with one's spiritual beliefs often offers a source of guidance, fostering a deeper understanding of life's challenges and promoting a sense of inner peace. Taking time to explore and incorporate your own beliefs into your well-being approach can be a meaningful part of your journey in managing chronic pain.

10



## Pets can provide numerous benefits to individuals living with pain.

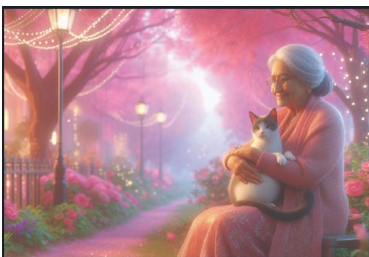
Some of the ways in which they have been reported to help are provided below.

**Emotional support:** pets can provide companionship and emotional support, which can help alleviate feelings of loneliness and depression often associated with chronic pain.

**Distraction:** interacting with pets can serve as a positive distraction from pain, redirecting individuals' focus and providing a sense of purpose and responsibility.

**Physical activity:** dogs, in particular, require regular walks and playtime, encouraging physical activity for their owners.

11



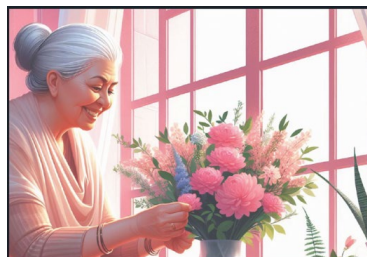
**Unconditional love:** pets often offer unconditional love and nonjudgmental companionship, creating a sense of comfort and security. This emotional connection can be especially valuable during challenging times.

**Routine and structure:** caring for a pet establishes a daily routine, providing structure and a sense of purpose. Having a predictable schedule can be beneficial for individuals managing chronic pain.

**Stress reduction:** interactions with pets have been shown to reduce stress levels and improve mood. This more positive emotional state can contribute to reducing pain perception.

Consideration should always be given to whether you can provide a pet with the attention, love, and care it requires before deciding to adopt one into your life.

12



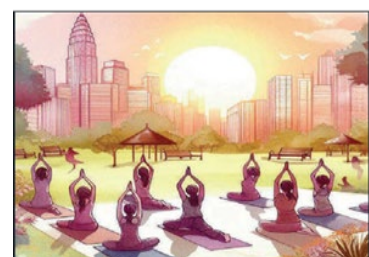
## Surrounding yourself with things that bring you joy

Surrounding yourself with things that bring joy and lift your mood is a simple yet powerful way to cultivate a positive and uplifting environment. This can be a piece of art or some flowers.

**Spending time with those whose company you enjoy.**



13



## Yoga and stretching

Yoga and stretching are helpful for pain management as they help improve flexibility, increase blood flow, and reduce muscle tension and stress. Stretching can release endorphins, the body's natural painkillers, which not only aid in pain reduction but also contribute to an improved mood. It is advisable to consult with your doctor to address any concerns about incorporating stretching into your routine. Stretching, when done regularly and with attention to your body's limits, can contribute to a more flexible and comfortable body, potentially reducing chronic pain.

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### Simple Stretches

Below are some simple stretches that have been found to be helpful. Remember to move gently and within your comfort range. Feeling a mild, gentle stretch is normal and can be an indicator that you are working on flexibility. However, listen to your body, stop, and seek advice from a health care professional if you experience any sharp pain. Breathe deeply and regularly during stretches. Holding your breath may increase tension. Stretching should feel like a gradual and gentle lengthening of the muscles, not a forceful or painful experience.

**Shoulders, upper back, and sides (obliques)**

Sit or stand comfortably. Clasp your hands together. Stretch your clasped hands up towards the ceiling.

Lean gently to the right to stretch the right side; hold for a few seconds.

Return to the centre.

Lean gently to the left to stretch the left side; hold for a few seconds.

Return to the centre.

Open your arms, lowering them back down.

Repeat the entire sequence 8 to 10 times.

**Shoulder Stretch**

Sit or stand comfortably. Gently roll your shoulders backward in a circular motion for 10 seconds. Then, reverse and roll them forward for another 10 seconds.

Repeat 8 to 10 times.

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### Neck Stretch

Sit or stand comfortably. Slowly tilt your head to the left side, bringing your ear toward your shoulder. Hold for a few seconds. Return to the centre. Repeat on the right side. Return to the centre. Repeat both sides 8 to 10 times.

### Back stretch

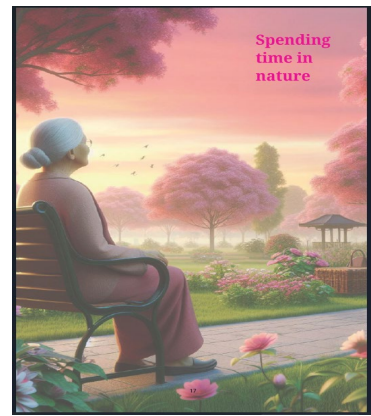
Sit on a sturdy chair with your feet flat on the floor. Without moving your hips turn your upper body to the left as far as is comfortable, using the back of the chair for support. Hold the twist for a few seconds. Return to the centre and repeat on the other side.

Repeat the sequence 8 to 10 times.

**Legs and ankles:**

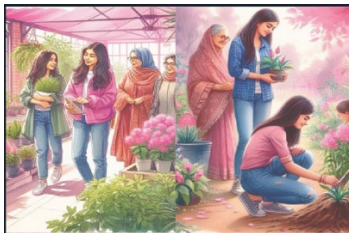
Sit on a chair with your back straight. Lift one leg straight out in front of you. Point your toes outward, stretching the top of your foot and ankle. Hold this position for a few seconds. Then flex your foot by pulling your toes back towards you, feeling a stretch in the calf and the back of your ankle. Hold for a few seconds and lower the leg back down. Switch to the other leg and repeat the sequence 8 to 10 times.

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### Spending time in nature


17



### The healing power of nature

Time spent in nature has been linked to improved mood, reduced anxiety, and enhanced overall wellbeing. These can all help to reduce pain. Engaging with plants, whether through gardening or simply enjoying green spaces, encourages mindfulness and a connection with the natural world.

18



### Engaging in hobbies

Investing time in hobbies and activities that bring joy and spending time with supportive individuals contribute significantly to a happier, more enjoyable, and more fulfilling life. While managing time for such activities may require careful planning, even small moments dedicated to them can have a beneficial impact. It is vital for individuals to acknowledge the importance of self-care and prioritise activities that bring them joy and relaxation, ultimately leading to improved health, wellbeing, and quality of life.

### Crafting a path to well-being

Anxiety, depression, and feelings of isolation can be alleviated through craft. Art can also have a positive impact on one's mental health. It can provide a distraction from pain, remind individuals about their skills, and provide opportunities for socialisation. Moreover, it can also provide enjoyment, stress relief, meaning, and a sense of normality in life and enhance psychological well-being.

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### Structure, routine, and purpose

Research indicates that individuals tend to become less active and more susceptible to low moods and depression when not engaged in work. The loss of structure, routine, and purpose can impact individuals' well-being. Being at work can also serve as a distraction from pain and may not necessarily exacerbate it. If certain aspects of your job pose challenges, consider discussing these concerns with your manager.

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### Workspace modifications, remote working, working flexible hours, and regular breaks

If you wish to continue working, emphasise your desire to do so and explore potential modifications that can make your job more manageable, or explore the possibility of working from home and working flexible hours. Open communication with your employer can contribute to a supportive work environment that aligns with your health needs. Even if working is challenging, you can still keep a daily schedule, structure, and goal by making plans to include pleasurable, beneficial, and meaningful activities.

22



### Set goals to make time and incorporate pleasurable, beneficial, and meaningful activities.

Setting SMART goals is an effective way to plan your days at home, particularly when it comes to improving physical activity. The acronym SMART stands for Specific, Measurable, Achievable, Realistic, and Timebound. An example of a simple, SMART goal is shown below.

I will walk for 15 minutes every morning before breakfast for the next three weeks, progressively increasing the time by 5 minutes each week. This will help me increase my physical activity, and at the end of three weeks, I hope to walk for 30 minutes every morning.

When faced with challenges, having a coping plan can be beneficial. Talking to someone in your support network can be one of the most effective ways to navigate difficult situations. By discussing your concerns, you can gain emotional support, different perspectives, and potential solutions. Exploring options together can provide valuable insights and contribute to a more comprehensive approach to managing whatever you may be facing.

**Coping plan?**

23







ਜਦੋਂ ਅਸੀਂ ਕਿਸੇ ਨੂੰ ਦਰਦ ਵਿੱਚ ਸੁਟਦੇ ਹਾਂ, ਤਾਂ ਇਹ ਉਨ੍ਹਾਂ ਨੂੰ ਬਿਹਤਰ ਮਹਿਸੂਸ ਕਰਨ ਵਿੱਚ ਮਦਦ ਕਰ ਸਕਦਾ ਹੈ। ਇਹ ਉਹਨਾਂ ਦੇ ਬੋਧ ਨੂੰ ਚੁੱਕਣ ਵਿੱਚ ਮਦਦ ਕਰਦਾ ਹੈ ਜੋ ਉਹ ਇਕੱਲੇ ਚੁੱਕ ਰਹੇ ਹਨ। ਜਦੋਂ ਕੋਈ ਸੰਚਮੁੱਖ ਸੁਣਦਾ ਹੈ ਅਤੇ ਪਰਵਾਹ ਕਰਦਾ ਹੈ, ਤਾਂ ਇਹ ਉਹਨਾਂ ਨੂੰ ਬਿਹਤਰ ਮਹਿਸੂਸ ਕਰਨ ਵਿੱਚ ਮਦਦ ਕਰ ਸਕਦਾ ਹੈ।



ਆਤਮਿਕਤਾ  
/ਗੁਹਾਨੀਅਤ  
ਅਰਦਾਸ/ਪਾਠ

92



ਸਹਾਇਤਾ ਲੈਣੀ

ਮਰੀਜ਼ਾਂ ਦੇ ਤਜਰਬੇ  
ਸਾਂਝੇ ਕਰਨਾ:

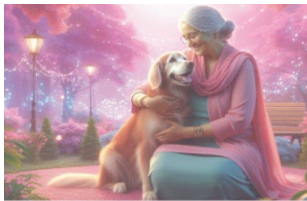
ਅਪਣੇ ਤਜਰਬੇ ਅਤੇ ਚੁਣੌਤੀਆਂ ਨੂੰ ਕਿਸੇ ਸਮਥਦਾਰ ਵਿਅਕਤੀ ਨਾਲ ਸਾਂਝ ਕਰੋ, ਜਿਵੇਂ ਕਿ ਦੋਸਤ, ਪਰਿਵਾਰਕ ਮੈਂਬਰ ਜਾਂ ਸਾਹਿਤਕ ਗਰੁੱਪ। ਜੇ ਰੁਹਾਨੇ ਦਰਦ ਨੂੰ ਸਮਥਦੇ ਹਨ, ਉਹਨਾਂ ਨਾਲ ਜੁੜਨ ਨਾਲ ਤੁਸੀਂ ਅਕੇਲਪਣ ਮਹਿਸੂਸ ਕਰਨਾ ਘੱਟ ਕਰ ਸਕਦੇ ਹੋ ਅਤੇ ਹੋਰ ਜ਼ੋਰ ਸਕਦੇ ਹੋ।

ਧੁੱਲੀ ਗੱਲਬਾਤ

ਮਾਨਸਿਕ ਸਿਹਤ ਵਿੱਚ ਸੁਧਾਰ ਦੇ ਸਕਦਾ ਹੈ। ਇਹ ਸਮਝਣਾ ਲੰਬੇ ਸਮੇਂ ਦੇ ਦਰਦ ਨੂੰ ਸੰਭਾਲਣ ਵਿੱਚ ਬਹੁਤ ਜ਼ਰੂਰੀ ਹੈ।

**ਮਦਦ ਮੰਗਣੀ**

ਮਦਦ ਮੰਗਣੀ ਅਤੇ ਇਸਨੂੰ ਸਹੀਕਾਰ ਕਰਨਾ ਠੀਕ ਹੈ। ਇਹ ਯਕੂਨੀ ਹੈ ਕਿ ਤੁਹਾਡੇ ਆਲੇ-ਦੁਆਲੇ ਸਾਥ ਦੇਣ ਵਾਲੇ ਲੋਕ ਹਨ ਜੋ ਤੁਹਾਨੂੰ ਮੁਸ਼ਕਿਲ ਸਮੇਂ ਵਿੱਚ ਸਹਾਯਾ ਦੇ ਸਕਦੇ।



ਪਾਲਤੂ ਜਾਨਵਰ ਦਰਦ ਨਾਲ  
ਰਹਿ ਰਹੇ ਵਿਅਕਤੀਆਂ ਨੂੰ  
ਬਹੁਤ ਸਾਰੇ ਲਾਭ ਪ੍ਰਦਾਨ ਕਰ  
ਸਕਦੇ ਹਨ।

ਭਾਖਾਤੂ ਜਾਨਵਰ, ਜਿਹੜੇ ਕਿ ਕੁੱਤੇ ਅਤੇ ਬਿੱਲੀਆਂ, ਦਰਦ ਦਾ ਅਨੁਭਵ ਕਰਨ ਵਾਲੇ ਵਿਅਕਤੀਆਂ ਲਈ ਅਨਮੋਲ ਸਾਥੀ ਸਾਬਤ ਹੋ ਸਕਦੇ ਹਨ। ਇਹ ਵਡਾਦਾਰ ਸਾਥੀ ਅਤੇ ਮਾਲਵਾ ਲਈ ਦਰਦ ਭੁੱਲਣ ਅਤੇ ਮਨ ਨੂੰ ਕਿਸੇ ਹੋਰ ਚੀਜ਼ 'ਤੇ ਕੇਂਦਰਿਤ ਕਰਨ ਵਿੱਚ ਮਦਦ ਕਰਦੇ ਹਨ। ਪਾਲਤੂ ਜਾਨਵਰਾਂ ਨਾਲ ਗੱਲਬਾਤ ਅਤੇ ਖੇਡਣਾ ਅਕਸਰ ਮਾਲਵੇ ਅਤੇ ਉਦਾਸੀ ਨੂੰ ਘਟਾਉਂਦਾ ਹੈ। ਇਸ ਤੋਂ ਇਲਾਵਾ, ਕੁੱਤੇ ਨੂੰ ਸੈਰ ਕਰਨ ਦਰਗੀਆਂ ਸਰੀਰਕ ਗਤੀਵਿਧੀਆਂ ਸਿਹਤ ਅਤੇ ਮਨਾਸਿਕ ਸੁਖ-ਸਮੁੱਚੇ ਨੂੰ ਸੁਧਾਰਨ ਵਿੱਚ ਮਦਦ ਕਰਦੀਆਂ ਹਨ।



ਪਾਲਤੂ ਜਾਨਵਰ ਅਤੇ ਕਿਵੇਂ  
ਕਰਦੇ ਹਨ  
ਉਹ ਬਿਨਾਂ ਕੁਝ ਚਾਹੇ ਪਿਆ  
ਪਾਲਤੂ ਜਾਨਵਰ ਬਿਨਾਂ ਕੁਝ  
ਵਿਅਕਤੀ ਇੰਨੇ ਹਨ ਅਤੇ

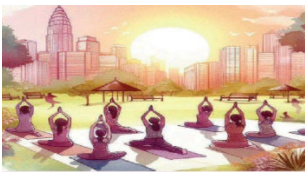
**ਕੂਟੀਨ:** ਪਲਾਜ਼ੂ ਜਾਨਵਰ ਦੀ ਦੇਖਭਾਲ ਕਰਨ ਨਾਲ ਹਰ ਰੋਜ਼ ਇਕ ਕੂਟੀਨ ਬਣ ਜਾਂਦੀ ਹੈ। ਇਹ ਤੁਹਾਡੇ ਮਾਨਸਿਕ ਸਿਹਤ ਲਈ ਚੰਗਾ ਹੈ।

ਪਾਸਤੂ ਜਾਨਵਰ ਨੂੰ ਅਪਣੀ ਜ਼ਿੰਦਗੀ ਵਿੱਚ ਲਿਆਉਣ ਤੋਂ ਪਹਿਲਾਂ, ਇਹ ਜ਼ਰੂਰੀ ਹੈ ਕਿ ਤੁਸੀਂ ਸੋਚੋ ਕਿ ਕੀ ਤੁਸੀਂ ਉਸਨੂੰ ਲੋੜੀਂਦਾ ਖਿਆਰ ਅਤੇ ਦੇਖਰਖ ਦੇ ਸਕਦੇ ਹੋ ਕਿ ਨਹੀਂ।



ਆਪਣੇ ਆਲੇ-ਦੁਆਲੇ  
ਅਜਿਹੀਆਂ ਚੀਜ਼ਾਂ ਰੱਖੋ  
ਤੁਹਾਨੂੰ ਖੁਸ਼ ਕਰਦੀਆਂ।

ਆਪਣੇ ਆਲੇ-ਦੁਆਲੇ ਉਹਨਾਂ ਦੀਆਂ ਚੀਜ਼ਾਂ ਨੂੰ ਰੱਖੇ ਜੇ ਤੁਹਾਨੂੰ ਖੁਸ਼ ਕਰਦੀਆਂ ਹਨ। ਜਿਵੇਂ ਕਿ ਇੱਕ ਸੁੰਦਰ ਤਸਵੀਰ ਜਾਂ ਕੁਝ ਫੁੱਲ, ਇਹ ਤੁਹਾਡੇ ਮੁਝ ਨੂੰ ਦਰਸਾਉਂਦੇ ਹਨ ਅਤੇ ਇੱਕ ਵਾਰੀਆਂ ਅਚੀਲ ਬਣਾਉਂਦੇ ਹਨ। ਉਨ੍ਹਾਂ ਲੋਕਾਂ ਨਾਲ ਸਮਾਂ ਬਿਤਾਉਣਾ ਵੀ ਜਰੂਰੀ ਹੈ ਜਿਨ੍ਹਾਂ ਦੀ ਸੰਗਤ ਦਾ ਤੁਸੀਂ ਆਨੰਦ ਮਾਣਦੇ ਹੋ।



ਸਟ੍ਰੀਚਿੰਗ

ਅਤੇ ਮਸਪੋਸੀਅ' ਦੇ ਤਣਾਅ ਨੂੰ ਘਟਾਉਂਦੇ ਹਨ।  
ਸਟ੍ਰੈਚਿੰਗ ਨਾਲ ਸਹੀਰ ਵਿੱਚ ਐਂਡਰੋਇਨ ਨਿਕਲਦੇ  
ਹਨ, ਜੋ ਪੁਰਾਣੇ ਮੂਤ ਅਤੇ ਦਰਦ ਵਿੱਚ ਮਦਦ  
ਕਰਦੇ ਹਨ। ਕੋਈ ਵੀ ਸਟ੍ਰੈਚਿੰਗ ਕਰਨ ਤੋਂ ਪਹਿਲਾਂ  
ਆਪਣੇ ਡਾਕਟਰ ਦੀ ਸਲਾਹ ਜ਼ਰੂਰ ਲਵੋ।



ਮੇਢੇ, ਉਪਰਲੀ ਪਿੰਡ, ਅਤੇ ਪਾਸੇ  
(ਚਿਖਲਿਕਮ)।

ਅਪਣੇ ਹੱਥ ਇਕੱਠੇ ਰੱਖੋ।  
ਅਪਣੇ ਹੱਥ ਫੌੜ ਵੱਲ ਚੁੱਕੋ।  
ਹੌਲੀ-ਹੌਲੀ ਹੱਥ ਪਹੀ ਵੱਲ ਮੋੜੋ ਅਤੇ ਕੁਝ  
ਸਕਿੰਟਾਂ ਲਈ ਹੋਲਕ ਕਰੋ।  
ਮੱਧ ਵਿੱਚ ਵਾਪਸ ਆਓ।  
ਹੌਲੀ-ਹੌਲੀ ਹੱਥ ਪਹੀ ਵੱਲ ਮੋੜੋ ਅਤੇ ਕੁਝ  
ਸਕਿੰਟਾਂ ਲਈ ਹੋਲਕ ਕਰੋ।  
ਮੱਧ 'ਤੇ ਵਾਪਸ ਆਓ।



ਮੇਰੇ ਸਿੱਟੇ ਬਾਗ਼  
ਬੂਟੇ ਹਿੱਸੇ ਨੂੰ ਜੀਵੇ  
ਹਿੱਸੇ ਬਾਗ਼ਦਾਰ ਨੂੰ

**ਪਿਛਾਣਾ:** ਚਿੰਤਾ  
ਮਾਨਸੁ ਹੁਕਮੀ ਤੇ ਜੀਤੀ ਅਤੇ ਹੋਰ ਹਾਥ 'ਤੇ ਹੀ।  
ਮਾਨਸੁ ਹੁਕਮੀ ਨੂੰ ਹਿਲਾਏ ਹੀ ਹਿਲਾ, ਮਾਨਸੁ ਮਾਨੀ  
ਹੁਕਮੀ ਤੇ ਹਿਲਾਏ ਹੀ ਹੁਕਮੀ ਹੀ ਹੁਕਮੀ ਹੀ ਹੀ, ਅਖੀਰ  
ਹੁਕਮੀ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ, ਹੀ ਹੀ ਹੀ  
ਮਾਨਸੁ ਮਾਨਸੁ ਹੀ ਹੀ।  
ਮਾਨਸੁ ਮਾਨਸੁ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ।  
ਮਾਨਸੁ ਮਾਨਸੁ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ।  
ਮਾਨਸੁ ਮਾਨਸੁ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ।  
ਮਾਨਸੁ ਮਾਨਸੁ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ ਹੀ।



ਕੁਦਰਤ ਵਿੱਚ  
ਸਮਾਂ ਬਿਤਾਉਣਾ



ਕੁਦਰਤ ਵਿੱਚ  
ਇਲਾਜ

ਬਰਤਰ ਵਿੱਚ ਬਿਤਾਇਆ ਸਮਾਂ ਤੁਹਾਡੇ ਮੂੰਹ  
ਲਈ ਚੰਗਾ ਹੈ ਸਕਦਾ ਹੈ, ਚਿੰਤਾ ਘਟਾ  
ਸਕਦਾ ਹੈ,  
ਅਤੇ ਇਹ ਮਾਨਸਿਕ ਤੰਦਰੁਸਤੀ ਨੂੰ ਵਧਾ  
ਸਕਦਾ ਹੈ।  
ਇਹ ਸਮਝੀਆਂ ਚੀਜ਼ਾਂ ਦਰਦ ਨੂੰ ਘੱਟ ਕਰਨ  
ਵਿੱਚ ਮਦਦ ਕਰ ਸਕਦੀਆਂ ਹਨ। ਇਹ  
ਫਾਇਦੇ ਵਾਲਾ ਨੂੰ ਦੇਖ ਕੇ, ਅਪਣੇ ਖੁਦ ਫੁੱਲ  
ਲਗਾ ਕੇ, ਸਮੁੰਦਰ ਦੇ ਨੇੜੇ ਸਮਾਂ ਬਿਤਾਉਣ  
ਨਾਲ ਪ੍ਰਾਪਤ ਕੀਤੇ ਜਾ ਸਕਦੇ ਹਨ।



ਉਹਨਾਂ ਚੀਜ਼ਾਂ ਵਿੱਚ ਹਿੱਸਾ ਲੈਣਾ ਜੋ  
ਤੁਹਾਨੂੰ ਖੁਸ਼ ਕਰਦੇ ਹਨ

ਉਹ ਚੀਜ਼ਾਂ ਜੋ ਤੁਹਾਨੂੰ ਖੁਸ਼ ਕਰਦੀਆਂ ਹਨ ਅਤੇ ਸਹਾਇਕ ਲੋਕਾਂ ਨਾਲ ਸਮਾਂ ਬਿਤਾਉਣਾ ਤੁਹਾਡੀ ਜ਼ਿੰਦਗੀ ਨੂੰ ਖੁਸ਼ਹਾਲ ਬਣਾ ਸਕਦੀਆਂ ਹਨ। ਇਹਨਾਂ ਚੀਜ਼ਾਂ ਲਈ ਸਮਾਂ ਕੱਢਣਾ ਜ਼ਰੂਰੀ ਹੈ। ਇਹਨਾਂ ਚੀਜ਼ਾਂ 'ਤੇ ਥੋੜ੍ਹਾ ਜਿਹਾ ਸਮਾਂ ਵੀ ਦੈਂਟਾ ਇੱਕ ਵੱਡਾ ਫਰਕ ਲਿਆ ਸਕਦੀ ਹੈ। ਇਸ ਜ਼ਰੂਰੀ ਹੈ ਕਿ ਤੁਸੀਂ ਅਜਿਹੀਆਂ ਚੀਜ਼ਾਂ ਚੋਣ ਕਰੋ ਜੋ ਤੁਹਾਨੂੰ ਖੁਸ਼ ਅਤੇ ਅਰਮਾਨਦਾਰ ਮਹਿਸੂਸ ਕਰਨ, ਜੋ ਤੁਹਾਡੀ ਸਹਿਰਤ ਅਤੇ ਜੀਵਨ ਨੂੰ ਲਾਭ ਪਹੁੰਚਾ ਸਕਦੀਆਂ ਹਨ।



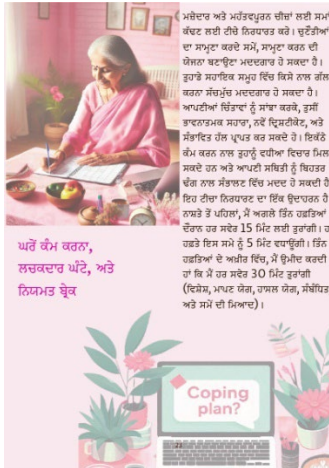
ਰੁਟੀਨ ਅਤੇ  
ਮਕਸਦ

ਨਹੀਂ ਕਰ ਰਹੇ ਹੁੰਦੇ, ਤਾਂ ਅਕਸਰ ਉਨ੍ਹਾਂ ਦਾ ਮੂਢ ਚੰਗਾ ਨਹੀਂ ਹੁੰਦਾ ਅਤੇ ਉਹ ਡਿਪਰੈਸ਼ਨ ਵਿੱਚ ਚੀ ਆ ਸਕਦੇ ਹਨ। ਕੰਮ ਕਰਨ ਨਾਲ ਤੁਹਾਡਾ ਦਿਮਾਗ ਦਰਦ ਤੋਂ ਹਟ ਕੇ ਕਿਸੇ ਹੋਰ ਪਾਸੇ ਲੱਗਦਾ ਹੈ। ਜੇਕਰ ਤੁਹਾਨੂੰ ਕੰਮ ਵਿੱਚ ਮੁਸ਼ਕਲਾਂ ਆ ਰਹੀਆਂ ਹਨ, ਤਾਂ ਆਪਣੇ ਮੈਨੇਜਰ ਨਾਲ ਗੱਲ ਕਰੋ ਕਿ ਉਹ ਕਿਵੇਂ ਤੁਹਾਡੀ ਮਦਦ ਕਰ ਸਕਦੇ ਹਨ।



ਵਰਕਸਪੇਸ ਸੋਧ,  
ਰਿਮੋਟ ਕੰਮ, ਕੰਮ ਕਰਨ  
ਦੇ ਲਚਕਦਾਰ ਘੰਟੇ,  
ਅਤੇ ਨਿਯਮਤ ਬਰੇਕ

ਜੇ ਤੁਸੀਂ ਕੰਮ ਜਾਰੀ ਰੱਖਣਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ  
ਆਪਣੇ ਕੰਮ ਨੂੰ ਆਸਨ ਬਣਾਉਣ ਦੇ  
ਤਰੀਕਿਆਂ ਬਾਰੇ ਗੱਲ ਕਰੋ, ਜਿਵੇਂ ਕਿ ਘਰੇ ਕੰਮ  
ਕਰਨਾ, ਲਚਕਦਾਰ ਘਟਿ, ਸਾਂ ਨਿਸ਼ਚਤ ਬੁੱਲ  
ਜਿੰਨਾ। ਅਪਣੇ ਬੁੱਲਗਦਦਾਰ ਨਾਲ ਖੁੱਲ੍ਹ ਕੇ  
ਗੱਲਬਾਤ ਕਰਨ ਨਾਲ ਇੱਕ ਸਹਾਇਕ ਕੰਮ  
ਮਾਹੌਲ ਬਣਾਉਣ ਵਿੱਚ ਮਦਦ ਮਿਲ ਸਕਦੀ ਹੈ,  
ਜੋ ਹੁਣਾਈਆਂ ਸਿਹਤ ਦੀਆਂ ਲੋੜਾਂ ਦੇ ਅਨੁਕੂਲ  
ਹੋਵੇ। ਭਾਵੇਂ ਕੰਮ ਔਖਾ ਹੋਵੇ, ਇਹ ਵੀ ਤੁਸੀਂ  
ਮਦਦਾਰ ਅਤੇ ਆਖਰਕਾਰ ਹੁਣਾਈਆਂ ਦੀ  
ਜ਼ਿੰਦਗੀ ਬਣਾ ਦੇ ਰੋਸ਼ਨਾ ਹੋਵੇ।



ਸੰਸਦਾਰ ਅਤੇ ਮਹੰਤਦਾਰਨਾਂ ਦੀਆਂ ਲਾਠੀ ਸਮਾਂ ਕੱਟਣ ਲਈ ਟੀਚੇ ਨਿਰਧਾਰਤ ਕਰੇ। ਚੁਣੌਤੀਆਂ ਦਾ ਸਮੂਹਾ ਬਣਾਉਣ ਸਮੇਂ, ਸਮੂਹਾ ਕਰਕਣ ਦੀ ਯੋਜਨਾ ਕਰਦੀਆਂ ਮਦਦਗਾਰ ਹੋ ਸਕਣਗੇ।  
 ਤੁਹਾਡੇ ਸਾਹਿਬਕ ਸਮੂਹ ਵਿੱਚ ਕਿਸੇ ਨਾਲ ਗੱਲ ਕਰਨਾ ਸੰਚੁਚਿਤ ਮਦਦਗਾਰ ਹੋ ਸਕਦਾ ਹੈ।  
 ਅਪਣੀਆਂ ਚਿੰਤਾਵਾਂ ਨੂੰ ਸਾਂਝਾ ਕਰਕੇ, ਤੁਸੀਂ ਭਾਵਨਾਤਮਕ ਸਹਾਯਾ, ਨਵੇਂ ਵਿਸ਼ੇਸ਼ਕੋਣ, ਅਤੇ ਸੰਭਾਵਿਤ ਹੱਲ ਪ੍ਰਾਪਤ ਕਰ ਸਕਦੇ ਹੋ। ਇਕੱਠੇ ਕੰਮ ਕਰਨ ਨਾਲ ਤੁਹਾਨੂੰ ਵਧੀਆ ਵਿਚਾਰ ਮਿਲ ਸਕਦੇ ਹਨ ਅਤੇ ਅਪਣੀ ਸਥਿਤੀ ਨੂੰ ਬਿਹਤਰ ਬੰਨਾ ਨਵੇਂ ਸੰਭਾਵਨਾ ਵਿੱਚ ਮਦਦ ਹੋ ਸਕਦੀ ਹੈ।  
 ਇਹ ਟੀਚਾ ਨਿਰਧਾਰਣ ਦਾ ਇੱਕ ਉਪਕਰਨ ਹੈ।

ਨਾਸ਼ਤੇ ਤੋਂ ਪਹਿਲਾਂ, ਮੈਂ ਅਗਲੇ ਤਿੰਨ ਹਫ਼ਤਿਆਂ ਦੌਰਾਨ ਹਰ ਸਵੇਰ 15 ਮਿੰਟ ਲਈ ਤੁਰਾਂਗੀ। ਜਦੋਂ ਹਫ਼ਤੇ ਇਸ ਸਮੇਂ ਨੂੰ 5 ਮਿੰਟ ਵਧਾਉਂਗੀ। ਤਿੰਨ ਹਫ਼ਤਿਆਂ ਦੇ ਅਖੀਰ ਵਿੱਚ, ਮੈਂ ਉਮੀਦ ਕਰਦੀ ਹਾਂ ਕਿ ਮੈਂ ਹਰ ਸਵੇਰ 30 ਮਿੰਟ ਤੁਰਾਂਗੀ (ਵਿਸ਼ੇਸ਼, ਮਾਪਣ ਯੋਗ, ਹਾਸਲ ਯੋਗ, ਸੰਬੰਧਿਤ, ਅਤੇ ਸਮੇਂ ਦੀ ਮਿਆਦ)।

## ਨੀਂਦ ਦੀ ਮਹੱਤਤਾ

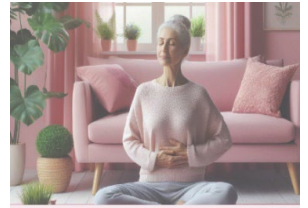
ਨੀਂਦ ਸਾਡੇ ਲਈ ਬਹੁਤ ਜ਼ਰੂਰੀ ਹੈ। ਜਦੋਂ ਅਸੀਂ ਸੌਂਦੇ ਹਾਂ, ਸਾਡਾ ਸਰੀਰ ਆਰਾਮ ਕਰਦਾ ਹੈ ਅਤੇ ਦੁਬਾਰਾ ਤਾਕਤ ਹਾਸਿਲ ਕਰਦਾ ਹੈ। ਚੰਗੀ ਨੀਂਦ ਨਾਲ ਸਰੀਰਕ ਅਤੇ ਮਨੋਵੈਸ਼ਿਅਾਨਿਕ ਸਿਹਤ ਸੁਧਾਰਦੀ ਹੈ ਅਤੇ ਦਰਦ ਦੀ ਸੰਵੇਦਨਾ ਘਟ ਸਕਦੀ ਹੈ।

ਨੀਂਦ ਨਾਲ ਦਰਦ ਘੱਟ ਹੁੰਦਾ ਹੈ: ਜੇ ਅਸੀਂ ਚੰਗੀ ਨੀਂਦ ਨਹੀਂ ਲੈਂਦੇ ਤਾਂ ਦਰਦ ਹੋਰ ਵਧ ਸਕਦਾ ਹੈ ਅਤੇ ਦਰਦ ਸੰਭਾਲਣਾ ਮੁਸ਼ਕਿਲ ਹੋ ਸਕਦਾ ਹੈ।

ਨੀਂਦ ਨਾਲ ਮਨ ਵੀ ਸਾਂਝ ਹੁੰਦਾ ਹੈ: ਚੰਗੀ ਨੀਂਦ ਨਾਲ ਮਨ ਖੁਸ਼ ਰਹਿੰਦਾ ਹੈ ਅਤੇ ਭਾਵਨਾਤਮਕ ਸੁਖ ਅਤੇ ਸਾਂਝੀ ਹੁੰਦੀ ਹੈ।

ਸੈਂਟ ਤੋਂ ਪਹਿਲਾਂ ਗਰਮ ਪਾਣੀ ਨਾਲ ਨਹਾਓ: ਇਸ ਨਾਲ ਸਰੀਰ ਨੂੰ ਆਰਾਮ ਮਿਲਦਾ ਹੈ ਅਤੇ ਤੁਹਾਨੂੰ ਘਟਦਾ ਹੈ। ਪਹਿਲਾਂ ਤੇਜ਼ ਨਹਾਓ: ਭਾਰੀ ਬਾਥ ਪਾਣੀ ਨਾਲ ਨਹੀਂ ਚਲਾਉਣਾ ਹੋ ਸਕਦੀ ਹੈ। ਕੈਲੀਨ ਤੋਂ ਪਰਹੇਜ਼ ਕਰੋ ਸੈਂਟ ਤੋਂ ਪਹਿਲਾਂ। ਅਰਮਾਇਕ ਬਿਊਟਰ ਵਰਤੋ: ਇਕ ਚੰਗਾ ਗੰਦਾ ਅਤੇ ਤੁਹਾਡੀਆਂ ਚੁੰਨੀਆਂ। ਗਰਮ ਦੁਧ ਅਤੇ ਹਲਦੀ ਦੀ ਮਸਾਲਾ: ਸੈਂਟ ਤੋਂ ਪਹਿਲਾਂ ਗਰਮ ਦੁਧ ਅਤੇ ਹਲਦੀ ਦੀ ਆਦਰਸ਼, ਲੈਂਡ, ਕਸਰਤ ਨੂੰ ਬਦਲ ਦਿਓ ਤੇਲ ਨਾਲ ਮਸਾਜ਼ ਕਰਨ ਨਾਲ ਵੀ ਆਰਾਮ ਮਿਲ ਸਕਦਾ ਹੈ। ਰੁਝ ਲੋਕਾਂ

ਮਦਦ ਮਿਲ ਸਕਦੀ ਹੈ। ਹਰ ਵਿਅਕਤੀ ਲਈ ਚੰਗੀ ਨੀਂਦ ਦੇ ਤਰੀਕੇ ਵੱਖਰੇ ਹੋ ਸਕਦੇ ਹਨ। ਅਪਣੀ ਲਈ ਸਭ ਤੋਂ ਵਧੀਆ ਤਰੀਕੇ ਅਜਮਾਉਣ ਅਤੇ ਚੁਣਨ ਨੂੰ ਅਪਣੀ ਜ਼ਿੰਦਗੀ ਵਿੱਚ ਸ਼ਾਮਲ ਕਰਨ ਦੀ ਕੋਸ਼ਿਸ਼ ਕਰੋ। ਮੁੱਖ ਗੱਲ ਇਹ ਹੈ ਕਿ ਚੰਗੀ ਨੀਂਦ ਸਾਡੀ ਸਿਹਤ ਅਤੇ ਖੁਸ਼ਹਾਲੀ ਲਈ ਬਹੁਤ ਜ਼ਰੂਰੀ ਹੈ।



ਬਿਹਤਰ ਠੀਕ ਲਈ ਸਾਹ ਦਾ  
ਕੰਮ

ਭੁਗਰਬੀ ਸਹ ਲੈਣ ਨਾਲ ਅਰਾਮ ਮਿਲਦਾ ਹੈ, ਤਣਾਅ ਘਟਦਾ ਹੈ, ਅਤੇ ਮਨ ਨੂੰ ਸਾਂਤੀ ਮਿਲਦੀ ਹੈ, ਜੋ ਦਰਦ ਨੂੰ ਕਾਬੂ ਕਰਨ ਵਿੱਚ ਵਾਇਦਾ ਕਰ ਸਕਦਾ ਹੈ। ਬੋਲੀ ਸਹ ਲੈਣਾ (ਪੇਟ ਦੀ ਸਹ) ਇੱਕ ਅਸਾਨ ਤਰੀਕਾ ਹੈ, ਜਿਸ ਵਿੱਚ ਹੌਲੀ-ਹੌਲੀ ਭੁੰਘੀਆਂ ਸਹ ਲਈਆਂ ਜਾਂਦੀਆਂ ਹਨ।<sup>੧</sup> ਸਹ ਲੈਣ ਦੀ ਕਸਰਤ:

ਆਰਮਦਇਕ ਮੁਦਰਾ ਵਿੱਚ ਬੈਠੇ ਜਾਂ ਲੇਟ  
ਜਾਓ।  
ਇੱਕ ਹੱਥ ਆਪਣੀ ਛਾਤੀ ਉੱਤੇ ਅਤੇ ਦੂਜਾ ਹੱਥ  
ਆਪਣੇ ਪੇਟ ਉੱਤੇ ਰੱਖੋ।

ਨੈਕ ਰਾਹੀਂ ਹੌਲੀ-ਹੌਲੀ ਸਾਹ ਰਹਿੰਦੇ (ਚਾਹ ਤਾਂ ਕਿਹੜੇ ਜਾਂ ਜਿੰਨਾ ਅਚਾਨਕ ਇਹ ਲੱਗੇ) ਅਤੇ ਮਹਿਸੂਸ ਕਰਦੇ ਕਿ ਜੁਹਾੜਾ ਧੱਕੇ ਫੁੱਕੇ ਜਿਹਾ ਹੋਵੇ।  
ਹੌਲੀ-ਹੌਲੀ ਸਾਹ ਛੱਡੋ (ਭੇੜ ਤੋਂ ਕਿਹੜੇ ਜਾਂ ਜਿੰਨਾ ਅਚਾਨਕ ਇਹ ਲੱਗੇ) ਅਤੇ ਮਹਿਸੂਸ ਕਰਦੇ ਕਿ ਜੁਹਾੜਾ ਧੱਕੇ ਫੁੱਕੇ ਜਿਹਾ ਹੋਵੇ।  
ਸਾਹ ਲੈਣ ਅਤੇ ਛੱਡਣ ਦੇ ਸਮੇਂ ਨੂੰ ਆਪਣੀ ਅਪ ਐਂਡਰਸਟੈਂਡ ਕਰੋ ਕਿ ਕੀ ਛਾਹੀਲੀ ਬਣਦੀ ਹੈ ਜਾਂ ਫਿਰ ਇਸ ਸਮੇਂ ਸਾਹ ਲੈਣ ਅਤੇ ਛੱਡਣ ਦੋਵਾਂ ਵਿਚ।  
ਜੇਹਨਾ ਪੱਧਰ ਉੱਤੇ ਸਾਹ ਲੈਣ ਨਾਲ ਜੁਹਾੜੀ ਆਪਣਾ ਮਹਿਸੂਸ ਕਰਦੀ ਹੈ ਜੁਹਾੜੀ ਸਹੀਦੀ ਦਾ ਤਣਾਅ ਧੱਕੇ ਹੋਵੇਗਾ।



ਦਿਲ ਸੁਝਾਏ

[illegible]

## ਹੈਰ ਜਾਣਕਾਰੀ

Healthtalk.org ਦੱਖ-ਦੱਖ ਸਿਰ

ਸਹਾਇਤਾ ਪ੍ਰਦਾਨ ਕਰਦਾ ਹੈ, ਜਿਸ ਵਿੱਚ ਸਾ  
ਸਾਡੇ ਦਾਦਾ ਦੀ ਸਹਾਇਤਾ ਹੈ। ਬਹੁਤ ਸ  
ਲੋਕਾਂ ਨੇ ਅਪਣੀਆਂ ਕਹਾਣੀਆਂ ਸਾਂਝੀਆਂ  
ਕੀਤੀਆਂ ਹਨ ਜੋ ਹੋਰ ਲੋਕਾਂ ਨੂੰ ਮਦਦ ਕਰ  
ਸਕਦੀਆਂ ਹਨ।

ਪੇਨ ਯੂਕੇ ਇੱਕ ਚੈਰਿਟੀ ਹੈ ਜਿਸ ਕੋਲ  
ਅਜਿਹੀ ਜਾਣਕਾਰੀ ਵੀ ਹੈ ਜੋ ਤੁਹਾਨੂੰ  
ਮਦਦਗਾਰ ਲੱਭ ਸਕਦੀ ਹੈ।  
<https://painuk.org/help-and-support>

ਸੈਟਲ ਹੋਸਪਿਟਾਟਾਂ ਦਾ ਫਾਇਨਾਂਸਿੰਗ ਅਤੇ ਮਾਨੀਅਰ ਦੇ  
ਮਾਨਸਿਕ ਸਿਹਤ ਅਤੇ ਤੰਬੁਲਾਈ ਲਈ ਸਹਾਇਤਾ  
ਅਤੇ ਜਾਣਕਾਰੀ ਦਿੰਦੇ ਹਨ।  
<https://www.mentalhealth.org.uk>  
<https://www.mind.org.uk/>

**Headspace:** 18 ਵੀਂ ਆਬਾਜ਼  
ਯੁਗਲ ਲਈ ਇੱਕ ਵੈਬਸਾਈਟ।  
[www.headspace.com](http://www.headspace.com)  
[www.getsetforhelp.co.uk](http://www.getsetforhelp.co.uk) (ਜੋ ਤੁਸੀਂ  
ਵਿਓਇਲੈਂਸ ਬੇਦੋਸ਼ੀ ਬਾਰੇ ਜਾਣਨਾ ਚਾਹੁੰਦੇ ਹੋ।)  
ਇਸੇ ਵੀ ਅਰਧਨਾਮ ਅਤੇ ਤੀਬਰ ਚਰਚਣ ਲਈ  
ਤੁਹਾਨੂੰ ਤੁਰੰਤ ਡਾਕਟਰੀ ਮਦਦ ਲੈਣ ਦੀ ਲੋੜ ਹੈ।



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persistent pain is of an injury



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2024

ਸਕੂਲ ਦਿਹਾੜਾ, ਸਾਹਿਤ, ਐਡ  
ਫੋਲ - ਕੋਲੋਰਿਡ