

**PATIENTS' PERSPECTIVES AND EXPERIENCES ABOUT PRIVATE  
PRACTICE HEALTH CARE MANAGEMENT OF THEIR CHRONIC  
MUSCULOSKELETAL PAIN.**

**By**

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## **DECLARATION**

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## ABSTRACT

**Background:** Understanding patients' perspectives about living with chronic pain in the South African context and their views about the private health care they received is important because it can identify facilitators and barriers for health care management. It was proposed that this information would produce meaningful information to be incorporated into the health care management of chronic musculoskeletal pain (CMSP) patients.

**Aim:** The purpose of this study was to explore patients' perspectives about living with CMSP and their experiences with health care management of their CMSP in the private health care sector of South Africa.

**Methodology:** A descriptive qualitative case study design with an interpretative and phenomenological approach was conducted. The sampling was purposive. Fourteen patients with CMSP were recruited to participate in semi-structured individual interviews. The research was conducted in the private health care sector of the West Coast region of the Western Cape, South Africa. The interviews were recorded and transcribed ensuring confidentiality. Inductive, thematic content analysis of the transcripts was undertaken. Initial codes were assigned and a codebook was developed, which was applied to the transcripts to develop categories and themes.

**Results:** Eight themes emerged from the data: (1) living with chronic pain, (2) disrupted identity, (3) knowledge and beliefs about chronic pain, (4) health care system factors, (5) interactions with health care providers, (6) management of CMSP, (7) hope (or hopelessness) for the future, and (8) barriers and facilitators to pain management in this context.

**Conclusions:** Participants with CMSP indicated that there were numerous challenges throughout their journey with chronic pain in the private health care sector of South Africa. Participants had a disjointed pathway of care and management of HCP did not offer the solutions that the participants were hoping for, which led to depersonalised care. This study supports the need for establishing a way of collaboration and communication to achieve multidisciplinary care to benefit the CMSP patients in the West Coast region. Two options are the formation of a multidisciplinary pain clinic or pain academy or group in the region. Case managers might also be an option to assist patients to navigate through the HCS.

Patients require pain education, self-management strategies and emotional support throughout the process of coming to terms with their chronic pain and redefining their self-identity.

Empowering patients with self-management strategies enhance coping mechanisms needed for chronic pain and to regain a sense of control over their lives. In the end this could lead to participants' being able to accept and manage their future with pain.

## OPSOMMING

**Agtergrond:** Oorweging van pasiënte se begrip van pyn en hulle perspektiewe oor 'n lewe met kroniese pyn in die Suid-Afrikaanse verband en die gebruik van privaat gesondheidsorg is belangrik, omdat dit fasiliteerders en hindernisse vir gesondheidsorgbestuur sal identifiseer. Daar word voorsien dat hierdie bewyse betekenisvolle inligting kan oplewer wat ingesluit behoort te word by die gesondheidsorgbestuur van pasiënte met kroniese muskuloskeletalepyn.

**Doel:** Die doel van hierdie studie was om pasiënte se perspektiewe en ervarings oor die gesondheidsorgbestuur van hulle kroniese muskuloskeletale pyn in privaat gesondheidsorgbestuur van Suid-Afrika te ondersoek.

**Metode:** 'n Beskrywende kwalitatiewe gevallestudie-ontwerp met 'n interpretatiewe en fenomenologiese benadering is uitgevoer. Die steekproefneming was doelgerig. Veertien pasiënte met kroniese muskuloskeletalepyn is gewerf om deel te neem aan semi-gestruktureerde individuele onderhoude. Die navorsing is uitgevoer in die privaat gesondheidsorgsektor van die Weskusstreek, Wes-Kaap, Suid-Afrika. Die onderhoude is met 'n bandopnemer opgeneem, die data getranskribeer en vertroulikheid is verseker deur deelnemers anoniem te laat bly. Induktiewe, tematiese inhoudsanalise van die transkripsies is uitgevoer. Aanvanklike kodes is toegeken, 'n kodeboek is ontwikkel en die kodeboek is toegepas om kategorieë en temas te ontwikkel, sodat die navorser die inligting kan ontleed en interpreteer.

**Resultate:** Agt temas is uit die data geskep: (1) lewe met kroniese pyn, (2) verlore identiteit, (3) kennis en perspektiewe oor kroniesepyn, (4) faktore in die gesondheidsorgstelsel, (5) interaksies met gesondheidsorgverskaffers, (6) bestuur van kroniese muskuloskeletalepyn, (7) hoop (of hopeloosheid) oor die toekoms, en (8) hindernisse en fasiliteerders tot pynbestuur.

**Gevolgtrekking:** Deelnemers met kroniese muskuloskeletalepyn het aangedui dat hulle reis met kroniese pyn in die privaat gesondheidsorgsektor van Suid-Afrika verskeie uitdagings opgelewer het. Deelnemers het 'n uiteenlopende pad van sorg gehad en die bestuur van die gesondheidsorgverskaffers het nie die oplossings gebied waarop die deelnemers gehoop het nie. Hierdie studie ondersteun die behoefte om 'n manier van samewerking en kommunikasie

te vestig en multidissiplinêre sorg te bewerkstellig, sodat dit pasiënte met kroniese muskuloskeletalepyn in die Weskus-streek kan bevoordeel. Twee moontlikhede is die vorming van 'n multidissiplinêre pynkliniek of pynakademie in die streek. Gevalbestuurders kan ook 'n opsie wees om pasiënte te help om deur die gesondheidsorgstelsel te beweeg. Pasiënte benodig pynvoorligting, selfhanteringstrategieë en emosionele ondersteuning gedurende die proses om hulle kroniese pyn te bepaal en hulle selfidentiteit te herdefinieer. Bemagtiging van pasiënte met selfhanteringstrategieë verbeter versorgingsmeganismes wat nodig is vir kroniese pyn en om 'n gevoel van beheer oor hulle lewens te herwin. Op die ou end kan dit daartoe lei dat deelnemers hulle toekoms met pyn kan aanvaar en bestuur.

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## LIST OF ABBREVIATIONS

ADL:	activities of daily living
CLBP:	chronic low back pain
CMSP:	chronic musculoskeletal pain
CT/CAT:	computed tomography
HPCSA:	Health Professions Council of South Africa
HREC:	Health Research Ethics Committee
HCP:	health care provider(s)
HCS:	health care system(s)
MRI:	magnetic resonance imaging
MRC:	Medical Research Council
NPRS:	Numeric Pain Rating Scale
NRF:	National Research Foundation
NSAIDS:	nonsteroidal anti-inflammatory drugs
NZ:	New Zealand
PDI:	Pain Disability Index
PHC:	primary health care
QoL:	quality of life
SA:	South Africa(n)
SU:	Stellenbosch University
TNE:	therapeutic neuroscience education
TENS:	transcutaneous electrical nerve stimulation
USA:	United States of America
VAS:	Visual Analogue Scale
YLD:	years lived with disability

## KEY WORDS

chronic musculoskeletal pain; chronic non-malignant pain; chronic pain; descriptive qualitative case study; health care management; health care providers; patients' experiences; patients' perspectives; primary health care management; private practice

## LIST OF DEFINITIONS

**Beneficence**—doing good, while **non-maleficence** means avoiding harm. In medical research ethics, the principles of beneficence and non-maleficence translate into responsibilities to maximise benefits while minimising harms, especially in terms of the study sample (Tangwa, 2009).

**Chronic musculoskeletal pain**—a constant pain of the musculoskeletal system and lasts for 12 weeks or more (Kawi, 2012; Upshur, Bacigalupe & Luckmann, 2010).

**Confidentiality**—a promise by health care practitioners to keep confidential information that was confided to them by their patients. Without such promises of confidentiality patients are less likely to divulge the often highly private and sensitive information that is needed for their optimal care (Gillon, 1994).

**Conformability**—the magnitude to which the outcomes of a study are based on the study participants and settings instead of researchers' biases (Frambach, Van der Vleuten & Durning, 2013).

**Credibility**—the extent to which the study findings are trustworthy and credible to others (Frambach et al., 2013).

**Dependability**—the extent to which the findings are consistent in relation to the contexts in which they were created (Frambach et al., 2013).

**Descriptive qualitative case study**—an intervention or phenomenon and the real-life context in which it occurs. It is a valuable method for health science research to develop theory, evaluate programmes, and develop interventions (Baxter & Jack, 2008).

**Health care management**—the process, comprising of social and technical functions and activities occurring within health care organisations for the purpose of accomplishing predetermined objectives through humans and other resources (Buchbinder & Shanks, 2016:2–3).

**Health care providers**—individual practitioners, groups of practitioners, or facilities that provide preventive, curative or rehabilitative health care services (Hanson & Berman, 1998).

**Justice**—fairness, reward or entitlement. Justice requires that human beings as moral equals be treated equally unless there is a reasonable justification for treating them differently. In medical research the principle of justice demands fairness in the treatment of individuals and communities and the justifiable distribution of the burdens and benefits of research (Tangwa, 2009).

**Patient experience**—managing both the emotional and physical roller-coaster a patient experiences while undergoing a health care procedure and maximising the patient's social, mental and physical health and wellness (Wolf, Niederhauser & LaVela, 2014).

**Patient perspective**—the self-perceived influence of the health condition on patients' lives, as their expectations of the consultation or the health care provider, and as their priorities regarding the outcomes of the treatment (Zanini, Sarzi-Puttini, Atzeni, Di Franco & Rubinelli, 2014).

**Private health care practice**—the practice of a health practitioner who practises for his or her own account, either in solo practice, or as a partner in a partnership, or as an associate in an association with other practitioners, or as a director of a company. The patient pays for the service provided in the form of medical scheme contributions or out-of-pocket payments (HPCSA, 2007:8).

**Primary health care**—essential health care based on scientifically comprehensive and socially acceptable methods, universally accessible to individuals in a community. (WHO, 2003:1–2)

**Respect for autonomy**—implies both the freedom of each individual to act, to make free choices and to make decisions without the constraint of another and the obligation of others to respect that freedom. The necessary pre-conditions of autonomy are competence (the capacity to be a moral representative) and right of freedom (Tangwa, 2009).

**Responsiveness**—relates to the ability of a health care system (HCS) to perform to the appropriate expectations of patients. This includes the way and environment in which patients are treated and the patients' experience of contact with the HCS (Peltzer, 2009).

**Scoping review**—a process of mapping the existing literature in order to express the extensiveness and depth of a field. Scoping reviews could also be used to identify research gaps (Armstrong, Hall, Doyle & Waters, 2011).

**Self-management**—the ability to manage the symptoms, treatment, physical and psychosocial consequences and life-style changes characteristic of living with a chronic condition (Matthias, Miech, Myers, Sargent & Bair, 2012).

**Transferability**—the magnitude to which the findings can be transferred or applied in different settings (Frambach et al., 2013).

## CHAPTER 1: INTRODUCTION

### 1.1 BACKGROUND

Chronic musculoskeletal pain (CMSP) is defined as a constant pain originating from the musculoskeletal system, which lasts for 12 weeks or more (Kawi, 2012; Upshur, Bacigalupe & Luckmann, 2010). Brown, Dean, Hay-Smith, Taylor and Baxter (2010) report that prevalence and consequences of musculoskeletal conditions comprise a significant and increasing problem. In South Africa (SA), musculoskeletal conditions contribute significantly to the years lived with disability (YLD), but the problem of CMSP is not prioritised in SA, due to the country's vast burden of disease (Global Burden of Disease study, 2016). CMSP has a substantial influence on health and quality of life (QoL), is a major cause of morbidity, and results in an immense economic burden for SA.

The prevalence of CMSP in low-income African countries is higher than in high-income countries and this condition is rising globally (Demyttenaere, Bruffaerts, Lee, Posada-Villa, Kovess, Angermeyer, Levison, De Girolamo, Nakane, Mneimneh, Lara, De Graaf, Scott, Gureje, Stein, Haro, Bromet, Kessler, Alonso & Von Korff, 2007). In SA the prevalence of CMSP is high as evident in published studies by Igumbor, Puoane, Gansky and Plesh (2011) and Rauf, Meyer, Marcus and Becker (2013). Both studies were done in the SA public health care sector. Igumbor et al. (2011) determined the prevalence, severity, risk indicators and responses of chronic pain among adults in Ngangelizwe, Mthatha, Eastern Cape. Igumbor et al. (2011) found an overall prevalence rate of 32.1% of chronic pain in men and women. They concluded that chronic pain is associated with high utilisation of health care services due to the significant influence of chronic pain on everyday functioning and QoL. Rauf et al. (2013) investigated the prevalence and intensity of chronic pain in patients attending primary health care (PHC) facilities in south-west Tshwane, Gauteng and found a prevalence rate of 41% of chronic pain in the sample. The study indicated that chronic pain is a significant problem in the SA PHC context and suggested that the high prevalence of chronic pain was due to poor awareness of chronic pain among health care providers (HCP) and consequent inappropriate treatment or a lack of treatment. The studies also reported that patients with uncontrolled chronic pain repeatedly visit health care facilities. Chronic pain affects society as it escalates the financial burden caused by increased use of health care services and medication, loss of productivity, absenteeism from work, and early retirement (Igumbor et

al., 2011). CMSP and its associated disability and morbidity have been recognised as a global health care concern, including areas such as sub-Saharan Africa (Ernstzen, Louw & Hillier, 2017). This condition has devastating consequences for the person experiencing the pain, his or her family and society. It influences the individual's wellbeing, limits activity, and reduces functional capacity, the ability to maintain an independent lifestyle, productivity and social relationships and ultimately decreases QoL (De Villiers, Maree & Van Belkum, 2015). It also has an effect on the individual's psychological health and wellbeing (Ernstzen, Louw & Hillier, 2016).

Currently SA has a multicultural, transitional health care system (HCS) that is categorised into a separate public and private HCS (Rowe & Moodley, 2013). The public sector, funded by general tax, is based on a district health system approach. Almost 70% of the population depend entirely on the public health sector, and only 16% of citizens can afford private medical scheme cover and are able to access private health care exclusively (Rowe & Moodley, 2013). The study by Rowe and Moodley (2013) focused on the private HCS and the contextual factors that might influence patients' perspectives, as well as health care management in SA. The private sector enjoys a favourable HCP to patient ratio (Rowe & Moodley, 2013).

The term private health care is associated with high quality services, personal attention to patients and modern facilities. In contrast, public health care often conveys an image of overcrowded waiting rooms and hospitals, and sub-standard health care services. Although private health care is expensive, it is not always of a high quality and even though public health care is underfunded and neglected, public health policies are often more rational and community-orientated (Berger, 2007:166). Even though there are relatively few problems in private health care compared to the public sector, there is an increasing concern that the high cost of using the private health sector and the distribution of private health facilities, mainly in urban and affluent areas, impairs the way that it functions (Berger, 2007:164).

Private and public sectors influence each other in the following ways:

- Government subsidises private medical schemes through tax benefits to companies (Berger, 2007:169). High-income earners benefit the most since the more expensive the product, the greater the subsidy.

- The private sector employs medical practitioners, who were originally trained at the public expense, thus the public sector loses its investment in training health professionals (Berger, 2007:169).
- Public servants receive contributions to the medical scheme of their choice (Berger, 2007:169). However, only higher-income public servants can afford this benefit.
- The Government often contracts with private organisations to provide hospital care and the use of private facilities (Berger, 2007:169). It also contracts private health professionals to provide periodic service in the public sector.
- Public sector health workers often hold a second job in the private sector in order to supplement their income (Berger, 2007:169).
- When private patients are referred to the public sector for treatment, the medical scheme must pay the full cost of the service (Berger, 2007:169). The public sector can benefit from private sector financing; however, most medical schemes use only private hospital facilities.

The private and public sectors are part of a single system and when there is an imbalance that favours the private sector, it necessarily has a negative impact on the public sector. Public resources (financial and human resources) mostly flow into private sectors (Berger, 2007:169). SA's entire HCS should operate well to ensure that health care fulfils its role as a social protection mechanism. This is necessary considering SA's HCS currently being transitional and reforming with the potential to unify private and public health services in the future and creating an integrated national health system (Berger, 2007:198).

The HPCSA (Health Professions Council of South Africa) (2007:8) describes private practice as comprising a health practitioner who practises for his or her own account, either in a solo practice, as a partner in a partnership, an associate in an association with other practitioners, or as a director of a company. In the private sector, word-of-mouth referral is an important part of the business and every patient can be viewed as a referral source (Potter, Gordon & Hamer, 2003). In this context, one would expect private practitioners to be patient-centred and focused on providing service delivery by identifying and meeting consumer needs. The fee-paying patient is essential for business success, because private practitioners are competing with other health professions as well as other private practices for clientele. Practitioners cannot afford the direct loss of patients who have had bad experiences, or their

unfavourable comments that may dissuade other potential patients from seeking the services of a particular practitioner or private practice in general. It is therefore imperative that clinicians seek patient input to identify their expectations and preferences about health services in order to remain patient-centred and to identify strengths and weaknesses of health care management from the perspective of the consumer (Potter et al., 2003).

According to Zanini, Sarzi-Puttini, Atzeni, Di Franco and Rubinelli (2014) the patient's perspective includes the self-perceived influence of the health condition on his or her life, his or her expectations of the consultation and his or her priorities regarding the outcomes of the treatment. Patient experience is framed by the domains of responsiveness, namely autonomy, choice, communication, confidentiality, dignity, prompt attention, and quality of basic amenities (WHO, 2003:1–2). Patients should engage with the emotional and physical aspects, concerns or challenges while undergoing health care procedures and maximise their social, mental and physical health and wellness (Wolf, Niederhauser & LaVela, 2014). Identifying patients' perspectives about their health care offers could influence decision-making about chronic pain interventions and promotes patient-centred care, which could lead to a focus on patient-specific needs and enhance patients' satisfaction with their health care (Zanini et al, 2014). It is important to gain patients' perspectives on aspects relating to the attributes of the service provided in the SA health care sector, because of the differences in health care context when compared to other international health care contexts (Benatar, 2013).

According to Bongani & Benatar (2014), SA measures up poorly against other middle-income countries with regard to age-related death rate, years of life lost from premature death; YLD and life expectancy at birth. Non-communicable diseases are also emerging in rural and urban area and with an increase in the proportion of people older than 65 years of age; it contributes to increasing pressure on short-term and long-term health care services (Bongani & Benatar, 2014). In the study of Bongani & Benatar (2014), they concluded that the long-term challenges in SA are to narrow disparities in wealth, health and education; in the medium term to improve access to sustainable and effective health care services and in short-term to strengthen public health care services, improving resource-allocation policies and training an appropriate balance of HCP. Capturing what matters to patients when they evaluate their health care is also increasingly recognised as important in quality assessment and improvement of health services (Del Baño-Aledo, Medina-Mirapeix, Escolar-Reina, Montilla-Herrador & Collins, 2014).

Understanding patient-centred care will lead to improved health outcomes and better QoL as health care is provided in a way that better meets the needs of patients (Baboo, Van Rooyen, Ricks & Jordan, 2016). According to Baboo et al. (2016), patient-centred health care can be achieved by respecting patients' values, preferences and expressed needs, treating them with courtesy and consideration, consulting patients about the level and quality of the services that they receive, giving them emotional support and involving family and friends, giving patients accurate information about their management, educating patients and allowing for continuity of care. It is important to establish a good patient–practitioner relationship, because power and responsibilities are shared and there is a therapeutic alliance in which the goals and requirements of the treatment are clearly understood (Kidd, Bond & Bell, 2011).

There is a lack of published research about CMSP patients' perspectives on CMSP and experiences of the private health care sector in the Western Cape, SA and Africa. Only one systematic review of qualitative studies about patient perspectives of chronic low back pain (CLBP) in SA has been conducted (Snelgrove & Lioffi, 2013). Snelgrove and Lioffi (2013) conclude that, in their study, chronic pain was reinforced multi-dimensionally by distressing pain, loss of function, loss of personal and social integrity and fear of the future. This review indicates that HCP should have knowledge about the effect of chronic pain on individuals and their perspectives of CMSP management in order to provide patients with appropriate health care services.

Parker, Burgess, Dubaniewicz, Gouws, Krone, Madden, Nortje & Parsons (2009), Wade and Shantall (2003) and Ernstzen et al. (2017) conducted three SA qualitative studies which focused on chronic pain. Parker et al. (2009) investigated satisfaction with a chronic pain management group in Cape Town, SA. This chronic pain management programme was based on patients' perspectives and experience of tertiary care in the SA health care context, but there are no published research on patients' perspectives and experiences of private health care in SA. Wade and Shantall (2003) provided a description of the effect of chronic pain on patients, and concluded that HCP have a significant influence on pain management and acceptance of their condition, which concurs with the findings of the present study. Ernstzen et al. (2017) investigated contextual factors that had an influence on the care of CMSP in the SA PHC sector in order to inform clinical practice guidelines; however, the study of Ernstzen et al. (2017) was conducted in the public setting. Therefore, there is a need for more qualitative research regarding CMSP patients' perspectives and experiences about private

practice health care management in SA, to determine the influence and management of CMSP, and to report on barriers and facilitators to care.

## **1.2 SIGNIFICANCE OF THE STUDY**

The aim of this study was to contribute to the field of knowledge by determining patients' perspectives about living with chronic pain in the SA context and their utilisation of private health care. In SA, CMSP is a major burden that is reported to be underfunded, not well researched, undertreated or inappropriately treated (Rauf et al., 2013). There is also a lack of understanding of the magnitude of the problem and a lack of clinical guidelines available, thus leading to poor pain management (Hoy, Geere, Davatchi, Meggitt & Barrero, 2014). Contextually applicable management strategies could be achieved by taking patients' perspectives and experiences into consideration. However, there is a lack of research on the influence and management of CMSP in SA settings (Ernstzen et al., 2017). This study contributes to the scarce body of knowledge on CMSP patients' perspectives and experiences in the private health care sector of SA. The strength of the study is that it explored the perceptions of a diverse group of people about their journey with CMSP, and the study reports on the barriers and facilitators to pain management in the SA private health care setting.

## **1.3 OVERALL AIM**

The overall aim of this study was to explore patients' perspectives and experiences about the health care management of their CMSP in the private health care sector.

To achieve the aim of the project, four research questions were considered:

- What are patients' perspectives about living with chronic pain?
- What is patients' pathway of care in private health care settings?
- Who is the HCP involved in the pathway of care and in the management of CMSP in the private health care setting?
- What are patients' perspectives about barriers and facilitators to pain management in the private health care setting?

## **1.4 RESEARCH SETTING**

The research setting was PHC, focusing on interdisciplinary and solo practices in the private health care sector of the West Coast region of the Western Cape, SA.

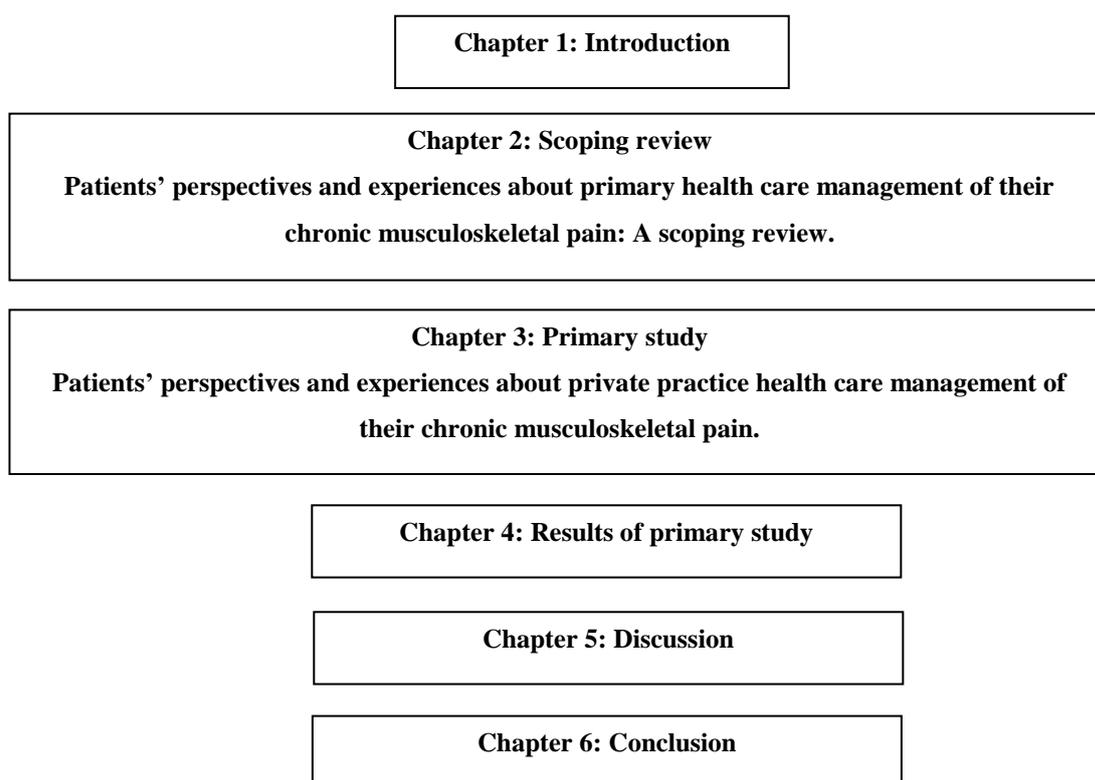
## **1.5 METHODS**

In the first part of the project, a scoping review about patients' perspectives and experiences regarding PHC management of their CMSP was performed. This was done to investigate the extent and type of evidence available to inform more focused knowledge synthesis and to identify research gaps to guide the primary study. According to Levac, Colquhoun and O'Brien (2010), complex concepts can be clarified by scoping reviews, and this could enhance subsequent research studies. The scoping review records key concepts about patients' perspectives and experiences about the PHC management of their CMSP.

In the second part of the project, a qualitative study was performed to explore patients' perspectives and experiences about the health care management of their CMSP in the private health care sector in SA. In the primary study a descriptive qualitative case study design with an interpretative and phenomenological approach was used. According to Creswell (2007:73), the purpose of this type of study is to condense individuals' experiences with a phenomenon to a description of the universal essence. The study focused on only one region in the Western Cape, to define the scope of this master's research, lending it to a case study approach. According to Baxter and Jack (2008), this approach acknowledges the importance of context in understanding patients' perceptions.

## 1.6 STRUCTURE OF THE THESIS

The thesis begins with an encompassing introduction and literature review (Chapters 1–2), followed by a chapter on the methodology (Chapter 3) and a detailed results chapter (Chapter 4). The thesis ends with an in-depth discussion chapter, which reflects the limitations and recommendations derived from the study (Chapter 5), followed by a short conclusion (Chapter 6). The structure of the thesis is illustrated in Figure 1.1.



**Figure 1.1: Structure of thesis**

## CHAPTER 2: SCOPING REVIEW

### 2.1 INTRODUCTION

It is important to take patients' perspectives of pain into account when it becomes chronic, as these perspectives are windows into the personal experiences of individuals with CMSP (O'Hagan, Coutu & Baril, 2013). Individuals living with chronic pain often struggle to present themselves as sincere when seeking medical care because pain is undetectable. It is therefore not uncommon for patients with chronic pain to report poor quality connections with HCP (Upshur et al., 2010). A lack of understanding about what patients with chronic pain expect from their management is a barrier to providing optimal health care. Patients' perspectives and experiences about the treatment, health care settings and HCP involved in the treatment, should be gathered to improve these (Mittinty, Lee, Williams & Curran, 2017). Integration of the patient's perspective is associated with greater satisfaction, enhanced compliance and better continuity of care (O'Hagan et al., 2013). Perspectives of patients should therefore be integrated and shared with HCP to provide feedback about the delivery of care and thus inform service development and management to improve health care services (Mittinty et al., 2017). Chronic pain is an extremely complex phenomenon and a need exists to define chronic pain experiences comprehensively from the perspectives of patients (O'Hagan et al., 2013). Patients' views of their care experiences should consequently be explored to improve practice strategies (Upshur et al., 2010).

Patients' understanding of pain and their perspectives about living with chronic pain may influence their beliefs about pain and its management (O'Hagan et al., 2013). Facilitators and barriers for optimal pain management can be identified if CMSP patients' perspectives about their PHC management are understood (Bair, Matthias, Nyland, Huffman, Stubbs, Kroenke & Damush, 2009; Potter et al., 2003; Upshur et al., 2010). Zanini et al. (2014) report that integrating a patient's perspective and experience has the potential to increase the patient's satisfaction with the consultation, as well as resulting in better decisions and in improved management of the illness and health outcomes. Identifying facilitators and barriers to pain management will help to inform the delivery of future pain interventions, as well as increase the effectiveness of these interventions.

Current published research on patient experiences in the SA health care sector is the study of Peltzer (2009) where they considered patient experiences and health system responsiveness in SA and concluded that health care access, communication, autonomy, and discriminatory experiences were priority areas for action to improve responsiveness of health care services in SA. The participants in the study by Peltzer (2009) did not have any specific diagnosis. Peltzer's study was conducted in private and government health care sectors. Another study by Igumbor et al. (2011) reports on the prevalence of chronic pain in a rural community in SA. Thus, no published literature was found on the prevalence of CMSP and patient experiences in the SA private health care sector. This concurs with the findings by Ernstzen et al. (2017).

The objective of the scoping review was to assess the state of knowledge regarding patients' perspectives and experiences about PHC management of their CMSP currently available, and to describe the scope and breadth of such knowledge. The scoping review focused on all health care sectors and not only on private practice health care, because PHC includes private and public HCS (WHO, 2003:10).

### **2.1.1 RESEARCH QUESTION, AIMS AND OBJECTIVES OF THE SCOPING REVIEW**

**Scoping review question:** What is the current state of published studies reporting on adult patients' perspectives and experiences about the PHC management of their chronic musculoskeletal pain?

**Scoping review aim:** Systematically identify and map the existing published literature about patients' perspectives and experiences about the PHC management of chronic musculoskeletal pain.

**Primary objective:** Ascertain patients' perspectives about pain management in the PHC settings and record patients' experiences in the PHC settings.

**Secondary objective:** Identify common concepts in participant's perspectives and experiences, which may serve to clarify the complex concept and inform the subsequent study.

## **2.2 METHODOLOGY**

### **2.2.1. STUDY DESIGN**

A scoping review was conducted. This approach permits identification of strengths and weaknesses in a frame of literature, as well as advanced theoretical observations (McColl, 2009). Complex concepts can be clarified by scoping reviews and this could enhance subsequent research studies (Levac et al., 2010). The present scoping review maps key concepts about patients' perspectives and experiences about the PHC management of their CMSP. The review helped to determine the extent and type of evidence available to inform more focused knowledge synthesis and to identify research gaps that guided the primary study.

### **2.2.2. STUDY CRITERIA**

The following inclusion criteria were used for selecting studies:

- articles reporting on qualitative studies on the topic;
- only articles published in the English language were considered;
- articles published since the inception of the database until January 2017, unless limits were applied;
- only studies situated in PHC were considered; and
- only studies of level I and II evidence were considered (see section 2.2.5 and Addendum 2).

Health outcome measures comprised but were not confined to the following:

- perspectives about pain management in the private health care settings; and
- experiences about the PHC management of patients' chronic musculoskeletal pain.

Exclusion criteria for the sample selection were as follows:

- studies focusing on patient perspectives about surgery and other interventional techniques not offered in the primary care setting;
- studies that focused on pain that is not musculoskeletal in origin; and

- studies focused on injury insurance compensation (receiving financial compensation is associated with a greater experience of pain and reduced treatment efficacy). Compensation status is related to the amount of time off work that individuals have following injury and which significantly affect recovery (Newton-John & McDonald, 2012).

### **2.2.3 SEARCH STRATEGY**

The following five computerised bibliographical databases were accessed through the library services of Stellenbosch University (SU): Cinahl, Medline, Pubmed, Science Direct and Scopus. The key search terms were: chronic musculoskeletal pain OR chronic pain OR chronic nonmalignant pain AND patient/client perspective/view AND primary health care OR primary care management. The search strategy was started in February 2015 and it was completed by the end of April 2015, although a follow-up search was conducted in February 2017. The complete search strategy for each database is included in Addendum 1.

### **2.2.4. SEARCH METHOD FOR ELIGIBLE STUDIES**

The researcher was responsible for the search process. For each of these databases the same search method was used (see Addendum 1). Each step of the search process was documented.

#### *Titles*

The search for titles was performed according to the search strategy. Studies were included and excluded according to the criteria indicated in section 2.2.2. The included and excluded titles were checked and confirmed by the supervisor. After consensus had been reached by the researcher and the supervisor the eligible titles were checked to eliminate duplicates.

#### *Abstracts*

The abstracts of the eligible titles were retrieved by the researcher, who read the abstracts and excluded those that were irrelevant according to the inclusion and exclusion criteria of this review. The included and excluded abstracts were checked and confirmed by the supervisor.

### *Full-text articles*

The full-text articles of the selected abstracts were retrieved by the researcher by accessing electronic journals or by searching journals manually.

#### **2.2.5. LEVEL OF EVIDENCE**

The researcher assessed the level of evidence of the included studies by making use of the hierarchy of evidence for assessing qualitative health research (Addendum 2) (Daly, 2007). This hierarchy of evidence is helpful in assigning a level of evidence to a study, where level I (generalisable) studies are of the highest quality, followed by level II (conceptual) studies, level III (descriptive) studies and level IV (single case studies). Only level I and II studies were included in this review.

#### **2.2.6 METHODOLOGICAL QUALITY APPRAISAL**

The McMaster Critical Review Form – Qualitative Studies (Version 2.0) (Addendum 3) was used to appraise qualitative research articles critically. The guidelines accompanying the Critical Review Form – Qualitative Studies was developed by McMaster University Occupational Therapy Evidence-Based Practice Research Group and revised by Letts, Wilkins, Law, Stewart, Bosch & Westmorland (2007:1–4). The Critical Review Form – Qualitative Studies consists of nine components, namely citation, study purpose, literature, study design, sampling, data collection, data analysis, overall rigour and conclusions and implications. The McMaster Critical Review Form – Qualitative Studies assesses research articles for four components of trustworthiness, because trustworthiness confirms the quality of the findings (Letts et al., 2007:1–4).

Each article was scored independently by the researcher and checked by the supervisor using the Critical Review Form – Qualitative Studies. The trustworthiness of articles that scored below 14 out of 22 in the McMaster Critical Review Form was questioned.

#### **2.2.7 DATA EXTRACTION**

Data extractions of all the articles were done manually by the researcher. The main categories of each article and the explanation that accompanied them were extracted into a Word

document. Information about the sample demographics, sample size, intrinsic factors (as defined in eligibility; see section 2.2.4), and health care settings, type of chronic pain, study procedures, findings and limitations of each study were also extracted. The supervisor extracted the data out of all of the studies, to ascertain the accuracy of data extraction.

## 2.2.8 DATA ANALYSIS

The researcher made use of thematic analysis, to identify core and common themes from the included studies (Creswell, 2007:75). The core concepts were identified after extracting the categories with their explanations. Patterns between studies were identified. Similar categories were merged and then new themes were constructed. Data from each article were summarised against each of the major themes identified. The researcher compared how themes were explained and interpreted within different studies, and emphasis was given in the analysis toward themes with a high level of explanatory value. A high level of explanatory value was determined by descriptive and recurrent themes between studies.

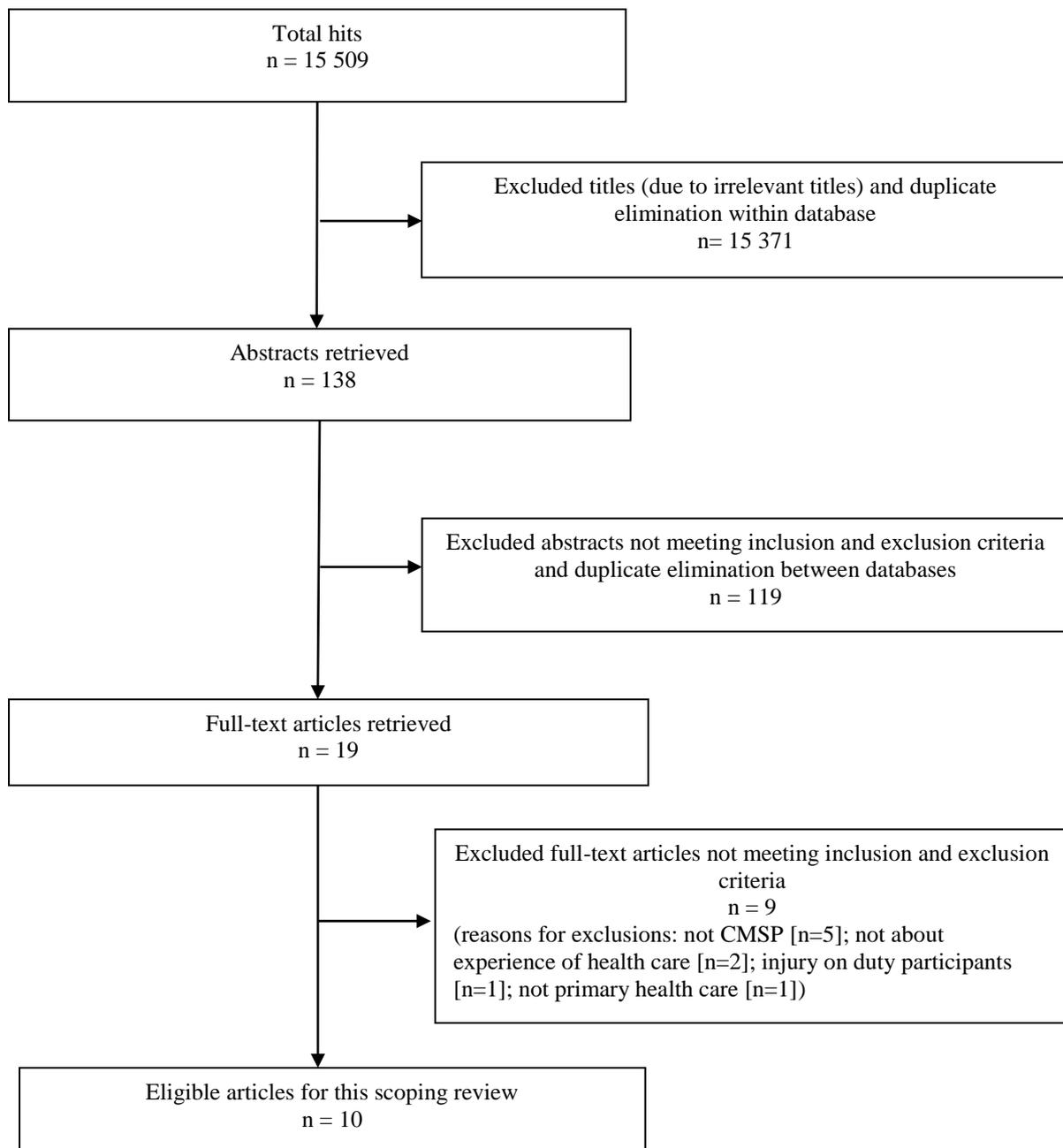
## 2.3 RESULTS

### 2.3.1 SEARCH RESULTS AND DESCRIPTION OF STUDIES

A total of 15 509 titles were found. Of these, 138 abstracts were reviewed of which 10 full-text articles were considered eligible for this scoping review. The search strategy and its results are summarised in Table 2.1 and Figure 2.1.

**Table 2.1: Results of search strategy**

Database	Total hits	Excluded titles and duplicate elimination within database	Included titles within database	Excluded titles and duplicate elimination between databases	Included titles between databases
<b>Cinahl</b>	6 219	6 201	18	119	19
<b>Medline</b>	8 269	8 253	16		
<b>Pubmed</b>	356	308	48		
<b>Science Direct</b>	304	276	28		
<b>Scopus</b>	361	333	28		
<b>Total</b>	15 509	15 371	138		



**Figure 2.1: Results of search strategy**

### 2.3.2 EVIDENCE HIERARCHY

All 10 articles included in this scoping review were of level II evidence (Bair et al., 2009; Brown et al., 2010; Cooper, Smith & Hancock, 2008; Kawi, 2012; Kidd et al., 2011; Matthias, Miech, Myers, Sargent & Bair, 2012; Medina-Mirapeix, Del Baño-Aledo, Oliveira-Sousa, Escolar-Reina & Collins, 2013; Øien, Steihaug, Iversen & Råheim, 2011; Potter et al., 2003; Upshur et al., 2010).

### 2.3.3 METHODOLOGICAL APPRAISAL

Table 2.2 provides a summary of the included articles' quality according to the critical review form. The 10 included qualitative studies scored 17 and higher out of 22.

**Table 2.2: Scores according to Critical Review Form – Qualitative Studies (Version 2.0)**

Critical review	Matthias et al. (2012)	Bair et al. (2009)	Potter et al.(2003)	Upshur et al.(2010)	Kawi,(2012)	Øien et al.(2011)	Cooper et al.(2008)0	Brown et al.(2010)	Kidd et al.(2011)	Medina-Mirapeix et al.(2013)
<b>Study purpose:</b> Was the purpose and/or research question stated clearly? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Literature:</b> Was relevant background literature reviewed? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Study design:</b> What was the design? (phenomenology, ethnography, grounded theory, participation action research, other)	Not stated	Not stated	Not stated	Not stated	Not stated	Case study	Not stated	Phenomenology	Grounded theory	Grounded theory
<b>Study design:</b> Was a theoretical perspective identified? Y/N	Y	Y	Y	Y	N	Y	Y	Y	Y	Y

<b>Critical review</b>	Matthias et al. (2012)	Bair et al. (2009)	Potter et al. (2003)	Upshur et al. (2010)	Kawi, (2012)	Øien et al. (2011)	Cooper et al. (2008)0	Brown et al. (2010)	Kidd et al. (2011)	Medina-Mirapeix et al. (2013)
Study design: Methods used? (participant observation, interviews, document review, focus groups, other)	Interviews	Focus group	Normal group technique	Focus group	Survey	Interviews, Focus group & Video recordings	Interviews	Interviews	Interviews	Focus group
<b>Sampling:</b> Was the process of purposeful selection described? Y/N	Y	N Random	Y	N Convenience	N Convenience	Y	Y	Y	Y	Y
Sampling: Was sampling done until redundancy in data was reached? Y/N/NA	Y	Y	Y	Y	N	N	N	N	Y	Y
Sampling: Was informed consent obtained? Y/N/NA	N	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Data collection:</b> Descriptive clarity – clear and complete description of site? Y/N/NA	Y	Y	Y	Y	N	N	Y	N	Y	Y
Data collection: Descriptive clarity – clear and complete description of participant? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Data collection: Descriptive clarity – role of researcher and relationship with participant? Y/N	N	Y	Y	N	Y	Y	N	N	Y	Y
Data collection: Descriptive clarity – identification of assumptions and biases of researcher? Y/N	Y	Y	Y	N	Y	Y	Y	Y	Y	N
Data collection: Procedural rigour – was procedural rigour used in data collection strategies? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Data analyses:</b> Analytical rigour – were data analyses inductive? Y/N/NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Data analyses: analytical rigour – were findings consistent with and reflective of data? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Data analyses: auditability – was a decision trail developed? Y/N/NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

<b>Critical review</b>	Matthias et al. (2012)	Bair et al. (2009)	Potter et al. (2003)	Upshur et al. (2010)	Kawi, (2012)	Øien et al. (2011)	Cooper et al. (2008)0	Brown et al. (2010)	Kidd et al. (2011)	Medina-Mirapeix et al. (2013)
Data analyses: auditability – was process of analysing the data described adequately? Y/N/NA	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Data analyses: theoretical connections – did a meaningful picture of the phenomenon under study emerge? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Overall rigour:</b> Was there evidence of the four components of trustworthiness? (credibility, transferability, dependability, conformability) Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	N	Y	N	Y	N	Y	Y	N	Y	Y
	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Implications:</b> were conclusions appropriate given the study findings? Y/N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<b>Did the findings contribute to theory development and future practice/research? Y/N</b>	Y	Y	N	Y	Y	N	Y	Y	Y	Y
<b>Total /22</b>	19	21	20	19	17	19	20	18	22	21

Keys: Y = Yes; N = No; NA = Not applicable

### 2.3.4 STUDY DESCRIPTIONS

The study descriptions are provided in Table 2.3. The participants in the included articles suffered from CMSP, but there was little reference to participants' comorbidities. Sample sizes ranged from n=8 to n=110 and ages ranged from 18 to 86 years. The majority of the studies were undertaken in the United States of America (USA) and Europe with representation from New Zealand (NZ) and Australia.

The predominant means of data collection were semi-structured interviews and focus groups. The schedules of questions used in interviews were frequently absent with little indication about how such schedules were constructed.

### **2.3.5 REVIEW RESULTS**

The synthesis of themes from the reviewed studies revealed four primary themes

- patients' pain self-management;
- patients' emotional support;
- patient–practitioner relationship; and
- barriers and facilitators to care.

The descriptions of the themes are outlined in Table 2.4.

**Table 2.3: Study descriptions**

Authors	Year	Country	Type of study	Aim of the study	Health care setting	Type of chronic pain participants had	Participants ages in years	Male or female	Number of participants	Number of interviews or size of each focus group and number of focus groups
Bair et al.	2009	USA	Qualitative study Focus group methodology	Identify perceptions of barriers and facilitators to self-management of CMSP among patients with comorbid pain and depression	Veteran Affairs (VA) University primary care clinics	CMSP of the low back, hip, or knee. Defined as a brief pain inventory score of 5 or greater and musculoskeletal in nature	27–84	7 male and 11 female	18	Four focus groups Three to six patients in each 2-hour session
Brown et al.	2010	NZ	Mixed-method study	Explore experiences of complementary and alternative medicine and/or conventional treatment for musculoskeletal pain	NZ population	Chronic back pain and musculoskeletal pain conditions affecting neck, shoulder, hip, knee, ankle or hand.	25–82	7 male and 10 female	17	2 semi-structured interview schedules Telephone interviews– 17 participants, lasted 20 min Face-to-face interviews– 13 participants, lasted 45 min
Cooper et al.	2008	Europe	Qualitative study Semi-structured interviews	Define patient-centeredness from the patient’s perspective of physiotherapy management of CLBP	Physiotherapy departments in Grampian region of Scotland, the UK National Health Service	CLBP patients	18–65	5 male and 20 female	25	Semi-structured interviews

Authors	Year	Country	Type of study	Aim of the study	Health care setting	Type of chronic pain participants had	Participants ages in years	Male or female	Number of participants	Number of interviews or size of each focus group and number of focus groups
Kawi	2012	USA	Qualitative manuscript Study with a descriptive design	Explore the views of CLBP patients on their self-management, self-management support, and functional ability	Two pain centres in Nevada	CLBP	19–86	45 males and 65 females	110	Surveys with open-ended questions
Kidd et al.	2011	New Zealand	Qualitative study design Semi-structured interviews	Determine the components of patient-centred physiotherapy and the crucial elements from patients' perspectives in the musculoskeletal area	Musculoskeletal outpatient physiotherapy at a provincial city hospital in NZ	General CMSP conditions	20–68	4 male and 4 female	8	Audio-taped semi-structured interviews Grounded theory
Matthias et al.	2012	USA	Qualitative interviews	To ascertain perceptions of a multicomponent intervention tested in a randomised controlled trial for veterans with CMSP (evaluation of stepped care for chronic pain)	Five VA primary care clinics	Musculoskeletal pain in the low back, cervical spine, or extremities (hip, knee, or shoulder) that had persisted for 3 months; and had moderate functional impairment	24–62	22 male and 4 female	26	Face-to-face interviews
Medina-Mirapeix et al.	2013	Europe	Qualitative study Focus groups	Identify elements of the environment in outpatient rehabilitation settings on which patients reflect when	Post-acute public interdisciplinary rehabilitation services from a	CMSP disorders	> 18	33 male and 24 female	57	Nine focus groups

Authors	Year	Country	Type of study	Aim of the study	Health care setting	Type of chronic pain participants had	Participants ages in years	Male or female	Number of participants	Number of interviews or size of each focus group and number of focus groups
				evaluating the quality of a care experience	HCP network in Spain Centres located in Barcelona, Madrid, and Seville					
Øien et al.	2011	Europe	Longitudinal multiple case study Cross-case analysis	Describe communicative patterns about change in challenging physiotherapy treatment situations	Clinical Norwegian psychomotor physiotherapy settings	Chronic muscular pain located in the back and/or neck	22–47	1 male and 10 female	11	Interviews, patients' personal notes, video-recorded treatment sessions and researchers' field notes 17 individual interviews, 11 patients, 6 physiotherapists Lasted 1 hour Focus group interview of all physiotherapists, lasted 2 hours
Potter et al.	2003	Australia	Nominal group technique	Explore patients' perspectives regarding the qualities of a good physiotherapist and to	Private practice settings	Chronic back pain	20–79	10 male and 16 female	26	Six nominal group meetings Three to five participants

Authors	Year	Country	Type of study	Aim of the study	Health care setting	Type of chronic pain participants had	Participants ages in years	Male or female	Number of participants	Number of interviews or size of each focus group and number of focus groups
				ascertain the characteristics of good and bad experiences in private practice physiotherapy				female		in a group Meetings lasted for 2 hours
Upshur et al.	2010	USA	Qualitative analysis of groups	Identify views held by chronic pain patients about their pain treatment experience and to identify ways to improve care	Four primary care practice populations in Central Massachusetts Federally qualified health centres One hospital-based family medicine clinic	Chronic pain (low back pain, arthritis, neck pain, headache/migraines, hand pain, pelvic pain, fibromyalgia, general)	21–68	23 male and 49 female	72	17 groups of 3–7 participants

**Table 2.4: Themes derived from the main findings of the articles included in the scoping review**

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
Bair et al. (2009)	<p>Pain is disabling and interferes with self-management practices.</p> <p>Depression and stress negatively affect self-management, but relief of depression symptoms help patients to engage in pain self-management.</p> <p>Activity modification is common.</p> <p>Participants mentioned the use of medication.</p>	<p>A lack of social support interferes with the use of pain self-management, but the presence of support from family, friends, and care managers assists patients in their efforts to execute their self-management practices.</p>	<p>Patients perceive their primary care physicians prescription medication as the sole modality to relieve pain. They did not receive instructions in pain self-management strategies.</p> <p>Health professionals act as gatekeepers to treatment and participants were accepting that.</p>	<p><u>Barriers:</u></p> <ul style="list-style-type: none"> <li>Over-reliance on medications by patients.</li> <li>Comorbid depression and stress interfere with self-management strategies.</li> <li>Lack of tailoring to meet patient needs.</li> <li>Fear of activity.</li> <li>Ineffective pain relief from some strategies.</li> <li>Time constraints, lack of motivation or self-discipline to engage in self-management practices.</li> <li>Lack of support from friends, family, employers or care manager.</li> <li>Limited resources (transport, financial) to access care.</li> </ul> <p><u>Facilitators:</u></p> <ul style="list-style-type: none"> <li>Improving depression after treatment.</li> <li>Supportive family, friends and care managers.</li> <li>Support groups with peers.</li> <li>Social comparison to put patients' pain in perspective.</li> <li>Positive thinking and being proactive</li> <li>Positive affirmations.</li> <li>Improving one's self-esteem.</li> <li>Goal setting and achieving goals.</li> </ul>

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
Brown et al.(2010)	Participants faced dilemmas about the condition and treatments and spoke about the need to 'just carry on'. Self-management and treatment-seeking behaviours fluctuated, with most participants seeking help only when the pain exceeded certain thresholds; once the pain had returned to a manageable level most stopped treatment until the pain again exceeded that threshold.	Trust in health professionals is a powerful facilitator for accessing treatment and on occasions meant that barriers were overcome.	Health professionals acting as gatekeepers to treatment for participants with musculoskeletal pain. Gate keeping was predominantly based on matters of power, searching for solutions and managing from day to day. General practitioners were viewed as someone they could trust and who would help them to actually find the right person, the right solution. Trust usually equated with knowledge of the health system and treatment options.	<u>Barriers:</u> Participants had difficulty in finding a balance to manage CMSP. Participants' journey through the health system is often back and forth between health professionals. <u>Facilitators:</u> When musculoskeletal pain continues despite diagnosis or treatment, the focus of participants often change from seeking a cure to looking for a palliative solution.
Cooper et al.(2008)	None	Good communication involves taking time over explanations; using appropriate terminology; listening, understanding and getting to know the patient; and encouraging the patient's participation in the communication process. Participants want quick and	Participants were happy for the health professional to make most decisions as long as these were accompanied by good explanations. Tailoring communication to the individual's needs is important. Participants wanted both treatment and the delivery of treatment to be individualised. Assessing a patient's wishes regarding	<u>Barriers:</u> Participants who are not able to discuss their needs or who received poor explanations did not feel involved in the treatment process. Exercises were not individually tailored to patients. Long waiting times for a follow-up visit or review by the health professional tend to result in dissatisfaction. <u>Facilitators:</u> Good communication between the therapist and participants related to participants feeling involved in the treatment process.

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
		direct access in the event of a flare-up.	<p>involvement in decision-making, and tailoring the subsequent approach to that decision-making appeared to be the key factors in patient-centred decision-making.</p> <p>Health professionals who are rushed could cause patients to interpret the lack of time as a lack of interest in them. What happens in the physiotherapy session may be more important than its duration or the number of sessions received.</p> <p>Abruptness of the health professional is linked with dissatisfaction.</p> <p>Participants appreciated consulting a health professional who was caring, friendly, pleasant and professional, and who showed an interest in their patients and made them feel at ease.</p>	<p>Participants who felt that their exercises made sense to them and were well explained also felt that their individual needs were addressed.</p> <p>Participants seen in departments offering an early triage appointment are satisfied with their short waiting time.</p>
Kawi, (2012)	<p>Participants took medication as the primary way of managing their chronic pain.</p> <p>Participants tried to maintain physical activity.</p>	Patients felt that prescribing medications was the primary way that their health care professionals gave them support in managing their	<p>Providing information.</p> <p>Participants felt supported in the management of their chronic pain when providers gave them valuable information and advice, answering</p>	<p><u>Barriers:</u></p> <p>Providers did not have adequate self-management support skills.</p> <p>Providers did not have appropriate education, training or knowledge.</p> <p>Providers did not have proper communication or relationship</p>

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
	<p>Participants tried to make wise decisions and lifestyle changes. Participants used heat and cold applications, rest and relaxation to manage their pain. Participants made use of other physical and alternative modalities (e.g. having procedures, interventional modalities, referrals, consultations, acupuncture, chiropractic and massage).</p>	<p>chronic pain. Health care professionals that give emotional support and encouragement are very valuable for participants. These behaviours include demonstrating understanding, concern, and compassion by listening, having a caring attitude, giving enough time for consultations, being in good spirits, keeping participants motivated in making lifestyle changes, or simply asking how the participants were doing and how their pain was affecting their daily life and work. Low family support is a major barrier to self-management in patients with chronic illnesses.</p>	<p>questions, allowing for discussions, and giving explanations about pain and the different modalities, including areas with regard to coping and staying motivated. Participants felt supported when appropriate follow-up appointments were scheduled to re-evaluate their chronic pain.</p>	<p>skills. Providers did not take participants' psychosocial aspects into consideration to understand and manage the influence of chronic illnesses on them better. Anxiety or fear is closely related to the unpredictability of pain, leading to increased vigilance and awareness of current pain situations. These in turn result in the participant missing out on life activities, limitation of movement in anticipation of pain (fear avoidance), externalisation of the body and alteration of oneself.</p> <p><u>Facilitators:</u> Development of self-management strategies increases confidence, and ability to take better control over the chronic pain. Health care professionals give support by prescribing medications and other treatment modalities, providing emotional support and encouragement, referrals, other alternatives, valuable information, and ensuring follow-up visits.</p>
Kidd et al.(2011)	None	Patients considered it important that the health provider demonstrated	Communication is a two-way transfer of information that both informs and reassures the patient. Components	<u>Barriers:</u> None

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
		empathy (especially in relation to pain), encouragement, and the ability to relate to people and be friendly.	include good listening skills, paraphrasing and explaining, and reassurance about pain. Participants require a therapist who is confident in explanations and attitude. Knowledge and expertise are considered essential elements of good health professionals. Patients' perspectives of patient-centred care involved a professional relationship that allowed space for the patient to recognise the therapist's knowledge, and to have input into the treatment plan and decisions about treatment.	<u>Facilitators:</u> The therapist's ability to communicate, his or her use of knowledge and expertise, his or her self-confidence, and his or her ability to create confidence in the patient led to a positive patient-practitioner relationship.
Matthias et al.(2012)	Patients set goals for themselves (e.g. daily walking, regular stretching, and going to the gym).	It was important for patients to have somebody to talk to about their achievements and challenges in using self-management strategies and to find solutions to challenges they experienced. It was very helpful to talk through the pain. The patients knew that they	Patients felt supported by having someone who simply listened. Patients believed that the contacts with the nurse care manger were helpful, personal, responsive, accessible and supportive. Having a working alliance with the nurse was important for patients.	<u>Barriers:</u> In some cases, patients indicated that they felt frustrated and unmotivated. They had difficulty adhering to their treatment plan, because of the pain. <u>Facilitators:</u> Patients moved from being held accountable to the nurse to being accountable and answer to themselves. This internal accountability progressed after seeing the benefits of self-management activities and feeling motivated to continue because of those benefits.

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
		would receive a follow-up phone call and that increased their adherence.		The follow-up phone calls were a source of motivation and encouragement. The nurse care manager was viewed as a brainstorming partner, a coach, a good listener, a strong source of support, and someone to help patients overcome frustration or a lack of motivation.
Medina-Mirapeix et al.(2013)	None	Many interactions with other patients during therapy had a positive influence on quality environment when the patients were supportive of each other in their efforts to improve health status. Participants evaluated the environment as motivational because it allowed them to get to know people with similar disability experiences and develop relationships of mutual help and emotional support.	Participants reported that having a high number of patients evident in the service setting increased feelings of saturation in the service setting and affected its ability to provide them with a good service. The extent and consistency of time spent with the therapist during a visit of care were appreciated. Being guided and supervised by someone were highly appreciated by participants.	<u>Barriers:</u> Participants felt low privacy when they needed to move from one room to another within the facility, and when they were attended by therapists or performed exercise in a large room that was used by other people. Participants felt low quality of care when time spent with the therapist was rare or variable across days. Participants perceived interruptions in their treatment time as negative. Risk situations to participants' safety were insufficient monitoring of the execution of guidelines and exercises and inadequate attention to problems of instability or imbalance during activity. <u>Facilitators:</u> Having private rooms when participants needed to change clothes for receiving therapy was perceived as high service quality.
Øien et al.(2011)	Over time, patients gradually became able to share vulnerable experiences, receive explanations about the	None	Patients emphasised and associated trust with treatment over time, as well as with specific moments where the participants explored specific tasks.	<u>Barriers:</u> Patients recalled earlier experiences of not being helped by physiotherapists to decrease their pain and were sceptic about their therapy.

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
	development of tension and explore earlier and new patterns of moving and acting.		Patients described how they had to depend on the physiotherapists' understanding of their problem in first parts of treatment.	During treatment, patients endured pain and struggled to communicate or to relax. <u>Facilitators:</u> None
Potter et al.(2003)	Patients' perspective on qualities of a good physiotherapist related to times when the physiotherapist provides self-help strategies, e.g. a home exercise programme and/or advice on what the patient could do for him/herself, follows up and actively involves the patient.	None	The first quality of a good physiotherapist is his or her communication ability. Patients relate to the physiotherapist's interpersonal skills, manner and teaching ability. Physiotherapists are expected to be organised and should demonstrate appropriate professional behaviour while providing a service that not only includes appropriate diagnosis and treatment but also provides self-help strategies for patients in a welcoming and easily accessible environment.	<u>Barriers:</u> Bad experiences related to criticism of the service provided and ineffective communication skills on the part of the physiotherapist. <u>Facilitators:</u> Most patients attributed good experiences to effective communication ability, followed by the high quality of service provided by the physiotherapist.
Upshur et al.(2010)	None	None	Elements of a positive provider-patient relationship were the ways providers expressed genuine concern for the patient and the way providers do or should facilitate access to care. Providers were perceived as caring, empathising, listening to the patient,	<u>Barriers:</u> Participants had perceived failures of providers to fully respect, trust and accept the patient, to offer positive feedback and support, and to believe the participants' reports of the severity and adverse effects of their pain. Participants described being labelled as hypochondriacs, and accused of drug seeking and of lying about their experience of pain, regardless of presenting with

Authors	Patients' pain self-management	Patients' emotional support	Patient-practitioner relationship	Barriers and facilitators to care
			<p>understanding the patient, and focused on shared decision-making, especially about medications.</p> <p>Positive provider interaction included acknowledgement of patients as individuals with goals and responsibilities.</p>	<p>CMSP.</p> <p>Participants reported sensing that providers viewed them as unworthy of treatment, and it was implied that they kept providers from seeing other patients with more important needs. They experienced providers avoiding them, hurrying them, or minimising their pain.</p> <p>Participants reported that providers sometimes stopped or limited opioid prescriptions because of concerns about abuse or diversion.</p> <p>Participants had concerns about barriers to talking to or seeing their providers quickly, particularly around prescription renewals and to break through pain episodes.</p> <p><u>Facilitators:</u></p> <p>Participants described good relationships and caring providers. Patients recognised that providers were cautious about opioid medications because of possible misuse. At the same time, they wanted a sincere engagement in finding a workable treatment, such as developing a plan with options and reviewing the options and recommendations with the patient.</p> <p>For some patients, opioid medications provided relief and patients were very positive about providers who let them have some control over dosing.</p>

### 2.3.6 SUMMARY OF RESULTS

CMSP was reported as disabling and interfered with self-management strategies. Depression and stress negatively affected participants' self-management and treatment-seeking behaviours fluctuated. Participants were content when the HCP made most of the decisions as long as they were accompanied by good explanations. Follow-up, providing self-help strategies and actively involving the patients helped with continuity of self-management strategies. Participants took medication as the primary way of managing their chronic pain. Participants also made use of other physical and alternative modalities and activity modification and pacing was common to manage pain. When participants changed their beliefs about their condition it increased the range of coping response, pain became less of a threat and participants became less fearful and avoidant of activity. When participants were able to manage their pain it restored their sense of self and lifted their mood.

Lack of support and understanding interferes with the use of pain self-management strategies in patients with chronic pain. Participants wanted quick and direct access in the event of a flare-up and long waiting times for a review or follow-up by HCP resulted in dissatisfaction. On the other hand, the presence of support from family, friends and care managers was helping participants in their efforts to execute their self-management practices. It was helpful to talk through the pain and to analyse with somebody to find solutions to challenges they experienced. Participants felt that prescribing medication was the primary way that HCP gave them support in managing their chronic pain. HCP that demonstrated empathy, gave emotional support and encouragement were very valuable for participants. Supporting communication from HCP involved taking time over explanations, using appropriate terminology, getting to know the patient; and encouraging the patient's participation in the communication process.

On the other hand, HCP who are rushed can cause the patients to interpret the lack of time as lack of interest in them. Participants reported that having a high number of patients evident in the service setting increased feelings of saturation in the service setting and affected its ability to provide them a good service. Patients' perspectives of patient-centred care involved a professional relationship that allowed space for the patient to recognise the therapist's knowledge and expertise, but to also have input into the treatment plan and decisions about treatment. Positive provider interaction included acknowledgement of patients as individuals

with goals and responsibilities. Participants emphasised and associated trust to treatment over time and that the extent and consistency of a treatment session was more important than its duration or the number of sessions received. Participants felt supported in the management of their chronic pain when providers gave them valuable information and advice, answered questions, allowed for discussions, and gave explanations about pain and the different modalities, including areas with regards to coping and staying motivated.

The following barriers to care were identified:

- living with chronic pain had a negative effect on relationships, impeded participants' social life and inhibited their work performances
- participants had difficulty in finding a balance to manage their pain
- some participants did not understand the underlying cause of their pain and lack of understanding provoked fear
- pain remained mysterious and participants lives continued in a state of chaos and depression, not moving toward an acceptable alternative
- other participants expressed knowledge of their problem, but had no control over it
- participants had difficulty staying positive despite the pain, pain was interfering in their life and they questioned why they had to live with pain
- many participants commented on the idea of either losing their independence or striving for independence
- movement through the HCS was often back and forth between HCP and participants recalled experiences of not being helped or not adapting to meet patients' needs
- participants did not feel involved when they were not able to discuss their needs or when they received poor explanations for their pain
- abruptness of the health professionals were linked with dissatisfaction
- participants reported sensing that providers viewed them as unworthy of treatment and it was implied that they kept providers from seeing other patients with more important needs
- participants perceived interruptions in their treatment time as negative and they felt low quality of care when time spent with the therapist was rare or variable across days
- participants had concerns about barriers to seeing their providers quickly, particularly around prescription renewals and to break through pain episodes

- some participants felt that providers did not have adequate self-management support skills
- participants had perceived failures of providers to fully respect, trust, and accept them, to offer positive feedback and support, and to believe the participants' reports of the severity and adverse effects of their pain
- participants expressed a want for providers to communicate with each other and to try and understand what medication or procedures a patient has already tried
- participants felt that the provider did not understand their feelings toward taking medication and assumed they were seeking out more prescriptions
- sometimes participants described being labeled as hypochondriacs and accused of lying about their experience of pain, regardless of presenting with CMSP
- with regards to physiotherapy, participants were fearful of activity and in some cases patients indicated that they were feeling frustrated and unmotivated, they also had difficulty adhering to their treatment plan when they had ineffective pain relief from some strategies

The following facilitators to care were identified:

- goal setting and achieving goals improved participants' self-esteem and mood and this led to positive thinking and being proactive
- effective coping increased participants sense of control in negotiating re-involvement in work and independently managing their symptoms
- HCP were viewed as someone they can trust and help them to actually find the right person and the right solution
- trust usually equated with knowledge of the HCS and treatment options
- HCP gave support by prescribing medications and other treatment modalities, providing emotional support and encouragement, referrals, other alternatives, valuable information, and ensuring follow-up
- HCP's ability to communicate, their use of their knowledge and expertise, their self-confidence, and their ability to create confidence in the patient showed a complex interdependent category relationship
- participants appreciated consulting HCP who were caring, friendly, pleasant and professional and who showed an interest in their patients and made them feel at ease

- good communication was related to participants feeling involved in the treatment process
- for some patients opioid medications provided relief and patients were very positive about providers who let them have some control over dosing
- development of self-management strategies increases confidence, and ability to take better control over the chronic pain
- nurse care manager and/or physiotherapists were viewed as supportive, brainstorming partners, coaches, good listeners and able to help patients overcome frustration or lack of motivation
- follow-up phone calls or visits were a source of motivation and encouragement
- supportive family, friends and a support group with peers led to positive affirmations and inspiration
- exercises that were well explained and addressed to individual needs allowed control over physical symptoms, psychological uncertainty and fear

## 2.4 DISCUSSION

This study assessed and described the scope and breadth of knowledge currently available regarding CMSP patients' perspectives and experiences about PHC management. The strength of the study is that it explored a diverse range of studies and identified four themes, namely patients' pain self-management, patients' emotional support, the patient–practitioner relationship and barriers and facilitators to care. The study emphasised the importance of the patient–practitioner relationship where patient-centredness, collaborative decision-making, knowledge, communication and individualised treatment are needed to manage CMSP.

All of the participants included in the articles suffered from CMSP, and three studies specifically mentioned that the participants suffered from CLBP. Four studies were undertaken in the United States, four in Europe, two in NZ and one study in Australia. All of the participants made use of PHC services, namely primary care clinics, pain centres, rehabilitation services or private practice settings. These countries are first world countries, whereas SA is a developing country. However, the identified themes in this scoping review is still important in the SA context, because it can inform SA on the challenges that the HCS is facing.

Participants reported that it was important to converse with someone about their accomplishments and challenges in using self-management strategies and to find solutions to challenges they experienced. Being guided and supervised by someone was highly valued by participants, they related to the providers' interpersonal skills, manners and teaching ability and they reported it as being helpful, personal, responsive, accessible and supportive.

Interactions with other patients during therapy were also described as positive, motivational, helpful and supportive. Some self-management strategies identified in this review included:

- the judicious use of medication (Kawi, 2012; Upshur et al., 2010);
- individually crafted physical activity and exercise (Bair et al., 2009; Matthias et al., 2012; Øien et al., 2011; Potter et al., 2003);
- alternative modalities (Kawi, 2012);
- goal setting (Bair et al., 2009; Matthias et al., 2012); and
- activity modification, pacing, rest, relaxation and breathing techniques (Bair et al., 2009; Kawi, 2012).

Adherence and continuity of self-management strategies were enhanced by HCP who supported and followed participants up on their pain management (Matthias et al., 2012).

However, the findings indicated that most of the participants were not able (or did not have the confidence) to be independent self-managers, and therefore required supported self-management where they could still access the HCP for assistance and support.

Support from family, friends and care managers helped participants in their efforts to perform their self-management strategies, and it was important for patients to have somebody to talk to about their achievements and challenges in using these strategies (Bair et al., 2009; Kawi, 2012; Matthias et al., 2012; Medina-Mirapeix et al., 2013). Many participants turned to their health providers for support and sometimes this included group therapy for peer support.

Participants evaluated a supported setting as motivational, because it allowed them to get to know people with similar disability experiences and develop relationships of mutual help and emotional support. Health care professionals who demonstrated empathy, compassion, gave emotional support and encouragement were appreciated by participants (Cooper et al., 2008; Kawi, 2012; Kidd et al., 2011). Supporting communication from the health care professionals involved taking time over explanations, using appropriate terminology, getting to know the patient; asking questions and encouraging the patient's participation in the communication

process (Cooper et al., 2008; Kidd et al., 2011; Potter et al., 2003). Follow-up appointments or phone calls also increased participants' adherence to self-management strategies. On the other hand, lack of family, social or health provider support interfered with the use of pain self-management strategies in patients with chronic pain. Some participants felt a lack of understanding from others regarding the pain they were experiencing. Participants wanted quick and direct access in the event of a flare-up and long waiting times for an evaluation or follow-up by health professionals resulted in dissatisfaction (Cooper et al., 2008; Upshur et al., 2010).

One of the main findings of the review is the participants' reliance on and trust in the HCP. Participants trusted clinicians as an invaluable source of information to assist them to understand pain and the reason for its persistence (Brown et al., 2010; Cooper et al., 2008; Kawi, 2012; Kidd et al., 2011; Øien et al., 2011; Potter et al., 2003). Trust was also a powerful facilitator for accessing treatment, and on occasions meant that barriers were overcome. Participants further required HCP to equip and empower them by educating them about their pain and ways to manage it. Kidd et al. (2011) report that pain became less of a threat and participants became less fearful and avoidant of activity when they understood their pain. Participants appreciated a positive provider–patient relationship in which they were invited to share decision-making about care. This professional relationship allowed space for the patient to recognise the therapist's knowledge and expertise and for the provider to acknowledge patients as individuals with goals and responsibilities (Bair et al., 2009; Kidd et al., 2011). These findings emphasise the power relationship between the patient and the practitioner, and confirm that communication, knowledge and patient-centredness are vital for the management of CMSP.

Positive and negative experiences relating to relationship building were shared by participants. They were clear on their expectations about positive relationships as patient-centred, collaborative decision-making, individualised treatment, knowledgeable and trustworthy HCP with good communication skills and characteristics, and acknowledgement of patients as individuals with goals and responsibilities (Brown et al., 2010; Cooper et al., 2008; Kawi, 2012; Kidd et al., 2011; Øien et al., 2011; Potter et al., 2003). The following aspects were barriers to the patient–practitioner relationship:

- no guidance in pain self-management strategies;

- saturation of patients in the health care setting that led to poor service;
- providers failing to respect the patient;
- hurrying them;
- minimising their pain;
- not giving positive feedback or support;
- accusing them of drug seeking; and
- not giving appropriate follow-up appointments (Bair et al., 2009; Medina-Mirapeix et al., 2013; Upshur et al., 2010).

These undesirable behaviours of the HCP indicated that the participants were dissatisfied with the attitudes and attributes of the HCP. These findings have a negative outcome on the provision of appropriate and adequate health care for CMSP patients. By identifying barriers, HCP could find ways to reduce or overcome these barriers and improve health care quality for CMSP patients.

The barriers and facilitators to care related strongly to relational factors with the HCP. Participants experienced many facilitators to care. Goal setting, effective management of symptoms and achieving goals improved participants' self-esteem and it increased participants' adherence to treatment programmes (Bair et al., 2009; Kawi, 2012; Matthias et al., 2012). In order to do this, participants consulted HCP for assistance and support. Most participants attributed good relationships and experiences to effective communication ability, followed by high-quality service provided by health care practitioners and the involvement of participants in the treatment process (Cooper et al., 2008; Kidd et al., 2011; Potter et al., 2003). Participants consulted HCP who were caring, friendly, supportive and professional, who showed interest, shared valuable information, prescribed medications and other treatment modalities and ensured follow-up visits (Cooper et al., 2008; Kawi, 2012; Kidd et al., 2011; Matthias et al., 2012). In terms of medication, providers were cautious about misuse and thus wanted to develop a plan with options and review the options and recommendations with the patient to find a workable treatment plan (Kawi, 2012; Upshur et al., 2010). High-quality health care for CMSP can be achieved by identifying facilitators and integrating them into health care strategies.

The development of self-management strategies also increased the participants' confidence and the ability to manage their pain better. Participants moved from being held accountable to the HCP to being accountable and to answer to themselves. This internal accountability developed after seeing the benefits of the self-management activities and feeling motivated to continue due to those benefits (Matthias et al., 2012). Supportive family, friends and a support group with peers also led to positive affirmations and inspiration. Participants felt that their treatment was tailored to their individual needs when it made sense to them and were well explained. Not all participants are open to self-management strategies; however, patients need to be educated and supported by the HCP in order to develop self-management strategies.

On the other hand, participants also experienced barriers to care. Living with chronic pain had a negative effect on their relationships; it impeded their social life and inhibited their work performance (Kawi, 2012). Some also had difficulty in finding a balance to manage their pain. Lack of understanding of the underlying causes provoked fear. Anxiety and fear were also closely related to the unpredictability of pain, leading to increased vigilance and awareness of pain situations (Bair et al., 2009; Kawi, 2012; Upshur et al., 2010). This resulted in participants missing out on life activities, limitation of movement in anticipation of pain, fear of losing their independence and having difficulty staying positive. Movement through the health system was often back and forth between health care professionals, because participants recalled experiences of HCP not adapting to meet their needs or receiving poor explanations for their pain (Brown et al., 2010; Cooper et al., 2008; Øien et al., 2011). Participants were dissatisfied with HCP who were avoiding them, minimising their pain, rushed or did not schedule follow-up appointments. Participants also had experienced failure by providers to fully respect, trust and accept them. Participants emphasised that providers needed appropriate education and training and enhancement of knowledge and skills on communication, collaboration, support and psychosocial aspects to understand and manage the consequences of their chronic pain better.

Participants wanted providers to communicate with each other and make an effort to understand which medication or procedures a patient had already tried. They expressed their concerns about taking medication and that providers assumed they were seeking out more prescriptions. Participants also had difficulty adhering to their treatment plan when they had ineffective pain relief from some strategies or when they felt that strategies were not tailored

to their individual needs (Bair et al., 2009; Cooper et al., 2008; Medina-Mirapeix et al., 2013; Øien et al., 2011). Bad experiences were also related to insufficient monitoring of the execution of guidelines and inadequate attention during therapy. In some cases participants were feeling frustrated, unmotivated and fearful of certain exercises. Other perceived barriers were limited financial or transportation resources (Bair et al., 2009).

There were a few limitations of the sources included in the scoping review, which added to evaluating the gaps in the available research. Two studies had the possibility of self-selection bias (Bair et al., 2009; Cooper et al., 2008), two studies reported that recall bias was a weakness (Brown et al., 2010; Medina-Mirapeix et al., 2013) and two studies were unable to capture all possible perspectives, due to respondent bias (Bair et al., 2009; Matthias et al., 2012). The following recommendations for future research were made:

- explore the role of communication, motivation and support in self-management longitudinally (Matthias et al., 2012)
- research modifications that better address barriers and facilitators (Bair et al., 2009)
- consider patients with other types of chronic conditions to understand whether patients with chronic pain have unique difficulties in seeking medical care (Upshur et al., 2010)
- examine the influence of self-management and self-management strategies on chronic pain outcomes (pain intensity, functional ability, quality of life, health care cost) (Kawi, 2012)
- study the relevance of patient-centredness in the wider population and evaluate patient-centred care (Cooper et al., 2008)
- investigate the influence of age, gender and ethnicity on people's perspectives of pain and treatment choice (Brown et al., 2010)
- explore methods used by HCP to bring about favourable outcomes through the therapeutic relationship (Kidd et al., 2011)
- consider longitudinal studies that include patients with different health conditions and follow the patients throughout the rehabilitation process (Medina-Mirapeix et al., 2013)

## **Limitations and strengths of the study**

The scoping review has limitations. Only selected databases were searched, and including other databases may have yielded more studies for inclusion. The researcher is bilingual and only Afrikaans and English studies were included. More studies could have been included had the researcher been multilingual and able to use studies of other languages. As this review mostly included qualitative studies, the premise was not to generalise the findings, but instead to identify common themes across the included studies. The included studies focused on patient perspectives and experiences presented by patients with CMSP and may not be similar to those of other patients with other types of chronic pain. A few studies used retrospective recollection of events by relying on participants' memory of past events (Bair et al., 2009; Brown et al., 2010; Cooper et al., 2008; Potter et al., 2003). Relying on participants' recall of former health care experiences could be a limitation, because patients' recall may be inaccurate and subjected to biases (Chenail, 2011). Other studies followed participants throughout their rehabilitation process, which limited recall (Kawi, 2012; Kidd et al., 2011; Matthias et al., 2012; Medina-Mirapeix et al., 2013; Øien et al., 2011; Upshur et al., 2010).

The review filled a gap in understanding patients' perspectives and experiences about chronic pain management. Strengths of the study are the inclusion of a diversity of studies in terms of sample sizes, age, gender and ethnic groups. The study generated rich and descriptive data from the studies. A further strength was the high quality (see section 2.3.3) of the included studies confirming their trustworthiness.

## **Recommendations for changes in clinical practice and future research**

This study was performed to investigate the extent and type of evidence available about patients' perspectives and experiences about PHC management of their CMSP. It would be beneficial for future research to explore the PHC management in other countries, because of the different HCS involved. PHC can also be narrowed down to public and private health care facilities, and further studies should be done in the private health care sector, due to a lack of this type of information. The scoping review included a few types of studies, but there was a shortage of qualitative studies. Future studies could determine whether additional facilitators and barriers to care can be identified using a different sample and setting.

This scoping review thus informed the primary study to be a qualitative study that should be conducted about patients' perspectives about living with chronic pain and their pathway of care in private health care settings; to explore the HCP involved in the pathway of care and in the management of CMSP in the private health care setting and to determine patients' perspectives about barriers and facilitators to pain management in private health care HCS of SA.

## **2.5 CONCLUSION**

This scoping review provided an important foundation for understanding patients' perspectives and experiences about the PHC management of their CMSP to improve clinical practice and further research. The participants' perspectives about their CMSP showed a lack of understanding their pain, anxiety and fear related to the unpredictability of pain, difficulty in finding a balance to manage their pain, limitation of movement, inhibited work performance and negative effects on their relationships. However, supportive family and friends led to positive affirmations and motivation. The participants' experiences regarding the health care management of their CMSP indicated a disjointed pathway of care and HCP not adapting to meet their needs. Participants had difficulty adhering to their treatment plan when they had ineffective pain relief or when they received no guidance in pain self-management strategies. Participants were dissatisfied with the attitudes and attributes of HCP; however, the HCP who included patient-centredness, collaborative decision-making and communication in their management were valued by participants.

## CHAPTER 3: METHODOLOGY OF QUALITATIVE STUDY

### 3.1 RESEARCH QUESTION, AIM AND OBJECTIVES

**Research question:** What are patients' perspectives and experiences about private practice health care management of their chronic musculoskeletal pain?

**Research aim:** The researcher wanted to explore patients' perspectives and experiences about the health care management of their CMSP in the private health care sector.

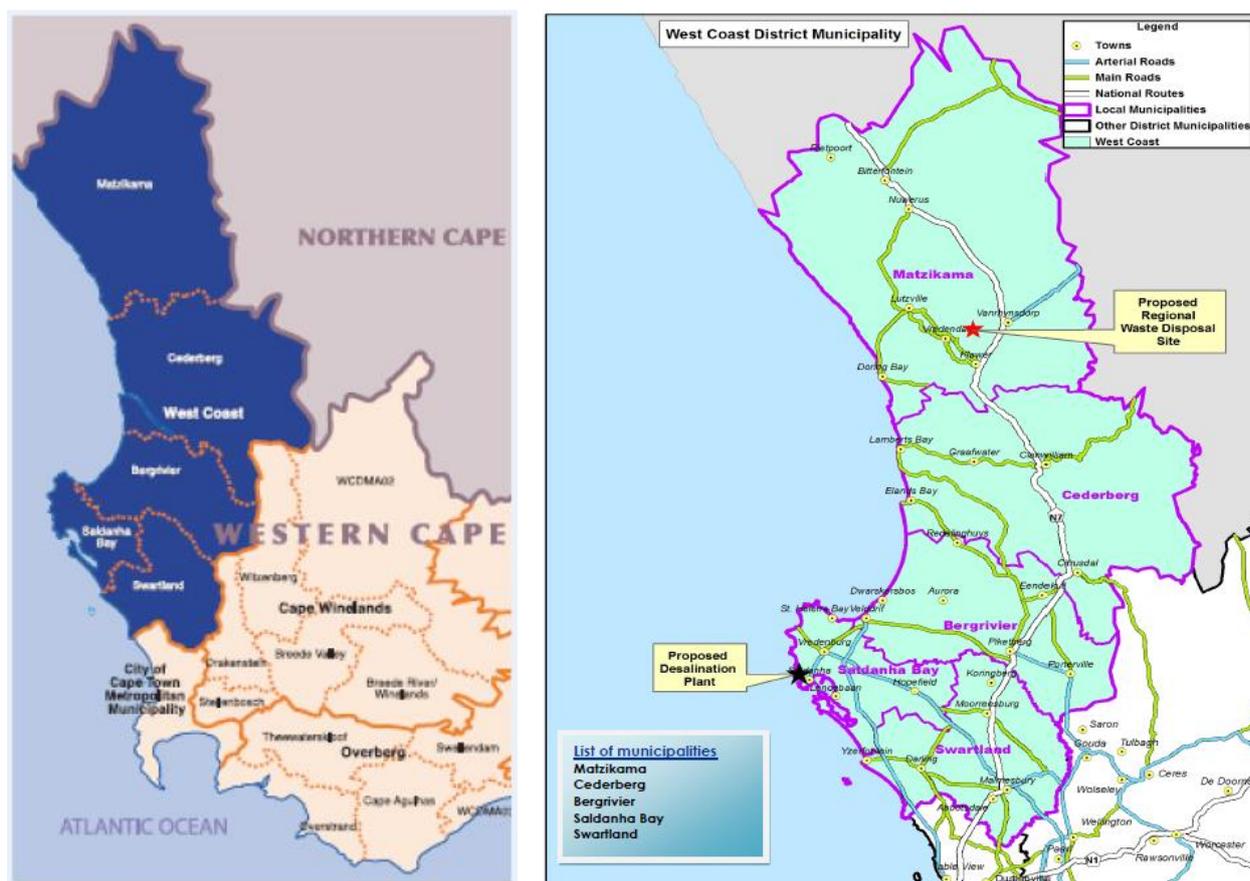
**Primary objectives:** The first objective of this study was to ascertain patients' perspectives about living with chronic pain and their pathway of care in private health care settings. A second objective was to explore who the HCP involved in the pathway of care and in the management of CMSP in the private health care setting is. The third objective was to determine patients' perspectives about barriers and facilitators to pain management in private health care settings.

### 3.2 STUDY DESIGN

A descriptive qualitative case study design with an interpretative and phenomenological approach was used. This type of study describes an intervention or phenomenon and the real-life context within which it occurs (Baxter & Jack, 2008). A phenomenological study describes for individuals the meaning of their lived experiences. The purpose of phenomenology is to condense individuals' experiences with a phenomenon to a description of the universal essence (Creswell, 2007:77). The phenomenon or shared experience in this study was patients' understanding of CMSP, their perspectives and experiences of living with chronic pain, and the management of such pain. The study focused only on one region in the Western Cape, to delineate the scope of this master's research, lending to it a case study approach. The case study approach acknowledges the importance of context in understanding patients' perceptions (Baxter & Jack, 2008).

### 3.3 STUDY CONTEXT

The study was conducted in the West Coast region of the Western Cape, SA. The West Coast region is located north of the City of Cape Town and nestled between the Atlantic Ocean and the Cederberg Mountain ranges.



**Maps 1 and 2: West Coast region (Cleophas, Prins & Williams, 2014:2–3)**

The key growth sectors throughout the region comprise fishing, manufacturing and mining (Cleophas et al., 2014:2). Fishing includes deep-sea fishing, line fishing, lobsters, mariculture and a growing aquaculture sector (Cleophas et al., 2014:2). Manufacturing is the second most prominent economic sector and comprises food processing, non-metallic mineral products, iron, and basic steel and non-ferrous metal industries (Cleophas et al., 2014:2). Mining includes limestone, diamonds, kaolin and phosphate for the processing and transport sectors. These support the needs of the mining industry in SA with a major iron ore terminal at the port of Saldanha. The population of the West Coast increased by 38.6% from 282 673 in 2001 to 391 766 in 2011 (Cleophas et al., 2014:54).

### 3.4 SAMPLING

Purposive sampling was used to focus on particular characteristics of the population, which best enabled the researcher to answer the research question. According to Baker and Edwards (2012:4,10), 14–19 interviews provide an excellent range of interviews that would serve as a valuable guide for qualitative researchers. According to Guest, Bunce and Johnson (2006), data saturation could occur within the first 12 interviews and after that, very little new information is likely to arise. Data saturation refers to the point at which no new concepts emerge from the review of consecutive data from a sample that is diverse in the appropriate characteristics and experiences (Curry, Nembhard & Bradley, 2009).

The following key inclusion criteria were used to ensure a diverse sample:

- individuals had to live within the geographical area (West Coast region);
- language (Afrikaans- and English-speaking participants were recruited as these are the two languages mostly spoken in the West Coast region. According to Lehohla (2012:11), 83.7% of the population speaks Afrikaans and 4% speaks English;
- cultural group (black, coloured and white participants were recruited, as these are the majority population groups in the West Coast region. According to Lehohla (2012:11), 67.1% of the population is coloured, 16.5% is black, 15.8% is white and 0.6% is Indian/Asian;
- age – adults between the ages of 18 to 81 years were recruited to include younger, middle-aged and older adults, in order to increase the sample size (Rustøen, Wahl, Hanestad, Lerdal, Paul & Miaskowski, 2005);
- gender – male and female participants were recruited, even though chronic pain is more prevalent in females (Dookie & Singh, 2012);
- CMSP – was defined as constant pain of the musculoskeletal system for 12 weeks or more (Kawi, 2012; Upshur et al., 2010);
- patients had to be managed by private health care practitioners in private practice, for example general practitioners, physiotherapists, occupational therapists and psychologists (Jeffery, Butler, Stark & Kane, 2011); and
- patients had to be able to read and have access to emails, in order to receive and read the information describing the study and the transcriptions of their interviews.

Exclusion criteria for the sample selection were as follows:

Patients with the following co-morbidities, which could have influenced their management and thus their experiences and perceptions, were not selected:

- pain that was not musculoskeletal in origin:
  - neuropathic pain – nerve compression pain, post-nerve injury pain, post-amputation pain, diabetic neuropathy, complex regional pain syndromes (type I and II), post-herpetic neuralgia and chronic post-surgical pain. According to Baron (2006), neuropathic pain syndromes and intense secondary changes occur in the spinal cord dorsal horn, and there is evidence of sensitisation of neurons in the brain;
  - visceral pain – distension of hollow viscera and colic pain. According to Sikandar and Dickenson (2012), visceral pain could negatively affect the general physiological state of how participants feel along with changes in autonomic controls. This has a strong affective component, and therefore can be reinforced by anxiety and depression; and
  - chronic pain in sickle cell anaemia. Maxwell, Streetly and Bevan (1999) describe this as a quadrumvirate of anaemia and its sequelae, pain syndromes, organ damage including infection, and comorbid conditions. Experiences of pain in sickle cell crisis may be influenced by sociocultural and psychological factors as well as disease severity.
- diagnosed psychological disorders (e.g. clinical depression –Barš, Đorđević, Gregurek and Bulajić, 2010)
- workmen's compensation, according to Newton-John & McDonald (2012) receiving financial compensation is associated with a greater experience of pain and reduced treatment efficacy. Compensation status is related to the amount of time off work following injury and significantly affecting recovery.

Three towns in the West Coast region were purposefully selected as they best represent the core business and thus employment sectors as indicated in Lehohla (2012:54). These towns are:

Langebaan,

Saldanha and

Vredenburg

In each town, one interdisciplinary private practice and a representative solo private practice were invited to participate in the study by providing permission to access their clients. This selection strategy was envisaged to ensure sample diversity/variability. Diversity of the study sample was achieved by recruiting participants of different languages, cultural groups, age and gender.

### **3.5 INSTRUMENTATION**

Semi-structured interviews and three questionnaires were used to gather the data.

- Semi-structured interviews

Semi-structured individual interviews provided the opportunity to generate rich data, gain insight into the perspectives and values of interviewees and to provide information on contextual and relational aspects needed to understand the interviewees' perceptions (Creswell, 2007:38). The researcher developed an interview schedule to ensure that all the topics were covered. The schedule comprised eleven questions (attached as Addendum 8). The interview schedule was based on the literature reviewed and reported on in Chapter 2, as well as the schedule developed by Ernstzen et al. (2017). The content of the interview schedule was evaluated by the supervisor and co-supervisor, who were familiar with the research objectives. A pilot study involving patients with CMSP was conducted to ensure the content validity of the interview schedule and to make sure that participants would be able to understand the questions. The pilot study also helped the researcher to construct the questions appropriately and to remove some of the questions that did not seem to serve a purpose. It also ensured that there was a flow in the way questions were asked.

Questions 1 to 5 aimed to determine the patients' perspectives about living with chronic pain and the pathway of care in private health care settings. Questions 6, 7, 10 and 11 aimed to determine the HCP involved in the pathway of care and in the management of CMSP in the private health care setting. Questions 8 and 9 explored the participants' perspectives about barriers and facilitators to pain management in the private health care setting.

In a qualitative study, the researcher is a key instrument, because he or she collects the information and data (Creswell, 2007:38). The researcher declared that she did not have

CMSP. At the time of the study, the researcher worked in private practice in the geographical region. The researcher's young age (26 years old) and female gender could have influenced the data collection, but the participants were talkative and open during the interviews. The researcher received basic training in qualitative training and conducting interviews beforehand.

- Sociodemographic and pain description questionnaire (Addendum 9)

This questionnaire was based on previous research (Ernstzen et al., 2017) and contained three sections: sociodemographic information, pain information, and health care-related information. Current pain intensity and average pain intensity for three months were measured using the Numeric Pain Rating Scale (NPRS). The NPRS is a simple, validated, self-report/practitioner-administered measurement tool for pain intensity (Kahl & Cleland, 2005). It consists of a line with a numerical point scale with two anchors, with 0 representing 'no pain' and 10 representing 'extreme pain' (Kahl & Cleland, 2005). The participants were asked to rate their average pain intensity on the scale for the past three months.

- K10 questionnaire (Addendum 10)

This questionnaire comprises a 10-item scale intended to produce a universal measure of distress based on questions about negative emotional states that a person has experienced in the preceding four-week-period. The K10 scale contains low- to high-threshold items. For each item, there is a five-level response scale based on the amount of time that a respondent experienced the particular problem. Each item is scored from 1 (for 'none of the time') to 5 (for 'all of the time'). The final score is grouped as follows: low (scores of 10–15, indicating little or no psychological distress), moderate (scores of 16–21), high (scores of 22–29), and severe (scores of 30–50, indicating very high levels of psychological distress). The K10 questionnaire is a simple, brief, valid and reliable instrument to detect mental health conditions in the population (Andrews & Slade, 2001).

- Pain Disability Index (PDI) questionnaire (Addendum 11)

This questionnaire is a simple and rapid instrument for measuring the effect that pain has on the ability of a person to participate in essential life activities. Participants used a 0 ('no disability') to 10 ('total disability') numeric rating scale. This tool measures seven areas of life activity: family/home responsibilities, recreation, social activity, occupation, sexual behaviour, and self-care and life-support activities. This gave an indication about how much the chronic pain influenced the participants' life and which aspects of their life were disrupted (Chibnall & Tait, 1994). The PDI was originally developed by Tait, Pollard, Margolis, Duckro and Krause (1987) for the assessment of pain-related disability in patients with chronic pain. Grönblad, Hupli, Wennerstrand, Järvinen, Lukinmaa, Kouri and Karaharju (1993) found that the PDI has good construct validity with respect to other measures of pain-related disability and distress and that it is valid for differentiating subgroups of pain patients. Grönblad et al. (1993) also concluded that the PDI was a useful and reliable test for the assessment of perceived disability in patients with pain. The final score is calculated by the sum of all seven parameters. The minimal index is 0 and the maximal index is 70. The higher the index, the greater the disability of the person because of the pain (Grönblad et al., 1993).

The sociodemographic and pain description questionnaire, the K10 questionnaire and the PDI, were used to describe the study sample and thus provide context to the study. All questionnaires were available in English and Afrikaans as they have been used previously in SA studies by Myer, Stein, Grimsrud, Seedat and Williams (2008), Kuo and Operario (2011) and Ernstzen et al. (2017).

### **3.6 RESEARCH PROCEDURE**

A pilot study was conducted following ethical approval. The aims of the pilot study were to test whether the questionnaires and interview schedule were applicable for the study sample and to gain content validity. Two patients with CMSP were recruited from a private practice not included in the main study. Written informed consent was obtained from all participants prior to the pilot study (Addendum 7). Confidentiality of information shared and anonymity of the participants' personal information were discussed before the study.

Pilot study participants were required to complete the questionnaires and provide feedback about the questionnaires. Interviews were conducted with the participants and they were also required to provide feedback about the interview schedule. The participants were asked to identify uncertainties and difficult questions in the questionnaires and in the interview schedule. The time taken to complete the questionnaire and the interview were recorded to decide whether the questionnaire was reasonable. The researcher assessed whether each question gave an adequate range of responses and whether the replies could be interpreted in terms of the information that was required. No changes were made to the questionnaires, because it took little time to complete and the participants did not have any difficulties to complete the questionnaires. The interview schedule also stayed the same, because a satisfactory range of responses were gathered. During the pilot study the interviewer was able to practice how to ask the open-ended questions and when to guide participants to provide the type of information required when they were deviating from the topic.

A list of practices in the three proposed towns was found on the HPCSA website (HPCSA, (S.a)). All the physiotherapists, occupational therapists and psychologists in the three towns were contacted, because there were only one or two private practices of each discipline per town. General practitioners from the three towns were chosen from the HPCSA list by making use of simple randomization. A computer generated random numbers table were used to randomly select three private practices in each town. These practices were recruited for participation by making an appointment with the practice manager/owner to explain the research aim, procedure and requirements for participation. Following the verbal discussion and agreement for participation, an information leaflet explaining the research aim and procedure and a written agreement (Addendum 12) were given to the respective HCP. When a private practice declined participation, another private practice was recruited by the same procedure.

Health care professionals at the private practices who gave permission to participate were requested to provide the contact details of eligible patients with a diagnosis of CMSP who have been managed at the practices over the preceding three to six months. The practitioners first asked the permission from the patients to give their details to the researcher. The researcher then enquired from the patients regarding their willingness to participate in the study by phoning them. An email with the informed consent form (Addendum 7) in which the study was explained was sent to them when they agreed to participate. The informed consent

form indicated that medical records would be accessed. Those who consented to participation were contacted via telephone for an appointment to sign the informed consent document and to participate in the interview.

The researcher conducted the interviews in Afrikaans or English, according to the preference of the participants, as she is proficient in both. Interviews were conducted when it was convenient for the interviewees and it took place in the interviewees' natural setting, i.e. their homes or places of work, taking into account the patient's preference, safety, physical space, the noise level at the setting and also the power-relationship (Van Hecke, Deforche, Van Dyck, De Bourdeaudhuij, Veitch & Van Cauwenberg, 2016). The researcher introduced herself as 'the researcher' on the day of the interview, she did not wear uniform and physiotherapy departments were not used to conduct the interviews. However, for ethical reasons and when she was asked directly, the researcher did disclose that she was a physiotherapist. Interviewees were asked to complete the three questionnaires after the interviews.

A digital voice recorder was used to record the interviews, which lasted between 20 and 80 minutes. The interviewer kept a reflective diary to write her thoughts down after each interview. The recordings were downloaded onto the researcher's laptop that was password protected. A unique serial number was allocated to each recording. A professional transcription company was employed to transcribe the interviews. Names of participants did not appear in the transcriptions. A copy of the completed transcript was provided via email in PDF format to each participant to assist with validation of the information. The research supervisor did not attend the interviews, but she listened to a selection of the recorded interviews to aid in validation of the interview process.

### **3.7 DATA ANALYSIS**

Inductive thematic content analysis was undertaken by using computer software (ATLAS.ti) to code and identify key themes and sub-themes from the interview transcripts (Vaismoradi, Jones, Turunen & Snelgrove, 2016). Data analysis was done in English when the transcription was in English and in Afrikaans when the transcription was in Afrikaans. This was to ensure that the meaning of words and phrases did not change during transcript-translations. The principle investigator (MS) and a supervisor (DE) studied a selection of six

of the transcripts and independently coded them. These codes were compared, discussed and merged to create a codebook. The implementation of the codebook allowed categories to emerge from data and to recognise the importance for understanding the meaning of the context in which an item being analysed appeared (Vaismoradi et al., 2016). The content analysis was validated by cross-checking of coding strategies and interpretation of data between the researcher and the supervisor. Codes were allocated to one or more categories. Themes were identified and the data were interpreted by the researcher.

The first step in analysing the data involved organising the data. Once the data had been organised, the researcher proceeded to the second step, namely description. During this stage, the researcher sought to describe the various relevant aspects of the study, which included the setting, individuals being studied; the perspectives of the participants and the description of what the participants had experienced and how they experienced it in terms of the condition, situations and context. The descriptive step was developed by the researcher to convey an overall essence of the experience (Creswell, 2007:58–60). The third step of the analysis process involved interpretation. The researcher explained the findings, answered the research question, attached significant exact results and placed patterns into an analytical framework. This was done until a point of data saturation was reached (Kohlbacher, 2006).

Analytical notes were kept about decisions made during analysis. Interpretation of the meanings of the themes and what the themes meant in terms of the study aims was discussed with the supervisor and co-supervisor.

### **3.8 ETHICAL CONSIDERATIONS AND PRINCIPLES**

Ethical clearance for the project was sought and obtained from the Health Research Ethics Committee (HREC), SU, SA (S15/09/196). This project was conducted according to the ethical guidelines and principles of the SA Guidelines for Good Clinical Practice (Department of Health, 2015:2), International Declaration of Helsinki (WMA, 2008:1–4) and the Medical Research Council (MRC) Ethical Guidelines for Research (MRC, 2012:1). The next section introduces and discusses ethical principles that were considered when designing and conducting the research.

### Respect for autonomy

During a personal visit, private practices were recruited for participation. An information leaflet explaining the research aim and procedure was made available when health care professionals agreed to participate. Their permission was asked to conduct the study with some of their patients and a written agreement was signed. Participation in the research was voluntary and based on informed choices. Information was presented to make a sound judgement regarding participation. The informed consent process took place before the research commenced and was affirmed during the course of the study, as part of the commitment to an ongoing consent process.

Written informed consent was obtained from all participants prior to the interviews. The participants were reminded that they had the right to withdraw from the interview at any time, they had the right to stop the digital voice recorder at any time during the interview and they could also refuse usage of the information that they have shared.

### Beneficence and non-maleficence

The principles of beneficence and non-maleficence are complementary ethical principles: one imposing positive duties and the other negative ones (Nsamenang & Tchombe, 2011:100). No harm was anticipated by the researcher as the study involved interviews. The study population was vulnerable because they shared very personal and private information, but the information was confidential and thus no risks were posed to participants. If participants were depressed or suicidal, the researcher encouraged them to discuss their issues with their HCP and if needed, a list of HCP was provided to contact them for further assistance.

As advocated in Crinson and Leontowitsch (2006), no advice was provided during the interviews, as this could have compromised the research relationship and turned it into a counselling/therapy relationship. This aspect could have influenced the research process. No patients had acute symptoms (given the eligibility criteria) and thus did not need to be referred to their required HCP for management. Furthermore, if the participants felt that they were not currently being managed optimally, the researcher encouraged them to discuss this issue with the HCP and if needed, provided them with a list of HCP whom they could contact for further assistance.

Participants were offered a gift voucher and refreshments during interviews. The most important benefit of this study was aiding future patients and HCP in the health care management of CMSP.

### Justice

Distribution of burdens and benefits among the study sample was justifiable. Burdens involve individuals whose circumstances may lead to their vulnerability in the context of the research project and limit their ability to fully safeguard their own interests (Nsamenang & Tchombe, 2011:99). Their situation may also compromise the voluntariness of consent (Nsamenang & Tchombe, 2011:99). Participants' particular circumstances and needs were considered in the context of the proposed research project. Individual participation in research contributed to the advancement of knowledge that may lead to improved CMSP management. Such knowledge may also inform other communities or society in general (Nsamenang & Tchombe, 2011:99). The researcher ensured that participating individuals were informed of how to access the results of the research. Recruitment, selection, exclusion and inclusion of participants for research were just and fair, based on sound scientific and ethical principles as explained in section 3.4 of this thesis.

### Confidentiality

The researcher took measures to ensure privacy and confidentiality interests throughout the research, including when disseminating results or findings. Before the start of a recording the participant's name was replaced by a number to ensure concealment of private information and a unique serial number was then allocated to each recording and its transcript. Only the researcher, supervisor and co-supervisor had access to the participants' personal information. Documentation and information that might identify the participants were not disclosed during the course of the research and will not be disclosed afterwards. Practices will not be named at any stage in this thesis or during publication of it.

## **3.9 QUALITY ASSURANCE**

The trustworthiness of qualitative research is presented by credibility, transferability, dependability and conformability (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs,

2014). Improving the trustworthiness of content analysis requires skills in data gathering, content analysis, discussion of trustworthiness, and reporting of results (Elo et al., 2014). Trustworthiness of the primary study was ensured by measuring credibility, transferability, dependability and conformability of this study.

Credibility is the extent to which the findings of the study are trustworthy and credible to others (Frambach et al., 2013). The researcher conducted a scoping review on the topic to ensure that different theories were accounted for. Data were collected for an extended period of time and feedback was required from the participants on the data or interpretation of the data by providing the completed transcripts.

Transferability is the degree to which the findings can be transferred to or applied in different settings (Frambach et al., 2013). The context of the study was stated in section 3.3, and in this thesis, the findings and their context are described in detail. The sampling frame was developed to ensure diversity of the sample and the sampling strategy was explained in section 3.4. The findings were discussed against the background of existing literature from different settings in Chapter 2.

Dependability is the extent to which the findings are consistent in relation to the contexts within which they were created (Frambach et al., 2013). The researcher's involvement in the selection of private practices, data collection, transcriptions and analyses were balanced by repeated discussions between the researcher and supervisor to strengthen the validity of the study. Collection of data took place until data saturation. Data were continuously analysed and re-examined and the researcher was flexible and accessible towards the process and topic.

Conformability refers to the degree to which the outcomes are based on the participants taking part in the study and settings instead of the researcher's biases (Frambach et al., 2013). The researcher's personal and intellectual biases were minimised by allowing open questions to develop the interviews naturally and by reporting a wide range of perspectives. The researcher kept a reflective diary to reflect on the process and the researcher's role and influence. The research process and findings were discussed with the supervisors and consultants where necessary. An audit trail with steps and decisions, which were made during the research, was kept.

### 3.10 CHAPTER SUMMARY

The objectives of this study were to ascertain patients' perspectives about living with chronic pain and their pathway of care in private health care settings; to explore the HCP involved in the pathway of care and in the management of CMSP in the private health care setting and to determine patients' perspectives about barriers and facilitators to pain management in private health care settings. A descriptive qualitative case study design with an interpretative and phenomenological approach was used. The study focused on the West Coast region in the Western Cape, to delineate the scope of this master's research, leading to it a case study approach. The key growth sectors throughout the region comprise fishing, manufacturing and mining. In this region, the population increased by 38.6% from 2001 to 2011. Three towns, Langebaan, Saldanha and Vredenburg, were purposefully selected as best represent the core business and thus employment sectors.

Purposive sampling was used to focus on particular characteristics of the population and data saturation occurred before the last interview. The researcher made use of an inclusion and exclusion criteria to determine the study sample. In each town, one interdisciplinary private practice and a representative solo private practice were invited to participate in the study by providing permission to access their clients. This selection strategy was envisaged to ensure sample diversity/variability. Semi-structured interviews and three questionnaires (sociodemographic and pain description questionnaire, K10 questionnaire and Pain Disability Index (PDI) questionnaire) were used to gather the data.

A pilot study was conducted following ethical approval to test whether the questionnaires and interview schedule were applicable for the study sample and to gain content validity. Written informed consent was obtained from all participants prior to the pilot study and confidentiality of information shared and anonymity of the participants' personal information were discussed before the study.

HCP at the private practices who gave permission to participate were requested to provide the contact details of eligible patients with a diagnosis of CMSP. An email with the informed consent form, in which the study was explained, was sent to them when they agreed to participate. Those who consented to participation were contacted via telephone for an appointment to sign the informed consent document and to participate in the interview. The

researcher conducted the interviews in Afrikaans or English, according to the preference of the participants. Interviews were conducted when it was convenient for the interviewees and it took place in the interviewees' natural setting.

A digital voice recorder was used to record the interviews, which lasted between 20 and 80 minutes. The recordings were downloaded onto the researcher's laptop that was password protected. A unique serial number was allocated to each recording. A professional transcription company was employed to transcribe the interviews. A copy of the completed transcript was provided via email in PDF format to each participant to assist with validation of the information. Inductive thematic content analysis was undertaken by using computer software (ATLAS.ti) to code and identify key themes and sub-themes from the interview transcripts.

The trustworthiness of this qualitative research is presented by credibility, transferability, dependability and conformability and ethical clearance for the project was sought and obtained from the Health Research Ethics Committee (HREC), SU, SA (S15/09/196). The following ethical principles were considered when designing and conducting the research:

- respect for autonomy
- beneficence and non-maleficence
- justice
- confidentiality

## CHAPTER 4: RESULTS

One interdisciplinary private physiotherapy practice in Vredenburg and two solo private general practitioner practices and a physiotherapy practice in Langebaan gave permission for access to their patients and their patients' records. Nine other general practitioners declined to participate due to a lack of time, unwillingness to ask their patients to participate or to give out their information, a lack of interest or not having seen chronic pain patients in the last six months. Four physiotherapy practices declined to participate because one physiotherapist was on maternity leave and the other were not willing to ask their patients to participate or give out their information, and two physiotherapists also declined due to a lack of time. Four occupational therapists declined because they were not working in the area anymore and the client load of two occupational therapists did not include any chronic pain patients. Four psychologists declined as their client base did not include any chronic pain patients.

A total of 32 patients were contacted to participate and 18 agreed to participate, but 4 patients cancelled prior to the interview. They did not provide a reason for cancellations. This possible source of sampling bias might have influenced the internal validity of the data and question the trustworthiness of the results. Eventually 14 patients agreed to participate and in the end, data saturation and a thorough exploration of issues were reached and therefore the researcher did not have to recruit more participants.

### 4.1 SAMPLE CHARACTERISTICS

Table 4.1 provides an outline of the participants' sociodemographic information, Table 4.2 presents an outline of the participants' health care information and Table 4.3 provides the percentage of participants making use of each type of HCP.

**Table 4.1: Participants' sociodemographic information**

Variable	Number (n=14)	%	Mean (SD)
<b>Gender</b>			
Female	11	79	
Male	3	21	
<b>Language</b>			
Afrikaans	11	79	

Variable	Number (n=14)	%	Mean (SD)
English	3	21	
isiXhosa	0	0	
<b>Age (years)</b>			41 (12.4)
<20	0	0	
20–30	4	29	
31–40	3	21	
41–50	5	36	
51–60	1	7	
61–70	0	0	
71 >	1	7	
<b>Ethnicity</b>			
Coloured	1	7	
White	13	93	
Black	0	0	
<b>Marital status</b>			
Married	10	72	
Widowed	0	0	
Single	0	0	
Divorced	2	14	
In relationship	2	14	
<b>Number of children</b>			
0	2	14	
1 – 3	12	86	
4 – 6	0	0	
>6	0	0	
<b>Employment</b>			
Full-time employment	9	65	
Retired/Pensioner	2	14	
Unemployed	0	0	
Disability grant	0	0	
Home executive	3	21	
<b>Occupation (present)</b>			
Receptionist and administration	2	14	
Salesperson	2	14	
Bookkeeper	1	7	
Pharmacist assistant	1	7	
Maintenance manager	1	7	
Storeman	1	7	
Researcher	1	7	
Homemaker	5	37	
<b>Highest educational level</b>			
Primary school	0	0	
Secondary school	6	43	
Tertiary education	8	57	

**Table 4.2: Participants' health care information**

<b>Participants</b>	<b>Condition</b>	<b>Duration of pain</b>	<b>Diagnosis</b>	<b>Chronic conditions</b>	<b>Health carers who treated the pain</b>	<b>Medication used for pain</b>	<b>Average pain on Visual Analogue Scale (VAS) Average = 8/10</b>	<b>PDI score Average = 63% disability</b>	<b>K10 score Average = 27/50 high</b>
<b>Participant 1</b>	CLBP	8 years	Facet joint degeneration L3-L5	Depression	General medical doctor Physiotherapist Orthopaedic surgeon	Tramacet Celebrex Mybulen	7/10	34% disability	14/50 low
<b>Participant 2</b>	CLBP and left leg pain	4 months	Acute disc lesion	None	General medical doctor Physiotherapist Orthopaedic surgeon Chiropractor	Oxynorm	6/10	80% disability	34/50 severe
<b>Participant 3</b>	Chronic widespread pain	3 years	Fibromyalgia	Fibromyalgia	General medical doctor Rheumatologist Physiotherapist	Celebrex Lorien Adco-Allopurinol Truston Colchicine Adco-Zopimed Epleptin	9/10	69% disability	32/50 severe
<b>Participant 4</b>	CLBP	1 year	Osteoarthritis	Osteoarthritis Anxiety	Physiotherapist Orthopaedic surgeon Biokineticist Psychologist	Mypaid Voltaren Spasmed Betapyn Myprodol	8/10	83% disability	33/50 severe

<b>Participants</b>	<b>Condition</b>	<b>Duration of pain</b>	<b>Diagnosis</b>	<b>Chronic conditions</b>	<b>Health carers who treated the pain</b>	<b>Medication used for pain</b>	<b>Average pain on Visual Analogue Scale (VAS) Average = 8/10</b>	<b>PDI score Average = 63% disability</b>	<b>K10 score Average = 27/50 high</b>
<b>Participant 5</b>	CLBP	11 months	None	None	General medical doctor Physiotherapist Chiropractor	Tramazac Ibuprofen Mybulen	6/10	67% disability	24/50 high
<b>Participant 6</b>	Chronic widespread pain	3 years	Postural pain and injury caused more pain	Hypertension Rheumatoid arthritis Depression	General medical doctor Physiotherapist Orthopaedic surgeon Neurologist Reflexologist Psychologist Psychiatrist	Disprin Panado Myprodol Mybulen Brufen Tramadol Muscle relaxants	10/10	94% disability	43/50 severe
<b>Participant 7</b>	Chronic widespread pain	3 years	Fibromyalgia	Fibromyalgia Asthma Anxiety	Physiotherapist Pulmonologist	Citraz Eltroxin	10/10	77% disability	33/50 severe
<b>Participant 8</b>	Chronic headaches	29 years	None	None	General medical doctor Physiotherapist Neurologist Ophthalmologist	Trepiline	6/10	46% disability	30/50 severe
<b>Participant 9</b>	CLBP	34 years	Degeneration of spine	Hypertension Stroke Anxiety Depression	General medical doctor Physiotherapist Orthopaedic surgeon Biokineticist	Anti-inflammatory drugs	7/10	66% disability	26/50 high

Participants	Condition	Duration of pain	Diagnosis	Chronic conditions	Health carers who treated the pain	Medication used for pain	Average pain on Visual Analogue Scale (VAS) Average = 8/10	PDI score Average = 63% disability	K10 score Average = 27/50 high
					Chiropractor Homeopath				
<b>Participant 10</b>	Chronic widespread pain	7 years	Fibromyalgia	Fibromyalgia Hypertension	General medical doctor Physiotherapist Orthopaedic surgeon Neurologist Acupuncturist Nurse	Tramadol Trepiline Tramazac	7/10	33% disability	22/50 high
<b>Participant 11</b>	Chronic left hip and leg pain	2 years	Labrum tear	None	General medical doctor Physiotherapist Orthopaedic surgeon	Different pain medication	7/10	81% disability	22/50 high
<b>Participant 12</b>	Chronic low back and coccyx pain	8 months	Possible broken coccyx	Tietze's syndrome	General medical doctor Physiotherapist Orthopaedic surgeon Chiropractor Reflexologist	Mybulen Muscle relaxants	8/10	59% disability	24/50 high
<b>Participant 13</b>	CLBP and right leg pain	4 months	Tear in disc	Hypertension	General medical doctor Physiotherapist Orthopaedic surgeon	Lyrica Tramacet	8/10	60% disability	26/50 high
<b>Participant 14</b>	Chronic bilateral hip pain	5 years	Trochanteric bursitis	Hiatus hernia	Physiotherapist Orthopaedic surgeon	Celebrex	8/10	33% disability	13/50 low

**Table 4.3: Percentage of participants making use of each type of HCP**

Types of HCP	Percentage of participants
Physiotherapist	100%
General medical practitioner	79%
Orthopaedic surgeon	71%
Chiropractor	29%
Neurologist	21%
Biokineticist	14%
Reflexologist	14%
Psychologist	14%
Rheumatologist	7%
Pulmonologist	7%
Ophthalmologist	7%
Acupuncturist	7%
Homeopath	7%
Psychiatrist	7%
Nurse	7%

## 4.2 MAIN FINDINGS: PARTICIPATION-DERIVED THEMES

Initial coding resulted in 45 codes, which were reduced to 15 categories and finally arranged into 8 themes (Addendum 14). Eight major themes emerged from the data:

- living with chronic pain;
- disrupted identity;
- knowledge and beliefs about chronic pain;
- health care system factors;
- interactions with health care providers;
- management of CMSP;
- hope (or hopelessness) for the future; and
- barriers and facilitators to pain management (Please see table 4.5).

**Table 4.4: Participation-derived themes and categories**

Theme	Categories
1. Living with chronic pain	Physical functioning and activities of daily living (ADL) Participation in functional activities Influence on psychological well-being Family and social life Occupational consequences
2. Disrupted identity	Disruption of identity and psychological aspects Disruption of roles and responsibilities
3. Knowledge and beliefs about chronic pain	Understanding pain Sourcing of information The importance of believability/credibility Participant's expectations
4. Health care system factors	HCP consulted Disjointed pathway of care Appropriate referral Waiting times Continuity of care Cost of care
5. Interactions with health care providers	Provision of information (inadequate) Clinician attributes and attitudes (Lack of) patient-centeredness
6. Management of CMSP	Interventions received and patient's perceptions of these Special investigations Medication Exercise Physiotherapy Self-management strategies
7. Hope (or hopelessness) for the future	Fears about the future Hopelessness Acceptance
8. Barriers and facilitators to pain management	Barriers Facilitators

In this section, the data are described in their context according to each theme, followed by supporting quotes. For the purpose of this thesis all quotes that were in Afrikaans have been translated into English by the researcher (Addendum 15).

#### 4.2.1 THEME 1: Living with chronic pain

This section describes how pain affects the lives of the participants and which aspects of participants' lives were affected and disrupted by pain. The description comprises how the pain affects physical function and structures, ADL, work, family and social life, health-related QoL and psychological matters.

##### 4.2.1.1. Physical function and ADL

Chronic pain was reported to limit physical activities such as getting up from a chair, bending, walking, sleeping, and performing self-care and physical exercise. Participants mentioned that activities had to be done carefully and effortfully and in some cases had gone from being unconscious and without thinking about it to planned, fearful, and threatening. All of the following quotations are reproduced verbatim and unedited.

‘...since then, I had to be careful about what I did and how I did it and I can't just bend down without thinking about it. You have to say to yourself, push your knees together, now bend down, don't just bend forward and fall to the floor ... But it feels to me, if some things fall on the floor then it has to stay there. I am actually too scared to bend and pick it up.’ (Participant 1, female, CLBP, 8 years)

‘...I cannot walk fast...And I cannot wash my head, because my hands are sore, my neck is sore and all of a sudden my shoulders are sore. And I cannot apply lotion to my body and all those things and it is a nightmare to climb down stairs.’ (Participant 3, female, chronic widespread pain, 3 years)

‘...all of a sudden I find that even basic things are difficult to do...all of a sudden I can't just stand up, I can't just pick things up that I want to...’ (Participant 4, female, CLBP, 1 year)

‘Because there are some days I cannot use my hands at all, that I cannot walk at all, every step is, you want to shout because of the pain.’ (Participant 7, female, chronic widespread pain, 3 years)

‘At home I only do the essential things when I get home at night. I would for example definitely not pack anything away; I will not sweep the floor or pick anything up in the evening.’ (Participant 11, female, chronic left hip and leg pain, 2 years)

#### 4.2.1.2. Participation in functional activities

Participants shared that the pain interfered with their participation in functional activities. These limitations ranged from the ability to perform domestic chores to gardening, shopping and driving. Personal care, such as shaving, washing hair, bathing, dressing and going to the toilet, was limited and painful. Daily tasks, such as cooking and housework, were often difficult and caused an increase in pain and fatigue. Coping with pain occupied individuals’ minds and energy, and some participants commented that their concentration and memory had been affected.

‘...and I already know if I have to switch on the vacuum cleaner, by the time that I get to the third room, then I know, my back felt that, also with sweeping and things. And also sitting. I don’t sit on the couch anymore; I sit on a hard chair...’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘...if I get home at night then I go and sit on the couch and that’s it. I don’t even go to the bathroom, because it is too painful to stand up and go to the bathroom. I go to the bathroom when I go to my room, because I have to walk past the bathroom to get to my room.’ (Participant 6, female, chronic widespread pain, 3 years)

‘...I haven’t exercised since then, because I can’t bear the pain. I don’t even really clean the house anymore, because the other day I swept the floor, like Monday was a public holiday and that evening I had severe pain, so you start to do things to avoid the pain.’ (Participant 7, female, chronic widespread pain, 3 years)

‘I find I’m no longer as mobile as I used to be. So for instance a lot of the jobs around the house and the garden that I used to do before, I don’t do anymore. You know, like climbing up ladders and cutting weeds and doing that sort of thing.’ (Participant 9, male, CLBP, 34 years)

‘...they have always said to me that I had the memory of an elephant, and nowadays, I notice that I forget things and it really affects my brain function.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...most of the time in my daily life I have pain. So I feel terrible and it doesn’t always feel that I can actually concentrate.’ (Participant 2, female, CLBP and left leg pain, 4 months)

#### 4.2.1.3. Influence on psychological wellbeing

The emotional consequences of chronic pain were emphasised by the participants. Participants reported fear, feelings of anxiety and depression, sleep disturbances and stress as variables that affected their psychological well-being. Such variables made it difficult for participants to perform tasks and impaired their cognitive ability, which in turn affected everyday activities in the workplace and at home. Chronic pain and its influence left many participants feeling hopeless and desolate.

‘You have an incredible deserted feeling, you panic, you are scared, you are anxious, all of a sudden you are emotional, you don’t think straight. It’s half as if the emotion takes over because the pain is so overwhelming, you cannot think rationally. And that worries me...I am so scared of the pain that I avoid things that can actually help me...it steals my happiness. It steals my joy in a way, because you cannot enjoy anything if you have constant pain.’ (Participant 1, female, CLBP, 8 years)

‘I have so much pain that I cannot sleep through the night. You are literally awake all the time because it hurts, it aches, you do not know how to lie...I am in two minds, because I am highly depressed, very angry, very upset, very fed up...if I tell you I am hopeless, I am beyond hopeless, because where do I go from here?’ (Participant 6, female, chronic widespread pain, 3 years)

‘...you have your off days that you feel depressed and nothing will cheer you up...the more pain you have the more anxious you get...yes you get irritated and yes, you ...I mean one can only handle so much pain. But the pain is...I would say that I endure it

during the day, but as soon as the evening comes, then you get heavily irritated.’

(Participant 7, female, chronic widespread pain, 3 years)

‘...your mood swings and mood levels fluctuate depending on how ill or how stiff you feel. You get depression, because you get to a point where you cannot handle the pain anymore...some days you can cope and other days you cannot cope, that it is just too much for me...’ (Participant 3, female, chronic widespread pain, 3 years)

‘...as soon as it hurts so badly or when it is very painful for a long time during the day, then I get irritated quickly. So if somebody just tells me something, then I snap at them, then it basically annoys me, it is an annoying pain...’ (Participant 12, female, CLBP and coccyx pain, 8 months)

‘It gets harder for me to write tests. It is for me, I don’t know why, but it is very hard for me. Especially to forget things, because I am a very precise person. And I will read something now and then in two months you can ask me something and I will tell you exactly where it stood and where it was. Now it is like okay, I don’t know, I cannot remember...’ (Participant 7, female, chronic widespread pain, 3 years)

#### 4.2.1.4. Family and social life

Participants experienced social and family-related consequences due to their pain. CMSP affected their social interactions, restricted their leisure activities and social contacts.

Participants indicated that their condition had prevented them from attending social or family events. The unpredictable and fluctuating nature of pain was identified as one of the causes of their social limitations. A subgroup of participants reported that they felt they were a burden to their families and that unreturned dependency on family members was associated with feelings of helplessness and guilt. The participants who received physical and emotional support from their family and friends were very thankful for it.

#### Influence on family relationships

‘...I feel very guilty towards my husband...he tries to understand where he can. It used to be difficult for him to understand... he works overseas and it makes it even more

difficult. Because just my illness alone makes me depressive and now not to have my husband with me, also works negatively on me and I would like to be there, but I have responsibilities in South Africa...it feels to me that I do not contribute to anything at home because I can't. He is the only one that is working and caring. Yes, then it bothers you a lot.' (Participant 3, female, chronic widespread pain, 3 years)

'And activities with the children. I cannot play with them on the grass, it is too painful. So yes, I cannot carry them around, throw or ramp and stuff like that...I am not taking long walks with my children, to go hiking or something, to go walk around and so, then I am to sore and everything.' (Participant 10, female, chronic widespread pain, 7 years)

'My husband thinks it is a pain of convenience and that is his exact words.'  
(Participant 6, female, chronic widespread pain, 3 years)

'I think if my husband, who never gets sick, has to experience my pain that I have every day, he may look at me with very different eyes.' (Participant 2, female, CLBP and left leg pain, 4 months)

### Influence on relationships with friends

'...it even affects your relationship with other people because you are in pain and you are annoyed and somebody asks you to do something or to help at home and things and you can't. (Participant 4, female, CLBP, 1 year)

'...I do not have any friendships. My husband thinks it is a pain of convenience...'  
(Participant 6, female, chronic widespread pain, 3 years)

'...my social life that I have is just because of cycling. So if it goes away, my social life goes too...that is all we really have in common...'  
(Participant 2, female, CLBP and left leg pain, 4 months)

### Family support

‘...my child who still lives in our house is very helpful. My husband is very helpful. If I say that I cannot do something then they will take over and do it. So I don’t have a problem with support, I actually have a lovely support at home.’ (Participant 1, female, CLBP, 8 years)

‘...but I have a wonderful husband that can help. He supports me a lot. The day when I don’t feel well, he will say to me listen here, you can rest, he helps the children, he makes the food, he does the laundry and he washes the dishes. So he will really, if I say to him listen here, wow I have a lot of pain tonight when I get home, he will say to me it is fine and he will take care of food and things.’ (Participant 7, female, chronic widespread pain, 3 years)

### Social isolation

‘...it is all about social withdrawal because many people were here, even like fourteen, fifteen people with my dad, and after an hour, I felt oh no, I realised that I couldn’t just go to my room. That's too much...sharp light work on me. Sounds work on me. And if you add all the other things, then they think yes no, she has to go to a mental institution. So it is hard.’ (Participant 3, female, chronic widespread pain, 3 years)

‘...so I think at this stage I take the pain as it comes, but I do nothing extraordinary, how can one say? Outside my comfort zone ... I do everything inside my comfort zone.’ (Participant 10, female, chronic widespread pain, 7 years)

‘...most of the times I will say no, I do not want to go here or there this evening, nor go out for a while. Then I will say, let me stay at my home, before I am in pain, I am a little bit, then I don’t want to be talkative and you know socialise.’ (Participant 13, male, CLBP and right leg pain, 4 months)

‘I do not easily go somewhere, because if I am going to sit down with someone or visit, I cannot sit for long.’ (Participant 2, female, CLBP and left leg pain, 4 months)

## Unpredictability

‘...it is unfortunate in my experience with fibro that it varies, I can feel good now, but a half an hour later I want to say just let me go, I am going to my room and I am putting the ‘Gone Sailing’ sign up. Do not even talk to me or something...Everything is back and then it is ten times worse than it was, and then you go through hell again for two days, it has flared up and you do not know how or why...The hand is funny, the arms are funny, the shoulder is funny, or I get out of the car funny and I walk two steps, I feel good, or five steps, like a normal person and then suddenly I have to reduce my pace and get the rhythm that my body can do...’ (Participant 3, female, chronic widespread pain, 3 years)

‘I have a new pain every day. Because my pain today...like today I have pain in my back and my feet, but tomorrow something else will hurt.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...as I do different activities the pain changes.’ (Participant 1, female, CLBP, 8 years)

### 4.2.1.5. Occupational consequences

Chronic pain also caused work-related consequences for participants. Pain was reported to have an effect on efficiency and productivity at work. Some participants had left their job or retired early because of the pain. Work-related factors acted as barriers to pain management, such as employer attitude and type of work. Additionally, recurrent flare-ups disrupted the consistency of work ability, which resulted in some participants reporting a fear about job loss and future financial insecurity.

‘...at work, because I have to be on my feet all day, there are times I cannot help people and I have to delegate from the counter. And it goes against my grit as the person I am. If somebody reports me then they have to report me, but what should I do?’ (Participant 6, female, chronic widespread pain, 3 years)

‘I try not to let it influence my work, but I have to be honest, it does influence my work. I will sometimes hide it from them and not tell them that I have pain, I will just

get quiet, but I am doing things slower and sometimes it feel like they, they think I am lazy or that...and sometimes I forget things too.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...I have to think at work before; I will pick the low things up last. I would rather do everything that is hip height and everything that is necessary. At work I have to remind myself all the time that I work with people; I cannot, for example, take it out on you when I have pain. I will also, you will notice that I am not taking my files out at the end of the day simply because it hurts too much to bend. I would rather avoid it.’ (Participant 11, female, chronic left hip and leg pain, 2 years)

‘...I feel that I cannot even get up in the morning because it is too painful. I do not want to go to work because it is too painful...I cannot carry things around at work. And to sit in front of a computer, yes, it makes it worse to sit in front of a computer all the time.’ (Participant 10, female, chronic widespread pain, 7 years)

‘...it is very hard for me to find a balance between the fact that I have stopped working because my body just couldn’t take it anymore, the posture, but now I have less money...I do not work at the moment, because we are trying to save my skeleton by not having to sit so much. But because I do not work, I do not have a salary anymore and there is less cash flow.’ (Participant 1, female, CLBP, 8 years)

A few participants reported that their employer was supportive or that their working hours were slightly flexible, which was a facilitator for their pain management; however, some participants also reported a lack of employer support.

‘Time, well I generally have time. If it’s severe, I will make time, so my work is fairly flexible in that sense. (Participant 5, male, CLBP, 11 months)

‘So I try to take leave as little as possible, but if I can’t then I will take leave and they will understand.’ (Participant 13, male, CLBP and right leg pain, 4 months)

‘...my boss said it was either the one or the other and then I had to choose to stay at work and not complete the physio...’ (Participant 6, female, chronic widespread pain, 3 years)

#### 4.2.2 THEME 2: Disrupted identity

CMSP changed and disrupted the participant’s identities and roles and responsibilities. This disruption was mediated by the psychological and emotional consequences of chronic pain. Participants reported they experienced themselves as being different to what they used to be. Problem of maintaining a normal family life in the presence of replacing valued roles at home and disruption to social roles were mostly challenging for the female participants. The complex relationship between identity, roles, responsibilities and the psychological aspects of chronic pain was reflected in the following statements:

##### 4.2.2.1 Disruption of identity and psychological aspects

‘I am a waste, because I cannot do anything now; I cannot be a mother, I cannot be a woman, I cannot be a housewife; I can’t even cook. I cannot even make a sandwich. I have to lie on the counter, just like I am lying here...’ (Participant 6, female, chronic widespread pain, 3 years)

‘...I am a little short-tempered and all the things at home, so I think I have a bit of negativity on myself.’ (Participant 13, male, CLBP and right leg pain, 4 months)

‘...when I go for a walk and I end up you know, really being sore by the time I get to the end. You know pain, it doesn’t exactly put a smile on your face...it’s really affected me in the sense that I’m more grumpy...’ (Participant 9, male, CLBP, 34 years)

‘I cannot play with the little one. She likes playing with strangers and my husband explains that it is because I do not play with her and she knows that they can play with her. Thus she likes them more and she prefers them to me and I am also never at home anymore, because I work all the time. So yes, to be comprehensive, it affects every other aspect.’ (Participant 6, female, chronic widespread pain, 3 years)

#### 4.2.2.2 Disruption of roles and responsibilities

‘...my son said to me the one day, Mother, it hurts me a lot because mother isn’t the mother that you used to be. And it was like knife stab in my heart. But he didn’t mean it like that. He meant it out of fear, out of lack of power and to see the woman that he was seeing isn’t really his mother anymore. And that is a fact, it is true. Because sometimes for myself when I look in the mirror and I think back, I had to create a different person and a different life and a different brain and everything different to experience all of this thing more. Because I walk differently, I sit differently, I sleep differently, I bath differently, I comb my hair differently; I drive my car differently.’ (Participant 3, female, chronic widespread pain, 3 years)

‘So this is frustrating for him, because I think and I mean now, then he cannot do the things that he planned to do, because now he has to take my role up as well. So it is frustrating for him too.’ (Participant 8, female, chronic headaches, 29 years)

‘...then I call my husband and say okay you have to quickly do this, quickly do that, I forgot this. I have to delegate. So I sound like this horrible monster at home who sends my husband up and down. He is fed up with me because I treat him like a slave.’ (Participant 6, female, chronic widespread pain, 3 years)

### 4.2.3 THEME 3: Knowledge and beliefs about chronic pain

#### 4.2.3.1. Understanding pain

The participants communicated a need to understand the cause of pain and the reason for its persistence. Most participants communicated a structural understanding of pain and a few participants referred to it as an illness. The persistence of pain, lead to questions about cancer and, in some cases, the uncertainty of the origin of the pain, left the person confused. Although participants expressed their pain within a biomedical model they also required recognition and understanding of the wider effect of the pain on their lives.

‘...now I have gout with the fibro. Now I don’t know anymore. Then I get completely and absolutely confused if I have pain and swelling. Because I don’t know if it is the

gout that causes swelling or is it the fibro that causes swelling...’ (Participant 3, female, chronic widespread pain, 3 years)

‘Well, I mean any suggestion that it’s a degenerative disease. I know one thing is for sure, that I’m not going to get any younger. So one assumes that as you get older, it will get worse and worse, you know?’ (Participant 9, male, CLBP, 34 years)

‘He said to me it is the only thing that makes sense for him with the symptoms that I have and what he experience is trochanteric bursitis and I mean he did not ask me what other doctors had said to base his opinion on it...’ (Participant 14, female, chronic bilateral hip pain, 5 years)

‘And it has an impact on you as a person you know? And then now if you sometimes walk funny or stiff, then you walk strange, you feel like a baby elephant and then it is chaos with your brain. And then many times, then you feel that you do not understand why this thing came on your path...and then in general you sometimes just sit and wonder why it happened to you.’ (Participant 3, female, chronic widespread pain, 3 years)

‘I am paranoid already, because what is this? I have asked them to test for me if it is cancer, because why the hell am I constantly paining? It is abnormal to pain the whole time. I am 30. I still have 30, 40, 50 year ahead of me and it’s only getting worse. So how am I going to be at 50? ...it is not normal. There aren’t other people of my age around me that I can see that permanently moan about everything.’ (Participant 6, female, chronic widespread pain, 3 years)

#### 4.2.3.2. Sourcing of information

Participants tried various options for finding about their condition in an effort to understand their condition and in search of treatment options for their pain. The Internet was a popular information source. However, their comments indicated that the answers they were seeking were still eluding them.

‘I have read up about it, yes and I have spoken to a few people that also have it.’

(Participant 10, female, chronic widespread pain, 7 years)

‘...I Google these things a lot, although Google is not my doctor, but I like to read about it and to watch exactly how those joints work and where is the place where they inject to make it better and to try and figure out how it looks to maybe understand which movements I can do. It is difficult if you don’t have the knowledge.’

(Participant 1, female, CLBP, 8 years)

‘...or you grab your iPad and sit through the night on your iPad and you read all sorts of sites and things and through other people’s things to see if it is so. Or yes, you try to, I assume like other people with a chronic disease or with cancer or something. There is no medication, they don’t talk the truth, or maybe this people have the right ointment or lotion. And at the end of the day it is just bogus. You waste your money. Especially those that are over the Internet and that are overseas.’ (Participant 3, female, chronic widespread pain, 3 years)

‘So it is not enough to justify that there is now big fault. Then I say okay fine, it’s not making sense. You say everything in my body is fine. And then later I am at my wits’ end...I read up by myself, because I’m trying to find an answer, but it just feels to me that people doesn’t want to look further.’ (Participant 6, female, chronic widespread pain, 3 years)

#### 4.2.3.3. The importance of believability/credibility

The lack of a satisfactory explanation and understanding of participant’s pain meant that they felt at risk of not being believed. Participants reported ongoing unresponsiveness to treatment that raised perceptions of them imagining their symptoms and of the symptoms being all in their minds. Some participants highlighted the biomedical nature of their chronic pain to try and justify that their pain was real. Without a valid explanation for their pain, the participants’ belief in diagnosis, treatment and cure was disturbed, driving feelings of anxiety facing an uncertain future.

‘...if one has pain, then you tend to think that people are going to think I am exaggerating. I cannot be here for the same thing again. But later you sort of ignore the warning signs that you have, like burning pain and all those things, because you think one is supposed to be strong. You are supposed to take it. You cannot show your weakness here. You must be able to take it. Everybody has pain, whether its backache or headache or a toe that pain or something. Everybody has pain in life. But it feels for you that sometimes you are alone in your pain.’ (Participant 1, female, CLBP, 8 years)

‘...on the outside with fibro, you look like a normal person, and I think it is the fastest where they, where people can be very cruel. And even in the beginning too, now it is terribly hard for me, to process it by myself, because I just thought what devils are this? No person can have these things; they are really going to think that you are crazy.’ (Participant 3, female, chronic widespread pain, 3 years)

‘...the physio asked me, ‘why are you limping again? The pain is in your head’ ...then I thought, you know what, that was a terrible remark; I would not have made it, but that’s okay. If my pain is in my head, I have to be able to control it in my head. Sorry, it does not work that way...’ (Participant 11, female, chronic left hip and leg pain, 2 years)

‘...at one time it was so bad that the guy gave my medication for my head. He said ‘it is all in the mind’.’ (Participant 12, female, CLBP and coccyx pain, 8 months)

‘...she had this unfriendly face, like how dare you interrupt my day for this? And I have already been there with not so great space of mind. And I think for any physiotherapist to go to a psych ward already says that I am not in favour of the patient lying in front of me, because the woman is not right in her head.’ (Participant 6, female, chronic widespread pain, 3 years)

‘But I mean I cannot prove it, so they are going to laugh at me if I say that my left hip is swollen and painful.’ (Participant 11, female, chronic left hip and leg pain, 2 years)

#### 4.2.3.4. Participant's expectations

Participants mostly approached their primary care physicians as gatekeepers to the HCS, with the expectation that their pain would be relieved and the cause diagnosed.

‘...because I am always a nagging person, if I have pain then I won't keep quiet, I will say I have pain, I have so much pain and then I will go somewhere, then I will go to the doctor, because I cannot see why you should sit with the pain if it can be fixed.’

(Participant 12, female, CLBP and coccyx pain, 8 months)

When their pain was not relieved or a cause or diagnosis not established, many participants became disenchanted with their HCP and the HCS. A subgroup of participants believed that physicians did not understand their pain and that they had a disbelief regarding their pain.

‘Which was quite frankly a waste of money as far as I'm ... I mean maybe doctors don't understand, I mean doctors I know have got their particular responsibilities but the patient's responsibility is just to want to have relief from their pain.’ (Participant 9, male, CLBP, 34 years)

Participants reported receiving conflicting information from different HCP and this caused participants to search for an answer or explanation for their pain. When this need of the participants was not addressed then they kept on searching for an answer or cure.

‘I tell you because every day there is another vulture and another thing, I really have too many things, and every single day there is something new...and the other day I said that I wish I can find someone who tells me that is wrong, that's wrong and that's wrong, and we are doing this and that is gone, that's gone and that's gone, then I am going to be happy because then everything is gone.’ (Participant 12, female, CLBP and coccyx pain, 8 months)

#### 4.2.4 THEME 4: Health care system factors

Participants sought opinions from a range of different HCP in the hope of finding a solution for their pain. Almost all of the participants only had consultations with a physiotherapist,

general practitioner and/or an orthopaedic surgeon. Many participants expressed that they wanted physicians to communicate with each other more and they found it desirable to secure a referral to a specialist, although it involved delays and exposure to dissociative care.

#### 4.2.4.1. HCP consulted

‘...I have seen the family doctor from time to time and then he would prescribe pain tablets and physio. Physio was always part of my treatment...medication and I saw an orthopaedic surgeon for the first time in 2010 about my back.’ (Participant 1, female, CLBP, 8 years)

‘I am like I say desperate at this stage and I told her, I know I had to get to a physio, just to complete the circle, because I went through all other options, the last link was to get to somebody that looks at the rest of the body...’ (Participant 6, female, chronic widespread pain, 3 years)

‘I also made a turn at the psychologist, because at a stadium, in the winter last year, it was really terrible for me.’ (Participant 3, female, chronic widespread pain, 3 years)

#### 4.2.4.2. Disjointed pathway of care

‘A few different physios. Acupuncture. And then I also went for tests, I got sent by the general practitioner, my family doctor sent me for tests. There were a few different doctors. I was at the brain doctor; I had a CAT [computed tomography] scan, scan for my back and my neck.’ (Participant 10, female, chronic widespread pain, 7 years)

‘I was at a general practitioner when he referred me to an orthopaedic surgeon and then he sent me for the MRI [magnetic resonance imaging] scan...I have to go to a physio and if it gets a lot worse than he will send me to a spinal surgeon, and I was at the chiropractor who did a bit of dry needling and it was very traumatic for me.’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘...took some tests and then I went to see the physician again and the physician said oh, I think you should see this person, and I thought, no you know the medical profession are just making money out of me, and with all those things I had, I got no relief whatsoever.’ (Participant 9, male, CLBP, 34 years)

#### 4.2.4.3. Appropriate referral

‘...perhaps he would then just refer me to somebody else, but I don’t think he was a back specialist, I think he was just a hip and knee...’ (Participant 5, male, CLBP, 11 months)

‘So I have seen three doctors already and then he sends me back to this one to make sure that what he sees is correct, so then I go back to him, then he will go back again and then it is four doctors later...’ (Participant 12, female, CLBP and coccyx pain, 8 months)

‘I do not like to mix physios, just as I do not want to go to a doctor today, next week to another and the week after to another. I like to stay at one practice, because they know my history. They already know it is my back of my neck or my shoulder blade. They know what I am going through, they know, they know me as a patient. I like to stay with people who know my situation.’ (Participant 1, female, CLBP, 8 years)

#### 4.2.4.4. Waiting times

‘...if you go to the Cape to a doctor, usually those people with this type of thing are very busy, then you feel awful, and nothing can be done for you, because for arguments’ sake you have to wait for another two weeks to see her...’ (Participant 3, female, chronic widespread pain, 3 years)

‘...physios are full a lot of the times and for example in the morning when I wake up and I feel oh my, something is really wrong, it burns and it hurt so that I cannot stand it, then it is only three, four, five days later that I get an appointment. That is the only thing that is bad for me.’ (Participant 1, female, CLBP, 8 years)

#### 4.2.4.5. Continuity of care

‘...you have to stay the course, so you have to stick with the type of treatment, and often the person as well. So as far as the physios were concerned, I think the problem with the physios was it was between Langebaan and Vredenburg, so I would see a new physio every time I went, so there was little continuity between them.’

(Participant 5, male, CLBP, 11 months)

‘...the nice thing about seeing the chiro was that it was continuous and it was one person, and it did bring relief...’ (Participant 5, male, CLBP, 11 months)

#### 4.2.4.6. Cost of care

Cost of care remained a concern for the participants. Participants reported less concern when the cost was covered by their medical aid. Other participant’s medical aid did not cover all health care services or funded it only partly. In some cases, the participants’ medical aid was depleted before the end of the year. These participants reported that funding limitations were barriers to access to care, and they reported that they either stopped this therapy or had to make adaptations to access the care.

‘...because he referred me to the wrong specialist, he actually exhausted my medical aid, because when I got to the other specialist, then he said listen here, it is definitely my neck and not my arm that is the problem and I had to, my medical aid is big, I had to make big contributions, so my medical aid was exhausted in January, where if people referred me to the right specialist I could have gotten easier or better advice...’

(Participant 2, female, CLBP and left leg pain, 4 months)

‘...money, the medicine that makes a difference is very expensive...’ (Participant 1, female, CLBP, 8 years)

‘...I cannot do physio anymore, because it is too much money...’ (Participant 3, female, chronic widespread pain, 3 years)

‘...the medical aid that I am on for example does not pay for physiotherapy. I don’t get physiotherapy with them. So it does affect the costs. So you are pretty limited to how many sessions you can do...’ (Participant 4, female, CLBP, 1 year)

‘...my idea is now to see that I do it one week, skip the next week, just because my finances can cope better with it...’ (Participant 2, female, CLBP and left leg pain, 4 months)

#### **4.2.5 THEME 5: Interactions with health care providers**

HCP who were primarily involved in participants’ medical management were physiotherapists (n=14), general medical practitioners (n=11) and/or orthopaedic surgeons (n=10). A few participants had consultations at a chiropractor (n=4), neurologist (n=3), biokineticist (n=2), reflexologist (n=2) psychologist (n=2), rheumatologist (n=1), pulmonologist (n=1), ophthalmologist (n=1), acupuncturist (n=1), homeopath (n=1), psychiatrist (n=1) and/or a nurse (n=1). There seemed to be a growing lack of faith in HCP as participants described how they were passed from HCP to HCP with little resolution. Participants described feelings of frustration towards health care professionals who could not fulfill their expectations of a pathway that included a credible explanation for their persistent pain, diagnosis, treatment and a cure.

##### **4.2.5.1. Provision of information (inadequate)**

‘...I didn’t even really know at that stage what a rheumatologist did...the woman evaluated me, asked questions and I told her. In the end she said I had fibromyalgia and she placed a booklet in my hand which didn’t have a lot of inscription in it...Then she prescribed medication and said I have to go to a doctor at home, because she was in the Cape. It is difficult...it was the new medication and I have to adapt by myself and what was happening with my body, and I have this terrible things...’ (Participant 3, female, chronic widespread pain, 3 years)

‘... I have to wait for another three months...after three months you are going to say sorry, it’s mechanical, you are fat, you need to lose weight, see the physio, do exercises, great stuff, there you go; you’ll be sorted. And then I asked the physio and

her orthopaedic surgeon replied and said yes, that's basically it. It's mechanical...and with the added note, cherry on top, your brain is screwing you over and it lies to you.' (Participant 6, female, chronic widespread pain, 3 years)

'...I came to see the physio and she helped me a lot. She gave me such a booklet to read through to understand a little more of the pain and everything and it really helped.' (Participant 7, female, chronic widespread pain, 3 years)

#### 4.2.5.2. Clinician attributes and attitudes

Participants reported that the positive attributes and attitudes they were looking for in HCP were compassion, empathy, respect, friendliness, honesty, approachability, accessibility and good communication skills. They also wanted the HCP to give their full attention, put in effort, make time for their patients, do a thorough evaluation, ask questions, explain processes and findings and be well educated and knowledgeable. Participants also illustrated the value attributed to the clinician being a skilled listener, even if the problem could not be solved.

Participants also reported negative attributes and attitudes of HCP. They described the HCP as abrupt, heartless, poor-mannered, apathetic and untrustworthy. Participants reported that HCP did not listen to them, did not answer their questions or discuss participants' expectations. The HCP also did not keep to their promises, they did not make follow-up appointments and they did not want to get involved with participants' care. Participants thought that some providers did not understand their pain or that the providers did not believe that their pain was real, but that they were imagining their symptoms. Some HCP could not convince their patients about the effectiveness of their intervention and the participants did not get relief as a result of their care. Participants also reported that some practitioners had limited knowledge about their condition and that they were lacking in resources and skills.

#### Positive attributes and attitudes

'...compassion for the patient is so important and you are not going to go to a physio or doctor because you want to pass the time. You only make the effort if it feels...you are going to try it, because you do not really know what else you should do. So I think

if they can understand or try to imagine how it should feel and they can have a softness for you without losing strictness...if you can have someone who has compassion for you, and who really makes you feel you know what, you are the only one with pain today, I will give you all of my attention, then you feel so much better about it, because it already has an influence on your personality. It affects your self-esteem. It affects how you think other people see you.’ (Participant 1, female, CLBP, 8 years)

‘It was a very nice physio...these people actually put in a lot of effort, asked questions, made time and made sure that you...go through the case and if I have questions then I can ask...she explained everything, really set out...’ (Participant 6, female, chronic widespread pain, 3 years)

‘I must say I will forever be grateful for his honesty and I think he is a stunning doctor...he was very honest with me throughout the process. And I think it had, the fact that he was so honest and did not hide anything from me for a moment, I think it brought a bit of reality home...it takes away the anxiety. Because the more pain you have the more anxious you get. And I think it helps. It does not take the pain away, the physio told me that she would never be able to take the pain away, but she would help to make it less.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...I have full confidence in the medical team that treated me...at the moment I am pleased with all the treatments that I have received...I was very happy with the doctor here. And with the physio ... she actually goes that extra mile with me and I can see it and what I really want to brag about her is... she referred me to the orthopaedic surgeon and I want to remember correctly, when I returned to work, the same day after the appointment, I got a text from her: ‘What does the doctor say?’ (Participant 13, male, CLBP and right leg pain, 4 months)

‘He makes you feel comfortable and makes you feel you know, the guy actually knows what he is talking about. And he never made me feel uncomfortable or anything, so it was actually very nice.’ (Participant 14, female, chronic bilateral hip pain, 5 years)

‘...I also got the idea that he really does not know, he could not really say you know, what is wrong... But he wasn’t impatient or disregard[ed] me he listened to what I said.’ (Participant 11, female, chronic left hip and leg pain, 2 years)

### Negative attributes and attitudes

‘...and he just said to me mind over matter, no matter how painful it is, you should take it and make the best of it...and I was like really? I have so much pain and that is all you can say to me?’ (Participant 7, female, chronic widespread pain, 3 years)

‘But I also got the idea when I went back to him that he just wanted to get rid of this woman. He did not really have time. He also didn’t have any notes, nothing... So I did not return. I really felt he did not do his part...one wonders quite occasionally, what is wrong? Didn’t something tear off or shifted down or what is really wrong? But now I also have to tell you that my trust in – I don’t know. I will not go back to the same doctor unless it is he is allocated to me in an emergency, but not straight off. I don’t know if it was necessarily his conduct, but it is still painful, do you understand?’ (Participant 11, female, chronic left hip and leg pain, 2 years)

‘...then I said to her great, what is range of motion? She told me that she would bring me pamphlets. I am still waiting for pamphlets. So obviously she did not feel there’s any level of importance, which I am fine with, if I do not register on her important scale or if she has really been just too busy, somewhere she must have kept record of seeing a patient, somewhere you still have a follow-up record to say I never went back to the woman...also if it is a doctor’s opinion, because he does not want to look further, because it is trouble. Or I explain something to him that I do not understand; that is why I don’t go to a doctor, not because I do not want to. It’s just a case for me; I just felt later that there is not a doctor or nurse who listens anymore. I do not want to go around between doctors, because then you are a weirdo...’ (Participant 6, female, chronic widespread pain, 3 years)

‘...I returned to the rheumatologist and I had a bad... I made an appointment, you have to wait a long time for the woman because she is very busy. And then I got there, then I got my pain drip, that is the cortisone drips, then she just said no, she has to go

somewhere else, she cannot see me now, and I drove all the way and all of that, and yes, now I have just decided that I will not go back to her again, because it does not help me. And now I have changed my doctor as well, because when I had to get the cortisone drip, then she arranged with my doctor, and then the doctor told her that she does not want to get involved. I cannot go on with such a doctor.’ (Participant 3, female, chronic widespread pain, 3 years)

‘And that didn’t last hardly any time at all. It was a very short time and he sort of shrugged his shoulders and he said well you know, there’s only 80% chance that it will work. And I thought well, that’s not very satisfactory.’ (Participant 9, male, CLBP, 34 years)

‘...I just think what is going on with fibro, the whole world is still so uncertain that they really fumble to see what they have to give you...’ (Participant 3, female, chronic widespread pain, 3 years)

#### 4.2.5.3. (Lack of) patient-centredness

Participants reported a lack of patient-centredness due to HCP not being responsive to their needs, a lack of communication, compassion and empathy by the HCP and no therapeutic alliance between the patient and providers.

‘...he told me I am the doctor, lie down...his exact words were you are lying on my table because of the way you look...’ (Participant 6, female, chronic widespread pain, 3 years)

‘But he couldn’t tell me how many anchors he has put in my leg, did he repair the labrum? How big was the tear? He couldn’t answer those questions. He actually said to me that I should swim in my heated swimming pool at home, which I don’t have. He has said that three times and each time I corrected him. Then I thought you know what, if you lack so much interest, rather leave it.’ (Participant 11, female, chronic left hip and leg pain, 2 years)

‘I wasn’t looking for you know, tests and things that went on ad infinitum without getting any relief of pain.’ (Participant 8, female, chronic headaches, 29 years)

‘Has already been through the rigmarole twice, just not in the mood anymore. Because it does not go anywhere. There is nothing. There is nothing they can say or do or give to you...’ (Participant 10, female, chronic widespread pain, 7 years)

‘...all of my previous physios were those people who had been in the industry for a long time and kind of already, you’ll get over it, you’ll survive it kind of attitude, which made it difficult for me, because later you literally feel you are just another one on their schedule, because they have to see you, they have to work with you and they must tick you off.’ (Participant 6, female, chronic widespread pain, 3 years)

#### **4.2.6 THEME 6: Management of CMSP**

Use of medication to manage pain was very common, with participants highlighting concerns around ambivalence about taking medication, fear of dependency, side-effects and the physical and emotional consequences that the medication has on them. Many participants expressed discontent with the lack of alternative treatment for pain management and often discussed how they used over-the-counter and prescription medication to cope with pain and to function in everyday life. Participants discussed the stigma attached to using pain medication. They expressed frustration and discomfort at being treated suspiciously by HCP such as when being restricted to a certain number of pills per month. While many of the participants defended their medication usage, they also expressed concerns about dependence and long-term medication use was interpreted as highly problematic. Participants reported their fear of dependency and the difficulty they had to weigh up the costs and benefits when considering whether or not to take the prescription medication. The immediacy and suffering associated with pain exacerbations sometimes left medication as the only apparent option. Some participants preferred either not to take any medication or to make use of coping strategies, personally derived postural adjustments and/or topical treatments and non-pharmacological options.

#### 4.2.6.1. Interventions received and patient perceptions about these

Participants shared the type of interventions they received during their journey through the private HCS. They discussed the effectiveness of these interventions and relayed their perspectives and beliefs about the interventions received. Interventions received were listed as special investigations, pharmacological management (medication), physiotherapy and exercise. Participants communicated a firm belief in medical technology (X-rays, computed tomography (CT/CAT) and/or magnetic resonance imaging (MRI)) as a means for presenting a definitive diagnosis.

#### 4.2.6.2. Special investigations

‘...I had a lot of scans, had a lot of CT scans, I had scans of the heart...everything comes back that everything is fine.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...I was never tested, I was not X-rayed, nothing...’ (Participant 1, female, CLBP, 8 years)

‘...Scans, X-rays and MRI scans and all that sort of thing. And he also did all sorts of things and he did blood tests and so on...’ (Participant 9, male, CLBP, 34 years)

#### 4.2.6.3. Medication

Participant’s conversations focused strongly on medication: effectiveness, access to, conceptions of, usage and side-effects. The participants communicated their reliance on analgesics for pain control, despite their acknowledgement about the lack of effectiveness of analgesics. Participants did not always have access to medication with a high scheduling status, but even if they did have medication, they did not use it regularly. A subgroup of participants believed that analgesics gave them some sort of relief, but it did not take the pain away. The rest of the participants believed that analgesics did not work for them and taking the medication was a waste of time. The side-effects commonly reported were constipation, stomach pain, sickness and withdrawal symptoms when they stopped taking the medication.

##### Effectiveness of analgesics

‘...then I throw a pain pill down my throat that can give a bit of relief for the day, then I can do my work all right...’ (Participant 13, male, CLBP and right leg pain, 4 months)

‘And also with medication, I find that it helps, but it doesn’t solve anything.’ (Participant 5, male, CLBP, 11 months)

‘...no matter what doctor you see. Look here is a Panado, there you go. Here is a muscle relaxant, there you go. And you talk to them and you are like please, understand, I am really in serious pain. I am not looking for a temporary solution; I don’t want this pain again...I can drink five Tramadol with so many Brufins and Panados in between just to see if that concoction does not work better. It does nothing. Absolutely nothing... They have prescribed sleeping pills for me to rest, to switch my brain off...there is no pill that can take it away. There is also no pill that can make it lighter. So, in my opinion, it is not somewhere that the chemicals are working.’ (Participant 6, female, chronic widespread pain, 3 years)

‘...the permissible medicine is also not always sufficient. I have asked him many times if there isn’t something stronger. If there is nothing better, then he says you are on the top of the range. I cannot give you anything else... I have used prescription medication and then I feel it does nothing. It really does not help and I will not ask for it again... I am very careful to buy something over the counter if I do not know for a fact that it works, because you may buy something that does not work and you only hurt your body or your stomach...’ (Participant 1, female, CLBP, 8 years)

### Access to analgesics

‘...the medical aid says no after the third month; you cannot get it again. You now had three months of it; you have to wait now. And it doesn’t work for me, because my pain doesn’t go away. The pain doesn’t go away in the time that I have to wait, until I can get pills again.’ (Participant 1, female, CLBP, 8 years)

‘He told me I was going to have withdrawal symptoms, he told me he would not inject me with Pethidine anymore, they are no longer going to give me Cyngem, they will no longer give me any more Lyrica, they will no longer give any of those things. They are just going to take everything away. All that I am going to get is Perfelgan that I call Panado water...’ (Participant 7, female, chronic widespread pain, 3 years)

### Conceptions about medication

‘...many people think pills help. Pills do not help. Pills do not help. Pills are poison. I have found out the hard way that pills are poison... I was on Cyngem and Lyrica and I was on Pethidine, strong, good stuff that’s poison. I never want it in my life again.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...at a stage I drank faithfully until the packet was finished and then I would ask again, but I left it, because it seemed to me almost like, I cannot say addiction, but it was as if I was afraid to become dependent on those pills to feel better and I did not want it. I started testing how it is to live without the pills... I just feel like going home with a bag of pills and now it is my rescue, it feels wrong to me. It does not feel right to me. I don’t feel that I want to shut my life off like that and it is actually my own choice that I make to not use the excess pills. At the moment the pills that I drink do not justify the small amount of time without pain...’ (Participant 1, female, CLBP, 8 years)

‘I feel like throwing that bag of medicine into the trash and maybe to be without it. Maybe I am better off without the things and they all just talked nonsense, I don’t have that thing, but then it is two days and it is the fastest that you are grabbing the bag of medicine again.’ (Participant 3, female, chronic widespread pain, 3 years)

‘...I was for one week without those pills. And the pain was absolutely unbearable. So those sort of suppress the pain a bit, and I have to say that I immediately felt my emotions run up and down and I am crying a bit more and I am depressed...’ (Participant 7, female, chronic widespread pain, 3 years)

Using medication

‘...I don’t want to have to take any more pills. I tend to keep away from medication if I can help it at all.’ (Participant 9, male, CLBP, 34 years)

‘I do not drink any of the pills that they gave me. It’s in the closet, if I feel it’s too bad then I’ll drink it. But I try not to drink it every day.’ (Participant 10, female, chronic widespread pain, 7 years)

‘I have a bag full of pills that I carry with me for incase there is a next time that there is pain somewhere because I constantly hurt. I am at the point of drinking water when I hurt because people have told me it’s toxins that cause headaches and I have been through the whole herbal setup, I have been through the whole water setup, I have been through eating all of those things, nothing is working.’ (Participant 6, female, chronic widespread pain, 3 years)

Side-effects of medication

‘...anti-inflammatories I can’t really do because of my stomach, it hurts my stomach.’ (Participant 5, male, CLBP, 11 months)

‘...he told me, but the only way he can help me is to stop all medication now and start from scratch...I became addicted to all the medications...without wanting to do it because I did not even drink it as they told me I should drink it. And it was quite bad, those withdrawal symptoms were hell. I never want it again. Now I know how druggies feel...I have to deal with the pain or I have to go on the medication again, and every day I relapse because it doesn’t work. Because I get all the side-effects.’ (Participant 7, female, chronic widespread pain, 3 years)

‘...inflammatory pills and strong pain pills, but with the strong painkillers, I can only drink it in the evening and then even the next day, it makes me feel terrible...’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘...the pain medication makes you sick later on; you get constipated, what I had before I had fibro. Now it makes it ten times worse...’ (Participant 3, female, chronic widespread pain, 3 years)

#### 4.2.6.4. Exercise

Some participants used to be very active and exercise was part of their lives. It was very frustrating, annoying and heartbreaking for them when they had to limit or stop exercising due to an increase in their pain behaviour. A subgroup of participants did not exercise at all, due to fear of pain exacerbation. A few participants tried to exercise to break the cycle of dependency from seeing HCP, but the exercises did not decrease the pain or take the pain away and thus they stopped with their exercises.

##### Effectiveness of exercise

‘...exercises...how to relax. And I have to say, like last night when I had a lot of pain, I tried it. It did not work.’ (Participant 6, female, chronic widespread pain, 3 years)

‘...I mean, obviously there is no exercise that I can do to decrease it or to take it away...’ (Participant 14, female, chronic bilateral hip pain, 5 years)

‘One thing that hasn’t helped, or one thing I should have done more of, or they perhaps should have recommended more, was a greater, an exercise routine that might alleviate the situation. So ways of...in the long term...of breaking from the cycle of dependency from seeing these practitioners...’ (Participant 5, male, CLBP, 11 months)

##### Fears regarding exercise

‘...if I am going to do twenty sit-ups now, what if I do not get up? I predict that I am not going to get up before I try. Because you are afraid it will happen.’ (Participant 1, female, CLBP, 8 years)

‘Like the other evening they went ice skating and I could not, I did not want to because I did not want the pain the next day.’ (Participant 7, female, chronic widespread pain, 3 years)

‘Like sports and stuff; I am not keen to go walking, keen to do sports or keen to do anything, because I know I am going to have severe pain the next day and I know my head is going to be severely painful and I am not in the mood for it.’ (Participant 10, female, chronic widespread pain, 7 years)

### Influence on ability to exercise

‘It is terrible... the pain too, many days I come here and I just cry for nothing. I know it affects me, the thing that I love the most, it is my cycling that became such a passion for me. I have built up to something that I can do and now it feels that it is going to be taken away from me.’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘To me at this stage, it is very frustrating. Terribly frustrating, because before this I was always very active...’ (Participant 4, female, CLBP, 1 year)

‘My sort of relaxation time is mostly exercise, so it does affect that a lot...’  
(Participant 5, male, CLBP, 11 months)

‘...it does affect my exercise. Because I am a walker and I cannot anymore. So it annoys me sometimes. I just have way too much pain tonight so I will not do it...’  
(Participant 11, female, chronic left hip and leg pain, 2 years)

#### 4.2.6.5. Physiotherapy

Although most participants had a great appreciation for physiotherapy treatment, some participants did not find value in physiotherapy. Participants’ expectations about the effect of physiotherapy focused on their need for pain relief. When pain relief was not achieved, satisfaction with physiotherapy was low and vice versa. A subset of participants communicated that physiotherapy was helpful when the physiotherapist promoted feelings of

mutual understanding and recognition, incorporated individualised care and gave clear explanations and reassurance.

### Appreciation for physiotherapy

‘I attach great worth to physio...it really works for me. I cannot imagine life without physios... If one removes treatment, physio treatment; I do not know what will happen to the ill. Medication helps, but treatment is more important to me than pills. A pill can clear or improve inflammation, but I believe the blood supply that gets stimulated by physio that works with her hands, or when the machine is doing its work is much more precious to me than when I just swallow a pill. A pill is so artificial to me, it’s such an empty thing for me, where treatment is in touch with my body and with those muscles, and with that, let’s say that where that burning pain is or if that area gets worked on and it gets warmed and it is rubbed and everything that gets done to it, it is worth gold to me compared to a pill.’ (Participant 1, female, CLBP, 8 years)

‘Where physio again, if I go once, then I can feel the difference right away. After two times of treatment I feel that I can drive far again and I don’t have pain anymore.’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘And I think my sessions at the physio also helped a lot. Wonderful insight and the way they talk to you and the other physio that did his acupuncture and the way you feel when that pain withdraws from your body; it does not take it away, it makes it less.’ (Participant 7, female, chronic widespread pain, 3 years)

‘But if it gets too painful, then I go for physio, because it feels for me, because it helps, it makes the pain less.’ (Participant 12, female, CLBP and coccyx pain, 8 months)

‘And the physios explain that here is this and there is that and this is less and that is more and this is what the inflammation does when you get hurt and then it gets swollen. There are several reasons, so you know those basic things, but I still think as a layman you know too little.’ (Participant 1, female, CLBP, 8 years)

### Criticism about physiotherapy

Participants were interviewed by a physiotherapist and this could have influenced participants' responses regarding physiotherapy care (positive or negative). However, the researcher only disclosed that she was a physiotherapist when she was asked directly and her personal and intellectual biases were minimised by using open questions during the interviews. According to Creswell (2007:224) potential response bias is minimised when the researcher does not comment in the interviews on past experiences, biases, prejudices and orientations.

‘...I thought I was going to die of pain, but specifically low back pain. And then I went to a physiotherapist for the first time and said it hurts very bad, I cannot move...I went for four treatments. I cannot say it really made a very big difference to me. It might have been a day or two relief...’ (Participant 4, female, CLBP, 1 year)

‘It does not make it any better. It is good for the moment and feels okay for the moment but tomorrow morning I hurt because it sometimes feels like blue spots and I am not going to physio anymore.’ (Participant 10, female, chronic widespread pain, 7 years)

‘...she gave me relaxation exercises, how to relax. I have to say, like yesterday I tried it when I had a lot of pain. It didn't work.’ (Participant 6, female, chronic widespread pain, 3 years)

‘...acupuncture...has worked a lot of the times, sometimes just for a short period of time. And then it was basically self-exercises in a way...’ (Participant 1, female, CLBP, 8 years)

#### 4.2.6.6. Self-management strategies

A few participants implemented self-management strategies, such as exercise and relaxation methods.

‘So all that I can do now is a hot beanbag and if I lie down...’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘...so you handle it, you stand up and stretch a bit...elastic band. So, then at home, for example, sometimes just a little bit of it, funny enough it brings, it takes a bit of the stiffness away...it brings just a little where you can say wow, I just swam or I walked on the treadmill now or whatever. Mentally it makes a big difference.’ (Participant 4, female, CLBP, 1 year)

‘I just try and stay active generally, like I like hiking, I do quite a lot of walking and cycling, mountain biking...Well I have to go and exercise well within my limits...’ (Participant 5, male, CLBP, 11 months)

That is why I am just moving a bit and resting a bit, move a bit and rest a bit. But yes, it affects my sleep. I have learned to take afternoon naps which are so nice...it is nice to rest and I had to learn it on the hard way. It was very difficult for me, because I always felt that people would think I am lazy...’ (Participant 7, female, chronic widespread pain, 3 years)

#### **4.2.7 THEME 7: Hope (or hopelessness) for the future**

##### 4.2.7.1. Fears about the future

‘You feel self-conscious. You feel a bit inferior. As if you still have to be finished. It’s as if the Creator semi-forgot about you. Not that I believe less or something, but you feel sorry for yourself and then you just think, not everybody understand it...other people will say to you for example pack the bull by the horns, join a gym and go. It is not that easy...I have a big fear of ending in a wheelchair one day because of my back. It will be an incredible blow to me. I think to accept it will be very hard. So I would really like to keep my mobility. I cannot necessarily walk marathons or climb mountains; I just want to stand on my own legs. That is the biggest thing; I just want to walk by myself. I just don’t want to lose mobility.’ (Participant 1, female, CLBP, 8 years)

‘I don’t know if I am still on the right track to connect with the right people that can help, but I almost want to say to you that I am not even sure if the exercises will fix this, because it’s not making sense. But now I don’t know if it’s not making sense because it’s literally not making sense, or is it not making sense because I am so tired and fed up and sore and sceptical about it?’ (Participant 6, female, chronic widespread pain, 3 years)

‘So the problem is that over the long term, one wonders to what extent will you ever be okay and ever be hundred percent healthy...’ (Participant 5, male, CLBP, 11 months)

#### 4.2.7.2. Hopefulness

‘I do not want pain every day, but I have pain every day, but to sort of control the pain that it does not take over your life...a lesson that I will take and learn from it. Learn that one has to rest. That you really have to look after yourself and not accept that your body will take care of itself... Tomorrow we will go on again and tomorrow is a new day...’ (Participant 7, female, chronic widespread pain, 3 years)

I wouldn’t say it discourages me, but I laugh when you actually want to cry and I think it is a pity that it has to be like this. I think it is something that I had to accept. And I don’t know if there is a perfect answer or cure for this. If there is then I would really like to know...but you cannot lose courage because it is not going well, because you have pain.’ (Participant 1, female, CLBP, 8 years)

‘So I hope that I will be healed and I would like to run the Comrades rather than just standing around the whole day.’ (Participant 13, male, CLBP and right leg pain, 4 months)

I would like to start exercising again. I would like to run a marathon again. I would really like to do the Foot of Africa. And yes, and then, I don’t know. I think my main goal is to support my children and to do things with them which wasn’t a problem before...I think the fact is to see what it does to my children...it motivates me even

more to overcome that stumbling block.’ (Participant 7, female, chronic widespread pain, 3 years)

#### 4.2.7.3. Acceptance

Participants emphasised difficulties in accepting pain when fluctuations in pain meant continuous adjustment had to be made, leaving them feeling insecure and uncertain, but a few participants took ownership. Coming to terms with chronic pain was difficult for the participants, as it entails accepting its continuing presence while retaining a sense of being active and purposeful. A few participants used self-management strategies that were suggestive of acceptance and adjustment rather than coping, with participants learning to live with the pain.

‘But I think it is a mind shift that you have to make...and just say listen here, no matter how sore it is, I will get up and I will go on...it is okay to be a mother and to have an off day. It is okay if a mother, how do I always say? I thought I am superwoman then I found out I’m just a woman. So it is okay to be just a woman and it is okay to have pain and have an off day as well... You don’t always have to be on the ball; you can fall off the ball from time to time. The children do not always understand it, but I think it only shows to you that you are human. You are not invincible.’ (Participant 7, female, chronic widespread pain, 3 years)

‘And it really cost to delve deep inside yourself, to take out, positive things to cheer you up, because nobody else will do it for you. You just have to do it yourself...because you are in it and you do not have a choice, you try to do the best with what you have.’ (Participant 1, female, CLBP, 8 years)

‘You are going to have to adjust your life according to the problem you have, otherwise it will not happen. Yes, so it makes me very worried because I do not want to do it...’ (Participant 2, female, CLBP and left leg pain, 4 months)

‘...there’s also timing. One has to also watch your own body and you’ve got to be your own, you know your pain, and you know your body, etc. So you’ve got to then take responsibility for getting well and that would entail some kind of independent

action and careful watching of the history of the problem and what triggers it. What is the actual cause, and those are the subtle things that you don't always, can't always see at the time, but could be apparent later on.' (Participant 5, male, CLBP, 11 months)

'...I decided then that if I wanted to do it on my own, then I should do it right. So I started to look what works for me and what does not work for me... So I think the way forward I really want to make a mind shift and to put it outside that box, maybe it reduces the pain. Hopefully. Hopefully. So I don't know; we take it as it comes.' (Participant 7, female, chronic widespread pain, 3 years)

#### 4.2.8 THEME 8: Barriers and facilitators to pain management

The barriers and facilitators to pain management are layered in the themes covered. In this section, a summary of the stated barriers and facilitators are provided in Table 4.5. The section reference for each quote is provided.

**Table 4.5: Barriers and facilitators to pain management**

Theme	Category	Barrier	Quote reference	Facilitator	Quote reference
<b>Influence of pain</b>	Psychological /emotional influence	Lack of involvement of counselors/psychologists in patient journey	4.2.1.3		
			4.2.4		
	Family and friends	Lack of support and understanding	4.2.1.4	Emotional support	4.2.1.4
	Influence of employer	Employer attitude (coldness) Type of work (strenuous)	4.2.1.5	Employer attitude(empathetic) Flexible working hours to allow access to health care	4.2.1.5
			4.2.1.5		4.2.1.5
	Seeking treatment	Hesitant to seek treatment due to unpredictability of pain	4.2.1.4		
<b>Knowledge of chronic pain</b>	Understanding pain	Participant poor biomedical understanding	4.2.3.1	Awareness of holistic nature of pain	4.2.3.1

Theme	Category	Barrier	Quote reference	Facilitator	Quote reference
	Credibility of disease	Unsettled belief in diagnosis and treatment	4.2.3.3		
<b>Health care system factors</b>	Lack of continuity of care	No follow-up appointments	4.2.4.5		
	Cost of care	High cost of care and medical aids depleted	4.2.4.6	Medical aids have funds to pay for costs	4.2.4.6
	Disjointed pathway of care	Participants sought opinions from a range of different HCP	4.2.4.2		
	Referrals	Inappropriate referrals	4.2.4.3		
	Waiting times	Long waiting time to get an appointment	4.2.4.4		
<b>HCP characteristics</b>	Attributes and attitudes	HCP refusal to be part of patients care plan Abrupt and poor-mannered Did not discuss participants' expectations No relief from care	4.2.5.2 4.2.5.2 4.2.5.2 4.2.5.2	Compassion Honest and empathetic Thorough evaluation and made time for participants	4.2.5.2 4.2.5.2 4.2.5.2
	Communication style	Insufficient provision of information	4.2.5.1	Explained processes and findings	4.2.5.1
<b>Interventions</b>	Exercise	Fears about pain exacerbation	4.2.6.4		
	Education about pain	Inadequate explanation of pain	4.2.5.2		
	Self-management			Made use of coping strategies	4.2.6.4
	Medication	Ambivalence about medication use Side-effects of medication HCP restricted access to medication	4.2.6.3 4.2.6.3 4.2.6.3	Slight relief of pain	4.2.6.3
	Physiotherapy	Criticism about physiotherapy	4.2.6.5	Appreciation for physiotherapy	4.2.6.5
	HCP management	Depersonalised care	4.2.5.3	Patient-centred care	4.2.5.3

## CHAPTER 5: DISCUSSION

This study contributes to the scant body of knowledge on patients' perspectives and experiences of living with CMSP in the SA context, particularly in the private health care sector. The strength of the study is that it explored the perspectives of a diverse group of people about their journey with CMSP and reported on the barriers and facilitators to pain management in the private health care setting in SA. The study confirms that CMSP has an immense influence on the identity and life of the sufferer (see section 4.2.2). One of the main findings of the study includes that the HCS was not conducive to supporting the patients in the way that they needed (see section 4.2.4). The lack of interdisciplinary care and communication between members of the medical team and a lack of patient-centred care was significant barriers for pain care (see section 4.2.5). Patient-centred care is important to meet the individual needs of patients, which could lead to patients being better able to cope with and manage their chronic pain (Adams, 2010). In this study, almost all patients reported that they were continuing to search for a credible understanding and cure for their chronic pain and that they were struggling to accept pain as a part of their future (see section 4.2.3 and 4.2.7.3).

Participants' profiles from this study were relatively similar to those of the participant profiles from the scoping review and thus an international sample, except that the participants in the present study had a significant higher level of psychological distress compared to the participants in the scoping review (see Table 2.3, 4.1 and 4.2). This could be a result of the participants reporting a high level of pain intensity on the VAS, where 11 out of 14 participants (79%) reported severe to worst pain possible. There is a strong relationship between high pain intensity and a high level of psychological distress (Rice, Mehta, Shapiro, Pope, Harth Morley-Forster, Sequeira & Teasell, 2016), which concurs with the findings of the present study. Participants' ages ranged from 28 to 73 years and in the scoping review, participants' ages ranged from 18 to 86 years. In this study, 79% of participants were female and 21% were male, which concurs with the scoping review's sample, which was predominantly female (59%) compared to males (41%). Although CMSP is more common in females than in males (Fillingim, King, Ribeiro-Dasalva, RahimWilliams & Riley, 2009), the lack of males in the sample could indicate that males were not actively seeking treatment for their pain, and this was not necessarily an indication of prevalence. The participants in the study were predominantly white, and this could be attributed to the geographical location

within which the study was conducted. This geographical location had a large number of white families in the higher-income brackets which could possibly be linked to them making use of private health care facilities (Lehohla, 2012:88). However, this could also be a shortcoming in the sample strategy used, where patients were referred to the researcher for inclusion in the study. The participants from both studies suffered from CMSP and in this study the most common type of pain was CLBP (29% CLBP and 21% CLBP with referred symptoms). In the scoping review, the most common type of pain was chronic widespread pain (59%). The high prevalence of CLBP could be higher in the primary study because of the setting within which the study was conducted. The main growth sectors in the West Coast region consist of fishing, manufacturing and mining (Cleophas et al., 2014:2), which are manual work and the nature of these activities may put them at risk for development and exacerbation of CLBP.

CMSP had a multidimensional effect on the participants' health and well-being and the significant emotional and functional effect on the person was most notably (see section 4.2.1). The results of the PDI and the narratives of the participants confirmed the level of functional impact as 10 out of 14 participants (71%) had more than 50% disability on the PDI (see Table 4.2). The functional limitations were associated with cautiousness and laboriousness and sometimes participants experienced activities as fearful and threatening. Difficulty performing tasks made participants anxious and depressed. The erratic and fluctuating nature of pain contributed to social limitations and had an influence on effectiveness and productivity at work. This concurs with a study in the United States where participants' emotional well-being, work and relationships with family and friends were affected when they experienced moderate functional impairment (Matthias et al., 2012). The K10 results confirm the level of emotional turmoil that participants were experiencing, where 8 out of 14 participants (57%) reported moderate to severe psychological distress (see Table 4.2). Pain influenced the participants' well-being by impairing their cognitive ability, which left many participants feeling despondent and isolated (see section 4.2.1.3). Participants also felt they were a burden to their families and the dependency on family members was associated with feelings of vulnerability and guilt (see section 4.2.1.4). Participants experienced negative emotional states, feelings of helplessness, frustration, fear, worry, anxiety and depression. The interaction between CMSP and emotional distress in private health care is further confirmed in two studies from the United States and NZ, indicating that participants had moderate to severe depressive symptoms, identity problems and emotional

responses due to the pain (Bair et al., 2009; Brown et al., 2010). This highlights the complexity of CMSP that is prevalent, not only in SA, but in other countries all over the world. Bair et al., 2009, suggested that support from providers can play a central role in patient self-management. Providers should offer emotional support, as well as equip patients with self-management skills such as symptom management tools, goal setting and planning, effective communication and accessing health information and resources (Bair et al., 2009).

Perhaps the most remarkable message that participants in this study wanted to communicate, was the effect and consequences of CMSP on participants' sense of self or self-identity (see section 4.2.2). According to Aujoulat, Marcolongo, Bonadiman & Deccache (2008), a successful process of empowerment occurs when patients come to terms with their threatened security and identity and it should be facilitated by HCP through the use of narratives. Patient empowerment is about integrating different and sometimes conflicting aspects of one's self in order to develop a renewed and valuable sense of self (Aujoulat et al., 2008). The process of reconciling identities is aimed at a search for coherence, which include the acceptance that not everything is controllable (Aujoulat et al., 2008). The participants' references to the influence of CMSP on their sense of self are notable throughout their narratives about their experience with the health care management of their pain. This concurs with the findings of Brown et al. (2010) where CMSP had a severe effect on the identities of participants in the study. According to Hagger and Orbell (2003), perceptions of an illness as highly symptomatic, having a chronic timeline and serious consequences was significantly correlated to avoidance and negative relationships with psychological well-being, roles and social functioning. The study by Crowe, Whitehead, Gagan, Baxter, Panckhurst and Valledor (2010) found that the influence of the symptoms of CMSP was compounded by a lack of predictability, a need for vigilance and an altered sense of self that led to limitations on lifestyle, fear of movement and a sense of being less than what they had been before. In the present study, participants reported a complex relationship between identity, roles, responsibilities and psychological well-being. The participants' social roles as spouse, parent, friend, and employee or homemaker were significantly disrupted. Pain experiences were reported primarily as persistent and distressing, while experiencing a loss of a previous lifestyle and changes in personality. The identity of participants was affected due to changes that they experienced in physical activities and function, family roles, careers and plans for the future (see section 4.2.2). CMSP affected participants very personally and this had negative implications for their health care. Participants recalled experiences of health

providers not adapting to meet their needs and making them feel misunderstood and disregarded (see section 4.2.5.2). The HCS also had an influence on participants' identity as they reported on a disjointed pathway of care and a lack of continuity of care (see section 4.2.4).

The context of this study was within the private health care setting of SA, where costs are funded by either medical aids or by the patients themselves. The majority of private health care professions work from a solo practice, with little to no contact with other HCP (Moosa, Luiz, Carmichael, Peersman, & Derese, 2016). Private HCP supply the full range of care for patients, from evaluation, pathology services, diagnosis, to treatment options, surgery, pharmacies and the maintenance of health (Berger, 2007). According to Berger (2007), unlike the public HCS, the institutions that offer these services are often independent of each other, sometimes in competition and the majority aim to make profits from their services. All HCP are subject to regulatory authorities, but in the private sector there are a number of associations responsible for representing and self-regulating their members (Berger, 2007). Most of these organisations seek to influence health policy and law and do not always concur with public health policy (Berger, 2007). The findings of the present study support the notion of solo practice, because participants reported a focus on management by doctors with medication (see section 4.2.6.3). Occupational therapists and psychologists were rarely involved in the participants' care. Occupational therapists and psychologists usually address the patient's psychological and social components and a lack thereof could have influenced the biopsychosocial approach to participants' pain management (Sturgeon, 2014). Participants reported a lack of interdisciplinary collaboration and communication between HCP and therefore they experienced a fragmented pathway of care. Participants reported that they felt lost in this system (see section 4.2.4). Interdisciplinary pain management interventions are the best evidence for CMSP (DeBar, Kindler, Keefe, Green, Smith, Deyo, Ames & Feldstein, 2012). Interdisciplinary approaches mainly focus on pain management and improved function, rather than cure and pain relief (DeBar et al., 2012). MacDonald (2000) concurs that interdisciplinary health care teams are the model of choice for health care organisations attempting to provide high-quality, efficient and effective services for pain care. Case managers might be an option to help patients to navigate through the HCS (MacDonald, 2000). Good teamwork in primary care settings results in enhanced continuity of care, better access to care as well as patient satisfaction (Farmanova, Grenier, Chomienne, Hogg & Ritchie, 2017). A recommendation emanating from this study is the need for

establishing a way of collaboration and communication to achieve multidisciplinary care for the benefit of patients with CMSP in the West Coast region. Multidisciplinary pain clinics is one option and the formation of a pain academy or group in the region is an option which could include regular team meetings and training to ensure ongoing communication and joint goals between HCP and patients.

Participants reported that the most significant facilitators to pain management were:

- support from their family, friends, employers and HCP (see section 4.2.1);
- an awareness of the holistic nature of pain (see section 4.2.3.1); and
- a positive patient-practitioner relationship where there was a therapeutic alliance, patient-centred care and open communication (see section 4.2.5.3).

These findings concur with the findings of the scoping review (see section 2.4), as well as findings by Lincoln, Pellico, Kerns and Anderson (2013), Becker, Dorflinger, Edmond, Islam, Heapy and Fraenkel (2017) and Simmonds, Finley, Pugh and Turner (2015). The differences in facilitators between the primary study and the scoping review were that the scoping review highlighted the use of self-management strategies by participants and that participants trusted their HCP much more in comparison to the primary study. Lincoln et al. (2013) reported that having universal protocols in place and the availability of complementary and alternative medical resources were also facilitators to care. In the primary study, participants did not mention anything about protocols, but they did speak about their appreciation for physiotherapy. Becker et al. (2017) identified facilitators to care when patients in their study believed in the efficacy of the treatment modalities and also that these modalities were part of a standard protocol, whereas this was identified as a barrier in the primary study due to participants' unsettled beliefs about their diagnosis and treatment. Simmonds et al. (2015) indicate that social workers are facilitators to care, because they help patients to navigate through the HCS. This was also a barrier to care in the primary study, because there was a lack of involvement of counsellors in the patients' journey.

The major barriers to optimal pain management identified in the present study were that chronic pain had a significant psychological or emotional influence on participants due to a non-existing cure. The primary study also indicated that this was due to a lack of involvement of counsellors or psychologist in participants' journey. In the primary study participants had a

biomedical understanding of pain and their credibility of disease was due to beliefs in diagnosis and treatment. The therapeutic neuroscience education (TNE) approach can be used to help patients understand their pain. TNE alters cognitions and beliefs through teaching patients about the neurophysiology and neurobiology of their pain experience (Louw, Diener, Burler & Puentedura, 2011). Evidence has shown that chronic pain patients benefit from TNE: it eases pain, decreases disability and pain catastrophising and increases physical movements and adherence to therapeutic treatments, including exercise (Louw & Puentedura, 2014). There is congruence between the barriers identified in the primary study, the scoping review and the studies by Lincoln et al. (2013), Becker et al. (2017) and Simmonds et al. (2015). All of the studies described a lack of support from family, friends, employers or HCP which left the patients in isolation and had a negative effect on their coping mechanisms. Simmonds et al. (2015) state that social isolation and a lack of support from providers, may encourage patients to place more value on analgesics and to dismiss non-pharmacological treatments. The studies concur that the participants in both studies received depersonalised care (see section 2.4 and 4.2.5.3). The value of patient-centred care is that it strengthens the patient–practitioner relationship, promotes communication, educates patients about their condition and facilitates their participation in their own care (Epstein & Street, 2011). This patient-centred therapeutic relationship is a purposeful, goal-directed relationship that is directed at gaining the best interest of and outcome for the patient (Epstein & Street, 2011). Patient-centredness may be achieved in private practice by training HCP to be more attentive, educational and empathetic, in order to transform their role from having authority to one that has the goals of partnership, cohesion, empathy and alliance (Epstein & Street, 2011). All of the studies had similar HCS factors:

- a lack of continuity of care;
- inappropriate referrals;
- long waiting times; and
- a disjointed pathway of care (see section 2.4 and 4.2.4).

According to Lincoln et al. (2013), patients' satisfaction with their HCP and HCS is associated with compliance with and adherence to their treatment programme. Therefore, the health care quality should be improved by better communication and a stronger collaboration between HCP to ensure accountability and appropriate consultations (Lincoln et al., 2013). Many HCS issues could be improved through an interdisciplinary approach (Lincoln et al.,

2013). This approach could provide support for patients, the treatment process can be monitored and it may help to manage patients with psychosocial and behavioural issues (Lincoln et al., 2013).

The primary study and the scoping review had similar pain management interventions. Participants were fearful of pain exacerbation while exercising, patients were ambivalent about medication use, they had side-effects from medication and the HCP restricted access to medication, participants voiced their criticism about physiotherapy services and they had depersonalised care from the HCP (see section 2.4, 4.2.5 and 4.2.6). Participants were fearful of exercise due to pain exacerbation during and after exercise and this led to limitations of movement in anticipation of pain. According to Booth, Moseley, Schiltenswolf, Cashin, Davies and Hübscher (2017), it is important for HCP to engage with patients to develop their self-confidence with movement, pace their daily activities and assist them to become more active. Exercise has the potential to improve symptoms, decrease the effect of pain and disability and improve function and QoL in a range of CMSP conditions (Booth et al., 2017). However, exercise should be individualised, supervised, safe, non-threatening and based on patients' clinical presentations, preferences and goals (Booth et al., 2017). According to the review by Babatunde, Jordan, Van der Windt, Hill, Foster and Protheroe (2017), the best evidence to treatment of CMSP in primary care is with non-pharmacological treatments, such as exercise therapy, self-management strategies and psychosocial interventions. Pharmacological interventions were only shown to offer short-term benefits for CMSP. Corticosteroid injections may be used in addition to non-pharmacological treatments, as well as NSAIDS and opioids, but possible adverse effects must be taken into consideration (Babatunde et al., 2017). Ernstzen et al. (2017) also report on evidence-based non-pharmacological and pharmacological management strategies for CMSP in PHC, and this concurs with the study by Babatunde et al. (2017). Physiotherapy (manual therapy, exercise and transcutaneous electrical nerve stimulation [TENS]), psychological support (cognitive behavioural therapy, respondent behavioural therapy), psychological treatment (referral to psychologist, antidepressant therapy, the use of serotonin re-uptake inhibitors for treatment of depression), and self-management strategies are non-pharmacological treatments (Ernstzen et al., 2017). Pharmacological treatments included paracetamol, alone and in combination with nonsteroidal anti-inflammatory drugs (NSAIDS), and opioid therapy for moderate to severe CMSP, but the therapeutic benefits of NSAIDS and opioids need to outweigh the potential harmful effects (Ernstzen et al., 2017). The participants in the primary study did not receive

the best evidence of care, because they did not receive any psychological support or treatment (see section 4.2.1 and 4.2.4) and only a few participants reported making use of self-management strategies (see section 4.2.6). Participants' expectations about the effect of physiotherapy focused on their need for pain relief and not empowerment (see section 4.2.6) and participants complained about the lack of effectiveness of the medication and the side-effects of it (see section 4.2.6.3). According to Ernstzen et al. (2017), appropriate and early referrals, multidisciplinary health care, psychological support and interventions, comprehensive education by HCP and teaching of self-management strategies could be done to provide patients with optimal management strategies.

In summary, the findings of this study reported on the exploration of patients' perspectives and experiences about the health care management of their CMSP in the private health care sector of SA. The identified themes in the primary study are unique to the SA context and it informs SA's HCS on the challenges that it is facing while it is currently being transitional and reforming, in order to create an integrated national health system. Participants in this study were in an uncertain state when it came to accepting their pain. They did not understand the basis of their pain due to a disjointed pain journey. The treatment by the HCP did not offer the solutions that the participants were hoping for and the participants were still looking for a cure. The fact that participants were still looking for a cure probably implies a poor understanding of their pain's chronicity. Acceptance of chronic pain, as opposed to a cure, is an important concept and requires an active approach. Pain acceptance has been defined as a behaviour pattern that happens when living with chronic pain but is not directed at changing the pain or otherwise being influenced by pain and still engaging in ADL and functions despite the pain (McCracken & Eccleston, 2003). HCP could facilitate acceptance by educating patients about their pain and ways to make use of self-management strategies, supporting them and providing a continuous pathway of care (LaChapelle, Lavoie & Boudreau, 2008). Acceptance and self-management of chronic conditions is important to reduce the focus on/demand for a cure. Coming to terms with chronic pain entails accepting its continuing presence while making use of coping mechanisms to manage their future with pain. McCracken, Vowles and Eccleston (2005) report on acceptance-related processes that may lead to positive results in pain, anxiety, depression and physical and social functioning. The present study raises several challenges that participants were facing in their journey of understanding to acceptance of their CMSP. Participants had a disjointed pathway of care, they did not receive the support and guidance that were needed from the HCP and this led to

depersonalised care. The findings strengthen the need for interdisciplinary collaboration to address participants' CMSP effectively. Patients reported on barriers and facilitators to pain management in the private health care setting. Significant facilitators were support from their family, friends, employer and HCP, an awareness of the holistic nature of pain and a positive patient-practitioner relationship where there was a therapeutic alliance, patient-centred care and open communication. The main barriers were the significant psychological or emotional effect that chronic pain had on participants due to a non-existing cure and a lack of involvement of counsellors or psychologist in participants' journey.

### **Implications/recommendations for practice**

In order for participants to learn how to live with pain they need to understand pain by receiving pain education from their HCP (Epstein & Street, 2011; Louw & Puentedura, 2014). They also need emotional support throughout the process of coming to terms with their chronic pain (LaChapelle et al. 2008). A counsellor/psychologist plays a vital part in helping participants to move toward redefining their self-identity (Sturgeon, 2014). According to Lincoln et al. (2013), appropriate and early referrals, as well as interdisciplinary collaboration and communication are needed to ensure accountability and appropriate consultations which should benefit CMSP patients. Access to a multidisciplinary pain management facility could prove to decrease emotional distress and promote the adoption of effective self-management strategies (Jeffery et al., 2011). Learning effective self-management strategies is essential in helping patients to cope better with the unrelenting nature of chronic pain and to regain a sense of control over their lives (Babatunde et al., 2017). These recommendations may inform HCS to provide patients with optimal management strategies and in the end, this could lead to participants' being able to accept and manage their future with pain (McCracken et al., 2005).

### **Recommendations for future research**

CMSP and its management present a challenge to patients, HCP and the HCS of SA. The private HCS is failing to meet the expectations of patients with CMSP and undesirable practice cannot be amended without considering feedback from patients. It is vital for researchers and clinicians to be aware of the facilitators and barriers potentially affecting patients, in order to establish better continuity of care and self-management strategies. More

studies are needed about patients' perspectives and experiences about the health care management of their CMSP in the private health care sector of SA. Barriers and facilitators to pain management should be explored and compared to the barriers and facilitators identified in this study. Therefore, future research should seek to replicate the aim and objectives of the present study with a different sample and setting in order to determine whether additional information can be gathered. Follow-up qualitative research for this study should explore the issue about identity disruption. In-depth interviews should be done in different samples and settings to determine the effect that CMSP has on the loss of patients' identities and what HCP could do to assist these patients. Another qualitative study should explore the effect that CMSP has on patients' family and work. Such a study could determine what is needed to support the patients' family and which work interventions should be implemented in order for patients to stay at work. A recommendation emanating from the present study is the need for initiating a multidisciplinary care program or a pain academy for CMSP patients in the West Coast region. HCP' perspectives about and interest in a multidisciplinary care programme or pain academy should be explored, because HCP have to be involved continuously to achieve successful outcomes. Further exploration of whether patients with other types of chronic conditions (such as diabetes or chronic obstructive pulmonary disease) who experience similar interactions with their HCP would add to the understanding of whether patients with chronic pain have unique difficulties in seeking medical care.

### **Strengths and limitations**

It is not the purpose of qualitative research to generalise to the wider population, but to demonstrate that findings can be conveyed and may have meaning if applied to other individuals, contexts and situations (Cooper et al., 2008). This is an important area of research and practice that is currently lacking in available evidence as well as being clinically relevant to patients and practitioners alike in SA. The present research has been presented in a detailed manner for the reader to judge to what extent the findings apply in similar contexts. The study was of an exploratory nature and the participants' recollection of events was retrospective, relying on their memory of past experiences. This could have caused recall bias due to the differences in the accuracy of the recollections retrieved. Significantly, positive or negative aspects of care were reported more frequently than neutral aspects. Methodological rigour was enhanced by organised coding and validating codes between the researcher and supervisor when comparing results. The fact that participants were being interviewed by a

physiotherapist about their health care management and experiences could have influenced the participants' responses toward HCP, particularly regarding physiotherapy care. This could have led to potential response bias; nevertheless, the participants were unreserved and willing to share their experiences with the researcher. The researcher's personal and intellectual biases were minimised by allowing open questions to develop during the interviews, and a wide range of views were expressed and incorporated into the study. The data analysis was done in English and in Afrikaans to ensure that the meaning of words and phrases did not change during transcription-translations, but the researcher translated the Afrikaans transcriptions into English after the data analysis and this might have influenced the quality and richness of the quotations. The sample was dominated by female participants and even though CMSP is more common in females than in males, the lack of males in the sample could indicate that males were not actively seeking treatment for their pain and this could have led to gender bias. The participants were referred to the researcher for inclusion in the study and this could be a shortcoming in the sample strategy used. The fact that four patients cancelled prior to the interview without reason can also be a potential source of sampling bias.

## CHAPTER 6: CONCLUSION

This study provided an important foundation in understanding patients' perspectives and experiences about the health care management of their CMSP in the private health care sector to improve clinical practice and further research. The participants with CMSP indicated that there were numerous challenges throughout their journey with chronic pain in the private health care sector of SA. Participants had a disjointed pathway of care. HCP management did not offer the solutions that the participants were hoping for, and thus led to depersonalised care. HCP attributes played a significant role in the patients' pain journey, because they cited positive and negative experiences.

This study supports the need for establishing a way of collaboration and communication to achieve multidisciplinary care to benefit the CMSP patients in the West Coast region. Multidisciplinary pain clinics is one option and the formation of a pain academy or group in the region is another option which could bring about regular team meetings and training to ensure ongoing communication and mutual goals between HCP and patients. Case managers might also be an option to help patients to navigate through the HCS.

Patients require pain education, self-management strategies and emotional support throughout the process of coming to terms with their chronic pain and redefining their self-identity. Empowering patients with self-management strategies enhance coping mechanisms needed for chronic pain and to regain a sense of control over their lives. In the end, this could lead to participants' being able to accept and manage their future with pain.

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**ADDENDA****ADDENDUM 1: SEARCH STRATEGY****a) CINAHL**

Limits applied to the database:

Type of search:	Advanced search
Publication dates:	Inception to January 2017
Population:	Humans
Languages:	Not specified
Sex:	Not specified
Ages:	Not specified

1	Chronic pain
2	Chronic musculoskeletal pain
3	Chronic nonmalignant pain
4	#1 AND (patient perspective OR patient view OR client perspective OR client view)
5	#2 AND (patient perspective OR patient view OR client perspective OR client view)
6	#3 AND (patient perspective OR patient view OR client perspective OR client view)
7	#4 AND (primary health care OR primary care management)
8	#5 AND (primary health care OR primary care management)
9	#6 AND (primary health care OR primary care management)

**b) Medline**

Limits applied to the database:

Type of search:	Advanced search
Publication dates:	Inception to January 2017
Population:	Humans
Languages:	Not specified
Sex:	Not specified
Ages:	Not specified

1	Chronic pain
2	Chronic musculoskeletal pain
3	Chronic nonmalignant pain
4	#1 AND (patient perspective OR patient view OR client perspective OR client view)
5	#2 AND (patient perspective OR patient view OR client perspective OR client view)
6	#3 AND (patient perspective OR patient view OR client perspective OR client view)

7	#4 AND (primary health care OR primary care management)
8	#5 AND (primary health care OR primary care management)
9	#6 AND (primary health care OR primary care management)

**c) PubMed**

Limits applied to the database:

Type of search:	Simple search
Publication dates:	2000 to January 2017
Publication types:	Not specified
Population:	Humans
Languages:	Not specified
Sex:	Not specified
Ages:	Not specified
MeSH Terms:	Chronic pain, chronic musculoskeletal pain, patient perspective, client perspective, primary health care management

1	(Chronic pain [MeSH])
2	#1 AND (patient perspective OR patient view OR client perspective OR client view)
3	#1 AND (primary health care OR primary care management)
4	#2 AND #3
5	(Chronic musculoskeletal pain)
6	#5 AND (patient perspective OR patient view OR client perspective OR client view)
7	#5 AND (primary health care OR primary care management)
8	#6 AND #7
9	(Chronic nonmalignant pain)
10	#9 AND (patient perspective OR patient view OR client perspective OR client view)
11	#9 AND (primary health care OR primary care management)
12	#10 AND #11

**d) Science Direct**

Type of search:	Expert search
Publication dates:	2007 to January 2017
Source:	Journals (article, review article, short survey, short communication, correspondence, letter, discussion, editorial)
Subject:	Decision Sciences, Medicine and Dentistry, Neuroscience, Nursing and Health Professions

1	Chronic pain
2	Chronic musculoskeletal pain
3	Chronic nonmalignant pain
4	#1 AND (patient perspective OR patient view OR client perspective OR client view)
5	#2 AND (patient perspective OR patient view OR client perspective OR client view)
6	#3 AND (patient perspective OR patient view OR client perspective OR client view)
7	#4 AND (primary health care OR primary care management)
8	#5 AND (primary health care OR primary care management)
9	#6 AND (primary health care OR primary care management)

**e) Scopus**

Limits applied to the database:

Type of search: Advanced search

Publication dates: 2007 to January 2017

Publication types: All

1	Chronic pain
2	Chronic musculoskeletal pain
3	Chronic nonmalignant pain
4	#1 AND patient perspective
5	#1 AND patient view
6	#1 AND client perspective
7	#1 AND client view
8	#1 AND primary health care
9	#1 AND primary care management
10	#1 AND patient perspective OR patient view OR client perspective OR client view AND primary health care OR primary care management
11	#2 AND patient perspective
12	#2 AND patient view
13	#2 AND client perspective
14	#2 AND client view
15	#2 AND primary health care
16	#2 AND primary care management
17	#2 AND patient perspective OR patient view OR client perspective OR client view AND primary health care OR primary care management
18	#3 AND patient perspective
19	#3 AND patient view
20	#3 AND client perspective
21	#3 AND client view
22	#3 AND primary health care
23	#3 AND primary care management
24	#3 AND patient perspective OR patient view OR client perspective OR client view AND primary health care OR primary care management

**ADDENDUM 2: A HIERARCHY OF EVIDENCE FOR ASSESSING  
QUALITATIVE HEALTH RESEARCH (Daly, 2007)**

Study type and level of evidence	Features	Limitations	Evidence for practice
Generalisable studies (level I)	Sampling focused by theory and the literature, extended as a result of analysis to capture diversity of experience. Analytic procedures comprehensive and clear. Located in the literature to assess relevance to other settings.	Main limitations are in reporting when the word length of articles does not allow a comprehensive account of complex procedures.	Clear indications for practice or policy may offer support for current practice, or criticism with indicated directions for change.
Conceptual studies (level II)	Theoretical concepts guide sample selection, based on analysis of literature. May be limited to one group about which little is known or a number of important subgroups. Conceptual analysis recognises diversity in participants' views.	Theoretical concepts and minority or divergent views that emerge during analysis do not lead to further sampling. Categories for analysis may not be saturated.	Weaker designs identify the need for further research on other groups, or urge caution in practice. Well-developed studies could provide good evidence if residual uncertainties are clearly identified.
Descriptive studies (level III)	Sample selected to illustrate practical rather than theoretical issues. Record a range of illustrative quotes including themes from the accounts of 'many,' 'most,' or 'some' study participants.	Do not report full range of responses. Sample not diversified to analyse how or why differences occur.	Demonstrate that a phenomenon exists in a defined group. Identify practice issues for further consideration.
Single case study (level IV)	Provides rich data on the views or experiences of one person. Can provide insights in unexplored contexts.	Does not analyse applicability to other contexts.	Alerts practitioners to the existence of an unusual phenomenon.

**ADDENDUM 3: CRITICAL REVIEW FORM – QUALITATIVE STUDIES**

(VERSION 2.0) (Letts Wilkins, Law, Stewart, Bosch & Westmorland, 2007:1–4).

Critical Review Form – Qualitative  
Studies (Version 2.0)

© Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M., 2007  
McMaster University

**CITATION:**

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	Comments
<p><b>STUDY PURPOSE:</b></p> <p>Was the purpose and/or research question stated clearly?</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p>	<p>Outline the purpose of the study and/or research question.</p>
<p><b>LITERATURE:</b></p> <p>Was relevant background literature reviewed?</p> <p><input type="radio"/> yes</p> <p><input type="radio"/> no</p>	<p>Describe the justification of the need for this study. Was it clear and compelling?</p>
	<p>How does the study apply to your practice and/or to your research question? Is it worth continuing this review?<sup>1</sup></p>
<p><b>STUDY DESIGN:</b></p> <p>What was the design?</p> <p><input type="radio"/> phenomenology</p> <p><input type="radio"/> ethnography</p> <p><input type="radio"/> grounded theory</p> <p><input type="radio"/> participatory action research</p> <p><input type="radio"/> other</p> <p>_____</p>	<p>Was the design appropriate for the study question? (i.e., rationale) Explain.</p>

<p>Was a theoretical perspective identified?  <input type="radio"/> yes  <input type="radio"/> no</p>	<p>Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective.</p>
<p>Method(s) used:  <input type="radio"/> participant observation  <input type="radio"/> interviews  <input type="radio"/> document review  <input type="radio"/> focus groups  <input type="radio"/> other          _____</p>	<p>Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?</p>
<p><b>SAMPLING:</b>           Was the process of purposeful selection described?  <input type="radio"/> yes  <input type="radio"/> no</p>	<p>Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?</p>
<p>Was sampling done until redundancy in data was reached?<sup>2</sup>  <input type="radio"/> yes  <input type="radio"/> no  <input type="radio"/> not addressed</p>	<p>Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?</p>
<p>Was informed consent obtained?  <input type="radio"/> yes  <input type="radio"/> no  <input type="radio"/> not addressed</p>	
<p><b>DATA COLLECTION:</b>   <b>Descriptive Clarity</b>          Clear &amp; complete description of          site:           <input type="radio"/> yes   <input type="radio"/> no          participants:   <input type="radio"/> yes   <input type="radio"/> no           Role of researcher &amp; relationship          with participants:                                   <input type="radio"/> yes   <input type="radio"/> no           Identification of assumptions and          biases of researcher:                                   <input type="radio"/> yes   <input type="radio"/> no</p>	<p>Describe the context of the study. Was it sufficient for understanding of the "whole" picture?                    What was missing and how does that influence your understanding of the research?</p>

<p><b>Procedural Rigour</b> Procedural rigor was used in data collection strategies?  <input type="radio"/> yes  <input type="radio"/> no  <input type="radio"/> not addressed</p>	<p>Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design &amp; data collection methods.</p>
<p><b>DATA ANALYSES:</b></p> <p><b>Analytical Rigour</b> Data analyses were inductive?  <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> not addressed</p> <p>Findings were consistent with &amp; reflective of data?  <input type="radio"/> yes <input type="radio"/> no</p>	<p>Describe method(s) of data analysis. Were the methods appropriate? What were the findings?</p>
<p><b>Auditability</b> Decision trail developed?  <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> not addressed</p> <p>Process of analyzing the data was described adequately?  <input type="radio"/> yes <input type="radio"/> no <input type="radio"/> not addressed</p>	<p>Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes.</p>
<p><b>Theoretical Connections</b> Did a meaningful picture of the phenomenon under study emerge?  <input type="radio"/> yes  <input type="radio"/> no</p>	<p>How were concepts under study clarified &amp; refined, and relationships made clear? Describe any conceptual frameworks that emerged.</p>



**ADDENDUM 4: ARTICLE THEMES**

<b>Articles</b>	<b>Strongest themes</b>	<b>Conclusion</b>	<b>Research gaps</b>
Matthias et al., 2012	<p>Helping patients find what works for their pain</p> <p>Holding patients accountable for their pain management</p> <p>Motivating and providing emotional support to patients</p>	<p>Self-management is a key component of many chronic conditions. Patients with chronic pain perceive self-management to be more than just exercises and other similar strategies. Having an informed, empathetic partner to help identify effective strategies, hold them accountable to their self-management activities, and provide motivation and support when needed. It is extremely important for successful pain self-management.</p>	<p>Future research should explore the role of communication, motivation, and support in self-management longitudinally.</p>
Bair et al., 2009	<p>Barriers to pain self-management: Pain is disabling and interferes with self-management practices Patients fear they will hurt more if they engage in exercise and physical activity Patients perceive their providers prescribe medications as the sole modality to relieve pain Depression and stress negatively affect self-management Patients report that some self-management practices do not work or are not tailored to them The lack of social support interferes with the use of pain self-management Other barriers to pain self-management</p> <p>Facilitators to pain self-management: Relief of depression symptoms helped patients engage in pain self-management Having the support of others facilitated the use of pain self-management practices Motivating themselves, patients would sometimes compare their health with that of others</p>	<p>A variety of patient-perceived barriers and facilitators to self-management were identified to relieve chronic musculoskeletal pain.</p>	<p>Future studies should consider ways to exploit the facilitators identified while at the same time addressing the barriers to pain self-management.</p>
Potter et al., 2003	<p>Qualities of a good physiotherapist The physiotherapy experience</p>	<p>Findings contribute to emerging research about patient-centred service delivery in private sector physiotherapy. By actively looking for patient input, the importance of the patient to the success of the physiotherapist–patient interaction is highlighted, and the benefit of adopting a patient-centred approach in physiotherapy is strengthened.</p>	<p>None</p>
Upshur et al., 2010	<p>Barriers to care Positive provider–patient relationships System barriers and recommendations</p>	<p>Implementing patient-centred approaches in caring for individuals with chronic pain and using principles drawn from the chronic disease management model to improve care systems may increase patient and provider satisfaction with</p>	<p>Further exploration of whether patients with other types of chronic conditions also experience similarly frustrating interactions with their medical</p>

		chronic pain care.	providers would add to the understanding of whether patients with chronic pain have unique difficulties in seeking medical care.
Kawi, 2012	<p>Ways patients manage their CLBP</p> <p>Ways health care professionals give patients support in the management of their CLBP</p> <p>Patients' concerns about their functional ability?</p>	<p>Patients are progressively counselled to take responsibility for their own care. Consequently, health care professionals need to provide support to facilitate self-management behaviours toward positive health-directed goals. Essential information on self-management, self-management strategies and the functional ability of CLBP patients are shared. This data provide an important foundation in understanding CLBP patients to improve practice and further research.</p>	<p>More research is needed to evaluate the self-management and self-management strategies of CLBP patients, which includes in-depth qualitative methodology. Further studies on the influence of self-management and self-management strategies on CLBP outcomes (i.e., pain intensity, functional ability, and QoL), including health care costs, are also important.</p>
Øien et al., 2011	<p>Negotiating the relationship</p> <p>Trustworthiness and transferability</p>	<p>A deeper understanding of the communicative complexity and the demanding negotiations of the alliance between physiotherapists and patients with chronic pain in long-term physiotherapy is provided. Meeting obstacles, the physiotherapists' sensitivity of and ability to negotiate the task, the emotions related to the task and the nature of the relationship seemed to restore the facilitation of change. The capacity of the patients- and of the physiotherapists to tolerate and come through appropriate challenging situations creates new ways of interaction. The demanding situations may generate a potential of development and improvement of treatment outcomes. Understanding such episodes as open and dynamic, in contrast to defining the patient as demanding, suggests a useful view for treatment.</p>	None
Cooper et al., 2008	<p>Communication</p> <p>Individual care</p> <p>Decision-making</p> <p>Information sharing</p> <p>The physiotherapist</p> <p>Organisation</p>	<p>Addressing these scopes of patient-centeredness should enhance the experience of physiotherapy for CLBP patients. Physiotherapists should be aware of the six dimensions that are of importance to patients, paying specific attention to communication.</p>	<p>Further research is required to explore the relevance of this patient-centred model of patient-centeredness in the wider CLBP population, and to evaluate patient-centred physiotherapy.</p>
Brown et al., 2010	<p>The role of the gatekeeper</p> <p>The swing of the interminable pendulum</p> <p>The solution of soldiering on</p>	<p>Issues of knowledge, beliefs, and control fed into the roles of HCP and participants acted as gatekeepers to treatment for people with CMSP. Gate keeping was mainly based on matters of power, searching for</p>	<p>Further research should investigate how people access and make sense of complementary and alternative medicine, and why people choose</p>

		<p>solutions and managing day to day. Participants faced problems about the condition and treatments and spoke about the need to keep on going on. A lack of knowledge of treatment options led to indiscriminate rather than deliberate choices between complementary and alternative and conventional medicine.</p>	<p>different treatment options and to whom people talk about their CMSP and from whom they take advice.</p>
Kidd et al., 2011	Patients' perspectives of patient-centred physiotherapy	<p>In particular, clinician/patient interactions that place the patient at the centre of the therapeutic relationship are based on: the ability to communicate; confidence; knowledge, expertise and professionalism; an understanding of people and an ability to relate; and transparency of progress and outcome. A clinician that fulfils a combination of these dimensions places the patient at the centre of the health care experience. The responses of the patients support patient-centred care and send a clear message to clinicians about what patients prefer in a clinical partnership.</p>	<p>Further research should explore patients' perspectives of care in different patient groups.</p>
Medina-Mirapeix et al., 2013	Physical environment Organisational environment	<p>Physical and organizational environments influence patients' perceptions of quality in rehabilitation settings. Physiotherapists and managers should review treatment settings from the point of view of patients. These needs are becoming much more important in the actual model of patient-centred rehabilitation care.</p>	<p>The findings imply a need and a chance to develop self-report questionnaires about patient experiences with the environment in rehabilitation services to provide experimental and quantitative research on several issues. This include: the association of isolated or combined environmental elements and implications about service quality; potential interaction effects between them; and relationships between environmental elements and outcomes, such as patient satisfaction and health status.</p>

**ADDENDUM 5: BUDGET**

A bursary of R10 000 was obtained from the NRF, and was used to help fund the project. The researcher funded the rest of the project, because the researcher benefited from the Communication Skills Course to obtain a degree (master in Physiotherapy) and owned a digital voice recorder. A budget was set up to ensure responsible financial management.

<b>Item</b>	<b>Unit</b>	<b>Cost/unit</b>	<b>Total in ZAR</b>
<b>Personnel compensation</b>			
Principal investigator			-
Supervisor			-
<b>Participant incentive/gift</b>			
Gift voucher	14	R100/voucher	R1400
Refreshments	14	R20/refreshment	R280
<b>Consulting services</b>			
Communication Skills Course	1	R2500/course	R2500
Transcription of interviews	424.82 minutes	R8/minute	R3398.56
Thesis editing	1	R7000	R7000
<b>Travel</b>			
Travel to participants	540 kilometres	R3.50/kilometre	R1890
Accommodation			-
<b>Equipment and usage thereof</b>			
Internet	30 months	R50	R1500
Phone calls	17 x 10 min	R1.50/min	R255
Printing	500	R0.50/page	R250
Computer software for analysis ATLAS.ti free trial	1	R0	R0
Digital voice recorder	1	1890 + VAT	R2205
<b>Other direct costs</b>			
<b>Total</b>			<b>R15178.56</b>
<b>Funding</b>			
NRF			<b>-R10000</b>
Researcher			<b>-R10678.56</b>
<b>Total</b>			<b>R0</b>

**ADDENDUM 6: TIMELINE**

A timeline is important in evaluating the feasibility of the research study and to give an overview of when each task will occur.

<b>Task</b>	<b>Date</b>
Write preliminary literature review to identify research problem	March 2015
Formulate research question and write detailed literature review	March 2015
Write proposal part 1: Background and research problem	April 2015
Write proposal part 2: Literature review	May 2015
Develop research design. Write proposal part 3: Research methods	June 2015
Draw up research budget	July 2015
Draw up project plan for thesis	July 2015
Draw up rough structure of thesis	August 2015
Submit proposal	September 2015
Wait for proposal feedback	September 2015
Obtain ethics approval	January 2016
Develop forms and piloting	January 2016
Interviews and data collection	January 2016 – April 2016
Transcriptions	April 2016 – June 2016
Data analysis	June 2016 – February 2017
Manuscript preparation	March 2017 – November 2017
Submission of thesis	December 2017
Data dissemination	After received feedback from examiners

**ADDENDUM7: PARTICIPATION INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:**

Patients' perspectives and experiences about private practice health care management of their chronic musculoskeletal pain.

**REFERENCE NUMBER:**

CF01

**RESEARCHER:**

Marna Webb

**ADDRESS:**

West Coast Rehab, Suit 15 Life Hospital, Vredenburg

**CONTACT NUMBER:**

0724490163 / marna@wcphysios.co.za

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about and why have you been invited to participate?**

- The project aims to explore patients' perspectives about living with chronic pain, to explore the pathway of care in private health care settings and to determine the management of chronic musculoskeletal pain (CMSP) in the private health care setting. The project also aims to explore patients' perspectives about barriers and facilitators to pain management in the private health care setting.
- You are invited to take part in an interview that will be conducted by the researcher in Afrikaans or English. The interview will be conducted when and where it is convenient for you. You will be asked to complete three questionnaires after the interview.
- The study will be conducted in four towns in the West Coast region. About twenty adults with chronic/persistent pain from muscles and/or joint structure who sought management in the private sector (at a general practitioner, physiotherapist, occupational therapist or psychologist) will be recruited.
- A Digital Voice Recorder will be used to record your interview. An interview is estimated to last between thirty and sixty minutes. All your personal information will remain confidential.
- You have been invited to participate because you have CMSP and you will be able to share your views and experiences about living with chronic pain and to share how you feel about the private health care settings and the management of your chronic musculoskeletal pain. You will also be asked to share your views about barriers and facilitators of your pain management in the private health care setting.

### **What will your responsibilities be?**

- The only responsibility that you have is to tell your story and answer questions truthfully.

### **Will you benefit from taking part in this research?**

- Contributing to this research project could lead to an understanding and thus better service to patients with chronic musculoskeletal pain.

### **Are there in risks involved in your taking part in this research?**

- There are no direct risks as the research involves taking part in a conversation about your joint and muscle pain. However, you may be in the position to share some sensitive information which may lead to emotional responses. Please inform the researcher should you be feeling such emotions, and if you need a break from the interview. The researcher can also refer you to a trained counsellor.

**If you do not agree to take part, what alternatives do you have?**

- The consultation will not be affected in any way if you do not agree to participate.

**Who will have access to your medical records?**

- The information collected will be treated as confidential and protected. The researcher will take measures to ensure privacy interests throughout the research period, including when disseminating results or findings. Only the researcher, supervisor and co-supervisor will have access to the information and record. Information that might identify participants will not be disclosed either during the course of the research or afterwards. If the information is used in a publication or thesis, the identity of participants will remain anonymous.

**What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

- No risks are anticipated as the research involves interviews and the completion of questionnaires.

**Will you be paid to take part in this study and are there any costs involved?**

- No, you will not be paid to participate. There will also be no costs involved for you. You will be presented with a small gift as a token of appreciation for your time and input.

**Is there anything else that you should know or do?**

- You can contact the HREC at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

**DECLARATION BY PARTICIPANT**

By signing below, I ..... agree to take part in a research study entitled “Patients’ perspectives/views and experiences about private practice health care management of their chronic musculoskeletal pain”.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) ..... on (date) ..... 2015.

.....

Signature of participant

.....

Signature of witness

### **DECLARATION BY INVESTIGATOR**

I (name) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (place) ..... on (date) ..... 2015.

.....

Signature of investigator

.....

Signature of witness

### **DECLARATION BY INTERPRETER**

I (name) ..... declare that:

- I assisted the investigator (name) ..... to explain the information in this document to (name of participant) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (place) ..... on (date) .....

.....

Signature of interpreter

.....

Signature of witness

## **ADDENDUM8: INTERVIEW SCHEDULE FOR PARTICIPANTS**

Introduction: aim, informed consent, the participant's rights. Thank you for your willingness to participate in the interview.

### **1. Please tell me the story of how your pain started.**

*Source of injury/pain*

*Type and severity of pain*

*How long have you lived with this pain?*

### **2. In your opinion why did the pain become chronic?**

*The reasons why the pain did not go away?*

*Now what do you think the source of pain is – where is the pain coming from?*

### **3. What are your perspectives/views about living with chronic pain?**

*What are the ways you manage your chronic pain?*

*Is your pain management adequate? How could it be improved?*

*Does the experience of living with chronic pain worry you?*

*Have you discussed your concerns with your family or health care providers (support)?*

### **4. Please describe to me how the pain influences your life.**

*Does it have an impact on your work?*

*How does it influence you to do things for yourself, your everyday function, life style?*

*Does it have an impact on your family?*

*Does it have an impact on your social life?*

*Does it have an impact on your feelings?*

### **5. Which factors in your life influences your choices regarding pain management**

*Aspects of family, work, finances, culture, distance or access.*

### **6. Could you tell me about the treatment that you have received for the pain?**

**Pathway of care:**

*When did you first seek help for the pain?*

*Where did you first seek help for the pain?*

*All the medical and non-medical personnel involved*

*Patient journey (what happened first and what happened next)?*

**Efficacy/usefulness:**

*What do you do to manage your pain?*

*Did the treatment bring any change/relief – possible reasons?*

*Which treatment helped you the most? In what way did it help?*

*Which treatments did not work for you (unsuccessful) – possible reasons?*

- 7. What do you hope to gain from the treatment – what are your goals or expectations for treatment?**

*What is your understanding of current options available for pain management?*

- 8. What, in your view, are the barriers to improving your pain management? How might those barriers be overcome?**

- 9. What, in your view, are the facilitators to improving your pain management? How might those barriers be overcome?**

- 10. What are your main expectations about how you would want your pain to be treated?**

*In your opinion, what can be done at the private practice to optimize/enable the treatment of pain?*

*Individual characteristics of a good health care professional?*

*Treatment characteristics which you would prefer?*

*Health care system issues at the private practice that could change?*

- 11. Could you share with me your opinion (concerns/plans) for your pain at this stage?**

Thank you for your contribution! Explain what will happen next.

## ADDENDUM9: SOCIODEMOGRAPHIC AND PAIN DESCRIPTION QUESTIONNAIRE

Please respond to each question by ticking the appropriate box with an X or by supplying the missing information.

**The aim of the questions in this section is to obtain general information about you.  
The information will be kept confidential.**

1. Age: \_\_\_\_\_ years

2. Gender:

Male		Female	
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3. Home language:

Afrikaans	English	Other (please specify):
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4. Ethnic group:

Asian	Black African	Coloured	White	Other (please specify):
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5. Marital status:

Married	In a relationship	Single	Divorced or separated	Widowed
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6. Number of children: \_\_\_\_\_

7. Highest level of schooling:

Primary school	Secondary (high) school	University or college	Other (please specify):
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8. Employment:

Fulltime work		Part-time work		Housewife	
Retired/pensioner		Student		Other (please specify):	

9. If you are employed, what is your occupation (job description)? \_\_\_\_\_

\_\_\_\_\_

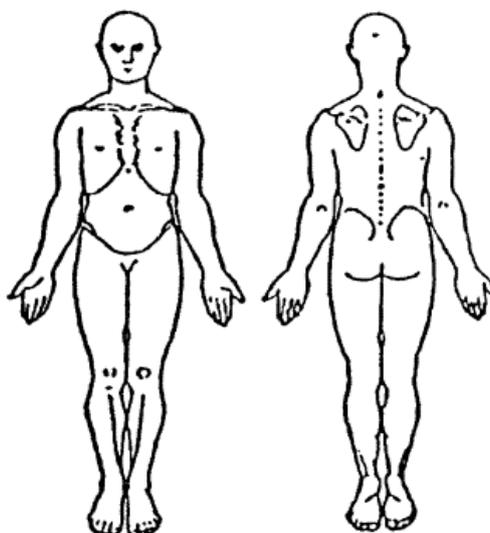
10. If you are a student, what are you currently studying? \_\_\_\_\_

\_\_\_\_\_

The purpose of the next section is to obtain information about your health.

The information will be kept confidential.

11. On the body chart below, please shade the area or areas where you have pain.



12. On the body chart above, please circle the area that hurts the most.

13. How would you rate the pain you are experiencing **today** – on a scale from 0 to 10, where 0 is no pain and 10 is unbearable pain?

0    1    2    3    4    5    6    7    8    9    10

No pain

Unbearable pain

14. How would you rate the pain you have experienced on average **during the past three months** – on a scale of 0 to 10, where 0 is no pain and 10 is unbearable pain?

0    1    2    3    4    5    6    7    8    9    10

No pain

Unbearable pain

15. How would you rate the **worst pain** you have experienced in the past three months – on a scale of 0 to 10, where 0 is no pain and 10 is unbearable pain?

0    1    2    3    4    5    6    7    8    9    10  
**No pain** **Unbearable pain**

**16.** How would you rate the least amount of pain you have experienced in the past three months – on a scale of 0 to 10, where 0 is no pain and 10 is unbearable pain?

0    1    2    3    4    5    6    7    8    9    10  
**No pain** **Unbearable pain**

**17.** Since when have you been experiencing the pain?

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**18.** Have you received a diagnosis or explanation for your pain?

Yes		No	
-----	--	----	--

**19.** If some-one did tell you, what is the name of your condition and how did they explain it?

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**20.** Which of the following chronic conditions do you have, if any?

Hypertension/High blood pressure	
Tuberculosis (TB)	
Osteoarthritis	
Fibromyalgia	
Scleroderma	
Stroke	
Peptic ulcer	
Anxiety	
Heart disease	
Asthma	
Rheumatoid arthritis	
Systemic Lupus	
Epilepsy	
Diabetes (Sugar)	
Depression	
Post-traumatic stress	

Other (please specify): \_\_\_\_\_

**21. Which of the following health carers have treated you for your pain?**

Biokineticist	
Chiropractor	
Homeopath	
Nurse	
Naturopath	
Occupational therapist	
Osteopath	
Physiotherapist	
Psychologist	
Pain clinic	

Acupuncturist	
Reflexologist	
Traditional healer	
Anaesthetist	
General medical doctor (GP)	
Neurologist	
Occupational health doctor	
Orthopaedic doctor	
Psychiatrist	
Rheumatologist	

Other (please specify): \_\_\_\_\_

**22. What medication are you using for your pain?**

**Name of medication:**

**How much/many per day (dosage):**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thank you for participating!

**ADDENDUM10: K10 QUESTIONNAIRE**

**These questions concern how you have been feeling over the past 30 days. Tick a box below each question that best represents how you have been.**

- 1. During the last 30 days, about how often did you feel tired out for no good reason?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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- 2. During the last 30 days, about how often did you feel nervous?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

- 3. During the last 30 days, about how often did you feel so nervous that nothing could calm you down?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

- 4. During the last 30 days, about how often did you feel hopeless?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

- 5. During the last 30 days, about how often did you feel restless or fidgety?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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- 6. During the last 30 days, about how often did you feel so restless you could not sit still?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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- 7. During the last 30 days, about how often did you feel depressed?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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- 8. During the last 30 days, about how often did you feel that everything was an effort?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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**9. During the last 30 days, about how often did you feel so sad that nothing could cheer you up?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
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**10. During the last 30 days, about how often did you feel worthless?**

1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time
---------------------	-------------------------	---------------------	---------------------	--------------------

**Signature** \_\_\_\_\_ **Print name** \_\_\_\_\_ **Date** \_\_\_\_\_

**ADDENDUM11: PDI QUESTIONNAIRE**

**The rating scales below are designed to measure the degree to which aspects of your life are disrupted by chronic pain. In other words, we would like to know how much pain is preventing you from doing what you would normally do or from doing it as well as you normally would.**

Respond to each category indicating the overall impact of pain in your life, not just when pain is at its worst. For each of the 7 categories of life activity listed, please circle the number on the scale that describes the level of disability you typically experience. A score of 0 means no disability at all, and a score of 10 signifies that all of the activities in which you would normally be involved have been totally disrupted or prevented by your pain.

**Family/Home Responsibilities:** This category refers to activities of the home or family. It includes chores or duties performed around the house (e.g. yard work) and errands or favors for other family members (e.g. driving the children to school).

No Disability 0\_\_ . 1\_\_ . 2\_\_ . 3\_\_ . 4\_\_ . 5\_\_ . 6\_\_ . 7\_\_ . 8\_\_ . 9\_\_ . 10\_\_ . Worst Disability

**Recreation:** This disability includes hobbies, sports, and other similar leisure time activities. No Disability 0\_\_ . 1\_\_ . 2\_\_ . 3\_\_ . 4\_\_ . 5\_\_ . 6\_\_ . 7\_\_ . 8\_\_ . 9\_\_ . 10\_\_ . Worst Disability

**Social Activity:** This category refers to activities, which involve participation with friends and acquaintances other than family members. It includes parties, theater, concerts, dining out, and other social functions.

No Disability 0\_\_ . 1\_\_ . 2\_\_ . 3\_\_ . 4\_\_ . 5\_\_ . 6\_\_ . 7\_\_ . 8\_\_ . 9\_\_ . 10\_\_ . Worst Disability

**Occupation:** This category refers to activities that are part of or directly related to one's job. This includes non-paying jobs as well, such as that of a housewife or volunteer.

No Disability 0\_\_ . 1\_\_ . 2\_\_ . 3\_\_ . 4\_\_ . 5\_\_ . 6\_\_ . 7\_\_ . 8\_\_ . 9\_\_ . 10\_\_ . Worst Disability

**Sexual Behavior:** This category refers to the frequency and quality of one's sex life.

No Disability 0\_\_ . 1\_\_ . 2\_\_ . 3\_\_ . 4\_\_ . 5\_\_ . 6\_\_ . 7\_\_ . 8\_\_ . 9\_\_ . 10\_\_ . Worst Disability

**Self-Care:** This category includes activities, which involve personal maintenance and independent daily living (e.g. taking a shower, driving, getting dressed, etc.)

No Disability 0\_\_. 1\_\_. 2\_\_. 3\_\_. 4\_\_. 5\_\_. 6\_\_. 7 \_\_. 8\_\_. 9\_\_. 10\_\_. Worst Disability

**Life-Support Activities:** This category refers to basic life supporting behaviors such as eating, sleeping and breathing.

No Disability 0\_\_. 1\_\_. 2\_\_. 3\_\_. 4\_\_. 5\_\_. 6\_\_. 7 \_\_. 8\_\_. 9\_\_. 10\_\_. Worst Disability

**Signature** \_\_\_\_\_ **Print name** \_\_\_\_\_ **Date** \_\_\_\_\_

**ADDENDUM12: HEALTH CARE PROFESSIONAL INFORMATION LEAFLET  
AND WRITTEN AGREEMENT**

**TITLE OF THE RESEARCH PROJECT:**

Patients' perspectives and experiences about private practice health care management of their chronic musculoskeletal pain.

**REFERENCE NUMBER:**

WA01

**RESEARCHER:**

Marna Webb

**ADDRESS:**

West Coast Rehab, Suit 15 Life Hospital, Vredenburg

**CONTACT NUMBER:**

0724490163 / marna@wcphysios.co.za

You are being invited to be involved in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to be involved.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

- The study will be conducted in four towns in the West Coast region. About twenty adults with chronic musculoskeletal pain (CMSP) who sought management in the private sector (at a general practitioner, physiotherapist, occupational therapist or psychologist) will be recruited.
- The project aims to discover patients' perspectives about living with chronic pain, to discover the pathway of care in private health care settings and to determine the management of CMSP in the private health care setting. The project also aims to explore patients' perspectives about barriers and facilitators to pain management in the private health care setting.
- Data will be collected in the form of semi-structured individual interviews. The researcher will conduct the interviews in Afrikaans or English. Interviews will be conducted when it is convenient for the interviewees and it will take place at interviewees' homes or at their work. Interviewees will be asked to complete three questionnaires after the interviews.
- A Digital Voice Recorder will be used to record interviews. Interviews are estimated to last between thirty and sixty minutes. All your personal information will remain confidential.

### **Why have you been invited to be involved?**

- You have been invited to be involved in the research study and contact eligible patients with a diagnosis of CMSP who was managed at your private practice in the prior three to six months from your practice's database.
- The researcher would like you to enquire from your patients regarding their willingness to participate in the study by handing out the informed consent form in which the study (including that medical records will be accessed) etc. is explained. Those who consent to participation may be contacted for an appointment to complete the informed consent form process. Those who agree to continue participation and participate in an interview must then sign the informed consent form.
- CMSP is defined as a constant pain originating from the musculoskeletal system for 12 weeks or more (Upshur et al., 2010; Kawi, 2012).
- Exclusion criteria of the sample selection is pain that is not musculoskeletal in origin:
  - neuropathic pain - nerve compression pain, post-nerve injury pain, post-amputation pain, diabetic neuropathy, complex regional pain syndromes (type I and II), skeletal muscle spasm, post herpetic neuralgia and chronic post-surgical pain (Baron, 2006.)
  - visceral pain - distension of hollow viscera and colic pain (Sikandar & Dickenson, 2012.)
  - chronic pain in sickle cell anaemia (Maxwell, Streetly & Bevan, 1999.)

- The information collected will be treated as confidential and protected. Information that might identify participants will not be disclosed either during the course of the research or afterwards.

**What will your responsibilities be?**

- The only responsibility that you have is to contact eligible patients with a diagnosis of CMSP and to give your permission for access to the patients' medical records.

**Will you benefit from your involvement in this research?**

- Contributing to this research project could lead to an understanding and thus better service to patients with chronic musculoskeletal pain.

**Are there in risks involved in you and your patients taking part in this research?**

- No risks are anticipated as the research involves interviews and the completion of questionnaires.

**Will you be paid to be involved in this study and are there any costs involved?**

- No, you will not be paid to be involved, but there will also be no costs for you. You will be presented with a small gift as a token of appreciation for your time and input.

**Is there anything else that you should know or do?**

- You can contact the HREC at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and written agreement for your own records.

**DECLARATION BY HEALTH CARE PROFESSIONAL**

By signing below, I ..... owner of ..... practice hereby give permission to be involved in a research study entitled "Patients' perspectives/views and experiences about private practice health care management of their chronic musculoskeletal pain".

I declare that:

- I have read or had read to me this information and written agreement and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that involvement in this study is voluntary and I have not been pressurised to take part.
- I may choose to withdraw from the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to withdraw from the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) ..... on (date) ..... 2015.

.....

Signature of health care professional

.....

Signature of witness

### **DECLARATION BY INVESTIGATOR**

I (name) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did not use an interpreter.

Signed at (place) ..... on (date) ..... 2015.

.....

Signature of investigator

.....

Signature of witness

## ADDENDUM13: ETHICS APPROVAL

### Approval Notice Response to Modifications- (New Application)

20-Jan-2016  
Steyn, Marna M

**Ethics Reference #:** S15/09/196

**Title:** Patient's perspectives and experiences about private practice healthcare management of their chronic musculoskeletal pain.

Dear Miss Marna Steyn,

The **Response to Modifications - (New Application)** received on **16-Nov-2015**, was reviewed by members of **Health Research Ethics Committee 1** via Expedited review procedures on **20-Jan-2016** and was approved.  
Please note the following information about your approved research protocol:

Protocol Approval Period: **20-Jan-2016 -19-Jan-2017**

Please remember to use your **protocol number** (S15/09/196) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### After Ethical Review:

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

#### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

**ADDENDUM 14: CODEBOOK****Codes**

1. Acceptance
2. Barriers
3. Coping
4. Credibility of disease
5. Employer influence
6. Family
7. Fear
8. Fear of abandonment
9. HC system: mixed
10. HC system: cost
11. HC system: care
12. HCP attributes
13. HCP communication
14. Health: Diagnosis
15. Hope
16. Identity
17. Impact: Cognitive
18. Impact: emotions
19. Impact: function
20. Impact: life
21. Impact: Occupation
22. Impact: sleep
23. Impact: Social
24. Impact: Symptoms
25. Internet
26. Lack of understanding
27. Management: Education
28. Management: non pharmacological
29. Management: PNE
30. Management: Self-management

31. Management: Medical
32. Management: Physio
33. Pain experience
34. Pathway
35. Psychosocial
36. Patient knowledge
37. Patient: emotions
38. Patient: personal trauma
39. Patient: perspective
40. Searching Uncertainty
41. Strategy: faith
42. Strategy: Humor
43. Stress
44. Trust
45. Unpredictability

### **Categories**

1. Patients' perspectives about living with chronic pain

Pain experience

Patient: emotions

2. Impact of chronic pain on patients' lives

Impact: cognitive

Impact: emotions

Impact: function

Impact: life

Impact: occupation

Impact: sleep

Impact: social

Impact: symptoms

Fear: abandonment

Fear: future

Hope

## Unpredictability

### 3. Disrupted identity

#### Identity

### 4. Knowledge about chronic pain

#### Patient: knowledge

#### Searching for understanding: uncertainty

#### Searching for understanding: internet

### 5. Beliefs about chronic pain

#### Patient: perspective

#### Credibility of disease: lack of understanding

### 6. Patients' pathway of care in private health care settings

#### Pathway

### 7. Health care system factors

#### Health care system: mixed

#### Health care system: care

#### Health care system: cost

#### Health care system communication

### 8. Health care practitioners involved in the pathway of care

#### HCP attributes

### 9. Interactions with HCP

#### Management: education

#### HCP communication

### 10. Management of CMSP

#### Management: pharmacological

#### Management: non pharmacological

#### Management: self-management

Management: physiotherapy

Health: diagnosis

11. Fear of the future

Fear

12. Hope for the future

Hope

13. Acceptance of chronic pain

Acceptance

14. Barriers to pain management

Barriers

15. Facilitators to pain management

Facilitators

## **Themes**

### **Theme 1: Living with chronic pain**

1.1. Physical function and ADL

1.2. Participation in functional activities

1.3. Impact on psychological wellbeing

1.4. Family and social life

Impact on family relations

Impact on friends' relations

Family support

Social isolation

Unpredictability

1.5. Occupational consequences

**Theme 2: Disrupted identity**

**Theme 3: Knowledge and beliefs about chronic pain**

- 3.1. Understanding pain
- 3.2. Information sourcing
- 3.3. The importance of believability/credibility
- 3.4. Participant expectations

**Theme 4: Health care system factors**

- 4.1. HCP consulted
- 4.2. Disjointed pathway of care
- 4.3. Appropriate referral
- 4.4. Waiting times
- 4.5. Continuity of care
- 4.6. Cost of care

**Theme 5: Interactions with HCP**

- 5.1. Provision of information (Inadequate)
- 5.2. Clinician attributes and attitudes
- 5.3. (Lack of) patient centeredness

**Theme 6: Management of CMSP**

- 6.1. Interventions received and patient perceptions about these
- 6.2. Special investigations
- 6.3. Medication
  - Effectiveness of analgesics
  - Access to analgesics
  - Conceptions about medication
  - Using medication
  - Side-effects of medication
- 6.4. Exercise
  - Effectiveness of exercise
  - Fears regarding exercise
  - Impact on ability to exercise

6.5. Physiotherapy

Appreciation for Physiotherapy

Criticism about Physiotherapy

6.6. Self-management strategies

**Theme 7: Hope (or hopelessness) for the future**

7.1. Fears about the future

7.2. Hopefulness

7.3. Acceptance

**Theme 8: Barriers and Facilitators to pain management**

8.1. Impact of pain

Psychological impact

Understanding pain

8.2. Interventions

Exercise

**ADDENDUM 15: EXAMPLES OF TRANSLATED QUOTES****Afrikaans and English versions**

*‘...as ek in die aande by die huis kom gaan sit ek op die bank en ‘that’s it’. Ek gaan nie eers toilet toe nie, want dis te seer vir my om op te staan en toilet toe te gaan. Ek gaan toilet toe wanneer ek kamer toe gaan, want ek moet verby die toilet gaan om by die kamer uit te kom.’*

*‘...if I get home at night then I go and sit on the couch and that’s it. I don’t even go to the bathroom, because it is too painful to stand up and go to the bathroom. I go to the bathroom when I go to my room, because I have to walk past the bathroom to get to my room.’*

(Participant 6, female, chronic widespread pain, 3 years)

*‘...by die werk, want ek moet heeldag op my voete wees, daar is kere wat ek mense nie kan help nie en dat ek ‘delegate’ van die toonbank af. En dit gaan teen my ‘grit’ as die persoon wat ek is. As iemand my gaan aankla, moet hulle my maar aankla, maar wat moet ek doen?’*

*‘...at work, because I have to be on my feet all day, there are times I cannot help people and I have to delegate from the counter. And it goes against my grit as the person I am. If somebody reports me then they have to report me, but what should I do?’ (Participant 6, female, chronic widespread pain, 3 years)*

*‘...dit beïnvloed jou ‘happiness’ terwyl jy ‘craft’, want jy sit later op die boud, dan op daai boud. En as jy heelyd moet opstaan om verligting te gee aan jou rug of jou heup of wat ook al, dan wil jy dit later nie meer doen nie.’*

*‘...it affects your happiness when you craft, because you sit on your one buttocks and then on the other buttocks. And if you have to stand up the whole time to give relief of your back or hip or whatever, then you don’t want to do it anymore.’ (Participant 1, female, CLBP, 8 years)*

*‘Dis half asof die emosie oorneem want die pyn is so oorweldigend, jy kan nie rasideel dink nie. En dit bekommer my. Dis regtig vir my ‘n bekommernis, en ek wil nie hê my kinders moet*

*eendag soos ek sukkel nie. Ek sal dit haat as hulle eendag so moet sukkel, want dis nie lekker nie.'*

'It is half as if the emotion takes over because the pain is so overwhelming, you cannot think rationally. And that worries me. It is really a concern for me, and I do not want my children to struggle one day like me. I will hate it if they struggle one day because it is not good...'  
(Participant 1, female, CLBP, 8 years)

*'...dit maak my partykeer regtig geïrriteerd as ek baie seer het. Dan is my geduld en my draad kort. Maar ek moet daardie selfbeheer uitoefen, want dis niemand se skuld nie.'*

'...it sometimes makes me really annoyed when I have a lot of pain. Then my patience and my thread are short. But I have to practice that self-control because it is nobody's fault.'  
(Participant 11, female, chronic left hip and leg pain, 2 years)

*'...ek moet by die werk dink voor, ek sal die laaste goed optel wat laag is. Ek sal liever heup hoogte alles doen wat nodig is. By die werk moet ek my heelyd herinner ek werk saam mense; ek kan nie as ek seer het dit op jou uithaal byvoorbeeld nie. Ek sal ook, jy sal agterkom ek trek nie meer aan die einde van die dag my lêers nie, bloot eenvoudig want dis te seer om te buk. Ek gaan dit liever vermy.'*

'...I have to think at work before; I will pick the low things up last. I would rather do everything that is hip height and everything that is necessary. At work I have to remind myself all the time that I work with people; I cannot, for example, take it out on you when I have pain. I will also, you will notice that I am not taking my files out at the end of the day simply because it hurts too much to bend. I would rather avoid it.'  
(Participant 11, female, chronic left hip and leg pain, 2 years)

*'Ek sê jou want elke liewe dag is daar 'n ander gier en 'n ander ding, ek het regtig teveel dinge, elke liewe dag is daar iets nuuts, iets nuuts...ek het nou die dag toe sê ek wens ek kan iemand kry wat vir my sê, daai is fout, daai is fout, daai is fout en ons doen nou dit en daai is weg en daai is weg, daai is weg en dan gaan ek 'happy' wees want dan is alles weg.'*

‘I tell you because every day there is another vulture and another thing, I really have too many things, and every single day there is something new...and the other day I said that I wish I can find someone who tells me that is wrong, that’s wrong and that’s wrong, and we are doing this and that is gone, that’s gone and that’s gone, then I am going to be happy because then everything is gone.’ (Participant 12, female, CLBP and coccyx pain, 8 months)

*‘...sodra dit so erg seer is of wanneer dit baie seer is vir ’n hele lang ruk deur die dag, dan raak ek vinnig geïrriteerd. So as iemand net vir my iets sê dan is ek soos, dan ‘snap’ ek ‘at’ hulle, dit is, dit irriteer my basies, dit is ’n irriterende seer...’*

‘...as soon as it hurts so badly or when it is very painful for a long time during the day, then I get irritated quickly. So if somebody just tells me something, then I snap at them, then it basically annoys me, it is an annoying pain...’ (Participant 12, female, CLBP and coccyx pain, 8 months)

*‘...ja, jy raak geïrriteerd en ja jy, ek meen mens kan net soveel pyn hanteer. Maar die pyn is, sal ek maar sê verdra ek deur die dag, maar sodra dit begin aand raak, dan begin jy ‘heavy’ geïrriteerd raak.’*

‘...yes you get irritated and yes you; I mean one can only handle so much pain. But the pain is...I would say that I endure it during the day, but as soon as the evening comes, then you get heavily irritated.’ (Participant 7, female, chronic widespread pain, 3 years)

*‘Dit raak vir my moeiliker om toetse te skryf. Dit is vir my, en ek weet nie hoekom nie, maar dis, en dit is vir my baie erg. Veral om goeters te vergeet, want ek is ’n baie presiese mens. En ek sal nou iets lees en dan oor twee maande kan jy vir my iets vra en dan sal ek presies vir jou sê waar dit gestaan het en waar dit was. Nou is dit ‘like okay’, ek weet nie, ek kan nie onthou nie.’*

‘It gets harder for me to write tests. It is for me, I don’t know why, but it is very hard for me. Especially to forget things, because I am a very precise person. And I will read something now and then in two months you can ask me something and I will tell you exactly where it stood and where it was. Now it is like okay, I don’t know, I cannot remember...’ (Participant 7, female, chronic widespread pain, 3 years)

*‘...my seun vir my gesê eendag, ma, dit maak my baie seer want ma is nie meer die ma wat ek was nie. En dit was soos messteke in my hart. Maar hy het dit nie so bedoel nie. Hy het dit bedoel uit bangheid, uit magteloosheid en te sien hierdie vrou wat hy sien, maar dit is ook nie my ma rêrig nie. En dit is ‘n feit, dit is so. Want vir myself partykeer as ek in die spieël kyk en ek dink terug na dan ek, dan ek moes ‘n ander mens skep en ‘n ander lewe en ‘n ander brein en ‘n ander, om alles hierdie ding meer te kan beleef. Want ek loop anders, ek sit anders, ek slaap anders, ek bad anders, ek kam my hare anders, ek ry my kar anders.*

‘...my son said to me the one day, Mother, it hurts me a lot because mother isn’t the mother that you used to be. And it was like knife stab in my heart. But he didn’t mean it like that. He meant it out of fear, out of lack of power and to see the woman that he was seeing isn’t really his mother anymore. And that is a fact, it is true. Because sometimes for myself when I look in the mirror and I think back, I had to create a different person and a different life and a different brain and everything different to experience all of this thing more. Because I walk differently, I sit differently, I sleep differently, I bath differently, I comb my hair differently; I drive my car differently.’ (Participant 3, female, chronic widespread pain, 3 years)

*‘Die hand is snaaks, die arms is snaaks, die skouer is snaaks, of ek klim ‘funny’ uit die kar uit en dan loop ek 2 treë, ek voel goed, of 5 treë, soos ‘n normale mens en dan ewe skielik moet ek my pas verslap en die ‘rhythm’ kry wat my liggaam dit kan doen...’*

‘The hand is funny, the arms are funny, the shoulder is funny, or I get out of the car funny and I walk two steps, I feel good, or five steps, like a normal person and then suddenly I have to reduce my pace and get the rhythm that my body can do...’ (Participant 3, female, chronic widespread pain, 3 years)

*‘Is nou al klaar deur die ‘rigmarole’ al twee keer gewees, en net nie meer lus nie. Want dit kom nêrens nie. Daar is niks. Daar is niks wat hulle vir jou kan sê of doen of gee...’*

‘Has already been through the rigmarole twice, just not in the mood anymore. Because it does not go anywhere. There is nothing. There is nothing they can say or do or give to you...’ (Participant 10, female, chronic widespread pain, 7 years)

*‘...En ek dink op dié stadium doen ek die pyn soos wat dit kom, maar ek doen niks buitengewoon, hoe kan ’n mens sê? Buite my ‘comfort zone’ nie; ek doen alles binne-in my ‘comfort zone’.*

*‘...so I think at this stage I take the pain as it comes, but I do nothing extraordinary, how can one say? Outside my comfort zone; I do everything inside my comfort zone.’ (Participant 10, female, chronic widespread pain, 7 years)*

*‘...hy sê dis spanningshoofpyne ook, so môreoggend negeuur het ek nou weer ’n afspraak met hom wat ek vir hom gaan sê okay luister, as dit nou spanning is, gee dan vir my iets beter as Trepiline of Urbanol of wat ook al om dit dan net weg te kry want op die oomblik, dit raak nou bietjie ‘hectic’.*

*‘...he says it is tension headaches as well, so tomorrow morning I have an appointment at nine o’clock with him and I am going to say to him okay, if it is tension now, give me something better than Trepiline or Urbanol or whatever to get it to go away, because at the moment it is getting a bit hectic.’ (Participant 8, female, chronic headaches, 29 years)*

*‘So dis vir hom frustrerend. Want ek dink tog ek meen as ek nou, dan kan hy nou nie die dinge doen wat hy beplan het nie, want hy moet nou soos in my rol ook nou opneem. So dis frustrerend vir hom ook.’*

*‘So this is frustrating for him, because I think and I mean now, then he cannot do the things that he planned to do, because now he has to take my role up as well. So it is frustrating for him too.’ (Participant 8, female, chronic headaches, 29 years)*

*Kyk hy het, wat vir my lekker was van hom, is hy het reguit vir my gesê, moenie vir my sê wat ander mense sê jy het nie, hy het gesê ek moet my hemp uittrek en hy het die hele ruggraat gevoel en die ‘alignment’ van die heupe, lae rug, my ruggraat en hy het my in ’n stadium het hy my op die bed laat lê wat hy die beweging van my heupe en my knieë gevoel en toe sê hy reguit vir my, maar dit is wat jy het. Dat hy vir my gesê het maar die enigste ding wat vir hom sin maak met die simptome wat ek het en dit wat hy ondervind is ‘trochanteric bursitis’ en ek meen hy het nie vir my gevra wat ander dokters gesê het om sy opinie half om dit te ‘base’ nie, hy het self, hy het vir my gesê na die tyd kan ons praat oor wat die ander dokters gesê het*

*maar nou eers, want ek meen dit was vir my, dit is 'n ouerige dokter maar die manier wat hy dit gedoen het, was vir my net fantasties...'*

'Look he had, what was nice about him, he told me straight away, do not tell me what other people say you have, he said to me I had to take my shirt off and he felt the whole spine and the alignment of the hips, lower back, my spine and at a point he had me lying on the bed that he tested the movements of my hips and knees. And then he said straight to me but that is what you have. He said to me it is the only thing that makes sense for him with the symptoms that I have and what he experience is trochanteric bursitis and I mean he did not ask me what other doctors had said to base his opinion on it, he himself, he told me that we can talk afterwards what the other doctors had said, but for now, it was for me, it is an elderly doctor but the way that he did it, was amazing for me...' (Participant 14, female, chronic bilateral hip pain, 5 years)

*'...ek meen 'obviously' daar is niks oefeninge wat ek kan doen om dit minder te maak of weg te vat nie...'*

'...I mean obviously there is no exercise that I can do to decrease it or to take it away...' (Participant 14, female, chronic bilateral hip pain, 5 years)

*'... ek is verslaaf aan hardloop sê ek, ek is 'addictive' aan 'n goeie iets, aan 'n sport...by 'n sekere tyd, dan skop sy my, gaan hardloop net dat jy net kan regkom want ek is bietjie kortaf en al daai goed in die huis...'*

'...I am addicted to running like I said, I am addicted to a good thing, to a sport...at a certain time, she will kick me, go and run that you can get better, because I am a little short tempered and all those things in the house...' (Participant 13, male, CLBP and right leg pain, 4 months)

*'So ek hoop ek gaan regkom man en wil graag Comrades gaan hardloop as wat ek net heeldag rondstaan nie.'*

'So I hope that I will be healed and I would like to run the Comrades rather than just standing around the whole day.' (Participant 13, male, CLBP and right leg pain, 4 months)

*'...my idee is nou om te kyk dat ek dit een week doen, een week 'skip', net omdat ek bietjie my finansies beter kan 'cope...'*

'...my idea is now to see that I do it one week, skip the next week, just because my finances can cope better with it...' (Participant 2, female, CLBP and left leg pain, 4 months)

*'Dis 'terrible'. Behalwe nou ek sê nou die pyn ook, baie dae dan kom ek net hier en dan huil ek sommer net vir niks en dit nie. Maar dit het my so, ek weet dit affekteer my ding waarvoor ek die liefste is, en dis my fietsry wat by my so 'n passie geraak het. Sjou ek het nou so opgebou om iets te doen, en nou voel ek dit gaan weggevat word van my.'*

'It is terrible. Except now I am saying the pain too, many days I come here and I just cry for nothing. I know it affects me, the thing that I love the most, it is my cycling that became such a passion for me. I have built up to something that I can do and now it feels that it is going to be taken away from me.' (Participant 2, female, CLBP and left leg pain, 4 months)

*'...die mediese fonds wat ek op is byvoorbeeld betaal nie vir fisioterapie nie. Ek kry nie fisioterapie by hulle nie. So dan beïnvloed dit maar die koste. So jy is maar redelik beperk tot hoeveel sessies jy kan doen...'*

'...the medical aid that I am on for example does not pay for physiotherapy. I don't get physiotherapy with them. So it does affect the costs. So you are pretty limited to how many sessions you can do...' (Participant 4, female, CLBP, 1 year)

*'Vir my op die stadium is dit baie frustrerend. Verskriklik frustrerend, want voor dit was ek altyd baie aktief...'*

'To me at this stage it is very frustrating. Terribly frustrating, because before this I was always very active...' (Participant 4, female, CLBP, 1 year)