Holistic Strategies for Clients suffering from Chronic Pain (CP) using Transdisciplinary Communication

A portrait of the insights and experiences of participants in the early stages of developing a chronic pain program, by collaborating between independently operating practitioners in a local community.

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DECLARATION

This work has not been previously submitted in whole, or in part, for the award of any degree. It is my own work. Each significant contribution to, and quotation in, this dissertation from the work, or works, of other people has been attributed, and has been cited and referenced.

Signature: ……. Date: ……

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ABSTRACT

Chronic pain (CP) affects millions of people and costs billions of dollars a year (Koch, 2012). The biopsychosocial approach understands that CP is caused by a complex interaction between cognitive, emotional, physical and social factors (Young, 2010). However modern health care is often fragmented leaving choices to clients (Scott, Ruef, Mendel, & Caronna, 2000). Often clients with CP don't receive or seek psychological interventions for a DSM 5 (APA, 2000) classifiable condition.

This study focused on an independently operating physiotherapist in the planning phases of developing a holistic intervention at her wellness centre. The goal of the research was to capture a portrait of the insights and experiences of participants in the early phases of planning transdisciplinary teamwork. Thus a qualitative research design was employed to capture the rich subjective experiences and insights of the participants. The physiotherapist selected the sample of: 5 clients, 4 health professionals, and 3 supportive professionals. Together they attempted to create a holistic strategy for CP. Three types of qualitative data collection were used namely: interviews, focus and collaborative working groups (CWG). Data analysis followed Braun and Clark's (2006) six-phase guide. The aim of this study was to encourage change in the local context and to inspire others in different context to attempt holistic practice.

The study found that implementing holistic teamwork was a lengthy and challenging process. Theory underlying treatment needed to be defined first and it was hard to reach consensus. Strategizing for holistic work was challenging, as it did not just involve combining treatments but creating an individual systemic non-linear process. Good communication was vital to the process and this again involved time, which was is not covered by medical aids. In terms of strategy what was highlighted is that the client needed to change their way of relating to their CP, as although sensory pain may not be diminished the suffering of the client would decrease. Of interest was whether CP was a new culture bound form of PTSD resembling our modern trauma's as much of the descriptions about CP matched PTSD symptomology. Further more focused study on each of the broad areas covered as well as the involvement of specialised expertise in the areas of ethics, and business management would be needed to commence transdisciplinary holistic teamwork.

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CHAPTER 1: INTRODUCTION

Chronic pain (CP) is increasingly being recognised as a growing pandemic. On average one in five South Africans who visit their doctors will be suffering from CP (Koch, 2012). American statistics show that CP affects 70 million people, costing an estimated 100 billion dollars a year. CP therefore creates a bigger burden on health care than other conditions like diabetes or heart disease (The Mayday Fund, 2009). This makes it a common cause of serious long-term disability and early retirement (Koch, 2012). U.S. Congress made 2001 to 2010 the "Decade of Pain Control and Research" and pain is now also considered the fifth vital sign and is likened to other vital signs like blood pressure (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

Secondly the publication of the DSM 5 has brought significant changes in the way psychologists diagnose mental pathology relating to CP. The new DSM 5 moves away from diagnosing mental pathology based solely on the absence of finding medical causation but rather looks positively for pathology in the client's relationship with the pain. This is because the DSM 5 gives support and recognizes the research developments in the biopsychosocial approach. This approach understands that: "symptoms could be initiated, exacerbated or maintained by combinations of biological, psychological, and social factors" (Young, 2010, p. 289).

Despite the complexity of the CP, many clients have been receiving disjointed care not covering the full spectrum of the predisposing or maintaining factors (Laskey, 2012). It would appear that most clients receive help in the medical arena rather than a psychologist's office and thus clients are often not receiving psychological assessment or help for what could be potentially a DSM classifiable condition. The reasons for this are numerous. The average person who consults their family doctor or a physiotherapist, for example, may have a biomedical understanding of pain, thus believing that the nature of their ailment is primarily physical (Stanos & Houle, 2006). The temporary relief that medication provides, may then support their belief systems that their problem is medical. Primary care is also cheaper than other more specialized types of care. The caregiver is familiar and thus the client may perceive it as a safer option. Literature also suggests that a fear of stigmatization contributes to this pattern of help seeking behaviour (Little, 2010). The most commonly sought treatment

is single disciplinary care (Albrecht, Connor, & Higginbotham, 2001) and this is sufficient if the degree of disability does not impair everyday functioning. Lack of specialized resources, time and cross-referral opportunities however means that these settings are often not an appropriate places to treat CP (The Mayday Fund, 2009). Yet clients continue to seek help in single discipline settings. The challenge is to establish a way to adequately treat these clients at a local community level or primary care settings where they are already seeking help (The Mayday Fund, 2009).

In our 'modern era' there has been a focus on health (as opposed to illness) and with that came a shift away from medical physician led care. This has resulted in is an increasingly 'disorganized & fragmented health care system' (Scott, Ruef, Mendel, & Caronna, 2002). One only has to observe how many street corners, in South African, are littered with offerings of all sorts of care. Health professionals, traditional healers, fitness coaches, and alternative healers all fight for the attention of the consumer. The client's discretion and budget often determines treatment choices, sometimes nudged on by the suggestions of a doctor.

There is thus a need to look for a feasible organized approach to chronic and complex conditions in local community settings. Currently there is a lack of specialized pain clinics and so most pain care is managed in primary care (Matthias, et al., 2010) where clients may have been left to wander between practitioners at their own discretion. My previous research (Laskey, 2012) led me to understand that community based private independent practitioners have a very different system of organization and challenges than large hospitals, clinics or other organized health care systems. Thus there is a need to find a system that respects the independence and financial challenges of these practitioners but that can harness the benefits of inter-disciplinary teamwork. That is why this study is aiming to capture the insights and experiences of participants in the early planning stages of developing a transdisciplinary CP program.

1.1 Background to the study

This study was based at a private physiotherapy practice in the Cape Town which operated from premises, which was shared with other types health professionals. A previous study (Laskey J. M., 2012) was conducted in 2011 to see how these professionals perceived

they could work together. However only limited informal teamwork had been practiced up until the commencement of this study.

The physiotherapist hoped to provide CP sufferers with a more holistic range of treatment from her community based practice. This study was to provide a structure, as well as theoretical and research backing to her development process. The strategy for implementing the changes was inspired by soft systems methodology, which is a trial and error approach (Checkland & Poulter, 2010). Each stage's success and failures were analysed and helped to inform the next.

The physiotherapist invited several registered health professionals (AHPCSA or HPCSA) to participate in the research. This included a psychologist, an occupational therapist, a medical doctor (MD) specializing in integrative medicine, and a chiropractor. She also got recommendations from her clients and invited other professionals who are not registered with a health council. These professionals needed to be a significant support to the client. An intuitive energy healer, a Pilate's instructor and a family wellness coach were recruited. In this study they have been referred to as 'support professionals'. The purpose of the support professional's input was to provide useful adjunctive information to the health professionals understanding of the client in order to maximise the benefits for the client. The advantage of working in a team was that their input to the client would be regulated by the insights and supervision of the registered professionals.

1.2 The Aims of the Study

This study aimed to offer a portrait of the insights and experiences of participants in the early stages of developing a CP program by collaborating between independently operating practitioners in a local community. Thus the aim of this thesis was not to engage in transdisciplinary teamwork (TDT) in order to treat clients but to capture the experience and insights of the participants who were in the early phases of brainstorming for creative solutions. Simply put this study was a snapshot of the insights gained during just the initial development phase before commencing treatment. This thesis was a general exploratory study, with the hope to identify more focused and specific areas for future research. The need for a broad study was because of the vastness of the subject and the general lack of literature and research on the subject. The aim was that the 'real life' experiences of the participants

would both motivate and inform future on-going research for holistic solutions in both this local context as well as other contexts.

The research question was: What are the insight and experiences of all participants in their initial attempt to establish transdisciplinary communication (TDC) to aid the development of a holistic CP program?

Specific goals under this question include:

- The participant's understandings of the concept of CP
- The client's intervention needs
- The effect of inclusion of the client's and their opinion
- The effect of psychology on the development process.
- The researchers evolving realisations

1.3 Structure of the thesis

After the introduction this thesis has a literature review. Outlined in the literature are the main topic areas highlighted by the research title namely: CP, teamwork, and communication.

Secondly there is the methodology section, which covered theoretical premises, research methodology and procedures. Thirdly the results section is broadly grouped into 2 sections: a theoretical section looking at what is CP and a treatment development section. Fourthly the significance and limitations are discussed before the conclusion. Lists of the main abbreviations used in this study are available in appendix 7.

CHAPTER 2: LITERATURE REVIEW

The literature review focused on the main terms related to the research topic including: Firstly a general definition of pain and then more specifically CP was explored. Secondly questions related to the diagnosis of CP were reviewed. Thirdly the review then explored treatment options for CP. Fourthly, brief definitions were explored for interdisciplinary and multidisciplinary teamwork as well as an in-depth review of TDT its definition and modus operandi.

2.1 Pain

2.1.1 A general definition:

The term 'pain' incorporates a vast array of semantic meanings depending on the culture and context. It is originally derived from the Latin word 'poena' from which the English words 'punishment' or 'penalty' can be derived (Bendelow, 1993). While this might resonate with some of the belief systems of sufferers, it is certainly neither an appropriate nor accurate definition. Bendelow (1993) also points out that there are distinct differences between a lay understanding of pain and professional definitions of this term. In order to effectively treat pain and to communicate as a health team: a shared and accurate definition of pain is needed. In other words one's definition would determine both what was treated as well as how the treatment was conducted. Yet despite our advances in technology, pain remains a bit of a *"proverbial elephant in front of 5 blind people"* (King & McCool, 2004). The International Association for the Study of Pain (IASP 1994) defined pain as:

> "An unpleasant sensory and emotional experience associated with actual or potential tissue damage" (Baranowski, et al., 1994).

This definition highlights a couple of important points. Firstly it has to be an unpleasant experience to be pain. Secondly this type of pain has to be a combination of both a sensory and emotional experience together. Thirdly it has to be associated with tissue damage in some way: either actual or perceived. There are other key features of pain that the IASP does not include in their definition, but is significant enough to further warrant attention, these are discussed below.

2.1.2 Other ideas about pain

2.1.2.1 Pain is a protective mechanism

While popularly pain is viewed as an unpleasant and unnecessary experience it actually serves an important protective purpose. Without the sensation of pain, people could continually injure or hurt themselves (Brannon & Feist, 2010).

2.1.2.2 Pain involves perception

Bendelow (1993) stated that perception incorporates feelings and fears as well as also cultural, existential or religious beliefs. Perception starts before our experience of pain, as we do not just view our sensory and physical environment at face value. To prove this Tabor and associates (2013) did a study using switches associated with certain stimuli. The deduction was that the perception of the type of stimulus or cue associated with the pain had a casual relationship on how the person experienced the pain.

The ‘gate control theory’ (Melzack & Wall, 1965) explains that the experience pain is modulated and is not the result of a linear process. Brannon & Feist (2010) report that the theory explains that modulation occurs in the spinal chord, which can act like a gate either opening or blocking pain messages from reaching the brain. This is influenced by a person’s cognitions and heir own unique pain beliefs.

2.1.2.3 Pain is multifactorial

Researchers have begun to insinuate that the brain thinks and that the brain also produces the sensation of pain. According to Thacker & Moseley (2012): philosophy would conclude that this is a meological fallacy, in other words – this logic is flawed as one cannot attribute the property of a whole being, to one part of the body. Thacker & Moseley (2012, p. 410) state that pain is emergent and: “emergent properties are possessed by the entire systems”. In other words pain is not just a product of the brain, as it takes other parts of the system, interacting with the brain to produce pain and none of the individual units can produce pain on its own.

2.2 Chronic pain

2.2.1 A Definition

Definitions of CP vary, some of the differences may appear subtle but these subtle differences could significantly affect treatment (Huang, Lee, & Chong, 2005). For instance certain studies define CP only based on the duration of suffering, while other studies include other criteria (IASP, June). Generally with CP it is expected that doctors would be unable to find medical pathology or there would be insufficient medical pathology to produce the amount of pain the client is experiencing. CP is generally associated with frequent visits to practitioners, and a lack of results seen from these treatments. Berg, Rogins and Risse (1985) consider it to be a somatization of depression while others say it is the somatic equivalent of depression or an expression of an underlying depression. It would appear that other factors such as environment, psychological factors and all impact with the tissue damage and encouraging continued pain and illness behaviour (Huang, Lee, & Chong, 2005, p. 250). Moseley (2007) also states that the amount of pain felt relative to the physical damage becomes less accurate or correlated, the longer pain persists. The definitions of CP need to be constantly reviewed by what is happening in the latest research (Moseley, 2007).

2.2.2 The Diagnosis of CP

2.2.2.1 Symptom or separate disorder?

Traditionally CP was viewed as merely a symptom of another disease or injury. This paradigm presupposed that CP in itself therefore could not inflict damage or death and therefore treatment was focused on treating the cause in the form of another disease or injury with the expectation that the pain would consequently end as the treatment progressed. Some new studies have however shown that pain could kill and that it often persists beyond physical healing. CP can often lead to more suffering than the original injury (Lynch, Craig, & Peng, 2011). There is debate over whether CP could be a disease in and of itself because of the permanent change to the nervous system and the severity of the symptoms and disability caused by CP. Brookoff (2000) suggested that if it were given a place as a formal diagnosis that it may be taken more seriously by client and practitioner alike.

If treatment is to be successful it is important not to confuse acute and CP, as they require different approaches as they have different origins. Teaching clients to listen to acute pain is an important guide to know when to rest and when to be active. However according to

Whitten and Cristobal (2005) to use that same strategy with CP clients is a “prescription for failure” as CP is not accurately correlated with disease or damage. CP is a separate condition from acute pain as it has its own “pathological changes, … clinical and behavioural characteristics” (Whitten & Cristobal, 2005, p. 43).

2.2.2.2 CP taxes the stress system

Gatchel (2004) stated that “CP is a stressor that will tax the stress system” by demanding constant on-going regulation of the system. This overuse results in the breakdown of muscle, bone, and the nervous system and this in turn causes more pain. When a person is in pain: cortisol is secreted, as per an emergency situation, in order to provided needed to cope with the emergency. This has all sorts of disastrous long-term health side effects. (Gatchel, Peng, Peters, Fuchs, & Turk, 2007)

2.2.2.3 Syndromes

While there is no formal diagnosis called CP, but there are syndromes, which are groups of symptoms (Brannon & Feist, 2010). Brannon & Feist, (2010) list the following pain syndromes: headaches, lower back pain, cancer pain arthritic pain and phantom limb pain. Headaches and lower back pain are more commonly experienced. Accompanying the syndrome may be other diagnosable conditions either medical or psychological. Such as Cancer, Aids, Fibromyalgia, polymyalgia and complex pain regional pain syndrome.

2.2.2.4 DSM-5

Health anxiety, somatic symptoms and pain can be symptom of many psychological disorders. For example generalised anxiety disorder does include the experience of bodily symptoms but the focus of the disorder is not on somatic symptoms. Depressive disorders have somatic symptoms but the depression or low mood is the core symptom. Illness anxiety disorder focuses on the anxiety but not on pain (APA, 2013). Perhaps the closest concurring DSM-5 (APA, 2013) mental health diagnosis to CP is ‘somatic symptom disorder with predominant pain’, this was previously called ‘Pain disorder’ in the DSM-IV (APA, 2000).

2.2.2.4.1 The DSM 5’s somatic symptom disorders

A somatic symptom disorder has a prominence of somatic symptoms associated with significant distress and impairment. These clients are normally found asking for treatment in

medical settings and not in psychiatric or psychological settings. While in the DSM-IV the focus of diagnosing such a disorder was based on the absence or lack of finding of medical reasons for the symptoms – the DSM-5 diagnoses somatic symptom disorder on 'positive symptoms'. Only diagnosing somatic symptom disorder when no medical causation for pain symptoms are found, only serves to reinforce mind/body dualism. It also could imply that the symptoms experienced by the client are fictitious or malingering. Also having a medical reason for the symptoms does not exclude co-morbid psychological diagnoses. These symptoms are very real and incorporate a great deal of suffering and the symptoms are not 'put on' unlike malingering or factitious disorder. Usually clients with somatic symptom disorder have multiple complaints that upset and distress them and their everyday functioning (APA, 2013).

These clients may have excessive worry or catastrophic thinking about their symptoms and spend a great deal of time and energy addressing these fears. They can also appear to experience severe side effects to medication. They can use a great deal of medical treatment and often use numerous doctors to treat the same condition. The impairment can be so bad that it can lead to invalidism (APA, 2013).

2.2.2.5 Alternative and complementary medicine diagnosis

Alternative medicine is becoming increasingly popular with clients. Perhaps one of the reasons is it is a place for the client where the lines between subjectivity and objectivity are blurred and their subjective report is more valued and not stigmatised. Kaptchuk, (2002) felt that the diagnosis in unconventional medicine is more likely to be something that is in line with what the client is expecting. This would also aid healing as it changes the mental and emotional state of a client who is now no longer in the limbo of uncertainty but now has a concrete diagnosis. The ying-yang would be in disharmony or the chiropractor would find the subluxation and thus repairing the self-image and confidence of a client who may have been told by medical doctors that there is nothing physically wrong and that the problem was all in their head (Kaptchuk, 2002).

2.2.3 Therapy and CP

2.2.3.1 Help seeking behaviour of CP clients

A group of United Kingdom (UK) based researchers (Thorstensson, Gooberman-Hill, Williams, & Dieppe, 2009) wanted to determine the help seeking behaviour of CP clients in their local communities. A screening questionnaire was conducted by over 26 000 chronic hip and knee pain clients in the south west of England. Contrary to expectations, most of these clients had not seen their doctors in the last 12 months. Also mental health comorbidities did not result in a significant increase in doctors' visits, as previously thought. Physical disability or reduction in movement, pain severity and obesity were actually the factors that brought clients to see doctors more often. Mobility issues were by far most important factor than any other factor that motivated help seeking behaviour.

Huang, Lee, & Chong (2005) interviewed one hundred clients, attending pain clinics in the USA. The psychiatrist diagnosed 94% of pain sufferers as having a comorbid depressive and yet despite this very few had sought psychological or psychiatric help but more mainstream medical treatment.

2.2.3.2 Medical Treatment

With acute pain the cause or aetiology easier to determine than with CP. This is because CP often has no obvious tissue damage (Brannon & Feist, 2010). Drugs and surgery are the main forms of treatment for CP. While drugs may be the most popular they carry some of the greatest risk. Surgery is only carried out when less invasive forms of treatment has been unsuccessful.

2.2.3.3 Pain and the Psychologist

However for CP to be successfully treated psychological factors underlying the pathology need to be addressed. It has long been thought that somatisation was as a defence for unconscious psychological conflict (Rodin, 1984). Thus it not only experienced by the psychologically ill but all human beings somatise when under stress.

Many theoretical psychological models have tried to explain how pain to develop into a chronic complaint due to psychological factors. Linton & Shaw's, (2011) summary of the prominent models is included in Appendix 1. Most of these models are based on the

biopsychosocial approach, which is seen as the most effective approach for understanding and treating pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). While traditional approaches see the mind and body as separate the biopsychosocial approach does not. Biopsychosocial research concludes that a difficult and complex interaction that occurs between biological, social and psychological process is responsible for the development of CP (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

Disease is an objective biological event; illness involves an individual's perception and experience of the disease. Nociception is the sensation of pain, which is separate from a person's pain behaviour, which is a visible communication of the suffering the individual experiences. Pain therefore can only be truly understood by understanding the person experiencing the pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

2.2.3.4 Complementary and Alternative medicine (CAM)

2.2.3.4.1. Why clients choose CAM?

A survey was conducted to determine why clients utilise CAM. The sample included 1035 people who live throughout the United States and had agreed to be part of a mail survey. The survey tested three hypotheses:

1. That these clients were in some way dissatisfied with conventional medicine
2. They saw CAM as offering more autonomy and control over health care decisions
3. CAM was more in line with the beliefs and values of the clients

The survey also took into consideration demographics, nature of illness and education of those completing the survey. The results showed that 40 percent of CAM users were better educated and held a holistic (mind, body and spirit) philosophy. Generally CAM users were no more or less dissatisfied with traditional medicine than non-users. The single greatest reason for use was the fact that they saw results (Astin, 1998).

2.2.3.4.2 Placebo effect

Kaptchuk (2002) stated that alternative practices work with mind, body and spirit. This creates very broad and vague goals, which makes it difficult to fail. He questioned whether or not alternative therapy is just a super-enhanced placebo effect or legitimate

healing. He was not talking about simple trickery as placebos have real and useful effects that promote healing. The placebo effect could be caused by the climate that alternative treatment has. This includes a good practitioner to client relationship; including compassion and focused attention. As well as the fact that it served to lesson anxiety, increase self-awareness and deals effectively with client expectations. Kaptchuk (2002, pp. 817-818) also suggests the therapy provides a:

> "… performative efficacy (which) ... relies on the power of belief, imagination, symbols, meaning, expectation, persuasion, and self-relationship."

Added to this is the fact that the very type of complaint a client may seek help from a CAM practitioner – may be the very type of condition that responds best to the placebo effect, especially highly subjective conditions like CP. Based on positive results -Kaptchuk (2002) questions whether this is a worthy legitimate therapy and whether the results are more important than the method.

Skevington (1995) felt that people's wariness of the placebo effect was that it made a person feels like they can't trust their senses. However she suggested that it could rather be looked on as the psychological power our mind has. She suggested the placebo effect had a legitimate place in symbolism and imagination.

2.2.3.4.3 Holism

One of the common foundational belief systems of CAM is holism. Aristotle's stated, "the whole is more than sum of its parts" (Health Partners UK/ SA, 2010, p. 1). This is the basic philosophy underlying holism. The whole cannot be understood by dissecting the parts. The whole has a greater quality than just its components and part of this could be understood by the interrelationship between the components as well as the context that the subject finds itself in.

Health Partners UK (2010) stated that the medical fraternity has not accepted holism. This may be because the word 'Holism' is a buzzword used in disciplines like mysticism that are not regarded as scientific. Also so many of the much-needed advancements in medical

science have originated from specialisation, which isolates certain parts to deepen knowledge and accuracy. This reductionist approach is an integral part of science (Dongping, 2007). The debate between reductionism and holism is on going in the scientific communities. At deeper level the choice here says a lot about one's opinion of causality, as to whether one supports causal reductionism or an inter-level causal view (Dongping, 2007).

Astin and associates (1998) did an actual literature review of 25 surveys conducted between 1983 and 1995. Contrary to Health Partners UK they found in America that many mainstream physicians saw the benefits of CAM and were referring to CAM practitioners. The study and the referrals by the physicians however focused on well-known therapies that already are recognised by the department of health and fall under the Allied health registration in South Africa and many medical aids pay for such therapy anyway. The referrals by doctors to acupuncture was 43 percent, massage was 21 percent, and chiropractic 40 percent. Physicians themselves often practised these CAM therapies, with 19 percent using chiropractic or massage therapy and 9 percent using homeopathy.

Holism is however being increasingly embraced by the public and there being widespread acceptance of its benefits. Thus we have seen a lot of growth in complementary medicine (Health Partners UK/ SA, 2010). However if one is to embrace holism in science – one has to have a scientific theory and management plan to implement it. Merely throwing together various components does not equate holism. Modern complexity sciences are working on strategies to "set up new methodology to deal with the world's complexity" (Dongping, 2007, p. 417). In order to truly embrace holism for treatment, teamwork is needed; this is discussed in the paragraphs that follow.

2.2 Teamwork

Two decades of research in the Biopsychosocial approach has highlighted the multi-causal nature of CP and thus encouraged the development of teamwork as a key component of a CP intervention. In fact the British government has been encouraging inter professional teamwork since the 1970's (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002).

For the last 30 years teamwork in general has been promoted as a way to achieve superior results for treatment for clients suffering from CP or other conditions. Common

reasons cited for this include higher rates of client satisfaction, improved staff morale and a greater cost effectiveness (Ruddy & Rhee, 2005). Appendix 2 gives a table outlining different types of teamwork. It is reasonable to deduce that no single person has enough expertise, resources and skills to provide the type of complex and quality care CP needs (Cartmill, Soklaridis, & Cassidy, 2011). As a result of this: multidisciplinary, interdisciplinary, transdisciplinary and other models of teamwork models were developed (Stanos & Houle, 2006).

2.3.1 Multidisciplinary

Multidisciplinary teamwork is when a group of professionals are selected based on their supplementary skills and training. Members of the team work individually strictly on their specific scope of practice. Very little communication occurs between team members but rather individually between a team member and the team supervisor who co-ordinate's and manages the case. This is called 'vertical communication' (Ruddy & Rhee, 2005, p. 248).

2.3.2 Interdisciplinary

Interdisciplinary teamwork tries to encourage team members to communicate more. This is because the model recognises that there is a lot of overlap between roles. Also because the model recognises the sum is more than the parts of the whole. Thus it encourages 'horizontal communication' (Ruddy & Rhee, 2005).

2.4 Transdisciplinary Teamwork (TDT)

Human health is the result of a complex interaction of systems that exist both within (physical and psychological) and outside (social and ecological) of the individual. Thus the findings of specialisation need to be supplemented with an understanding of interrelatedness. In transdisciplinary work the assumption is that health problems do not in reality exist in a single discipline space but rather in a 'transdisciplinary space' (Albrecht, Freeman, & Higginbotha, 1998). Transdisciplinary thinking is about taking all the specialised in-depth knowledge from many disciplines and combining it until we can get the most complex and complete understanding of the problem (Albrecht, Connor, & Higginbotham, 2001) Thus the goal is to create a new 'common conceptual framework' (Albrecht, Freeman, & Higginbotha, 1998) usable by any discipline. Ideally, discipline boundaries disappear altogether or are

‘transcended’ and a new or ‘transdisciplinary’ way of explaining a problem is created (Albrecht, Freeman, & Higginbotha, 1998).

2.4.1 How is the team structured?

2.4.1 High levels of collaboration

TDT involves a greater level of collaboration than other models. This is because the intervention is not structured around the function of the various disciplines but rather looks at the client holistically. In order to create a holistic solution for the client the transdisciplinary team transcends the disciplines.

2.4.2 Client centred

TDT is client centred and focuses on the clients goals with the client being a central and empowered part of the team who is involved at all stages in decision making (Cartmill, Soklaridis, & Cassidy, 2011). Sometimes the choices that the client may make may surprise the practitioners. That is why it is important for practitioners like social workers and psychologists to be involved and have an understanding of the nature and context of the client. Then the team can better support and understand the decisions the client makes. Margaret Dawson Hobbs (2005) shared an example of this from her experience as a social worker. A woman was refusing to take her medication because she was scared it would make her too sleepy. Further investigation revealed that she had young children, and she was afraid she might not be adequately able to care for them while on such heavy medication. So based on this information the team was then able to make other recommendations so that she could take medication and still fulfil her duties.

2.4.3 Creative and unorthodox solutions

With TDT, solutions may be found in unorthodox places and creative inter-professional collaboration my find solutions in the gaps that fall between disciplines. Also people who not usually considered part of a medical team like sports coaches or family members may be called on to join the team as part of the solution. Frequent communication is encouraged both vertically and horizontally. Lay health care providers can be used to lower costs. They can lead what Ruddy and Rhee (2005, p. 250) termed “self-management programs” Completely unique to TDT is the client and possibly their family can be included as team members at all stages of the intervention. (Ruddy & Rhee, 2005)

2.4.4 Flexibility and role swapping

Team members need to have a great deal of role flexibility. For instance overlapping of roles is prevented and the roles are assigned to the team member who exhibits the minimum skill needed to do the task. Thus high skilled scarce skilled members are reserved exclusively of the jobs that only they can do. Cross-disciplinary training is continuous and constant. Team members can thus perform minor screenings or jobs to lessen the need for extra consultations. In fact team members become so familiar with each other's tasks that they can become to some extent interchangeable (Cartmill, Soklaridis, & Cassidy, 2011). Cartmill, Soklaridis, and Cassidy (2011) saw that there was a synergistic interaction between disciplines with a free flow of information and communication.

2.4.2 Who does TDT best serve?

One of TDT's applications has been to service poor, under-resourced or rural areas. It reaches into the gaps between professions and seeks to fill gaps due to lack of specialised resources, By doing this it can provide a fairly comprehensive service at primary care level (Nandiwada & Dang-Vu, 2010). Constant cross training means other team members are more equipped and can perform basic tasks outside of their usual scope - in the absence of their colleagues or in emergency situations. While research supports teamwork in general, there has not been enough research done specifically on TDT in these contexts (Little, 2010). Jenson and Vaughn (2007) in their studies of rural Australia felt that still too much of what is currently practised is done more on an ad hock basis to serve an urgent need. Their opinion was that much work is still needed to make this a legitimate strategy.

Another application for TDT has been in hospitals. Cartmill, Soklaridis and Cassidy (2011) conducted a study on practitioners at an academic hospital in Ontario, Canada. There were four teams involved in a functional restoration program for clients with chronic disabling musculoskeletal pain. Each team had a physiotherapist, a cognitive-behavioural therapist, occupational therapist, a kinesiologist and a return to work co-ordinator. Between the teams there were also doctors and psychologists acting as consultants, one resource specialist and a clinical practice lead. This was a qualitative study, which used the grounded theory approach to data collection and analysis. Data was captured using interviews and was then coded into themes. The data from the interviews with the clinicians concluded that transdisciplinary teams are suitable for treating clients with complex and chronic conditions

such as CP. However there were some crucial issues like organisational backing and communication that needed to be adhered to in order to ensure success. The limitation of this study is that it was only conducted in one setting and so cannot be generalised to other contexts.

Satterfield et al (2009) found that transdisciplinary evidence based practice (EBP) was useful to establish an explicit and rationale process for making clinical decisions. They did this by comparing and contrasting across different practices the strengths and weaknesses of each. They took special note of how the discipline had different processes, content and philosophies. The evidence could be drawn from could be either quantitative or qualitative data depending on the type of question being asked about a practice or policy. However this needed to be weighed up against the team's professional expertise and their collaboration skills and communication skills. As well as how the environment and organisational factors might impact on the success of treatment.

Gibb et al (2002) found that TDT was valuable in the National Health Services (NHS) in the United Kingdom. This is because it fitted in well with the policy and goals of the institution. Gibb stated that the aim of their study was to inform the development of integrated health and social services. Gibb used soft systems methodology that was developed by Checkland and Scholes (2010). He describes their research as an "iterative debate that occurs between the practice situation and conceptual models that leads to decisions about action". The data was collected using focus groups. The limitations of this study are that it did not contain a wide range of different professionals as would normally be seen in a transdisciplinary team.

2.4.3 Barriers to teamwork

The current barriers to team work are numerous and in some contexts may seem insurmountable. These include basic issues like the extra time and commitment it takes to work in a team. "Terminological isolation' between health professions creates barriers as each has different terms, and understandings of disorders (Little, 2010). Thus it may also be difficult to agree on common goals around treatment due to etiological and conceptual differences. Then there are also peer difficulties that come from perceived status inequalities,

which may mean the medical model is favoured within the team or there is conflict around team leadership and decision-making.

There is also currently a lack of data showing the impact of team work or lack of evidence to support the model, this makes implementation difficult as evidence based systems are prioritised by most medical aids and institutions. Difficulties also arise around finances and affordability of having multiple practitioners involved and then payment systems mostly do not currently reimburse members for the extra time that the co-ordination of teamwork demands (Ruddy & Rhee, 2005).

2.4.4 What makes teamwork effective?

Like sports teams, health teams require a great amount of effort and training. The big difference is that a health teams are dealing with people's lives (Nandiwada & Dang-Vu, 2010). Training in teamwork is crucial to effective teamwork but there is currently very little training in healthcare teamwork. A proper TDT curriculum still needs to be developed and there is no consensus yet on how this should be structured (Nash, 2008).

Having clearly defined roles and understanding other team member's scope of practise is also vital (Cartmill, Soklaridis, & Cassidy, 2011). Inequality between disciplines needs to be reduced and the team leader needs to recognise that each member is an expert in their field and needs to be flexible to step back and let those members lead in situations in which they may be the more knowledgeable experts (Nandiwada & Dang-Vu, 2010). It is also vital to decide as a team just how far role blurring and cross-disciplinary practice could or should go (Ruddy & Rhee, 2005).

Cartmill, Soklaridis, and Cassidy (2011) stated that it helped the team if they were all focused on a single type of condition like chronic musculoskeletal pain. That would give the team a specific goal and focus and the team members could then develop as specialists.

Cartmill, Soklaridis, and Cassidy (2011) found that organisational backing was foundational to the success of the team. The organisation needed to hire all members as staff to avoid competition for clients. Standardised systems that guide the structure and procedures

involved in teamwork are essential. This is because it eases the burden of repetitive work such as form filling and other administrative work. It also allows for clearer, easier and more efficient communication between team members. Allowing practitioners to be situated in the same physical location also aids interaction. Part of the strategy could be an open plan office space and a large shared therapeutic space with separate functional areas.

2.5 Communication

Communication has been given a separate section in the literature review as it was a central focus in this research study and is vital to the effectiveness of teamwork. Accurate communication between practitioners on the team as well as between practitioner and client is vitally important.

2.5.1 Communication between practitioners

2.5.1.1 Formal and informal communication

Cartmill, Soklaridis, and Cassidy (2011) found in their study of transdisciplinary teams that both formal and informal communication is needed to sustain teamwork. Formal communication would effectively be the organisationally structured opportunities to communicate like rounds, meetings, report and chart writing. Informal communication takes place between team members whenever the opportunity naturally occurs. This gives an opportunity for practitioners to support each other with sharing knowledge but also a chance to vent frustrations and difficulties. This is a vital part of maintaining the mental and emotional health of all involved (Cartmill, Soklaridis, & Cassidy, 2011).

2.5.1.2 Language

Language is foundational to communication. Nash (2008) stated that team members needed to be able to understand the language of all the different disciplines involved in order to be effective. This takes a lot of time and can be very frustrating and confusing. Nash (2008) also mentions the need for a hybrid language to develop. This is a language that utilises all the core components of the different disciplines – as well as aspects that might be unique to TDT.

2.5.2 Communicating with clients

2.5.2.1 Measuring pain

It is important that the practitioner is able to accurately understand how much pain the client is in. Most practitioners reportedly underestimate the amount of pain a client is in. It is also inaccurate for the practitioner to merely judge this by listening to an unguided subjective rhetoric led by the client. Thus communication techniques for reporting pain have been established. These include self-report ratings, behavioural assessments and psychological measures (Brannon & Feist, 2010). Skevington (1995) states it is important that these measures while trying to be objective do not lose the subjectivity of the client's experience. Measuring not only helps practitioners to understand the amount of pain but also creates a base line to check for improvement. Thus measuring is vital to evaluating how well the treatment is working (Joint Commission, 2003).

2.5.2.2 Communication and compliance

One of the most common reasons for a client's non-compliance is poor communication between client and practitioner (Brannon & Feist, 2010). Knowing barriers to compliance with treatment helps to improve future interventions. Good client centred communication has been associated with fewer client concerns, better emotional health and a decreased need for diagnostic testing (Matthias, et al., 2010). The initial goal of the practitioner's communication should be to form a successful client-practitioner alliance (Brannon & Feist, 2010). A client needs to know that the practitioner has really understood their complaint and that they have been included in the decision making process by the practitioner. This results in the best compliance and thus a greater chance of success in the treatment process.

According to Thacker and Moseley (2012) a common complaint from clients is that the practitioner did not truly listen. This creates a great risk of client dissatisfaction and disempowerment. It also encourages an "*up-regulation of … protective systems, most notably the nociceptive pain system."* (Thacker & Moseley , 2012, p. 410)

2.5.2.3 Communication struggles for practitioners

Most of the focus of the literature in this study has been focused on meeting the client's needs around CP. An important part of meeting those needs however is to ensure that

caregivers are properly supported. A study (Dobscha, Corson, Flores, Tansill, & Gerrity, 2008) was conducted of a relatively small sample of conveniently selected Doctors who had been involved in randomized clinical trial (with War veterans in Oregon and Washington, USA.). The results revealed that while 77% felt that treating CP was a high priority, 73% of the practitioners found clients with CP to be a major source of frustration and 38 % also were dissatisfied with their ability to treat CP clients. The study suggested the disparity between interest and satisfaction showed greater support was needed for these practitioners.

The literature showed several challenges for practitioners when communicating with clients. A study was done at a Medical Centre in Indianapolis, Indiana, USA on client to practitioner relationships in CP cases (Matthias, et al., 2010). Twenty practitioners were selected on specific criteria. They had to be from different clinics from within the centre, and have different ranges of experience, as well as equal male and female representation was deemed necessary. Sampling continued until no new themes emerged from the data. This qualitative research was thorough in their thematic analysis using a team to compare results. This study provides useful information as to the feelings of this particular group of providers but further studies would need to be done if one is to generalise this beyond this group. What was found was that the provider's needs should not be ignored if CP care is to be improved. CP clients tend to have long-term relationships with their practitioners. Many of the practitioners complained that this was a thankless task, saying that interactions with clients often felt strained and unproductive. They described them as a 'difficult' client group. Firstly it was difficult to feel effective as they were treating a chronic condition. Secondly, practitioners could only rely on the client's personal report. With no objective measures for pain there was room for scepticism on the practitioners' side and deception from the client. Doctors often felt guilty about not prescribing medicine, or concerned when they did. Often clients would become abusive and angry when doctors did not grant their requests. Concerns centred on whether the 'narcotics' would be illegally sold on the street or if clients were faking their symptoms to get disability grants. Sometimes clients did not seem to want to get better because they would lose disability benefits. (Matthias, et al., 2010)

The focus of this thesis was more experiential thank literature based as the research question for this thesis was: 'what are the insight and experiences of all participants in their initial attempt to establish transdisciplinary communication (TDC) to aid the development of

a holistic CP program?' Which meant that data capture needed to go beyond reviewing literature. The type of study, the goals and the vastness of subject all needed to be factored into the research design. This is discussed in the next section under methodology.

CHAPTER 3: METHODOLOGY

3.1 Theoretical framework and research design

The theoretical framework of this study is primarily qualitative research using thematic analysis based on Braun and Clark's (2006) six-phase guide. Inspiration from certain qualitative research sub styles was also incorporated, such as the value of reflexivity, action research and soft systems methodology. However, the study is not based on those research models.

3.1.1 Qualitative Research

This study incorporated qualitative methods of data collection and analysis. The value of qualitative as opposed to quantitative methods is sometimes questioned in psychology and psychiatry, but it could be viewed rather as complementary rather than contradictory. Rutter (2006) states that the 2 fields are merely asking different questions. Qualitative studies are more interested in the how, what and why; while quantitative studies ask questions relating to issues such as quantity and frequency. This study was interested in accessing the participant's perceptions and recognized that those perceptions were based on a person's subjective experience but that the subjectivity did not invalidate the data. Rutter (2006) stated that much of diagnosis in psychiatry relies on qualitative interviewing and therefore it should also be valued in research. Thus qualitative methods rather than being limiting, allowed the researcher to create an environment where perceptions could be voiced in a social context. The qualitative method is less interested in finding universal patterns or laws of human behaviour but making sense of human behaviour within a context. This data cannot be understood separate from the context it was created in, which has its unique social experience, language and history. (Terre Blanche & Durrheim, 2004, 398)

While this study was not action research (AR), it had some important foundational values that motivated my research. AR has been referred to as more as an approach than a method which values equal levelled co-collaboration (Ballinger, Yardley, & Payne, 2014). Action research originated with Kurt Lewin in the 1940's in the industrial context. He included workers as equal contributors in the problem solving industry difficulties (Adelman, 1993). In the medical industry, which sometimes can typify bureaucratic control, it felt

attractive to introduce the idea of democracy. AR values the input of people who are living in the situation that is being researched. This is because they have invaluable knowledge that no one else has. Thus the involvement of both clients and practitioners who are involved in the trenches of dealing with CP, was not just about equality, but it was scientifically important as both their experiences provided valued data for the research.

3.1.2 Reflexivity and the position of the self

A lot of time was spent considering where to place 'myself' in this research. Finley (2003) in her book on reflexivity reflects a similar struggle to 'position the self' in research. She questioned whether it was realistic, possible or necessarily desirable to be "objective". Finley and Gough (2003) state that the researcher is drawn into the research because of their passion. That passion comes largely from whom they are and their experiences. After a personal injury requiring reconstructive surgery, I realized how physical pain caused suffering which potentially changed a person's life and affected a person's psyche. I can all too well relate to the gripping effect of pain on every aspect of one's life, leaving a person's body constantly on edge, with the parasympathetic nervous system raging in full force. Then there is the confusion of trying to find appropriate help and the fear of the practitioner dismissing one's concerns. This short period of time was a turning point that showed me a great area of need and motivated me to pursue clinical health psychology. Consequently one of the aims was to see the impact that psychological interventions could have on CP, as well as how psychological mindedness could impact the treatment strategies of doctors, surgeons and other practitioners in the field. I especially contemplated how simply having empathy and listening to clients could impact a treatment process. I felt that clients should not just be bystanders in the treatment process but active participants with opinions to be heard and understood.

While CP may be a confusing concept to some practitioners, psychologists are used to working with subjective reports and conditions that apparently manifest mostly in a person's mind. With CP sufferers seeking help mostly in the domain of medicine, it seemed suitable to bring a qualitative study into a realm that did not initially understand the value of subjectivity. It is with this in mind that I have included a focus on reflexivity in the study.

However, the impact of my reflexivity needs to be acknowledged and especially the negative aspects. Reflexivity has been described by some literature as a swamp that needs to be carefully negotiated (Finlay, 2002). To balance this reflexivity I have included a couple of strategies. The results from previous sessions where shared with the participants for their comments at the onset of the following meeting. This was to check that the interpretation was an accurate reflection of what the participants where saying. I attended psychotherapy, which became partially a supervisory role and ensured that my issues where processed and that I held in mind how my own experiences where impacting the interpretation of the research material. Throughout the process the physiotherapist's opinion was consulted in order to balance my own reflexivity. Of common concern with reflexivity is whether the researchers own opinion has overshadowed the participants. Also this style may subtly suggest that only the reflection of the researcher matters and that the researcher has more authority on the subject matter or is more knowledgeable than the participants. It can easily become a narcissistic self-centred approach (Rutter, 2006). The researcher attempted to balance these pitfalls by linking personal opinion and experience to current literature throughout the discussion.

> "Reflexivity, like hypnotherapy, has various levels… Some dabble near the surface, dipping into reflexive moments... Others attempt to confront the fear of the monster lurking in the abyss by descending into the deeper realms of reflexivity." Macmillan 1996 as cited by Finlay (2002)

3.1.3 Research Design

The design and methods used by this exploration where inspired by the research study done in the British NHS (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002). The original study used Soft Systems methodology (SSM) that makes use of a continuous learning cycle. Firstly, a real life problem situation is identified. Secondly, the team then jointly constructs a solution and then thirdly takes action to implement change. After a period of time the cycle starts again by evaluating progress and relooking at the problems (Checkland & Poulter, Soft Systems Methodology, 2010). SSM as a methodology is particularly effective in social and organisational settings and gives particular focus to the existence of conflicting worldviews (Checkland & Scholes, 1995). See Appendix 3 and 5 for further information on SSM. SSM creates an:

> "Iterative debate … between the practise situation and conceptual models that leads to decisions about action." (Gibb et. al., 2002, p. 6)

This study was however not an AR study and did not incorporate the full soft systems methodology as the original study did. Firstly the researcher was not an active participant, nor was there practical interaction with a problem, as a treatment program was not established. The goal of this exploratory study was only to capture the first initial planning phase and it seemed that an open ended wide introductory discussion of the topic was a good way to explore the topic. The goal of this exploratory study was to capture the first initial learning cycle of the team in the planning phase. It was up to the individual practitioners and managing owner to continue the development process after the research was completed, as they continued to tackle the challenges of developing something in their local context. This was not to be part of the study. After the research process the practitioners began a limited amount of collaboration. Over the course of the development process, several other groups have been run modelled on the same format as the original two. These where not recorded and did not form part of the research. There has also been a psycho educational training for clients and practitioners on CP at the wellness centre.

3.2 Population

This study's population was small and consisted of a group of private practitioners who operated from a wellness centre in the southern peninsula region of Cape Town**.** They were either registered with the Allied Health Professions Counsel of South Africa (AHPCSA), Health Professions Council of South Africa (HPCSA) or other bodies. The population for the study also included the clients who received treatment at the wellness centre for CP from the physiotherapist.

3.3 Sample

Three strategies where employed for sampling that is: convenience, quota and judgmental sampling (Terre Blanche & Durrheim, 2004). Firstly the sample was conveniently chosen, based on the participant's availability and a willingness to participate. Those chosen had to have been directly impacted by CP in some way. Therefore the sample had to be 'issue owners' (Checkland & Poulter, Soft Systems Methodology, 2010).

In this study there where three groups of ‘issue owners’: the clients, the health practitioners, and other supportive people that formed part of the treatment team. Therefore quota sampling was used. Quota sampling simply ensures that an appropriate representation of each subgroup is present in a study (Terre Blanche & Durrheim, 2004).

As stated, the first group was the CP clients. The pain had to have been created, exacerbated or maintained by both physical and psychological factors. The study was originally going to be limited to three clients, but the data coming from the clients was so informative that five clients were included in the initial interviewing. The health professionals who potentially could be involved in the treatment team in the future were the second group of issue owners. It was deemed essential to have at least three professionals at any point in the study. During the course of the study a MD specializing in integrative medicine, a physiotherapist, a psychologist, an occupational therapist and a chiropractor took part. Depending on their availability they participated in different sections of the process.

The third groups of issues owners were four other people who are not directly involved in professional treatment but provided support to the clients. In this study we had a family wellness coach, a Pilates instructor, an intuitive energy healer and a person who studied equine assisted therapy.

Judgmental sampling was also a very important principle employed. This process simply means purposely-choosing individuals from the population based on knowledge and judgment. The expertise of the physiotherapist, whose clients were participating in the research, was used to select the sample (Terre Blanche & Durrheim, 2004). Her choice of clients was based on her judgment as to whether their CP had psychological aspects impacting on it. The clients also had to be fairly robust and they needed to be able to endure and benefit from the research process. Also the physiotherapist needed to judge whether the support team members and practitioners involved were in the best interests of the client. Thus the physiotherapist was an important doorkeeper in the research process and especially the selection of the sample. The total sample size was within the original proposed limit (9-15) and ratios with 12 participants in total.

Exclusion criteria for the clients were: that they needed to be robust and capable to participate without negatively impacting on the treatment progress and they needed to be clients of the physiotherapist. Inclusion criteria were that they needed to have CP, with mostly psychological origin. For the practitioners and support team the inclusion criteria was that they needed to be involved in the centre and willing to participate in the study. The exclusion criteria, for practitioners and support team members, was that their expertise needed to be helpful to the CP clients. Inclusion and exclusion was left to the discretion of the physiotherapist.

3.4 Data collection

Various types of data collection were be used to create a rich picture of the process (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002). In this study, individual interviews, a focus group and a collaborative working group (CWG) were originally planned and employed to capture the insights and experiences of the participants. However introspective and inter subjective reflexivity as a fourth source of data came to the forefront (Finley, L & Gough, B). This was because in the process of trying to co-ordinate the research process, I found a lot of my responses to the interactions as well as my internal reflection as helpful. This was captured immediately after the sessions but also as I went through the recordings to transcribe.

3.4.1 Interviews

Interviews were conducted on 5 clients, 4 practitioners and 3 support team members. The purpose of this was to capture individual ideas from the different backgrounds of experience and training of the participants (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002). As the purpose of the interview was to capture the depth of individual ideas and experiences, a semi unstructured interview was conducted with simple open-ended questions per session based on the research aims (Terre Blanche & Durrheim, 2004). Appendix 4 contains examples of what questions were asked in the interviews and group sessions.

Five clients were interviewed at the start of the process to capture their individual understanding of CP. This was to give them a chance to express their experiences of treatment in a confidential setting. It was hoped that these interviews would also offer

security to the participants as it provided an opportunity for them to voice any concerns. The interviews, though not intended, had a therapeutic benefit to some of the clients who found further personal clarity through discussing their insights and experiences.

3.4.2 Focus Group

A focus group (FG) discussion was the first of the group processes. It was used as a means of collecting data and 3 practitioners and 3 support team members attended. A FG is a group that shares an experience but is not naturally constituted as a group (Terre Blanche & Durrheim, 2004, 388). The wellness centres professionals were rental tenants who shared an office complex. They were not a collaborated treatment group. The point was to take a group who have a shared experience of sharing office space and bring them together to collaborate. The gatekeepers that were recognised in this context were firstly the wellness centre management /owners, secondly the individual professionals and thirdly the respective ethical standards of the boards of the professionals involved.

The aim of the FG was to create a joint conceptual understanding of the problems around fragmented care, and what CP is and how theoretically it should be treated. While the FG's goal was intended to be more theoretical and idealistic – it was almost impossible to avoid discussion around treatment strategies as the professionals were earthed in the practical real life problem solving needs of their practices (Elliot and associates, 2005).

A semi-structured questionnaire was used to shape the direction of conversation in the FG. The questions were mostly open ended in attempt to draw out from the members their own professional or personal understanding of the matters at hand. The aim was to do this without being over directive or leading and thereby possibly missing the unique worldview or understanding that the individual contributed to the team (Terre Blanche & Durrheim, 2004, 296).

The FG drew out the inter-subjective experiences of the professionals. It attempted to focus on both commonality and differences between participant's viewpoints (Terre Blanche & Durrheim, 2004, 388). The researcher facilitated the group. Two reliable recording devises were used to get an electronic audio recording (Blanche & Durrheim, 2004, 390).

A big advantage of the FG approach was that it encouraged teamwork and modelled a method of transdisciplinary collaboration. Professionals experienced what it was like to collaborate with one another even before actually commencing transdisciplinary practice. They were able to build on each other's ideas and get a better idea of the viewpoint and strengths of the individuals in the group.

Difficulties were finding a time to get all the busy professionals together. Due to time constraints of both the professionals and researcher, only one FG was planned and one collaboration group held. Creating the transcript from the audio recording was susceptible to human error and both the transcription and analysis was very time consuming. Sound recordings were occasionally inaudible as people talked over each other. Then there were the usual group dynamic problems such as people hoarding conversations, misunderstanding, diversions and potential arguments that were diverted to other meetings. Depending on the reader's viewpoint on qualitative research, the subjectivity of the opinions of the group could be viewed either negatively or positively.

The Focus groups allowed for perceptions to be shared in a social group context and they then became open to adjustment and reinforcement by other group members. Thus focus groups also had a transformative aspect in that the perceptions of the individuals changed as they collaborated. This process could also empower the professionals involved with a means to continue with a process of implementing and discussing the development of a CP treatment program (Denzin & Lincoln, 2011, 233).

3.4.3 Collaborative Working Group (CWG)

A CWG followed 2 weeks after the FG. It followed the same principles as the FG but it focused less on theory and more on developing a general working model for treatment. This was challenging and the group only highlighted areas or an outline for potential practice, which would need further study and collaboration in different areas before development could be finalized. It was suggested that the team delegate different areas to different team members to develop or consult external professionals regarding this and then feed back to the group. Areas of enquiry such as ethics, business agreements, IT systems and premises could be referred to outside expertise. These could be discussed in a later FG. This was not part of

the scope of this study but would help carve the way forward for development of transdisciplinary practice.

3.5 Data analysis

3.5.1 Thematic Analysis

A large part of the aim of the study was to capture the themes and meanings that reflected participants' views. At the end of every group and interview the facilitator verbally summarize the discussion and ask for verbal consensus from the group. The discourse was audibly recorded and transcribed verbatim. Then it was thematically analysed and divided into themes. It was originally intended to give a summary of the main themes to participants with the opportunity to contemplate the meaning of the data and add to or object to any of the content (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002). However most group members only commented during the group sessions and did not have time to comment outside that space.

Throughout the study: Data analysis broadly followed Braun and Clark's (2006) six-phase guide. Initially after every stage of the data collection, the discourse was transcribed verbatim and the researcher familiarized herself with the data by coding and analysing it for themes. Pertinent themes arising from the interviews were fed back to participants both by written report and verbally at the FG and CWG. Participants were given the time to comment on them. These themes were constantly reviewed throughout the planning process. After the consensus was obtained at the CWG the themes were finalized.

3.5.2 Coding

Due to the substantial amounts of data that was transcribed from interviews, focus groups and CWG: very specific parameters needed to be set around coding. Coding was done with the research questions in mind. In other words only codes, which directly answered the research questions in some way, were used. Also mainly deductive coding was used initially. This is the idea of coding based on existing theory was used in order to prevent 're-inventing the wheel' (Bauer & Gaskell, 2000). So themes were sought based on what was found in existing literature. For example the IASP's definition of pain was used to analyse the results around defining CP in the initial interviews, these were then in turn compared to the results from the group processes. So there was systematic comparison both between the literature

and interviews and the group processes. Inductive coding also was used to extend to extra code that were not found in the literature in order to allow for the research to reveal new ideas (Joffe & Yardley, 2004). An outline of codes and themes from the data is available in Appendix 6.

3.6 Procedure

Firstly the physiotherapist identified potential participants, whom she verbally invited to join the process. Once interest was shown, she emailed them an official invitation document (see appendix 5), which was jointly compiled by the researcher and the physiotherapist. This document introduced and explained the research and the treatment process. Participants were invited to email any questions to the researcher or the physiotherapist. Informed consent and a confidentiality agreement were also included in the document. The identity of the approached clients was not disclosed to any participants until the physiotherapist received their consent form, confirming in writing that they were willing to participate. The researcher obtained consent from both the practitioners and support team, and the managing owner.

Individual interviews were then commenced before any introductory talk. The purpose of this was to give them a chance to express their experiences in a confidential setting and to ensure that the individual understandings and experiences of CP were captured. All the individual interviews were recorded using digital audio recording devices and transcribed into text by the researcher. The transcribed interviews were individually thematically analysed, and summarized into main themes.

The next process was the FG, which was run on a Saturday from 9am to 3pm. The intention was to include time for participants to get to know each other, give feedback from the interviews, and have focused discussion. As originally planned summarized themes from on-going individual interviews with the clients were fed back to the group and formed a foundation to the group discussion. The vastness of the data from the interviews was problematic as it was important not to dominate the short amount of time available. It was also important to consider what could realistically be absorbed in the session so as a result

only a few very prominent themes that were directly relevant were discussed. After the FG again the recordings were transcribed and coded and summarized.

A CWG was held two weeks after the initial FG. This gave time for reflection on the previous session (Gibb, Clarke, Cook, Morrow, Gertig, & Ramprogus, 2002). Again a summary of the data gained from the FG was shared. While the FG established a conceptual framework, the CWG established a general working framework for treatment.

In order to respect the time constraints of professionals' further discussion was encouraged in a private closed internet based chat forums (email, Facebook and Whatsapp) While the online communication was useful to pass on information, arrange meeting times and short reflections. It did not facilitate deep discussion and the discussions did not form part of the research data. Lastly all the interviews and groups codes were combined and reviewed to obtain the final codes

3.7 Ethical considerations

The HPCSA (2006) has strong guidelines as to how research should be conducted in the health arena, and these are highlighted in the paragraphs below. Firstly the principal investigator should be HPCSA registered. Onsite this is the physiotherapist who will at all times ensure that ethical guidelines are maintained. All the professionals involved, were each trained the in the ethics of their individual discipline informed by their regulations bodies as well as health practice ethics in general. Thus to inform this process, at every stage and in every interview, and group meeting, space will be made for the professionals to address any ethical issues.

No treatment was conducted as part of this research, as the researcher writing this report was not yet HPCSA registered and therefore was not allowed to practice in association with HPCSA professionals thus care was taken at all times to clarify the roles of all involved.

As per HPCSA (2006) requirements the study needed to ensure that the risks of the clients are reduced and the benefits increased. The client's interaction with the research process was minimized and data captured from clients were limited to carefully monitored individual interviews. Individual interviews of clients, as apposed to group involvement

ensured that the client's sense of wellbeing could be monitored throughout the process and adjustments made accordingly.

Informed consent was obtained at the outset of the study and all participants were informed that they could revoke their consent at any time. The principle of continued consent was also employed. Due to the multiplicity of participants involved confidentiality could be guaranteed but every means possible was taken to ensure this. Requirements regarding confidentiality were outlined in the information form (see Appendix 5) and all participants were required to sign a statement saying that they will respect confidentiality for both of the identity and discussions of participants. The report and final thesis does not include any identifying information of participants and only general summaries of the themes and findings. To support confidentiality all data was stored on a password locked computer and a secure online storage facility with access for only the authorized participants.

CHAPTER 4: ANALYSIS AND DISCUSSION

An outline of the themes in this section is available in Appendix 6. An analysis for the themes is included in this section. With certain themes a small sub-section of discussion was included only where it was deemed to be of importance to have a discussion or that it added clarity to the analysis.

4.1 Developing Theoretical foundations of practice:

It was important to have a unified theoretical base before beginning a joint treatment venture; this seemed to be foundational to the process. Theory guides treatment, enables communication and helps develop a unified approach in a team. This was a lengthy process, and ‘ was hard for the group to reach consensus and the task in its entirety was too ambitious for a brief exploratory study. The results discussed below reflect what one might be able to do given a more focused study just on theory. The discussion involved widely accepted/ research based definitions as well as the participant’s own experience. This collaboration of ideas reflects the unique type of results and perspectives one can develop through a transdisciplinary approach. This theme emerged from the discussion as participants were asked to answer the question: ‘what is CP?’

4.1.2. The basics of CP

4.1.2.1 CP is about chronicity

It was easy for the team to agree that CP is Pain that extends past the expected time frame for healing, and this is also a standard definition in most literature (NIH, 2011). Most of the group members felt that CP had to do with a time frame but the exact length differed amongst practitioners and varied between 1 and 6 months. The Medical Doctor (MD) stated:

> AL: “The chronicity (of CP) … is that it is carrying on longer than a practitioner may have expected it to, with their reference of how a particular imbalance or malfunction eventually gets better.” (Al int 1)

The holistic healer felt that the time frame that determined if pain was chronic should be relative to each individual and what he or she perceives they can cope with. She reported that some people may feel the suffering sooner than others. Both practitioners and clients

agreed that it is harder to deal with pain when your perception is that it is here to stay or that it is a chronic immovable condition. This perception only adds to the suffering:

> M: “You know short term pain you can kind of cope with … but if it goes beyond a certain time (it becomes difficult to cope). And I think that certain time is relative to each individual and each circumstance.” (M int 1)

4.1.2.2. CP is limiting

CP was seen to have a significant impact on many levels of a person’s life. Every day activities are affected and a client with CP could feel the need to be avoid or alter certain activities because of the pain. With CP it is not a healthy avoidance of activity to prevent further injury, rather it is a permanent avoidance of necessary everyday tasks. This means that the condition becomes debilitating and reduces the person’s ability to function independently. The Pilates instructor also noted that strong compensatory movement patterns resulted in muscles shortening and created other injuries.

> J: “In CP… when someone has developed a strong compensatory movement patter…they always look left … and now when they try and look right they realise that over the years the muscles have shortened and they can’t do that.”(J int 3)

> J:“ Someone stopped doing something they have always done in their lives…example is they … can’t carry their handbag anymore, … they have to put everything into the trolley…So it is an everyday thing – that they realise...”(J int 2)

4.1.2.3. CP is unconscious and genuine pain

Most of the team felt that CP was an unconscious and automatic:

> J: “I know a very big percentage of my … CP client’s (pain is) psychological… not made up (but) genuine pain.” (J int 6)

The healer felt that the person is not able to be honest with himself or herself on some deep level and so it results in the experience of pain: If the person were able to face the problem consciously, they would not have CP:

> M: “Because I am a man I shouldn’t cry or… feel those things … be honest with yourself and if you can do that now you wouldn’t have a problem…” J: “... So in terms of CP – a lot of CP sufferers struggle to have a voice other than in CP?” M: “Yes.”(M int 9)

4.1.2.4 Discussion

In essence the basic agreement around CP was that it was pain that went on for an extended time period and it had a limiting effect on the clients life. The group agreed that it was genuine pain and not malingering or factitious in that even if there was no physical source to explain the pain, that it was then subconsciously rather than consciously produced. Either way the experience of pain was extremely painful. This is keeping with main stream literature ((NIH, 2011) and a basic premise that is useful to build on. The healer’s idea that CP represented some unconscious issue that the client was unable to face is valid and represents the idea of somatization. Somatization is:

> “ … a tendency to experience and communicate psychological distress in the form of somatic symptoms and to seek medical help for them.” (Lipowski, 1988)

4.1.3. Further Ideas about CP

4.1.3.1 CP is a relationship

The psychologist promoted the idea that a client has a particular relationship with their pain:

> Da: “If I look (at CP) from a psychological point of view… they were struggling with their relationship with the pain … how are they relating to the pain… how they are thinking about the pain – how they are feeling about the pain … do they try and make it worse, (or)…take it away, (or) get … overinvolved with it?? (Da int 1)

While the psychologist explicitly used the term ‘relationship’, other participants demonstrated or mentioned different types of relationships people could have with their pain. The physiotherapist related that clients were stuck in a repetitive pattern:

> Ad:“(CP is a)…repetitive pattern or a cycle…” (Ad int 1)
> Ad: “(CP is a)… loop that keeps on running … like a record that gets stuck.” (Ad int 5)

This pattern was problematic, as the cycle would continue without improvement to the client’s condition. With the feeling of being stuck comes the feeling of suffering:

> Al: “That perception that CP would go on forever is one of the features of what causes…. suffering … suffering would be that feeling of being stuck within a symptom”(Al int 2)

The healer, who is also a CP sufferer, retorted that part of the reason that her CP has improved is because she has changed the way she relates to it:

> M: “Because I am not tense and fighting with it, we… survive together with lots of bad language.” (CWG 6)

Practitioners noted that there were often “ two extreme” patterns of relating to pain that typified the CP sufferers:

> Ad: “(With CP there are) two extremes…(namely:) avoidance and overwork.”(Ad int 9)

The above means that sufferers either had pain as part of a subconscious attempt to avoid dealing with the responsibilities of their life or those who injured themselves because of overworking and not caring for themselves. There was a sense that this type of relating may be a pattern for the client and that they may have also related to significant others in their life in a similar way:

> Da: “Does it remind you of anything in your past - where you related like that (before)?”(Da int 3).

Perhaps the nature of the relationship a person has with their pain, determines whether or not it is CP. In other words CP is a type of relationship that someone has with his or her pain. According to the Oxford dictionary (Oxford Dictionaries) a relationship is “the way in which two or more people or things are connected, or the state of being connected”. Every person has many levels and types of relationships both with themselves, others, society, culture, and objects. Very little occurs in isolation from relationship. Relationships are a needed and unavoidable part of human existence (Meyer, Moore, & Viljoen, 2010). The way one relates is a key part of a person’s personality and is therefore relatively stable and predictable (Meyer, Moore, & Viljoen, 2010).

4.1.3.2 CP starts with failure

Practitioners and clients both reflected that the diagnosis of CP is given when there is a failure of treatment. CP then becomes the logical explanation. It seems that the client blames the practitioner for not seeing what is truly wrong with them and that the practitioner blames the client’s mental and emotional condition for the reason why the client is not recovering:

> Ad: “So (we do) all the … normal physio treatment … but our client’s … pain is not improving and everybody starts to feel like failures, (and) starts shifting blame and they (the client) keep on searching and we keep on not being able to provide answers…which leads to a lot of frustration.” (Ad int 8)

On reflection: a diagnosis of CP based on not finding medical causation is open to a lot of abuse. Jean Martin Charcot’s theatrical and popular early studies around hysteria meant that every non-understandable behaviour women betrayed began to be classified as hysteria (Herman, 1997). So this understanding of CP has the remnants of such ‘antiquated’ definitions that typified the pioneering into a new space. It seems ‘cocky ‘and ‘brash’ to use such a definition when science has so many gaps and there are still many unknown illnesses and conditions that need to be discovered. Yet that “brashness” perhaps typifies the bold

claims of certain practitioners and medical institutions that claim control over so many. The DSM 5 states:

> "The presence of somatic symptoms of unclear aetiology is not in itself sufficient to make a diagnosis of somatic symptom disorder." (APA, 2013, p. 314)

4.1.3.3 CP is a system imbalance

Practitioners described people as having different layers or systems of being and several members of the group felt that when CP occurs, several layers of that person are involved or affected including:

S: "physical, mental, emotional…" (S int 5)
M: "…. as well as possibly spiritual." (M int 15)

In the group discussion it appeared that it was sometimes difficult to establish the origin of the pain. However most participants felt that the pain affects every part of a person's being and existence. The Pilates instructor stated that she considered physical causes to be the least likely origin for CP and the MD related that CP was an imbalance:

> J: "The imbalance of lifestyle …has created the problem and eventually … I think there is a lot less that is first a physical problem …like a structural problem … very few of my clients had the structural problem first, I think usually it is all this other stuff …" (J int 7)

> Al: "(CP is an imbalance in)…one of the various areas that make up people" (Al int 3).

Some of the practitioner's alluded to the idea that the ailments in the body were in fact communicating something deeper for the client. The healer described this phenomenon as body wisdom and stated that the body's way of communicating is through illness, pain, and a tight muscle for example.

> M: "Sometimes the body responds quite aggressively with pain in order … to get you to notice…. the body knows what it is doing. Its subtle as far as consciousness goes but the body has a wisdom of its own." (M int 6)

The wellness coach stated that the body could be seen as a physical manifestation of a person's unconscious mind:

> S: "Your body is your physical manifestation of your unconscious mind… (and) physically it holds what's going on for us unconsciously … whatever we feel in our heads we can feel in our bodies as well." (S int 6)

She also stated that pain finds a plausible spot in the body to exist:

> S: I think (that when) people develop CP, when they have been very stressed for a long period of time and that area of the body that is vulnerable or … weak, …because they had an injury when they were a child, or something that happened years ago … That's where CP is going to sit – but there is often … physically nothing wrong." (S int 6)

Looking into the spiritual was considered important as a potential place to find causation and consequently therefore a way of finding healing, the MD stated:

> Al: "people can approach CP through spiritual healing too." (Al int 4)

There seems to be a growing move in healthcare towards incorporating a holistic approach. Included in this is there awareness of the spiritual aspects of the client. Dr. Shultz (2005) notes that we live in a unique time, in this information age, were we have access to so much more knowledge than we did before. People have access to both traditional and scientific forms of knowledge. She reports that we can deal with what appears to be conflicting types of knowledge in one of three ways. Firstly there can be conflict, secondly overpowering of traditional knowledge by western medicine or thirdly a creative merging. She concluded that:

> "As these different cultures and different worldviews converge, we can begin to see the birthing of a creative solution to many of the problems we face today." (Schultz, 2005)

4.1.4 Is CP a new form of PTSD?

When participants were discussing CP symptoms, it seemed that they were mentioning a lot of Post Traumatic Stress Disorder (PTSD) symptoms. While initially it was not grouped or named as PTSD symptomology by the group there was growing awareness of similar symptoms that became prevalent through the analysis of the data. Once the theme became apparent and was discussed by the group, the transcripts of this research were analysed using deductive coding. The DSM-5 (APA, 2013) criteria for PTSD were used as the framework for coding in this section. CP and PTSD had 4 elements in common. They were: direct or anticipated exposure to trauma (criteria A in DSM-5), re-experiencing (Criteria B in DSM -5), avoidance (Criteria C in DSM-5) and hyper arousal (Criteria D and E in DSM 5). Dissociation, a specifier in DSM-5 is also a common occurrence in both CP and PTSD.

4.1.4.1. Exposure to Trauma

The first requirement of the DSM for PTSD is direct exposure to trauma. The CP clients reported in the interviews that they had been exposed to some sort of significant trauma which was either physical or psychological or both. It may have also have been an earlier emotional trauma and then a subsequent physical trauma with poor recovery and lingering CP. Some of the clients stated that they developed CP because of unprocessed emotional trauma from earlier years. However all of the clients interviewed had experienced a life-threatening trauma, which could have potentially put them at risk for PTSD. Some also highlighted that the experience of the accident or illness in itself was a significant trauma that they had overlooked.

> De: "Well I have actually had about 6 near death experiences… and I never thought about that until I was reading the other day" (De int 9)

> K: …That toes thing (amputation as a result of gangrene) … that was the biggest experience of my life! (K int 8)

> Deb: "...And it ended up being an absolutely horrific marriage… he was…violent and controlling … so my son and I ran away - it was the only way to get out of there alive… the only way that I could survive it without breaking down completely was by pretending this never happened … I just absolutely blocked it out… so trauma definitely I understand is part of (the pain)." (Deb int 2 & 8)

The Synopsis of Psychiatry (Sadock & Sadock, 2007) suggested that those most vulnerable to PTSD were those who were exposed to war in males, and assault or rape in woman. However serious accidents were also cited as a cause. All 5 of the clients had had a serious traumatic experiences and/ or injuries of sufficient magnitude to significantly challenge any person's psychological defences.

4.1.4.2 Re-experiencing

The DSM -5 (APA, 2013) requires the presence at least one 'intrusion symptom' as a result of the trauma that starts after the traumatic event occurred. This could be intrusive memory; dreams, flashbacks or reacting to cues in the environment that may remind the individual of the trauma. Many of the participants, alluded to pain being a memory, but one of clients actually reflected on that in a very informative manner:

> De:" (The pain is) very real to me and I still get it, but I now recognise that it is not my body telling me something, it is my body remembering something…. and giving me the pain of that memory. It doesn't make the pain any less real because it is very real. But there is almost like a short circuit in my brain triggering those very deep seated memories." (De int 1)

Most commonly the literature suggested that the pain could act as reminder of the traumatic event and so retriggering an 'arousal response' in the sufferer (Otis, Keane, & Kerns, 2003). However so many of the participants in this study described that CP in itself is in itself actually a memory of previous pain. It is the body's way of remembering an event.

So the question is whether pain triggers a memory or pain is an actual memory. If the experience of pain is an actual memory then that has a big impact on treatment. One research study (Salomons, Osterman, & Katz, 2004) found that clients who experienced extreme pain after waking up prematurely during operations would incur re-experiences of that pain in a similar fashion to PTSD sufferers re-experiencing trauma. The pain thus re-occurs or is re-experienced as a sensory memory. The pain would be as intense and horrific and in the same locations as during the initial pain experienced in surgery. If pain is a memory of sorts then this could mean that the experience of pain could be a dissociative reaction of an intrusive memory or flash back. Then a person is actually reliving a trauma. The here and now quality of the experience of some CP sufferers together with the sympathetic arousal that seems to co-occur would suitably fall into that category (Leidl & Knaevelsrud, 2008). Like the marked physiological reactions a PTSD sufferer would experience when reminded of trauma (APA, 2013), some participants described that their clients experienced a "stress state" when in pain. In this state they would experience things like: *"Tunnel vision"* (Ste int 5) and *"Sympathetic guarding"* (CWG 38),

4.1.4.3 Avoidance

Research reports that avoidance is not only a symptom of both PTSD and CP but that it also maintains both conditions (Otis, Keane, & Kerns, 2003). Participants reported that avoidance was common with CP:

> M: "… because of the tension, …holding … protecting yourself against the possible pain or the memory of the pain." (M int 4)

> S: "(When doing Pilates) even in a movement that aren't painful, or… sore they want to brace, … hold, and…protect. So it takes quite a lot of encouragement to let them release a little bit." (S int 5)

The healer, who has also done a significant amount of trauma counselling and started an organisation to help victims of sexual abuse many years ago, stated that her experience was that the pain represented the original trauma, and part of avoiding the pain was avoiding remembering that painful trauma:

M: “Many of them were abused as children …so the pain represents the abuse so… by controlling the pain they are controlling the abuse” (CWG3)

4.1.4.4 Negative thoughts and mood

The DSM 5 (APA, 2013) mentions that the PTSD sufferer experiences a negative change in cognition and mood after a traumatic event. The clients reported many negative beliefs that perhaps were neither true nor helpful. The most common belief was that CP lasted forever:

Ka: CP is a pain that you have that … you are going to live with that till you die basically that is as far as I know anyway …short term pain is something that anybody can handle…so (with short term pain) I just have to count the hours if you like. (Ka int 1)

Ad: “… (They feel they) don’t have a choice out of this.”
Al: “(and they think:) I don’t see a way out (then that is)… disempowerment.” (Al int 2)

A large part of these negative cognitions were because of:

Da: “a lot of fear and panic” (Da int 4)

D: “ Fear is the emotion of pain. Pain can be physical and fear is the emotion” (FG 21).

There was also a strong sense of disempowerment, which came through:

Sh: “She has given up and I really feel her fear.” (Sh int 6)

M: “Sometimes …(I) see CP almost as this punishment, like this big monster following me…you feel helpless and it is the feeling of helplessness that makes it worse- if there is something you know you can do about it or there is some explanation for it, it makes it easier to get a grip on.” (M int 14)

Sh: “I see her having been a vibrant gardener artist, (now since in CP) she …(is) just depressed!” (Sh int 1)

Some practitioners found that this consistent negative mood from the clients made their work harder:

D: “So even if there is positive feedback in a particular consultation – they are in such pain they can’t accept it.” (CWG 9)

This negative mood seemed to affect the client’s attitude towards getting medical help too; there was a sense of hopelessness and anger towards medical practitioners:

AL: “There is a lot of anger”
J: every single (client) ... said … that the medical community are not able to help and that came through over and over again”
Al: “that is a very big generalisation … a big sense of disempowerment too”
J: “catastrophization!” (CWG 8)

4.1.4.1.5 Hyperarousal

The DSM 5 (APA, 2013) states that with PTSD there are significant changes in the how a person is aroused or reacts. A person needs to meet two of the following 6 sub-criteria for a PTSD diagnosis: irritable and angry outbursts, reckless or self-destructive behaviour, exaggerated startle response, problems with concentration, hyper vigilance and sleep disturbance. The following listed below were highlighted in the data as being symptoms of CP too:

4.1.4.1.6 Irritable behaviour and angry outbursts

Clients described themselves as becoming more short tempered and self-absorbed as a result of suffering from CP. The practitioners also noticed that CP clients seem a lot more “ irritable and angry.

M: “Because … (the) emotion … (is) not processed …they get angry …and … sad… and then frightened again and …again and it’s hard to get (them) past that. “(CWG 56)

4.1.4.1.7 Hypervigilance.

Hypervigilance came up as one of the most central symptomology. However it was observed more by the practitioners than the clients. They were described clients as:

Al:“…over vigilant to protect” (Al int 1),

Al:“…(being) in a hyper alert very stressed state” (CWG 29)

S:“… Becoming hyper sensitive to everything around them” (S int 5).

4.1.4.1.7 Sleep disturbance

A common complaint by clients was that their sleep was significantly disrupted by pain. The Pilates instructor stated that when people start losing sleep she sees that as one of the signs of true CP.

J: “(They) Is…loosing sleep... so (it) affects their life … then … that is CP.” (J int 2).

Some patients referred to their beds as the enemy:

De: “I started seeing my bed as the enemy... I would be tossing and turning and … sleep deprivation is a very …well used form of torture.” (De int 5)

41.4.8 Dissociation

There is a specifier in the DSM-5 (APA, 2013) for dissociative symptoms with PTSD. Dissociation came up a lot for CP with both mostly the depersonalisation subtype featuring:

S:“ I think the CP dissociates parts of you.” (FG26)

One participant stated that the suffering becomes so much a part of her life that she no longer realises that she is suffering, and this for her signifies a significant dissociation:

> D: "So you have suffered for so long that you don't feel that it is suffering any more… that's when you dissociate." (FG70)

This participant also reported that she just continued, without acknowledging that she had pain. Her focus was on other things such as her work that she had not even realised that she had lost sensation in certain parts of her body because of dissociation:

> D: "I never acknowledged the emotional pain that I experienced and over time I went through a shut down period – that's why I think it is quite important to identify the dissociation – to the point that I couldn't feel certain areas of my body" (FG69)

> De: "That's how I coped and that's when I started shutting out my body – this is not me**.** My body is not me – it was too painful." (De int 2)

4.1.5 Discussion

During the literature review the closest psychological diagnosis to CP found was the DSM 5's 'somatic symptom disorder.' However during the individual interviews and group sessions the personal experience of those involved seemed to link CP closely with PTSD, which provided a more full and multi levelled description of CP. Subsequent to the data analysis, a small proportion of the literature on the links between PTSD and CP was found. These more current journal articles do suggest a growing realisation of a very close and significant relationship between PTSD and CP. The main thread of the theory suggests that these two conditions often co-occur and interact in a way that complicates treating either (Otis, Keane, & Kerns, 2003). PTSD is a common comorbidity with CP. In some literature as much as 35% of the sample of CP clients had PTSD. This was as apposed to only 3.5% in the general populace. Also, 51% of the clients with chronic lower back pain had significant PTSD symptoms. In another study of clients who experienced CP following a motor vehicle accident, researchers found that 50% of the clients developed PTSD (DeCarvalho, n/d).

Some researchers would see PTSD as a culture bound phenomena (Jones, et al., 2003). PTSD has an interesting historical development with initially hysteria being reported

and later symptoms related to shellshock for example. Perhaps CP is a new type of culture bound PTSD? A new disease displaying the type of trauma we face today in a culturally acceptable manner. While this is an interesting development, there is not enough scientific evidence in this study to make such a claim and future study could explore this.

4.2 Treatment

The mechanism of how to engage in holistic treatment was a focus for the CWG. Themes were taken from the answers of the practitioners to this question.

4.2.1 Developing a Treatment Strategy

In response to concerns about being systematic and scientific about the development of the treatment strategy, there was a mix of responses from participants. The Pilates instructor reported that not all disciplines needed a scientific process:

> S: "It almost seems in the more structured disciplines…like the … health council disciplines (there) is the assumption that you need to be able to reference whatever you say …but there are also disciplines where things just work because they just work and we don't have to have a reason why and sometimes … you would intuitively bring something through because that just feels right." (FG42)

The MD stated that it is important to hold an intention as to the reason why one brings treatments together. She recommended evidence-based practice as a good model to use in terms of integrating different practices/ treatments into a unifying strategy. She reported that it is a method of problem solving that involves asking questions around what is the best way to solve a problem, looking at different solutions but then not assuming that they all go together. She stated that the method was valuable with integrating treatments because one needs to examine how the treatments are going to function as a unit once integrated (FG 46). Most of the group were supportive of this approach.

> "Evidence based practice … isn't structured in a way that it gives you an answer in a particular way. You have to formulate a question and then if that doesn't answer (your query), … you have to go to the next and … the next.

> And if antidotal evidence is the only evidence that is available – (and)… if there is no evidence of harm (then the practise can be used)" (FG42)

On reflection is that while seeing private practitioners have many advantages, it does not mean that a client receives better care. Firstly they lack the funding to provide teamwork. However also unlike a large government institution, no one monitoring or instructing the practitioner to adhere to more than basic ethical principals or evidence based practice. It has been noted in the literature that private practices have been under-researched and few of the available studies compare public and private sector quality of care (Smith, Brugha, & Zwi, 2001). Smith et.al. (2001) cited Swan and Zwi (1997) stating that the evidence actually shows that there are serious technical deficiencies in the services supplied by many private practitioners and providers.

4.2.3 Structuring the process

One of the team members who had suffered from CP for 30 years felt that it was important that the client's starting point was respected and once the team had gained the client's trust then it would be appropriate to introduce other levels of treatment. The team felt that it was important to start with the client's presenting problem and there was also the suggestion that the initial contact practitioner becomes the primary contact person for the team and also the starting point for the treatment:

> D: "I think that you have to (start with their presenting problem) because as you pointed out earlier on - the clients will not accept that it might be an emotional issue as well. They present to you with a physical problem so you have to respect that … everyone is going to present with different needs." (CWG32)

> J: "... what they are presenting with – is what needs to be addressed first … there is also the idea that whoever that person links with initially … becomes that link … contact person …(and) would lead the team for … that client." (CWG32)

The MD however felt that the process may be different for each person, for instance while it may appear that most may present for physical treatment first they may not have the motivation for that type of therapy. In some instances a client may need to be suggested another process first to motivate them to be compliant with other types of treatment:

> Al: “not all people have access to the motivation to do (physical rehabilitation). Someone who says they have absolutely had it – they are not going to do this any more …(may) need emotional (treatment) first otherwise, they are not going to go and do the detox ….so it depends on the client.” (CWG32)

Deductively a few in the group felt that not too much attention should be given to the order of the process at this stage, but rather the focus should be on the components that needed to be included in a holistic treatment process and that could be made available as tools for the clients:

> Ad: “I think again what we are doing is not necessarily getting a sequence but getting what we need to do now because we are trying to do too many things at once. Rather just try and focus on, what are all of the elements that we feel needs to be included and then we will figure out what, how, where.” (CWG32)

The group felt that with every individual the process would need to be different. They stated that it was not necessarily a linear process anyway given that healing is such an individual process. It also meant that different people could handle different amounts of therapy on the same day for instance.

> Ad:” so which way round (the program is structured) that would be quite specific so (that it is) individually tailored that your needs are met – you are not fitting into the program – the program is fitting to you.” (CWG 39)

> Al: “the program is alive”
> Ad:” the program is alive in that it changes” (CWG39)

> Al: “do you think it would be too much for a person to an a day have sessions with more than one person? Because some of these treatments they are not, … a linear thing… doing one might access another one more deeply if you do it on the same day. It depends?” (CWG38)

4.2.4 The importance of teamwork

The team acknowledged, that it is not effective for a singular person be a “one stop shop”. Having different practitioners meant that the treatment will be more likely to address more parts of the persons suffering. With more on offer there is also a greater chance that the program will appeal to the client.

> K: “I just think sometimes for myself it is hard to come up with all those bases (of treatment) on your own ... because you can’t realistically have a whole days appointment for one person. I would rather do a half an hour … and refer them to someone else for help, which I think would be more effective” (FG35)

> Al:” also what is nice about that (teamwork) is that … each individual … (brings) different issues that resonate because of … life experiences …so if a person sees a whole lot of practitioners they will resonate with more parts of that particular presentation that’s coming up.” (FG36)

4.2.5.Diagnostic / assessment:

4.2.5.1 Assessment and diagnosis should be holistic

The MD described assessment as looking at the spider web of all the aspects that made up the person:

> Al: From an integrative medicine point of view … CP is viewed as an imbalance in all the different areas of what make up people … physical, emotional, … mind… spiritual, … social, and …their … cultural … religious understanding, The aim then is … to hold cognisance of all of those areas and then refer…” (FG31)

According to the MD, the problem with allopathic diagnostic systems is that the symptom becomes the diagnosis:

> Al: “because pain has been seen as a physical symptom in the past so … allopathic practitioners look at … at the physical primarily, they look at symptoms primarily and they often end on that symptom as a diagnosis… and then … treat chemically or structurally...”(FG29)

The MD felt that with integrative treatment there should be a much larger focus on: *“the subjective reality, individual perception of the person suffering the pain”* (Al int 3).

The physiotherapist highlighted that diagnosis had two distinct components and that it is important to distinguish between these when assessing the client. These 2 components were: the level of disability and the level of impairment. These two should be seen as two separate aspects. For example someone with a major disability could have adapted and thus the actual impairment level is very low. Another client could have a very small disability but have limited functioning relative to the injury and thus the level of impairment is much higher than the level of disability:

> Ad: The ICF which is the international classification of function, which is a… very valuable tool … In there … there is the impairment side … and then there is the disability. So (the question is) what disability does the impairment cause? So it really looks at two levels of what the problem is…” (FG11)

The other concerns about diagnosis in general were the negative and emotional impact of a diagnosis on the patient. Certain patients described diagnosis negatively:

> De: “So I was quite upset and depressed … when the diagnosis came through.” (De int 2)

> Ka: “CP is a pain that you have that is … … it is never going to go away and … you are going to live with that till you die basically.” (Ka int 1)

Some of the members of the CWG felt that diagnostic labels could be disempowering, especially with mental health or psychiatric diagnosis that could potentially render a patient powerless to defend themselves and may invalidate their testimony:

> Al: “I visited the old mental institutions … in Aberdeen … and … these big old mansions buildings … are far out of town because you don’t want to hear the people who are screaming… once they are locked in there and often it happened that the husbands were a little bit tired of their wives and found some sort of diagnosis to put them in there, scary hey! Cos once you are in there you can’t defend your sanity.” (CWG 44)

4.2.5.3 Considering the personality of the client

The population of clients that were initially interviewed appeared to be “Type A” personalities, in that they worked too hard and then found it hard to stop when they developed CP. Below are some quotes that typified their responses:

> De: “ I am a very very competent person. I run a very big company, I am very passionate about what I do. I work hard… I am a perfectionist and I am quite a control freak and I know that I like things done my way and that is fine by me “(De int 8)

> L: “I’ve had back pain for ... years ... (I would) just ride through it ... just keep going but then I couldn’t...” (L int 4)

> K: “You see it’s in your personality, ... I can’t stand people who wallow in self-pity or the poor me syndrome...” (K int 13)

The practitioners agreed that there are definitely different types of CP clients and this has an impact on treatment:

> Al: “There is a definite feeling that there is groups of CP sufferers… and that you almost need like a different approach with each of those groups.” (All agree)(FG74)

The practitioners identified another population of clients who enjoyed the sick role and used pain in order to manipulate things to their advantage or escape from responsibility. The psychologist and healer reported that there seems to be 2 dysfunctional extremes with CP sufferers being either over involvement with their pain or ignoring it:

> Da: “(Clients are either) very involved and contracted around the pain…(or they) pushed it away” (Da int 3).

> M: “I have had people who have had CP – who … (when they are) sore … life stops: I need help I am in pain! Don’t expect me to do anything! I can’t I’m in pain! I don’t want to be fixed.” (FG74)

4.2.5.4 Discussion

It was important that a Holistic focus was consciously held for the whole treatment process as it has fundamental differences to single discipline work. The diagnosis and assessment needed to be multi-axle, biopsychosocial or a multi-level approach of some sort. Examples of this include the DSM-IV system or the healers focus on mental, physical, emotional and spiritual aspects of a person. When considering holistic treatment, the underlying premise is that one is looking at the person on all levels of their being (physical, mental, emotional and spiritual). The practitioner is not just treating symptoms but also looking for the underlying cause of those symptoms too (Farlex, n/d). Holistic treatment is also traditionally very individual, as it involves listening to the individual on many levels and so planning. Thus a generic intervention would not result in holistic treatment. Part of developing something unique for the client would be considering their personality and how that impacts on their CP and maintains their condition.

4.2.6 Communication

This theme was drawn deductively from the title of the study and the data was searched for subthemes relating to communication. Subsequent to choosing the title, it was

discovered by analysing the data and the insights of the practitioners that communication was to be a very central and relevant theme on many levels. Firstly pain is a form of communication that is important to listen to in order for treatment to be effective. Secondly communication is needed between team members and thirdly communication with clients is foundational for practice.

4.2.6.1 Listening to the pain

Pain was perceived as a message by most of the team. This message had been ignored for a long time and is trying to get the client's attention.

> J: "(The clients are just) doing whatever they do, which is what got them into this position (CP) and … a lot of them have denied (that) the body was giving them dashboard warning lights for ages and they have ignored it. Now they have to address it." (Just int 6)

> M: "I have found that the body will have a problem that it is being ignored because often we ignore…and … abuse our bodies and … push through or take some medication to mask the pain so that we can keep going and … keep pushing …and sometimes the body responds quite aggressively with pain in order … to attract your attention to get you to notice". (M int 11)

> Al: "pain… seems to be an experience that signals a need for change. So something needs to change to relieve the suffering …" (AL int 1)

The physiotherapist stated that CP occurs when the message of pain is distorted by perceptions and past experiences. Then the way the client listens to the CP needs to be different and those messages need to be re-interpreted to help the client untangle from the experience of CP. For instance instead of interpreting the pain as physically dangerous the client needs to understand that perhaps it could be signalling an emotional need.

> A: "The problem comes in with how the… (client) interprets that message and that (interpretation) often comes from their previous experience which could result in an incorrect interpretation." (Ad int 1)

> Ad: “The message gets from the bottom of the body to the brain thro the various pathways. There it gets interpreted by your previous experiences, our beliefs (and) our parents beliefs (etc.)” (Ad int 1)

> Ad: “(CP) is when the pain has outlasted its usefulness. Acute pain is a warning signal to warn us of possible danger and to let us know about tissue damage… with CP then there is a loop (of beliefs) that keeps on running so there is a lot more focused in the brain. (The) cycle keeps being repeated like a record that gets stuck so it… is not really useful (but) it is a… continuous endless cycle …” (Ad int 1)

4.2.6.2 Communicating with clients

Part of listening to the pain, is also listening to the client’s expression of their pain. The CWG stated that listening is foundational to good communication. They reported that most of the clients might not have had practitioners in the past who were empathic towards their plight because the practitioners had not experienced CP themselves.

> St: “A lot of practitioners haven’t experienced CP so they have no connection to what that (CP) is about… there is no empathy ... (which) … changes the whole way that you look at it.” (CWG 12)

The team saw a value for the patient being able to express him or herself, as they might not have opportunity for this:

> M: “(What is needed) is a lifeline…were people would just phone up and moan”
> Al: “just express…”
> J: “you can only talk …to family so many times.” (CWG 12)

Another area of challenge was around communicating levels of pain and suffering. The physiotherapist felt it was important to have a quantifiable measure and felt it could balance the subjective report of the clients:

> Ad: "…use of questionnaires… provides an objective tool for managing... so objectifying the subjective." (FG 12-13)

A client developed their own scale for measuring pain, which has been put in the table below linked with relevant quotes. This scale shows the clients own subjective rating scale of levels of pain:

K's rating scale	
Level	Description
0	" So 0 is think about your knee cap (the troubled area) – oh I can't feel it" (K int 2)
3	"3 would be yes my knee cap is slightly cold or slightly hot" (K int 2)
5	"5 is gosh I need to take a Panado (pain medication) type pain." (K int 2)
6-7	"6 or 7 are a little more serious, you are going to do something about them" (K int 2)
8	"8 is when you are quite seriously distracted where you can't concentrate on what you are doing for the pain" (K int 2)
9	"9 is when you are actually physically showing symptoms like sweating, hyperventilating." (K int 2)
10	"10 would be then passing out" (K int 2)

Certain of the practitioners reported that clients may get "absorbed" by their pain. That they forget about the other parts of themselves and that it is difficult to get them to shift.

> M: "If someone suffers from CP – that is only part of who they are – they are also a whole lot of other people as well – they have got other strengths – other hats they wear and they tend to forget those – they are just the pain like a walking lump of pain and to try and make them remember they are also a mother and a sister and a daughter and a lover or tennis player or whatever (is difficult)." (CWG 16)

The practitioners felt that CP impaired a client's ability to listen, even to positive feedback. One of the reasons given for this was because of strong mental filters, while others

stated that it was because the client was in fight, flight or freeze mode and that their pre-frontal cortex's had been shut down due to being in a state of trauma.

> De: "Don't you also think that somebody who is in CP can't hear properly?
> (All agree)
> De: "So even if there is positive feedback in a particular consultation they are in such pain they can't accept it…. Their filters are on! "
> J: "It's fight or flight, you are in that state of absolute desperation … instinct takes over your logic." (CWG 9)

Thus the team members felt that the style of communication with clients was important and its impact needed to be thoughtfully considered. The group was ambivalent about the value of medical terminology, which they reported reinforced the hierarchical divide between client and practitioner. However some in the group felt it might be necessary to help create a impression of professional competence which was important as clients approach practitioners because of their expertise.

> Al: "if one adds too much scientific, very structured information then… hierarchy comes into play and they (clients) don't open up." (FG 46)

> St: "Clients … come to you because you know more than they do … I get what the negative barrier is but it is also necessary because otherwise the client won't seek help. They are looking for … help." (FG 47)

> De: "…from a patient point of view … you are going to say please help me I am desperate! …Not please help me to help myself! … Before the patient is able to perceive that the patient is able to help him or herself… you need to teach the patient to help themselves but initially it is simply not possible…" (FG 47)

> Both practitioner and clients felt misunderstood at times:
> AL: they (male medical doctors) work even harder to be seen as sensitive…"

> J: "…my sense is that there is misunderstanding (on both sides) … clients feel misunderstood by doctors …(and doctors are misunderstood by clients."
> Al: "yes (firm) absolutely"(all agree) (CWG 15)

There was also a sense of separation created between client and practitioner. The use of the phrases such as 'they' reinforced this divide. The practitioners noted that this may be about a human tendency to group things but on another level it could be about a desire to seen as separate. The members of the CWG noted that the group had been doing it the whole time too.

> M: it is not only... a separation, it is deliberate on my side as well. I don't want to be connected with those people – its not that they don't understand me. I don't want anything to do with them – it's a two-way street…"
> Ad: in our talk … this morning we have been doing it (saying they) the whole time." (CWG 7)

A practitioner reported that being in CP constantly evokes anger, as well as the feeling of being misunderstood that could create constant feelings of loss. This may trigger memories of early abusive experiences of authority, which may perpetuate the divide between practitioner and client.

> Al: "… they are going through this anger which was interesting to me, anger because it makes me feel what they are going through is micro-losses all the time or big losses … they are stuck in that anger phase of feeling disempowered." (CWG 15-16)

> M: how many of them were abused as children? … That's what they are responding to. So the pain represents the abuse…" (CWG 3)

> D: "Let me say, to draw on Margaret's theme, that comes back to the whole abuse story because the lack of respect for authority was presumably – those people were abused by a person in authority." (CWG 5)

The healer reported that:

> M: "… sometimes what a child sees as abuse is simply circumstance, it is not deliberate, and you know it is not caused by any bodies malice, it's just financial circumstance." (CWG 5)

This statement seemed to also infer that clients like children might feel disrespected and abused when the circumstances dictate less than ideal type of treatment.

4.2.6.3 Communication for teamwork

The challenge of teamwork was communication. Communication was seen as important to avoid duplication of assessment and treatment. One of the key solutions was to try and operate from the same premises:

> K: "yes well … that's what Adele and I were talking about. It is nice to have something in place where you can have …
> AD: "Communication so that you don't have to go through the whole assessment again." (FG 36)

> Da: "…if you are all situated in one building - then you are all paid by the same people - I have worked in places like that - then it is a lot easier to have a place to come from where you can at least … have a coherent approach to dealing with clients." (Da int 5)

The psychologist mentioned that it was important that each member of the team knows what the other does, however this can be time consuming but it can help provide a coherent way forward for a client:

> Da: " I guess … they wouldn't understand much of what I do, … unless over the years we had formed a relationship or … where we had bothered to hang out with each other long enough to get a sense of (them)..." (Da int 5)

4.2.6.4 Education

The practitioners felt that psycho-education especially on the nature of CP was an important part of treatment and an excellent form of communication. For example most clients had the perception that if they feel pain that they are injuring or hurting themselves. The physiotherapist reported that when clients understand that if they have CP, their pain is not dangerous, then clients are happy to experiment and problem solve to lesson the pain and improve effectiveness of movement. Thus communicating these facts clearly can play a vital role in treatment:

> Ad: "Very often is enough just to know that their pain is not dangerous…that takes a big load off. " (Ad int 9)

4.2.6.5 Discussion

Communication appears to be a vital building block to care and a specialised field that most health care providers, other than psychologists are not trained it. The last decade of research provides some evidence that there is a high correlation between the effectiveness of the practitioner's communication and the recovery of the patient:

> "Research evidence indicates that there are strong positive relationships between a healthcare team member's communication skills and a patient's capacity to follow through with medical recommendations, self-manage a chronic medical condition, and adopt preventive health behaviours. Studies conducted during the past three decades show that the clinician's ability to explain, listen and empathize can have a profound effect on biological and functional health outcomes as well as patient satisfaction and experience of care." (IHC, 2016)

The importance of communication extends past the client but is also important between practitioners. The quality communication affects working relationships, job satisfaction which in tern has a profound impacts patient care (IHC, 2016).

4.2.7 Aspects of the intervention

4.2.7.1 Multiple layers

The integrative MD stated that the levels and parts or subsystems of what make up a person's being are intricately held in a spider web of balance and when one part is affected it pulls the rest out of balance. In order to work holistically the practitioner needs to have an awareness of all these levels but not necessarily work all of these levels. They need to centre their practice on their client and not their personal preferences or skills. The MD described it as follows:

"Al: "…like a spider web of what makes up a patient and … when strings are tugged in particular areas it affects the whole web of balance … But that tug can be in their social relationship interactions and can eventually affect their gut balance because of going thro stress hormones etcetera… but if you don't address that cause then fixing the gut is you know is (pointless)." (FG 32)

To do this a referral base needs to be built up with a sound knowledge of what that referral base does:

> Al: "…in integrative medicine, you have a feeling for (and) … educate yourself enough to have a feeling for what everybody is doing… so that you can build a referral base and a team type approach."(FG 32)

The Chiropractor, who also studied integrative medicine, reported that balance of a person is affected over a timeline and sometimes plotting things on a timeline helps to see the connections between the different levels of a persons being and how the issues developed over time affecting all the different areas of that person's life:

> K: "When I was 3 years old … a major incident (happened), (and) it is like a ripple effect down the line."
> AL: "and physical things would start at that same age (as that major incident) but they wouldn't make the connection because physical stuff is another area (and emotions are not the focus of) … doctors… and physiotherapists and OT's and people work with the physical … that's not to do with emotional stuff."(FG 33)

Brannon and Feist, (2010) state that the biopsychosocial model, which was developed by out of systems theory, recognises that any approach to health should include biological, psychological and social approaches in assessment and treatment. The model also views health not as the absence of disease, as a person may not be sick but that does not mean that they are healthy. This would also support the inter-dimensionality of the spider web model that the MD speaks of and the interplay of the parts to form a whole. Systems theory would speak to the complexity of the interrelatedness of the systems of a person that hold the fragile balance of the spider web together. Of concern is how the group proposes to address all these layers of the person because so far in the study, as mostly just treatment options were just listed by the group. More work would be needed to be integrative or holistic:

> "We propose that combination medicine (conventional plus CAM) is not integrative medicine. Integrative medicine is a system of care that considers health (or disease) as an emergent property of the person in an environmental context conceptualised as an intact, indivisible system. Integrative medicine is a complex, dynamic, higher –order system of systems, conventional and CAM." (Bell, Caspi, Schwartz , Grant, & Gaudet, 2002)

4.2.7.2 Changing the Relationship with pain

The psychologist reported in the same way that people have interpersonal patterns of relating, so clients also have distinct patterns of relating to their own pain:

> Da: "…the big thing from my angle (is) how are they relating to the pain? I don't suppose I would be approaching anybody from the angle (claiming that) I can take the pain away. That wouldn't be what I would be focused on at all. I would be interested in what the relationship would be … in terms of how they are thinking about the pain? How they are feeling about the pain? So the relationship is what… they do with the pain. Do they put the pain over there … or do they get … overinvolved with it? What do they do? What beliefs, what ideas?" (Da int 1)

He stated that the relationship the team fostered with the client was an important part of correcting the way the client related with their pain. If for example if a client's relationship with their pain was hard or judgmental then the therapeutic relationship needed to model a different way forward through relating to the client in a more empathic way.

> Da: "I think each practitioner in their own way would constantly be trying to grow their relationship with their client ... And it is in the growth of the relationship that they can relax more, reveal and broaden and soften and relax." (DA int 6)

Due to CP being a chronic condition the team highlighted that their relationship with the client is most likely a long-term relationship. Most team members agreed that it was important to demonstrate trustworthiness and genuine care to facilitate the development of the relationship with the client.

> De: "if you are truly going to get rid of that CP … You are now entering into a long term relationship and part of that long term relationship…(is clients) …want to find someone they can trust, someone that they feel comfortable with, someone that they feel … care and … you are going to show them because they have been (disappointed) everywhere else." (FG 48)

In order to develop trust the Occupational Therapist (OT) felt that it was very important to work with the client on their level and thus starting where they are. That meant respecting the client's fear of their pain and slowly building the client's trust. She stated that she was able to accomplish more with her clients when they trusted her and she reported that this was because the client knows that she will not hurt them or push them past their limits:

> Sh: "She … had a stroke and … so even sitting on a chair and doing some integrative art work … with her eyes closed … is very scary for her. So it is again respecting her fear, and trying to … slowly help her … at some point, look this is a early therapeutic relationship I have with her, … when she trusts me more that – that I can get … (co-operation to do tasks)." (Sh int 7).

Jon Kabat-Zinn, Ph.D., professor emeritus of medicine at the University of Massachusetts medical School, used mindfulness to treat CP and illness. A pain sensation is the body's nervous system responding to stimulus that is perceived as harmful. Pain has 3 aspects: the physical sensation, the emotional feelings and the cognitive meaning of the pain. Mindfulness that is based on Buddhist meditative practices lowers the experience of pain without reducing the sensory pain levels. Mindfulness addresses the emotional and cognitive aspects that exasperate the pain. This perhaps is the basis of what the psychologist in our study, who specializes in mindfulness meant by changing the relationship with pain:

> "Once you've changed your relationship to the pain, the physical discomfort may decrease… You change your relationship to the pain by opening up to it and paying attention to it. If you distinguish between pain and suffering, change is possible. As the saying goes, "Pain is inevitable; suffering is optional." (Kabat-Zinn, 2002)

4.2.7.2 Pain medication

The group felt that allopathic medication had a place but that its purpose needed to be reframed for clients. The client needed to be informed that pain medication provided only symptom relief and not a cure for CP.

> Al: "… it is about shifting the perspective of the medication as a symptom relief … because people see the medication as a solution, that's where they get frustrated."
> Ad: "That (pain medication) is something that … you want to wean off…so there is a time limit for how long I have this tool … this is not a forever treatment, it is something to give us the opportunity to start moving"
> (CWG 38)

Most in the group did not advocate abstinence from pain medication. This is because pain can be very difficult to cope with, if insufficient medication is given. The physiotherapist stated that treatment was much more effective when client's pain was well managed with medication as it meant that fear levels were reduced and this prevented a potential fearful response pattern from occurring which would hamper a physical therapy

intervention. She likened this to a baby crying and how it was much easier to sooth a baby when it starts crying, than leaving a baby to scream and then try and sooth it:

> Ad: “(not taking medication) is also a problem because you are letting the pain go to such an extent that you can’t cope with it anymore and then to get it back down is so difficult – it is like letting a baby scream for three hours.” (CWG 14)

Pain according to research interrupts attention and demands attention (Eccleston & Crombez, 1999). Therefore it is hard to work with a client in pain. Thus the role of medication should be to restore concentration enough so that the client can address things in therapy. The group was however concerned about the side effects and efficacy of the pain medication:

> De: “it (medication) is a last resort.”
> Ad; part of that reason (that medication is a last resort for clients) is because of the side effects of the medication so it is the drowsiness… the cotton wool in my head it’s the ulcers, its all the other stuff...” (CWG 14)

A long-term CP sufferer and a healer stated that she felt that medication ”dissociates” the person from himself or herself. She stated that a person suffering from CP already lives in their mind, because the spiritual, emotional and physical parts of them are too painful to be present to:

> “D: you see and you have submerged your physical, you have submerged your emotional, you have certainly submerged your spiritual – so it is only your mind that is going ‘ meep meep’ and what do doctors do – they medicate us…”
> Al: “(they) dissociate you more”. (FG 52)

As stated by the participant above, research (Walker, Katon, & Wayne, 1992) shows that woman in CP are most likely to use dissociation as a defence mechanism. Also certain types of pain medication are known as dissociative drugs such as Ketamine. Ketamine is

known to impair memory, have psychogenic and dissociative effects (Curran & Morgan, 2000).

4.2.6.3 Psychological intervention is important

The physiotherapist mentioned that at pain clinic level the focus is not on massage therapy but on the mental/psychological aspects of the pain. She reported that clients have been through years of unsuccessful physiotherapy before they arrive at a pain clinic:

> Ad: "Some of the physio's on the course … don't do any hands on treatment because they are at the pain clinic level so people have gone through months of physio before they have been sent there. So they work purely with … getting people out of the pain focused life. Which is our downward spiral." (Ad int 9)

Research is in support of this view:

> "In the years following the delineation of the gate control theory of pain, the field of psychology has been at the forefront of the scientific investigation of pain, the development of instruments to assess the multidimensional nature of pain, the development and application of various treatment modalities that target the complex nature of the pain experience, and the advocacy of policies and practices that seek to reduce disparities in the assessment and treatment of pain." (Robert, Kerns, Sellinger, & Burel, 2011)

4.3 Summary

The analysis of the data found that theoretical understandings were deemed foundational to practice. Thus based on this hypothesis: it appeared that a whole field of scientific development in terms of theory was needed and this would involve years of research. However transdisciplinary discussions could provide some useful understandings to help guide further study. Using evidence-based practice principles was deemed as a effective and acceptable model of practise in the interim. It would provide a unified and consistent way the team could integrate different practices/ treatments. Teamwork ensured more aspects were covered in treatment and good communication ensured that the correct aspects were

covered through feedback. The philosophy's underpinning holism and psychology needed to be applied through the entire treatment process and include the way diagnostics was approached.

CHAPTER 5: SIGNIFICANCE AND LIMITATIONS OF THE STUDY

5.1 Significance of the Study

This thesis hopes to add a contribution to the body of knowledge that is being developed around holistic, systemic and transdisciplinary treatment as well as CP. More specifically it provides a portrait of the insights of the team members in this process. While this study may not convey qualitative scientific evidence it does reflect the perceptions and struggles and opinions of health professionals who are engaged in the 'trenches' of private practice far removed from the ideals of academics and large state funded institutions. The primary benefit is to actually initiate TDC in that local context; however the insights and experiences of the participants could both motivate and inform other contexts as to potential implementation possibilities. This study seeks to create a start of a process of researching how practitioners can communicate in a way that is transcends disciplines to create a holistic strategy for the client. While the process is slower than hoped for, these professionals still plan and attempt to do some levels of teamwork and the plan is to formalise it in the future. However there are many administrative and ethical dilemmas, which need to be resolved before that.

What was really positive about this approach was that the different viewpoints from different disciplines on the same issues provided a richer thinking process and provided a lot more problem solving options. This study's significance lies in demonstrating the unique and innovative solutions that can be achieved by teamwork. The hope is that this study will encourage practitioners to consult across disciplines for solutions even if it is not in a formalised manner. This study hopes to inspire other practitioners to include psychological interventions in their recovery strategies for clients. Thus this study aims to make a difference in the local context and to add to the momentum of the bigger change in the way health care is being conducted. It hopes to inspire other professionals working privately to build on the study and collaborates to find their own unique solutions in their own situation. On a smaller scale it hoped to encourage and create and expand on the development of a practical framework for the wellness centre professionals to find a suitable model for operation and teamwork.

The practical knowledge of the practitioners proved invaluable as most of these professions follow apprenticeship type training and therefore just reading the intellectual

material available would not give the same level of insight into each other's practices. This was an invaluable insight into the living reality of these practitioners.

5.2 Limitations

There were a couple of challenges with this study. Firstly the subject matter that needed to be covered was very broad and the team very quickly realised that the agreed amount of group sessions would not be enough to cover everything needed to set up such an operation. Although this was not the goal for this study, the extent of the process became evident through the study. One of the reasons it took longer was because involving a team means that there are a lot more people that need to input into the process. Having team members meant that it was also harder to reach consensus as a team on a subject. This is not because of a lack of agreement but it hard to decide when a topic had been saturated for discussion, as there are so many levels of insights one could go into, especially given a multidisciplinary approach. One solution could be to delegate different responsibilities to appropriate team members who are experts in that area, as well as call on outside expertise. It was deemed necessary to call on outside expertise especially for ethical, financial and business structure aspects.

This study only consulted with health professionals and other type professionals that would have been involved in treatment. Much of what would be needed in order to even begin with transdisciplinary practice would involve more of the ethical, health management and business aspects of such a venture. Without sound advice in these fields such a venture could not even begin. The group felt that given the lack of expertise in these areas it would not be worthwhile to discuss. Hiring such professional services is expensive for a small local initiative of independent developing practices.

The limitation of this study is that it merely captures those insights but does not substantiate those insights nor is able to prove the scientific evidence or the source of the information provided by participants. It merely records their opinions. Nor was this study able to thoroughly explore any one aspect but more opened up areas that need to be explored in future and there may be other more effective ways to research the different questions in future. Both the sample and the context were conveniently chosen based on the researcher's

knowledge of interested participants and therefore generalization to other contexts is not possible.

The other limitation of this study is that it had a single author who was a psychology student. Thus the recording of the data favoured the psychological aspects and was interpreted from that frame of reference.

5.3 Recommendations for Further Study

The researcher originally intended to design a study similar to Gibb et al (2002) in which a collaborative effort of focus groups, interviews and practical trial and error would result eventually in the most effective model being found. This would have paved the pathway towards developing a theory. However with the limited time of this study it had to be limited to gathering the initial perceptions of those involved. However unlike my previous research, the initial data collection results were able to inform the next discussion, which meant that there, was a process of refining and improving through collaboration. What would have been ideal would have been to include actual treatment trials on a client and to record quantitatively any progress in terms of treatment, as well as record the qualitative experience of the participants. A doctoral level study over 5 years would be more suited to this approach.

CHAPTER 6: CONCLUSION

CP is increasingly being recognised as a growing pandemic (Koch, 2012). Despite the complexity of the CP, many clients are receiving disjointed inappropriate care in private practice (Laskey, 2012). There is thus a need to look for a feasible organized approach to chronic and complex conditions in local private community settings (Matthias, et al., 2010).

This study was based at a private physiotherapy practice in the Cape Town. Involved in the study were: CP clients, registered health professionals (AHPCSA or HPCSA) and unregistered professionals who played an important role in the participating clients lives**.** This study aimed to offer a portrait of the insights and experiences of participants in the early stages of developing a CP program by collaborating between independently operating practitioners in a local community. This thesis was a general exploratory study, because of the vastness of the subject and the general lack of literature and research on the subject.

The literature review covered the main topic areas namely: CP, teamwork, and communication. According to the literature: pain is a confusing term with conflicting viewpoints on what it is. There is debate over whether CP could be a disease in and of itself because of the permanent change to the nervous system and the severity of the symptoms and disability caused by CP (Lynch, Craig, & Peng, 2011). Brookoff (2000) suggested that if CP were given a place as a formal diagnosis that it may be taken more seriously by client and practitioner alike. While there is no formal diagnosis called CP, but there are syndromes, which are groups of symptoms. Perhaps the closest concurring DSM-5 (APA, 2013) diagnosis to CP is ‘somatic symptom disorder with predominant pain’ (APA, 2000).

Alternative medicine is becoming increasingly popular with clients. Research shows that the single greatest reason for CAM use was the fact that clients saw results (Astin, 1998). Teamwork in general has been promoted as a way to achieve superior holistic results for treatment for clients with CP. This is because no single practitioner has enough expertise, resources and skills to provide the type of complex and quality care CP needs (Cartmill, Soklaridis, & Cassidy, 2011). TDT is vastly different to other teamwork as it is all about taking all the specialised in-depth knowledge from many disciplines and combining it until the most complex and complete understanding of the problem is obtained (Albrecht, Connor, & Higginbotham, 2001). It involves a greater level of collaboration than other models.

Cartmill, Soklaridis, and Cassidy (2011) found that both formal and informal communication is needed to sustain this type of teamwork. Language is also foundational to communication and Nash (2008) stated that team members needed to be able to understand the language of all the different disciplines involved to be effective. Good client centred communication has been associated with better treatment outcomes (Brannon & Feist, 2010).

In this study: individual interviews, a FG and a CWG were used to capture the data. Coding was done with the research questions in mind. Thematic analysis of the data was based on Braun and Clark's (2006) six-phase guide. Developing a plan for how to engage in holistic treatment was a focus for the CWG. There were mixed feelings on how theoretical or systematic development needed to be done. Using evidence based practices as a way to hold an intention was the most supported strategy.

The research question for this thesis was: 'what are the insight and experiences of all participants in their initial attempt to establish transdisciplinary communication (TDC) to aid the development of a holistic CP program?'

Specific goals under this question include:

1. The participant's understandings of the concept of CP
2. The client's intervention needs
3. The effect of inclusion of the client's and their opinion
4. The effect of psychology on the development process.
5. The researchers evolving realisations

These were addressed in this thesis and the following was found:

1. The participant's understandings of the concept of CP

The participants understanding of the concept of chronic pain was foundational to practise. Therefore there was first a focus on developing a unified theoretical base before beginning a joint treatment venture. This was because theory guides treatment, enables communication and helps develop a unified approach in a team. This was a lengthy process, and it was hard for the group to reach a consensus. CP was seen as having a prolonged time frame, being limiting and being genuinely painful. Psychologically CP could be defined as a stuck relationship the client has with their pain. This creates a sense

failure, which leads to feelings of suffering. A lot of the suffering in CP has to do with the emotional and cognitive aspects rather than the original sensory input. Often with CP it seems that clients would relate to their pain in 2 extreme patterns of either avoidance or over-involvement. CP was seen as an imbalance in: either the mental, emotional, physical aspects of the person. Some of the practitioner's stated that ailments in the body were communicating something deeper for the client. The phenomenon was called 'body wisdom' and described as the body's way of communicating. The body was also seen as a physical manifestation of a person's unconscious mind.

2. The client's intervention needs

It was felt that the clients starting point or presenting problems was to be respected. The initial contact practitioner thus becomes the primary contact person for the team and also the starting point for the treatment. This however should be flexible, as the process would need to be individual. Teamwork, assessment, diagnosis and treatment all needed to be holistic. This process could not merely focus on symptoms as with allopathic medicine but needed to find and address the underlying cause of the symptoms. This could be for example a traumatic experience in childhood. The person's subjective reality as well as quantitative assessment (using questionnaires and rating scales) should be used to decipher the problem. The actual functional disability in a client versus impairment also needs to be distinguished. Diagnosis should be approached sensitively as this could be discouraging and disempowering.

3. The effect of inclusion of the client's and their opinion

Communication, was a central theme in this research, and appears to be a vital building block to care and a specialised field that most health care providers, other than psychologists are not trained it. The last decade of research provides some evidence that there is a high correlation between the effectiveness of the practitioner's communication and the recovery of the patient. (IHC, 2016). Thus the same principles apply in the effectiveness of treatment data and the input of the clients made a big impact on the data and provided a new angle. Emerging from this was the understanding that the way clients relate to their own pain needed to change. The therapeutic relationship needed to model a different way forward through relating to the client in a more empathic way. It was important to demonstrate trustworthiness and genuine care to facilitate the development of the relationship with the client.

4. The effect of psychology on the development process.

Treatment should involve all layers of a persons being in order to work holistically. Psychology creates a good foundation to aid this awareness. These aspects of being where described to be like a spider web of balance. Of concern is how the group proposes to address all these layers of the person because so far in the study treatment options have been just listed by the group. More work would be needed to be truly integrative or holistic. Simply combining conventional medicine with CAM is not integrative medicine. Integrative medicine or holistic practice is:

"A complex, dynamic, higher order system of systems, conventional and CAM."
(Bell, Caspi, Schwartz , Grant, & Gaudet, 2002)

Psychological principals would play an important role in treatment. The role of medication was to be reframed as temporary symptom relief and not a cure for CP. This was to provide a temporary window period to assist the client to focus not on their pain but on therapy. Psychological therapy thus becomes more central in the treatment process of CP.

5. The researchers evolving realisations

One of the more interesting evolving realisations was the relationship between CP and PTSD. Questions were raised as to whether CP is a new form of PTSD, as participants mentioned PTSD symptoms when describing CP. These included: direct or anticipated exposure to trauma, re-experiencing, avoidance, hyperarousal and dissociation (APA, 2013). During the literature review the closest psychological diagnosis to CP found was the DSM 5's 'somatic symptom disorder, but in the results PTSD symptomology became a leading descriptor. CP and PTSD are both a culture bound phenomena (Jones, et al., 2003). PTSD has an interesting historical development and perhaps CP is a new type of culture bound PTSD? There is not however not enough scientific evidence in this study to make such a claim.

This thesis hopes to add a contribution to the body of knowledge that is being developed around holistic, systemic and transdisciplinary treatment as well as CP. While it only provides a subjective portrait of the insights of the team members in this process, these are the perceptions and struggles and opinions of health professionals and clients who are

engaged in the ‘trenches’ of private practice far removed from the ideals of academics and large state funded institutions. What was really positive about this approach was that the different viewpoints from different disciplines on the same issues provided a richer thinking process and provided a lot more problem solving options. This study’s significance lies in demonstrating the unique and innovative solutions that can be achieved by teamwork. The hope is that this study will encourage practitioners to consult across disciplines for solutions even if it is not in a formalised manner.

The study found that implementing holistic teamwork was a lengthy and challenging process. Theory underlying treatment needed to be defined first and it was hard to reach consensus. Strategizing for holistic work was challenging, as it did not just involve combining treatments but an individual systemic non-linear process. Good communication was vital to the process and this again involved time, which is not covered by medical aids. Further, more focused study on each of the broad areas covered as well as the involvement of specialised expertise in the areas of ethics, and business management would be needed to commence TDT.

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APPENDIX 1: A SUMMARY OF THE MODELS OF CP

Impact of Psychological Factors in the Experience of Pain

Table 2.
Summary of Psychological Models of Pain and Disability Highlighting the Psychological Processes Involved and Examples of Treatment Interventions

Theory	Description	Psychological Processes Featured	Mechanism	Examples of Treatment Intervention Strategies
Fear-avoidance model	A painful injury may result in catastrophizing and fear, which lead to avoidance of certain movements. This behavior, in turn, leads to more avoidance, dysfunction, depression, and ultimately more pain.	• Cognitive: interpretation featuring catastrophizing • Emotions: fear, worry, and depression • Attention: fear keys attention on internal stimuli (hypervigilance) • Behavior: avoidance of movement	Activity avoidance leads to physical degeneration and social isolation; vicious circle	Promote physical and social activation (eg, with graded activity)
Acceptance and commitment model	Rigid beliefs (eg, that the pain must be cured) may block the pursuit of long-term life goals. Reducing futile attempts to achieve unrealistic goals (acceptance) produces flexibility and engagement in pursuing important life goals (commitment).	• Cognitive: flexibility in beliefs, life goals, and commitment • Emotions: anger and frustration • Behavior: commitment, pursuing goals	Repeated (futile) attempts to control or alleviate pain lead to frustration	Provide realistic treatment goals and encourage client participation in decision making
Misdirected problem-solving model	Normal worry about pain may tune the patient into certain ways of solving this problem (eg, medical cures). When this does not actually solve the problem (eg, with chronic pain or certain forms of musculoskeletal pain), it results in more worry and an even narrower view of the nature of the problem, making it less likely to actually solve the problem.	• Emotions: worry as a driving force • Attention: pain demands attention • Cognitions: beliefs about cause of pain • Behavior: attempts to solve problem	Hypervigilance to pain symptoms contributes to rumination and failed attempts to escape pain; vicious circle	Redirect problem-solving efforts toward achievement of functional goals
Self-efficacy model	The belief that a person is capable of coping with pain is directly related to self-management; low self-efficacy, with feelings that the pain is uncontrollable cause physical and psychological dysfunction.	• Cognitive interpretation: beliefs concerning controllability of pain • Behavior: coping skills	Fluctuating pain reduces perceptions of control and mastery over pain	Encourage self-care and self-management strategies, reduce dependence
Stress-diathesis model	Significant psychological stress and limited coping resources predispose a person to pain and being less prepared to deal with it. Thus, pain is more likely to result in functional difficulties and emotional distress.	• Emotions: stress, depression, and anxiety • Behavior: coping strategies and skills	Protective psychosocial factors buffer the emotional impact of pain, whereas distress and emotional dysregulation predispose to pain	Improve stress management skills and social support

(Linton & Shaw, 2011)

APPENDIX 2: A COMPARISON OF DIFFERENT TYPES OF TEAMWORK

	Health problem/ problem boundary	Teamwork/ collaboration	Role of conceptual framework	How knowledge is applied
Single disciplinary	The health problem is what a single discipline thinks it to be.	None.	Arises from a single discipline.	Production of `specialised' knowledge and reductionistic accounts of problem or intervention.
Multidisciplinary	The health problem is what several disciplines working independently think it to be; hard disciplinary boundaries are placed around the problem facets.	None or limited; disciplines work independently on distinct facets of a broadly conceptualised problem.	Mutually exclusive conceptualisations juxtaposed and broadly cumulative.	Interventions suggested by isolated, discipline-specific problem explanations.
Interdisciplinary	The health problem is what several disciplines working together agree it may be. Aspects of the problem from disciplines not included may be ignored. The health problem is defined by the totality of `soft' boundaries between the various disciplines working together.	Collaboration using limited knowledge-bases. Different disciplines address inter-connected aspects of specifically defined health problem, mainly bringing to bear their own theories and conceptual frameworks.	Isolated explanations of a problem from a limited number of disciplines are assembled and connections among them are sought.	Interventions sensitive to an explanation of the health problem informed by understanding the connections among participating disciplines.
Transdisciplinary	Problem is defined as part of an open, dynamic system operating at multiple levels. Problem broadly expands to include all relevant disciplinary insights.	Open ended collaboration. All disciplinary insights required to define the problem are assembled.	Common conceptual framework is sought which will be useable by any discipline, achieving a new insight about the problem.	Interventions with the greatest possibility of success follow from a synthesis of knowledge from disciplinary collaboration.

(Albrecht, Freeman, & Higginbotha, 1998, p. 59)

APPENDIX 3: THE SSM CONTINUOUS LEARNING CYCLE

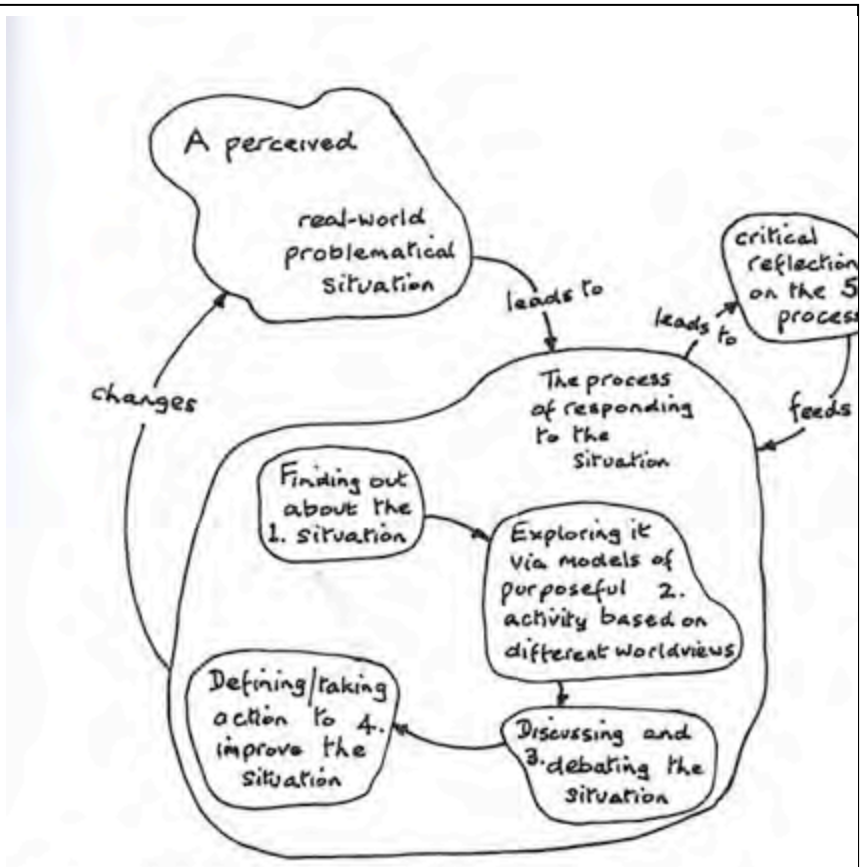

Fig. 5.26 The five activities which flow from SSM's seven principles

(Checkland & Poulter, Soft Systems Methodology, 2010, p. 235)

APPENDIX 4: EXAMPLES OF INTERVIEW AND GROUP QUESTIONS

Semi-unstructured Individual Interview Questions:

1. What is CP?
2. What is the cause of CP?
3. How should one treat CP?
4. What are your personal beliefs around CP?
5. What is your feeling about fragmentation of health care services?

Focus Group 1

1. What is CP?
2. What is the cause of CP?
3. How should one treat CP?
4. What is your feeling about fragmentation of health care services?
5. How can mental health issues be incorporated in a non-threatening manner?

CWG 1

How are we going to implement our concept of CP (and how it should be treated) in our upcoming pain program?

APPENDIX 5: SSM

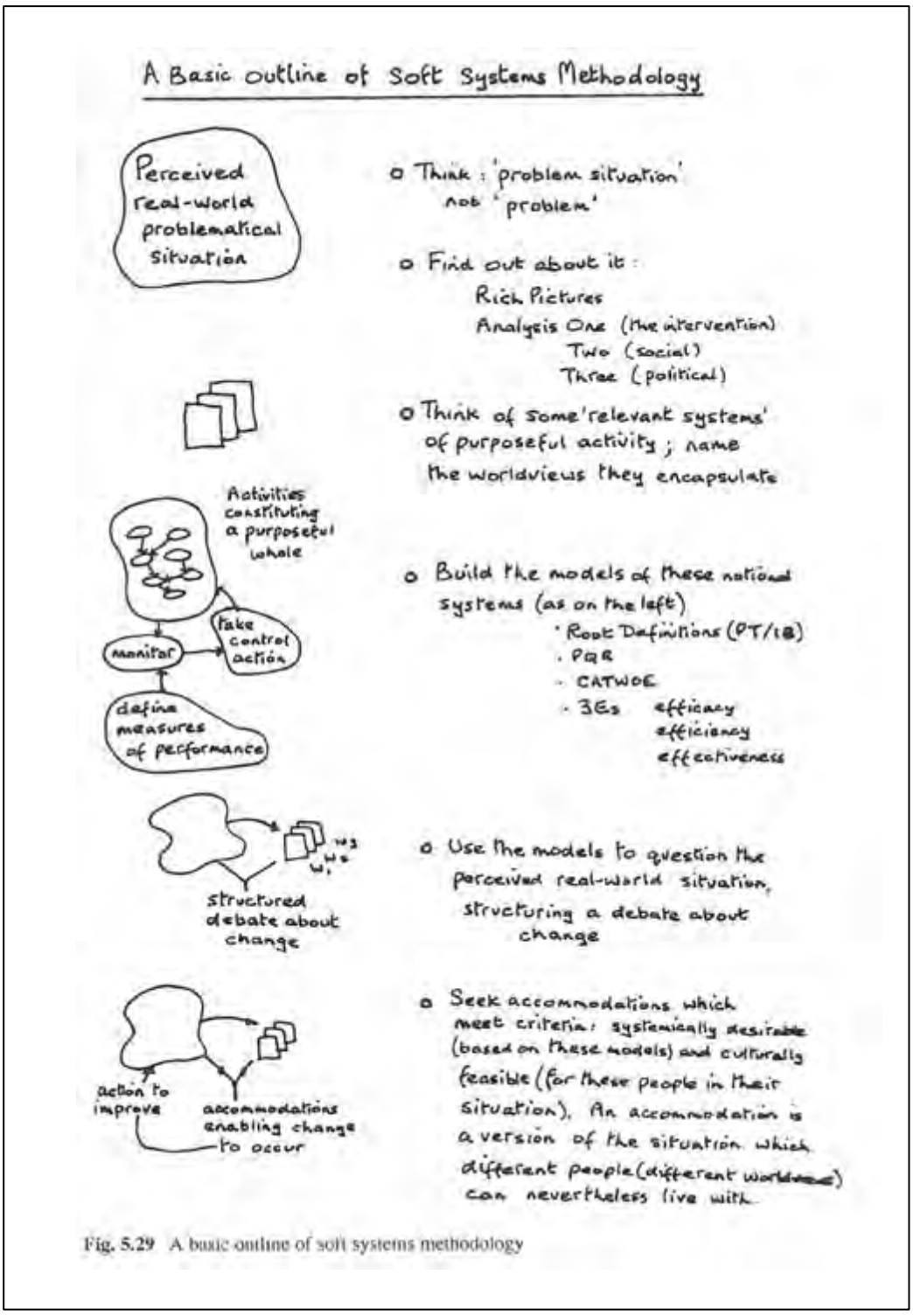

Fig. 5.29 A basic outline of soft systems methodology

(Checkland & Poulter, Soft Systems Methodology, 2010, p. 241)

APPENDIX 5: CLIENT'S INFORMATION DOCUMENTS

UNIVERSITY OF CAPE TOWN

Holistic Strategies for CP Clients using Transdisciplinary Communication

Dear

An Invitation to Participate in our Research Program

I would like to invite you take part in a research project that Joanne and myself are doing together. As most of you know I have always sought to be holistic in my practice of physiotherapy. Not only looking at the area of ailment but trying to get to know you and your needs. I have also noticed how disconnection between all the different practitioners has caused some difficulty. Joanne and I have joined forces to try and implement a more holistic approach by incorporating the expertise of other professionally trained people into a team. Some of you know that I have been doing specialized modules in pain management and so now the will be on developing something like a 'program' for CP sufferers. For the 'experimental' stage of the program I will only be able to select three patients, although I hope to include many more of you in the full program in the future! To ensure fairness an outcomes measure will be used to determine who gets to participate.

I will need you for about an hour and a half once a week. I will make sure this a convenient time for everyone. This in addition to, and is not a replacement of your normal physio slot with me. At this stage the idea is that this program will be more informative than treatment based and will help give you tools to implement in your own time. There may also a couple of group sessions with some therapeutic value.

Warm regards
Adele de Klerk

Introduction to the Research

While Adele will be heading up the treatment process, I will be providing the research structure for capturing and analysing the data. This is to ensure that Adele's program is informed by both your needs and the best expertise too. This study is also of personal benefit to me too as my involvement here will help me to fulfil my thesis requirements for my Masters in Clinical Psychology at the University of
Cape Town.

If you decide to take part in this study then for research purposes you will need to attend a couple of one on one interviews with me from April to July. I will need to see you at least once a month for between 30 to 60 minutes. During that time I will be asking you a couple questions about your experiences and views of CP and treatment. This interview will be recorded, transcribed and then coded into themes. These themes will then be made available to the professionals involved in treatment so that their choices can be informed by you personally. Before anything is given to them you will be required to read through my summaries and sign to say that what I have summarized is in fact an adequate reflection of what you have said. The information that is given back to the professionals is very general

feedback combined with other clients views and will not provide any information that links you directly to the statements.

Risks, Discomforts & Inconveniences

There are no known risks to patients, as all the people who will be involved in treatment are registered health professionals. It may however be uncomfortable to see new professionals who may be involved in the program. Therefore to help, we would like to encourage you to invite any professionals you may be already seeing or would prefer to be involved with us in this study. Also we would like you to invite a one or two other supportive or significant people in your life to also be involved in our team. This could possibly be a sports coach, family member or a healer. Not only does this help us to understand you better. But the advantage of this is that their input into your life can be shaped and encouraged by our professional team to ensure its maximum benefit to you. The study will require a fair amount of your time. The interviews and Adele's weekly meetings combined will probably take about 8 to 10 hours a month in total above your regular therapy time.

Please list the names of any supportive people you would like in the team and state their profession or relationship to you:

_____ _____

_____ _____

Please list the names of any health professionals who are currently treating you or you would like to be in the team and state their profession:

_____ _____

_____ _____

Benefits

While we are trying to use this study to improve our services to ADK physiotherapy clients in general, and add to scientific knowledge, there are benefits to you personally. You will find yourself immersed in an extremely supportive and non-judgmental environment. You will also benefit from new knowledge about chronic pain and the tools should help you cope with it better.

Financial Costs

Any research related activity such as the interviews or new treatments introduced will be free for the period of the study. However normal charges for your already established private consultations will continue. If you wish to continue with the extra treatments after July 2013, you will be charged as per medical-aid rates. If your medical aid fund will not be depleted by the extra costs of the program, payment would be appreciated, but is not a requirement for participation.

Are there other options for me besides this program?

You are welcome to decline participation in this study and continue with treatment as per before. You do not have to attend this study to learn about chronic pain. There are many other sources of help. If you are looking for a different approach or more information about chronic pain from a different source, feel free to consult your doctor for more information or a referral to a different facility. The treatment direction you select, is completely up to you. Also you are free to withdraw from the study at any stage without a need to give any reason for your withdrawal. Should you wish to withdraw simply email or call Joanne or Adele.

Privacy and Confidentiality

This study will take great precautions to preserve your confidentiality and requires you to respect the confidentiality of other participants at all times. We will take strict precautions to safeguard your personal information throughout the study. Any information from the interviews will be kept on a password-protected computer and secure online storage facility. This is only accessible to the researchers and practitioners. The research data available online which is available to the wider team will consist only of generalized themes and will not contain any personal details or names unless authorized for a specific purpose in writing by you.

Treatment records will be kept as per normal Health Professional rules be kept locked in a secure area. The details of your case will only be discussed amongst team members who you give consent to be involved in your case. They are all professionals who are bound by the oath of confidentiality. Confidentiality will be encouraged in the group sessions with other patients, who will be all asked to respect the confidentiality of each other and sign a confidentiality agreement. However participants must understand that confidentiality cannot be guaranteed in these settings, only encouraged.

In Case of Injury

Participation in this study is entirely at your own risk. If you are injured as a direct result of participating in the study, treatment can be made available if in the expertise of the practitioners involved - including physiotherapy, first aid, and certain types of follow-up care. There is no money set aside to pay for such events but it will be charged to you or your medical aid. If you are not prepared to take on this possible cost, you should not participate in this study.

What to do if you have questions?

If you have any questions and would like to speak to someone about the program please call Adele's office and ask the receptionist to leave a message for either Adele or Joanne to call you back. Joanne will be available for questions about the research process and Adele will be available for questions about the treatment program. Alternatively you can email info@wellsprincentre.co.za. If at any stage you would like to withdraw from the study you can contact either Joanne or Adele either by telephone or email.

What will the research data be used for?

All data used in this research will be reported in a way that will keep the identity of the participants confidential unless the participant specifically wants to be recognized for their contribution. Firstly the data will be used by Adele to guide her future treatment programs. Secondly it will be used for Joanne's master's thesis. It is also hoped that it may be used to inform other future research. Thus the summarized thematic data will need to be stored long term. However recordings and any details containing names will be erased once the master's thesis has been marked. There is also a chance that data could be published in other documents such as professional journals. As cautious as any research be about protecting its participants, there is always a risk that data could fall into the wrong hands. This is a risk you agree to take if you participate in this or any other study. If you are unhappy with any of the above, you should decline to participate in the research study. However if you decide to participate but then later feel you do not want your data used, you are free to pull out your contribution at any stage by emailing or calling Joanne or Adele regarding this.

Warm regards
Joanne Laskey

Signatures

_____ has been informed of the nature and purpose of the study including time requirements and risks. He or she has been given time to ask any questions and these questions have been answered to the best of the investigator's ability. A signed copy of this consent form will be made available to the subject.

_____ _____
Researcher's Signature Date

I have been informed about this research study and understand its purpose, possible benefits, risks, and discomforts. I agree to take part in this research as a subject. I know that I am free to withdraw this consent and quit this project at any time, and that doing so will not cause me any penalty or loss of benefits that I would otherwise be entitled to enjoy.

_____ _____
Participants Signature Date

Validated By

University of Cape Town Child Guidance Clinic Committee:

Approved _____

Expires _____

Protocol Number _____

Initials _____

APPENDIX 6: OUTLINE OF CODES AND THEMES FROM DATA

Developing Theoretical foundations of practice:

The basics of CP:

- *CP is about chronicity*
- *CP is limiting*
- *CP is unconscious and genuine pain*

Further Ideas about CP

- *CP is a relationship*
- *CP starts with failure*
- *CP is a system imbalance*

Is CP a new form of PTSD?

- *Direct Exposure or anticipated to Trauma*
- *Re-experiencing*
- *Avoidance*
- *Negative thoughts and mood*
- *Hyperarousal*
- *Irritable behaviour and angry outbursts*
- *Hypervigilance.*
- *Sleep disturbance*
- *Dissociation*

Treatment:

Developing a Treatment Strategy

- *Structuring the process*
- *The importance of teamwork*
- *Diagnostic / assessment:*
  - *Assessment and diagnosis should be holistic*
  - *Considering the personality of the client*

Communication

- *Listening to the pain*
- *Communicating with clients*
- *Communication for teamwork*
- *Education*

Aspects of the intervention

- *Several layers of a persons being are involved*
- *Changing the Relationship with pain*
- *Pain medication*
- *Psychological intervention is important*

APPENDIX 7: ABBREVIATIONS USED IN THIS STUDY

AHPCSA: Allied Health Professionals Council of South Africa

CP: Chronic Pain

CWG: Collaborative Working Group

DSM: Diagnostic and Statistical Manual of Mental Diagnosis

FG: Focus Group

HPCSA: Health Professionals Council of South Africa

ICF: International Classification of Functioning

ISAP: The International Association for the Study of Pain

MD: Medical Doctor

TDT: Transdisciplinary Teamwork

TDC: Transdisciplinary communication

PTSD: Post Traumatic Stress Disorder

SSM: Soft Systems Methodology