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# Turkish Women Experiences of Psychological Treatments for Chronic Pain

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Portfolio submitted in fulfilment of the requirements for the Professional Doctorate in Psychology (DPsych)

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July 2021

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## **Acknowledgments**

To my research supervisor, Jessica, I would like to say thank you for all your support, guidance, and understanding and for believing in this research and to me. Thank you for all your trust and encouragement. You have kept me going to achieve my career gaol.

To the participants who agreed to take part in this study, thank you for sharing your time, experiences, and selves. This study would not have been possible without you and I hope the final product goes some way towards making your voices heard.

To the wonderful team at the Locomotor Pain Clinic in which my research took place, I am thankful to you for your support and expertise.

To my mum, your patience, understanding, your support with childcare and all the delicious food prepared for us and your kindness and encouragement over the past five years (and beyond) has been unfaltering. You have always encouraged me to be a strong independent woman and believed in me and my potential; without your support, I could not have made this journey and become the women, mother and soon to be qualified Counselling

Psychologist I will be. I am so lucky to have you as my mother; you have been a guiding light throughout and I know you will continue to be.

And to my baby boy Oliver-Cinar, you were 10 months old when I started this journey and now you are five years old. We had to sacrifice a lot of precious moments with you during this time but you have always showed your understanding with your smiles and warm cuddles when we reunited. I owe you so much time and I promise I am going to make up with lots of happy memories. I want you to know that you were the reason for me to never give up on my dreams.

This portfolio is dedicated to all of you.

## **Declaration of Powers of Discretion**

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#### Introduction to the Portfolio

This portfolio is made up of three pieces of work, each representing a different aspect of my training. It begins with a doctoral research project that explores the psychological therapy experience of Turkish-speaking women with chronic pain, and follows by presenting a clinical case study where pluralistic approach was provided to a service user in an inpatient psychiatric setting within the National Health Service (NHS). The portfolio closes with a research article that will be submitted to *Patient Experience Journal* to disseminate the research findings.

Over the previous four years, many aspects of my training have inspired me, but nothing has entranced and encouraged me as much as the research I present here which offers opportunity for service user involvement and opportunity for voices of marginalized groups to be heard. I first became curious in the treatment experience of service users when I started to practice clinically within unitary models of psychotherapy in NHS. As a woman from a Turkish background, I experienced a tension within my practitioner role and my cultural identity especially whilst working with individuals from similar backgrounds. In my personal and clinical experience, Turkish speaking individuals appeared to take a passive role as defined by Board, Childs and Boulton (2020) within the patient-clinician interaction where little to no active involvement is observed in the decision- making process regarding their care. There is a strong emphasis on regarding professionals as experts and aligning them the full responsibility in the management and treatment of their chronic pain. Hence the idea of partnership and collaboration that is strongly encouraged in today's NHS healthcare was unfamiliar to me. I was learning new ways of approaching and receiving healthcare and was then expected to deliver this in my practice.

I experienced delivering Cognitive Behavioural Therapy (CBT) in one of the highly diverse London Borough very challenging. The individualistic emphasis of CBT model created challenges when delivered to individuals from collectivist backgrounds. I also experienced an internal conflict whilst delivering this model, for me it did not fully appreciate thewholeness of a person. At the time, I was at the beginning of my career and did not have the insight or knowledge to reflect on this internal tension or recognise the possible influences in my clinical practice. I became interested in culturally sensitive delivery of psychological therapies and

was fortunate to co-author a research study that explored the Guided Self- Help experience of Turkish-speaking service users in Improving Access to PsychologicalTherapy Service. The insight I gained through the descriptions of service user experience enabled me to be involved in projects that improved the access and delivery of services for individuals from Black and Ethnic Minority groups (BME).

As I became more involved in projects for BME groups, I realised how important it is for health professionals to develop skills and competencies from other areas of psychological theory and model to meet the changing, varied, and diverse needs of service users and to approach individuals from a more holistic perspective, considering their background and their lived experience, and to see them beyond their symptoms or diagnosis.

Counselling Psychology emerged as a critical reaction to pathologisation of psychological distress together with emphasis on respecting personal, lived experience over and above the notions of diagnosis, measurement, and cure which I believe position itself well with my commitments and values (Bury & Strass, 2006). Nevertheless, I continued to work within mental health teams and health care settings where medical model, notion of mental 'illnesses and standardized approaches to treatment prevail (Bury & Strauss, 2006). This therefore created another internal tension and brought the challenge of how I position myself in my clinical practice. This positioning of myself in clinical settings and practice required me to develop and build confidence in my reflective skills.

This portfolio therefore represents my journey in becoming a pluralistic, reflective, and scientist-practitioner Counselling Psychologist that offers me the opportunity to make a difference in a way that extends far beyond therapy room. Depending on service user's needs I can choose to strengthen my scientist-practitioner role and adopt their 'illness' frame of reference, or adapt a reflective and humanistic principles to challenge pathological discourses and advocate for more person-centred and pluralistic approaches to benefit service users with varied and diverse needs. I've also realised that I have the potential to influence not only people in the therapy room with me, but also the personalities, services, and societies that form them.

Going forward, I intent to continue working with diverse populations across their lifespan to develop my skill, competency and confidence in different psychological theory and modelsas a pluralistic and reflective practitioner, and will continue to advocate for voices of service

users to be heard through my scientist-practitioner identity by initiating or contributing to projects, to improve access and delivery of services for underrepresented populations of our society.

#### **Preface**

#### **PART A: Doctoral Research**

This first section comprises the doctoral research, entitled: *Turkish Women Experiences of Psychological Treatments for Chronic Pain'*. This research aimed to explore the lived experience of Turkish-speaking women's psychological therapy for chronic pain in a multidisciplinary pain service of NHS. This research project has provided opportunity to explore cultural and systemic influences that shapes the perception and lived psychological therapy experience of Turkish-speaking women. Six semi-structured interviews were conducted with a sample of women, age 45-55, which had undergone psychological intervention for their physical health- chronic pain. Their data was examined using Interpretative Phenomenological Analysis and five superordinate themes emerged. The findings are considered within the context of existing literature and theory. Implications and suggestions for Counselling Psychology are presented.

This research project offered me the opportunity to explore lived experience of participants in a highly medicalized setting of a physical health condition that is known to have both physical and psychological impact on a person. This project positioned itself within the ethos of Counselling Psychology by providing a more critical lens to pathological focus on physical health condition with a psychological impact. By adopting the IPA methodology, this project also offered me the opportunity to reflect on my cultural, generational, and societal biases in relation to participants from a similar background, to make sense of participant's sense making. I believe, researching a medicalized condition in a medicalized health care setting within a culture concordant researcher-participant encounter developed my confidence as a reflective-scientist practitioner.

#### **PART B: Client Study**

In this section, I present a study of clinical work I undertook with a service user in a multidisciplinary team at a Hertfordshire NHS psychiatric hospital. Service user had an official diagnosis of a personality disorder and had a different cultural and societal background in relation to me. I was asked to work with her to reduce her suicidal thoughts and selfharming tendencies to prepare her for discharge. A standardized treatment approach was recommended. However, I chose to work within a pluralistic, non-diagnostic approach in a highly diagnostic setting. This case emphasis my working with service users beyond their symptoms and diagnosis in a medicalized setting and adapting interventions to provide an individualized care that is tailored to meet her own needs. This client study demonstrates key aspects of my development as a pluralistic Counselling Psychologist.

#### **PART C: Publishable Paper**

I present, in this final section, a publishable paper which explores the findings from my research project. My aim is to have it published as a peer reviewed in *Patient Experience* Journal (see Appendix A for Patient Experience Journal Author guidelines). I decided upon this journal because it offers opportunity to explore various areas, push boundaries and is comfortable to challenge conventions, considerations, or organisational biases that impact on patient experience. Furthermore, it encourages the voice of patients and family members to inform or influence research and practice. It further encourages dissemination of qualitative research that focuses on patient lived experience.

I believe the objective and aim of the journal positions itself well with my personal and professional values as well as within the aims and objectives of this research and Counselling Psychology ethos. It has been noted that at least two patients sit on the editorial board of the journal which for me it represents journal's commitment in representing voices and different perspectives on their editorial board.

The publication of my research findings will reach a global community of practice dedicated to improving patient experience through collaboration and shared knowledge. Findings are noted to reach 6500 institutions in 200 countries and territories. I hope the publication of the findings can provide those working within the field an understanding of service user characteristics, cultural backgrounds, and systemic challenges to better meet individual needs, thereby increasing access of black and ethnic minority groups to effective psychological therapy interventions for chronic pain.

## **PART A: Doctoral Research**

## Turkish Women Experiences of Psychological Treatments for Chronic Pain

**Gozde Arslan** 

**Supervised by Dr Jessica Jones Nielsen** 

#### **Abstract**

Increase in ethnic and racial diversity in UK requires National Health Service to deliver care to non-English speaking patients. The literature suggests that effective pain treatment and psychological treatments for chronic pain must be tailored to meet cultural experiences of pain and belief about pain treatment. Yet there appears to be lack of research into UK- based psychological therapy experience of ethnic minorities and non-English speaking patients. This paper presents findings from a qualitative study that explored the psychological therapy experience of Turkish-Speaking women with chronic pain. Data were collected using semistructured interviews with six women who had received psychological treatment in National Health Service for their chronic pain. An interpretative Phenomenological Analysis (IPA) approach was applied in the research process, identifying five superordinate themes: living with chronic pain, when paths crosses psychology, my painis real, out of control and control within the system and outcome of therapy. Each superordinate theme consisted of several subthemes which described participants' experience. Passive position taken up by participants during their psychological therapy experience emerged as significant in Turkishspeaking women with chronic pain. Cultural and systemic factors that maintain this passive position within psychological therapy is explored. Input directly from Turkish-Speaking women can be combined with findings from other studies to improve understanding of psychological therapy experience of individuals with chronic pain from different cultures. A better understanding of cultural differences and systemic challenges in the experience psychological pain treatment can provide support for tailoring services to meet the needs of individuals from ethnic backgrounds.

## **Chapter 1. Introduction**

Pain which is a sensory and emotional experience that is associated with potential tissue damage becomes defined as chronic if it persists longer than three months, loses its adaptive function and is unresponsive to medical treatments (Cano-Garcia, Gonzalez- Ortega, Sanduvete- Chaves, Chacon-Moscoso & Moreno-Barrego, 2017).

Chronic pain is considered as a global and complex human experience which is known to impact on person's physical, behavioural, cognitive, emotional, social, and financial wellbeing (Gatchel, Peng, Peters, Fuchus & Turk, 2007). It is associated with reduced neuropsychological functioning (Herbert, Afari, Robinson, Listvinsky, Bondi & Wetherell, 2018) that has shown to impact specifically on attention, working memory, processing speed, learning and executive functions (Apkarian, Baliki, & Geha, 2009), and increased pain intensity, pain catastrophising, disability and depression (Legarreta, Bueler, DiMuzio, McGlade & Yurgelun-Todd, 2016). According to Tang & Crane (2006) the lifetime prevalence of suicide attempts for chronic pain suffers range from 5-14%. Furthermore, sense of helplessness, hopelessness, frustration, anger, and guilt is reported to be common experiences for individuals with chronic pain. The impact of chronic pain is also an economicone, use of Sickness Impact Profile found chronic pain to be associated with reduced ability to work and difficulty in performing daily activities (Smith, Elliot, Chambers, Smith, Hannaford & Penny (2001). In United Kingdom, chronic back pain is known to lead to 65 million days lost from work per year (Philips, 2009).

Chronic pain is regarded as a public health concern as it represents the most prevalent, disabling, and expensive public health condition by the Global Burden of Disease Reviews (Vos, Flaxman, Naghavi, Lozano & Michaud, 2012). In Europe, it is accounted for 19% of the aging population suffering from chronic pain (Cano-Garcia et al, 2017), and in United Kingdom estimated prevalence of chronic pain is 43% which equates to just fewer than 28 million people, with women being more likely to experience chronic pain then men. Prevalence of chronic pain appears to rise steadily with age, affecting over 62% of the population over the age of 75 years. Within the 28 million, 7.8 million identified their chronic pain within moderately to-severely limiting (Fayaz, Croft, Langford, Donaldson & Jones, 2016).

Multidisciplinary pain management programmes that commonly incorporate psychological therapies have been used effectively to improve health-related outcomes, including pain intensity for people with chronic pain. However social parameters governing the access and

delivery of psychological care receive little attention and remain poorly understood, particularly in marginalized populations (Institute of Medicine Committee on Advancing Pain Research Care, and Education, 2011). Inequalities and injustices in access and delivery of services responding to management of chronic pain contrasts with declarations that pain management is a fundamental human right (Brennan, Carr & Cousins, 2007).

I will now present my rationale for the current study, before going on to discuss the contribution I hope to make to the field of Counselling Psychology. This chapter concludes with a brief clarification of some of the key terms I have used throughout the work.

#### 1.1Rationale for the Study

Having decided I wanted the broaden focus of my research to be on psychological treatments for chronic pain, I immersed myself in the literature. I found myself drawn into access and delivery of psychological care for chronic pain in marginalized populations. Addressing healthcare inequalities and injustices has always been my ambition and it was here that I wanted to locate my clinical ambition as a Counselling Psychologist.

As I read more about the topic, I learned that health care professionals were more likely to care for people from different backgrounds that are different from their own due to increased racial and ethnic diversity in countries around the word; however, the research evidence that guides treatment guidelines continue to be gathered from empirical and actual data which promotes control in meaning and power. Furthermore, most research exploring the radical and ethical disparities focused mainly on non-Hispanic black and white patients that informed differences in pain appraisal, belief about pain and ways of coping with pain, or conducted with upper- middle class patients in English speaking countries or predominantly from US and Canada. There appears to be three main challenges with the current research in the literature when guiding practice; first is that the results would be difficult to consider in the light of practice in the United Kingdom with different cultural groups and healthcare system. Second, the influence of acculturation, which is the process of adopting the values, beliefs and culture of the country people have emigrated to (Peacock & Patel 2008) has received little attention in the current literature. Finally, results cannot be considered in the light of individuals from ethnic minority groups and with different socioeconomic backgrounds.

Furthermore, most qualitative studies in this area tend to examine patients' experiences with chronic pain treatment specific to medical or physiotherapy interventions and few studies have considered patient's experience with psychological therapy.

Furthermore, the concept of gender-blindness which is defined by Celik, Lagro-Jamssen, Widdershaven and Abma (2010) as the 'nonawarness of the fact that a great deal of knowledge is based on research performed on men' has been identified as an obstacle for gender equity in health care. According to Sex, Gender and Pain Special Interest Group of International Association for the Study of Pain, females are underrepresented in animal and human studies and consequently sets their recommendations for 'both constructs (Sex and Gender) to be examined, when possible, in order to understand their relative contribution to differences between men and women' (Greenspan, Craft & Lerensche, Arendt-Nielsen, Berkley, Fillingim, Gold, Holdcroft, Lautenbacher, Mayer, Mogil, Murphy & Traub, 2007).

Hegemonic masculinity which describes a pattern of masculine attributes, behaviours, and practices as idealised norms which both men and women are evaluated in healthcare. Hegemonic masculinity expresses a dominance of men over women and over other men according to idealized norms. For example, in the context of pain, masculine attributes such as strength and endurance are valued higher than feminine attributes like sensitivity and willingness to share emotions (Bernardes, Keogh & Lima, 2008). Another example is when research on men is shown as a bases for treatment for both men and women (Samulowitz, Gremyr, Eriksson & Hensing, 2018). Likewise, andronormativity – where masculine and male values are regarded as normal to an extent that femininity and female values are invisible has been applied in healthcare. Both Hegemonic masculinity and andronormativity leads certain conditions to be prioritized while others are down prioritized in research and healthcare. This study therefore conducts research with Turkish women to further challenge and to bring an alternative view and understanding to gender-blindness within research and healthcare.

As a Counselling Psychologist, I have a duty to question our practice both in terms of therapeutic skills and of political and cultural discourses to address the ethical questions about the role of psychology or therapy in our society. One way for us psychologists to do this is by advocating for ethical therapy by promoting opportunities for service user involvement's both in research and clinical practice. This study therefore aims to offer insight into

complexities of the Turkish Speaking Women's psychotherapy journey for chronic pain to further clinician's understanding and ability in offering culturally sensitive and individualized psychological treatments. It is also hoped that it will enable professionals to identify different ways of relating to treatment to develop practice and effective treatment pathways to reach this population. This seems to be particularly timely given the extent of strain chronic pain imposes on scarce healthcare resources in UK.

#### **1.2Contributions to Counselling Psychology**

One of the key motivations for conducting research is the positive contributions one might make to their field. This study contributes on an area that is under researched despite the enormous health and societal impact (Vos, Flaxman, Naghavi, Lozano & Michaud, 2012). One of the reasons for this is argued to be the underfunding in pain research which has limited clinician's ability to provide most up to date, evidence- base treatments to individuals suffering from chronic pain (Gereau, Sluka, Maxixner, Savage, Prince, Murinson, Sullivan & Fillingim, 2014).

It is important to consider that the discipline of Counselling Psychology emerged as a critical reaction to the positivist medical model of understanding human distress (Milton, Craven & Coyle, 2010). The exploration of psychological therapy within the literature has almost exclusively been conducted within the confides of this model, putting it at the odds with the value of Counselling Psychology on lived experience and the meaning that we, as human begins, are intrinsically embedded within our environments. This study intends to rectify this by viewing the phenomenon of psychological therapy experience of Turkish women through a more humanistic, Counselling Psychology lens. By doing so, this study willgenerate useful knowledge for National Health Service (NHS), and position itself well with Service User Strategies, which was expressed in White Paper Equity and Excellence: Liberating the NHS, No Health without Mental Health and Putting Patient's First, and will facilitate Counselling Psychology to enhance its profile within the public sector.

#### 1.3Clarification of Key Terms

I have used the term 'participants(s) throughout the study when referring to those in receipt

of psychological therapy for the chronic pain in pain clinic. I have considered the use of alternative terms, such as client, service user or patient but felt that the participants presented themselves differently during research process in comparison to how they presented during their psychological therapy experience. All disclosed to be more comfortable and 'honest' in their disclosures during research interviews (discussed further in analysis and discussion section) and therefore I believe the term 'participants' reflected their presence in the study appropriately.

## **Chapter 2. Literature Review**

This chapter will present a critical review of the literature and the empirical findings relevant to the topic of research. A brief overview of psychological interventions for chronic pain is offered, with particular attention paid to cross-cultural interactions in health care. Cultural disparities in the assessment and treatment of pain are explored and consideration given to the Turkish speaking culture's perception and experience of chronic pain and to thenumber of Turkish-speaking immigrants in UK. Discussion then turns to the research in cross-cultural context and gender disparity and identifying gaps in knowledge.

#### 2.1 Psychological Intervention in Chronic Pain

It is a well-established fact that chronic pain has a significant impact on individuals, causing distress and disability. Cognitive and Behavioural therapies designed to alleviate distress and disability have been around more than 40 years (Fordyce 1968; Keefe Rumble 2004 cited in Eccleston, Williams & Morley, 2019).

Psychological interventions for chronic pain entail a social interaction between the clinician and the patient in which the clinician encourages the patient to change 1) their thoughts about pain, which primarily targets the prefrontal cortex, 2) their behavioural responses to pain, which primarily targets the prefrontal cortex, ACC, and sensory cortex, and 3) their sensory experience, targeting the sensory cortex (Jensen, 2010). According to neuromatrix theory, changes in pain-related cognitions, behavioural reactions, and sensory experiences, would lead to long-term improvements in patient functioning (Jensen, 2010).

A psychological pain intervention is shown to be effective and recommended treatment for chronic pain. According to Society of Clinical Psychology, the evidence is particularly strong for Cognitive-Behavioural Therapy (Morley, Ecclesten & Williams, 1999; Huguet, Barbet, Belletier, Monteil, Fagot, 2014; Cherkin, Sherman, Benjamin, Andrea, Melissa, Rene, Kelly & Judith, 2016), and acceptance and commitment therapy (Veehof, Trompetler, Bahlmeijer, Schreurs, 2011, 2016; Hann & McCracken, 2014) and mindfulness (Lauche, Cramer, Dobos, Langhorst, 2013). There have also been periodic publications of meta-analyses and systematic reviews (Flor, Fydrich, & Turk 1992) and many recent studies have focused on specific patient groups such as those with musculoskeletal pain syndromes (Dixon 2007; Guzman 2001; Hohman 2007; Henschke 2010a), and older adults (Ersek, 2008) (Cited in Williams et al, 2019). Yet psychological interventions have been shown to be not widely accessible to culturally diverse patient groups (Kress, Aldington, Alon, Coaccioli, Collett, Coluzzi, Huygen, Jaksch, Kalsoc, Kocat-Kepska, Mongas, Ferin, Mavroccodatos, Morlion, Muller- Schwere, Nivolocu, Hernandea, Sichere, 2015). The national pain audit (2012) discovered 28 primary care practises that did not provide multidisciplinary chronic pain care. Furthermore, psychological therapy (Chan, Fam, & Ng, 2009), which has been found to be clinically beneficial and cost-effective, is only considered when other treatment options have failed to give appropriate pain relief (Kress et al, 2015).

Evidence on the efficacy of psychological intervention in chronic pain has been criticised for assuming homogeneity among patients with chronic pain, and for efficacy studies being conducted in ideal conditions with funding for adequate selection of participants, expert psychologists, and patients with middle-high educational levels who are motivated to participate (Cano-Garcia et al, 2017). This usually leads to evidence- base for unitary models and dominates mental health services, as it is important in improving outcomes in health and social care (Camberlain, Roberts, Jones, Marsenich, Sosna & Price, 2012). Evidence of unitary models demands change that is aimed at raising standards and improving practice whilst demonstrating value for money by relying on latest NICE guidelines or Department of Health's recommendations (Godar, 2017). This criticism on evidence-base medicine came to be known as the 'humanistic turn' which has relations to women's right movement (Arney & Neil, 1982), postmodern criticism of medicine (Bauman, 1992) and phenomenological and narrative approaches to the practice of medicine (Bueno- Gomez, 2017).

In relation to 'humanistic turn' Narcross & Wampold (2011) argued for the absence of the

'person of the patient, beyond his or her disorder' in the current evidence-base for psychological interventions in pain (Lazarus, 1990) for not considering the demographic, medical, psychological differences among patients that are relevant to treatment response (Reese and Mittag, 2013). Lazarus further pointed out to Bandura's (1989) work to illustrate the importance of relationship variables in the modelling work for the treatment of phobia disorders and argued that it is difficult to eliminate the relationship variables which confound all research attempting to demonstrate the effectiveness of unitary models of psychotherapy (Patterson & Watkins, 1996). In addition, Beutler & Clarkin (1990) highlighted the environmental as well as therapist variables in their system of matching clients to treatments.

Culture is also shown to have a vital influence on illness beliefs and behaviours, health care practices, health-seeking activities, and receptivity to medical or psychological interventions (Lash, Lynch, Rutherford, Sherman & Webster, 2006). Culture is defined as group of people sharing beliefs, language, behaviours, customs, and knowledge that provide people with a pattern of living and relating with each other that is transmitted from one generation to another (Tan, Jensen, Thornby & Anderson, 2005). A cultural identity is developed from a person's interaction with their culture, which is their sense of belonging to a cultural group while holding on to a unique inner identify, with own beliefs about reality, concept of self, sense of morality, concept of time as well as non-verbal behaviours, use of language, relationship patterns, expression of emotions as well as shaping and understanding of problems and solutions and concept of healing (McLeod, 2013).

It is important to note that there are differences both between and within cultural groups and to note that identities of many people in our current modern societies derive from multiple cultures due to increase in cross cultural relationships and a person's freedom of choice of certain cultures in adulthood (Josephs, 2002). Due to these variations, it is far more crucial for clinician not to make stereotypic judgements based on person's ethnic heritage and to consider both inter and intracultural differences when working with a patient. This appears to more important than ever as in many countries their growing proportion of society is represented by communities from culturally and linguistically diverse backgrounds and health care professionals and providers are more likely to care for people from backgrounds that are different from their own. This is particularly true in countries like United Kingdom. The 2011 Census has shown that England and Wales have become more ethnically diverse, 'with

minority ethnic groups continuing to rise since 1999, with London being identified as the most ethnically diverse region, where 40% of residents identified with either the Asian, Black, Mixed or other ethnic group (2011 Census Analysis, 2011). Hence, this cross-cultural interactions in health care and especially in psychological care may be complicated further by clinicians and patients coexisting, potentially incompatible beliefs, values and explanatory models of health and illness (Brady, Veljanova & Chipchase, 2017).

In the field of psychotherapy, it is now recognized that 'one size fits all, unitary models of psychotherapy as inappropriate and in some cases unethical (Narcross & Wampold, 2011). Therefore, the evidence for efficacy of psychological intervention for chronic pain raises many questions and limits the reliability and generalisability of the evidence to different populations.

In the light of covid-19 pandemic and the Black Lives Matter movement, recognising and incorporating the views and values of culturally diverse patients and addressing health inequalities has become more important than ever. The NHS Race and Health Observatory in June (2000) and Patient and Carer Race Equality Framework (PCREF) have set out plans to improve access, experience, and outcome for Black and Ethnic Minority communities. The NHS Five Year Forward Plan which also includes the Mental Health Implementation Plan 2019/2020-2023/24 also sets the expectation for that all systems to reduce mental health inequalities by 2023/24.

#### 2.2 Cultural disparities in the assessment and treatment of pain

Across a wide spectrum of medical disorders, decades of study have demonstrated major discrepancies in the delivery of health care services (Institute of Medicine, 2003). While chronic pain patients have been identified as being at risk of under treatment in general, ethnic minorities are a particularly vulnerable subgroup. This section will first discuss concerns with chronic pain assessment that make ethnic minorities vulnerable to mismanagement, before moving on to elements that may influence therapy, such as patient-clinician interaction and the public health environment.

#### 2.2.1 Assessment of chronic pain

The assessment of chronic pain is complicated due to its nature of subjective pain, and lack of objective diagnostic tests (Rhodes, McPhillips- Tangum, Markham, & Klenk, 1999). Furthermore, objective medical evidence frequently fails to correlate with the reported levels of pain intensity, and patients can report high levels of chronic pain in the absence of objective diagnostic evidence (Beattie & Meyers, 1998) or can report no pain despite objective medical findings (Rhodes et al, 1999). This leads to reliance on the use of self- report measures to assess pain (Tait, Chibnall & Kalauikalani, 2009). However, these measures lack the capacity to capture the multidimensional experience of chronic pain and disadvantage people with limited English proficiency, which increases their vulnerability to inadequate care (Nguyen, Ugarte, fuller, Haas & Portency, 2005).

Research evidence also demonstrates judgements about pain that are influenced by the features of the patient race and ethnicity, the medical evidence, and the provider (Tait et al, 2009). Negative stereotypes have been documented for racial/ethnic minorities that experience pain (Dovidio & Fiske, 2012). For example, primary care providers have been shown to be more likely to underestimate the pain intensity in Blacks than on other sociodemographic groups (Staton, Panda, Chen, Genao, Kurz, Pasanen, Mechaber, Menon, O'Rorke, Wood, Rosenberg, Faeslis, Cary & Calleson, Cykert, 2007). Stereotypes are automatic, affect-laden, intuitive processes that contribute to clinical judgement biases (Hirsh, Jensen & Robinson, 2010). Evidence-base processes can also be considered as another bias impacting of the clinical judgement. Although, physicians frequently report no bias towards radical/ethical group, biases were demonstrated in a study of implicit and explicit biases using Implicit Association Test (IAT) (Greenwald, Noseck & Banaji, 2003) towards Latinos and Blacks in a large sample of community physicians (Blair, Havrenek, Prince, Hanratty, Fairclough, Farley & Stenier, 2013).

#### 2.2.2 Patient-clinician interaction

Patient-clinician interaction has a great importance in chronic pain conditions as there is a high need for collaborative decision making in the management (Hadjistavropoulous, Craig, Duck, Cano, Goubert, Jackson, Mogil, Rainville, Sullivan, Williams, Veruoort & Fitzgerald,

2011). Research has shown improved patient engagement in self-care management and feedback from patients regarding effectiveness of intervention for working patient-clinician integration (Dorflinger, Kerns & Auerbach, 2013).

Language skills are shown to be an important moderator of the patient-clinician interaction (Tait et al, 2014). Limited English proficiency seen in minority groups can impact on communication adversely and can be a barrier to adequate health care (Nguyen et al, 2005). Furthermore, minority patients have been found to be less active in their communication when the encounter of culture is discordant (Cooper- Patrick, Gallo, Gonzales, Vu, Powe, Nelson & Ford, 1999) and more active when the encounter is culture-concordant (Saha, Komaromy, Koepsell & Bindman, 1999). Hsieh, Tripp & Li-Jun (2011) also find patients to be more likely to report distressing pain to a culture-concordant clinician.

Clinician bias has been shown to play a role in the challenges in patient-clinician interaction. For example, Cooper, Roter, Carson, Beach, Sabin, Greenwald & Inui (2012) showed high racial bias seen in less patient-centred dialogues towards black with black patient biases of clinicians. Empathy studies have also revealed that for people of the same culture, the neurological substrate for empathy is heightened (Xu, Zuo, Wang & Han, 2009; Avenanti, Sirigu & Aglioti, 2010). These biases will greatly discourage minorities' participation in clinical decision making (Tait et al, 2014).

#### 2.2.3 Individual patient factors

There is vast amount of research documenting the racial/ethnic differences in pain sensitivity (Zatzick & Dimsdole, 1990). Patients presenting high levels of pain/ disability also are more likely to exit treatment which can explain the ethnic differences in the treatment response (Tait et al, 2014). Hsieh et al (2011) showed that patients were more likely to report pain behaviours when they were in culturally concordant pairs. Green et al (2003) showed that blacks were more likely to report higher levels of pain across range of painful conditions. However, it is important to note some major methodological limitations in the reports of patient's perception of pain as they are usually based on restricted nature of samples, lack of control over the severity of pain condition and lack of control over pre-existing treatments (Tait et al, 2014).

Racial/ ethical differences are also observed in the coping and adjustment to pain. Blacks are

more likely than whites to use passive coping strategies such as prayer (Jordan et al, 1998) while whites are more likely to use active coping self-statements and perceive themselves to be more in control and responsible in their pain management (Clark, Anderson, Clark & Williams, 1999). The definition of 'passive' and 'active' coping strategies appears to change depending on the literature and the culture it is associated with. For example, according to Jordan et al (1998), prayer is 'passive' coping strategy that incorporates the spiritual aspect of patient coping. Board et al (2020) on the other hand appears to consider passivity in terms of the cultural norms that requires deference to healthcare professionals' authority- the need to show respect and avoid conflicts with clinicians in clinical encounters. Yet, Michaëlis, Kristionsen and Norrendom (2015) would consider seeking healthcare, altering everyday life, managing and prioritising daily activities and taking pain-killer drugs as active coping strategy. As these are considered as asserting agency, offering a way to manage an otherwise uncontrollable situation to maintain everyday life and restore a level of health that enables them to function and complete their social roles in a way that empowers them to take responsibility for their own health. This study will align more closely to Board et al (2020) definition of passivity -as it considers cultural norms. Furthermore, previous research- for example Yazar and Littlewood (2001) is indicative of deference behaviour in Turkish-speaking individuals in healthcare settings which, according to Board et al (2020) definition can be considered as passive. However, this study will be cautious and will consider the impact of the clinician's and services general approach within the relational interaction between clinician and patient when aligning participants of this study to a particular definition of active or passive positioning in their healthcare behaviour.

#### 2.2.4 Pain and public health

It has been noted that ethnic minority groups distrust in medical profession, coupled with lowered expectations of treatment benefit results in reluctance to seek care (Tait et al, 2014). Ibrahim et al (2002) showed how blacks were more likely to decline treatments compared to whites which confirms the impact of patient expectations impacting on care decisions. Furthermore, Blacks were found to be three times more likely than Hispanics to see the medical system as racist (Lillie-Blanton, Brodie, Rowland, Altman & Mcintcsh, 2000).

Racism, which is defined as the 'beliefs, attitudes, institutional arrangements and acts that tend to denigrate individuals or groups affiliation' (Clark et al, 1999), was also seen as a major

public health issue within ethnic minority groups. Blacks were noted to report more stress related to racism which added to their disease burden (Burgers et al, 2009). Clinician behaviour has also been reported as a public health concern, with clinicians' actions leading to under treatment and slow referrals for specialist care. Many minority patients believe their referral to specialist care was delayed because of clinician behaviour (Green & Hart- Jonson, 2010). Given the above challenges, it is no surprise forethnic minorities to feel high levels of stereotype threat in medical settings (Burgerss, Grill, Noorbaloochi, Griffin, Ricards, Van Ryn & Partin, 2009), and have low expectations from treatment (Ibrahim, Simiroff, Burant & Kwch, 2002).

Minorities are also disproportionately represented in lower socioeconomic position (Mayberry, Mili & Ofili, 2000) and are at higher risk of pain (Institute of Medicine, 2011), as they are more likely to relate to physically demanding employment and less opiate availability (Morrison, Wallenstein, Natale, Senzel, & Huang, 2000). Ethnic minority receiving lower levels of care demonstrated poorer outcomes than non-Hispanic whites (Chibnall, Dabney & Tait, 2005).

#### 2.2.5 Perception and experience of chronic pain in Turkish Culture

In Turkish and other Mediterranean cultures, the body/mind separation is not as salient as in Western society and as a result it appears natural for emotional distress to be expressed publicly through bodily complaints (Ulusahin, Basoglu & Paykel, 1994). This somatisation — where psychological distress is expressed through physical pain (Kleinman & Kleinman,1996) is seen as more acceptable in cultures which are more explicitly physical in everyday interactions, where non-verbal behaviours communicate more than verbal communication (Blacking, 1977).

Turkish cultures appear to be past orientated. In Yazar and Littlewood (2001) study, most participants were political refugees, with many having experiences of themselves or relatives being imprisoned and/or tortured. Many of them also left their children behind in Turkey and experienced loneliness, boredom and insecurity as well as dealing with the loss of country, loss of friends and relatives and loss of language and therefore attribute their pain into non-organic causes, projecting their loss, separation, and guilt onto their organs. They appear to struggle to leave their past to focus on their future, which appears to be further

complicated by uncertainty about their civil status in foreign country, unstable accommodation, anxiety about friends and family in the country she/he fled; poverty; racism and hostility in the host county. Furthermore, the experience of torture- the personal meaning they attribute to as well as the previous life experiences and inter-cultural differences will all contribute to their current physical or psychological problems or exacerbate the existing ones (Carlesson, Mortensen & Kastrup, 2006).

Turkish culture's make use of metaphors in their description of pain, which is rooted in historical and cultural factors (Yazar & Littewood, 2001). Furthermore, Turkish culture appears to refer to their pain to concepts such as balance of elements of hot/cold and wet/dry (Good, 1977) and in relation to blood vessels. Blood vessels are known to be used inTurkish culture to express a person's state of being (Yazar & Littewood, 2001). The location of the pain has symbolic significance. For example, head is known to be associated with thinking processes; the stomach is associated with issues of shame and reproductive organs with womanhood and manhood. Hence pain is generally used by Turkish culture as a representation of personal distress (Yazar & Littewood, 2001). It has also been noted in the studies of chronic pain in survivors of torture, which can also be relevant for Turkish speaking immigrants of refugees is that direct disclosure of torture might be difficult for this group of people for many reasons. They may be convinced that nobody will believe in their story or will reject them. Similarly, the healthcare professionals may hesitate to ask questions directly on torture due to uncertainty about the survivor's reaction. Where both clinician and survivor are silent about the trauma, together with cultural use of metaphors to describe pain, it will be extremely difficult to make sense of the individual's presentation and to have a mutual agreement within the possible cross-cultural interaction (Amris & Williams, 2015).

In Turkish culture, bodily complaints are known to be the preferred form of appeal for help from the community as mental illness is understood as the sufferers own personal responsibility (Van Moffaert & Vereecken, 1989). It appears that men get more attention in terms of affection when they appeared ill, and women tend to get more help in terms of assistance with housework and childcare (Yazar & Littewood, 2001). Turkish culture has a salient agreement on housework being a women's role, while the man usually works outside the home (Kagitcibasi, 1982). It appears that it is only when a woman is recognised as sick she receives help in the home and childcare (Yazar & Littewood, 2001). Good (1977) found that 'heart disease' among Turkish speaking Iranian women is a way of asking for assistance from

people around them. Similarly, Mirdal (1985) in their study of Turkishspeaking women in Denmark found that they express their distress to others through bodily complaints, especially with reporting 'tightness' in their chest.

Diet and steam baths were used as traditional treatments for psychological distress to restore the body's humour balance. Religious medicine was also utilised, which is based on the Qur'anic cosmology and local notions that articulate such relationships as Jinns (spirits) and the evil eye as disease agents, as well as the logic of healing through the sacred word or touch of sacrificed men (Littlewood & Dein, 1995). As a result, touching is valued in Turkish culture, and it is nearly difficult for a Turkish patient to have faith in a doctor who does not touch them (Yazar & Littewood, 2001). However, on the other hand, touch or other events or cues such as waiting or uniforms may trigger flashbacks for torture survivors- which are intrusive memories that leads to re-experiencing of traumatic events, sometimes to extent of individuals losing touch with present reality to be able to fully engage with their treatment (Amris & Williams, 2015).

Despite the fact that most people in Turkish cultures believe they will not get better until the condition that caused their disease is treated, they expect the treatment to result in a painfree existence and a change in their personality that will allow them to stop worrying and learn to be joyful. It has been noted also in torture survivors which again can be applicable to Turkish speaking immigrants is that it can be difficult for them to accept the permanence of pain, to abandon hopes of complete relief and accept in pain reduction and improvement in activity and social level functioning that will require physical, practical, and psychological skill development (Amis & Williams, 2015). As a result, instead of taking responsibility in their own health, individuals in Turkish culture appear to align the full responsibility to healthcare professionals to examine, manage and relieve the suffering of pain whilst taking a passive stance in every stage of decision- making process regarding their care (Board et al, 2020). Therefore, most Turkish culture members report feeling misunderstood by their doctors or that their discomfort worsens following a visit to the doctor (Yazar & Littewood, 2001). Hence, some studies have demonstrated that Turkish immigrants are less likely to seek professional care and exhibit higher dropout rates and lower rates of treatment compliance than native populations (Arens, Balkir & Barnov, 2013). For instance, Hassen, Lambert, Yagdiran & Krausz (1997) study provided evidence for lower rates of admission to mental health care services in Turkish immigrants compared to the native population. Furthermore, a study on mental health service utilization in female immigrants in Amsterdam found that Turkish women made considerably less use of mental health services than native-born women (Ten Have & Bijl, 1999). In addition, a study carried out in Switzerland found that female Turkish inpatients had higher rates of compulsory admission, were more likely to be readmitted, and spend significantly shorter time in hospital compared to female Swiss inpatients (Lauber, Lay & Rossler, 2005).

#### 2.2.6 Turkish-speaking immigrants in London, United Kingdom

There is high population of Turkish-speaking immigrants in London, United Kingdom (Enneli, Modood & Bradley, 2005). According to Home Affairs Committee (2011), there was a total of about 500,000 people of Turkish origin in UK, with 200,000 in London alone (Home Office estimates, 2011). Turkish speakers in London comprises of Cypriot Turkish, Turkish and Kurdish people. For each the reason and pattern of immigration has been different. For Cypriot Turkish the immigration started after the Second World War,in fifties during the struggle of Cypriot Independence. In Turkey, there were three main periods of immigration. The first was in mid-seventies for economic reasons. This immigration consisted mostly of men leaving there families behind to find a better life. Although they managed to bring families later, they did suffer long separations from their family, economic hardships, and the stress of living in foreign country, language difficulties and racism. Second period of immigration was in 1980's military coup in Turkey. These were mainly professional and intellectuals who immigrated and political refugees and experienced the insecurity of refugee life, fear of deportation and lack of access to intellectual life as they were forced to find unskilled work. The third period of immigration was in late 1980's and composed of Turkishspeaking Kurds to flee the conflict between the PKK (Kurdish Workers Party) and Turkish army (Barkey & Fuller, 1999). They were largely from the Alevi sect of Islam, which has a history of family members being imprisoned and tortured. They faced persecution because of their Kurdish ethnicity and religious beliefs. They were forbidden from speaking Kurdish, and children were denied equal health and educational opportunities (Yazar & Littlewood, 2001). As all families mostly immigrated from traditionally rural areas of Turkey and parents worried about their children becoming too 'westernised' (Kandiyoti, 1998). There are ideas of medicine also remained heavily influenced by humoural and Islamic conceptions (Yazar & Littlewood, 2001).

#### 2.2.7 Perception and experience of chronic pain in women

Although, chronic pain has been shown to affect all individuals of all ages, races and genders, it is reported to be more common among women (Harker, Reid, Bekkening Kellen, Bala, Riemsma, Worthy, Misso, Kleijnen, 2012; Jensen, 2013).

Women were observed to show lower pain thresholds, a greater ability to discriminate painful sensations, higher pain ratings and lower tolerance to pain (Berkley, 1997). Despite conflicting results for experimental and clinical studies, there is an agreement among researchers that certain factors such as perceptual ability and physiologic mechanism, do explain gender differences to pain and its treatment (Vallerand & Polomano, 2000). Menstrual cycle, pregnancy and oral conceptive use have been shown to affect women's response to pain which confirms that hormones are related to pain response (Keogh, 2006 cited in Vallerand & Polomano, 2000).

Psychological factors have also been put forward as an explanation for sex differences in pain experience and response. Pain as a subjective experience has been shown to be influenced by gendered norms for how to respond to pain (Samulowitz et al, 2018), and to this date appears the influence the way in which people perceive and report pain, which has wider consequences hegemonic masculinity and andronormativity seen in pain research and healthcare. For example, In Sammons (2000) study, tension and stress were cited as significant cause of pain for both genders but were found to be leading cause of pain among women. Furthermore, women were also observed to become more upset than men when pain prevented them from performing socially defined primary role responsibilities (Vallerand & Polomano, 2000). To minimise the disruption of these primary roles, women were observed to seek healthcare sooner than men (Unruh, 1996).

There appears to be enough evidence indicating a varied experience in different gender's pain experience and management, therefore it becomes appropriate to study the experience of treatment experience with individual genders. Unfortunately, to date there appears to be limited research that takes this into gender differences when exploring the experiences of non-pharmacological treatments for chronic pain.

#### 2.2.8 Intersectionality in the experience of Chronic pain

The observed differences between men and women in terms of pain experience and response cannot be explained purely through the lens of sex and gender- biological differences as the experience of pain is interrelated with psychological and social differences between men and women (Samulowitz et al, 2018).

The interplay between gender, age, culture, socioeconomic status as well as the migration process is significant and complex. For example, chronic pain is reported to be more common among women, groups with lower educational and lower income, groups living in compromised housing areas (Michaelis, Kristiansen & Norredom, 2015), individuals with lack of personal support (Jensen, 2011) and among immigrants. For example, chronic pain has been shown to be higher among immigrants in Europe than among native European population (Mullersdorf, Zander & Eriksson, 2011). Intersectionality in the experience of chronic pain makes immigrants, especially women, a particularly vulnerable group (Michaelis et al, 2015).

The context of an individual's environment- physical, social, and emotional can influence individuals Perception and coping with pain experience, as well as the ethnic diversity by healthcare (Mullersdorf et al, 2011).

Similarly, to how sex and gender cannot provide a pure and direct explanation to differences in chronic pain experience and response, affiliation to ethnic group or being an immigrant may not be necessarily responsible to the observed differences in the perception, experience, and response to pain, as these variations can further be affected and explained by socioeconomic status and level of education (Mullersdorf et al, 2011). Hence, immigrants are considered as a vulnerable group since they can be affected by wide range of factors which makes it difficult to access healthcare in destination countries. Language and health literacy are common challenges for immigrants (Mullersdorf et al, 2011). Furthermore, healthcare professionals may experience challenges in encounters due to language and cultural differences, resulting in misunderstandings and frustrations from both perspectives, patients, and healthcare professionals, resulting in poorer treatment and clinical errors at

worst (Jensen, Nielsen & Krasnik, 2010). Thus, perception and experience of pain as well as

how an individual copes depends on number of intersectional factors, which needs to be

considered when conducting research on chronic pain for participant group- for this

research- Turkish women.

2.3 Qualitative Research into Psychological therapy for chronic pain

In this section, I will review a selection of published papers considered to be most relevant

to the current study. It seems important to bring to the reader's attention the paucity of

research from U.K, with much research emanating from various parts of the world particularly

in US and Canada. While international research throws light on the cultural factors that impact

on immigrant population's treatment experience for chronic pain, direct compassions may

not be possible since the healthcare system in UK differs from that of other countries. In

addition, many papers reviewed focused on the following key words: 'the experience of

Turkish-speaking', 'psychological therapy', chronic pain', 'treatment', 'and qualitative

research'. However only a few papers included every key word since there is limited number

of studies that have used qualitative methods to explore the cultural factorsinfluencing the

pain and pain treatment experience of ethnic minority groups. Notably most of the reviewed

research is quantitative.

2.3.1 Literature Search Strategy

I searched for qualitative studies in JSTOR, APA PsychArticles, APA PsychInfo, SAGE, Science

Direct and Web of Science via City University Library Databases and Cochrane Review. The

following criteria was used to identify potential articles.

Selection Criteria:

Review articles, research articles, mini articles with early to open access

Publication date: 2010-2022

Key words used:

'the experience of Turkish-speaking', 'psychological therapy', chronic pain', 'treatment', 'and

qualitative research' 'psychological interventions for chronic pain'

Criteria for considering studies for literature review:

I included qualitative studies that explored the experiences of psychological interventions with

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chronic pain. No criteria were given for type of psychological therapy or chronic pain. Studies were included if they:

- Were available as a full publication
- Had design that considered psychological treatment as active treatment for chronic pain
- Published in different countries or with different ethnic backgrounds

#### 2.3.2 Chronic pain research in cross-cultural context

In pain research, patient-centred approaches, including qualitative methods have been shown to provide valuable information regarding pain disparities in ethnic minority groups (Im, Guevara & Chee, 2007; Katz et al 2011; Escarce & Kapur,2006; Upshur, Luckmam, Savageau, 2006; Zettel-Watson, Rufledge & Aquio, 2011. Years of research has notedcultural differences in concept of reality (Dickson & Kim, 2003), Sense of Self, construction of morality (McLeod, 2013), concept of time, significance of place, verbal and non- verbal behaviours (Landrine, Klonoff & Brown-Collins, 1992), kinship and gender relationships (Brady et al, 2017), expression of emotion and attitudes and practices of healing (McLeod, 2013). Falicov (1995) suggested consideration of family structure, life cycle and the living environment and person's experience of migration and acculturation as an alternative way of mapping cultural variables when understanding the pain disparities in ethnic minority groups.

McCracken, Matthews, Tang and Cuba (2001) found in their comparison study between blacks and whites seeking treatment for chronic pain in United States showed that after controlling for pain severity, the black group reported more avoidance of activity, more fearful thinking and more physical symptoms. Significant cultural difference was also found in self-care behaviours and preferences for pain management programmes. Research has also shown the appraisals of patients treatment to be significantly influenced by cultural factors which appears to determine adherence to treatment (Bishop, Yardley & Lewith, 2008; Bucks, Houkins, Skinner, Horn, Seddon & Horne, 2009).

Vina, Masi, Green & Utset (2012) examined the role of racial/ethnic differences in treatment preferences regarding lupus and found that an increased level of trust in the physician and knowledge about the treatment impacted on the decision to accept or reject the treatment recommended. Similarly, Ford, Konrad, Godette & Corbie-Smith (2008) found that racial congruence in the patient/provider dyad made a difference in the outcomes for women with

sexually transmitted diseases. Wallace, Varcoe, Holmes, Moosa-Mitha, Moor, Hudspith & Craig (2021) studied the relationship between chronic pain and diverse experiences of social marginalization as well as implications for interventions, to recommend equity-orientated healthcare approaches. Community based qualitative study using focus groups was used for Thirty-six participants identifying with Indigenous, LGBT and Refugees group, who are known to experience high levels of discrimination and stigma in Canada. Thematic analysis guided by coding techniques from grounded theory was used as data analysis. Findings from this study illustrated the complexity of experience and meaning of pain for people living with pain and facing social disadvantages of stigma, discrimination, and structural barriers such as poverty, systematic racism, sexism that are embedded and supported by policies and social arrangements. This study emphasised the inadequacies of an exclusive biomedicalorientation to understanding and treatment of pain, in particular the over-reliance on pharmaceutical management. Furthermore, unique experiences of these participants highlighted the connections among pain with mental health, substance misuse and shows how stigma, discrimination and dismissal of the meaning and experience of people living with pain can be maintained through systematic challenges.

Torres, Thorn, Kapoor and DeMonte (2017) explored the foreign-born Spanish speaking Hispanics, with low acculturation, perspectives in seeking medical care for pain management to understand the cultural beliefs in understanding pain management decisions. Twenty-four individuals (17 females and 7 males) with self-reported chronic pain completed the study. This study used qualitative design with quantitative measures to describe the sample. Participants attended a focus group and shared about their pain management practices and experiences with medical care for pain management. Descriptive data on pain and mood variables were collected to examine how this population compared with the norms reported in the literature. Qualitative data was analysed using inductive thematic analysis. Findings highlight barriers to pain management that might be unique to collectivist cultures like Hispanic culture that prioritize family needs over individual needs and view pain management as a last resort for care. In most cases, participants opt for natural treatments reflecting on cultural values. However, use of self- care practices and folk remedies may be partially due to patient's unfamiliarity with available treatment objects and parallelism with treatment options employed in their home country. Furthermore, participant's perceived stigma about their financial ability appeared to be a significant barrier for their care. These findings help illustrate the sociocultural and contextual factors that play important role in our understanding of pain disparities, however due to the nature of qualitative inquiry, the transferability of the findings is limited due to the depth of information and understanding obtained from this sample.

Torres et al (2017) study was focused on the cultural factors on seeking medical care for chronic pain. Yang, Bogosian, Moss-Morris & McCracken (2015) on the other hand conducted a study to understand the south Asian patient's experience of seeking psychological treatment for chronic pain in Singapore. Fifteen participants took part in semi-structured interviews. Thematic analysis was performed in data with elements of grounded theory. Findings of this study identified the importance of empathic health professional that listened to patients and was knowledgeable in pain management and psychological interventions for chronic pain, high treatment costs and time taken to attend treatment as potential barriers. Torres et al (2017) recommended educating patients, health care professionals on benefits of psychological treatment in the management of chronic pain to reduce disparities and improve access to psychological treatments for chronic pain. Considering that healthcare system and treatment delivery in every county around the world to be different, results of this study help us to understand participants experience in relation to the context and suggested for health professionals to look beyond just treating the pain problem as a physical condition.

Although qualitative research has been used to understand pain disparities in ethnic minority groups, most appear to be limited to thematic analysis on the experience of medical and psychological interventions for chronic pain. Interpretative phenomenological analysis on the other hand, has been widely used to examine the personal lived experience of chronic pain (Smith & Osborn, 2008; Marriott & Thompson, 2008), but to date IPA has not been used to examine the lived experience of an individuals who had undergone psychological interventions for their chronic pain, especially in Black and Ethnic Minority group. Although Jonathan Smith's studies provided useful information on understanding of the complex, ambiguous and emotionally laden experience of chronic pain in depth, the personal meaning of receiving psychological interventions for chronic pain in ethnic minority groups are limited, despite the recommendations in the published studies (Smith & Osborn, 2015). For example, Burton and Shaw (2015) conducted a systematic review to better understand the outcome of chronic pain management programme (PMP's) for ethnic minority and non-English speaking patients to explore the perspectives on and experiences of chronic pain for these groups.

Systemic review identified 26 papers meeting the inclusion criteria, but no papers reported on the outcomes of PMP's delivered in the UK. The findings indicate a lack of research onto UK based pain management for ethnic minorities and non-English speaking patients. The literature suggested that effective PMPs must be tailored to meet the cultural experiences of pain and beliefs about pain management. The review calls a need for further research to explore the cultural beliefs in non-English speaking groups in UK, to be able to provide culturally sensitive evaluations of PMP's to assess the effectiveness of current provision. Furthermore, Eccleston et al (2019) conducted a systemic review in UK, to evaluate the effectiveness of psychological therapies for chronic pain (excluding headache) in adults, and compared this with treatment as usual, waiting list control, or placebo control for pain, disability, mood, and catastrophic thinking. They compared two main classes of treatmentcognitive behavioural therapy and behaviour therapy with two control conditions- treatment as usual and active control. Overall, CBT has been shown to be the useful psychological approach to the management of chronic pain. However, Eccleston et al (2019) also calls out for further research to identify which components of CBT work for which type of patient on which outcomes and to understand the mechanisms why- which takes us back to the issues of generalisability of efficiency of these approaches to different populations.

# 2.4 Summary of Debates and Implications for the Current Study

Chronic pain is regarded as a public health concern as it represents the most prevalent, disabling, and expensive public health condition by the Global Burden of Disease Reviews (Vos, Flaxman & Naghavi, 2012). Chronic pain is known to impact on person's physical, behavioural, cognitive, emotional, social, and financial wellbeing (Gatchel, Peng, Peters, Fuchus & Turk, 2007).

Multidisciplinary pain management programmes, which frequently include psychological therapy, have been shown to enhance health-related outcomes, including pain intensity in chronic pain patients. The research evidence that guides treatment guidelines for psychological therapies continue to be gathered from empirical and actual data and falls short in exploring the radical and ethical disparities. This makes it difficult for results to be generalized to practice in the United Kingdom with different cultural groups and healthcare system and varying actualisation experiences of individuals. Furthermore, most qualitative

studies in this area tend to examine patients experiences with chronic pain treatment specific to medical of physiotherapy interventions. This study therefore aimed to explore the experience of Turkish-speaking women's psychological therapy experience through a more humanistic, Counselling Psychology lens.

# **Chapter 3. Methodology and Methods**

This chapter considers the methodological concerns of the study and methods used. Although 'methodology' and 'method' are often treated in interchangeably they each reference different components of research practice (Finlay, 2006). 'Method' describes the specific research techniques used whereas the 'methodology' is the underlying assumptions and principles guiding the development of the research question and the techniques chosento answer it.

I begin this chapter by setting out the research aims and research question of the current study, before exploring the philosophical assumptions, perceptions and values that have guided me in the development. This is then followed by the discussion of the methodological approach I have chosen to answer the question, Interpretative Phenomenological Analysis, and why this seemed the best fit. I then turn more to method related matters, by describing how the participants were recruited and the procedures undertaken for data collection and analysis. I close the chapter by addressing the credibility of the research and describing the ethical considerations.

I recognise that my methodological approach to research question will inevitably influence the context of what I am investigating. I have sought to explore these influences throughout my discussions. My broader reflexive issues will be addressed at the end of this chapter.

## 3.1 Research Aim and Research Question

Overall research question: How do Turkish-speaking women experience psychological treatments for chronic pain?

#### Research aims:

- **1.** To understand Turkish-speaking women's psychological therapy experience for their chronic pain.
- **2.** To explore what psychological therapy meant for their chronic pain.
- **3.** To offer 'patients' the opportunity to raise their concerns and have their voice heard in their treatment journey.
- **4.** To identify Turkish-speaking women's perspectives and needs to enable clinicians working with them to understand the 'person beyond their diagnoses'.

# 3.2 Locating the Philosophical Position of the Research

My focus on the way in which Turkish-speaking women experience psychological therapy for their chronic pain contrasts with the traditional concerns of psychology's root within the philosophy of science, which have been more centred around locating the 'true' nature of illness and the best treatment to 'cure'.

The philosophy of science provided psychologists with a framework for their quest for knowledge (Willig, 2008), as well as a set of assumptions about the nature of reality (ontology), the nature of knowledge (epistemology), and the proper research process and techniques (methodology) (Denzin & Lincoln, 2000).

Realist ontology is known to be at the heart of science philosophy, based on the notion that there is a single, distinguishable 'reality' that 'exists' independently of human experience (Willig, 2008). It adopts the positivist viewpoint that phenomena and conceptions can be empirically classified and that there is a direct relationship between these phenomena and concept and people's experience of them (Cocioppo, Semin & Bernston, 2004; Willig, 2008).

The dominating paradigm in psychology for the past 150 years has been positivism, which explains why quantitative, objective studies of behaviour are preferred over qualitative, subjective studies of experience (Strawbridge & Woolfe, 2010). Many people have questioned whether the same methods used to study the natural world should be used to study the human world, and they have advocated for an alternative to the traditional, empirical positivist model. These kinds of humanistic and phenomenological concerns gave rise to Counselling Psychology as a subject, as well as its developing application.

Qualitative research, like quantitative research, can be founded on a realist ontology, which embraces the concept of "truth" and sees the world as largely knowable and objectively identifiable (Madill, Jordan & Shirley, 2000). This type of qualitative research would employ a method to build an explanatory account of psychological and social processes to learn more about the "truth" of what is going on (whether in a person's life or in their thoughts) (e.g. Grounded Theory; Glaser & Strauss, 1967).

In contrast to quantitative study, qualitative research could be motivated by an antirealist relativism ideology. Relativism is incompatible with positivist epistemology in classical science because it rejects the realist definition of "truth" in favour of many created "realities" (Madill

et al., 2000; Willig, 2008). Relativists believe that all experiences are influenced and coloured by the social, historical, cultural, and linguistic contexts in which they occur (Madill et al., 2000; Willig, 2008). As a result, language is regarded as critical in social interactions, as it determines rather than just portrays a person's "reality" (Burr, 2003). Relativist qualitative research is more concerned with how a specific experience is discursively communicated within a given context than with the experience itself (e.g. Discursive Psychology; Potter & Wetherell, 1987). There is also a more extreme relativist version of social constructionism, in which the emphasis is on the culturally available 'discursive resources' that govern what people can experience when they discuss a topic (Willig, 2008). On this premise, the study method Foucauldian Speech Analysis is based, and it explores the power relations within society as reflected via language (Arribas-Ayllon & Walkerdine, 2008).

Qualitative research can be based on ideologies that are halfway between realism and relativism. The philosophy of critical realism is of special importance to the current research (Bhaskar, 1978). Critical realism shares the realist concept that there is a "real" reality with stable and enduring features that exists independently of human cognition. However, it also distinguishes between the "real" and "observable" worlds, claiming that people perceive and experience authentic events and phenomena in different ways based on their perceptions and beliefs (Bhaskar, 1978; Finlay, 2006)

While critical realism supports a relativist epistemological perspective in this case, it does not endorse the more extreme relativist behaviours of social constructionists. To put it another way, critical realist knowledge is founded on deconstruction, but not to the point where all evidence is methodologically reduced to a single point of view (Pilgrim, 2013). Within a critical realist account, "it is not reality which is deemed to be socially constructed rather it is our theories of reality, and the methodological priorities we deploy to investigate it" (Pilgrim & Bentall, 1999, p.262). While critical realists do not claim to be able to reach true objectivity, they believe they can and should seek to analyse reality itself, with the condition that their developing theory be exposed to constant critical contextual assessment. Critical realists believe that by doing so, they can improve understanding of the true nature of things by substituting more scientific and therapeutically relevant notions with misleading or prejudiced ones.

# 3.2.1 A Qualitative Design

To stay true to the study's objectives, a qualitative research approach was used to investigate the meaning and account for the complexity of participants' worldviews by describing the phenomenon in the participants' own words (Taylor & Bogdan, 1998, p. 128, cited in Ponterotto, 2005). I was more interested in the richness and texture of the participant's psychological therapy experience as a qualitative researcher than in finding a cause-effect relationship (Willig & Stain-Rogers, 2008). Individual narratives are related to their own context, which then becomes part of the total meaning based on the subjective experience of the individual. These contexts can be used to connect a person's experience with their social, cultural, and structural surrounds (Langdrige, 2007). Qualitative research offers contextual descriptions or interpretations based on personal lived experience, and it was these types of responses that felt best suited to the type of question offered by my research. As previously stated, existing research in the field is sparse, therefore I reasoned that using a qualitative methodology would allow me to provide knowledge that included novel and unexpected insights on the individual, social, and institutional components of psychological therapy experience of Turkish-Speaking women with chronic pain as well as providing opportunity to 'give voice' to underrepresented and unheard population.

The emphasis on researcher reflexivity in qualitative technique also appealed to me. Unlike quantitative research, qualitative approaches admit rather than deny how a researcher's personal characteristics determine how much time and attention they give to various aspects of their work (Willig, 2008). I felt a qualitative approach would allow me to evaluate these aspects as they applied to the study because I was aware that my own experiences as a Turkish-speaking women prompted me to pursue research in this area.

## 3.2.2 Epistemological Framework and Research Paradigm

A study design must be consistent with the researcher's understanding and belief about the nature of reality and the information that may be created because of that understanding and belief to be effective (Willig, 2008). With this in mind, I've spent a lot of time considering my own epistemological position and how it should influence the design of my study.

As a Counselling Psychologist, my purpose has always been to help others explore the personal meanings they attribute to their experiences, rather than to find a single "truth" that

"explains" their lives to them. While I believe in reality (as opposed to true social constructionists), I feel that fully capturing that truth is neither relevant nor attainable, given how our perceptions of the world are formed by our beliefs and prejudices.

In terms of how my research question has been shaped by this approach, I acknowledge that chronic pain 'exits' in the sense that individuals can and do experience persistent pain without an observable tissue damage or injury. I also believe in the existence of psychological interventions based on empirical research. Nonetheless, I also believe that we must be aware of the various ways in which the 'reality' of chronic pain and psychological therapy can be experienced, considering the sociohistorical dynamics that control itsdetection, observation, and treatment.

After realising my own values and assumptions, I recognised critical realism (Bhaskar, 1990) as the paradigm best suited to my research. It promotes a philosophy of ontological realism and epistemological relativism that I could support. Contextual constructionism (Madil et al, 2000) admits that our beliefs and meaning systems influence how we see how things are are in the world (Larkin et al, 2006), and is founded on the assumption that knowledge is situation dependent (Jaeger & Rosnow, 1988). As a result, depending on the context in which the data is acquired and analysed, the results may differ. Individual decision-making, like critical realism, can produce numerous viewpoints on the same phenomenon (Willig, 2001).

As a researcher, I am conscious that my own experiences, as well as my personal and cultural viewpoints, will influence my perception and knowledge of the topic under inquiry (Madill et al, 2000). The researcher-participant interaction will play a role in the findings made about the participants' realities and experiences (Larkin, Watts & Clifton, 2006). This I believe is especially important to explore as having to train in a service with a therapist/researcher role. To avoid credibility problem, I will be exploring my relationship with my participants throughout the research procedure through reflexivity.

To summarise, this study supports critical realism-based contextual constructionism. With realist claims, the data obtained from participants is considered as reality, while with relativist claims', comprehending the participant's reality entails an interpretative process (Madill et al, 2000) through the relationship between the participant and the researcher. To gain access to participants' experiences, I understand and accept that I will be focusing on the "person-in-context," who is embedded within social, cultural, and historical context, andthat these should be explored through reflexivity throughout the research to gain access to participants'

psychological therapy for chronic pain experiences.

# 3.3 An Interpretative Phenomenological Analysis

The positivist paradigm continues to have a strong influence on health psychology (Yardley, 2000), and it is difficult to transition to a more relativist epistemology (Stoppard, 2002). Although there have been some recent commitments to relativism, they have sadly been limited to thematic analysis (Parker, 2005). Funding problems as well as 'what works' subculture has been shown to be the barriers to undertake more relativist approach in health psychology research (Birnkmann, 2005). Adopting an IPA approach for this study can therefore overcome some of the shortcomings in the current literature by being complementing its aims and critical realist positioning and aid the presence of qualitative research and Counselling Psychology's commitment in the development of health psychology. In this section, I will provide a brief overview of IPA before examining in detail why it was the preferred choice, over and above alternative qualitative methodologies.

IPA was developed by Jonathan Smith in 1996 in response to positivist stance to introduce a more pluralist approach that will enable to capture the subjective and experiential accounts relevant to psychological enquiry. In most cases, the IPA researcher invites participants to share stories about an important life experience. The researcher then records, transcribes, and analyses these narratives, with the results based on both the participants' interpretations of their experiences and the researcher's unavoidable interpretation of the data. This illustrates a two-fold component of meaning-making, named the "double hermeneutic" by Smith and Osborn (2003).

While IPA is a cutting-edge approach to qualitative research, its intellectual roots may be traced back to phenomenology and hermeneutics (Smith, Flowers, & Larkin, 2009). The main theoretical underpinnings of IPA will now be explored in detail:

# 3.3.1 Phenomenology

Phenomenology is described as the 'study of human experience' (Langdrige, 2007). By focusing on the experience, IPA provides an alternative to the predominant quantitative research in health psychology, as it is concerned with how individuals perceive their world within a particular context, time and mental state and uses this conscious information to

create meaning (Starks & Trinidad, 2007). This relationship between the perception of the world in consciousness (neoma) and the meaning created in the conscious depending on the perception of the world (noesis) is referred to as intentionality (Langdrige, 2007).

Phenomenology was founded by Edmund Husserl (1927) in the twentieth century as a way of studying people's perception of objects, as they seem in their consciousness. Transcendental phenomenology was the name given to Husserl's approach as it involved the process of Epoche, which means to 'bracket' out the natural attitude (assumptions and perceptions) of the researcher (Giorgi, 1992), to directly access the experience as it naturally occurs in a specific time and context (Bernet, Kern & Marbach, 1993). Husserl's phenomenological method, which entails sequence of 'reductions' termed 'imaginative variation' and 'edietic reduction' to be able to capture the essence of experience (Smith, Flowers & Larkin, 2009). Husserl's transcendental phenomenology approach was criticised and developed by his student Martin Heidegger (1962). Heidegger did not believe in the complete 'bracketing' (Epoche) and argued that people's interplay with the world usually required a natural attitude- a Dasein (being there) and consequently interpretation is usually involved in the phenomenological understanding (Langdrige, 2007). Heidegger's approach is termed as the existential approach of phenomenology and it encourages working with the researcher's assumptions and interpretations rather than 'bracketing', to attempt to understand the lived experience of the individual (Eatough & Smith, 2008). As Smith (1996) pointed out, access to direct experience is 'partial and complex' and involves construction by the participant and researcher (Larkin et al, 2006). This construction is to be achieved by the process of researcher's reflexivity. IPA used for the current study will subscribe to Heidegger's (1962) existential approach to phenomenology, developed by Jonathan Smith in1990s.

#### 3.3.2 Hermeneutics

IPA is influenced by hermeneutics or the study of interpretation. Hermeneutics incorporate the study of written texts or descriptions with the role of the researcher's attempts to make sense of individual's narratives. Ricoeur (1970), Schleiermarcher (1998), Gadamer (1989) and Heidegger are the prominent hermeneutic theorist whose ideas I will utilise during my analysis stage.

There are different interpretative stances for researchers. Larkin et al (2006) for example,

proposes interpretation by positioning the initial description of the experience of the participant in relation to a wider social, cultural, and theoretical context. IPA combines empathic hermeneutics with suspicious hermeneutics, which attempts to understand participants experience whilst asking critical questions. Ricoeur (1970) proposes the combination for richer analysis as it accounts for the totality of the person. Schleiermacher (1998) proposes an interpretation that accounts for both grammatical (description of the experience) and the psychological (the hidden meaning beneath the grammatical elements) to understand the experience in full (Smith et al, 2009). Gadamer (1989) emphasises the historical and cultural context of interpretation from a perspective of interpexter and interpreted. These proposals from hermeneutic theorists refer to Heidegger's influential 'double hermeutic circle', which illustrates the dynamic relationship between the 'part' and 'the whole'. In IPA, this is illustrated by researcher's active role in trying to make sense of participant's attempts in making sense of the experience under study (Smith & Osborn, 2008). Hence IPA findings acknowledge the co-production between researcher and participants as interpretations are recognized as being dependent on participant's ability to articulate the experience and researcher's ability and skills in analysing the data within the double hermeutic circle (Osborn & Smith, 1998).

# 3.3.3 Ideography

In contrast to the dominant nomothetic approach in traditional psychology that attempts to establish general laws of human behaviour, IPA is concerned with particular. IPA's mode of enquiry is ideographic; it makes use of smaller samples and in-depth analysis to apprehend the experience to gain an understanding of the general structures underlying such experience (Eatough & Smith, 2008). IPA achieves this through detailed, through and systematic in-depth analysis.

#### 3.3.4 IPA Characteristics

The interrogative feature of IPA helps psychology by shedding light on past research. While IPA looks at a data set in great detail, its findings should be viewed in the context of past research on the issue (Smith et al., 2009).

IPA is inductive, using a range of tactics to encourage the emergence of new, often

unexpected, themes during the analysis. The goal of IPA research is not to confirm or refute specific assumptions based on previous research; rather, it asks more general questions to obtain more thorough data (Smith et al., 2009). Finally, IPA makes no claim to having a unique epistemological viewpoint and is defined by epistemological "openness" (Larkin et al, 2006).

#### 3.3.5 Rationale for IPA

For a variety of reasons, IPA was deemed an appropriate methodology. For starters, their phenomenological roots attracted to me since they allowed the researcher to establish an "insider's view" by inviting a full exploration of experience and meaning making (Smith, 2010), and produces an account of lived experience that is independent of pre-existing theoretical perceptions (Smith & Osborn, 2015). In addition, its broadly critical realism viewpoint complimented my own epistemological standpoint. According to Nelson (2010), IPA allows for some creation on both the researcher's and participant's parts while yet maintaining the existence of a respectable empirical reality.

A particularly useful use of IPA is to investigate topics that are complex, ambiguous and emotionally charged. Pain is a prime example of such a problem since it involves complex psychosomatic interactions and is difficult to describe. Hence, IPA provides opportunity to explore participants, experience at a micro-level, giving close attention to what participant has said to account for the lived experience (Smith & Osborn, 2015).

IPA appealed to me as well due of its versatility. It looked to give participants the freedom to say whatever they wanted about their experience while also allowing the researcher to adjust their questions to this description. This appeared to me to be the ideal approach for participants to explore a variety of interpretations while also allowing me to ask questions if I believed something about their experience was missing or unclear (Smith & Osborn, 2003).

Another important component was the researcher's assessment by the IPA. The method has been critiqued for failing to identify whether the researcher is a "discoverer" of reality or a 'constructor'. However, I enjoy the lack of differentiation because a researcher, in myopinion, should be able to do both. This is also beneficial, in my opinion, because it allows the researcher to have a deeper understanding of the situation. In the early stages of data collection and analysis, for example, I wanted to grasp the participants' perspectives. Because of the inherent subjectivity of the researcher-participant connection, I had to do some creating. When it came time to analyse and explain my findings, I used these "discoveries" to

draw connections to more abstract or theoretical levels of interpretation (Finlay, 2008).

#### 3.3.6 Consideration of Alternative Qualitative Methodologies

With diverse philosophical and methodological viewpoints, all qualitative approaches share the goal of enriching our understanding of the phenomena they research. Alternative approaches were investigated during the research planning phase, but were later ruled out. Within this section, I will explain my decisions to choose IPA over other three methodologies that I considered: discourse analysis, Grounded Theory and Thematic Analysis.

One of the methodologies studied was discourse analysis, which was introduced by Potter and Wetherell (1987) and is concerned with 'language-in-use' in context (Starks & Trinidad, 2007). It claims that how people use language in different situations shapes reality and meaning (Starks & Trinidad, 2007). The process of analysis entails looking into how people use language and what impacts them (Willig, 2013). It adheres to relativist ontology since it aims to comprehend a process rather than a phenomenon. Furthermore, discourse analysis holds that language is used to construct truth (Willig, 2013). Current study is seeking to understand a phenomenon, which is the experience of psychological therapy for chronic pain by acknowledging the influence of researcher's values, assumptions and precognitions as a 'witness' rather than as being the 'author' of the findings (Starks & Trinidad, 2007). Based on the above intention of current research, discourse analysis was considered not appropriate to explore the current research question.

Another methodology that was investigated was grounded theory. Glaser and Strauss created it in 1967 to allow for the development of new theories of social processes in their environment (Willig, 2013). It has a realist character because the goal of analysis is to build ideas that are based on data (Willig, 2013). It also adheres to a realist epistemology, in which the researcher is only considered as a witness in the sense of their ability to represent the social reality rooted in the data (Willig, 2013). On the other hand, a social constructivist variant of grounded theory assumes that the researcher creates the social reality under inquiry (Willig, 2013). Both the ontology and epistemological positions of grounded theory did not seem appropriate to explore the current research question and was therefore eliminated from the options.

Finally, for this study, thematic analysis was examined as an alternate methodology. Thematic

analysis, according to Fereday and Muir-Cochrane (2006), is focused with identifying themes to describe the phenomenon under investigation. However, unlike other approaches, these themes do not adhere to a certain theoretical framework (Willig, 2013). The researcher must select what the themes represent based on their research question and be committed to the analysis; otherwise, the analysis' credibility may be jeopardised (Willig, 2013). Ryan & Bernard (2000) proposed thematic analysis as a tool or an ability of generic qualitative designs rather than a methodology due to a lack of theoretical grounding. The goal of examining the shared meaning of the experience in thematic analysisdid not seem fit with the current research because it is concerned with identifying individualmeanings about the experience (Fereday & Muir-Cochrane, 2006). Furthermore, as means to introduce other qualitative methods other than thematic analysis and to improve the qualitative research profile within health psychology, thematic analysis was ruled out (Parker, 2005).

# 3.3.7 Challenges and Limitations of IPA

The IPA has been chastised for the generalizability of its findings, claiming that the results would not be able to yield generalizable findings due to the small sample size used. However, using a limited number of participants allows for more in-depth analysis (Smith et al, 2009), allowing for a new viewpoint on the experience and opening new research possibilities. According to Smith et al. (2009), IPA does not have "stand-alone integrity," which means it is not a quality guarantee. The approach's success is therefore dependent onits application and the researcher's reflexivity in addressing the researcher's assumptions when analysing the data, both of which are key concerns within IPA.

Another challenge with IPA is the requirement of participants to adequately communicate the richness of their experience. Language and health literacy can be common challenges to individuals who are immigrants in a foreign country. Moreover, challenges of income, education level, limited social support or difficult housing situations are known to further impact on individual's ability to articulate their perception, experience and coping with pain experience (Mullersdorf et al, 2011). In addition, limitations in methods used-like IPA not being inclusive or culturally applicable can further challenge participants opportunity to fully articulate themselves. Considering all above challenges, option was provided to participants to conduct the interviews in their own language. This enabled participants to provide rich data regarding their experience in their own language. Furthermore, considering different

dialects and in-between cultural use of language- I also made use of their words, world views and modelled emotional expressions to make them more comfortable to express their experience and emotions (Liamputtong, 2010).

#### 3.4 Methods

# 3.4.1 Sampling and Participants

Qualitative research makes use of purposeful sampling to enable researchers to answer and elaborate understanding of the research question (Cresswell & Cresswell, 2018). This study used purposeful sampling to explore and gain insight into Turkish- speaking Women's psychological therapy experience for their chronic pain. As proposed by Smith et al. (2009) a homogeneous sample of six participants were recruited to facilitate a detailed exploration of psychological variability of the converges and divergences which may arise within the sample. All six participants were women who have completed their treatment within the last three months. Smith & Osborn (2003) suggested between five to ten interviews to enable detailed analysis. In accordance with Smith & Osborn (2003) suggestion and with the time and researcher's personal constraints, six participants were recruited for sufficient information to be extracted. All potential participants expressed permission to be contacted for research purposes during treatment. Participants were recruited according to studies research protocol, which included an initial telephone screening by myself to ensure suitability (Appendix 4). Screening questions included ethnic origin, date of birth, duration for their experience of chronic pain, their progress in treatment, whether they receive any other psychological therapy and for any other health concerns. Telephone screening ended with an arrangement to meet for the research interview.

Studies have reported prevalence of chronic pain in young people (aged 18-39) to be as high as 30% and with an increasing prevalence with increasing age from 14.3% on 18-25 years old, to 62% in the over 75 age group (Fayaz, Croft, Longford, Donaldson and Jones (2016). For the current study, age range between 18-65 was used to cover the age group with the highest prevalence in chronic pain. This study has avoided over 65's toprevent further co-morbidities to confront the research question.

Based on Erikson (1964) comprehensive and empirically validated theory of human development, the 18-65 age range appears be the group that is in process of identity issues

and where necessary physiological, cognitive, and social expectations factors are all present. It is at this stage where the participant will be able to show how well he or she is accepting the 'normative' crises of his or her 'age group' within the context of his or her social position (Marcia & Josselson, 2013). It will further explore whether the therapist/ professional's approach matched with the person's handling of 'normative' crises in their developmental stage.

Participants were further recruited according to the following inclusion and exclusion criteria:

Table 1: Inclusion and exclusion criteria for sample

Inclusion Criteria	Exclusion Criteria
Individuals who identify themselves as Turkish women (UK citizen, Turkish passport holder or dual citizen) who has received psychological treatment atLocomotor service (within Homorton University Hospital Trust NHS site)	Participants who do not fall into inclusion criteria
Aged between 18-65. I decided to cutoff at 65 years in case to decrease thechance of any age related co- morbidities and age related memory difficulties.	Participants who have current other mental health issues or co-morbid health problems, this was to keep the groupas homogenous as possible.
Potential participants are capable of giving written consent to participate.	Participants attending psychological therapy elsewhere or for other reason.
Participants to have completed psychological treatment within a year, or approaching the end of their treatment or those who have droppedout early.	
Participants to be willing to be interviewed for approximately 60 to 90minutes and be willing to share their experiences of psychological treatment and about their chronic pain.	

## 3.4.2 Participant Recruitment and the Participants

The process of recruitment involved informal discussion with the Locomotor Service. I had good knowledge of the service as I had been on placement prior to deciding to conduct my research and I was being informed about some of the challenges Turkish- speaking women presented to the service. Most service users within this community also appeared to be females.

Recruitment for participants involved a standardized flyer, distributed by myself (Appendix 1) to suitable patients via the clinic staff at a pain services clinic. The flyer emphasized their opportunity to share their experiences to improve service delivery. Information about an £10 M&S voucher incentive has also been included in the flyer to show appreciation for their time and effort. In addition, clinic staff was asked to inform and encourage participants who seem interested to contact researcher by email or phone number. I was further given names and contact details of Turkish-speaking women by clinical staff that preferred to be contacted instead. I also approached potential participants in the waiting area to inform about the current research and hand out the recruitment flyer. Once participants make contact or requested contact via clinical staff, I contacted the potential participants and explained the study in detail, answered any queries and arranged to call back in a week to give them time to consider participating. The call ended by emailing or posting Patient Information Sheet (Appendix 2) and Consent Form (Appendix 3) and arranging a time to call back. Participants who wished to proceed with the study provided a verbal consent and a brief 10-15 minute, confidential pre-interview telephone screening (Appendix 4) to check the participant's suitability according to research's inclusion and exclusion criteria and to collect their demographic information. The call ended with mutually agreeing a date, time and location to undertake the interview. The Pain servicewas the suggested venue; however, if this was not convenient then another venue was arranged- usually participants home. Participants were reminded that interviews would be recorded. After each telephone conversation, the screening notes and reflections were discussed with the line manager who is overseeing the research. Table 2 below includes relevant information from the participants who took part in the study. Pseudonyms have replaced real names to ensure anonymity.

**Table 2: Profile Characteristics of Participants** 

Name	Age	Ethnicity	Duration for chronic pain	Stage of Treatment	Any other psychological support	Any other health concern
Gul	48	Turkish	8 years	Completed	No	Panic attacks (treated with medication and therapy)
Yesim	47	Turkish	16 years	Completed	On waiting list	Migraine
Ayse	50	Kurdish	7 years	Completed	No	No
Fatma	45	Kurdish	13 years	Completed	No	Cholesterol
Zerrin	49	Kurdish	18 years	Completed	No	Digestion problem
Hanim	53	Kurdish	9 years	Completed	No	No

All participants complained of pain for which for some physical cause was found and for others no physical cause was found. All had been seen in Britain by several doctors, referred to specialists and subjected to numerous tests and undergone many times of interventions. They were all now being seen by the pain clinic. The participants all spoke Turkish and were all interviewed in Turkish, five in their home and one in the clinic. The age of four was between 45-50 years old and two was in the age range of 50-55 years old. Length of time living in UK ranged from 10 years to 25 years. All appeared to belong to third period of immigration in late 1980's. The education level was generally up to secondary school level. All of the women were housewives. The ones that worked in Britain lost their job because of the pain they were experiencing. Almost all the sample lived with their spouse and children. Most identified themselves as the heterodox Alevi sect of Islam.

#### 3.4.3 Data Collection

The purpose of IPA methodology is to gather comprehensive accounts of a specific experience from a specific group of people (Langdridge, 2007), which are influenced by their subjective and social-cultural perspective (Marks & Yardly, 2011). The most appropriate wayof gathering this kind of data in IPA is semi-structured interviews, which enable participants to communicate the details of the experience of the phenomenon under study as much as possible (Langdridge, 2007). Smith and Osborn's (2015) guidelines for conducting semi-structured interviews for IPA was consulted and practiced in research seminars prior to constructing the interview schedule for this study. Focus of the interview schedule was to be collaborative in nature, positioning the participants as the experts and aiming to make them as comfortable as possible.

In the Semi-Structured Interview Schedule (Appendix 6) the questions were open-ended and non-directive, to enable tapping into the 'affective evaluations' of the experience (Haddock, Zanna & Esses, 1993). This type of questioning also allows truth value to emerge- which is subject orientated and not influenced by the researcher (Guba & Lincoln, 1989). Questions were asked about their thoughts and feelings regarding referral to psychological treatment for their chronic pain, their experience of the psychological treatment, their best and worse aspect of their treatment, meaning they attributed to being in treatment as well as their understanding of change following treatment. Participants were offered the opportunity to be interviewed and responded in Turkish or English.

Questions on interview schedule were memorised to avoid distraction with constant referencing and to aid active listening and genuine interaction. Participants were interviewed once for the purpose of the study.

## Interview Schedule

Smith et al (2009) interview design recommendation was followed to help guide the interview preamble (please see appendix 5). I found that planning an interview schedule ahead of time allowed me to anticipate potential problems and how to best address them, such as deciding on the most sensitive way to phrase a potentially contentious topic. I also believe that by planning for the various ways the interview could go, I was better able to focus on the

participants' stories as they told them throughout the interview. The interview questions I asked were based on the study's objectives and the gaps I discovered during literature review. Smith et al (2009) suggested that interview questions be open- ended and alternate between those that need participants to be descriptive and those that require them to be more analytical. As a result, I began the interview by asking participants to explain their treatment history in broad terms. It was hoped that this relatively gentle opening would assist to put them at ease, allowing us to begin to create a relationship that would subsequently allow them to provide a more personal and analytic account of their treatment experience (Kvale & Brinkmann, 2004).

By providing the participants as much control over their narratives as possible throughout the interview, I hoped to encourage individuals to share their minds honestly. As a result, I frequently followed them down unexpected conversational paths to see where they would lead us. According to Smith et al. (2009), these unexpected twists can be particularly useful because they teach us something we didn't anticipate to know and are likely to be of particular value to the participant because they occur unprompted.

#### **Pilot Interview**

A pilot interview, as Kim (2010) proposed, can aid in the testing and refinement of one or more parts of the final study. A pilot interview was conducted with the first of six individuals. This participant happened to be the first one who was willing to meet with me. After conducting the pilot, I realized that my original interview schedule was too descriptive, therefore after discussing this in supervision, prompts were added to extract the feeling from the experience, and hence the interview schedule was adjusted for the next participant.

## Interview procedure

Six participants were interviewed over a period of eight months in April- December 2018. Interviews for the five out of six participants were carried out in participants home as they were unable to travel to clinic due to health concerns and financial limitations. The rooms at Pain service were used for only one participant, who preferred to have their interview on the day of their appointment with the team- e.g. specialist doctors or physiotherapy appointment.

When we first met, I asked a warm-up question, as advised by Smith et al. (2013), that they would answer more descriptively to help them get used to the interview process. This also avoided the potential of discussing sensitive material before a rapport was established between us. Later, participants were given a verbal explanation of the aim of the study-Interview Preamble (Appendix 5) how the interviews would be used, and anticipated duration of the study and offered an opportunity for participants to ask any questions regarding the study. The expected interview style was also discussed to ease any nerves and meet expectations to facilitate a comfortable interaction and aid the development of rapport between us. Participants were given a consent form to sign (see Appendix 3), offered a copy and reminded that they can terminate the interview at any point without providing a reason for doing so or to pause the recording. Participants were informed that I will at some points make notes for the purpose of the study. Participants were informedthat their names would be changed for the study to ensure anonymity. Interviews were recorded and took between 50-90 minutes. A write up of observations and reflections were completed after each interview.

To allow participants the opportunity to discuss the study, or their concerns, or to answer any further enquires a verbal debrief was conducted at the end of each interview. Participants were further given a debriefing form (Appendix 7) which provided the details of researcher and organisations they can contact for support if they become distressed following their participation. Upon completion of the interview, participants were presented with £10 M&S gift voucher to show my appreciation for their time. Once all interviews were completed, recordings were transcribed and analysed using IPA analytic strategy (see below). Finally, all findings were written up in this final thesis.

#### Post- Interview notes

During and following each interview I took some notes about the interview and the participant. These provided me with a contextual record of interviews (please see figure 1. for an example) and was useful when starting to interpret the date. With the notes, I described how participants presented to me, recorded my emotional response and described the atmosphere I felt with them, bearing in mind how my subjectivity would inform the analysis.

25 April 2018

Yesim came across as overly anxious and fragile. Presented herself as someone who has lost her soul and freedom to pain. She talked about being depended to her children for day to day care and talked about her fears about how she would not be able to manage when her children move out one day.

She emphasised her physical struggles and pains as if she was trying to convince me on how much she was struggling and needed help. She talked about how she was before her pain, probably again in an attempt to prevent any judgement.

Figure 1: Post-Interview notes for Yesim

# Transcribing and Translating the Interviews

All participants preferred to conduct the interview in Turkish. Researcher was able to offer this opportunity as a bilingual researcher, offering a sense of autonomy and control to participants by expressing themselves in their own language (Schippert, Grove, Dahl-Michelson, Silvola, Sparboe-Nilsen, Danielsen, Asland & Bjornners, 2021). concurrent interaction between the research and participant may have also eliminated the 'ethnocultural discordance' which is the lack of cultural understanding within the interaction (Kvale & Brinkmann, 2009). This opportunity for a sense of familiarity may have contributed to higher degree of informality and mutual trust - hence, empowering Turkish-speaking women and balancing the power dynamics between the researcher and participant during the interview, from both perspectives. It has enabled the researcher to switch between being the 'insider' of the experience by having the knowledge of the culture as well as the language, to an 'outsider' position of the unknown, but curious researcher, that is trying to make sense of the participant's experience, engaging in a constant transference dance to aid interpretation. Balancing of the power dynamics is particularly important when researching this participant group, considering the traumatic past and traumatic migration as well as possible acculturation process of Turkish women experienced. The sense of empowerment that comes with the ability to express their experience in their own language to a culture-concordant researcher may have reduced the likelihood of experiencing triggers which is likely to have supported their ability to articulate their experience of psychological therapy experience for chronic pain. Yet, this rich data had to be translated for the analysis purposes, and it is vital to note here that the translation process may have affected the depth as well as the interpretation of responses as the conceptual and emotional meaning of participants responses can be lost or diluted through literal translations (Board et al, 2020).

Each interview was transcribed verbatim in Turkish, in accordance with Smith et al (2009) guidelines (I was reluctant to make use of transcription service due to sensitivity of other's experience. Each transcription was double-checked for accuracy against its recordings and anonymised. I changed all identifying details and names and assigned each participant pseudonyms: Gul, Yesim, Ayse, Fatma, Zerrin and Hanim. None of the pseudonyms coincided with any of the originals. A document was produced that described which participant corresponded towhich pseudonym and transcript and was kept separately and securely from research datain a locked cabinet.

Semantic level transcription was used as recommended by Smith and Osborne (2013), which included significant pauses, false starts, laughter and other idiosyncrasies which were indicative of personal or particular meaning. Clarification was sought when I was unsure of their meaning during the interview. I removed some *ums* and *errs* from quotes for ease of reading in the final analysis if they appeared unneeded to the meaning. Despite the best intentions, non-verbal communications are excluded in transcripts (Langdrige, 2007). Although it is not necessary by the IPA to take notes on prosodic detail in conversation analysis, I tried to do so by taking brief notes during and after each interview if I thought it would help the participants understand what they were saying.

Each interviews transcription was translated to English by researcher and double-checked with approved interpreter in the service that followed the confidentiality principles. The transcripts were formatted with large margins on either side or each line numbered to facilitate practicality during the analytic process. All auto files were destroyed once transcriptions and translations were complete. Please see Figure 2 for an example.

```
Researcher: what do you attribute this to?
416
417
418
       Participant: the fact that it is short. It was very short.
       Like we didn't even have the opportunity to get to
419
       know each other and then it finished.
420
421
422
       Researcher: hmm, so what do you think the
423
       difference would be if it was for longer?
424
425
       Participant: first of all, I think I could have explained
426
       myself better. It would have given more opportunity
427
       for the person opposite to understand more what I
428
       was trying to say.
429
430
       Researcher: hmm
431
432
       Participant: I don't think we understood each other
433
      because the time was not enough... and the second
434
       problem is ... erm ... when there is a translator in-
435
       between ... er ... it is not good. Because I tried
436
       psychology therapy with and without translator....
437
       [sigh]... the conversation with the translator is very
       different... like you explain to her and then she
438
       explains to the other. I wish they could have provided
439
440
       a Turkish speaking therapist. Like if they can provide
       Turkish therapist then the communication would be
441
```

Figure 2: Extract from Gul's Transcript (Lines 416-441)

#### 3.4.4 Data Analysis

Participant's data were analysed using Interpretative Phenomenological Analysis (IPA). IPA uses participant's narrative to understand the complexity and meaning of their world (Smith and Osborn, 2008). As a novice researcher in this area, I have broadly followed the 6-stage analysis strategy as proposed by Smith et al (2013). As emphasised by the authors I have adopted a 'healthy flexibility' in the analytic process (Smith et al, 2013, p.79). Throughout the process, concepts were modified and reorganised, and they were reintroduced to literary context to validate interpretations (Langdridge, 2007). As suggested by Smith et al (2013) and in line with IPA's Idiographic stance, I considered the interviews individually before looking across participants. Here I have described my personal ways of working through the analytic stages for this study.

# Stage 1: Reading and re-reading

Consistent with IPA's Idiographic in nature (Osborn & Smith, 2008), the initial focus of the analysis was to work through each individual transcripts one at a time. For each transcript I

attempted to reconnect with each participant and the interaction at the time to gain an overall feel for the interview. To achieve this, I returned to each of the audio recordings several times whilst simultaneously reading and re-reading the transcripts before any initial comments were made. Initial interview notes and observations were preserved to help me immense myself fully to participants moment-to-moment experience. Smith et al (2013) suggests that this helps to limit the habitual tendency of researcher's to quickly reduce and summarise information and guarding participant's voice in the process.

# Stage 2: Initial notations

Each transcript was formatted in landscape with a wide margin on left and smaller margin on the right side to allow notes to be made. Lines and pages were numbered for ease of referencing. With an open mind, each individual transcript was read several times before making exploratory and descriptive notes on the left hand margin. These notes included anything of interest, for example, language styles, contradictions, convergences, primarily interpretations and summaries using the participant's own words. These notes broadly followed Smith et al (2013) suggestion to focus on the following three areas: descriptive, linguistic and conceptual (Willig, 2013). Appendix 10 shows an excerpt from Gul's original transcript. Each line of enquiry was conducted separately and was noted green, yellow, pink highlights respectively. After some time, I revisited the transcripts to help me stand back from my exploratory comments to ensure I have remained close participant's text and meaning (Langdrige, 2007; Smith & Dunworth, 2003).

Descriptive comments reflect events, experiences or features of their lifeworld that were at great importance to the participant and that were highlighted through their descriptions, emotional responses, and linguistic idiosyncrasies (Smith et al (2013). Linguistic comments reflected the specific language participants use to describe content. Laughter, pauses, fluency and hesitancies were noted, which at this stage were accepted at face value. Conceptual notes reflected my own initial interpretations or questioning tone that attempts to interpret participant's experience via my interaction with the data (Smith et al., 2013). I attended each line of enquiry separately and noted any links between different parts of the transcripts or any apparent contradictions.

# Stage 3: Emergent themes

This stage involved development of emergent themes, recorded in the right hand margin. The aim of this stage was to create an individual theme label that paraphrased or summarized participant's experience without losing the particulars or patterns and connections noted during the initial stages (Smith & Osborne, 2013). The transcripts were revisited and themes were checked to ensure that they were fully representative of emerging themes to ensure validity. Supervision was further utilized at this stage to check that emerging themes could be linked back to text. In line with iterative process, I remained open to new themes emerging and flexible to check and amend throughout analysis (Langdridge, 2007). Please refer to Appendix 11 to see an example of stage 2 and 3 of analytic process.

# Stage 4: Finding connections across emergent themes

Once the preliminary analysis was performed on the transcripts, I have recreated the transcripts. Each transcript was reviewed to ensure that quotes selected were representative of emerging themes. I then typed individual transcript's emergent themes, printed them out and cut each into paper strips. I laid these on the floor and began to reorganise them into clusters. (Figure 3). Aim here was to produce over-arching themes that represented the individual lived experience of each participant while also representing higher-order theoretical ideas. I used Smith et al (2013) suggestion of abstraction, polarisation, subsumption and contextualisation during this process.

Abstraction was the technique suggested for similar themes to be grouped together and given a name that was representative. Polarisation is clustering opposing themes together. Subsumption involved one theme becoming the new theme label to join others together, assuming higher status. Finally, contextualisation is the one that connects themes through identification of cultural, temporal and narrative features. I found this particularly helpful not only on major theme level but also at super-ordinate theme level to identify aspects of cultural, gender and physical health identity. During this stage some of the themes were reduced or discarded if they overlapped and meaning was not impacted. Each decision regarding the themes were recorded and original list of themes were preserved in word document. I identified nine subordinate themes and gave each one a meaningful label. I then

reviewed the process to make sure the codes represented the initial themes and major themes represented the initial themes. For each participant the most relevant and appropriate quote was chosen. Appendix 12 illustrates the cluster themes from Ayse's Interview.



Figure 3: Process of finding connections across emergent themes

# Stage 5: Moving to the next case

Steps 1-4 was followed with the next participant data. In line with IPA's idiographic stance each transcript was explored separately. Although I attempted to bracket any ideas of themes from the previous transcript by writing them down in my research diary, I know however, that would have not been able to stay completely objective and would be inevitably influenced by the analysis from the previous transcripts.

# Stage 6: Across case analysis

The final stage involved me looking at for patterns across all participants. Each major theme was compared and contradicted across participants. In order to do this, I typed all clustered themes that has emerged from individual transcripts along with codes (e.g. T1), to be able to identify each participants transcripts. I later printed the typed cluster themes and cut out

the individual row of themes containing the transcript codes (Figure 4).

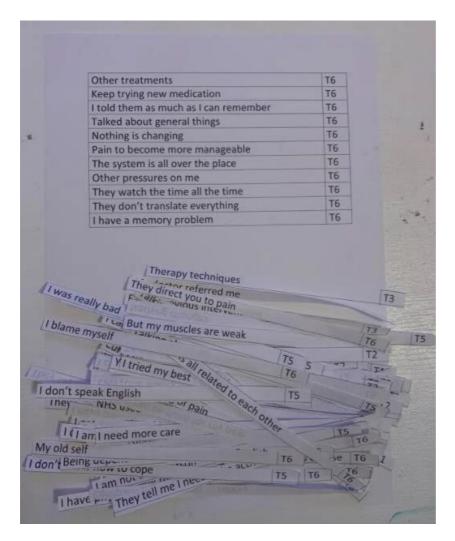


Figure 4: First step in identifying patterns across transcripts

I stuck each cut cluster themes on a large white wall with blue-tac and began the process of re-clustering them in accordance with shared high order qualities (Figure 5). I labelled newlyemerging clusters with green highlighter to represent the level of recurrence across cases when grouping, naming and discarding superordinate themes (Smith et al, 2009).



Figure 5: Second Step in identifying patterns across transcripts

Once saturation was achieved, a final table was created illustrating the higher order themes with exemplar quotes from each of the individual participants (Appendix 13). Throughout the analytic process, the participant's accounts were carefully attended purely and only to draw out psychological theory only when triggered by participant's personal account. Supervision was utilized throughout the process to test the coherence and plausibility of interpretations. As analysis is a subjective process, it was important for me to be aware of my own conceptions as well as those of participants. To aid this process, I kept a research diary in order to record my thoughts and ideas, revisited contents of transcripts and made use of regular supervision to be able to maintain a reflective stance. Appendix 13 shows a brief extract of my reflective diary.

## 3.5 Ethical Considerations

# 3.5.1 Conception of the study

Knowledge and power, in line with my critical realism viewpoint, are intertwined in my mind. Power is founded on knowledge, but it also makes use of it. Power has the ability to recreate knowledge in a form that suits its purposes. Thus, by deciding to focus on the experience of Turkish-speaking women's psychological therapy experience for their chronic pain, my aim was for this knowledge to not only benefit the participants by giving them a voice but also to benefit broader group of black and ethnic minority groups that presented with chronic pain to psychological therapies, through it being disseminated and applied in clinical practice.

#### 3.5.2 Design and Implementation of the Study

The proposal for this research was granted approval from the Department of Psychology at City, University of London (REF: PSYETH (P/L) 12/1864) and NHS Ethics Committee (REF: 238023). Full consideration was given to the study's ethical guidelines in accordance with the British Psychological Society Code of Ethics and harm (psychological and physical), their dignity and rights are maintained by confidentiality and anonymity.

Although not currently with diagnosis or treatment plan, all participants in this study were adults with a prior diagnosis or experience of depression and anxiety in the context of past trauma, migration and actualisation process to foreign country, which increased the potential for further distress resulting from participating inthis study. Measures were put in place to reduce the likelihood of this potential by conducting supervised telephone screening, face-to—face interviews at a place participants found themselves most comfortable at, a protocol to follow when participants became distressed during interviews (Appendix 8), a completed risk assessment detailing possible risks and measures (Appendix 9), a debriefing sheet with details of support organisations as well as contact details for researcher and supervisor (Appendix 7), and a reminder of their right to withdraw and participant information sheet (Appendix 1). In regards to privacy and confidentiality, complete anonymity was guaranteed to the participants who have provided their personal data. Clear description of my role was provided to each participant (Appendix 1) to manage expectations of dual role as trainee counselling psychologist and researcher. Inline with BPS guidelines, I have not interviewed participants whom I worked as a patient to ensure no bias or harm is involved. Research

supervision was further utilised to identify and discuss further ethical dilemmas in occupying multiple role. As stated by BPS code, I respected individual, cultural and role differences by use of reflexivity and recognised and reflected on my limitations regularly in supervision.

Individual, written informed consent (Appendix 3) was obtained prior to participation. Sufficient time was provided between participants agreeing to take part and their interview, to ensure they had the space to think through the implications of taking part without feelings rushed or pressured. Recordings and transcripts was encrypted and stored securely in accordance with good research practice to ensure confidentiality. Participants were offered the opportunity to read the summary of the results. A gift voucher incentive was offered with clear rationale- to demonstrate their time was valued.

The researcher's safety and welfare was considered due to cultural and personal closeness to participants, risk assessment and measures were in place and personal therapy was utilized to address any psychological distress.

# 3.5.3 Write up of the Study

Finally, there were some major ethical problems to consider when it came to writing up the outcomes of my investigation. I tried to preserve the data as near to the participants' original phenomenological accounts as possible during the transcription process. Similarly, I spent a lot of time reading over the data to figure out what it meant and selecting the extracts that best conveyed the voices of my participants throughout the investigation.

# 3.6 Quality Criteria in Qualitative Research

Feldman (1995) rejected the concept of a universal code of practice for evaluating the use of qualitative methods. He argued that it is difficult to construct set criteria to assess quality due to varieties in qualitative methodologies. Madill, Jordan & Shirley (2000) emphasised the importance of evaluative criteria to be comparable with research's ontology and epistemological positions. The lack of set evaluative criteria restricts the development of qualitative research as the requirements and standards for qualitative research is not recognized by the standards required for traditional publications (Yardley, 2000). Quantitative research has sparked various controversies about its validity and reliability. For example,

qualitative research is frequently criticised for failing to use a representative sample of participants (Yardley, 2000). Qualitative research, on the other hand, uses theoretical sampling and small sample sizes to investigate a phenomenon or process in greater depth. As a result, a statistically representative sample is neither required nor acceptable (Charmaz, 1990). It has similarly being criticised for lack of reliability, however qualitative methods seeks to understand many of individual experiences, processes and discourses, therefore reliability is not an appropriate standard (Charmaz, 1990). In regards to objectivity, Manning & Cullum-Swan (1994) was against pre-defined rules for coding as they believed it limits 'contextdepended' interpretations. However, qualitative research requires a means of assessing quality in order to be useful, and these criteria must be flexible enoughto support a variety of epistemological frameworks within qualitative methodologies (Secker, Wimbush, Watson & Milburn, 1995). Several criteria have been developed to judge the quality of qualitative research in psychology (Henwood & Pidgeon, 1992; Elliott, Fischer & Rennie, 1999; Finlay & Evans, 2009). For this study, Yardley's (2000) four characteristics for evaluating 'good qualitative research' will be utilized to assess validity as recommended by Smith et al (2009) for IPA methodology.

#### 3.6.1 Sensitivity to Context

Yardley (2013) suggests researchers to demonstrate sensitivity to relevant theory/literature, to socio-cultural contexts and participants. This study aimed to show sensitivity of context throughout research process, from literature review- to data collection, analysis and discussion. The current study emerged from a gap in literature, established through a detailed literature review of the subject matter. A through literature review can be found in chapter two demonstrating the rationale and development of research question by acknowledging the existing theory. The socio-cultural setting of study is taken into consideration by recruiting Turkish women with chronic pain and by designing the study that would incorporate the Turkish researcher's, actions and characteristics through reflexivity. The study's foundation in the concept of IPA methodology, for its potential to elicit each participant's perspective, achieves sensitivity to perspective and socio-cultural context. Participants were offered the opportunity to meet at the Locomotor service, wherethey had already received treatment, or in their own homes in order to ensure that they feltentirely comfortable throughout the interview process. The use of semi-structured interviews, which allow participants to steer the conversation through open-ended and flexible questioning, as

well as the interactional aspect of the interview environment, improves the study's context sensitivity. In analysis section, voices of participants are present via verbatim quotes, which help reader to consider researcher's interpretations and highlights the distinction between the participant's raw data and researcher's interpretations (Smith and Osborne, 2013). In discussion, the findings are connected to existing theory and literature.

#### 3.6.2 Commitment and Rigour

For commitment and rigour, Yardley (2000) recommended the extensive engagement with the topic, careful data collection, immersion in data and through analysis. Commitment for developing methodological competence/skills was further suggested by Smith et al (2013). The researcher attended all IPA specific supervision groups at university and practiced interviewing and analysis skills. Personal commitment and investment was provided throughout the research process to attend to participants needs. Flexible nature of semistructured interviews supported the process of establishing good relationships. During analysis, I engaged excessively with Turkish-speaking women's narratives about their psychological therapy experience, part of what Smith et al. (2013) suggests contributes to a rigorous study. The utilisation of quotes from participants to emphasise analytic themes is also a sign of rigour. Efforts were made to ensure that this investigation was carried out diligently and methodically in accordance with Yardley's suggestions. However, efforts were made to strike a compromise between preserving rigour and utilising IPA's methodological flexibility. Smith et al. (2013) encourages imagination, sensitivity and playfulness alongside methodological rigour. In terms of sample, it should be noted that time, constraints and researcher's difficult personal circumstances were taken into account and the study was conducted with these limitations in mind.

# 3.6.3 Transparency and Coherence

This is concerned with the clarity and coherence of the research as a whole, how it is presented and whether it is consisted with the underpinning theory (Yardley, 2000). Transparency requires full disclosure of all relevant aspects of research process. A full description of the design and techniques is provided, along with a bibliography. To exemplify the process of 'disconfirming case analysis to prevent personal biases,' several experiences that contradict the growing patterns of themes are described (Yardley, 2008, p.242). Further

attempts were made to ensure transparency by keeping a 'paper trail' from the original paperwork to the final report, preserving the details as the investigation progressed and providing a mechanism to check the data (Yardley, 2008). This process was further reviewed in research supervision sessions which Smith et al (2013) argues to significantly contribute to the validity of qualitative study. Reflexivity was utilised throughout research process by keeping a reflective diary which recorded by own experiences, reactions, and emerging awareness of any assumption or biases. Regular research supervision that enabled 'critical and sustained discussion' further enhanced the transparency of the study.

#### 3.6.4 Impacts and Importance

This is about the significance and impact of research (Yardley, 2000). Current study contributes to our understanding of research in context by linking research with practise (Swanson, Durham, & Albright, 1997), which is hoped to lead to new insights. Furthermore, it is hoped that the rich, contextual and interpretative description of the meaning, context and complexity of Turkish-speaking women's psychological therapy experience will enable a professionals to have a better understanding of patient characteristics and the 'real' level evidence base to guide their practice and plan their services. Furthermore, it is envisaged that this research will provide an alternative to the mainstream quantitative approaches employed in health psychology and will provide new knowledge to the National Health Service, thereby raising the prominence of counselling psychology in the public sector.

## 3.7 Reflexivity

Qualitative research relies heavily on reflexivity. It allows researchers to become more conscious of their own role in the construction of meanings about a participant's experience of the topic under investigation. In line with Heidegger (1962) existential approach to phenomenology, it is not possible for researchers to stay outside of the subject matter during research process, and with their natural attitude- Desein (being there) researchers will be contributing with their own personal circumstances, culture and history. Reflexivity therefore urges researchers to explore their influence and how it informs the research under study (Nightingale & Cromby, 1999).

To this end, I have reflected on my being located within the study as, not only a researcher and trainee Counselling Psychologist, but also as a Turkish-speaking women receiving healthcare in UK- – I am very much "embedded in the research process rather than a distant observer" (Charmaz, 2008, p.166).

This, of course, implies that my interest in the research issue, as well as the manner in which I conducted the research, were impacted by my own treatment experiences and feelings. Growing up in an individualist culture with a collectivist background was my biggest challenge growing up in United Kingdom and it took me three years of personal therapy to navigate myself and develop my authentic self. I am from a cultural background that no matter what we have learned to respect and obey the elderly and authority. This meant silencing our own thoughts, ideas and desires as well as avoiding any challenges. This way ofbeing was also reflected in my interactions with health professionals in health care. I learned to regard doctors and health professionals as highly and to take them recommendations without any questioning and challenging, even at times when it did not feel comfortable or relatable. I was relating to health professionals at a position of inexpert.

This position and my role changed when I started to practice as a CBT practitioner at one of the widely diverse Improving Access to Psychological Therapy Service (IAPT) in London. I was now relating to service users from a position of expert. This was a difficult but at the same time a very important transition for me to recognise the importance of advocating for the voice of service users to be heard in their treatment journey, especially for those from ethnic minority groups where their expectations and relations may differ due to their cultural background.

I was at times, left in a position of not feeling empowered as a service user of National Health Service whilst also being in a position of possibly silencing the service users at times in my practice due to the position of expert in the context of my evidence-base practice, guidelines and protocols and as a provider of National Health Service. This is where my curiosity to understand this tension began and my desire to bring a balanced position whereit enables service user's voices to be heard. Fortunately, I have been a co-author of a qualitative research study that explored service user's voice in the experience of Guided-SelfHelp of Turkish-speaking service users in IAPT- 'Guided self-help experience of Turkish- speaking service users in Improving Access to Psychological Therapy Service' which was published in 2018, which I also believe have shaped my research interest for my doctoral thesis.

I became curious about the influence of history, background, culture and circumstances on the understanding, expectations and experience of treatments of service users and the impact this may have on shared understanding and collaborative working in psychological therapy experience. To further my understanding in this area, I first needed to reflect on my values, experiences, believes, personal and political commitments and my social identity prior, during and after research process.

Through reflections on my own position with this research, the predominant issue has been my own relationship with locomotor service, where I had a clinical placement. Questions included: how would I feel to conduct research in my clinical placement? How would my experience of working in Locomotor service, and my knowledge about treatment pathways, evidence base, challenges affect my interpretation of participants experience? How would my relationship with colleagues and management impact on my own research agenda? Would my research impact on my clinical work or my therapist work impact on my research work? How would I position myself as a researcher, therapist, or as a woman from Turkey? How would the knowledge of the culture and being women in our community impact on my interpretations? How would I impact on my participant's propensity to talk openly? Would they see me as an expert, or as a friend, a relative – part of them or external to them? Should I be open about my role as a practitioner or trainee? Would they assume I had any links with the clinics or a different agenda? These were some of the queries I had. I therefore kept a reflective diary throughout research process that captures my experiences from the onset of the research and frequently discussed by thoughts about how this research may have changed me as a person, as a clinician, and as a researcher, in supervision and through personal therapy.

Finally, I'd like to address certain disciplinary concerns (Wilkinson, 1988). Some of the key disciplinary elements that I feel have influenced my study (e.g., my perspective on the status of phenomena and my function as a researcher) have already been highlighted, but maybe the most crucial disciplinary aspect has gone unnoticed. The research's political goal is a crucial factor to examine. What was it that I wanted to accomplish? I've seen the potential usefulness of Counselling Psychology in the treatment of chronic pain and other more "medicalized" mental health illnesses from the beginning. The research's main political goal has been to emphasise this potential. I feel the study is consistent with Counselling Psychology's critique of normative thinking patterns, notably the medical paradigm that

dominates mental healthcare (Bury & Strauss, 2006; Strawbridge & Woolfe, 2003). The patient's lived experience, social milieu, and psychological impacts are frequently overlooked in medical treatment. One of the main purposes of this study was to address this issue in some way, namely in terms of people's experiences with psychological therapy for chronic pain.

## 3.8 Summary

The technique and approach of the study were discussed in this chapter. The IPA method was chosen because it was thought to be the best fit for the study's goals and epistemological perspective. This section also included the study's methodology and data analysis, as well as questions of reflexivity, quality, and other ethical concerns.

# **Chapter 4. Analysis**

'...they should consider people with complex presentations separately and individually... planning a unique treatment... also they should explain... like they should explain the consequences of doing things despite the pain... like they should maybe mentally prepare you for having more pain'

Yesim, 848

This chapter will present and discuss nine subordinate (or subthemes) which were clustered into five superordinate themes using IPA. Derived from of all transcripts individually and across participants, the themes are presented in an organised manner, and I will demonstrate overlaps between them as well as conveying the convergences and divergences to offer a rich and nuanced description of the Turkish-Speaking women's experience of psychological therapy for chronic pain (Starks & Trinidad, 2007).

Phenomenological understanding of the experience requires a 'double hermeneutic cycle' where the researcher tries to create meaning from participants attempts of constructing meaning of their experience (Osborn & Smith, 1998). Interpretative phenomenological analysis of data therefore offers a co-construction of meaning between participant in the study and myself. As such, the emergent themes for this study are my own interpretations and another researcher may have prioritized different themes. The positioning of subordinate themes within super-ordinate themes reflects a subjective choice for eliciting the experience

in question. It does not imply exclusivity and every effort were made to remain grounded in the data by returning and checking the original transcripts.

Due to the volume of data, it is impossible to integrate every aspect of each participant's story or account for everything that has emerged. I have therefore concentrated in creating a journey through the experience by presenting in-depth accounts of prevalent and prominent themes that best illuminates the research question and offer insights in the areasthat were previously neglected in the literature. The analysis of six interview transcripts resulted in five superordinate themes and nine subordinate themes. The coherence across participants experience is noticeable. Similar themes emerged with different emphasis, represented by different theme labels for each participant.

For each superordinate theme the raw data will be presented and explained using verbatim quotations followed by a general summary to demonstrate the shared and collective experience whilst acknowledging individual idiosyncratic experiences. Use of verbatim quotations from participants provides transparency and rigour of the study by providing the voice of participants in the analysis and enables reader to consider researcher's interpretations from participant's raw data (Smith & Osborn, 2013). Participants will be presented with pseudonyms in order to preserve confidentiality. This will be followed by the line number of the quotation as appeared within the original transcript. For example: (Participant, line number).

#### 4.1 Overview of Themes

**Table 3: Overview of Superordinate Themes** 

Superordinate Themes		
Living with chronic pain		
When path crosses psychology		
My pain is real		
Out of control and control within the system		
Outcome of therapy		

The first superordinate theme describes participant's experience of focusing predominately on their physical symptoms of pain and a sense of loss of self. Second superordinate theme

describes participant's experience of their referral to psychological therapy and the meaning they attribute to this referral. The third superordinate theme describes participant's experience of psychological therapy, failing to acknowledge their subjective experience, be that due to different understanding of their pain experience or the standardized and generalized care they perceive to receive as well as their sense of feeling judged. The fourth superordinate theme describes participant's experience of not feeling in control in their psychological therapy, due to dependence to interpreters and by the wider systemic influences. The final superordinate theme describes participants experience and meaning of the ending of their psychological therapy.

The five superordinate themes represent the prominent aspects of the participant's treatment journey. There are a variety of subordinate themes (or subthemes) within the superordinate themes. Because the nature of experience is unseen from a phenomenological standpoint, any interpretation I made is not meant to be literal. Rather, it is meant to be a full portrayal of the participants' experiences as I, the researcher, have interpreted them. Please refer to table below for a summary of the superordinate themes, their subthemes and the participants whose accounts contributed to their development.

The titles of the themes represent my overall interpretation of participant's common descriptions of their experience. For example, 'Living with chronic pain' is derived from participants overall descriptions of their chronic pain and the meaning attached to this experience. Within the critical realist epistemology, IPA is concerned with subjective meaning and acknowledges a reality but is more concerned about how this reality- i.e. in this case chronic pain is specifically experienced by Turkish-speaking women. As the researcher, I derived titles that stay close to participant's raw experience by using their words as well as acknowledging my interpretations of their experience.

Table 4: Summary of all themes and their participant contributors

Superordinate Themes	Subordinate Themes	Contributions
Living with chronic pain	Focus on Physical Pain '…and I have physical pain. Like right now I cannot explain the pain I am in…every part of me is in pain'	All but Gul
	<b>Loss of self</b> 'because my life before and my life now is very different'	All Participant
When path	<b>Referral source</b> 'it was my doctor who referred me'	All but Yesim

crosses	Expectation: desperation	
psychology	'I thought it will maybe…be cure (tearful)…I don'tknow…'	All participants
My pain is real	Making sense of chronic pain  'They tend to look at pains separately. I think they needto  consider them as related'	All participants
	Generalized care  'they only ask about that moment. They don't ask much about the past. They only focus on the present. No one knows what you experienced in your past'	All Participants
	Feeling Judged  'Like you don't have pain but you are doing it psychologically. This feeling just surrounds you'	All Participants
Out of control andcontrol within the	Dependence on Translators  'like there is an interpreter and she does translate everything you say but it takes a lot of time'	All participants
system	Awareness of wider control within the system 'nothing continues for longlike with time there are more limitations on sessions and I don't think people will recover with all this limitations'	All Participants
'ту р	Outcome of therapy sychology was upside downthey made me feel worse'	All participants

## 4.2 Living with Chronic Pain

This superordinate theme encapsulates how Turkish-speaking women participants experience chronic pain. It examines participant's accounts of focusing on physical and bodily symptoms when describing and articulating their pain and the meaning they attach to the experience of their chronic pain. There appears to be a common experience of sense of loss of self with the experience of chronic pain. This superordinate theme consists of two subthemes: Focus on Physical Pain' and 'loss of self'

## 4.2.1 Focus on Physical Pain

'...for me, the cause of my pain is the problem in here [showing her legs]'

(Zerrin, line 159)

This subtheme considers how Turkish-speaking women experience and express their chronic pain. All participants made references to aspects of their body that can be physically seen, felt or touched to articulate their experience of chronic pain. For example, Zerrin (above) points to her legs when describing the cause of her pain.

Similarly, Yesim makes references to her foot pain and sensations in her head.

'...like it starts in my foot but travels all the way to my head. When it reaches my head at the end...I feel like my brain can no longer control by body...'(Yesim, line 379)

Ayse on the other hand makes direct reference to her diagnosis to describe her pain:

"...I have arthritis. I have a real problem..." (Ayse, 13, 346)

Participants focus on physical sensations, bodily symptoms or diagnosis can be multi-layered. First of all, all participants are seen at a multidisciplinary pain clinic where the treatment model is usually medical/ biological and the language that is used to communicate is based on medical terms. It is therefore possible that participants might have picked up the medical language from the service and 'professionals' to express their experience of chronic pain. This is especially more likely for individuals from ethnic minority groups with limited English proficiency. Although interpreters were provided to all participants in the study, these

interpreters were also part of the multidisciplinary team of pain clinic. Furthermore, touching and observing can be deemed important based on participant's healthcare experience back in their host country- Turkey. I know as a Turkish researcher that individual will have no faith in doctors who does not touch them or undertakeintensive investigations with tests. Hanim, for example specifically points to lack of tests in her treatment:

'like I don't know...maybe they can refer me to a test? Or a specialist hospital? (Hanim, 248).

Ayse makes direct comparisons with treatments that are available back in Turkey:

'like in Turkey apparently there is a treatment with light...they say physiotherapy with light'
(Ayse, 820)

Another possible explanation for participants focus on physical sensations and bodily symptoms is to seek validation and acknowledgment of their experience of chronic pain. All participants expressed an experience of being judged during their treatment experience (this experience will be discussed in subsequent sections), and participants may have reached to a conclusion that focus on physical sensations or bodily symptoms in a medicalized pain clinic will get them the validation and acknowledgment for their experience of chronic pain.

Bodily complaints also appear to be a preferred form of appeal for help from their close ones. For example, Fatma describes the support she gets from her children:

'like for two days my eldest son had to stay with me to look after me' (Fatma, 43)

Although emotional distress is experienced and acknowledged by participants, these tend to be expressed through bodily complaints. This somatisation appears to be more accepted among participants in this study. For example, Hanim describe experiences of 'suffocation' and need to 'scream' but then appears to connect this with her difficulty to move her muscles:

'It's like something is suffocating me. Like I want to scream but I can't even talk...like I want to wake up but I can't even move my muscles...'(Hanim, line 697)

Body/mind separation does not appear to be as salient in the accounts of Turkish-speaking

women when describing their experience of chronic pain.

Overall, Turkish-speaking women focuses on physical sensations, bodily symptoms and diagnosis when describing and expressing their chronic pain. Participant's preference to express their chronic pain in this way can be in the context of them being seen in a medicalized pain clinic, their limited English proficiency, their previous healthcare experience in their host county, their desire to be validated and acknowledged, to appeal for support and somatization- their preferred way of expressing emotional distress. Participants appeared to have different possible explanations but overall, they all preferred to articulate their chronic pain experience by focusing on physical manifestations of chronic pain.

#### 4.2.2 Loss of Self

'I was looking like a robot'
(Gul, line 365)

This subtheme considers the extent to which participants experience change in their sense of self as a result of the chronic pain experience. Participants refer to changes in their physical appearance, cognitive abilities, their emotional wellbeing, financial status and social interactions. For example, Fatma expresses the concern over friends recognising the change she underwent following her chronic pain experience:

'My friends used to tell me that I changed a lot...that I became worse...' (Fatma, line 360)

There is a sense of participants trying to emphasise the change they underwent as a result of chronic pain experience possibly to get validation and acknowledgement for their chronic pain. Fatma in this instance appears to make use of friends account to get validation for her change of self. Whereas Yesim on the other hand, makes references to her past self to seek this validation for the change she underwent and makes direct comparisons of herself from the past and present:

'Like...for example about ten years ago I was very active person, I never used to stay at home' (Yesim, line 31)

'...because my life before and my life now is very different' (Yesim, line 27)

These references to past appear to encompass a sense of loss. Loss of their sense of self as a once active and healthy individual. However, it may also be possible that participants in this study are attributing their experience of loss of other areas of their life into their chronic pain. All participants of this study where immigrants from late 1980's and four out of six fled Turkey because of the conflict between PKK (Kurdish worker's party) and Turkish army. They consisted mostly of heterodox Alevi sect of Islam with an experience of discrimination and injustice. They were forced to leave their family, friends, and land behind for their safety. This experience of loss of country, attachments and language is likely to be projected as chronic pain and expressed in terms of loss of their past self. For example, Hanim expresses her difficulties of moving to UK in following sentence:

...'like since stepping into this country I always have problems...since the day I moved until now. Problem in my marriage, problem in my life, then it's my health...then my kids...not knowing English is the biggest damage to my life' (Hanim, 570)

Hanim, Ayse, Yesim and Fatma also made references to changes in their cognitive abilityespecially on their memory:

'I didn't know who I was and I did not understand what people were saying to me. It was like my memory was in a different side' (Fatma, 354)

Hanim, in addition makes references to changes in her emotional wellbeing and general personality as well as to changes in her memory:

'I cannot think of anything... I am completely numb. I have memory problems, I feel stressed, and I feel angry like I get angry very quickly' (Hanim, 49)

Ayse in fact expresses a change in how she views herself:

'...I am not a full person. I am a half a person because I was someone who did not walk at all' (Ayse, line 186)

All participants express a sense of undergoing a change as a result of their chronic pain experience and that change involves a loss. Loss of how they are perceived in their friendship

group, loss of activity, loss of their self in the past as they see, loss of their cognitive ability and even a loss in their perception of themselves. This sense of loss may also encompass the loss they have experienced as a result of their move to UK, their loss of land, family, friends and language and hence they may be more attuned or sensitive to the loss it comes with the experience of chronic pain. In addition, this sense of loss appears to be further maintained by the message they hear by professionals and through their interactions with the health services. For example, Hanim articulates her experience of being told to 'forget' about her old self in following sentence:

'I know I can't be like how I used to be. I learned that here. They said I should forget my old self' (Hanim, line 366)

Experience of undergoing change and sense of loss that accompanies this change appears to be significant in Turkish-speaking women with chronic pain.

## 4.3 When Path Cross Psychology

This superordinate theme explores Turkish-speaking women's referral experience to psychological therapy for their chronic pain. It specifically addresses their unique understanding and expectations from psychological therapy. Participants in general appear to hold a passive position in their referral process- implying that they generally show a deference to healthcare professionals authority and engage in minimal to non in the process of shared decision making. Their desire to end their experience of distress as a result of their experience of chronic pain and seek 'cure' seems to dictate how they position themselves in referral process. All appear to accept the suggestion of a referral from an 'expert' to psychological therapy without questioning and challenging the benefits for their own difficulties. However, it is also important to consider the relational concept of the shared-decision making and the role of clinician and services within this dynamic. This superordinate theme consists of two subthemes: 'Referral source' and 'Expectation and Desperation'.

## 4.3.1 Referral Source

'I was seen by physiotherapist. I was referred my physiotherapy route'
(Gul. line 152)

All participants were referred by an internal or external professional within the pain clinic. Gul (above) is referred internally by the physiotherapy route. And Ayse and Fatma are referred externally from pain clinic by their GP:

'...my doctor said I must definitely see a psychological doctor... to have talking therapy support' (Ayse, line 135)

They appear to trust the suggestion of a referral by the professional and appear to make their own conclusions regarding the referral. For example, Hanim considers the referral to psychology was suggested as a result of failed previous interventions:

'I think it was because I did not benefit from any medication, treatment or physiotherapy to date. Like they tried everything but nothing worked. So they wondered if this was due to my unconscious... like whether it was psychological. I think they referred to find this out...'

(Hanim, line 41)

Participants appear to accept- i.e. without challenging or questioning the 'expert' recommendation of referral to psychological therapy service.

For example, Yesim expresses her position in referral in the following sentence:

...'I will go everywhere they refer me with a hope...because I am really fed up now' (Yesim, line 22)

As Yesim expresses, this position they take up within the clinician-patient interaction in the referral process can be due to her feeling fedup of her experience of chronic pain and the distress that accompanies this experience. However, considering the similar position held by all participants in this study, it is possible that there is a more general and possibly culturally significant reason for holding on to this position. First of all, language skills can be an important moderator for patient-clinician interaction and can be significant in collaborative decision making. Participants in this study lacked English proficiency and all relied on interpreters for communication. This might have been a barrier for collaborative decision making regarding their referral to psychological therapy.

Secondly, most participants were seen and referred by professionals that had a different background and culture from their own. This might have influenced how confident they feel for active communication and collaboration. Nearly, all of the participants expressed a sense

of feeling freer and more confident in communicating their distress and experience whilst being interviewed for this research. This could be explained in terms of culture-concurrent interaction between the researcher and participant. For example, Hanim expresses her feeling of being relaxed during research process with the following sentence:

'like if you were a foreign I don't think I would have been this relaxed!' (Hanim, 477)

It was also interesting to note from the interviews that participants considered themselves to be more honest and authentic during interview process. For example, Ayse, implies being honest by expressing that her psychological therapy experience was not beneficial:

'hmm...do you want me to be honest? I did not see any benefit. All my problems stayed with me at the end but I was just able to speak about it a little' (Ayse, 154)

Furthermore, sense of being judged (which is prominent in this study and will be discussed below) can discourage Turkish-speaking women from participating in shared decision making regarding their referral to psychological therapy. In addition, as they are viewing themselves as 'half' (as above) or 'diseased' as a result of their chronic pain experience it is likely that they are expected to be 'fixed' by the doctor' and align doctors the responsibility to investigate, manage and relief their pain experience. The concept of morality therefore appears to be different in Turkish culture where personal responsibility and personal choice is limited for their health care. However, their lack of language proficiency and culture discordant patient-professional interaction might have also limited Turkish-speaking women's internal locus of evaluation and their capacity to make choices on the bases of their individual needs.

Overall, participant's referral to psychological therapy for their chronic pain via an expert appears to place them in a position, where they show respect to expert recommendation without challenging. This positioning of Turkish women can be understood in the context of their lack of language proficiency, culture discordant interaction with the professional, sense of being judged or in the context of how they perceive themselves and the status and role they align to professionals, which can all be determined by the Turkish culture.

## 4.3.2 Expectation and Desperation

'Er...to be honest I am always looking for a cure' (Fatma, line 161)

All participants expressed an expectation of 'cure' from psychological therapy to their chronic pain experience. Four out of six of the participants used the word 'cure' indicating a desire to end their chronic pain experience.

Zerrin , instead of using the word 'cure' expressed this wish by saying she wants to 'get rid of pain'

'I thought it will get rid of my pain...that's what I thought' (Zerrin, line 3)

Gul, on the other hand expresses a wish for a pain free experience:

'I expected it to be more beneficial...like no pain' (Gul, 86)

Yesim on the other hand mentions the word 'solution' to describe her expectation from psychological therapy.

I really thought it will be something...something that will keep me going...like...maybe a solution will be found for my problems...that's why I went there...' (Yesim, line 5)

Overall, it appears that Turkish-speaking women expect psychological therapy to result in a solution to their problem of chronic pain and lead to a pain-free life. This expectation does not come at a surprise considering participants focus on physical symptoms, their use of medical terms to describe their pain experience, and their sense of loss of self and perception of self as someone who is 'half' and diseased. This appears to lead naturally to an expectation of a professional or an expert to 'cure' their half and diseased self. Hence, how participants experience their chronic pain appears to influence what they can expect from psychological intervention.

Furthermore, psychological therapy is considered as an alternative and as a criticism to positivist medical model that encourages collaborative interaction between the clinical-patient and personal responsibility to change thoughts, behaviours, and feelings regarding the pain experience. However, Turkish-speaking women do not align well with this model of

healing. Their healing model appears to be more aligned towards a position where they align the responsibility to professionals and experts to end their chronic pain. This healing model of Turkish- speaking women can be strengthened further due to their language skills and culture discordant interactions with the professional and sense of feeling judged (see next superordinate theme). Participants perceived failed previous interventions and a referral to psychology by an expert as a last resort might have also influenced participants understanding and expectation from psychological therapy for their chronic pain.

With an expectation of 'cure' comes desperation. Nearly all participants expressed that they will be doing anything they can or have done everything they can to end their chronic pain experience. For example, Zerrin talks about her willingness to try anything for hope of getting 'cured':

'Like I said whatever they want I must do but you look for hope everywhere' (Zerrin, line 54)

This sense of desperation to end their chronic pain experience may also encompass the desire to end their distress and challenges of living in a foreign country and their loss of land, friends and family which may also be projected into the experience of chronic pain. For example, Ayse expresses her need to run away from everything:

'I just wanted to run away from everything [tearful]' (Ayse, 401)

All participants express a desire to be cured from their chronic pain experience. Their perception of themselves as result of experiencing chronic pain, their culturally determined healing model, previous failed interventions and their experiences and losses associated with actualisation experience appears to lead to desperation for a pain-free life which appears to be in the conflict with the actual purpose of psychological interventions for chronic pain.

## 4.4 My Pain is Real

This superordinate theme explores participants' perceptions that their treatment failed to acknowledge their individual lived experience of chronic pain. Specifically, psychological therapy was experienced as not matching their understanding of chronic pain experience, their expectation, and unique needs. For many of the participants, this was perceived as they are being judged at different levels and not being cared appropriately.

## 4.4.1 Making Sense of Chronic Pain

'There were differences between my understanding and their understanding'
(Hanim, 333)

All participants in this study experienced an incongruity with their clinician in the understanding of their chronic pain experience. They in general did not feel their unique experience of chronic pain matched with the understanding of their therapist or service in general. Zerrin in addition questioned her diagnosis:

Like I don't even know the proper diagnosis of my illness...ok my muscles are weak but what is the name of this condition? (Zerrin, line 159)

It is important to note that she uses the word diagnosis for her experience of chronic pain, implying a sense of being ill or disease. This is consistent with participant's experience of chronic pain explored in 'living with chronic pain' superordinate theme above.

Hanim, specifically pointed out to differences in the approach taken to reach an understanding of the chronic pain experience:

They are seeing it differently. Like they have separated into different departments. Like this department deals with this etc. I don't understand different departments. I am being called from different departments to come for an appointment. Like what is the point of all this?

Why can't they just locate all in one department? (Hanim, line 623)

Yesim appears to hold a similar view: *They tend to look at pains separately. I* think they need to consider them as related' (Yesim,line 294)

Overall, what is clear from the participant's accounts is that they do not feel their understanding of chronic pain experience is matching with the explanation or approach taken by the clinician or service in general. For example, Gul explicitly expresses this mismatch:

'It doesn't match. Now they don't directly say it is because of your brain or psychology...but they always say it is an important contributing factor' (Gul, line 164)

Although, participants appear to focus on their physical symptoms when describing their

chronic pain experience (as in 'My pain is real' superordinate theme above), when it comes to understanding their chronic pain experience, participants appear to acknowledge a unity of the experience of chronic pain. There is a sense of them wanting to be understood as a whole with their physical, mental and spiritual self as a single unified reality rather than separate domains of beings. Yesim, expresses this need clearly in the following sentence:

'I realized this because when they were assessing me they did not consider the totality of me...like for example when she was encouraging me she was only focusing on my foot pain' (Yesim, line 362)

In addition to the above, it is also possible that lack of English proficiency among participants and their sense of being judged (see below) may have influenced the patient- clinician interaction and their capacity for a collaborative understanding of chronic pain experience. Nevertheless, the incompatibility of understanding of chronic pain appears significant from the accounts of participants which seems to lead to more difficult experiences as expressed by Hanim below:

'This contradiction just ruined my life' (Hamim, line 592)

#### 4.4.2 Generalized Care

'I have a unique problems I need an individualized treatment'
(Yesim, line 742)

All participants in this study experienced their chronic pain as unique. All referenced to specific bodily parts, their diagnosis and to their day to day difficulties in living with chronic pain to express the uniqueness of their pain experience. Zerrin for example, emphasised her diagnosis to express the uniqueness of her chronic pain:

"...every pain is different. Like mine is lupus... it is different. Like for example when I go out to the sun I will suffer from bone pain all night. I cannot relax because of pain" (Zerrin, line 273)

Yesim, on the other hand emphasises the relation in her pain experience to express the uniqueness of her chronic pain:

'...my pain is all connected. I have a unique problem so you need an individualized treatment' (Yesim, line 742)

Hanim, interestingly made reference to her mental health struggles to emphasise the uniqueness of their chronic pain:

'... I don't just have pains. I also have psychological problems...' (Hanim, line 32)

Ayse on the other hand expressed her concern of clinician's approach in focusing on present to reach to an understanding of her chronic pain experience:

'They only ask about that moment. They don't ask much about the past. They only focus on the present. No one knows what you experienced in your past' (Ayse, line 1203)

Gul and Fatma on the other hand made references to the severity and co-morbidity of their pains to express their perception of uniqueness of their chronic pain experience. Although all participants make references to physical/ bodily symptoms when describing their pain, they also appear to acknowledge that their pain experience is not in isolation and that is influenced or impacted further by other experiences. There appears to be a desire from all participants in this study for their unique chronic pain experience to be acknowledged. Zerrin summaries the overall desire to be acknowledged individually by their treatment in the following sentence:

"...I don't think every ill person is the same or every illness is the same (Zerrin, line 364)

However, it appears that participants experience psychological therapy fall short in acknowledging their unique pain experience. Hanim for example, emphasises the difficulties with money, friends and ability to be able take on bored the general advice provided by the psychological therapy:

'They tell me to go out more but do they consider how? Whether I have friends? Money? Or ability?' (Hanim, 835)

Similarly, Gul emphasises the different views she holds regarding her psychological intervention:

'Like they think my pain would improve if I am active. But my thinking is completely the opposite' (Gul, line 229)

Participant's practices and attitudes about healing appears to be different than what the psychological therapy was proposing. Psychological interventions entail a social interaction

between the clinician and the patient in which the clinician encourages patient to make changes at cognitive and behavioural level to support the management of illness (Jensen, 2010). This kind of social interaction assumes a sense of collaboration in the part of a clinician and patient. Yet, the interaction between the Turkish-speaking women in this study appeared to be one-sided- with a clear indication of preference for clinician to make decisions on their behalf and little challenging and questioning from their part. Cultural understanding of clinician-patient relationship and expectation may have certainly played a role in patient's positioning. However, it is also important to consider the impact of clinician's and service approach and their interaction with the patient. For example, it important to consider whether patients were given opportunities to be involved in collaborative interaction with their clinician- in the context of their language, health literacy and other social and economic unique challenges? This overall experience of psychological therapy not acknowledging their unique needs appears to leave participants to feel not understood or cared. Fatma, for example reports feeling of not taken seriously:

'Err...to be honest I don't think they take my problems seriously. That's at least what I think' (Fatma, line 458)

All participants disclose a desire to be met at individual level, beyond their diagnosis or pain, and for their total experience to be acknowledged and accommodated in their psychological therapy. Ayse describes this as 'going deeper into our lives and our stories':

I would have liked them to care more. I would have like them to go deeper into our lives and our stories. Like how did it start...when did you realize it? Like if they could have more questions to go deeper...maybe that would have helped...I don't know' (Ayse, line 1192)

What is important to note from here is that all participants perceive their chronic pain experience to be unique and they all perceive psychological therapy to fail them in acknowledging their unique experience and needs and they all express a desire to receive a more holistic and individualized psychological therapy for their chronic pain.

## 4.4.3 Feeling Judged

'They look at you in judgemental way...you can tell that as soon as you meet them' (Yesim, 882) Participant's sense of not feeling heard and understood and the perception of participants being exposed to generalized care that fails to acknowledge their unique chronic pain and needs appears to lead to feeling of being judged by psychological therapy experience. It appears that strong emphasis on evidence —base formulation and treatment is perceived by Turkish-speaking women as not acknowledging their unique experience and needs of chronic pain. Although there appears to be a general sense of being judged, how and in what context they sense of being judged varied. Yesim for example, sensed being judged for exaggerating her chronic pain:

'...it was like I was exaggerating everything. Like I don't have a problem but I am making it up...like even the way they used to look at me...it was very belittling' (Yesim, line 869)

She further expresses how this sense of being judged develops into a 'barrier' between her and her therapist and then the difficulties in expressing her 'honest feelings'

'Some directly judge you. They talk to you in a very judgemental way, like when they start talking to you in a very judgemental way...you immediately put a barrier between you too.

And when there is that barrier you will not share your honest feelings' (Yesim, line 166)

Similarly, Hanim expressed her sense of being judged through her fabricating her chronic pain:

"...I worry people going to assume I am faking it to avoid going to work" (Hanim, line 359)

With Hanim, there is a strong sense of 'them/us' within the patient-therapist interaction. This separation appears to be more apparent for Hanim where she considers to be laughed behind her back for her disclosures:

'Then I regret talking like this because they laugh behind my back because I know...I know they do' (Hanim, line 637)

Overall, there is a sense of feeling judged in psychological therapy. Culture discordancy of the therapeutic encounter, perceived therapist biases regarding their culture or even the limited language skills or the Turkish speaking women's focus on physical symptoms may be contributing factors for the sense of feeling judged within the psychological therapy. This sense of judgement appears to leave itself to feel uncontained within the therapeutic encounter. For example, Ayse expresses a sense of being referred on to different services:

'Then they referred me somewhere else...like everyone just wants to get rid of me' (Ayse, line 845)

This sense of judgement and being uncontained in psychological therapy further appears to lead to patients obeying and accepting all recommendations and suggestions by their therapist. Turkish-speaking women's position of not question or challenge the expert- in referral appears to be further maintained during the treatment stage of psychological therapy. For example, Yesim expresses the need to doing everything she has been asked in her therapy:

'so I did everything that was asked me to do. Took every word seriously...' (Yesim, line 340)

Gul, in fact talks about how she obeyed the recommendations even if that lead to her experiencing more pain and distress:

'Like when they said continue to walk even if it is painful...I did but later I was bedbound for couple of days' (Gul, line 183)

Hence, Turkish-speaking women participate in their psychological therapy from a position of showing deference to healthcare professionals. It is possible that considering Turkish-speaking women's experience of moving to UK, or their sense of feeling unsafe in the host country as well as their experiences during transition, they may have been more sensitive and attuned to experiences of feeling judged during their psychological therapy.

Overall, there appears to be a significant experience of being judged by Turkish-speaking women in this study. This sense of judgment can be in context of mismatch in the understanding of chronic pain, perceived generalized care, culture discordancy within the therapeutic encounter with biases and limited language proficiency of participants in this study.

## 4.5 Out of Control and in Control within the system

This superordinate theme explores participant's perception or sense of being controlled in their psychological therapy experience. Sense of control appears to be experienced by the use of interpreters to aid communication and via the more general systematic control that participants appear to perceive to have an impact on their individual psychological therapy

experience. This superordinate theme consists of two subthemes: 'dependence on translators' and 'awareness of wider control within the system'.

## **4.5.1 Dependence on Translators**

'I really dislike talking to translators'
(Hanim, line 496)

All participants in the study lacked English language proficiency and made use of interpreters for their psychological therapy to aid communication between themselves and the clinician. However, they all expressed dissatisfaction with their reliance on translators. Gul for example, expressed the concern regarding the three-way communication:

'the conversation with the translator is very different...like you explain to her and then she explains to the other' (Gul, line 437)

Yesim expands on this concern by referring to difficulties in communicating emotions through translators:

'I don't know English and the person opposite me does not know Turkish. I think this is very important. Because at the moment you can't really explain your emotions to the person opposite you' (Yesim, line 567)

Yesim makes an important point here as acceptable emotions in public and ways of expressing emotions can be culture specific. Feeling words or emotional expressions of Turkish culture may not match with the clinician's culture which may lead to biases and misunderstandings. Ayse specifically expresses this cultural difference in communicating emotions in the following sentence:

I think the issue is that our Turkish women finds it difficult to express themselves...you know because of the language' (Ayse, line 945)

This process can be further complicated using translators in the therapeutic relationship. The use of a translator will bring another person into the counselling relationship and the

translator's personal style, attitudes and culture will be critical in conveying patient's emotions to the therapist. This lack of emotional communication may lead to emotional distance which is likely to affect the overall effectiveness of psychological therapy experience. Yesim expresses this possible emotional distance in the following sentence;

'The person opposite only has the information that is available from the translators to make a decision and act accordingly' (Yesim, line 592)

She further adds that with interpreters she is unable to explain her problem as a 'whole' indicating that she is unable to fully communicate her difficulties to her therapist:

'Like if I can communicate from my own language I will be able to explain my problem as a whole but through an interpreter I can only explain in sections...separately...focusing on one thing which misses the bigger picture' (Yesim , line 816)

Both Hanim and Yesim also make references to the quality of interpretations by the translators. Both shares the view that advocates fails to translate their communications appropriately to the therapist. Yesim in addition expresses the helplessness in her reliance to translators:

'Like I don't believe translators translate everything words to word...but what can you do?

You need them' (Hanim, line 280)

Constraint in the therapy duration as a result of using translators also appears to be shared concerns within the participants in this study. For Ayse, she felt she did not have enough time to express herself:

'Like you have half the time to talk and express yourself. You can only speak three to five words then the session ends' (Ayse, line 964)

The perceived challenges in the quality of translation from translators as well as the challenges and complexities involved in communicating emotions in a culturally discordant therapist-patient interaction and limited duration in therapy appears to leave participants with a sense of having no control in being able to communicate their distress/ emotions in their psychological therapy journey. Hanim's following sentence appears to reflect this general feeling of giving away of the power and control to their translators:

'Like I can only explain myself when I talk to someone one-to-one..like if for example I did not understand something then I will have the opportunity to ask or confirm. Like I get really angry when I cannot explain myself' (Hanim, line 507)

The complexity in the therapeutic relationship with a translator can also be intensified with clinician's approach to the translator or patient's perceptions of their relationship. It appears from Hanim's extract that she perceived her translator as a part of her therapist/ service team rather than as having a natural position of a translator:

'She [translator] made me talk for no reason. Like if I was talking about something irrelevant then cut me off and say this is not what they asked you. And direct me to the right conversation' (Hanim, 554)

It is important to note that this possible sense of loss of control in participants to communicate their pain and emotions directly to their therapist can be associated with the sense of loss of control Turkish-speaking women's experience through immigration, transition and actualization experience. Hence, an already present sense of loss of control inTurkish-speaking women's life may have been further exacerbated with the use of translators in their psychological therapy experience which is likely to position patients that inhibits the expected collaboration in clinician-patient interaction. Hanim's following extract summaries this sense of dependence to translators and sense of loss of control in psychological therapy experience:

'Like why am I dependent on others to explain my health problems to professionals?'
(Hanim, line 466)

# 4.5.2 Awareness of wider control within the system

'...NHS used to do more work in the past... but now it is just like that. When you need something then it is not available'

(Fatma, line 303)

There appears to be a shared feeling of a wider systemic control by all participants in regards to their psychological therapy. Although, the kind of perceived systemic control varied depending on the individual, the sense of lack of control in their psychological therapy

appeared to be shared by all. Gul for example, expressed the sense of control through the duration and number of her psychological therapy session. She understands that the duration and number of sessions is dictated by the NHS organisation:

'Time is not enough. They say NHS does not approve longer sessions' (Gul, 462)

In fact, Gul also acknowledged the limited control and power held by her therapist in regards to the number and duration of the sessions:

'But I think she did not have much power in her hands... in regards to time of sessions...I think like that' (Gul, line 476)

According to Ayse the confines on NHS with regards to session numbers and durations were dictated by the government:

'I don't think there is enough support from the government' (Ayse, line 1017)

And for Fatma, this was perceived as more intentionally towards foreigners in UK, especially

Turkish people:

'Like NHS did a lot about this...they did a lot of cutting in money...and I think they did it more to our Turkish people... I am aware of this because Turkish people don't know how to ask for their rights' (Fatma, line 321)

Yesim, takes Fatma's view a step further and expresses her experience of racism in her psychological therapy:

'I don't think they would have done the same to an English person. This is racism. You cannot explain it or proof it but you can feel it' (Yesim, line 880)

Yesim even goes as far as reporting racism to have caused her 'trauma':

'I think the reason why I experienced trauma it was because of this racism...I know there is racism' (Yesim, line 902)

Participants sense of being unheard and understood, sense of psychological therapy not meeting their unique individual needs as well as sense of being judged (explored in 'My Pain is Real' superordinate theme) and challenges of being depended on translators might have had an accumulating impact on their general view of psychological therapy. It is possible

that patients may view shortcomings of culturally sensitive psychological therapy as racism and culture discordant encounter between patient-therapist and possible therapist biases to then maintain or confirm this sense of racism in participant's experience.

On the other hand, Hanim considers the system/ organisation set up in general to be accountable for the challenges facing in NHS. She appears to reach to this conclusion based on her experience of the health system in her host county:

'Until you identify the right about you have already caused a lot of damage in your body. That's the system here. But in turkey it is different. You give your money and are seen by the right department without delay. They ask you about your problem and what you need and they give it to you. You get your scan, your MRI or tomography. What ever you want. You get your right treatment and feel better. But here... you go to different places and end up waiting to get the right treatment...' (Hanim, line 729)

Hanim further expresses how this set up in system and organisation is impacting on her treatment from chronic pain experience:

'Like there are lots of contradictions. The system is all over the place. It is all separated and until you put everything together to makes sense..it is just too late. You are now experiencing severe pain and you are in severe depression...you feel overwhelmed and stressed and then you end up in a place you cannot go back' (Hanim, line 840)

In addition, Hanim also expresses the sense of pressure or control from other organisations regarding her health and ability to work:

'Then give me my letter as evidence that you can't do anything so I can resolve my other issues. This side doesn't help me... other side puts pressure on me...they really fucked me up psychologically' (Hanim, line 646)

Overall, there is a shared sense of control by a wider systemic organisation; NHS, government, system step up or benefit agencies. There is a sense of participants feeling not in control of their psychological therapy journey and consequently a sense of helplessness, a sense feeling of 'them' against 'us'. Yesim below extract represents this sense of helplessness clearly:

'But then you think to yourself...what difference is going to make? Everyone will back each

other up...how am I going to prove this? But I experienced this belittling...this trauma for years. Like you can understand if someone is racist straight away...their attitude...the way of looking just gives away everything. When you feel belittled then you start to belittle yourself...they give you that feeling' (Yesim, line 893)

Participants sense of not being in control of their psychological therapy journey in the context of being dependent on interpreters and wider systemic challenges appears to lead to sense of learned helplessness and once again places participants in a position that requires deference to healthcare professionals and an inferior position within their psychological therapy journey.

# 4.6 Outcome of Therapy

'But when I go there and when I start talking I feel better...only until I get back home' (Ayse, line 1282)

Unlike previous superordinate themes, which explored Turkish-speaking women's experience of chronic pain and psychological therapy journey, this theme explores the overall meaning Turkish-speaking women gave to their psychological therapy experience fortheir chronic pain.

All participants experienced their psychological therapy as having temporary benefit, no benefit or making them 'worse' in regard to their chronic pain experience. Gul for example considered her psychological therapy to provide her no outcome. Considering her expectation from psychological therapy was to experience 'no pain', her overall evaluation of the psychological therapy is not surprising;

'Like you don't get any outcome' (Gul, line 511

Fatma on the other hand expresses feeling worse physically following her psychological therapy experience:

'like when I came back home I couldn't even walk...it was like my bones were broken' (Fatma, 238)

Hanim and Ayse on the other hand experienced psychological therapy as having temporarily benefit during their sessions but this ended up with them feeling worse both physically and

emotionally:

'then I get really bad headache at home because I have tensed myself throughout the consultation...' (Hanim, 760)

Zerrin on the other hand expressed feeling worse of psychologically, especially after her perceiving the message from her therapist about nothing much can be done for her chronic pain experience:

'my psychology was upside down...they made me feel worse' (Zerrin, 311)

Considering the suggestion for a psychological therapy were made by professionals following previous failed interventions, it is understandable for Zerrin to feel worse after being told by professionals that nothing much can be done for her chronic pain. There can be multiple meanings attached to professionals' comment but what appears to be significant the way Zerrin make sense of that comment. I get a sense that she interprets this comment as an end point as if there is no solution or cure based on her expectation for psychological therapy which leads to sense of hopelessness.

Yesim, in fact expresses this sense of helplessness directly when she experiences pain again following her psychological therapy session:

'So when you experience that pain again...you feel very hopeless. Like you feel ok when you are in the room but then when you leave you have the pain again. It was very hopeless place to be ...[sighs]...the hope is only temporarily but even that is good for me....i don't know it is good for me' (Yesim, line 487)

The perception of the failed psychological intervention appears to have an influence on how patients then see themselves in the process. For example, Yesim appears to consider herself to be responsible with the failure of her psychological intervention:

'But at some point I did really question myself...because...because talking to her made me feel like this...like I can do it...that I can go out. So when she said stuff like this...so I thought maybe it is me...maybe the problem is me' (Yesim, line 345)

Yesim further expressed the challenges of the language proficiency and difficulty in them not being able to explain themselves to their therapist, which she appears to perceive as feeling blamed and punished by their therapist/ system:

But for some reason I get the blame and punishment. And because I get the blame...I can't explain myself fully to the person opposite because I cannot speak the language' (Yesim, 619)

The shared feeling of therapy not being beneficial for them especially in regard to their pain experience may in fact make participants question the purpose of psychological therapy and confirm their distrust the psychological model for their chronic pain experience. It may further confirm their cultural belief regarding the medical model and the mind/body separation and place them back into a position that limits collaboration within the patient-clinician encounter.

# 4.7 Analysis Summary

In summary, the analysis is sought to present the key aspects of psychological therapy experience for Turkish-speaking women with chronic pain.

Participants in this study experienced a loss of self with their chronic pain. This loss appears to be projected via the emphasis on bodily expressions of chronic pain experience and leads to a sense of desperation for pain free life.

Participant's desperation for pain free life appears to lead to the acceptance of referral to psychological therapy by an expert, without challenging or questioning. This positionining of participants appears to be further maintained by the experience of treatment failing to acknowledge participants understanding of chronic pain, lack of acknowledgement of individual and unique need and with their sense of feeling judged in therapy. Dependence on translators coupled with the wider systemic control and limitations appears to lead to feelings of learned helplessness and to further the uncollaborative position held by the participants in their psychological therapy journey. This positioning of participants appears to contradict the expectation of the psychological therapy- which is predominantly emphasises partnership and collaboration.

Participants appear to leave the psychological therapy with an experience of not benefiting or feeling worse and perception of therapy failing to meet their needs. This consequently confirms their loss sense of self and sense of desperation which will continue their desperation to be cured by the clinician in their psychological therapy. It is important to

acknowledge the role of systems in the maintenance of participant's position within the psychological therapy.

# **Chapter 5. Discussion**

#### 5.1 Introduction

Within the literature of access and delivery of psychological care for chronic pain in marginalized populations, research evidence that guides treatment guidelines continue to be gathered from empirical and actual data which promotes control, meaning and power. Evidence is also gathered mainly on non-Hispanic black and white patients who informed differences in pain appraisal, beliefs about pain and their coping strategies. Literature also appears to focus more on experiences with chronic pain treatments specific of pharmaceutical and physiotherapy interventions. However, this study puts forth an alternative view, having chosen to explore the meaning that Turkish-speaking women give themselves to their psychological therapy experience for chronic pain. Its findings make an original contribution to the field as, while a few qualitative studies have touched on psychological interventions of chronic pain (Burton & Show, 2015), this is the first investigation in UK to explore ethnic minorities or non-English speaking groups psychological therapy experience for their chronic pain.

In this chapter, I will delve deeper into the study's themes, analysing how they support existing theory and research while also highlighting areas where new understandings or problems have surfaced. I will then assess the study as a whole, taking into consideration its different strengths and weaknesses, and reflecting on my role in each stage of the process. It is my hope that the study's findings will be provide useful information on patient characteristics that will predict the responsiveness and explore ways to promote access to interdisciplinary and personalized psychological pain treatments to optimize the use and access of currently available treatments known to be effective. With this in mind, several therapeutic practise ideas and potential research opportunities are also suggested.

## 5.2. Contextualizing the Analysis

#### 5.2.1 Living with Chronic Pain

The findings showed that participants preferred to focus on their physical/ and bodily symptoms to communicate their chronic pain. All made references to their senses, touching,

sensing and seeing when describing their pain. This common experience can be understood in the context of cultural influences in pain perception and expression which was identified in the early work of Zborowski (1952) and suggested that the meaning and expression of pain and suffering to be socially learned with cultural significance. Culture has shown to have conditioning influence in forming the individual's patterns of responding to and expressing pain (Lovering, 2006). As Lasch (2000) puts it 'Culture has a vital influence on illness behaviours, health care practices, help-seeking activities, and receptivity to medical care interventions' (p.18).

Van Moffaert & Vereeckon (1989) has pointed out that cultures where psychological complaints and feelings of depression, anxiety and guilt are less publicly acceptable and involve high degree of personal responsibility appear to develop mechanisms such as bodily complaints to get the attention they require from their community. According to Akar and Eke (1994) these cultures discourage open display of emotional distress and encourage more physical complaints as they are known by the individuals in the culture to be more acceptable. Interestingly, this 'somatisation' of distress in European or American culture is regarded by some clinicians as lack of psychological understanding or inability to verbalise their pain, whereas somatisation in Mediterranean cultures is regarded as body's acceptable expression of the stress of the mind (Blacking, 1977).

It was also noted in this study that body/mind separation was not as prominent and there appears to be more focus on the behavioural and functional limitations on one's life due to physical pain. According to Yazar & Littlewood (2001) Turkish and in other Mediterranean cultures illness is not distinguished into separate mental and physical spheres. For example, steambaths are often used to treat psychological distress and evil eyes are usually ascribed as the cause of physical illness (Mirdal, 1985). Religious medicine is widely used, and it is grounded in the cosmology of Qur'an and in local concepts which articulate notions as sprits and evil eye as agents of disease, and a logic of healing from a touch of sacrificed man (Littlewood & Dein, 1995). Classical Greek Humoural Medicine continues to be influential in illness perception and communication within Turkish Culture. According to this, illness is seen as the imbalance in the bodily humours such as dry/wet or hot/cold (Good, 1977). Pain is therefore used in these cultures as a physical metaphor to express emotional distressand bodily complaints appear to be the preferred form of communication to appeal for helpin the community (Yazar & Littlewood, 2001).

Some participants also preferred to use medical terms or diagnosis when explaining their chronic pain experience. Although this may be their preferred sense of communicating their distress, it is also possible that this is the language they may intentionally choose to use to seek the validation and acknowledgment for their pain experience. Turkish culture is agreed on housework being a women's role, while the man usually works only outside the home (Kagitcibasi, 1982) and it is noted that it is only when women get physically sick that she receives help in home and childcare. Hence, use of medical terms and diagnosis may be providing this validation for their 'physical sicknesses' to appeal for help. For example, Yesim reported that she gets support from her children with her day-to-day activities and disclosed her fears of how she would manage if her children one day move out. This was consistent with Moffaert & Vereecken (1988) findings of their study that bodily complaints in Mediterranean people can be viewed as an appeal for practical support. It is also consisted with the behavioural approaches where it suggests that the pain behaviour is maintained by secondary gain, where external reinforcement promotes the maintenance of chronic problem (Fordyce, 1976).

Interestingly, all participants in this study have described a change in their sense of self in the context of their reduced activity or not being able to engage in their given role duties. Similar findings were also found in Yazar & Littlewoods (2001) study where many of the informants of the study recognised their main problem caused by their illness as inability to work whether in housework, job or childcare and emotions become divided into 'good' and 'bad' with the bad emotion being associated with the pain. Hubner (1984) describes this sense of isolation by 'to be in pain, involved being separated, being alone, and adds 'at no time we are more alone than when we are in the grip of pain' (P.447).

Just like emotions become divided into 'good' and 'bad', it was apparent from this study that participants also tend to divide their sense of self according to different time phases in the context of their chronic pain experience. Most noticeably into sense of self prior chronic pain, sense of self with chronic pain and their sense of self in future with chronic pain. This fragmentation of self as well as comparisons to past and others was also observed in Smith and Osborn (2015) study to explore the personal experience in chronic pain. Thereappears to be no fluidity of acknowledgment of transitions between these different phases of sense of self. There was an attempt by all participants to hold on to their past, their life before chronic pain. They discussed in detail what they were capable of doing in the past; expressing a great

deal of loss compared to their current functioning and abilities and how they predict their future based on their current being. According to Smith and Osborn (2015) past memories are recalled to help maintain some morale in the present, manage their distress and uncertainty and help to construct a personal meaning of their chronic pain. As Van Moffaert and Vrancken (1989) described it, participant's chronic pain appeared to becomes their mode of being or their which they now had to be endured on a daily basis (Smith and Osborn, 2015). This was consisted with Charmaz (1983) descriptions of chronically ill individuals, who struggled to lead valued lives and maintain definitions of self which were positive and worthwhile. Just as Bueno-Gomez (2017) suggested, their current sense of self becomes meshed in complaints about life. This was observable in this study where in general participants appeared to be dissatisfied with life, disappointed with doctors and generally feel angry with life which ultimately led to participants to experience a sense of 'self - alienation' (Bueno-Gomez, 2017) and a further need for validation and acknowledgment of their physical and bodily symptoms. Although the aim of the study was not to explore the phenomenological conceptualization of their chronic pain experience, all participants disclosed their experience of chronic pain possibly reflecting on how their experience of chronic pain has become the centre of their life. The need to reconstruct a self-concept in the impact of chronic illness has been a common theme in many previous studies (Kelly, 1992; Yoshida, 1993). This conceptualization provided a viable alternative to dualism beliefs and a mechanical knowledge of the human body (Wilkinson, 2005). It has aided in the process of 'embodying the mind' by emphasising the role of the body in human experience, as well as Frenkel's concept of 'minding the body,' in which the body is capable of meaningfully responding to demanding situations (Beueno-Gomez, 2017). Here, meaningfully responding takes into account the individual's cultural, societal, and psychological elements, confirming the existence of various pain experiences. As Kleinman states, 'It is critical to avoid essentializing, naturalising, or sentimentalising suffering'.

This superordinate theme therefore reflects the quotation by Bueno-Gomez (2017) where he states: 'There is no single way to suffer; there is no timeless or space less universal shape to suffering'. This study therefore once again confirms that there is different perceptions and experience of chronic pain depending on the individual and their culture and background. It is therefore more important for this to be taken into consideration especially for individuals from different cultures.

## 5.2.2 When path crosses psychology

Another central feature that emerges from participant's accounts was that all were referred via an internal or external professional who clearly hold an expert authoritative position following their failed previous interventions. Although they admitted taking part in conversations regarding the referral, participants commonly reported feeling this referral to be expert-led and they felt the need to agree out of desperation to end their chronic pain experience. Cultural norms that required deference to healthcare professionals were observed in some ethnic minority groups (Rocque & Leanza, 2015). This was consisted also with the findings of Board et al (2020) study where participants reported perceiving clinicians as 'professionals' or 'experts' and they believed they should follow the advice of these professionals. This expert led interaction led to limited engagement in decision-making process regarding their care, some even reporting a sense of guilt if they wavered from prescribed treatment (Board et al, 2020). Which is clearly is in jeopardy with the aims of psychosocial model for chronic pain as most focus on active participation, collaboration and commitment (Kumar, Nkansa-Dwamena & Throne, 2014). Ferguson and Candib (2002) argued that the cultural beliefs alone can impair communication and shared decision-making in intercultural patient-clinician relationship.

Psychological therapy for chronic pain is an attempt to challenge the classical medicine and Cartesian view of pain as defined only in neurological terms and acknowledges the suffering by considering the person with pain as psychophysiological and sociocultural beings. Pain is defined as a process of somatosensory perception as a mental image in the brain that is followed by unpleasant emotion and changes in the body (Bueno-Gomez, 2017). It is now widely accepted that cognitive awareness (Boeyink, 1974), interpretation (Cassel & Symon, 2004), behavioural dispositions (Damasio, 2006), cultural (Rey, 1995) and educational factors (Boeyink, 1974) play an important role in pain perception and tolerance of the person. Catastrophizing, frustration, pessimism, self-criticism and pain preoccupation have been associated with the distress of the sufferer of chronic pain (Lefebvre, 1981). As Bueno-Gomez (2017) points out pain is now seen as part of person's life which incorporates various experiences including pain and suffering in the context of person's attitudes, resources for management, person's attachment to life and choices. This is further consisted with the New Horizons report which concluded that the psychosocial model was more effective, especially

for people from BME communities (Kumar et al, 2014). However, the evidence-base for psychological therapy for chronic pain the professionals and experts rely on continues to be driven from evidence-base medicine, as the vast majority of services are commissioned by NHS, that is based on medical model and where pain and suffering were treated scientifically (Kumar et al, 2014). This included pain and suffering to be systematically organised in clinical environments, where patients could be observed and symptoms and disease compared. However, this produced many challenges as the medicine based on observation and objectification of symptoms and experimentally proven treatments fails to take into account circumstances such as culture, educational level, moral or religious believes or personal attitudes and idiosyncratic responses to treatments (Bueno-Gomez, 2017). Participants in this study as well as in the study of Board et al (2020) questioned prescribed treatments, where they appeared to be more comfortable putting forward their own views of treatments in the interviews when not in the presence of the treating clinician.

This criticism on evidence-base medicine came to be known as the 'humanistic turn' which has relations to women's right movement (Arney, 1982), postmodern criticism of medicine (Bauman, 1992) and phenomenological and narrative approaches to the practice of medicine (Bueno-Gomez, 2017). The goal of healing was replaced with care and management of illness which subsequently changed the identity and the role 'patients had in healthcare. The care and management view of pain and suffering positioned patients in a more active role and they were no longer viewed as passive beings waiting for treatment and cure from and expert (Bueno-Gomez, 2017). The modern patient is expected to negotiate the medical decisions as they were no longer seen strictly 'scientific' but also moral and/or political (Bueno-Gomez, 2017). The medical decision-making emphasised cooperation as it valued the personal values and priorities of the person with pain. With this movement, the physician is required to consider non-somatic pain, secondary effects of treatment and personal circumstances. Yet the consideration of personal circumstances appears to fall short when it comes to cultural considerations of a patient. As McLeod (2013) points out personal circumstances of a person is likely to differ according to their cultures concept of self, how their reality is constructed, their sense of mortality, concept of time, and the value they give to their land / environment, their use of language and non-verbal behaviours, belief about healing, expression of emotions and relationship patterns.

It appears from this study that falling short on the considerations of cultural factors challenges

the attempted modern patient position within the therapeutic encounter. For example, every culture is known to have its own understanding of wellbeing, illness and cure (McLeod, 2013). The theory of healing can be based on scientific understanding, as described above, such as in Western industrial nations, or it can be based on supernatural beliefs or traditional/spiritual ways to healing, which may also coexist in many cultures. Hence, expecting western approaches to psychological therapy to be seen asacceptable and relevant to people from different backgrounds would be futileness. For example, it is acceptable within the Turkish culture to perceive the professional as the expert and as holding authority and aligning the responsibility for their pain management to professionals. This view and belief would make it difficult for an individual from Turkish culture to understand the principles of collaboration and partnership within therapeutic relationship. This could be further exacerbated with clinician's racial biases within culture discordant encounter (Copper-Patrick et al,1999) and limited English proficiency (LEP), where Nguyen et al (2005) found evidence that LEP is in general barrier to adequate healthcare. According to Dovidio and Friske (2012) implicit biases of unconscious stereotypes and prejudices that influences behaviour and interaction, to be more prevalent among clinicians in healthcare. This was further supported by the Commission on race and ethnic disparities report (2021) where it argued that the big challenge of our current times was not the overt racial prejudice, as it is building on and advancing from the progress won by the struggles of the past 50 years, but more of an implicit stereotypical and racial prejudice. This leaves the patient to position them naturally within the classical medicine viewing self as inferior in reference to the perceived expert position held by the clinician. As a result, it appears to influence patients coping strategies and their expectation for the care-which has been noted to be cure of solution. For example, participants from the study appears to engage behaviours that reflect the perceived expert position held by the clinician (Jordan et al, 1998), which further explains the common sense of desperation and their expectation for a cure and for individuals to engage in more pain catastrophizing. This then appears to contribute to poorer pain adjustment (Sullivan, Rogers & Kirsch, 2001) that is in conflict with the aims of psychological therapy.

## 5.2.3 My pain is real

The findings of the study highlights that all participants experience their chronic pain as unique experience by referencing to their individual diagnosis, pain locations and day-to-day challenges and their relation to other pains, their emotional wellbeing and their childhood experiences. Although participants appear to acknowledge the holistic nature of their pain experience they regarded this as being unique to them individually. Surprisingly, participants understanding of pain and describing as 'real pain' in this study reflected a more holistic understanding, contradicting with Williams and Hughes (2020) systemic review where 'real pain' was more referred in terms of describing a more biomedical understanding of pain, i.e. 'The pain is real- it's not in my head' (Cochrane Review, 2020).

Zerrin for example talked about her journey to United Kingdom and the challenges she experienced in foreign country and how this has impacted on her mental and physical health. Similar disclosures were also seen in Yazar & Litttlewood (2001) study where participants talked about feelings of loneliness, boredom and insecurity as well as the loss offriends, relatives and sometimes their children as a consequence of their move to UK. Hanim on the other hand related her pain to challenges in her childhood and the emotional impact this may carry. Consisted with Smith and Osborn (2015) study, they showed a strong motivation to make sense of the pain, which has been shown to be a typical response to uncertainty. It was interesting to note that although participants did recognise a unique holistic nature of their chronic pain they were able to express this only via their physical symptoms which appear to be the most acceptable method in their culture. Nevertheless, according to Galenic and Islamic Medicine, the location of a pain has some immediate symbolic significance (Good, 1977). For example, the pain in head is associated with thinking processes; the stomach is known to be associated with feelings of shame and guilt and the reproductive organs with womanhood and manhood. It is possible from this view that some of the related pains disclosed by participants are used as a representation of personal distress related to these types of functioning (Yazar and Littlewoods, 2001).

It appears that participants did not feel a sense of their unique holistic nature of pain experience to be acknowledged which let to conflicts and mismatch in their understanding of individuals challenges and experiences. Although Cassell's Medical Humanism define

suffering as a threat against the 'intactness of a person' (Buero-Gomez, 2017, p.5), it did not make clear what 'intactness' of a person mean and how thus may vary depending on induvial' s background and culture. For example, Svenaeus (2014) challenges this perception of a 'person as a whole' (Bueno-Gomez, 2017, P.5) and emphasis the experiential dimension which acknowledges the life is not a single narrative and different versions of person's experiences are continuously being written from different points of view and thus does not guarantee the wholeness among the Cassell's identified dimensions. Cassell's definition of a person therefore appears to contradict the contemporary theories of the self (Bueno-Gomez, 2017). For example, Freudian Psychoanalysis challenges the idea of autonomous self and argues that self is under the influence of psychological, social and power-relations. Hence Cassell's definition fails to identify the common experiences of suffering. Braude (2012) further challenges the Cassell's assumption that suffering can be communicated. Braude emphasis on the 'truly subjective element' of suffering that cannot be directly communicated via language and 'can and should never ultimately become an object, medical or otherwise' (Bueno-Gomez, 2017, P.6).

Both Svenaeus (2014) and Braude (2012) criticism of Cassell's Medical Humanisim resonates with the experiences of the participants in this study. All of participants reported not feeling validated or heard in their treatment journey, this may be in the formulation or intervention stage. It is possible that intervention's based on Cassell's perception of 'care' considered different dimensions proposed to view the person as a whole but it missed the cultural and existential experience of the suffering of the person. Furthermore, although Cassell's Medical humanism has started to vindicate more holistic views of human being, the evidence base for treatments continues to come from randomised controlled trials which take into account homogenous diagnostic symptoms and experience and misses the subjective and meaningful dimensions of pain, hence missing the person in the suffering leading to negative epistemological and practical consequences (Bueno-Gomez, 2017). The participants frustrations in this study highlighted the dominance and essential weakness of application of unitary or biomedical model in their attempts to conceptualise Turkish speaking women's psychological therapy experience (Smith and Osborn, 2015). In addition, psychological interventions require active participation from the 'patient' and this is expected at a minimal level in terms of communicating their suffering. However, as Braude(2012) pointed out this very subjective experience of suffering might not have the language to be communicated.

Although Cassell's medical humanism challenges the many aspects of classical medicine by introducing the wholeness of the experience, it still appears to fall short in acknowledging the cultural and existential side of the experience. This in turn appears to be perceived and experienced by induvial as interventions not acknowledging and meeting their unique holistic needs and hence challenges the concept of collaboration within the therapeutic encounter (Griffith & Griffith, 1994).

A Sense of being judged was also a very common experience within the sample of this study. This was consisted with the findings in Smith and Osborn (2015) study, where awareness and understanding other people had of their chronic pain was poor and not been judged or believed appropriately. This is likely to be expected if a collaborative relationship failed to be established. All participant's appeared to view themselves as the 'outsider' of the relationship rather than 'us' or as a team. This sense of not belonging and otherness was also observed in Kumar et al (2014) report on Ethnic Inequalities in Mental Health: Promoting Lasting Positive Change Report, 2014). Participant's view of perceiving themselves as 'other' in the relationship can be traced back to the beginning of the medicine becoming science at the end of the eighteenth century with the emergence of clinical evidence base medicine (Bueno-Gomez, 2017). Within this scientific context the pain and suffering were distanced from the suffering of the soul, and patients were placed in clinical environments to be observed and symptoms and diseases to be compared against each other and this required the physician to distance themselves from the 'person' of the diseased to be able to learn the truth of pathological fact (Foucault, 1997). This way disease and body started to be considered to be situated in the bodies and their processed viewed as standardized and universal and this unfortunately gave rise to the current problematic approach in approaching pain and suffering. As Rey (1995) pointed out, this approach did not consider the multiple contributing factors in pain and the relationship between the patient and the physician's influence on the experience of pain. This appears to be further coupled with the individual's cultural beliefs and expectations. Fredman (2007) notes the importance of patient and therapist beliefs and prejudices in influencing the positions taken in the relationship. It is possible that the therapist subconsciously position's itself in the expert position due to being influenced by the power provided by the evidence base medicine as opposed to Anderson and Godishian (1992) approach of viewing 'clients' as experts on their own problems. This 'expert' disclosure of being a professional in the healthcare setting will offer the patient a different position in reference to each other. In this study, it appears that the expert lead position taken by the professional's palaces the participants in a passive patient position. The positioning of the patient is further reinforced by the cultural discourses and emotional positions. Within Turkish culture there is a discourse of respecting the expert and authority figures and discourages them to question or challenge. These discourses in therapist and the participants appear to play out in the therapeutic relationship which influences the expectations, engagement and interpretations about how the person relates to other (Fredman, 2007). Positioning within a relationship (Harre & Langenhove, 1999) also appears to influence the language used and dictate the emotional posture. According to communication theorists, language involves both saying and doing which they named as speech-acts (Cronen & Pearce, 1985). According to Watzlawick, Bauelas & Jackson (1967) each speak act of a person calls for a response, in the presence of others which continue to shape and reform the relationships. Hence the positioning taken up by the therapist and thepatient within the encounter may lead to different perceptions of the other and in the relationship. This may then further be coupled with possible therapist and patient biases within the race-discordant encounters and may lead to sense of being judged which will further confirm patient's inferior position in respect to the professional 'expert' position.

#### 5.2.4 Out of Control and Control within the system

Findings showed that there is a shared sense of lack of control regarding participant's psychological therapy journey. This appeared to be perceived internally though their reliance on interpreters and through a more external systemic influence.

In the United Kingdom, NHS England Guidance for Commissioners: Interpreting and Translation Services in Primary care (2018) Suggesthat clients with a limited command of the English language should be supplied with foreign language interpreters in order to receive consultation and treatment, and not to prevent form them receiving the same quality of healthcare as others. All participants in the study have made use of the provision of interpreters in their treatment. Yet, they all shared the experience of not being authentic or able to express theiremotions via interpreters. Although mental health interpreters have been known to play crucial role in providing clinical support in immigrant population (McLeod, 2013) where they can at times facilitate the establishment of trust and rapport between patient and clinician, at other times it has been shown to create tensions. This is either by interpreters brining their own knowledge, experiences and values or when there is an

asymmetry between their and the patient or clinician's understanding and goals (Mirdal et al, 2012).

Furthermore, when discussing sensitive issues, there may be concerns about being judged (Hadziabdic & Hjelm, 2014), as well as concerns about confidentiality when working with interpreters from one's own community and working with interpreters who may have different political views and allegiances (Tribe, 2009). In addition, introduction of an interpreter into a therapeutic system is also known to shift the dyadic alliance to triadic alliance, creating a more complex relational dynamic. For example, interpreters are given the position of a colleague where their neutrality and integrity are supported. They are also expected to act as a practical andinformative guide for patients within the healthcare system and to be able to read and understand the written information within the health care system (Hadziabdic & Hjelm, 2013). This work naturally changes the relational dynamic and power balance within the relational dynamic. Patients who are from refugee or immigrant backgrounds would be more sensitive to this change in therapeutic alliance due to traumatic backgrounds (Kerbage, Maeeanconi, Chamoun, Brunet, Richa & Zaman, 2020).

Another aspect that is worth considering is the gender of the interpreter. Men and women are known to use language in different ways and have different gender roles (McLeod, 20013) which might affect the communication between the patients and interpreters and how this is then conveyed to the clinician. Together with this is the consideration of class, appearance or attitude of an interpreter which may affect communication. Social class or position is known to imply differences in educational levels, which may influence the everyday language, expressions and verbal ability (Giger & Davidhizar, 2008). Hence, the challenges of interpreters brining their own knowledge, experience and values as well as difference in the understanding and concerns regarding being judged and confidentiality can change the dynamic in the therapeutic relationship. Cultural understanding of gender, gender roles and value given to social status may all have an impact on the power or control perception and experience within the relationship and without a clear rule or policy regarding the language right this could easily lead to patients feeling of losing control and their power regarding their psychological treatment journey with interpreters.

The findings further suggest a loss of control by the wider systemic factors. For example, the number and duration of therapy sessions was one of the concepts all participants appeared

to struggle. They all reported a sense of frustration of not having enough time in order to fully express their difficulties and feelings. Many existential philosophers have pointed at the significance of culture in the experience of time (McLead, 2013). For example, it makes sense for counselling clients to be assigned hour-long appointments at the same time each week in societies where linear, segmented; clock-defined time is dominant. These arrangements just do not make sense in some other cultures, and clients would expect to be allowed to see a counsellor whenever it feels right to them, rather than when the clock or calendar suggests they should (McLeod, 2013).

Participants in this study have also disclosed an awareness of lack of funding or support from the government. This is considered to be actual challenges despite the enormous health and societal impact in the treatment of chronic pain conditions that reduce its burden in the population or health care (Gereau, Sluka, Maixner, Savage, Prince, Murinson, Sullivan., & Fillingim, 2014). Underfunding in pain research has limited clinician's ability to provide most up to date, evidence- base treatments to individuals suffering from chronic pain (Gereau et al, 2014). The American Pain Society (APS) advocates for more funding for pain research and sets up an agenda for further research. APS identifies five goals for future research, one of which is to progress towards 'presentation, diagnosis and management of chronic pain' (Gereau et al, 2014).

The lack of personalized care was also perceived as act of racism by some of the participants in this study. National Health Service first documented racism in 1983 (Commission for Racial Equality, 1987) and studied extensively by Anwar and Ali (1987). Racism was viewed mostly as a personal bias at the time, but a recent book by Coker and Mansfield (2001) highlights the pervasiveness of institutional racism in the medical industry. The existence of 'institutional' or 'systemic' racism was further documented in the Ethnic Inequalities in Mental Health: Promoting Lasting Positive Change Report (2014) and Commission on race and ethnic disparities report (2021). Commission on race and ethnic disparities report (2021) further acknowledges the recent incidents where ethnic minority groups rightly felt down by the Grenfell tragedy and the Windrush Scandal, as well as the disproportionate impact of Covid-19 on some ethnic minority groups.

the 'Stop Rickets Campaign' and the 'Asian Mother and Baby Campaign' and known to be further fuelled by the article in Lancet (Goel, Campbell, Logan, Sweet, Attenburrow & Arneil, 1981). As a result, when problems were recognised as being rooted in 'culture,' solutions were also rooted in 'culture,' with 'culture' being viewed as an unchanging fixed attribute of a group of people. Howitt, Owusu-Bempath & Owusu-Bempath (1994) tracked several expressions of racism in psychiatry and psychology, which were sometimes disguised as 'genetic' or 'cultural' observations and deductions. For example, Leff (1973) theory of emotional differentiation states that '[people from] developed countries show a greater differentiation of emotional states than [do people from] developing countries. Yet, it was the Stephen Lawrence and David Bennet's killings and the inquiries into their deaths that identified institutional racism in police and mental health services respectively. This then lead to pressures in government to provide a more structured response in the relation to mental health to challenge the mainstream understanding about racial discrimination within society and complicity of organisations and systems and introduced the concept 'institutional racism' which led to further enquiries and policy developments to tackle the ethnic inequalities in mental health during 1997-2010, e.g. Inside Outside project (National Health Service, 2003), Delivering Race Equality (Lau, 2008), understanding the concept of 'Circles of Fear' (Keating, Robertson, Francis & McCulloch, 2002) and other action of defence mechanisms operating at personal, organisational and institutional levels (Kumar et al, 2014)

Despite the fact that a considerable energy commitment has been put over the years by practitioners, policy makers and activities to develop provision and improve disparities in this area, in over 50% of studies exploring the reason's for this disparity, continues to identify ongoing 'racial biases' and 'negative stereotypes' (Kumar et al, 2014). For example, Fergusan and Candib (2002) showed that minority patients, particularly those with limited English, were less likely to engender empathic responses from clinicians. Moreover, clinicians has been shown to be less positive, provide less patient-centred care and are less likely to encourage patient participation during interactional encounters when compared with same-race encounters (Johnson, Saha & Arbelaez, Beach & Cooper, 2004). Holloway, Smart, Foresti and Beach (2019) further added that ethnic minority groups were particularly vulnerable to such biases due to widespread negative perception of refugees and asylum-seekers in UK, where they are often portrayed by media as a threat to the stability of community and a burden on healthcare system. Patients' responses to such biases alongside their own biases

as well as 'expert position' biases described above, is likely to compound ineffective patientclinician interactions, leading to erosion of trust and belief in professionals and healthcare and consequently to reduced healthcare seeking behaviour and ultimately to poorer health maintaining the disparity within the ethnic minority groups in healthcare (Board et al, 2021).

Although overt and blatant racism in the mental health field is uncommon at current times, and Commission on race and ethnic disparities report (2021) described UK to be more 'open society', institutional racism is still appears to be prevalent (Marecek, 2021). Racism operates through processes and procedures within the institutions and ways of thinking that underpin it, just as it does in society at large. In this regard, institutional racism in psychiatry and psychology is a big issue. The continuation of widely discussed issues in the past is one form of institutional racism in psychiatry (Marecek, 2021). For example, in Germany racism towards Turkish-Muslims is muddled with anti-Muslim sentiments. Racial assumptions and prejudices often combined with misunderstanding, impact clinical practise and therapeutic alliances, which are a serious problem in both clinical practise and research (Fernando, 2021). Commission on race and ethnic disparities report (2021) makes number of recommendations to improve the health disparities within the ethnic minority communities- one of which is to look beyond race to other causes of disadvantage and to view the issue from a more holistic and intersectional lenses.

#### **5.2.5 Outcome of Therapy**

One of the shared and common experiences from participants in this study was that they either got a temporarily relief from therapy- whilst in therapy room by talking or no benefit or for some it was an experience that made them feel worse both emotionally and physically. This was consisted with the findings of Board et al (2021) study on trauma-survivors of chronic pain, where experience of unsuccessful treatments left participants confused, frustrated and hopeless. Sense of helplessness in their journey at some instances appears to lead them to blame selves for the failure of the intervention. This sense of blame was also reported in Smith and Osborn (2015) study, where participants considered themselves to blame after the best efforts of others to fail to manage their chronic pain. One possible explanation of this could be related to the racial/ethically discordant patient- physician dyads. For example, Schenthaler et al (2014) found no change in blood pressure control among African-American

patients in racial discordant patient-physician dyads. Whereas on the other hand White patients receiving care from race concordant physicians were more likely to report better medication adherence, implying the presence of possible implicit bias in healthcare (cited in Board et al, 2021).

Furthermore, chronic pain is known to be linked to societal stigmas and prejudice (De Ruddere & Craig, 2016). As a result, chronic pain becomes more than a health issue; it should be understood as a social issue of equity and justice linked to discrimination and structural violence in social situations (Frenkel & Swartz, 2017). For example, social trauma resulting from experiences and impacts of racism and colonization (Green, Anderson, Baker, Campbell, Decker and Fillingim, Kalauokalani, Lasch, Myers, Tait, Todd, Vallerand (2003), the stigma and lack of responses to mental health issues (Hooten, 2016), misogyny and intimate partner violence (Ford, Giboe, Wuest, Varcoe, Davis, Merritt-Gray, Campbell & Wilk, 2009) among other challenges has been shown to contribute significantly to the experience of living with chronic pain (Wallace et al, 2021). Hereafter, if the above challenges are not considered and incorporated in the treatment of chronic pain, it is likely for these interventions not to feel tailored according to them and meet the unique needs of individuals. According to Shaw, Rosen and Rumbold (2011), a lack of integration of healthcare is not a new finding and that better person-centred and coordinated care has been a priority for the UK NHS for many years. There also appears to be paucity of research into understanding the manifestations of unique mechanisms of systemic racism in the treatment of chronic pain and in society marginalized groups to inform clinical practice and policies to enable practice meeting the needs of individuals (Wallace et al, 2021). Trost, Sturgeon, Guck, Ziadni, Nowln & Goodin (2019) showed that patients with chronic low back pain to report greater sadness and disability outcomes following perceived injustice in their treatments.

Bishop, Yardley & Lewith (2008) on the other hand focused on different appraisals of health care based on their patient's different healthcare experiences. Participants in this study reported to have both healthcare experiences in Turkey and in UK and some made direct comparisons. Furthermore, there are also concerns regarding whether ethnic minority groups understand the Western meaning of self-management, which is commonly utilised in psychological therapy interventions as part of chronic pain management. It appears that these comparisons as well as repeated encounters with no improvements in pain led to

disappointments, reduced trust influencing adherence to treatment and lack of engagement and their perception regarding the outcome of the intervention (Board et al, 2021).

## **5.3 Evaluation of the Study**

The study set out to explore the experiences of Turkish-speaking women undergoing psychological therapy for their chronic pain. Chronic pain is considered a public health concern since it is the most common, disabling, and costly public health disease. Multidisciplinary pain treatment programmes, which frequently include psychological therapy, have been shown to improve health-related outcomes for persons with chronic pain, including pain severity. However, the research that guides these psychological interventions continues to be based on empirical and real-world facts, which fosters meaning and power control and falls short in considering the racial and ethical disparities in the experience of chronic pain and their treatment journey.

The current study aimed to address this gap by exploring the perspectives of Turkish-speaking women undergoing psychological therapy for their chronic pain in order to enrich current understanding of treatment journey in marginalized groups and to gain a better insight into the meaning of psychological therapy from their perspective. Using IPA, a number of key themes emerged from the accounts of participants. Findings of this study highlighted the complex, interactive relationship between participant's pain, cultural understanding of pain, healing and treatment, psychological distress and wider social difficulties, all impacting their ability to access and engage effectively with the healthcare service. These difficulties were compounded by lack of service integration. Overall, I believe the study achieved its objectives, albeit with certain limitations, which will be discussed further below.

#### 5.3.1 Strength and Limitations of Study and Avenues for Future Research

There were number of strengths and limitations identified for the current study. One of the most apparent limitations was in the sampling. The group of women who were interviewed may not have been homogenous enough. First of all, some of the participants appeared to have psychological interventions for their pain before or they were familiar with psychological interventions for their other mental health problems in different settings while for other

participants it was there first time in psychological therapy. Their understanding and expectation therefore varied. Participants also appeared to have different varieties of chronic pain diagnosis and their pain experience was experienced in different body parts. This difference was not factored in for this study. Upon reflection I can now understand that this can influence a person's understanding and management of pain and there familiarity with treatment and services. The kind of psychological treatment was also not factored in this study. Although the aim of the study was to explore participant's lived experience of psychological treatment in general without exploring on the possible change processes of specific treatment approach, the model of intervention may have had asignificant influence on participant's perception and experience of the treatment. Another sampling limitation can be considered as the ethnicity of the participant's. There were four Kurdish and two Turkish speaking participants in this study. It is possible that there may be subtle cultural differences and their reasons and experience of moving to UK might have been different which can directly or indirectly influence their beliefs and experience about pain and the treatment. For more valid and reliable study, the group needs to be more homogeneous.

Another limitation of this study was that the study focused on one NHS pain clinic in UK with a specific way of working and with a small sample. This may have not yielded comparable results to other pain clinics within UK. Furthermore no other study of this kind in UK exits, it is therefore not possible to ascertain whether findings are typical. Therefore, further research is needed in different pain clinic centres in UK on a larger scale to determine whether perceptions and experiences of participants differ. Furthermore, recruitment via a healthcare professional, into a study examining the healthcare experiences, carries the risk that patients might be selected on the basis of likelihood of holding positive views about the service. Although every effort was made to mitigate this through recruitment process, there is a possibility of this interfering with the trustworthiness of findings.

Absence of male comparison group can be seen as another limitation of this study. Previous research indicates differences in experience and explanatory models within genders therefore it is possible that there may be gender differences in the experience of psychological treatments for chronic pain. Further research in male's experiences can therefore provide additional information that would be valuable in conjunction with, in comparison to, or separately from studies investigating women's psychological therapy experience for chronic pain.

Methodological limitations were also identified. While IPA has enabled to provide a detailed description of participants lived experience of psychological therapy experience for chronic pain, which reflects the individual's lifeworld, it cannot explain social processes and it does not assume generalisability. Grounded theory can be further performed to understand some of the processes within the phenomenon, for example, participants commitment and engagement with therapy and unlike IPA it assumes to be more generalizable based on theoretical saturation. A mixed methods study would have created more robust findings enabling a more detailed qualitative exploration.

A key strength of this study is that it has focused on service user's experience, offering participant's an opportunity to tell their story and have their voices acknowledged. This was achieved through the 'detailed and inductive approach of IPA, with its roots in phenomenology and hermeneutic enquiry' (Eatought & Smith, 2006, p. 496). This has added to the evidence base by providing the layer for the 'real' level evidence and contributing to the more Casell's (1982) humanistic medicine. Furthermore, it has contributed to psychological research and mental health policy that is committed to involve service user involvement as essential component for matching the person to psychological therapy and service delivery at all levels. It is also contributing to Naylor, Das, Ross, Honeyman, Thompson & Gilburt (2016) identified area that required improvements in chronic disease management within theintegrated care programme. I would therefore argue this research to be timely, original and responded to current need in literature and service delivery. I propose that further research is conducted in this area to build a picture of this phenomenon from a broader perspective to enable a more universal understanding and contribute to evidence-base with 'real' level evidence that captures the socio-cultural context.

Another strength of this study was the age of participants which was not factored in but contributed to the homogeneity of the sample. With coincidence the age of participants fell in the range of 45-55, this might have at least kept the sample homogeneous in terms of the generational point of view.

Findings from this study led to more questions to be raised, creating further need for research. As Vassilev & Pilgrim (2007) remind us: 'there is no single theory that can tell us everything about a phenomenon; the best we can hope for is to zoom in and change the angles of our observation to improve our understanding' (p, 350). I hope that the findings of this study have given experts and psychologists a new perspective on the phenomenon, as

well as suggestions for clinical practise while working with this group.

#### **5.3.2 Implications for Practice**

The results from this in-depth qualitative study ass an alternative to the perspectives on the Utilisation of mental health services within the ethnic minority groups, as well as expanding the existing literature on the lived experience research.

Considering participants' narratives, this study can make the recommendation to offer psychological therapy in the native language, when possible, to decrease the difficulties observed within the culture-discordant interactions, clinician and patient biases and the communication difficulties. This may require services to improve the diversity in their workforce-which is also listed as a recommendation in both Ethnic Minorities in Mental Health: promoting Lasting Positive Change (2014) and Commission on Race and Ethnic Disparities Report (2021). If an interpreter is to be used, professional interpreters should be used, not only to translate what the clinician or the patient is say to one another, but also as a cultural guide for both. This can be ensured by to having all interpreters obtain appropriate training, qualifications. Regional dialect, background, religion, gender should also be accounted for where possible, although Turkish women in this study showed incredible resilience in the face of great adversity, instigating meaningful change in the care of chronic pain within this population requires services to strive to deliver a better integrated care by taking a more holistic approach in understanding their chronic pain, where medical and psychological understandings are integrated and clearly explained to their patients. To ensure appropriate understanding and to facilitate shared-decision making between clinician and patient's follow-up questions should be incorporated, as well as rephrasing words during interaction, summarising the understanding of patients accounts. Clinicians should be aware of the possibility of trauma or torture within the population, and in an event to aid disclosure and facilitate appropriate management. It is therefore imperative to establish trust and explore the likelihood to possible exposure to physical and psychological assaults. Williams & Hughes (2020) also recommend clinicians to have an awareness of the likelihood of torture/ trauma being carried out in the patient's country of origin, and if so, to plan to minimise likelihood of flashbacks by providing a calm atmosphere, detailed explanation of plans and obtaining fully informed consent and empowering patients' participation in the

treatment process. The invitation to disclosure is usually a relief for the patient and demonstrates respect and concern, and appreciates the complex interrelational aspect of chronic pain.

Clinicians should also reflect upon the potential for unconscious biases to influence their practice, while employing bias-reducing strategies such as deliberate perspective taking and individualisation. Treatment should be evaluated, not only for pain relief or management but for aspects of quality of life, such as social support, community involvement, general health and of course, distress.

## 5.3.3 Significance for Counselling Psychology

Psychological research and current UK Mental Health and Integrated Care for Mental Health and Physical Health demonstrate a commitment to involve service user involvement as an essential component for matching the person to the psychotherapy (Paul, 1969) and to enhance the current evidence-base practice. Counselling Psychology takes a more holistic approach to understanding the development and maintenance of human distress and to locate service user's behaviour and experience within a biographical, developmental and social context to fully understand how the phenomenon is being experienced. This therefore enables to achieve the 'real' level evidence that appears to be absent in the evidence base and challenges the predominant role and ideological power within the therapeutic relationship. Counselling Psychologist's Code of Ethics and Conduct (BPS, 2018) recommends Counselling Psychologists to have a responsibility to ensure that the power of influence is probably managed. It is hoped that the findings of this study offers some power to service users via their voice in this study and will inform Counselling Psychologists and other health professionals about how to work with this population. The implications of this study are, therefore, of particular interest and significance to Counselling Psychology, since the aim is to generate alternative knowledge from the service user's point of view to be applied to clinical practice in a range of setting.

#### **5.3.4 Pluralistic Stance**

The present study has discussed the complexity involved in the experience of Turkish-

speaking women undergoing psychological treatment for their chronic pain. For the women in this study, it emerged that they considered their chronic pain to be unique, and it was their wish to be treated in this way within the therapeutic context, rather than treated generality based on a certain treatment protocol. Women in this study talked about different stages within their treatment journey and different positioning in response to theirtherapists and the different impacts of systemic challenges. Based on these findings, psychologists are advised to explore and consider socio-cultural factors, placing the women's narratives into context, taking into account service user's worldview to be able to offer more individualized treatment. As Mearns & Cooper (2005) points out our understanding of individual's distress cannot be separated from the context. Furthermore, understanding the heterogeneity and complexity of psychological treatment experience for chronic pain in ethnic minority groups, may enable Counselling Psychologists to be mindful of, and to challenge existing cultural discourses within their practice.

Counselling Psychologists are therefore encouraged to adopt a pluralistic stance, drawing on from their expertise from different paradigms, based on humanistic, existential, phenomenological, psychodynamic, cognitive behavioural, narrative, systemic and social constructionist to enhance understanding individuals' uniqueness within the therapeutic encounter. As Cooper and McLeod (2007, p.6) points out 'different explanations will be true for different people at different points in time and therefore different therapeutic models will be most helpful for different clients at different instances' (cited in Milton, 2010).

## 5.3.5 The Reflective Practitioner and Therapeutic Relationship

The BPS, Division of Counselling Psychology Professional Practice Guidelines (2015) outlines the importance of Counselling Psychologists to develop their self-reflective skills, and gain an understanding of their 'use of self' in their professional work. This is further echoed by Blair (2010) who asserts professionals to understand their role in the therapeutic work and how they affect it.

It was apparent in this study that both the participants and therapists were positioning themselves based on their cultural, sociological and professional discourses in relation to other which was further maintained during the formulation and intervention state. Fredman (2007) argued that without reflecting on the position one is taking in relation to the other, there is a risk of mobilising the therapeutic relationship. Whereas a reflective stance in both professional's understanding their position will enable to meet the service users in a relationship of a position of 'tranquillity' (Fredman, 2007) which is inviting the service users to a relationship that is marked with curiosity, mutual listening, respect and focusing on connecting with each other on reflecting by supporting the service user to move from pre-reflective position to reflective position to help service users to embrace new possibilities.

### 5.3.6 Counselling Psychologists in NHS

There is a drive for Counselling Psychologists to take up roles within the public sector and given that this study was based in a NHS setting, it is important to recognise and consider the impact of this context in therapy process (Lemma, 2003). The medical model is prevalent in most NHS services, which are made up of interdisciplinary teams. There are additional waiting times, outcome metrics, management, and organisational politics to consider, all of which have an impact on treatment planning and interventions. Although, professionals intentions within the multidisciplinary team is to provide the most helpful and evidence base treatment to an individual in distress, the reality is that sometimes decisions has to be made in the context of limitations, tensions and lack of resources. When the rationalistic approach to scientific inquiry predominantly justifies the decisions made by those with more power, Counselling Psychologists within a multidisciplinary team in an NHS setting can bring the humanistic view that sees the importance of relationships and shared creating of meaning. Counselling Psychologists presence within the NHS setting can support the team to be more reflective and encourage the co-creation of a resource-full community in people that invite tranquillity among team members to facilitate a joint working of peoplewith different abilities to support the care of the service user.

#### 5.3.7 Dissemination of research findings

Considering the significance of research findings on counselling psychology practice, pluralistic approach, and NHS, it is important for findings to be disseminated to raise awareness and understanding, and to challenge and change practice to meet the needs of

this population. It is crucial that raising awareness should not be limited only to clinicians or academics and findings and recommendations to further reach research and general population. For research findings to reach academics and clinicians, the findings can be published in health psychology journals, to improve the profile of qualitative research, and especially phenomenological approaches, these journals can be specifically targeted- for example, *Patient Experience Journal*. Findings can further be presented at national conferences or meetings of professional associations, and disseminating in NHS trusts website.

For findings to reach research and general population, findings can be shared on local radio for both English and Turkish speaking population. Hosting health promotion events at local community, cultural and health centres will enable to reach larger number of audiences.

#### 5.4 Reflections

## 5.4.1 Reflection on Analysis

The IPA method of analysis was chosen because it was deemed the most appropriate approach to answering the research question and generating the type of knowledge I hoped to gain. It attempted to bring together critical realism and contextual constructionist epistemology to produce an account of subjective experience of individuals. This approach recognises that knowledge is local, provisional, and contingent, and that different perspectives on the same phenomenon might yield different interpretations. This was apparent in this study where different viewpoints, understandings and perspectives emerged from the narratives of Turkish-speaking women. However it is important to note that some participant's focused more on the descriptions of the experience and appeared to struggle to express emotions, thoughts, perceptions in order to communicate the texture of their experience (Willig, 2001). In these instances I was careful to consider contextual factors and be mindful of not to allow my own assumptions and experiences to influence my interpretations of the analysis. As suggested by Smith et al. (2009), throughout the analysis stage I used the method of analysis as a guide rather than asstrict instructions and gradually enjoyed the 'openness' and flexibility of the approach. The approach provided me the opportunity to overcome uncertainty, manage my dependence on specific protocols and instructions and gain confidence in trusting my interpretations in making sense of the sense making of my participants. Analysis stage of the study hasdeveloped me into a confident researcher with a confidence in her interpretations and organisation of themes and categories.

## 5.4.2 Reflections on my Influence on the Research

Willig (2001) acknowledges researchers influence in shaping the findings of the research as imperative in qualitative research. In this section, I would like to consider how I have being involved in the shaping of this research. I believe my position as a 35 year old Turkish female, mother; a researcher and as a trainee Counselling Psychologist working in NHS for the last twelve years, as well as my epistemological stance has influenced the data collection and analysis.

Despite my decision to not to disclose my dual role at the pain clinic unless promoted, I believe many participants assumed I was part of the clinic. However on the other hand, being Turkish and participants opting out to conduct the interviews in Turkish might have also led to an assumption from participants that I was part of them. This was apparent in some of the interviews where they disclosed feeling more confident in speaking to me during the interview process than they ever did with their therapist during their therapy sessions. Most attributed this to language difficulties and cultural differences. At the same time it appeared that they were careful in choosing their words and not to appear as being judgmental and ungrateful of the services they received. I believe unintentionally I have put the participants in a position of incongruity and tension. Interestingly, as a researcher I also found myself feeling incongruent and tense within my dual role as a researcher and practitioner as well as my identify as a Turkish researcher. There were times where I felt closer to participants, not some much in terms of their experience of chronic pain but in terms of the cultural similarities, with the challenges of moving and adapting to UK and navigating through a foreign health service, whilst at other times I was drawn closer to pain service due to my understanding of the service delivery, psychological theories and interventions. Reflecting back now while writing this section of the thesis, I come to realization the impact of this 'transference dance' (as I would like to call) on the positioning of ourselves with the relationship during the interview and the influence of this on the data produced by the participant's narrative. My lack of experience on IPA research and in general in my ability to reflect during interview stage, at the time of interviews for this study, therefore might have influenced the data I collected and subsequently analysed. Now with more experience in being a reflective practitioner, more experience in research and skill (and hindsight), I believe I will be able to gather richer data from participants which will influence my overall findings of any research. These observations emphasise the inevitability of researcher influence on the study process and results. Although the impact is unavoidable, it must be acknowledged as a vital element of the research process and findings.

#### **5.4.3 Reflective Statement**

The beginning of this study was marked by anxiety, uncertainty, and doubt in my ability to navigate this massive task of planning, collecting data, analysing, and accurately representing the voices of study participants; perhaps in some ways resembling the uncertainty women face during their treatment journey. However, unlike the women in this study I was fortunate enough to be supported by my supervisor, colleagues and peers to keep me on track and helped me through their understanding, support and guidance to find my way through and encourage me during the challenging times.

Due to some unfortunate personal circumstances, I started my research journey with very low confidence and strong ambivalence and challenge in balancing the scientist- practitioner role. I had to lose my identity as a women, mother, scientist- practitioner and gradually reborn a as women, mother, a scientist-practitioner and a new me as a whole. This required a lot of hard work, patience and determination. As a result there was a gap between my data collection and data analysis and write up of this thesis. By the time I started to work on my analysis a new me was emerging; a more resilient and confident women, mother and a scientist- practitioner, a me that valued voices to be heard more than ever. During the analysis stage of the research the scientist-practitioner gap in me narrowed as I gained moreinsight into qualitative research, and having being working as a trainee (unfortunately not being treated as trainee after a while due to demands in services in response to covid-19 pandemic) counselling psychologist within a specialist mental health service developed my confidence in my identify as Counselling Psychologist. Gradually I found myself growing into my role as a practitioner in my work-setting and researcher role at home whilst working on my thesis and learning to enjoy the process and emergences of knowledge from the participant's narratives.

The experience of listening to such detailed life accounts, both at work and through the recordings of interviews and revisiting the transcripts was immensely rewarding even at times it was more of a struggle to switch from a day long practitioner role into researcher role at home in the evenings. I felt privileged in my role as a scientist-practitioner for my clients as well as my participants to place their trust in me, allowing me to share their inner worlds. Discovering my participants' perspectives in their raw form has been both enlightening and humbling, shedding light not only on the positive and negative aspects of therapy, but also on the finer nuances of their experience as influenced by their world of objects, relationships, language, and culture. This underlined to me the difficulties of having the time to reflect on clinical practise or receiving thorough feedback to inform practise. Theuse of qualitative questionnaires as a means of gathering feedback on a patient's experiencewith a service restricts the amount of information that can be offered, and this study once again demonstrated the value of having this reflective space.

During this the research and thesis write-up process and my clinical experience within NHS setting, my hermeneutic reflection evolved and developed which led to new ideas, awareness and treatment recommendations to emerge. I gained confidence in listening to what participants' words actually meant, attempting to engage in silences, posture, voice, and speech changes, as well as words that were not stated, and placing myself in their shoesas I sought to experience what they felt. This enabled me to enter participant's world of shame, fear and helplessness. At times this was exhausting and heavy, especially after a very challenging day at work followed by home schooling my five year old son. I realized that my response in these times was cut off myself from these feelings and move to a smoother distraction which led to much procrastination episodes during the write up of this thesis. This may also resemble participant's tendency to distract difficult emotions by focusing more specifically on the descriptions of their pain experience. This is something I'velearnt to be aware of in my clinical sessions, since there is a propensity to move away from painful sentiments experienced by my clients and myself in order to make the session feel more comfortable. Furthermore, this project has made me appreciate and respect the tenacity and strength displayed by the women in the study, who may have had to manage and juggle a variety of adversaries in their lives. This understanding informed both my clinical work and my observations outside of my professional role.

As this part of my journey comes to end, a new one begins as I am now undergoing number

of significant transitions in my personal and professional life, in middle of a global pandemic. This results in a renewed sense of insecurity, anxiety, and excitement. Meeting other women, mothers, and coworkers who have gone through similar experiences allows me to learn, share my feelings and experiences, and navigate these transitions. My experience serves as yet another reminder of the importance and power of being heard, understood and accepted. I promise myself that I will continue both in my personal and professional life to advocate for voices to be heard and person's to be understood and accepted. I feel very proud for my research to provide a platform for participants of this study to be heard and I hope they feel they have benefited from this opportunity. I will always hold each of the six women in mind, and hope that this research will encourage and give confidence for them to use their voice more often in their lives.

#### 5.5 Final Reflections

The field of chronic pain management is multi-layered and complex and psychological interventions add another layer to this complexity. Although individuals with chronic pain might appear to be unified group, this research has highlighted that Turkish-speaking women with chronic pain is in fact a group of unique individuals sharing the human condition and basic need to be understood individually, accepted and connected at a mutual level. Underneath the chronic pain lie not only their vulnerability and helplessness but also their perception, relation and sense making to the available treatments which are usually culturally determined. This research has highlighted the central role of cultural and systemic influences on the positioning of individuals and professionals in the therapeutic relationship and how it shapes the person of the patient in the psychological treatment of chronic pain. Further research is needed to understand more about the person of the patient to establish more effective ways to help and treat individual's with chronic pain and to contribute to the 'real' level evidence within the evidence-base practice to achieve a more humanistic approach for the psychological treatment of chronic pain in ethnic minority groups.

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# **Chapter 7. Appendices**

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**Appendix 13-** Extract from Reflective Journal

## **Appendix 1: Participant Recruitment Flyer**



"Turkish Women's Experiences of Psychological Therapies for Chronic Pain"

#### I would like to hear from you if

- ✓ You identify yourself as Turkish women (UK citizen, Turkish passport holder or dual citizen)
- ✓ You are in psychological treatment or completed psychological treatment for chronic pain at the Locomotor Service (Physiotherapy and Pain Service) within a year
- ✓ You are aged 18 or over

### What is this study about?

My name is Gozde Arslan and I am a counselling psychology doctorate student conducting a study exploring Turkish women's experiences in undergoing psychological treatment for chronic pain. Participating in this study might also be a chance for you to have your voice heard in a safe, confidential environment, and perhaps to empower others who share a similar story.

## What would your participation entail?

A face-to-face interview with me, lasting between 60-90 minutes, which will be audio-recorded. The interviews will take place at a time and place convenient for you, and your participation will remain confidential. You will have a right to withdraw your participation from this study at any point. You will be offered a voucher of £10 as a gesture of appreciation for your time.

#### Contact me

If you think you may be interested in participating, or you would like more information, please contact me on 020 7040 8755 or email me at: <a href="mailto:Gozde.arslan.2@city.ac.uk.">Gozde.arslan.2@city.ac.uk.</a>This study has been reviewed by, and received ethics clearance through the Department of Psychology Research Ethics Committee, City, University of London [PSYETH (P/L) 17/18 64]. This research is being supervised by Dr Jessica Jones Nielsen (jones.nielsen.1@city.ac.uk)

## Do You Have Any Concerns?

If you would like to complain about any aspect of the study, please contact the Secretary to the University's Senate Research Ethics Committee.

## **Appendix 2: Information Sheet**



Department of Psychology School of Arts and Social Sciences City University London Northampton Square London EC1V OHB

**Participant Information Sheet** 

Title of study: "Turkish Women's Experiences of Psychological Therapies for Chronic Pain"

Thank you for your interest in my project. You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please taketime to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

#### What is the purpose of the study?

There is evidence suggesting that psychological treatments are underutilised for chronic pain especially among ethnic minority groups. The purpose of this study is therefore to gather information on psychological treatment experience of Turkish-women to provide abetter understanding of the cultural determinates and insights into the psychological services for chronic pain.

This study will form a part of a doctorate in counselling psychology that I am undertaking at City University.

Why have I been invited?
You are being invited to take part in a research study because:
You identify yourself as a Turkish women (over 18 years old)
You are or have experienced chronic pain, and

You have either completed, dropped out or are currently undergoing psychological treatment for your chronic pain at Pain service.

#### Do I have to take part?

Your participation in this study is voluntary, and that you are under no obligation to take part. If you decide to take part, you will be given this information sheet to keep and ask to sign a consent form. You are still free to withdraw at any time and don't need to give a reason. You will not be penalized if you choose to withdraw. If you complete the interview you have up to 4 weeks to contact me to withdraw your consent where upon any data already collected from you will be destroyed-voice recordings will be erased and any hard copies will be shredded.

### What will happen if I take part?

If you decide to take part in the study you will be invited for an interview at a time and date that is convenient for you. Upon arrival you will be asked to confirm that you have read this information sheet and will be asked to sign a consent form. There will be one interview session lasting up to 60-90 minutes and they will usually take place in the Locomotor Service. In an event that it is difficult for you to get to the Locomotor service, the interviews will take place at an alternative, mutually agreed venue. During the session I will interview you about your psychological treatment experiences. The questions will be open-ended and non-directive to provide opportunity for you to speak openly about your experiences. You can choose to express yourself in Turkish or English. The interview will be recorded. Following each interview, you will be given the opportunity to discuss any questions or concerns that may have arisen during the interview.

### Will I be paid for my time?

Travel expenses will be paid if requested and a £10 M&S voucher will be given to you at theend of the interview to show our appreciation for your time.

#### What do I have to do?

You will be asked to attend one interview, during which you will be asked to sign consent form and keep a copy. We will have a discussion lasting 60-90 minutes about your

experience of psychological treatment for your chronic pain. You will only be asked to share experiences that you feel comfortable with. This is your interview and I would like to be guided by you and things that you feel are comfortable to discuss.

What are the possible disadvantages and risks of taking part?

This study does not carry any risks to your health and aims to re-create a supportive environment in which you are encouraged to speak openly and honestly about your experience. However, it is possible that disclosure of personal information may evoke some distress. If this is the case you will be given information about relevant counselling or support organisations in your area.

#### What are the possible benefits of taking part?

Some people find it helpful to discuss their experience in a safe environment. On a broaderscale, the results of this study could benefit future patients and contribute to the under- researched area in counselling psychology.

### Will my taking part in the study be kept confidential?

Confidentiality of participants will be assured: all information collected for the purpose of the study will remain anonymous: each participant name will be changed to ensure full anonymity. Voice recordings from interview will be transcribed verbatim and stored on encrypted computer. Identifiable data will be kept in separate from the data, in locked filling cabinets on Locomotor site. Identifiers will be stored in filling cabinets for the duration of the study but will be shredded once the study is over. The paper copies will be shredded immediately. However, supervisor and the markers will have access to the anonymous electronic transcripts. All identifiable information collected would be withdrawn from the study if you lose capacity to consent during the study. Data which is not identifiable may be retained.

## Information Sharing and Confidentiality

All information you share will be kept confidential. However, if there appears to be risk to self or others or children then I am obliged to break confidentiality for safeguarding reasons. I will discuss with you the action I will propose to take but will be unable to keep the matter

quiet, as it is a legal requirement. I may also consult with my supervisor but we are all ethincally and legally bound to treat this information confidentially.

What will happen to the results of the research study?.

Following the interview your audio recordings will be transcribed verbatim to enable me to reflect and compare with other participants to see if there are any similarities or differences the experience. Anonymity will be protected at all times. After analysis, the findings will be submitted as part of the researcher's doctoral portfolio and may be submitted for publication in academic journals and presented at conferences. Direct quotations may be used, however information will not be attributable to any participants. The data, not the identifiable date, will be kept securely for 12 months to 3 years, in accordance with good research practice. The findings from this study can be posted or emailed to you if you wish.

### What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone xxx. You can then ask to speak to the Secretary to Senate

Research Ethics Committee and inform them that the name of the project is: "TurkishWomen's Experiences of Psychological Therapies for Chronic Pain".

You could also write to the Secretary.

City University London holds insurance policies which apply to this study. If you feel youhave been harmed or injured by taking part in this study, you may be eligible to claim

compensation. This does not affect your legal rights to seek compensation. If you areharmed due to someone's negligence, then you may have grounds for legal action.

#### Who has reviewed the study?

This study has been granted ethical approval from the Senate Research Ethics Committee atCity University. The researcher and research supervisors are trainee and qualified psychologists respectively and are professionally bound to adhere to the British Psychological Society's Code of Ethics and Conduct (BPS, 2009), British Psychological Society's Code of Human Research Ethics for students (HCPC, 2012) and City, UniversityLondon Code of Ethics.

### If you would like more information:

If you have questions about the study or would like to take part, please contact GozdeArslan for specific details

### Gozde Arslan

Trainee Counselling Psychologist Email: <u>Gozde.arslan.2@city.ac.uk</u> Dr Jessica Jones Nielsen,Research Supervisor City University, Email: <u>jones.nielsen.1@city.ac.uk</u>Tel: 020 7040 8755

Thank you for taking the time to read this information sheet.

# **Appendix 3: Consent Form**



## **Participant Consent Form**

**Title of Study:** "Turkish Women's Experiences of Psychological Therapies for Chronic Pain" Ethics approval code: **PSYETH (P/L) 17/18 64** 

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information	
	sheet, which I may keep for my records.	
	I understand this will involve	
	Being interviewed by the researcher	
	Allowing the interview to be audiotaped	
2.	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
	I understand that if there appears to be risk to myself, others or children then the researcher is obliged to break confidentiality for safeguarding reasons. I understand that I will be informed about the proposed actions to be taken.	
3.	I understand that my participation is voluntary, that I can choose not to	
	participate in part or all of the project, and that I can ask to remove myself from the analysis within four weeks without being penalized or disadvantaged in any way.	
1	Lagran to City University Landon recording and processing this information about	
4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	
	Name of Participant Signature Date	
	Name of Researcher Signature Date	

When completed, 1 copy for participant; 1 copy for researcher file.

## **Appendix 4: Telephone Screening Guide**



#### **TELEPHONE SCREENING**

## What I might say:

I wanted to have a quick chat with you on the phone to make sure you understand what this research is all about and just to make sure everything is completely clear. I also want to ensure that you will be a suitable participant, and match the research requirements. You may also find that once we've gone through my questions you feel it's not something you want to continue with which is fine too. If at any stage you have some questions for me please do ask.

Before we start, can I confirm if you have received and read Participant Information Sheet and Participant Consent Form? Is anything unclear? Do you have any questions?

The Participant Information Sheet will be reviewed at the start of each interview and you will be asked to sign the consent form.

I'm looking for eight Turkish individuals who are in treatment or have completed psychological treatment at Locomotor (Physiotherapy and Pain) service for chronic pain and who are willing to talk about their experience of the psychological therapy in detail. Anything you tell me will remain confidential and this research will not have any impact on any remaining sessions you may have left in treatment. All results will remain confidential and this will in no way impact on your treatment plan.

I'm interested in your complete experience of psychological treatment; from the point at which you decided to seek psychological help, how you found out about the psychological therapy, what it was like for you when you first came in for your therapy, what was offered, where you are up to with your psychological treatment, how you perceive your relationship with your therapist, whether it has been helpful or unhelpful, how you felt, what you were thinking, anything at all however small. I'd also like to hear about how things have been for you in general since you started psychological treatment. I'm keen to hear as much detail as possible, even if you think it's irrelevant.

I would now like to ask you few demographic questions to check if you meet the research requirements as a participant. This information will also enable me to put your experiences in context and tell those who read my research about the cross-section of people that the

study involves. All names and identifying information will be changed to ensure confidentiality.

- 1. How would you describe your ethnic origin?
- 2. What is your age now?
- 3. How long have you been experiencing chronic pain?
- 4. Where are you up to in your psychological treatment with Locomotor service?
- 5. Are you receiving psychological therapy anywhere else?
- 6. Do you have any other health or mental health concerns?

### Interview Details:

DATE	TIME	LOCATION

## **Appendix 5: Interview Preamble**



#### INTERVIEW PREAMBLE

Before we begin I just wanted to set the scene for the interview:

- I wanted to let you know that very little has been written about Turkish females psychological therapy experience for chronic pain. So I'm very interested in your personal experiences. As such your responses to my questions are valid and there is no such thing as a right or wrong answer.
- Importantly I wanted to remind you that you can choose to end the interview at any point and ask to remove yourself from the analysis within four weeks.
- I also want to remind you that anything you tell me will remain confidential and this research will not have any impact on any remaining sessions you may have left in treatment.
- There's possibility that some questions may be self-evident but because I am trying to understand how you see things and don't want to assume anything.
- After I've asked you a question feel free to take your time to think and talk- it might be helpful to think of this as a one-sided conversation where I ask you questions and you answer.
- You may also see me making short notes; this is to help remind me of points that could be helpful to return to.





#### **SEMI-STRUCTURED INTERVIEW SCHEDULE**

- 1. Can you tell me about what it was like for you when you were referred forpsychological treatment for your chronic pain?
  - (Prompt): what did you think about psychological treatments before you were referred?
  - (Prompt): have your feelings about psychological treatments changed now that you have received it?
  - > (Prompt): How?
- 2. Can you tell me about your decision in seeking or agreeing for psychologicaltreatment for your chronic pain?
  - ➤ How did you feel when it was offered for you?
  - ➤ How did you feel about the referral process?

- 3. What was it like to receive psychological treatment for your chronic pain at thepain service?
  - (Prompt): What was it like to come to first session?
  - (Prompt): What was it like to come to session after that?
  - (Prompt): What kind of things has come out of being in psychological treatment?
  - (Prompt): What was it like to end your psychological treatment?
- 4. Has anything influenced your experience of psychological treatment and journeyfor chronic pain?
  - (Prompt): How did you feel about being female and receiving psychological treatment for chronic pain?
  - > (Prompt): How did you feel about being Turkish and receiving psychological treatment for chronic pain?
- 5. Has anything changed since attending/completing psychological treatment? Andto what do you attribute this?
- 6. What do you think about the psychological therapy service that worked with you?
  - (Prompt): what did you think about the professionals involved in your psychological treatment?
  - What did you think about the service?
  - ➤ How did you feel?
  - ➤ What do you think were the good things about your psychological treatment?
  - ➤ What do you think were the difficult things about your psychological treatment?

## Summing up question

Is there anything else you would like to add to your experience with psychological treatment for chronic pain that we have missed?

## **Appendix 7: Participant Debrief Information**



#### PARTICIPANT DEBRIEF INFORMATION

Title of study: "Turkish Women's Experiences of Psychological Therapies for Chronic Pain"

Thank you for participating in this research project and telling me your experiences of psychological treatment for your chronic pain. Your experience will make a valuable contribution to counselling psychology practice. I hope you got something from the experience too. I would now like to offer you some time to discuss anything, which may have arisen during the interview process.

Is there anything in particular that you would like to talk about that came from this interview?

Do you have any further comments or questions before we end for today?

If you think of anything after we have finished, I will be available by e-mail to answer any questions you may have.

If you have experienced distress as a result of talking about your experiences and would like further support please contact:

City and Hackney IAPT Derman for the Wellbeing of Kurdish and Turkish

St Leonards Hospital Communities

Nuttall Street The Basement, 66 New North Road

London London N1 5LZ N1 6TG

Tel: 020 7683 4278 Tel: 020 7613 5944

Email: <a href="mailto:services@derman.org.uk">services@derman.org.uk</a>

### **City and Hackney Mind**

8-10 Tudor Road Hackney London E9 7SN

Tel: 020 8525 2301

Right to withdraw from research

Withdrawal from the study is possible at any time within the next four weeks. Importantly due to the fact that data from different participants will be aggregated it may be difficult to

remove the entirely of your contribution from the data if you ask to withdraw consent after four weeks. If you think that you would like to withdraw consent please contact me by email at the address below.

#### **Declaration**

I confirm that this interview has been conducted in a professional manner, that the interviewer took care to check I was not in distress upon leaving and I'm happy for the research to proceed using my material.

Name of Participant: Signature: Date: Name of Participant: Signature: Date:

#### Please note:

If you have any concerns about any aspect of your participation in this research, or any other queries, please raise this with myself (researcher). If you feel that the researcher has not adequately addressed your concerns please raise them with the research supervisor.

Researcher contact details: Research supervisor contact details:

Ms Gozde Arslan Dr Jessica Jones Nielsen

Department of Psychology
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SciencesCity University London

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Tel: 020 7040 8755

Ethics approval code: PSYETH (P/L) 17/18 64

## **Appendix 8: Distress Protocol**

### PROTOCOL TO FOLLOW IF PARTICIPANTS BECOME DISTRESSED DURING THEINTERVIEWS

CITY
UNIVERSITY OF LONDON

Title of study: "Turkish Women's Experiences of Psychological Therapies for Chronic Paint"

This protocol details signs of distress that the researcher will look out for, and the actionsthat will be taken.

#### **MILD DISTRESS**

## Signs to look for:

- Tearfulness
- Voice becoming choked with emotions
- Difficulty speaking
- Participant becomes distracted or restless

### Actions to take:

- Ask participants if they are happy to continue
- Offer them time to pause and compose themselves
- Remind them they can stop any time if they wish if they become too distressed

## **MODERATE DISTRESS**

## Signs to look for:

- Uncontrolled crying, inability to talk coherently
- Panic attack- e.g. hyperventilation, shaking
- Intrusive thoughts

### Actions to take:

- The researcher will intervene to terminate the interview
- The debrief will begin immediately
- Relaxation techniques will be suggested to regulate breathing
- The researcher will normalize the experience
- If any unresolved issues arise at the interview, accept and validate their distress, but suggest that they discuss with mental health professionals and remind participants that the interview is not designed as a therapeutic interaction.
- Details of counselling and therapeutic services will be offered to participants

#### **SEVERE DISTRESS**

## Signs to look for:

• Severe agitation and possible verbal or physical aggression

## Action to take:

- Maintain safety of participant and researcher
- If the researcher becomes concerned for participant's or other's safety, she will inform them that she has a duty to inform supervisor and appropriate mental health service.
- If the researcher believes that either the participant or someone else is in immediate danger, then she will suggest that they present themselves to the local A&E Department.

## **Appendix 9: Psychology Department Risk Assessment Form**

## **Psychology Department Risk Assessment Form**

Please note that it is the responsibility of the PI or supervisor to ensure that risks have been assessed

Date of assessment: 12<sup>th</sup> July 2017 Assessor(s): Dr Jessica Jones Nielsen

Activity: Date of next review (if applicable):

•

appropriately.

Hazard	Type of injury or harm	People affected and any specific considerations	Current Control Measures already in place	Risk level Med High Low	Further Control Measures required	Implementati on date & Person responsible	Complete d
Use of face-	Interviewee	Researcher &	Maintain safety of researcher	Med	If the researcher becomes	Prior to start	
to-face	s could be	Patients from	and participants at all times		concerned for	of research	
interviews	upset by	Locomotor			participant's or other's		
	interview	Service	Contacting patients at clinic		safety, she will inform	Person	
	and		using clinics phone numbers.		them that she has a duty	responsible:	
	become		No personal phone numbers		to inform supervisor and	research	
	aggressive		will be given and only		appropriate mental health	supervisor	
	or violent		university email address will		service.	Dr Jessica	
	toward		be provided.			Jones Nielsen	
	researcher				If the researcher believes		
			Colleagues and supervisor will		that either the participant		



			be informed about when and		or someone else is in		
			where the interview will take		immediate danger, then		
			place.		she will suggest that they		
					present themselves to the		
			Researcher will behave		local A&E Department.		
			inconspicuously, avoid making		ран и постана		
			personal remarks about		If feeling uncomfortable,		
			people or environments, and		trust instincts and find an		
			dress appropriately so as to		excuse to end the		
			not attract undue attention		interview or questionnaire		
			not attract and a attention		interview or questionnaire		
			Protocol (Appendix 8) will be				
			followed if participants				
			become severely distressed				
			during interview.				
			daring interview.				
			If possible check history of				
			violence				
Use of face-	Particpants	Participants	Participants will be clearly	Medium	Research supervisor will	Prior to start	
to-face	and	and researcher	informed about the aims of	(As the	be debriefed	of research	
interviews	researcher	from	study, interview procedure	aim of the	be debriefed	orresearen	
interviews	could	Locomotor	and about how the results will	study is to		Person	
	become	Service	be used after the interviews.	study		responsible:	
	upset by	Scrvice	be used after the interviews.	participan		research	
	interview		There right to withdraw from	ts		supervisor	
						•	
			, ,	-			
						JOHES MICISCH	
	and suffer psychologic al effects		study at any time during interview and 4 weeks after interview will be stated clearly	experienc e of psychologi		Dr Jessica Jones Nielsen	

			Debrief sheet provided with information on sources of support  No deception involved  Protocol (Appendix 8) will be followed if participants become distressed during interview.	cal treatment rather than their condition)			
Sensitive data	Exposure to data or information which may cause upset of distress to researcher	Researcher	Use supervision and personal counselling to safeguard against possible psychological distress	Medium	To keep to researcher boundaries and remind participants that the interview is not designed as a therapeutic interaction.	Prior to start of research  Person responsible: research supervisor Dr Jessica Jones Nielsen	
Sensitive data	Lost of participant	Patients	Anonymity will be guaranteed; all names and identifying	High		Prior to start of research	

	information		information will be changed to ensure confidentiality and recording and transcripts will be encrypted and stored securely and destroyed once the research requirements are fulfilled.  Password protected folders will be used on computers			Person responsible: research supervisor Dr Jessica Jones Nielsen	
Physical activity	Pain experience	Participants	Use of comfortable chairs  Choose a room that would not exacerbate patients pain when traveling to and from the room/ venue  Informing patients that they are free to get up to walk around if pain becomes uncomfortable during interview  Offering the option to arrange a convenient place and time to meet with the participant for the interview.	High	Might require transport arrangements	Prior to start of research  Person responsible: research supervisor Dr Jessica Jones Nielsen	

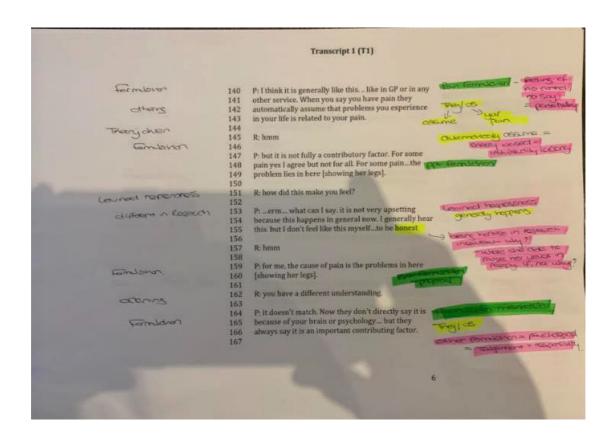
Sensitive issues i.e. Gender/ Culture	Exposure to vulnerable situations/ sensitive issues that may cause distress to interviewer or interviewee	Researcher and participants	Providing a supportive and non-judgemental environment  To have a curious and non-judgemental stance  Use of researcher from same culture  Engage in on-going reflexivity  To be aware of ways in which to establish right 'social distance'- neither over-familiar or nor too detached	High	To get advice from research supervisor  Check if there is local tensions to be aware of, such as strong cultural, religious, political or racial divisions  To avoid appearing out of place, dress inconspicuously and non-provocatively, taking care of the cultural norms  To be aware of the potential gender dynamics	Prior to start of research  Person responsible: research supervisor Dr Jessica Jones Nielsen
Lone	Meeting at	Researcher	Call participants in advance	High	potential gender dynamics of interactions  Informing and liaising with	Prior to start
working	patients home or	and participant	(e.g. for screening) to assess how comfortable I feel about		service and universities safety liaison officer.	of research
	place they		them, and to enquire whether		,	Person
	choose to do		any other members of the household will be at home		If possible carry a personal alarm to attract attention	responsible: research

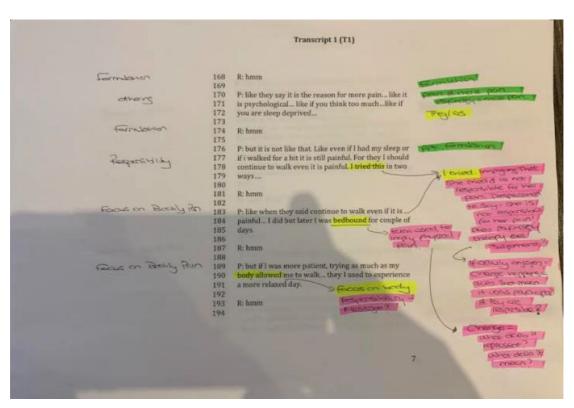
interview	Informing a friend/ colleague/	in an emergency	supervisor
	supervisor before, during and		Dr Jessica
Travelling	after the interview meeting.	Study map of the area.	Jones Nielsen
through		Thinking about escape	
potentially	Providing friend/ colleague /	routes.	
unsafe	supervisor my personal		
areas to	contact details and next of kin	Input local taxi numbers	
reach	and having their contact	into mobile phone in	
project site	details safe on my phone.	advance	
	Mobile phones to be switched		
	on at all times.	Equipment and valuable	
		items should be kept out	
	Informing participants that you	of sight where possible	
	have a schedule and that other		
	people know where I am in a	If possible carry a personal	
	general conversation	alarm to attract attention	
		in an emergency	
	Always obtain permission		
	before entering private	Informing friend/	
	land/property	colleague / supervisor	
		about researchers health	
	Always carry identification	status	
	Checking for reliable local		
	public transport or check if it is		
	safe to use private car and		
	leave them in the area		

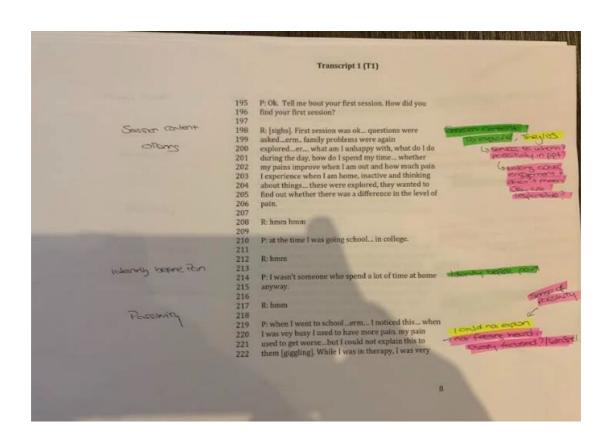
# • Contacts

- •School Safety Liaison Officer:
- •University Safety Manager:

Appendix 10: Example of stages two and three of analytic process: Section of Gul's interview transcript with initial noting and emergent themes







Appendix 11: Example of Stage Four of Analytic Process: Table illustrating cluster themes from Ayse's interview, along with their associated emergent themes, line numbers and quotes.

CLUSTER THEMES	EMERGENT THEMES	LINE NO.	QUOTE
Focus on physical pain	Pain symptom	698	'I have very bad pain in my foot'
		765	'like for the last couple of days my arms are swollen and very painful'
		774	'I started to develop wear and tear in my neck'
		801	'they say I have wear and tear in my neck, shoulders, back and everywhere'
Change of person	Impact of pain on life	709	I can't walk like maybe for only 10-20 meters. I can't even walk probably at home'
		778	'like I can't even lift my arms like for three months my arms where left in the position [showing still and downwards]
	Relationship with pain	27	'I started a war with these pains'
		401	'I just want to run away from everything'
		419	'like I do want a place for womenfor women only where they can just go for few days to escape from everythinga place for pain and all this'
	Memory problems	613	'I have memory problems. I forget very easily my bucket is now full'
		612	'Yes my mind is full. It doesn't take new information anymore'
		670	'they talked about a lot of things but I can't remember'
Expert-led referral	Referral source	537	'it was my doctor who referred me'
		1220	'I think it is related to doctor's recommendations. If doctors say if pain is here or there'
Failed interventions	Previous treatments	541	'suggested me to see them because I have
<u> </u>			

			seen physiotherapist for many years'
		565	'yeslike there was not much benefit from seeing physiotherapist'
Comparing treatments in Turkey	Treatments in Turkey	820	'like in Turkey apparently there is a treatment with lightthey say physiotherapy with light'
		1065	'I want to go Turkey but I can't go. I thought maybe physiotherapy with hot massage might help my pains in neck, shoulders and backand in general'
Experience of previous psychological therapy	Other psychological treatments	253	'I did attend many sessions in different organisationsfor example in Derman like Derman I've seen for weeks, maybe fifteen sessions. It was talking therapy but nothing really changes for me'
Understanding psychological therapy for pain	Understanding referral	17	'but this was only talking therapy for my pains. They did not offer any other treatment'
		79	'maybe they thought if I can relax psychologically y a littlethen maybeI can relax my body'
		1037	'I think they mean in the way for me to adapt'
Desperation	Willing to try any offer	294	'I am open to anythingbecause I think maybemaybe it will benefit me. I did not say no to anything'
		299	'I accepted everything they offered'
Expectation from therapy	Hope for therapy	281	'I thought it will maybebe cure [tearful]I don't know
		258	'hmmlike some hopemaybe I will relax a little'
		1103	'I know nothing is going to changebut then I thinkI think it is hope'
		1108	'yes maybe they will say something newI don't know'
		1112	'like maybe they will try something new'

Formulation	Doctors explanation	41	'my doctor say the same thing. When I feel more painthey say this too'
		641	'most relate back to depression.  Sometimes I agree with this because when I am not well mentally I feel more pain in my body'
		736	'also they say the pains are connectedlike I don't agree with that. My pain is here [showing her shoulders] is not related to my pain [showing the bottom of her foot]
	Patient understanding of pain	32	'I don't just have pains. I also have psychological problems'
		646	'but when my mood is slightly betterit is like my pains are more manageable'
		899	'my only understanding isthatin an early agechild age(tearful)like in very early ageI was doing a lot of workheavy work. I started working at a very young agein fact an occupational therapist visited my home for my bathroomthey changed it now but she said ninety percent of Turkish have thisshe said they get chronic pain and asked me why. So I thought to myselfmaybemaybe it's because we were made to do heavy labour at a young agewe don't like our childhood'
		1041	'they are related'
		1133	'like things were done in the pastlike it stays inside your brain it doesn't get deleted'
		1139	'but I said everything is up there [showing her head]
Generalized care	Theory-driven	1192	'I would have liked them to go deeper into our life'sour stories. Like how did it startwhen did you realize it? Like if they could have more questions to go deepermaybe that would have helped'
			'they only ask about that moment. they

		1203	don't ask much about the past. They only focus on the present. No one knows what you experienced in your past'
		1214	'maybe they would have a better understating of what they can dolike what treatment they can offer. They would treat with more understandingI don't know this is what I am thining'
		1225	'just that time you see? If you have pain at that moment then they only focus on that'
			'they just offer treatment for the moment'
		1225	'it's only in the surface'
		1292	
Awareness of	Dough ale sieel structure		(Like this I feel year timed when I san't stars
psychological influence	Psychological struggles	63	'Like this I feel very tired when I can't sleep probably. Like you feel ityour body is not relaxed so your brain can't switch off'
	Insight into psychological problems	1173	'My head. I need to empty my head first'
Uncertainty about future	Fear of future	276	'I can't imagine I will get better and I wonder what is going to happen to me in the next ten years. '
		783	'Like I am scared to goi don't want to go. I don't want to lie it is like that now'
Passive engagement in therapy	Passitivity	630	'they used to offer me an appointment and I used to go'
Feeling responsible for the failure of therapy	Blaming herself	1256	'or maybe I couldn't explain myself'
Feeling helpless	Not much can be done	199	'like when I last saw himhe said my pains are too much that it is very chronic and that there is not much he can do'
		635	'like I don't knowI don't think it is going to help with anything just like doctors say there is nothing much that can be done and I just have to learn how to live

			with this pain'
		719	'they say there is nothing that can be done and that I should learn to live with my pains because these nerves are from my nerves'
		724	'they said this is the problem and the rest is normal so learn to live with the pain'
		788	'for the pains they just look at my face
		1296	'like your doctor looks into your face and says there is nothing we can do and that I need to learn how to live with these pains'
Feeling like a burden in therapy	They want to get rid of us	757	'exactly like that they all want to get rid of me'
		839	'to get rid of us. They refer from one place to anotherasking me to go there and then there'
Therapy content	Talking approach	238	'then I've seen her for another few sessions for talking sessions'
		362	'they just talked really'
		366	'like it was talking approach. They troed that and medication too'
		1152	'I did talk about the violence I suffered as a child'
	Techniques used	512	'hmm. I don't remember much to be honestI think the only thing I can remember is the breathing technique'
		521	'like for relaxationlots of things like that'
		525	'deep breathinglike that'
		582	'theylike physiotherapist's ask you where does it hurt and you tell themyou say this and that'
		587	'and they give you exercise for that specific area. Then it is just talkingthey explain stuff they give paper for you to take

		1168	home and say repeat this exercise'  'they said they wanted me to think more positivelybut I can't'
Commitment to therapy	Trying her best	1027	'I try my best to do the exercise that has been recommended but I don't see any benefit'
Outcome of therapy	Positive feeling after therapy	13 104	'talking helped me to relax'  'yesI don't really want to go but I do need to leave the house because I am not someone who leaves the house as often'
		165	'I am alone. Because of this sharing with people you don't know helped me to relax'  'for a short time maybelike I goI talkI
	Feeling worse after therapy	864	explain and then I feel better'  'like I went to therapy yesterday for example I started to talk and I remembered a lot of thingslot of things from bad days and I started to feel bad and I couldn't hold it together (tearful)
Awareness of lack of service resources	Lack of government support	1017	'because of lack of communicationI don't think there is enough support from the government'
Boundaries with sessions	Number of session	625	'I think about three to four sessions'

Dependence on Interpreters	Challenges with advocates	492	'if you want an advocate then the waiting time is longer'
		964	'like you have half the time to talk and express yourself. You can only speak three to five words then the session ends'
		1345	'like I can't find words that describe what I am trying to say in English and with translator it takes a long time to be seen'
Language barrier	Language difficulties	475	'now she was speaking in English so I didn't understand much and I couldn't really explain what I wanted to explain'
		488	'but still I can't really explain myself the way I wanted too'
		977	'my painmaybe if I could have explained it in my own language'
		1328	'I think it is the language issue'
		1330	'so not feeling understood'
Minority challenge	Being Turkish	945	'I think the issue is that our Turkish women finds it difficult to express themselvesyou know because of the language'
Therapy suggestions	Patient suggestion	1252	'I would have liked to be seen by someone who speaks my language'
Being more herself during research interview	More confident to open up	154	'hmm do you want me to be honest? I did not see any benefit. All my problems stayed with me at the end but o was just able to speak about it a little'
		496	'and to be honest I prefer to have one-to- one sessions'
		630	'I did not have any expectations to be honest just like that'

Appendix 12: Example of Stage Six of Analytic Process: Table illustrating the higher order themes for the group with exemplar quotes from each of the individual participants.

	TABLE OF SUPERORDINATE THEMES	
1. LIV	ING WITH CHRONIC PAIN	
i.	Focus on Physical Pain	Line No.
Gul	'for some painthe problem lies in here [showing her legs]'	148
Yesim	'I couldn't sleepmy hands and feet were weak and shakyone minute I am cold and the next minute is like I am on fire'	676
Ayse	'they say I have wear and tear in my neck, shoulders, back and just everywhere'	801
Fatma	'last year my shoulders used to get locked quite often'	189
Zerrin	'like I have all forms of arthritislike I can't move and some days I scream because of my pain'	285
Hanim	'and I have physical pain. Like right now I cannot explain the pain I am inevery part of me is in pain'	54
ii.	Loss of Self	
Gul	'Like for example when I go out to sun I will suffer from bone pain all night. I cannot relax because of the pain'	
Yesim	'because my life before and my life now is very different'	27
Ayse	'I can't walklike maybe for 10-20 meters. I can't even walk probably at home;	703
Fatma	'my friends used to tell me that I changed a lotthat I became worse'	52
Zerrin	'I couldn't even go to hospital and no one was able to touch meI had a lot of pain. No one was able to touch me I had a lot of pain. No one was able to touch meI couldn't even go to toiletyes	21

toiletmy muscles were so weak that I couldn't go and no one was able to touch me because of my painI am still the sameI have really bad pains at night I cry in my sleep because of this pain	
'they said I should forget my old self'	366
HEN PATH CROSSES WITH PSYCHOLOGY	
Referral Source	
'I was seen by physiotherapist. I was referred my physiotherapy route'	52
'it was my doctor who referred me'	537
'referral was likelike you go first go to GP and then GP refers you to somewhere else and you wait for hours and then they finish the appointment with just talking'	250
'like the GP referred me and MRI results showed lots of problems'	349
'I think it was because I did not benefit from any medication, treatment or physiotherapy to date. Like they tried everything but nothing worked. So they wondered if it was due to my unconscious like whether it was psychological. I think they referred me to find this out'	41
Expectation: Desperation	
'I expected it to be more beneficiallike no pain'	86
'I really thought it will be somethingsomething that will keep me goinglikemaybe a solution will be found for my problemsthat's why I went there'	5
	able to touch me because of my painI am still the sameI have really bad pains at night I cry in my sleep because of this pain  'they said I should forget my old self'  HEN PATH CROSSES WITH PSYCHOLOGY  Referral Source  'I was seen by physiotherapist. I was referred my physiotherapy route'  'it was my doctor who referred me'  'referral was likelike you go first go to GP and then GP refers you to somewhere else and you wait for hours and then they finish the appointment with just talking'  'like the GP referred me and MRI results showed lots of problems'  'I think it was because I did not benefit from any medication, treatment or physiotherapy to date. Like they tried everything but nothing worked. So they wondered if it was due to my unconscious like whether it was psychological. I think they referred me to find this out'  Expectation: Desperation  'I expected it to be more beneficiallike no pain'  'I really thought it will be somethingsomething that will keep me goinglikemaybe a solution will be found for my problemsthat's

Ayse	'I thought it will maybebe cure (tearful)I don't know'	281
Fatma	'like maybe there is a cure for this? Like if they can just do some extra checksmaybe there is something else that can be done?'	86
Zerrin	'I thought they will be able to get rid of my pain'	3
Hamim	'maybe I should just go and try and see what happenslike maybe it is psychological. Like it might be unconsciousand they might be able to resolve that'	6
3. MY I	PAIN IS REAL	
i.	Making sense of chronic pain	
Gul	'like they don't say they do not agree with me. They say the experience of pain can change from person to person. But I also don't disagree with them completelylike off course psychology would have an impact on your pain. You like it or not, when you have problems you will fell unhappy and your body will be more tensebut I don't agree that the pain is caused only from psychological problems or that it is a big contributing factor'	239
Yesim	'They tend to look at pains separately. I think they need to consider them as related'	294
Ayse	'also they say the pains are connectedlike I don't agree with that. My pain is here (showing her shoulders) is not related to my pain 9showing the bottom of her foot)	736
Fatma	'I think it is physiological because there is pain in my body'	208
Zerrin	'yes it is part of itlike you are in pain so you will be upsetyou will think how you going to deal with itlike you want to do things but you can't'	64
Hamim	'they are seeing it differently. Like they have separated into different departments'	623

ii.	Generalized care	
Gul	'When you say you have pain they automatically assume that problems you experience in your life is related to your pain'.	141
Yesim	'they viewed it separatelymaybe at the beginning if they have looked at the whole'	536
Ayse	'they only ask about that moment. they don't ask much about the past. They only focus on the present. No one knows what you experienced in your past'	1203
Fatma	like that's all they say. No one says let's check her thoroughly and understand what is wrong with her'	70
Zerrin	'I think they are treating every person the same but I don't think every person is the sameor every illness is the same'	364
Hanim	'they tell me to go out more but do they consider how? Whether I have friends? Money? Or ability?	835
iii.	Feeling Judged	
Gul	'Like you don't have pain but you are doing it psychologically. This feeling just surrounds you'	135
Yesim	'I don't think they would have done the same to an English person. There is racismyou ca not explain it or proof it but you can feel it'	880
Ayse	'they all want to get rid of me'	757
Fatma	'I am aware of this because Turkish people don't know how to ask for their rights'	323

Zerrin	'like I am not asking her to give me the hospital or treat me any differentlyall I am doing is talking about my problemsI was talking about my illness'	369
Hamim	'like if I don't worry people going to assume I am faking it to avoid going to work'	359
4. FEI	ELING OUT OF CONTROL: CONTROL WITHIN THE SERVICE	
iii.	Dependence of Translators	
Gul	'But I don't think she did not have much power in her handsin regards to time of sessionsI think like that'.	474
Yesim	'I think there is a problem with translators. I think the problem is with the translators and because of this the communication and relationship between the doctor and the patient is not helpfulthere is a disconnection'	760
Ayse	like you have half the time to talk and express yourself. You can only speak three to five words then the session ends'	964
Fatma	'you explain to her and she then explains to her and then it's finished'	341
Zerrin	'but really what can you explain in one session? And especially if that session finishes in two minutes because you have to use an interpreter?	139
Hanim	'like there is an interpreter and she does translate everything you say but it takes a lot of time'	15
iii.	Awareness of wider control within the system	
Gul	'it was not authorized to be continued. Because they said they have a limit in how they can offer the service'	44

Yesim	'they should adapt their treatment to my individual needs'	736
Ayse	'because of lack of communicationI don't think there is enough support from the government'	1017
Fatma	'NHS used to do more work in the past but now it is just like that. When you need something then it is not available'	341
Zerrin	'nothing continues for longlike with time there are more limitations on sessions and I don't think people will recover with all this limitations'	125
Hanim	'the system is all over the place. It is all separated and until you put everything together to make sense, it is just too late. You are now experiencing severe pain and you are in severe depression you feel overwhelmed and stressed and then you end up in a place you cannot go back'	840
5. <b>OU</b> 1	TOME OF THERAPY	
Gul	'But when I came homeI used to feel more pain'.	224
Yesim	'So I tried but every time I tried I felt worse. It took me two-three days to recover'	357
Ayse	'then I come home feeling more tired and then I feel worse'	191
Fatma	'like when I came back home I couldn't even walkit was like my bones were broken'	238
Zerrin	'my psychology was upside downthey made me feel worse'	311
Hanim	'then I get really bad headache at home because I have tensed myself throughout the consultation'	760
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## **Appendix 13- Extract from Reflective Journal**

26 Feb 2021

Reading interviews today. and what strike me most was the word 'honest'. It was interesting to note that nearly all participants used this when describing their experience of psychological therapy. They said they were being honest with me so did that mean they were not honest in their psychological therapy? How can psychological therapy be beneficial if they can't be honest or be fully themselves? And were they honest because they see me part of them? How would this influence the data in that case? What might have I done to complicate of confuse this role? Could it be the language? Culture? Maybe it was that they were able to express themselves easier and considered that to be honestly? Nevertheless conducting interviews in Turkish appears to give voice to participants from different levels...