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Social Responses to Pain Behaviors. The Role of Friendship on the Adaptation to Chronic Pain

Inês Filipa Neves Almeida

Master in,

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Supervisor:

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To my parents, for always believing in me

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Resumo

A dor crónica (DC) é uma doença que afecta cerca de 37% da população adulta portuguesa. É uma experiência subjectiva e complexa e, portanto, pessoal. Estudos demonstraram que as respostas de parceiros românticos podem promover ou prejudicar a adaptação de um indivíduo à DC. Não são só estas as relações que podem afetar o nosso bem-estar, as amizades quando oferecem apoio social e companhia podem ter um impacto positivo neste, mas a literatura em relação às experiências de amizade de adultos com DC é reduzida. O objectivo deste estudo foi explorar os efeitos promotores e dificultadores das respostas dos amigos à DC e o impacto da dor nas amizades. Dezasseis indivíduos participaram em entrevistas individuais (87.5% mulheres; $M_{idade} = 43$ anos). A análise temática revelou dois temas. O primeiro inclui experiências nas quais os amigos tanto promoveram ou prejudicaram a adaptação à dor através: (a) demonstração (in)disponibilidade para dar apoio, (b) dão apoio (des)necessário, (c) (não) promovem aceitação e flexibilidade, e (d) (não) promovem compromisso com a vida. O segundo estava relacionado com o impacto da DC nas amizades, através de mudanças nas atitudes e comportamentos dos indivíduos com dor e os seus amigos em relação à amizade. Estudos futuros são necessários para determinar factores das amizades, mecanismos e potenciais diferenças de género que possam influenciar a adaptação de uma pessoa à DC. Ajudar aqueles com DC a manter e a fortificar as suas amizades pode melhorar a sua capacidade de aquisição do apoio social que lhes é necessário.

Palavras-Chave: Grupo e Processos Interpessoais, Psicologia da Saúde e Medicina, Dor Crónica, Amizades, Adultos

Abstract

Chronic pain (CP) is a condition that affects roughly 37% of the Portuguese adult population. Pain is a subjective and complex experience and thus personal. Studies have found that responses from romantic partners can promote or hinder one's adaptation to CP. However, these are not the sole relationships that effect our well-being. Adult friendships also provide one with social support and companionship that can have a positive impact on well-being but there is little research on the experience of friendships of adults with CP. The purpose of this qualitative study was to explore the promoting and hindering effects of friends' responses to CP and the impact of pain on friendships. Sixteen individuals with CP participated in individual interviews (87.5% women; M_{age} = 43 years). Thematic analysis revealed two major themes. The first captured how friends either promoted or hindered adjustment to CP by: (a) demonstrating (un)availability to provide support, (b) providing (un)needed support, (c) being (not) accepting and (not) accommodating and (d) promoting life (dis)engagement. The second captured the impact of CP on friendships, by changing individuals' and their friends' attitudes and behaviors towards the relationship. Further research is needed to determine friendship factors, mechanisms, and potential gender differences that influence one's adaptation to CP. Helping those with CP maintain and strengthen friendships may improve their ability to garner needed social support.

Keywords: Group & Interpersonal Processes, Health Psychology & Medicine, Chronic Pain, Friendships, Adults

Contents

List of Tables

Introduction

Pain most often serves the useful purpose of warning individuals of the possible existence of threats to their body. It is also a universal experience, in the sense that most individuals at some point in their lives have felt some kind of pain (Hallenbeck, 2012), which can be regarded as acute pain since as the body heals it tends to disappear. However, in some individuals, even after the physical injury heals, the pain persists, and thus what was once acute turns chronic and stops serving its' useful purpose (Turk & Burwinkle, 2007).

It is estimated that chronic pain (CP) affects roughly 20% of the European population (Breivik et al., 2006) and in a recent study in Portugal, it was estimated that 36.7% of adults suffer from some form of CP (Azevedo et al., 2012). These prevalence rates stress the importance of studying this phenomenon, in order to help individuals manage their situation and consequently to reduce the burden of CP on healthcare systems and economy (Breivik et al., 2006; Dueñas et al., 2016). However, pain is a complex, subjective and personal experience, that involves not only biological components, but also psychological and social determinants in a dynamic interplay that shape cognitions, sensations and reactions (Gatchel et al., 2012; Pillai Riddell & Craig, 2018) and thus requires further research to address these various dimensions.

Psychosocial determinants and their relationship with CP have gained a greater focus in recent literature. This emphasizes the necessity of observing and assessing individuals and their pain with a more holistic approach, where the physiological is not disassociated from the psychological or the environment, as they mutually influence each other (Jensen & Turk, 2014). Indeed, the social environment plays a key role in human life in general, as we are naturally social creatures (Lyons et al., 2006), but also in pain experiences in particular. The reduced or lack of social contact with others may cause feelings of loneliness and be involved with the development or exacerbation of CP (Blyth et al., 2007).

Although researchers have been increasingly interested in the role of interpersonal relationships on CP experiences, and several studies have shown that friendships are a crucial part of our support networks, the main focus has mostly been on the role of romantic partners on CP adjustment (Bernardes et al., 2017). This leaves a gap in the literature about the role of friends on CP adaptation. The social support (SS) we generally obtain in our relationships is directly related to their function and quality, occurring through an interactive process that can be associated with the perception of reciprocity, a sense of obligation and altruism (Schwarzer & Knoll, 2007). SS can help people with CP redefine their situation, shift their attention from their disease, decrease intrusive thoughts that one cannot cope with the pain, and reduce restrictions on activities (Holtzman et al., 2004; López-Martínez et al., 2008).

Friends have been identified to provide positive resources to others, in fact, our friendship networks influence our well-being and happiness (Demir et al., 2007; Dunbar, 2018), while being an important source of SS (Lansford et al., 2014; Mendes de Leon, 2005). Friendships can ameliorate negative effects in several contexts, perhaps by providing affection, intimacy and loyalty (Hodges et al., 1999; Roberto & Husser, 2007). They contribute to the development of self-esteem, sense of acceptance and belonging, positive mental health and social skills, thus also acting as a protective factor when facing problems (Nabors et al., 2015). In addition, having support from friends has been associated with better outcomes for individuals with CP or other chronic conditions (Walker et al., 2001).

The role of friendships in the adaptation to CP is an area in expansion. Most studies have been conducted with adolescents (e.g., Forgeron et al., 2011, 2013; Forgeron & McGrath, 2008), where there is growing evidence regarding the role of positive and negative interactions on the lives of teens with CP, as they may interpret their friends' behaviors towards their pain as supportive or non-supportive. Similarly, friends can be a source of positive SS or a source of stress for adults with CP, however, the role of friendships on adult's CP adaptation is under investigated.

Therefore, the main purpose of this dissertation was to investigate the reciprocal relationship between adult friendships and CP experiences. Overall, we aimed to understand how (1) can friendships influence the adaptation to CP, and more specifically, we also sought to investigate which friends' attitudes and behaviors would be considered helpful and unhelpful by the individual with CP, as well as, (2) how CP can influence adult friendships.

With regards to the structure of this dissertation, the first chapter gives an overview of the most relevant research on pain (CP and epidemiology) and friendships (normal processes within friendships), as well as, the influence of friendships on pain and the influence of pain on friendships. Chapter two describes the qualitative methodology used in this study, in which sixteen adults with CP were individually interviewed. Chapter three describes and illustrates the main themes and sub-themes extracted from the interviews with a thematic analysis. Finally, chapter four presents a critical analysis of the findings against the current state-of-the-art and a discussion on the study's limitation and implications for future research and clinical practice.

CHAPTER 1

Literature Review

This chapter summarizes the most pertinent literature on pain in general, emphasizing its' characteristics, how it affects the body and expresses itself, as well as, what is CP in particular, and what toll it takes on individuals and society. Herein, a brief overview of research on friendships and how they may influence one's pain and vice-versa is also provided. CP is complex, thus, this review is intended to give the reader the most relevant facts to assist with the interpretation of the findings of the study.

1.1. Pain

Historically, pain has had different definitions and meanings throughout the centuries. Ancient Greeks like Hippocrates attributed pain to an imbalance in vital fluids, whereas Aristotle attributed pain to gods and evil spirits (Linton, 2005). In the 16th century, Descartes hypothesized that pain could be a disturbance that went up the nerves until the brain responded in a mechanical manner similar to the brain ringing a bell to alert the individual of the pain (Robinson, 2020). Pain was regarded as strictly physical or psychological, a vision based on the assumption of a division between mind and body (Robinson, 2020). More recently, pain has been regarded under a model that incorporates the biological, psychological and social aspects of pain perception (Linton, 2005), which is the base of the following review.

Pain is defined as "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage*" (Merskey & Bogduk, 1994) with psychological, social and cultural dimensions, which can affect an individual's physical and mental wellbeing (Gatchel et al., 2007). The normally functioning nervous system mediates noxious stimuli input, receiving and interpreting the sensory information from our bodies. If the brain interprets this information as damaging, we experience pain to protect and warn us. However, due to several factors, the nervous system can change and make the individual more or less sensitive to painful stimuli (Woolf, 2010).

Pain is often categorized in two main ways. One way is to categorize pain based on the underlying physiologic mechanisms (despite pain having cognitive and emotional aspects as well), including *nociceptive, neuropathic and nociplastic* pain. *Nociceptive* pain is usually experienced after an injury, inflammation, or disease (e.g., related to tissue damage) and serves as a signal to protect the affected area (or seek medical assistance) in order to alleviate the pain. *Neuropathic* pain, is due to damage (e.g., lesion) to the somatosensory nervous system (e.g., neuropathies associated with diabetes, Sloan et al., 2018). Lastly, *nociplastic* pain arises from a dysfunction in the sensory neurons – and does not require nociceptor activity nor somatosensory nerve damage (Campbell et al., 2019; European Pain Federation, n.d.; Trouvin & Perrot, 2019; Woolf, 2010). The other way to categorize pain is by its duration – acute vs. chronic. Acute pain is usually nociceptive but can have a neuropathic component, whereas CP is commonly neuropathic or nociplastic but can have a nociceptive feature (Campbell et al., 2019). Acute pain is relatively brief in duration and typically resolves as we heal, whereas, CP lasts for longer than three months but can extend for long periods of time and can be either persistent or recurrent (Raymond & Abd-Elsayed, 2019; Treede et al., 2019; Turk & Burwinkle, 2007).

Despite the ability to categorize pain into types, all pain is a subjective experience and therefore, at present, the only way to know how much pain someone has is to ask them and make inferences from their behaviors (Turk & Burwinkle, 2007). Inferences from behaviors need to be interpreted with caution as they are usually inaccurate unless a validated pain assessment tool is used (Dansie & Turk, 2013). The difficulty with trying to measure pain is that the experience of pain and subsequent expression are the result of interactions between genetics (biological component) and environment within a myriad of physical and social settings that vary over the course of the individuals' life. This dynamic interplay of factors means that pain is a complex and unique experience that is a product of biological mechanisms and determined by psychological and social factors. These affect and shape the way an individual interprets and reacts to pain, because the pain experience is comprised of thoughts, feelings and sensory features (Gatchel et al., 2012; Pillai Riddell & Craig, 2018).

Indeed, a number of psychological processes – attention, cognitions, emotions and coping mechanisms – play a key role in the adaptation to physical and environmental challenges, and are involved in most pain problems (Linton & Shaw, 2011; Pillai Riddell & Craig, 2018). First, pain demands our attention, so being vigilant may increase pain intensity by requiring a greater amount of cognitive resources and, thus hindering the ability to direct attention elsewhere (Eccleston & Crombez, 1999; McCracken, 1997). This vigilance refers to an abnormal concentration on possible signs of pain, which can be linked to anxiety and fear, possibly leading to a necessity to take actions such as avoidance or escape (Leeuw et al., 2007). After one pays attention to the pain stimulus, they use cognitive processes to make interpretations about its' meaning (Linton & Shaw, 2011). The interpretations one makes and the beliefs they hold may increase pain and disability due to interference with internal pain dampening processes (e.g., down regulation of pain) (Price, 2002). Individual pain beliefs are influenced in some ways by cultural norms (e.g., men don't cry) and these beliefs also help give meaning to the stimuli (e.g., harmful versus beneficial) and are influenced by social settings (e.g., stoicism when in pain) (Orhan et al., 2018; Sharma et al., 2020). Moreover, people experiencing pain usually have ideas about the etiology of their pain, how they should manage it and what are the optimal times for recovery (Linton & Shaw, 2011). These ideas shape expectations of what the pain experience should be (e.g., intensity, duration, characteristics) and thus have an impact on the experience of pain by helping modulate coping behaviors. When one's pain experience is not aligned with their beliefs about pain, these beliefs may generate negative cognitions and promote the use of unhelpful behaviors (Linton & Shaw, 2011).

Second, in the process of interpreting of our bodily signals there is a clear influence of our cognitions, meaning one can make a misjudgment of actual events, leading to a pattern of reality distortion (Linton, 2005; Sullivan et al., 1995). One example of this type of misinterpretation in the context of pain is known as *pain catastrophizing* (Linton & Shaw, 2011)*,* which is a negative and exaggerated orientation towards pain, where a neutral event is catastrophized irrationally (includes feelings such as helplessness, pessimism and rumination) (Sullivan et al., 2001). A variety of problems comes associated with pain catastrophizing that undermine recovery and escalate the possibility of developing persistent pain and disability (Edwards et al., 2016; Linton & Shaw, 2011; Main et al., 2010). Studies have found that even after adjusting for indices of anxiety and depression, pain catastrophizing remains significantly associated with a myriad of poor outcomes including delayed return to work (Gauthier et al., 2006; Sullivan et al., 2005), increased pain related physical disability (Hirsh et al., 2011), risk for misuse of opioid prescription (Martel et al., 2013, 2014), pain intensity (Archer et al., 2015), pain tolerance (Trost et al., 2015), suicidal ideation (Edwards et al., 2006) and decreased SS (Buenaver et al., 2007).

Third, emotions also shape our pain experience and our behaviors, and even though positive emotions might decrease pain, a key disruptive feature of pain is emotional distress (Linton & Shaw, 2011). Emotional distress is typically associated with anxiety, fear, anger and depression, all of which may increase pain related disability. So, the manner with which one copes with emotions influences one's pain experience (Linton & Shaw, 2011; Pillai Riddell & Craig, 2018). Even though psychosocial factors are largely viewed as reactions to pain, variables such as depression, anxiety and distress are robust predictors of the transition from acute to CP (Asmundson & Katz, 2009; Bair et al., 2003; Edwards et al., 2011, 2016; Linton et al., 2011; Nicholas et al., 2011; D. A. Williams, 2013), suggesting that strategies to decrease emotional distress may be powerful interventions to improve pain related outcomes, since emotional distress may be a precipitant of pain symptoms, may modulate the severity of pain, or be a consequence of recurrent and persistent pain (Gatchel et al., 2007).

Lastly, the coping mechanisms can be explained in light of Lazarus and Folkman's (1984) transactional model of stress and coping, where they define stress as a transaction between an individual and their environment, and coping as *"constantly changing cognitive and behavioral efforts to manage specific external or internal demands that are appraised as exceeding the resources of the person"* (p. 141). Individuals with chronic pain (ICPs) normally deal with more than just daily stress due to their pain, how they conceptualize this stress determines their adaptation or coping strategies. This appraisal can be positive when stress is viewed as a challenge, which in turn promotes mastery and growth, or maladaptive and negative when they feel their situation and pain is not under their control, and consequently, see their pain as a threat (Lazarus & Folkman, 1984). When pain is viewed as a threat, several strategies are initiated to deal with it which can be cognitively activated (e.g., visualization, ignoring) or are overt behaviors that the individual believes are able to reduce the threat (e.g., relaxation). These strategies are shaped by learning experiences that give feedback on their efficacy and thus the ICPs can understand which strategies work best for their condition (Linton & Shaw, 2011).

In sum, the psychological processes previously mentioned are part of a greater system, that is influenced and influences reactions and behaviors of the pain sufferers, as well as, to some extent their environment (Linton & Shaw, 2011). These influences can assist or hinder the adjustment to CP, therefore, the main focus of this review is CP, which will be discussed in more detail in the next section.

1.2. Chronic Pain

CP is a serious public healthcare problem in both developed and low- and middle-income countries, with several implications for the individuals themselves and also for the economy and society (Breivik et al., 2006). CP affects not only individuals' quality of life but also their relationships, when there are perceptions of a myriad of negative attitudes and distrust from their families, colleagues and healthcare providers (Breivik et al., 2006). The International Association for the Study of Pain (IASP) developed a new classification for CP, defining it as a disease in its own right (Treede et al., 2019). This new classification was adopted by the World Health Organization (WHO) in the (11th) newest version of the International Classification of Diseases (ICD-11) with the hope of facilitating the diagnosis of CP, and thus improve research on treatments and increase patient access to pain treatments.

Initially, CP was defined as pain that persisted beyond the normal tissue healing time (Bonica, 1953), and it can be elicited by an injury or disease but it is most likely perpetuated by other factors (Turk & Okifuji, 2010). Currently, according to the WHO (2019), CP is pain that persists or recurs for longer than three months and can be further classified in two sub-categories – chronic primary pain and chronic secondary pain. Primary CP is a multidimensional type of pain, which consists of biological, psychological and social factors, exists in one or more anatomical regions and is associated with significant emotional distress (e.g., depressed mood, anxiety, anger, frustration) and/or functional disability (reduced participation in social roles and interference in daily activities) (World Health Organization, 2019). Primary CP is presented by a person having no other diagnosis that would better account for the symptoms (World Health Organization, 2019). Examples of primary CP include chronic widespread pain (e.g., fibromyalgia), complex regional pain syndrome, chronic primary headache or orofacial pain (e.g., chronic migraine), chronic primary visceral pain (due to functional or unexplained mechanisms, for instance, irritable bowel syndrome) and chronic primary musculoskeletal pain (Treede et al., 2019).

Secondary CP is pain associated with other diseases, for which pain may be a salient symptom. However, even if there is another underlying disease, secondary CP is pain that continues after successfully treating that disease. Examples of secondary CP is chronic cancer-related pain (caused by the cancer itself or by its treatment), chronic postsurgical or posttraumatic pain, chronic neuropathic pain (caused by an injury or disease of the nervous system), chronic secondary headache or orofacial pain (disorders that have underlying causes), chronic secondary visceral pain (originates from internal organs) and chronic secondary musculoskeletal pain (develops as part of the disease, like rheumatoid arthritis or symptomatic osteoarthrosis) (Treede et al., 2019; World Health Organization, 2019).

In addition to not being beneficial to the individual, both types of CP can cause damage to one's physical and mental health such as changes in the immune system and subsequent susceptibility to infections (APED, n.d.), as well as, loneliness (Allen et al., 2020; Forgeron et al., 2011, 2018; Wolf & Davis, 2014) and depression (Gerrits et al., 2015). Several risk factors for CP can be identified that may affect the duration, intensity and effects of pain, such as psychological factors (e.g., emotional distress, attitudes and beliefs, and coping skills), social factors (e.g., interpersonal relationships, culture, environment, and work), and biological factors (e.g., diseases, pain intensity and sleep disturbance; Dorner, 2017; Mills et al., 2019). Mitigating negative factors and boosting positive ones are helpful in the prevention and management of the condition (van Hecke et al., 2013). Therefore, social and psychological stressors can affect the mental health of someone with CP, such as their coping strategies, emotions and ways of thinking, family dynamics, environment (socioeconomic and employment), being able to access healthcare, as well as, their place in society as an individual with CP (ICP) (Gatchel et al., 2012).

To better understand CP, it is relevant to consider the Biopsychosocial Model of Pain, that emphasizes the multidimensional and dynamic interactions between psychological, social and biological variables. This model suggests that the pain experience is modulated by genetic components or predispositions, learning history, specific characteristics of the individual, emotional states, beliefs and behaviors. So, pain severity depends on more factors than physical injury or damage to the nervous system. Indeed, pain severity may be intensified due to maladaptive appraisals of one's condition, situation and self-efficacy (Turk et al., 2004). For instance, in studies with ICPs it was demonstrated that self-efficacy positively influences psychological and physical functioning (Asghari & Nicholas, 2001; Rudy et al., 2003), and improvements in self-efficacy (with the use of cognitive-behavioral therapies and self-management) are associated with improvements in functional status, psychological adjustment and pain (Keefe et al., 2004; Marks, 2001).

Therefore, the biopsychosocial factors mutually influence each other, often resulting in pain persistence (Gatchel et al., 2014; Jensen & Turk, 2014; Schatman, 2010). The Biopsychosocial Model of Pain further defines and conceptualizes the notion of CP as a *disease* (including anatomical, pathological, or physiological changes to body structures or organ systems) and as an *illness* (including the subjective experience of the disease). Taking into account both concepts reveals a more holistic approach to pain (Jensen & Turk, 2014; Schatman, 2010), which in turn facilitates the development of an interdisciplinary pain management approach that embodies the notion that doing a comprehensive assessment and treatment of all of the aforementioned variables is the most successful, therapeutic and cost-effective way to manage pain conditions (Gatchel et al., 2007).

In sum, it is necessary to evaluate the ICPs with consideration for every sphere in their life (biological, psychological and social), since individuals are not dissociated from their history or personality. This holistic approach tries to encompass all the factors involved in pain adaptation and that can promote or hinder adjustment to it.

1.2.1. Chronic pain epidemiology and burden

To understand CP, it is also relevant to know specific statistics that help comprehend the urgency countries are facing to deal with a growing problem. These statistics highlight the epidemiology and the burden of CP worldwide, as well as in Portugal.

Studies report that between 11.5 and 55% of the population worldwide live with some form of CP (Breivik et al., 2006; Harstall & Ospina, 2003; Johannes et al., 2010; Johansen et al., 2012; Landmark et al., 2012; Ospina & Harstall, 2002; Schopflocher et al., 2011; Tsang et al., 2008; van Hecke et al., 2013; Verhaak et al., 1998). More broadly, the WHO estimated that the prevalence of CP is around 37.3% in developed countries and 41.1% in low and middle income countries (Tsang et al., 2008). In addition, the 2017 Global Burden of Disease Study reports that even though the main causes of early death are ischemic heart diseases, neonatal diseases, and stroke, the leading causes of disability are low back pain, headache disorders (mainly migraines) and depressive disorders, with females having higher levels of disability than males (Institute for Health Metrics and Evaluation, 2018).

Taken together these findings stress the significant burden that CP has for society, healthcare systems, the economy and the individuals.

In fact, the CP burden derives not only from the utilization of resources within the healthcare system, with 60% of people visiting a physician between two and nine times within a 6-month time frame and 11% visiting at least 10 times (Breivik et al., 2006), but also from the loss of productivity (e.g., Leadley et al., 2012; Mayer et al., 2019) as the intensity, duration and location of the pain can play a major role on a patient's performance (Kawai et al., 2017). In fact, CP is one of the main reasons for work absenteeism (disability pensions and sickness absences) (Dorner, 2017). In that sense, the financial cost to society is high – over 200 billion euros per annum in Europe and between 560 and 635 billion dollars per annum in the United States (Barham, 2012; Gaskin & Richard, 2012; Oliver van Hecke et al., 2013).

In Portugal, the 2019 National Health Survey (Instituto Nacional de Estatística, 2020), estimated that 37.3% of people, aged 15 years or above, reported suffering with low back pain or other chronic back problems, and 27.1% with cervical pain or other types of chronic neck problems (an increase of 3 to 4% in relation to the previous survey conducted in 2014) (Instituto Nacional de Estatística, 2016) and another study estimated that 36.7% of Portuguese adults live with CP (Azevedo et al., 2012). More evidence showed that the average annual costs per ICP were €1,883, and nationwide the total per year was €4,612 million, corresponding to 2.71% of the Portuguese GDP. However, these calculations did not include hospital inpatient care which, if included, would moderately increase the estimates of CP costs (Azevedo et al., 2016).

Epidemiological studies also showed that CP is significantly linked with sociodemographic variables. Specifically, being female, older, retired, and or unemployed, and being from a lower socioeconomic status are risk factors for CP (Azevedo et al., 2012; Tsang et al., 2008). Despite the agreed upon definition of CP being 'pain that has persisted for three months or more', studies suggest that the majority of people (60%) have been living with CP for 2 to 15 years and 21% had lived with CP for more than 20 years (Breivik et al., 2006). Similarly, in Portugal people who have CP have lived with it for a median duration of 10 years (Azevedo et al., 2012).

CP interferes with activities of daily living and social roles due to pain related disability and affects one's perception of their overall health (Reid et al., 2011), and thus also affects their quality of life (QoL). In fact, the European survey previously mentioned, showed that most people report difficulties in performing everyday tasks, like lifting objects and doing household chores (Breivik et al., 2006). They also had trouble sleeping, exercising, walking or attending social activities, and thus CP negatively affected their QoL (Breivik et al., 2006). Likewise, in other studies, patients indicated they were unable to attend to social or family events due to their condition (Moulin et al., 2002) and negative emotions often affected their relationships and levels of stress (Henwood & Ellis, 2004). Moreover, some adults with CP withdraw from activities that increase the severity of pain (Akbari et al., 2017; Cabrera-Perona et al., 2017; Jones et al., 2017), and this decrease in activity levels is associated with more severe pain, comorbidity of diseases like diabetes or obesity, as well as, a greater use of healthcare services and increased difficulty in self-care (Pitcher et al., 2019).

Pain can also severely impact the psychological wellbeing of the individuals, and in Breivik et al.'s (2006) study, 21% of the respondents stated they were diagnosed with depression because of CP, and 54% consulted between two to six doctors for their pain. Clearly, CP places not only a burden in terms of prevalence but it is also a persistent problem for those who live with it and thus strategies that improve their quality of life (QoL) warrant more study. Therefore, this dissertation will have a focus on the role of interpersonal relationship on CP adjustment as friendships are a critical feature of one's social functioning.

1.3. The role of others on CP adjustment: Theoretical Models

Throughout the years several models were put forward to try and explain CP, more recently some conceptual models were found in the interpersonal, pain communication, and empathy literature that showcase the interpersonal dynamics experienced by ICPs that can impact their pain. Furthermore, since this dissertation is focused on the social dimensions of pain and this is an area of research currently in expansion, it is relevant to present a brief overview of main theoretical models on the role of others on CP experiences, since these models may provide a possible pathway to better understand the specific role of friends in this type of adjustment.

1.3.1. The Operant Conditioning Model of Pain

The first models were based on the operant conditioning model of pain by Fordyce (1976), which gave a substantial contribution to the understanding of CP. In general, this model posits that the behaviors people in pain display can be modified and maintained, that is, these behaviors can be learned and preserved from their consequences, either from positive or negative reinforcements (Fordyce, 1976). Even though, pain is a subjective experience, it was argued that people display particular behaviors to others that communicate the existence of pain, which Fordyce termed as *pain behaviors*, and these can be maintained through reinforcement, independent of pain. The behaviors included here are verbal complaints of pain, paraverbal sounds (e.g., moans), gestures and posture (e.g., grimacing), displaying functional limitations, as well as, behaviors related to pain reduction (e.g., use of painkillers) (Fordyce, 1976). Due to their frequent contact with ICPs, significant others like family members and intimate partners can be influential sources of positive/negative reinforcement or punishment, which can increase or decrease the presence of pain behaviors. Afterwards, cognitive-behavioral models emerged in the literature further expanding the conceptualization of the role of social responses on CP adjustment.

1.3.2. The Communal Coping Model

As noted previously, pain catastrophizing was described as a pattern of negative and exaggerated cognitions oriented towards pain, that may include feelings like rumination, magnification and helplessness (Sullivan et al., 2001). The communal coping model was elaborated in an attempt to describe how pain catastrophizing can be used to communicate a need for more support, more specifically, to elicit empathy and assistance from others (Clark et al., 2018). Pain catastrophizing can have an impact on the perceptions regarding pain severity, as pointed out by Sullivan and colleagues (2006). When ICPs receive support as a result of pain catastrophizing, it may decrease their pain but can also validate the assumption that pain is difficult to deal with. Additional evidence suggests that when a partner is present, ICPs engage in more pain catastrophizing and report feeling more support from their partners. Partners, also seem to exhibit less negative responses towards them when this happens (Burns et al., 2015).

In sum, there is evidence to support this model, which provides a greater picture of the pain experience from an interpersonal standpoint. It has been progressively recognized that coping often happens in a social context and stressors affect not only the person but also their social networks, with the latter also influencing how the individuals cope with stressors (Helgeson et al., 2018). It is not known if friends have the same influence as partners, and if ICPs also engage in more pain catastrophizing behaviors in their interactions with friends as a way to obtain more support. Therefore, a communication model of pain was put forward to try understand both sides of the relationship – the ICPs and the observers, since understanding how pain catastrophizing aspects are communicated may assist in the development of targeted interventions (Clark et al., 2018).

1.3.3. The Social Communication Model of Pain and Empathy

This socio-communication framework aimed to comprehend pain related communication, both self-reported and observed pain. According to this conceptualization, pain is first processed by the person experiencing it and this process is influenced by specific contextual factors unique to the individual. This is followed by the expression of pain to others (either verbal or non-verbal), which is decoded by the observer. The decoding process is heavily influenced by observers' biases (Hadjistavropoulos et al., 2011), and several cognitive and environmental factors (Goubert et al., 2005). In fact, developmental and social features of the ICP and the observer (e.g., partner, friend, family member) can influence their communication skills (e.g., expression of pain, meaning of the expression by observer, and meaning of the observers response by ICP), and thus influences each individuals interpretation of potential pain related threats of actual injury, or elicit emotional or instrumental support (Clark et al., 2018).

Communication models are also related to empathy, to the extent that individuals can choose to help someone for empathic reasons related to the ICP or for reasons that serve themselves (Batson & Shaw, 1991). Therefore, responses to distress (e.g., anger, anxiety, sadness) in others can be viewed as personal distress or empathy, with the latter being related to the inner desire to ameliorate pain in others (Batson & Shaw, 1991). Empathic responses have been conceptualized to have positive and negative outcomes like emotional validation, which demonstrates acceptance and effort to understand the individual’s pain-related emotional distress (Cano & Goubert, 2017; Cano & Williams, 2010; Edmond et al., 2015; Linton et al., 2008). Acknowledging the emotional disclosures of pain-related distress and its effect in a validating way promotes well-being in the ICP, as well as, intimacy and closeness to others (Cano & Goubert, 2017). This, in turn, can also provide feelings of gratification to the observer for helping the ICP feel better. However, witnessing others in pain can also lead to psychological distress, and thus for some observers they may distance themselves from the ICP as a form of self-protection (Batson, 1987).

In sum, the literature on these models suggests that responses to pain may change based on individual, interpersonal and contextual factors. It highlights the bidirectionality of the relationships, and that some observers may be distressed by another’s expression of pain. Moreover, what the observer perceives as empathic might function negatively for the ICP (Clark et al., 2018). This framework has been used to understand how successful spouses were at interpreting pain related communication relayed by ICPs (e.g., Leonard et al., 2013) but further research is needed to possibly confirm a similar effect in friendships.

1.3.4. Intimacy Process Model

This perspective derives from the work of Reis and Shaver (1988) as an alternative to the operant model, and they highlighted that intimacy increases when one individual engages in emotional disclosure and the other is responsive to it. This model expects some degree of empathy in the observer, but overall, the focus is on acceptance of pain expression as real. That is, when a partner emotionally validates the responses of the ICP, there is an increase in each person’s sense of intimacy, whereas the opposite (invalidation) disturbs emotion regulation (Reis & Shaver, 1988). Indeed, some studies have found that interactions with others may suppress pain, although these effects are dependent on the relationship history, individual differences and expectations about intimate interactions and whether these are believed to produce feelings of safety (Krahé et al., 2013). When an observer responds to emotional distress with emotional validation and acceptance, this might reinforce pain expression without reinforcing the emotional distress (Clark et al., 2018). This does not mean an observer agrees with the ICPs experience, but rather recognizes that their emotions, feelings and reactions are valid, whether or not they are accurate (Clark et al., 2018).

Furthermore, since CP is a very subjective and personal experience, it is important for the ICPs to feel understood in their social settings, that is, feeling they are accepted and not judged (Clark et al., 2018). In spite of this, ICPs often experience distrust from others regarding their symptoms (Herbette & Rimé, 2004). For instance, evidence from a study that measured ICPs pain related verbalizations, showed that these individuals felt they were not understood nor that their pain was recognized by their close others (Herbette & Rimé, 2004). In sum, when loved ones provide validation of ICPs pain experience, it contributes to their increased well-being, affect regulation and stress reduction, which in turn improves intimacy. However, this is contingent on the perception of empathy, which determines the positive or negative outcomes for the individual with pain (Clark et al., 2018).

Overall, the theoretical models presented in this section clearly stress the pivotal role of significant others on CP adaptation processes, as they may shape pain behaviors, adjustment and distress (Clark et al., 2018). Drawing conclusions based on more models other than the operant conditioning model of Fordyce (1976), offers a more integrative way to assess expectations, relationship dynamics and thoughts, and thus possibly provides more insight for the development of clinical interventions that assist the ICPs and their loved ones better adjust to CP. However, it is not known yet if these models can explain the myriad of relationship elements that exist or how behavioral or verbal responses by significant others (e.g., family members, spouses) impact and are impacted in the context of pain. Therefore, in order to evaluate an observers (e.g., partner, spouse) (in)validation and whether it reinforces pain behaviors, it is necessary to incorporate the communal coping, the social communication and empathy, and the intimacy process models in the analysis, as a way to also assess ICPs' and observers' perceptions of support and empathy.

In light of what was explained previously, it is argued that these models may be applied in some extent to other type of relationships such as friendships, but more research is needed to support these assertions, since most studies within the social dimensions of pain were focused on spouses or romantic partners (Bernardes et al., 2017). Therefore, as a way to bridge the existent knowledge regarding their role (spouses or partners) in CP and the current aim of this dissertation (understanding the reciprocal relationship between adult friendships and CP experiences), a brief overview of the role of the significant other on the adaptation to pain follows.

1.4. The Role of the Significant Other on CP adjustment: From partners to friends

Most of the existing literature on the role of interpersonal relationships and CP focuses on the role of romantic partners, and how they can promote or hinder the adaptation to pain (Bernardes et al., 2017). Partners' cognitions and behaviors play an important role in health-related outcomes of individuals with chronic illnesses (Snippen et al., 2019), because some responses may lead to decreased suffering and pain relief, whereas others may perpetuate individuals' distress and pain (Kindt et al., 2018).

Indeed, some studies with headache and musculoskeletal pain patients showed that responses facilitating well behaviors were negatively associated with physical disability (Pence et al., 2008; Schwartz et al., 2005). And other findings suggested that SS can help pain sufferers become more confident to cope with stress and perceive pain as less threatening (Corley et al., 2016; Holtzman & DeLongis, 2007; Kerns et al., 2002; Vlaeyen et al., 2009; Waltz et al., 1998). A higher psychological functioning (sense of mastery, self-esteem) was associated with higher emotional support or social interaction, which was linked with lower pain severity (Waltz et al., 1998). SS can help people with CP shift their focus away from the pain, decrease thoughts about not being able to cope with the pain, and reduce restrictions on activities (Holtzman et al., 2004; López-Martínez et al., 2008).

Conversely, CP can shift the equality of the intimate relations, to a state where the ICP becomes dependent upon the other for assistance in individual daily activities (e.g., showering) and household chores (Snelling, 1994). In studies with couples, evidence shows that partners' responses to expressions of pain influences individuals' adjustment to CP (Cano & Leong, 2012; Newton-John & Williams, 2006). For instance, maladaptive interactions and distress within the relationship are associated with depression and pain behaviors, severity and interference (Leonard et al., 2006; Pence et al., 2008; Schwartz et al., 2005). Higher spousal solicitousness was also associated to greater reports of disability in men with CP, greater pain-related interference, and lower pain tolerance in women (Boothby et al., 2004; Fillingim et al., 2003).

In sum, this section highlighted that ICPs' perceptions of their romantic partners' responses to pain may help or hinder CP adjustment. Whether a similar pattern would be found for the role of friends' responses to pain is under investigated. In fact, this gap in knowledge is worrisome as many ICPs may not be involved in romantic relationships. Moreover, there is evidence suggesting that CP increases the likelihood of separation/divorce or conflict in romantic relationships (Leonard et al., 2006; Peterson, 2011; Schwartz et al., 1996). Therefore, it is vital to understand what other social resources ICPs may have, which is the general aim of this dissertation – to draw a clearer picture of the role of adult friendships on pain adaptation.

1.4.1. The mutual relations between friendships and health

Social relationships are important features of one’s life, since humans are inherently social creatures (Laursen & Hartup, 2002). Therefore, exploring how friendships and their inherent SS processes may influence the adjustment of adults to CP is not only pertinent but needed. As such, in this section, a brief overview of friendships, what they are, what is their purpose, and how they may influence health in general, and pain in particular, as well as, how health can influence friendships, is presented.

Friendships are dynamic relationships that progress and grow over time (Blieszner & Adams, 1992), and can be described as reciprocal and voluntary (Rubin & Bowker, 2018). However, if one is asked “What is a friend?” there are several possible answers that come to mind, for instance, Sapadin (1988) asked 156 individuals living in New York, Boston and Los Angeles to complete the sentence “A friend is someone…”, and the three most frequent responses were “with whom you are intimate”, “you can trust” and “you can depend on”. These types of relationships are also characterized by a shared history, mutual platonic affection and companionship. People usually choose friends who are similar to themselves (e.g., considering characteristics such as gender, age, or interests), and these similarities are reflective of the varying degrees of closeness they feel to each of their friends (Rubin & Bowker, 2018; Wrzus et al., 2017). The different relationships we hold fulfill different needs in our lives, friendships usually meet our need for social integration but may also meet the need for attachment (Fehr, 1996; Weiss, 1969, 1974).

Across the lifecycle, friendships have been identified as a relationship of substantial significance. People obtain positive relationship provisions from relations with others, like psychological intimacy and social integration, and benefit from friendship processes (i.e., forms of interaction between friends such as self-disclosure and companionship) (Rubin & Bowker, 2018). These benefits can ultimately help assess friendship quality (Weeks, 2013). Friendship provisions can also influence positive outcomes such as social-cognitive skills and perspective-taking, that appear to lead to optimistic feelings about the others and the self, positive well-being and psychological health (e.g., higher levels of self-esteem and lower levels of depression and anxiety) (Rubin & Bowker, 2018; Uchino & Reblin, 2009; Wills & Ainette, 2009).

Indeed, throughout adolescence, friendships become progressively more intimate and influence psychological adjustment outcomes. However, if one is unable to form them, one may suffer psychologically, as individuals without friends report higher levels of loneliness (Rubin & Bowker, 2018). Later on, during midlife, friendships contribute to adults’ well-being as friends usually offer affection, companionship (that increases positive affect), SS and understanding, and they can also affect attitudes, behaviors and values (Adams & McCullough, 2009; Rook & Charles, 2018). These common characteristics of friendships are grounded in quality communication between friends, as they are more relaxed with each other than with acquaintances due to their shared mutual knowledge and higher levels of self-disclosure (Adams & McCullough, 2009).

People form lasting and close relationships which are usually beneficial for them by reducing stress, lowering their risk of disease, and even increasing longevity (Holt-Lunstad et al., 2010; Rook & Charles, 2018; Seyfarth & Cheney, 2012), as the size and quality of our friendship networks can influence our well-being, physical health, and happiness (Demir et al., 2007; Dunbar, 2018). Friends' behaviors are helpful when they are congruent with the needs of the recipient and the recipient feels validated, understood, and cared for. For example, there is evidence that during childhood and adolescence, having at least one friend can protect individuals from peer victimization and its negatively associated anxiety and aggression problems (Hodges et al., 1999; Rubin & Bowker, 2018).

SS friends are able to provide can be further classified as received or perceived support, and most studies examine health and relationships in terms of these two types of supportive roles (Uchino & Reblin, 2009). Received support is related to perceptions of past SS interactions provided by others, whereas perceived SS relates to perceptions of availability of support if needed (Dunkel-Schetter & Skokan, 1990; Holt-Lunstad, 2017). Friends provide emotional reassurance and instrumental assistance, which reduces the harmful effects of stress in one's life (Rook & Charles, 2018). This stress buffering effect occurs because the relationships we have can influence our interpretation (appraisal) of a stressful situation (Uchino & Reblin, 2009). Therefore, the way individuals cope with their illness and/or disability is largely determined by their relationships with friends and family, and the SS provided (i.e., instrumental or emotional) (Lyons & La Fontaine, 2009). Although positive in many instances, friends and family behaviors can also exert negative effects, especially as the chronic illness continues, as early support may wane overtime (Lyons & La Fontaine, 2009) or their friendship actions are not perceived as helpful by the person with the chronic illness.

If it is clear that friendships may influences individuals' health, health-related factors can also influence the development, maintenance and dissolution of friendships (O'Malley & Christakis, 2011), although this topic has been less explored. Indeed, people with chronic illnesses and disability usually have smaller and more dense social networks. For example, adults with CP have reported withdrawing from interactions with others to preserve energy and reduce fatigue (Lyons & La Fontaine, 2009), which highlights the bidirectionality of friendships and health.

In sum, there is enough evidence to conclude that friends play an important role in someone's life, regardless of the existence of a chronic condition, since they provide affection and support that promotes well-being and happiness (Demir et al., 2007; Dunbar, 2018). Noteworthy is the potentially relevant role friends may have in an ICPs' life (Lyons & La Fontaine, 2009). However, as previously mentioned, the literature exploring links between friendships and CP adaptation is scarce and warrants more study. Bridging this gap will be a major aim of this dissertation. An overview of current evidence on the friendship influence on pain experiences and the influence of CP on friendships is provided below.

1.4.2. Friendships influence on (chronic) pain experiences

Friendships may influence one's pain experiences through the SS they may offer (Lyons & La Fontaine, 2009). The first studies highlighted here to explain this relationship pertain to both family and friends, as researchers did not provide a clear separation of both when reporting their findings. Therefore, it is necessary to exert some caution with the interpretation of these results in terms of attributing them entirely to friendships. However, there is also a growing body of literature specific to the role of platonic friendship and adolescent CP (Forgeron & King, 2013), which is relevant to answer the research questions put forward, and thus those findings were also described in this section.

Evidence suggests that ICPs may interpret their friends' behaviors about their pain condition as either supportive or non-supportive and therefore it was proposed that the same platonic friends can have both positive and negative effects (Affleck et al., 1988; Forgeron et al., 2011, 2013; Forgeron & McGrath, 2008). A few studies with individuals suffering from rheumatoid arthritis have shown that friends and family support may have beneficial effects on adaptation to pain, such as a greater psychological adjustment when ICPs are satisfied with their SS (Affleck et al., 1988; Holtzman et al., 2004), encouragement for the use of active problem solving to cope with pain, distraction from pain (Holtzman et al., 2004), and reduction in depressive symptomatology in individuals with elevated pain intensity (Park et al., 2017). This suggests that when ICPs feel they are supported they use a greater number of coping strategies (Holtzman et al., 2004), which can be beneficial for the adjustment because they can increase functional status and decrease functional impairment (López-Martínez et al., 2008). Indeed, having a friend or a family member that listens to their concerns and feelings, and encourages positive appraisals of their condition, while giving hope and being optimistic was extremely valued and considered helpful (Affleck et al., 1988).

However, these studies also showed that SS from friends and family may bear negative effects such as, for example, maladaptive pain coping mechanisms when they push ICPs too hard and cause, even if inadvertently, overexertion (Holtzman et al., 2004). Also, friends' failure to acknowledge the severity of ICP's condition, with some making insensitive dismissals like stating the pain is all in their head, made the coping with the illness more difficult (Affleck et al., 1988; Holtzman et al., 2004). Additionally, when friends were oversolicitous and demonstrated pity or even when they excluded the person in pain from social plans, also took a toll on ICPs pain and their coping strategies (Affleck et al., 1988).

Other investigations with adolescents, directly related to the role of friends in CP, suggest that supportive friends improve attitudes and functioning in youth with chronic illnesses, which may also buffer the detrimental effects of pain (Nabors et al., 2015). However, another study using narrative vignettes showed that adolescents with CP may develop a sensitivity to negative social interactions if they did not feel supported by friends due to their CP (Forgeron et al., 2011). When adolescents have positive relationships with friends they have been found to be pushed beyond their limits and improve their daily functioning despite high levels of pain, resulting in independence and better perceived social competence (Pinquart & Teubert, 2011; Walker et al., 2002). Furthermore, higher perceived support from friends was associated with decreased loneliness and depressive symptoms in adolescents with CP (Forgeron et al., 2018), leading to the conclusion that perceived support may also have a buffering effect on depressed mood.

Despite children and adolescents with CP experiencing difficulties with friendships and peer relations, the causes for these challenges are not entirely known. However, some potential causes have been suggested, such as, the absence from typical social environments (e.g., school, leisure activities), experiencing disbelief from others, lack of insight into one’s pain condition, and holding expectations that friends may not be able to fulfill (Forgeron et al., 2011, 2013; La Buissonnière-Ariza et al., 2018). Furthermore, even though friends who do not share the condition may be supportive and understanding in the beginning, over time they may feel that their friend with CP does not satisfy their own friendship needs and may seek other alternative friends (Forgeron & King, 2013).

In sum, the research shows that platonic friends may be a source of positive SS or a source of stress for adults and adolescents with CP, yet the literature on friendship patterns of adults with CP does not make a clear distinction between friends and family and their respective influences on the adaptation to pain. Therefore, this warrants more study, not only pertaining to the role of friends on the adjustment to pain but also to the influence of pain on friendships since these are reciprocal relationships and pain might be disruptive to those exchanges (Shumaker & Brownell, 1984). To address these gaps, the first goal of this dissertation was to explore how adult friendships influence the adaptation to CP, and more specifically, which friends’ attitudes and behaviors would be considered more helpful and unhelpful by adults with CP.

1.4.3. Chronic Pain influence on friendships

Less is known regarding the possible impact that CP may have on friendships. When participants described their sources of stress in living with their condition, they often mentioned disruption in relationships (with family and friends) (Affleck et al., 1988; Shumaker & Brownell, 1984). Stigma associated with disability and an uncomfortable feeling of dependency on loved ones, created a tendency to distance themselves (Affleck et al., 1988), perhaps because they felt that by accepting the SS provided and not being able to reciprocate could create a cycle of indebtedness that would not be easily repaid. However, if the solution ICPs employ to resolve this dilemma is to reject the support, the friendship will most likely deteriorate (Shumaker & Brownell, 1984). In other instances, CP actually enhanced adults' relationships with friends and family, since there was a greater sensitivity and appropriateness of the provided support (Shumaker & Brownell, 1984).

Pain seems to have an impact on family members' psychological well-being, specifically it may create extreme distress and psychological burden (Romano et al., 1989), with a direct effect on anxiety and depressive symptoms (Schlesinger, 1996; Schwartz et al., 1991; Stephens et al., 2006). In fact, some studies also showed that negative emotions of family members mirror ICPs own emotional distress (Schwartz et al., 1991), with high levels of congruence in anger and depression among dyads dealing with osteoarthritis (Druley et al., 2003). The pain effect on family members' well-being may also be contingent on the verbal and non-verbal communication an ICP has regarding their symptoms (A. A. Smith, 2003), as a greater perception of a loved one's distress might influence one's depressive symptoms (Stephens et al., 2006). However, it is not known if these effects can be extended to friends, therefore, the possible connection between pain and friendships needs further study.

In sum, the available evidence regarding the influence of pain on friendships is limited. It is known that given the voluntary characteristics of friendships, if a friend does not feel that their support is reciprocated by the ICP, the relationship may be strained, and they may choose to dissolve the friendship. However, if one chooses to deal with the strains and tensions and still provide support, it is not known what the long-terms effects are for the friend in particular and the friendship in general, one can assume that the effects may be similar to the ones previously mentioned for family members, but the evidence to confirm it is inadequate. Therefore, in an attempt to provide some insight into these effects, the second specific goal of this dissertation was to investigate how CP can influence adult friendships.

To better understand the reciprocal relationship between adult friendships and CP, this dissertation presents a qualitative study. This study sought to contribute to the literature on the role of friendships in the adaptation to CP, more specifically how can adult friendships promote or hinder the adjustment to pain as well as, how can CP influence adult friendships. The next chapter details the methodology used to explore these research goals.

CHAPTER 2

Methodology

2.1. Study Design

The present study used a qualitative descriptive methodology (QDM) to understand the influence of friendships in the adaptation to CP. Qualitative descriptive research is warranted when a new area of research is being explored as the intent is to gain a deep understanding of the phenomena under study from participants perceptions of their lived experience (Polit & Beck, 2017; Sandelowski, 2000). Thus, the exploration of friendship experiences of adults with CP, through a recounting of their everyday events, would provide insights into how friendships may shape one’s adaptation to CP and how CP shapes one’s friendships. A QDM provides not only an outline of individual understandings and social practices, but also offers an opportunity to analyze issues like stigmatization, the effects of poverty in health and illness or cultural aspects such as marginalization, that would be most likely less understood if a quantitative approach was used. QDM is more open and therefore, gives the participants the opportunity to tell their story in more detail and in their own words, while also providing the researcher with valuable information such as non-verbal communication (for instance, in the case of interviews) that would be otherwise missed (Willig & Stainton-Rogers, 2017).

2.2. Procedure

2.2.1. Participant recruitment and ethics

Participants were sought out using community advertisement. Specifically, postings to advertise the study were sent to several Portuguese pain associations (e.g., Myos - Associação Nacional Contra a Fibromialgia e Síndrome de Fadiga Crónica and Liga Portuguesa Contra as Doenças Reumáticas), posted on an array of Facebook groups that target individuals with chronically painful conditions (e.g., Dor Crónica em Portugal), as well as, the authors’ personal Facebook. The postings included a brief description of the study, explaining the general objectives, emphasizing that the individual interviews would be confidential, and the researcher contact information for those who may be interested in taking part in the study. Furthermore, to participate in this study, the individuals had to be 18 years old or older, currently living in Portugal and living with CP for more than 3 months per the most recent definition of CP (World Health Organization, 2019).

Interested individuals were sent the informed consent (Annex A) via email, which reviewed the purpose, potential risks, and that participation was voluntary. The consent form also acknowledged the need to audiotape and transcribe the interviews for analysis, and the steps to protect confidentiality of the data. Consenting individuals were then scheduled for an individual web-based videoconference interview with the researcher. During the transcription of the audiotaped interviews, the participants were given an alias (Table 2.2.1.) and identifying information (e.g., friends names, places of work) were removed or changed to protect their identity. This study followed the Code of Ethical Conduct in Research of ISCTE-IUL and the Ethical Principles of Psychologists and Code of Conduct of the Portuguese Psychologists Association (Ordem dos Psicólogos Portugueses, 2011).

Table 2.2.1.

Participants sorted through attributed alias, gender, age, type of pain, pain duration, Marital and Employment Status

Participant Alias	Gender	Age (years)	Type of Pain	Pain Duration/ Pain Onset	Marital Status[a]	Employment Status[b]
Rosa	Female	26	Endometriosis	5 years	M	E
Jéssica	Female	50	Fibromyalgia	17 years	D	U
Maria	Female	48	Fibromyalgia	9 years	M	E
Bianca	Female	36	Fibromyalgia	6 years	D	E
Patricia	Female	55	Fibromyalgia	>10 years	D	R
Raquel	Female	56	Arthritis; Fibromyalgia	45 years	M	R
Luísa	Female	61	Fibromyalgia	31 years	M	R
Ana	Female	53	Ankylosing Spondylitis	26 years	M	E
Paulo	Male	18	Spinal Pathology	4 years	S	E
Tiago	Male	37	Fibromyalgia	Since childhood	CL	E
Amélia	Female	59	Spinal Pathology	16 years	S	E
Joana	Female	45	Connective Tissue Disease; Fibromyalgia	Since childhood	D	E
Dora	Female	28	Arthritis	5 years	S	E
Sara	Female	49	Sjogren's Syndrome	Since adolescence	M	E
Vanessa	Female	29	Fibromyalgia	Since childhood	S	U
Alice	Female	45	Lupus; Vasculitis	33 years	S	E

[a] **Marital Status**: CL – Common-Law; D – Divorced; M – Married; S – Single

[b] **Employment Status**: E – Employed; R – Retired; U - Unemployed

2.2.2. Data collection

The qualitative descriptive nature of this study required an in-dept approach to data collection, since the goal is to generate more information to complement the existing literature, therefore the best way to do so is to elicit the views of the participants with open-ended questions that allow them more freedom to explain their experiences. More specifically, individual semi-structured interviews were used as a way to obtain more detailed understanding into the friendships of individuals with CP than could be elicited from a questionnaire. This way of collecting data allows the interviewer more flexibility in orienting the interview towards the research goals, as well as, an opportunity to develop certain directions that may arise during the conversation, while still providing room for the interviewee to express their thoughts and feelings (Merriam & Tisdell, 2016).

To assist with the interviews a semi-structured interview guide (Annex B) was used that moved from general pain related questions such as "Can you tell me a bit about your pain?" and "What are some of the coping strategies you use to deal with pain?" to more specific questions regarding their friendships like "Has your pain affected or does it currently affect your relationships with friends? If so, how?" and "Can you tell me about a situation that your friends tried to help you when you were in pain and you felt that action was helpful?". Some of these questions were more exploratory in nature, and consequently provided more liberty to the interviewee to tell his/her story, and others were alternatives (e.g., probe questions) that could be used if it was necessary to direct the interview towards the research goals.

For instance, questions like "Can you tell me about a situation that your friends tried to help you when you were in pain and you felt that action was not helpful?" or "Can you tell me about a situation where you felt your friends did not support you?" tried to provide answers to one of the research goals – (1) in what manner can friendships influence the adaptation to CP. In particular we sought to capture in the interviews, which behaviors exhibited by friends were considered helpful or not and how does that affect the way they cope with their pain. In addition, exploratory questions such as those mentioned in the preceding paragraph tried to provide answers to the other research goal – (2) in what way can CP influence adult friendships.

The interviews were conducted using Zoom Conference Calls© or Facebook© and varied in length and lasted from 15 minutes to 1 hour. The use of voice over internet protocol applications is especially useful for qualitative research as it brings a more intimate approach to facilitate communication between people (Moylan et al., 2015). When both participants and the researcher have web cameras the videoconferencing allows for an interview experience that is more in keeping with in-person versus telephone interviews as nonverbal communication can be observed (Redlich-amirav & Higginbottom, 2014), allowing for researchers to express empathy and capture visual cues that otherwise would be missed if the interview modality was voice only (Hamilton, 2014). Also, the uptake of web-based videoconferencing is growing. In fact, 73,5% of the Portuguese population aged 16 years and above report using a computer and/or internet (INE, 2019), suggesting that web-based videoconferencing would be an acceptable strategy to allow for participants who may live in a significant distance from the research to take part in the study.

There are several other advantages of web-based interview methods, such as low-cost and time efficiency by supplying a quick way to connect without leaving one's house (Redlich-amirav & Higginbottom, 2014). Applications like Zoom (or Skype) also have features that enables the host to record the meeting, and thus facilitating the audio or videotaping aspect necessary to conduct further analysis post interview (Zoom Video Communications Inc., 2020). The audio recording was transcribed and translated into English by the author.

2.3. Qualitative Data Analysis

The data was analyzed using a qualitative thematic analysis (QTA), which is a systematic, flexible way to reduce and interpret data in order to give meaning to seemingly unrelated information (Boyatzis, 1998). The main objective with this type of qualitative analysis is to create a story from the data (parts of the text) that are relevant to the research questions. This is accomplished by the investigator bringing together the salient themes and patterns in the texts (Guest et al., 2012; Saldana, 2009). QTA ends when saturation of the data is reached, that is, no more themes are identified (Ando et al., 2014).

Clarke & Braun (2014) identify a six steps process for QTA, which was used in this study. The first step starts with the familiarization with the data and the identification of potential pieces of information that may be of interest. This was accomplished with the reading of the transcripts of the interviews and the highlighting of bits of text that seemed relevant. The second step involves the generation of initial codes or nodes that identify important aspects of the data that are relevant in answering the research questions. This was done by segmenting and tagging the data, meaning that smaller bits of the interviews were coded inductively from the text with a brief description or a word. The third step in this process involves the search for themes, where the investigator looks for greater patterns of meaning. This was achieved with the examination of the codes previously created and the sorting of the quotes into overarching themes that could represent the data. Step four pertains to the review of the created themes, which involved the refinement, combination or division of the data in a way that aims to answer the research questions and tells the story of the data. In this study this was accomplished by collapsing emerging themes from step three into larger themes, and associated subthemes, based on the objectives of the study with a further sorting of the quotes from the interviews. The fifth step involves the naming and definition of the created themes by attributing names to the themes based on the research questions along with the definitions to represent a close description of what the participants mentioned. Finally, the sixth step pertains to the creation of a narrative that articulates the data with the existent literature.

Data analysis was assisted with the use of QSR International's NVivo 12 Pro software, which helps with the organization of the data and treatment of non-structured information. The categories and themes were created to reflect the concepts under study, ensuring that they were empirically grounded (Dey, 2004). The results that follow entail a description of the content of the main categories (themes) by explaining their meaning (GAO, 1996) with included exemplars from participants to aid with the credibility on the research findings (Graneheim & Lundman, 2004).

2.3.1. Quality Criteria

Lincoln and Guba (1985) approach to rigor—assessing the trustworthiness of the study—was used in this study. Lincoln and Guba proposed four criteria for to determine trustworthiness: credibility, transferability, dependability and confirmability. Credibility is used to ensure that the study measures what it proposes to measure. In this study peer debriefing was used to ensure creditability (Houghton et al., 2013), as input from the advisors were sought in the creation of the codes and themes.

Dependability refers to the stability of the findings and if the same results would be obtained if a similar study was conducted in a similar context (Polit & Beck, 2017). An audit trail is a strategy suggested to demonstrate dependability which involves a documenting and explaining the decisions made during the research process. In this study, this was achieved by maintaining records of the interview transcripts, the data reduction, pilot results and drafts of the final document (Polit & Beck, 2017);

Confirmability is related to ensuring that the data represents the information participants provided and that interpretations of the data were grounded in the participants experiences (Polit & Beck, 2017),and not invented by the researcher. This was achieved by including others in the analysis (the primary author and the advisors met to review codes, findings and discuss themes) and through the use of close descriptions of what was shared by the participants with exemplifying quotes.

Lastly, transferability refers to the extent to which the findings can be extrapolated to other settings or groups. Transferability is enacted by the reader but researchers use strategies like thick descriptions, providing detailed accounts of the context and research methods, so readers can make their own interpretations and ultimately decide if it is transferable to another context (Graneheim & Lundman, 2004). In this study the inclusion of details such as the unique characteristics of the participants (i.e., demographics, as well as, pain frequency, duration and diagnose), the approach used to collect data (i.e., semi-structured interviews) and the data analysis (i.e., qualitative thematic analysis) and rich description of the findings with participant quotes are aimed at improving the transferability of the findings.

In the next chapter, an outline of participants' demographics will be given, and the results will be discussed in more detail with supportive quotes.

CHAPTER 3

Results

3.1. Participants

A total of seventeen individuals participated, but one man was excluded because it did not present any pain, therefore not fulfilling every criterion for participation. Of the sixteen, fourteen were women (87.5%) and two were men (12.5%), 37.5% were married (n=6), 25% were divorced (n=4) and 31.3% were single (n=5). The respondents ages ranged between 18 and 61 years old, with the average age being 43 years (SD = 12.98). Regarding their level of education, 31.3% only completed High School and 56.3% completed a higher education (Bachelor or Master). In terms of employment, 68.8% were employed (n= 11) and 18.8% were retired (n=3) (Table 3.1.).

Furthermore, with regards to pain diagnose, nine participants reported suffering from Fibromyalgia (56.25%), with two of them simultaneously suffering from other related conditions (Arthritis and Connective Tissue Disease). The remaining individuals suffered from one of these conditions: Ankylosing Spondylitis, Arthritis, Spinal Pathology, Endometriosis, Lupus, Vasculitis or Sjogren’s Syndrome (n=7). The majority of the participants reported feeling pain everyday (93.8%), with most of them (81.3%) reporting mild to moderate pain (Boonstra et al., 2016), and a pain duration of at least 4 years since the onset of CP (Table 2.2.1.). The most common pain locations among the individuals were back (43.8%), extremities (31.3%), arms (25%) and knees (25%), with 35.3% of the respondents also manifesting a generalized pain (Table 3.1.).

Table 3.1.

Patient Demographics, Pain and Medical Characteristics

	M	*SD*	*Statistics*	
			Minimum	*Maximum*
Age (years)	43.4	12.98	18	61
	Total			
	n	*%*		
Gender				
Female	14	87.5		
Male	2	12.5		
Total	16	100		
Marital Status				
Married	6	37.5		
Divorced	4	25.0		
Single	5	31.3		
Common-Law	1	6.3		
Highest Degree Completed				
Elementary	2	12.5		

High School	5	31.3
Bachelor or Higher	9	56.3
Employment Status		
Employed	11	68.8
Retired	3	18.8
Unemployed	2	12.5
Diagnose		
Fibromyalgia	9	56.3
Arthritis [a]	2	12.5
Spinal Pathology	2	12.5
Ankylosing Spondylitis	1	6.3
Connective Tissue Disease [a]	1	6.3
Endometriosis	1	6.3
Lupus [a]	1	6.3
Vasculitis [a]	1	6.3
Sjogren's Syndrome	1	6.3
Most Common Pain Locations		
Generalized	6	35.3
Back	7	43.8
Extremities	5	31.3
Arms	4	25.0
Knees	4	25.0

[a] Some individuals reported suffering from more than one condition (e.g., one individual suffered from both fibromyalgia and arthritis)

3.2. Main Results

Thematic analysis revealed several themes in the friendship experiences of adults with CP. However, overlap amongst the themes exist, and are expected, as the delineation of themes negates the integrated experiences of participants. As previously mentioned, to assure the confidentiality of the interviews, aliases were attributed to the participants (Table 2.2.1.).

Within this first theme we identified four subthemes that are inclusive of experiences where friends either promote or hinder adjustment to CP. More specifically, these themes, or dimensions of behaviors, include **Friends demonstrate (un)availability to provide support**, which highlights the friends' concern in showing they are present and available, as well as, the opposite – they do not make an effort to assist their friend in need. The second subtheme entitled **Friends provide (un)needed support**, pertains to the physical and emotional support friends actually provide, as well as, the support they provide that ICPs do not want or is perceived as overbearing and out of place. The third subtheme, **Friends are (not) accepting and (not) accommodating,** relates to how accepting, flexible and non-judgmental (or not) friends are towards the person with pain. Finally, the fourth subtheme, **Friends promote life (dis)engagement,** highlights the way friends are able to promote active life engagement and how that affects the lives of ICPs, as well as, the way they promote a disengagement when treating someone with pain as a sick person. These will be further described below.

3.2.1. Friends influences promote or hinder adjustment

3.2.1.1. Friends demonstrate (un)availability to provide support. Availability or the unavailability to provide support stems from responses that promote adjustment (showing availability) to responses that hinder adjustment (not showing availability). Support availability describes the collection of friend's behaviors that identify attitudes and behaviors friends display towards ICPs where they show concern for their friend when they are in pain. These behaviors include asking if the person needs anything, if they can do something to help and, thus adjust their support accordingly, as illustrated in these two quotes and echoed by others: (…) *but when they see me in pain they ask 'what do you need? Do you take anything? What can we do?', I think there's that attention from friends*. (Rosa, 26 years old).

"There are people who look at me, I may be normal in conversation, but they look at my face and they can see, because they say that I change my facial expression a lot and I get bags under my eyes, they realize that you are in pain and then they try [to ask] 'what do you want to do? Do you want to do this? Do you want to do that? Do you want to go away?" (Tiago, 37 years old).

Availability of support is not solely related to when friends are physically present. Friends who live further away also show that they are available to offer support or are available to talk with the ICPs. This form of availability is described as important for the ICPs as it provides a sense of caring and value as a person and friend and not solely a person with pain. The following quotes highlight how friends are available despite physical distance.

"Just to say that I have friends in several other places, because I have lived in several places, and even those who are further away, always stayed my friends and when I was down, because there were times when I was very down, they always wanted, although they could not be with me, they wanted to talk to me and see if they would help me" (Paulo, 18 years old);

"There are those who call me and really talk to me and it's usually about matters that have nothing to do with the pain, I mean, it's more a strategy to be with you, let's talk about things that are not heavy and that are my business and yours" (Amélia, 59 years old).

In fact, some participants stated that some of their friends actively try to understand and research their health condition to better understand their needs. This type of investment by their friends into understanding made those with CP feel supported and understood, as illustrated here by Tiago and echoed by Vanessa.

“They were also careful to get informed about things, they were careful to understand, if we are going to deal with [Tiago] for the rest of our lives, if we want him to remain our friend for the rest of his life, we also have to find strategies to help him without overloading him” (Tiago, 37 years old).

“I have a colleague of mine [who is also a friend] who I think understands my situation the most, for example, when she sees something about it [fibromyalgia], she immediately sends me a message, and tries to find out more about it, which I think is good, because it is good when your friends show interest in understanding what is going on with you, and I think that right now she is the only one, apart from my boyfriend, who tries to find out about it” (Vanessa, 29 years old).

In contrast, some participants shared experiences of friends unavailable to provide support and help. These behaviors are perceived as friends not making an effort to help their friend in need and make those with pain feel devalued as a friend and person. Here Raquel describes how some friends have not been available to help: *Now those who sometimes say, 'ah if you need help say something', but we don't see them. I do not ask much* [from them] *either, I should...* (Raquel, 56 years old). In an extreme case of unavailability by friends one participant felt abandoned by her friends as she reported that her friends did not try even reach out to her and to understand how she was doing. This situation left Jéssica feeling that she does not have anyone who could provide her support when she needs it the most, as shared here:

“My friends are common friends with my ex-husband. They knew and nobody called me, for example, asking if I was okay, if I needed anything, they heard the story. They're still my friends, then they heard the other side of the story... 'ah we didn't know you were so sick...'. And the reality is that I don't have anyone to bring me a glass of water, even when I'm in crisis, so I always have my pantry with some things, the freezer with soup and some other things, just in case of a crisis so I don't have to make food” (Jéssica, 50 years old).

In sum, the majority of the participants reported that their friends show availability, even if it is in the form of a telephone call. These gestures of availability to support the ICPs create opportunities for ICPs to feel valued by knowing that there is someone who cares for their well-being. For the few participants whose friends did not offer support or outright abandoned them the effects were significant as these participants felt alone and uncared for. Overall, there were no notable differences between genders, most men and women in the study reported some form of availability.

3.2.1.2. Friends provide (un)needed support. This second subtheme describes the experiences of participants’ friends providing actual support that fits ICPs needs and promotes adjustment to CP, as well as, the hinderance of adjustment to CP resulting from friends providing unneeded, unwanted, or misplaced support. The following quotes identify actual supportive behaviors friends took towards the ICPs that they deemed needed and helpful in their situation.

The provision of instrumental support can be isolated to a specific event, as described here by Joana: *When I make big trips, I can't get out of the car, then them* [friends] *helping me getting out of the car is a big help, although I don't like it (Joana, 45 years old)*. Even though, in this particular instance, Joana reported not liking the need for help as it makes her condition visible, she considered the situation as helpful because without this help she would not to be able to get out of the car in a timely manner. This type of physical support was also experienced by others as noted her by Amélia when she had to deliver a rent-a-car and was not able to do, so her friend drove:

“I, for example, have had a situation of having had an accident and all of those logistics of picking up a replacement car and having to deliver the car on that specific day, until 7 o'clock, I was having difficulties in driving the car to the place where I had to deliver it and a friend came to do it with me” (Amélia, 59 years old).

Other forms of instrumental support included friends helping with cooking when the host (with pain) could not and go with the ICP grocery shopping. Friends were also instrumental in assisting their friends to access care for their CP condition, which helped the promotion of adjustment to life with CP. Here Tiago spoke of how his friend took him to the hospital to get more assistance, since his friend felt powerless watching him suffer with pain and not knowing what could be done to ameliorate it.

“He took me to the hospital, to his psychiatrist and said 'please see my friend, my friend needs help, he needs something, because it's not normal for me to see my friend grabbing and biting on a pillow, full of pain, so something has to be done', and that's when I curiously accepted that I needed extra help…” (Tiago, 37 years old).

Alice, on the other hand, described the provision of emotional support by a friend when she had to go to the hospital after an unexplained pain exacerbation. In this situation as soon as one of her friends knew she was in the hospital he rushed to the hospital to provide comfort, support and a friendly face. The benefits of this display of emotional support are described here in this quote by Alice:

“R stayed with me, but when my mother arrived, she went with me to the hospital. M who was with me earlier called J (they are all from the same group of friends) saying that I had gone to the hospital in an emergency, J went straight to the hospital and when he came in, I was in bad shape, we exchanged some jokes, and we started laughing, and my mother says 'oh J, good, at least Alice laughed'. I mean, he didn't really do anything, he didn't help me physically, and I continued to have the problem, and fainting, that day was a horrible day... but I always felt supported" (Alice, 45 years old).

Contrarily, friends may also provide support that the ICPs do not want or need in a particular situation and that this form of unwanted support might, at times, be perceived as overbearing or oversolicitous. Unwanted support was experienced by numerous participants as illustrated here by Tiago:

"I have friends of mine when the weather changes, who know that pain is very affected by sudden changes in temperature, they send me messages 'you must be in more pain today, right? What do you need?' (…) Although I had a time when I had to punch the table and say, 'calm down, you can help, you're my friends, but don't be too friendly either'" (Tiago, 37 years old);

Bianca, one of the participants also stated that having a friend that is very insistent while trying to be helpful, has the opposite effect of what was intended and is perceived as overbearing and stressful, as seen here:

"There are moments for everything, I was feeling vulnerable and the person was insisting (it was a friend of mine who works with me) that she wanted to come pick me up and take me to her house and I kind of wanted to be in my corner and tell her to leave me alone, so much so that it ended up stressing me out more and I ended up turning off my phone and disappearing from the face of the earth, and I don't think that helped me at all" (Bianca, 36 years old).

In addition, another participant voiced that when friends demonstrate too much pity for their condition or try to offer themselves to come over and do certain tasks, is perceived as oversolicitous and therefore, unwanted or misplaced help, as Amélia described:

"I have a friend, she always reacts in a way that doesn't do me any good, she tells me 'oh poor little A, poor little A, can I go there now? Maybe I could come and do the dishes or whatever you need', I know she is a person that I do not want around when I have to do a management that is very much mine, you know? This excess of concern, this excessive need to express that you're sorry and that you understand, that's something that makes me uncomfortable. It's not exactly good for me" (Amélia, 59 years old).

Overall, friends were described as providing support when needed through their attitudes and behaviors that assisted the ICPs in their daily lives and tasks. Even though some participants referred to having friends whose behaviors were perceived as overbearing and overly solicitous, these situations related to an incongruency between what the ICPs desired as a form of emotional support more so than the instrumental support behaviors described and the insistence of the friends to help.

Thus, the participants in this study spoke mostly of being satisfied with their friendships provision of support as this provision was in line with the support, they desired, with no notable differences between genders.

3.2.1.3. Friends are (not) accepting and (not) accommodating. Throughout the interviews, participants spoke of times when friends were being accepting and accommodating as a response that promoted participants positive adjustment to life with CP but also spoke of times when friends were not accepting nor accommodating which hindered their adjustment to CP. Friends who accept the individuals' limitations, were flexible and non-judgmental, were described as trying to accommodate the needs of ICPs, were understanding of certain situations such as accepting that ICPs might not be able to attend some gatherings due to pain were perceived as being helpful. In fact, despite limitations accommodating friends were perceived as not only being flexible to the limitations of ICPs but that they still tried to do spend time with them by engaging in activities in which ICPs could engage. Moreover, participants spoke of how these accommodating friends were not judgmental when participants were unable to do a certain task or activity, as shared in these quotes and mirrored by others:

"I have a group of friends from work, we have lunch, usually we take our lunch, and then we go out for a cup of coffee, (…) we always go for a walk, and I often don't go, because I've already done my physical exercise at 7 am, and on the one hand I am tired or I am in pain, and I always say 'I cannot go with you today, you walk a lot, you run a lot and I cannot walk with you', I have never felt the distance from them [because], they usually say when you can, you come, when you cannot, you won't, you are always welcome" (Ana, 53 years old).

"I say I'm avoiding red meat [increases her abdominal pain] and people say, 'so let's not eat a hamburger, let's eat salmon or go to a different restaurant'. There was that attention from people, and I think that's the positive part. They tried not to make me feel bad, like eating a steak in front of me and I can't" (Rosa, 26 years old).

Conversely, friends that do not accept the ICPs limitations, are not flexible towards their condition nor try to accommodate their needs were viewed as unhelpful and resulted in some participants distancing themselves from these friends. It was not solely the inflexibility in changing plans that caused some of the participants to distance themselves from friends but also that unaccommodating friends typically exhibited attitudes and/or behaviors that were dismissal of pain complaints and/or devaluation of their feelings, mostly by not believing their pain was real or as intense as they stated. In the following two quotes Dora and Tiago, share their experiences with unaccommodating friends:

“I was in a lot of pain and it was like 'oh no, but you're fine... let's go', but I'd say 'no, I'm really in pain, I'm not in the mood', 'no, but let's go, you need to relax', of course I'd make up an excuse, do things to try not to go... sometimes I'd even go to the coffee shop and come home” (Dora, 28 years old).

“They [the friends] also said, 'but you have such an active life, you do so many things, I don't know what else… how is it possible?', 'why are you not in pain in those moments and now you are here looking as if someone owes you something, if you don't want to be with us don't come, no one forces you to be [here]” (Tiago, 37 years old).

The fluctuating nature of CP, as well as, the fact that many participants experienced constant pain was an added complexity for some friends. These pain related characteristics result in exchanges with friends and colleagues that left participants feeling judged or harassed for experiencing pain. The following two quotes illustrate these experiences, but unfortunately these experiences were not isolated and were echoed by other participants.

“Sometimes when I'm at work and I say, 'today I'm really uncomfortable, today my back really hurts, today I can't do it', and someone asks, 'but didn't you go swimming?' and I say 'I did', 'but doesn't that help?', 'yes it helps, but the problem is here', this annoys me” (Ana, 53 years old).

“I am the oldest of a group of friends, also with my sister, and we were spending a weekend at a friend's house, and they all wanted to go out at night, and in a way they couldn't because I was in pain and I didn't really want to go right? And in a way they forced me a little, they forced me out of the house, 'come on, we're only here for this short while’…” (Paulo, 18 years old).

In other instances, friends were reported as not being flexible to ICP’s limitations and were not open to accommodating their needs, even after being alerted to them, as Sara states here.

“There was a situation where there was an activity in which I had offered to participate, it involved using my hands, peeling food and so on, and when the day came I couldn't, I was in pain and I couldn't, but I went there anyway, 'I came but I can't help, I can't even stand here' and people said to me 'so go home, go away', and I didn't see it that in way, I wish I had stayed there” (Sara, 49 years old).

Friends were also found to inadvertently discourage pain talk, even if the individual does not usually speak much about it, as seen in this quote: *Men ask 'so Patricia, is everything okay? I don't want to hear any whining' and I think ‘so, do you want me to say that I’m okay if I’m not? I'm not even a whiner* (Patricia, 55 years old). This sort of exchange reminded participants that some friends may not truly be interested in their well-being, leaving them to provide socially acceptable answers.

In extreme instances non-acceptance were in the form of stigma and discriminating responses. Most participants did not experience stigma or discrimination by friends. However, those who did found that these experiences were mostly from colleagues and more casual friends. These experiences may be categorized more as the social stigma associated with living with CP, because colleagues and casual friends seem to not understand CP and view the ICPs as being lazy or exaggerating what they are feeling, as exemplified in this quote:

“I think it has affected me more at work than friendships because people are sometimes a little selfish and think 'ah right, that person is pretending to feel bad' or is exaggerating because maybe they don't want to work” (Rosa, 26 years old).

Compounding the issues related to stigma and discrimination was that these participants did not have a visible condition and often times with no known causes or cures. For those who experienced stigmatizing reactions from friends it led to loneliness and lack of support as illustrated in Vanessa’s quote:

“But at first it was very complicated. I felt very lonely, and it's a bit... and for those of us who are going through a process that hurts and we don't know how to solve it... it's hard because we don't have support, we just want it to end, or in my case that something would be noticed so as not to get that discrimination” (Vanessa, 29 years old).

In sum, the participants experienced both supportive and non-supportive interactions with friends. Supportive friends exhibited behaviors such as being accepting, flexible and non-judgmental of one’s condition, situation or feelings. Non-supportive friends questioned the validity of their pain and often did not believe their pain should limit their ability to attend social activities. There were also a few extreme cases, where colleagues and casual friends exhibited behaviors that were discriminating or stigmatizing. Gender wise, women reported feeling less support than men and more judgment from not being able to attend social functions, however, it is necessary to exert cautious when drawing these gender conclusions since our sample was comprised of mostly women.

3.2.1.4. Friends promote life (dis)engagement. The fourth subtheme describes how friends’ responses could promote life engagement in that their responses facilitate adjustment, but the opposite was also found. Friends responses could promote life disengagement, and this would hinder the adjustment to CP. In fact, when friends promote life engagement, they are providing a nurturing environment to their friends in pain that seems to promote growth and give a sense of direction, as seen in this quote:

"In conversations we tried to really address the issue, they almost forced me to touch the issue in order to give me their advice and various strategies to help me deal with the pain, at the same time they also made me ... they also helped me to find a direction ... almost a direction like 'you have this, you live with this, what do you want to do with this?'" (Tiago, 37 years old).

Friends were also found to be integral to helping ICPs remain independent in their normal functions of daily living or to adapt to their new reality with pain. For example, friends were said to encourage them to remain active and engaged, especially when the person with CP seemed discouraged and withdrawing from activities, as seen in these quotes:

"They already know and know me, it's already part of my personality (…) but they can already identify and encourage me 'go for a walk', 'go do something, get out of this situation', the closest ones already recognize the situations and are already themselves saying 'go, go, now' and I'm ready, okay, I'll drag myself along (laughs)" (Bianca, 36 years old).

"Trying to cheer me up, trying to get me to go out, because I lock myself in at home... trying to get me to go out, to be with them longer, to have fun..., but it's really hard for me to go out." (Raquel, 56 years old).

In other instances, friends seem to provide a way for ICPs to not focus so much on pain and to socialize, as well as, to be a source of strength and support, as illustrated here by the following quotes:

"When I'm doing something with a friend that I really like, even if I'm in pain, I try to put that aside and I can focus more on what I'm doing with the friend, it relaxes me a bit" (Paulo, 18 years old)

"People who accompany people with CP are actually miraculous because they have this ability to make us forget that we have pain, because in CP, and I learned this a long time ago, we have to shift the focus, we have to focus on a lot of things to try and forget what we are feeling physically" (Sara, 49 years old)

"Even when I don't feel like it and would rather be sitting, I still go, because it relieves me. Distracting me also helps me" (Dora, 28 years old).

Conversely, friends may promote life disengagement by attributing a sick role to ICPs. More specifically, some friends treated participants as someone who is not able to do anything in fear that they may exacerbate their pain, as Raquel described: *'Ah you don't do that because you're very sick, you can't do anything, you just sit there quietly, or you'll be in pain'. The way they talk makes you feel bad"* (Raquel, 56 years old).

These forms of responses were viewed as unhelpful leading the person in pain to feel extremely frustrated and useless, as Tiago and Joana stated:

“So I'm useless, because I have pain, so I can't do anything, because I have pain, I can't be with my friends, and they are contributing to that, instead of trying to distract me, they are almost creating a bubble ‘let it be quiet, we keep doing our things and let it be quiet', that to me at the time hurt me a lot” (Tiago, 37 years old).

“At times when I'm worse off, they do treat me like a sick person, and that's something I don't like, as a matter of fact I've split up [with partner] largely because of that, I'm separated, because at one point I was the sick one in the family, I don't deal with that status well” (Joana, 45 years old).

In conclusion, friends provided a safe environment for ICPs, that is nurturing and empathic, where they encourage individuals to progress with their lives and not stay home focused on pain, emphasizing the necessity of the friends’ companionship and distraction, which seems to be a good strategy to manage pain for ICPs since it provides a way to shift the focus away from the pain, and in some cases ameliorating it. Conversely, friends also seem to attribute a sick role to ICPs, even if they do not have an intention to do so, this leads to frustration and feelings of uselessness, which might hinder their adaptation to CP. There were no significative differences between genders and in general most participants reported that their friends tried to encourage an active life as a way to reduce pain.

The last two themes identified in the data – **Impact of CP on friends’ reactions towards the relationship** and **Impact of CP on ICPs reactions towards friendships** – address how CP influenced the friendships of the participants. These will be described below.

3.2.2. Impact of CP on friends’ reactions towards the relationship

This theme depicts how CP impacted friends’ reactions towards the relationship with the ICP and includes two subthemes: **(a) Some friends do not (try to) understand my pain** and **(b) Some friends walk away**. Overall, once CP emerged in their lives, adults experienced multiple negative reactions when interacting with their friends. These negative reactions were reported as the friends’ inability to adapt to the participants reality of living with CP and to comprehend their situation. The participants rationalized their friends’ reactions as being largely due to their difficulty in understanding the difference between acute and CP, resulting in misbeliefs and inaccurate assumptions about CP. Difficulty in understanding CP led to frustration by both parties. Troubling was that for many participants the new friendship normal was the actual loss of some friendships.

3.2.2.1. Some friends do not (try to) understand my pain.

This first subtheme speaks to friends often being unable and/or willing to understand participants pain experiences, out of a lack of knowledge about CP. This is described here by one of the youngest adults in the study:

“It's an illness that you don't see, the people around me, no matter how much they tell me that they understand, that they know, as they don't live it with me they end up not really understanding, and I felt that a lot when I was in college (…) the people in my class were much younger, many didn't even know what fibromyalgia was, until it started to be talked about a lot on TV” (Vanessa, 29 years old).

It is not solely the lack of knowledge that was problematic within the reaction’s participants experienced by friends and others but also the frequency with which they encountered friends not willing to make an effort to understand what it meant to live with CP. Participants described that friends made assumptions about them such as they were malingerers and not trying to get better. This experience was shared by many of the participants.

“I was in pain, nobody understood me, I was not accepted. Most of them think that this is just in our heads and that we have to be able to overcome this, and why we don't take the pills. 'take it, you’ll get better’” (Sara, 49 years old).

Some friends’ recommendations were also perceived as downplaying the challenges of CP and once again reflecting the lack of understanding that their friends had about CP and confusing this with their own experience of acute pain as identified here by Vanessa and echoed by others:

“I've had advice like 'ah if you go for a hot water bath, you'll see that it'll pass', and I say 'it won't pass, hot water baths can help to relax but don’t take the pain away', but people don't understand, they say 'you'll see that it'll pass, get a massage or something, you'll see that it'll pass” (Vanessa, 29 years old).

Indeed, some participants mentioned that since CP is not a visible condition nor does it always have objective medical evidence of pathology, such as diabetes, people associate those who live with CP to have solely a mental health condition as opposed to a change in pain processing with physical elements. This leap to solely being a mental health condition devalued the participants’ feelings and sensations, as seen in these two quotes below:

“While for example, I sometimes think, diabetes, everybody knows what it is, most of them will know what it is (…), but when we talk about CP, people always associate it with a psychological ill-being. When it's not, in fact, it's not... it's actually taken me many years to realize that this wasn’t all in my mind” (Sara, 49 years old).

“When you tell someone 'I have some super simple disease', people understand. Why? They know [someone who has it] 'oh yes, my aunt had that too'. When you explain to someone 'I have juvenile rheumatoid arthritis', they say 'oh but I don't understand, isn't that an old people's disease?’ and you have to be there explaining, trying to make people understand what it is and they still don't understand” (Dora, 28 years old).

Overall, most participants reported that their friends do not understand CP and what they go through since often times it is not a visible condition and people do not have much knowledge about the difference between chronic and acute pain, leading them to believe it is something that can be cured with time.

3.2.2.2. Some friends walk away. This second subtheme emphasizes the consequences on friendships when friends do not understand the conditions and question what the person is feeling. Some of the participants spoke about a loss of friendship since the onset of their CP. For some this was a significant loss while for others it was a change in the strength and closeness of the friendship. Regardless of the degree of friendship loss, participants spoke of these friendship losses as troubling, as illustrated here by Raquel “*Some people who were friends and questioned [the pain] and who have now drifted apart. And it's hard to see them walk away*” (Raquel, 56 years old).

Participants with CP also described feeling rejected by friends when they could not keep up with the activities friends wanted to engage in, resulting in the participants having a decrease in/or lack of companionship. This loss of companionship, which is captured in the quote below by Luísa, was widespread amongst the participants “(…) *because then people end up not inviting you or telling you to come over at first it was complicated*” (Luísa, 61 years old). However, for many participants the friendships that were lost were more superficial or casual as demonstrated by the following two quotes.

“It decreased [friendship contact], yes it decreased, counting on those social [casual] friends, those friends from the outings, yes it decreased, people drifted away, they couldn't handle what I was dealing with” (Tiago, 37 years old).

“In fact, in these difficult times we can see who really likes us and who cares about us and which are those very superfluous friendships, those quickly disappear” (Sara, 49 years old).

The reasons cited for friends walking away from the relationship were varied. One of these reasons was that friends were perceived as not wanting to hear the patient talk about their condition, as illustrated by the following quote:

"Who [previous friend] is more distant, or avoids talking about it, or even tells me that these are excuses, that everyone experiences pain, that I appear to be fine, that if I appear to be normal how have I got this?" (Vanessa, 29 years old).

Friendship loss was also attributed to friends not wanting to accept or adjust to the person with CP declining would need to refuse a social invitation for pain related reasons, as described here by Rosa.

"We have the friendships that we see from time to time and I think the biggest difficulty for a person who has pain is that (…) you stop doing things and people invite you 'ah let's go to the beach!' and I'm not feeling well and I say 'look I'm not feeling well...' and they say 'ah but let's go' and it's like 'I'm not feeling well we can't do anything else? 'oh, but the plan was the beach', there's this kind of conflict" (Rosa, 26 years old).

Lastly, some participants reported feeling that friends walked away because they disbelieved their pain, illustrated by the following quote:

"Many times I was also told that in studies they read [the friends] about fibromyalgia, it appeared in older people, they did not believe I had this diagnosis, it is very complicated to deal with it, because the pain is real" (Vanessa, 29 years old).

In sum, ICPs felt that some of their friends rejected them when they were not able to keep up with the usual activities they did together, which they attributed to reasons ranging from their friends not wanting to hear them express pain related talk, not accepting that they might not always be able to attend certain events or fulfill already made plans, to not believing they actually had CP. This loss of friendship resulted in loss of companionship which for some was more in terms of casual friends with most maintaining their stronger friendships. Overall, there were no notable differences between genders regarding rejection, noteworthy though, most did not mention understanding their friends' side, only spoke regarding their own misunderstanding.

3.2.3. Impact of CP on ICP's reactions towards friendships

This theme depicts the variation in ICP's reactions towards their friendships, namely, actions they report taking to avoid feeling misunderstood, helpless, or a burden within their relationships. However, the enactment of behaviors to avoid emotional discomfort from friends' reactions were not uniform. Despite pain related challenges, some participants remained engaged in certain activities and were also willing to continue to provide information about their condition to friends. This ability to remain open may have increased understanding and acceptance by their friends of their pain related limitations. This theme encompassed four subthemes: **(a) ICPs distance themselves from some**

friendships, **(b) ICPs stop self-disclosure**, **(c) ICPs reduce contact and engage in a restricted range of activities with friends** and **(d) ICPs become more selective in their friendships**.

3.2.3.1. ICPs distance themselves from some friendships. This first subtheme largely pertains to the individuals' protecting themselves from negative reactions by no longer engaging in certain activities that they were able to do before they experienced pain. These participants distanced themselves from friends to various degrees, that is, some reported reducing contact with friends and others reported completely stopping interactions, such as an outing with a friend to avoid being confronted with their own limitations. Many of the participants also disengaged from activities that were difficult due to their pain as a way to protect their friends' from having to worry about them. Here Alice describes her decision making to miss out on socializing with her friends as she was concerned about how she would get home and did not want to be a burden to her friends:

"But it's largely to not upset others,... and that has a lot to do with my temperament, as I want to see others well, I don't think I can be a burden to others and therefore I don't want to be that burden and I don't want them to be worried about calling this one, that one or another [a cab or similar]" (Alice, 45 years old).

Some participants, reported drifting away from friends because they did not seem to understand why they kept refusing invitations, as Luísa explained here:

"Yes, it made me reject invitations to go somewhere for a long time, even when I was feeling better, I was afraid I wouldn't feel well, and I kept rejecting it, and it made me drift away from people" (Luísa, 61 years old).

In other instances, like Amélia described here, those living with CP started prioritizing other aspects of their lives, and thus left some friendships behind as they learn to manage their life with CP.

"In order to accompany those people and to keep myself in that record [lots of outings], I would be physically very weak and I think that in that perspective I have changed my friendship relations, because even though I manifested some difficulty, people did not change anything to keep me present. This made me privilege my physical well-being, because it was leaving me very weak and with time it turned us away, because naturally, I wouldn't be with them anymore, I didn't accept certain outings, I wasn't with certain people so often" (Amélia, 59 years old).

However, not all participants distanced themselves from their friends. A few participants described that friendships were a vital part of helping them live with CP and brought joy to their lives. Here Ana describes how important it was for her to continue to socialize with friends regardless of the pain she experienced.

“If for some reason I don't go out, I'm one of those people who goes out every day to have coffee after dinner, even in the winter when there’s rain, I go out to the café across the street, I drink my coffee and talk to the people there, period. And if I don't have that for some reason, I start to get into a depressive state, so I avoid it [not going out], because I know I need to live with people” (Ana, 53 years old).

The importance of socializing with friends was critical to some of the participants and without social interactions with friends they felt that they would stop living, as seen voiced in this quote by Joana:

“What I try to do is to make life completely normal even at times when I'm not... when I'm doing bad, because there are times when I'm very bad, but I do everything normal anyway, exactly because if I'm entertained doing other things, the pain is less... I don't think it hurts less, it costs less to bear (…) for example, I never stop going to a place because I am feeling bad, I do everything the same as if I was well, because otherwise I quickly stop living” (Joana, 45 years old).

In sum, participants seemed to distance themselves from friends for a variety of reasons, mostly to not be a burden to them if something happens, not be challenged due to lack of understanding as to why they refused invitations, and to start prioritizing other aspects of their lives because they had to pace activities throughout the day to manage their pain. However, some participants also stated that they did not distance themselves from friends, in fact, the socialization helped them adjust to the situation and still retain a bit of normalcy.

3.2.3.2. ICPs stop self-disclosure. The avoidance of self-disclosure of personal information by participants (e.g., how they were feeling, if they are in pain) was attributed to friends not being able to understand or not interested in understanding their situation, as illustrated by the following quote:

“Often people think that you're faking it and you're not and so I think I've learned a bit to contain it for me, to feel pain, even in social situations and avoid a bit of demonstrating it, because I think no one will understand” (Dora, 28 years old).

However, a consequence of avoiding pain related talk with friends meant that for many of the participants they do not ask for needed help, except when it is a really bad pain day as Bianca stated: *I only ask for help, usually when I can't stand it anymore* (Bianca, 36 years old), and that most friends avoid speaking about the subject, as illustrated by this quote:

“My closest friends don't talk about it much to me, I feel that at the time [when she got a diagnosis] they talked more, and I had a few who actually talked to me and asked me to vent, they said they understood” (Vanessa, 29 years old).

Some exceptions to avoiding self-disclosure were found amongst the participants but these were not the experiences of the majority of ICPs. Here Tiago describes that he involved his friends in the disease, giving them the tools and the knowledge to understand his limitations and to comprehend that if he was not going somewhere was not because he did not like them but because he was not able to, as illustrated by this quote:

“I also started to involve my friends in my life and in my disease, either through information or through sharing interviews that I gave about the disease, that is, I started talking to them in a normal way, so that they realized that there were days that I would be able to be [present], there were days that I wouldn't be able to, and [for them to] realize that although I wasn't going, it wasn't because I didn't like them, but in fact because I couldn't go” (Tiago, 37 years old).

In summary, most ICPs reported keeping their feelings and pain to themselves (e.g., avoid disclosing how they are feeling), because they believe their friends generally do not understand their situation. Moreover, they did not want to be a burden to friends and so they also only ask for help in extreme circumstances (e.g., they required help to stand). However, some participants described friends as being involved and their role in remaining open with them which led to a better understanding from friends. Overall, there were no notable differences between genders, most reported keeping their feelings to themselves.

3.2.3.3. ICPs reduce contact and engage in a restricted range of activities with friends. This third subtheme emphasizes the limitations participants have when attending an outing or program with a friend, since CP causes them certain restrictions that limit their daily lives, as Paulo and Joana explained here:

“When this started [the pain] I was in school and the year was going perfectly, I had lots of friends, I did lots of things, then this somehow stopped everything, I stayed at home, and in that year I went back to school to take the exams under special conditions, I was in total 3 or 4 more times in school that year, I did not see anyone else” (Paulo, 18 years old).

“It affects, for example, with not going to visit because they live far away and the trips are difficult, I have difficulty driving on long trips because of the hands, so I end up not going, because otherwise someone has to drive or I have to go by public transport. Okay, the same things goes for when I am there, the bed has to have certain characteristics…” (Joana, 45 years old).

In fact, the participants reported only making plans, when it involved things, they know they can do, as exemplified by Tiago and Dora:

“I started to refuse many invitations to go out, because I couldn't stand, for example, going out at night for a long time, standing up a lot, it's a long time, going to closed places, with a lot of light, a lot of noise, with a lot of people, so there was a certain distance from both parties, on my part because sometimes pain was also a bit of a shield and an excuse for not wanting to go out” (Tiago, 37 years old).

“There are certain things, I don't do... For example, if they get together and go kickboxing, like they did a while ago, I'm not going. I wish sometimes I was normal enough to do that. And that affects me negatively” (Dora, 28 years old).

Although most say they stay in contact through social media or phone, there is also a reduction in contact due to fewer outings with friends, as these participants suggested:

“They do... they do. We're still on social media, they try to reach me, find out how I'm doing. (…) . I'm still keeping some contact, phone basically, because I don't go out, I don't go to dinners, I don't have a social life” (Jéssica, 50 years old).

“I was in contact with them less [the friends], even with mobile phones, messages, social networks, I didn't have a great disposition for it either, so in a way I didn't stay in contact with some people either” (Paulo, 18 years old).

In sum, this subtheme emphasizes the constraints and limitations participants reported having when contacting and interacting with their friends. More specifically, it affects their mobility, scheduling of a restrict range of activities and fewer outings due to pain, and even though, some still maintain contact through social media or phone, it is reduced.

3.2.3.4. ICPs become more selective in their friendships. This last subtheme highlights the quantitative reduction in friends. The friends that stay are people with whom they have a strong and close bond that value and esteem their friendship, as demonstrated here: “*friends are not many, but they are people who remain, our relationship is not based on the pains of one and the other, do you understand? There are always other reasons*” (Amélia, 59 years old). Conversely, participants talked about individuals that do not try to understand the situation have no place in their lives, as illustrated here:

“Only people who are really close to me remained, because most of the friends in the face of this great misunderstanding that they have, we also felt the need to walk away from those people because people do not understand us” (Sara, 49 years old).

In terms of the changing nature of friendships in both the frequency of interactions and who they socialized with, some participants started to gravitate towards others who had CP citing that these shared experiences resulted in feeling accepted and understood. However, not all of these interactions with peers were face to face as noted in this quote by Dora.

“I went through this alone because I don't have anyone in my environment who has a similar illness, only now do I have a friend who recently discovered that she had fibromyalgia, but I was the only one. The only way I had to find people like me was with the league, they have a forum, a Facebook group with people from all over the world who have arthritis and suffer with CP and they talk, and it's the only thing I have from people who understand me in certain issues, you know?” (Dora, 28 years old).

Participants seem to gravitate towards individuals that offer some comprehension and understanding, therefore, they become more selective when it comes to their friendships. ICPs also take refuge in groups of people that suffer from the same conditions as them, perhaps as a way to feel they are not alone in this process.

ICP’s reaction towards friendships described how they excluded themselves from situations that may cause them conflicts or discomfort and how they retained only a few select friends who provide support and acknowledge their pain as real. However, even within the reduced network size, most participants prefer not to engage in pain-related talk as a way to protect their friends and not be viewed as a burden. Some, but not all of the participants, with pain also voiced that their friends were critical to their well-being and that it was important for them to feel that they also mattered in their life, described here by Alice:

“It is important that friends say 'I learned this from you, you made me see things like this...', because in fact, and listening to what they say, we realize that I have gained a way of seeing the world differently with this [the pain], and to give importance to things that they may not give, and that they learned to do so from me and feeling grateful for it, whilst not going through the experience that I have gone through, learning to value things that they may not have valued before. Seeing in others something of ourselves, that after all we are still useful, that I can still contribute something, I still need it” (Alice, 45 years old).

Friends influences could promote or hinder one’s adjustment to CP, these influences could be seen in more tangible attitudes and behaviors, and were translated into this major theme of responses that impact the adjustment to CP – which address which friends’ responses ICPs perceived as helpful and unhelpful in the process of adjustment. Promotion of adjustment was attributed to friends’ behaviors that were reported to have a positive influence on ICPs and their illness adaptation process, such as the provision of support. Moreover, amelioration of pain was promoted through companionship or the offer of assistance/understanding. Conversely, friends may hinder the adjustment to CP when they do not promote or actively interfere with this process. Examples of such hinderance includes when friends provide support that is unwanted or misplaced, not providing any type of help, and dismissing pain claims.

CHAPTER 4

Discussion

The main objectives of this study were (1) to understand friendships influence on the adaptation to CP; more specifically, which friends' attitudes and behaviors were perceived by ICPs as helpful and unhelpful, and (2) how CP can affect adult friendships. First and overall, our findings showed that friendships bear the potential to promote or hinder individuals' adjustment to CP. Second, our results also showed that CP has a detrimental impact on friendships. These findings are discussed below and their contributions for research and practice highlighted.

4.1. Friendships may promote or hinder adjustment to CP

The interviews with the ICPs provided relevant information that highlighted both the possible adaptive and hindering roles of friends in their adjustment to CP. This is consistent with the existing literature that suggests that ICPs may interpret their friends' behaviors as either supportive or non-supportive, highlighting the potential positive and negative effects of friendships (Affleck et al., 1988; Forgeron et al., 2011, 2013; Forgeron & McGrath, 2008). In fact, on one hand, studies have shown that SS from friends (and family) can have beneficial effects on the adaptation to pain, such as psychological adjustment (Affleck et al., 1988; Holtzman et al., 2004), distraction from pain (Holtzman et al., 2004) and reduction in depressive symptomatology (Park et al., 2017). In specific research with adolescents, friends were found to improve attitudes and functioning in youth with CP, which may buffer the detrimental effects of pain (Nabors et al., 2015). On the other hand, previous research has also highlighted the possible hinderance friends may cause in the adjustment to CP. Negative effects related to the SS provided by family and friends are, for instance, maladaptive pain coping mechanisms (Holtzman et al., 2004) and the experience of disbelief from others (Forgeron et al., 2011, 2013; La Buissonnière-Ariza et al., 2018).

The results highlight four subthemes of friends' behaviors that may promote or hinder the adjustment of an individual to CP. Within each of these four subthemes, friends' behaviors were experienced along a continuum from promoting adjustment to pain to hindering adjustment to pain. First, the subtheme - *friends demonstrate (un)availability to provide support* - refers, on the promoting adjustment end of the continuum, to behaviors such as asking ICPs their needs, still reaching out even if they are not able to be physically present, and actively researching about their friends' condition, which made them feel understood and supported. Conversely, on the hindering adjustment end of the continuum, ICPs experienced behaviors from friends such as not making an effort to help them or outright abandonment. These attitudes made them feel devalued as a friend and as a person. In fact, these findings are in line with literature showing that perceived availability of SS can buffer the impact of stress on health by activating more adaptive coping behaviors and appraisal patterns (Cohen, 1988; Forgeron et al., 2018; Pinquart & Teubert, 2011; Uchino, 2009; Walker et al., 2002). There is extensive evidence on the buffering effect of perceived availability of SS on harmful effects of stressors like pain (Clay et al., 2008; Fiore et al., 1986) and on psychological well-being (Burckhardt, 1985; Faucett & Levine, 1991; Murphy et al., 1988; Turner & Noh, 1988). Studies with spouses demonstrated that when ICPs have a greater perception of spousal support, these were associated with decreased pain severity, decreased psychological distress and decreased pain catastrophizing (Cano et al., 2004; Williams et al., 2004), whereas, an inadequate or lack of perceived SS from friends can hinder the adjustment to CP. Indeed, some studies highlighted that invalidating responses from partners to pain behaviors were associated with poorer psychosocial and physical functioning, greater pain intensity and increased depression (Buenaver et al., 2007; Schwartz et al., 1991; Turk et al., 1992).When a partner (or friend) invalidates pain responses, this may cause disruptions to emotion regulation (Reis & Shaver, 1988), which in turn can reinforce pain expression and emotional distress (Clark et al., 2018).

The second subtheme, *friends provide (un)needed support*, is mostly related to friends' provision of instrumental (e.g., physical assistance, performing a specific task, obtaining extra care) or emotional (e.g., by being present and offering a sympathetic ear) support that is congruent with the ICPs needs and desires. Desired received SS was found to promote adjustment to CP. However, when this support was provided when it was not needed or unwanted it was perceived by ICPs as misplaced help, hindering adjustment to pain, as friends were viewed as overbearing and/or overly solicitous. The findings within this subtheme can be explained in light of the matching hypothesis of SS (Cohen & McKay, 1984; Cohen & Wills, 1985). This hypothesis suggests that SS is perceived as more helpful when the SS matches the needs of the ICPs (Thoits, 1995). Therefore, when a friend provides instrumental or emotional support that is line with what the ICP needs at the moment, this support may be more helpful. There is literature indicating that if, for instance, an individual needs emotional support but receives other types of SS instead, this may increase psychological distress (Horowitz et al., 2001; Thoits, 1986). The results of this study support previous work suggesting that the benefits of SS are more individualized in terms of the right type of SS at the right time is what promotes adjustment to CP.

Furthermore, ICPs reported a mismatch between the friends' need to help compared to their desire for the help in describing some overly solicitous behaviors. Mismatches in provided versus desired SS resulted in the ICPs feeling distressed as these friendship behaviors suggest that ICPs were incapable of even some self-care behaviors (e.g. raising out of a chair) due to their pain. These findings resonate with the evidence that exists, which states that SS from friends and family can also have negative effects on the ICPs (Affleck et al., 1988; Forgeron et al., 2011, 2013; La Buissonnière-Ariza et al., 2018). In fact, the literature on oversolicitous behaviors demonstrates that this extreme attentiveness to ICPs pain behaviors is frequently associated with decreased psychological and physical functioning, disability and higher pain severity (Jensen et al., 2011; Leonard et al., 2006; Newton-John, 2002). For instance, studies show that solicitousness amplified the negative relationship between disability and pain severity (Ginting et al., 2010), and also significantly moderated the positive association between pain catastrophizing and affective pain (Ginting et al., 2011), highlighting the impact that unwanted or misplaced help may have on the relationships or on the ICPs pain.

The third subtheme, *friends are (not) accepting and (not) accommodating*, refers to the continuum that, at one end, has friends accepting ICPs limitations, being flexible and non-judgmental of ones' condition and thus promoting adjustment. On the other end of the continuum, friends were perceived as not being accepting of ICPs limitations, not being flexible, and even being judgmental. These hindering behaviors included the dismissal of pain claims and/or devaluing feelings, discouragement of pain talk, and in some extreme cases stigma and discrimination. These findings highlight the importance and benefits of positive friendship interactions, since friends have been found to contribute to one's sense of acceptance and belonging, the development of self-esteem, as well as, positive social skills and mental health (Holtzman et al., 2004; López-Martínez et al., 2008; Nabors et al., 2015), and thus function as protection against stressors like CP. In fact, consistent with the research on the impact of friends on pain conditions, it seems that having a friend that listens and encourages positive appraisals of ones' condition can increase the number of coping strategies used by ICPs, and consequently, improve functional status, while decreasing functional impairment (Holtzman et al., 2004; López-Martínez et al., 2008; Park et al., 2017).

Conversely, the reports of the participants in this study feeling stigmatized and discriminated against resonates with research on stigma, which shows the ubiquity of feeling stigmatized against in the lives of ICPs (e.g., Holloway et al., 2007; Monsivais, 2013; Newton et al., 2013). In fact, the existing evidence indicates that often ICPs do not feel believed by friends (Toye & Barker, 2010), family (Monsivais, 2013) and romantic partners (Holloway et al., 2007). Moreover, when there is no clear medical explanation for their pain (which is the case for many who live with CP) (De Ruddere et al., 2014; Ruddere et al., 2013), people in general feel less sympathy for the ICPs (De Ruddere et al., 2012, 2014; Ruddere et al., 2013), suspect that they are being deceptive, dislike the individuals more (MacNeela et al., 2010; Matthias et al., 2010) and are less inclined to provide help (Taylor et al., 1984). Some studies show the negative impact of stigma on the well-being of ICPs, with stigmatizing responses of others being associated with poorer psychological and physical well-being (Kool et al., 2013), which seems to hinder the maintenance of their sense of dignity and self-esteem (Werner & Malterud, 2003). In this study some participants reported having non-supportive friends that questioned their pain and often did not believe pain was a limitation to justify not attending social functions, leaving the participants feeling devalued, disbelieved as though they are malingering or craving attention. Thus, the findings are congruent with the aforementioned literature.

Friends not accepting the ICP's pain as real and/or not accommodating the needs of ICPs caused some participants to distance themselves from friends due to the lack of support and understanding. When friends respond negatively to pain behaviors and expressions, ICPs may feel the necessity to display protective pain behaviors instead (Martel et al., 2012), which can lead to higher levels of pain severity (Tait et al., 2009). Even though the participants of this study reported experiencing more positive SS than negative social interactions with their friends, the invalidation that some ICPs felt from some of their friends may have an effect on their health (Lincoln, 2000). For instance, studies with rheumatic patients and older people found an association between negative social interactions, fatigue and pain (Mavandadi et al., 2007; Riemsma et al., 1998; Stephens et al., 2002), and therefore, suggest that invalidation may have negative implications for physical health, and be a barrier to seeking therapy for pain management (Nicola et al., 2019).

One could argue that the intimacy process model may offer a pathway to explain why friends that are flexible and non-judgmental can be a positive influence on the adaptation to CP. When a partner provides emotional validation of pain responses these responses result in an increased sense of intimacy, but the opposite can disturb emotion regulation (Reis & Shaver, 1988). The same pattern may apply to friends given that the SS friendships offer may influence the ICPs pain experiences (Lyons & La Fontaine, 2009). For instance, when a loved one (e.g., close friend) reinforces pain expression with acceptance, it provides validation for the reactions and emotions of the ICPs, but does not reinforce emotional distress (Clark et al., 2018). This validation contributes to increased well-being, stress reduction, and affect regulation for ICPs (Clark et al., 2018). In fact, participants in this study spoke of how those who provided validation of their pain experiences made them feel valued as a person and brought joy to their lives, further supporting this pathway.

Lastly, the fourth subtheme *friends promote life (dis)engagement* is related to the nurturing environment friends seem to foster, which promotes growth, gives a sense of direction, provides encouragement to remain active, and also acts as a source of distraction with the provision of companionship on the promoting adjustment end of the continuum. Conversely on the hindering adjustment end of this dimension's continuum, friends can also promote life disengagement by treating the ICPs like they are incapable of successfully accomplishing tasks or roles on their own. These results highlight the importance of obtaining positive relationship provisions from friendships (e.g., social integration and psychological intimacy) as well as benefits from friendship processes such as self-disclosure and companionship (Rubin & Bowker, 2018). This is beneficial for the ICPs because friendship provisions can influence other positive outcomes like perspective-taking and social-cognitive skills, which in turn may have an effect on optimistic feelings about the self and others, as well as, psychological health and a positive well-being (Rubin & Bowker, 2018; Uchino & Reblin, 2009; Wills & Ainette, 2009). Friends can provide affection and companionship (which increases positive affect), but they can also influence attitudes, behaviors and values (Adams & McCullough, 2009; Rook & Charles, 2018). Therefore, when participants emphasize that their friends are able to promote their growth while giving a sense of direction, encouragement and companionship, it showcases the positive outcomes one can gain from fulfilling relationships like friendships.

On the contrary, when friends act like the individuals are incapable of solely completing activities due to their conditions, attributing a sick role to them, it may hinder their adjustment. These behaviors were categorized by the participants as being frustrating and creating a sense of uselessness. This can be understood in light of autonomy support, that is, friends provide an effective SS when it involves giving choices to the ICP, understanding their perspectives, providing encouragement to initiate activities and minimization of pressure on the ICP, which in turn can enhance well-being (Ryan & Deci, 2002; Ryan & Solky, 1996). This type of support encompasses several other types and has features of emotional, informational and self-esteem SS (Cohen, 2004; Cutrona, 1990; Cutrona & Russell, 1990; Vangelisti, 2009). However, autonomy support can become harmful in some contexts such as CP when loved ones become overly solicitous (Coyne et al., 1988). For example, when close others are intrusive, overprotective, and try to give support excessively they may inadvertently create a controlling environment and discourages autonomy (Rafaeli & Gleason, 2009). Congruent with this explanation are the findings of studies with spouses and ICPs. These studies show that when ICPs perceived more autonomy support related to their CP they also reported to have benefited from responses that promote task persistence, as well as, a greater well-being (Bernardes et al., 2017; Newton-John & Williams, 2006; Uysal et al., 2017). However, it is not known if the same outcomes would be observed with close friends.

In sum, when friends demonstrate availability, provide support, are accepting and accommodating and promote life engagement, it appears to create opportunities for ICPs to feel valued and cared for, therefore, positively influencing their adaptation to pain. Conversely, when friends demonstrate the opposite (unavailability, no provision of support, not accepting nor accommodating, thus contribute to life disengagement) it may hinder one's adjustment to CP due to these negative interactions can have on ICPs.

4.2. CP influences friendships

The results of this study suggest that it is not solely friend's reactions and behaviors that impact how ICPs adapt to a life with pain but also show how living with CP may influence the individuals' and their friends' reactions towards their relationship. Here we highlight how CP can impact these friendship relationships, however, it is noteworthy that participants spoke mostly of their own reactions towards friendships. This bidirectional relationship stresses the reciprocal role of friendships (Rubin & Bowker, 2018), and how a pain condition might not only affect the individual directly but also affect their friendships.

4.2.1. Impact of CP on friends' reactions towards the relationship

Friends reactions towards the relationship are reported to go one of two ways. First, they do not try to understand the pain their friend is suffering from, by displaying a lack of knowledge regarding the condition, not trying to understand the situation and making recommendations that seem to downplay their feelings. That appears to be similar to other results found in the literature that state when friends fail to acknowledge the severity of the ICPs condition, it makes the coping more difficult for the ICPs (Affleck et al., 1988; Holtzman et al., 2004). However, the specific nuances as to why friends display these reactions are not known.

Second, some friends walk away, which was rationalized by the ICPs to be due to their friends' lack of comprehension and inability to adapt to the ICP's new reality. However, we can also interpret this in light of the new context ICPs, and respective friends find themselves, that is, this new reality produces new challenges and may have changed the characteristics of their friendships due to the CP limitations. This can create difficulties for the friendship when we consider the role that reciprocity has in the maintenance of relationships (Feeney & Collins, 2015; Sias & Bartoo, 2007). In fact, reciprocal SS from friends enhances the overall health of individuals (Sias & Bartoo, 2007), and if one is able to maintain a network of general support providers, obtaining targeted SS is facilitated. For instance, when facing a serious event like a chronic illness, obtaining targeted support from friendships is important because it acts as a buffer to those stressors (Sias & Bartoo, 2007). However, the existence of an inequality or deficiency in this reciprocity between friends, such as being over involved, negative, inconsistently responsive or neglectful, can create insecurities, unhappiness with the relationship and even mental and physical deterioration (Feeney & Collins, 2015), which eventually may lead to friendship deterioration and possible dissolution of the relationship (O'Malley & Christakis, 2011).

These effects of failed reciprocity on friendships can be explained in light of the importance these type of relationships have to people in general. Moreover, the friendship provisions (e.g., social integration and psychological intimacy) and the friendship processes (e.g., companionship and self-disclosure) people obtain from relating to others can influence positive outcomes such as positive well-being and physical health (Rubin & Bowker, 2018; Uchino & Reblin, 2009; Wills & Ainette, 2009). If one is unable to reciprocate the friendship provisions and processes, it may lead ICPs to withdraw from attending social events or activities that increase the severity of their pain (Akbari et al., 2017; Cabrera-Perona et al., 2017; Jones et al., 2017; Moulin et al., 2002), and the negative emotions often associated can impact their levels of stress and relationships (Henwood & Ellis, 2004).

Participants spoke about rejection that resulted from not being able to do certain activities, leading to a possible absence of companionship. These rejections may be due to friends feeling that their friend with CP does not satisfy their own friendship needs, and therefore, decides to seek other alternative friends (Forgeron & King, 2013), since friendships are characterized by their voluntary nature and thus, dissolution may be easier when compared to a kinship/partnership (O'Malley & Christakis, 2011). It can be highlighted, though, that pain can have an impact on family members' psychological well-being, which may create distress and psychological burden, and therefore, can also be an explanation as to why some friends walk away (Druley et al., 2003; Romano et al., 1989; Stephens et al., 2006). However, direct evidence pertaining to the impact of CP on friends is warranted. Interestingly, most participants pointed out that the friendships that were lost were casual friendships as opposed to their close friends. This is significantly different than the friendship loss of adolescents with CP who experienced rejections and friendship loss of some of their closest friends (Forgeron et al., 2013). It may be that the onset of CP in adults occurs after close friendships have a long history of reciprocity and thus greater affection and are more poised to withstand the pressures that CP may exert on the friendship.

4.2.2. CP impact on ICPs reactions towards friendships

The participants reactions towards their friendships seemed to be mostly actions taken to protect themselves from feeling helpless, misunderstood or a burden. ICPs reduced contact with some of their friends to avoid these negative feelings as many times they could not engage in the activities that were proposed. However, friends were reported as not understanding why ICP refused so many social invitations. A common reason for declining various social invitations were that the social activities were beyond their abilities due to pain. However, this was not the sole reason for declining social invitations. ICP also prioritized other aspects of their lives such as work, since they had to pace their activities so that they did not exacerbate their pain. Indeed, some ICPs might not have stopped contacting friends altogether, but most reported being reticent to self-disclose much about their pain such as their reasons for not accepting a social invitation as they felt friends were not interested in understanding their condition. However, a consequence of those not disclosing to friends was that they rarely asked for help.

Conversely, there were a few participants who described decreasing their self-disclosure as a way to protect their friends against the burden of living with CP as opposed to withholding self-disclosure as a self-protective strategy. Being reticent to disclose may be explained by the cycle of perceived indebtedness created when ICPs accepted the SS provided and were not able to reciprocate (Affleck et al., 1988; Shumaker & Brownell, 1984). Unfortunately, it has been proposed that rejection of SS is an approach to resolve this perceived indebtedness, which may lead to friendship deterioration

(Shumaker & Brownell, 1984). This can also be explained by the social constraints on disclosure (Lepore & Revenson, 2007). These constraints usually emerge from social situations (e.g., others' denial or reproach) and may lead ICPs to feel misunderstood or unsupported when they are trying to garner SS from their social network (Lepore & Revenson, 2007). So, the social barriers put up by friends can hinder self-disclosure, and consequently, the adaptation to pain.

In addition, CP caused participants to be restricted to a range of activities they could perform with their friends, which lead to a reduction in outings and time spent with friends as many only accepted plans that they were able to do. This is congruent with research that states that ICPs tend to distance themselves from friends when they feel stigma or dependency on loved ones (Affleck et al., 1988; Martel et al., 2012). ICPs in this study became very selective of their friendships and only allowed people with whom they had close bonds with to stay in their lives. Their relationships were most likely enhanced because friends and family demonstrated a greater sensitivity and appropriateness when providing support (Shumaker & Brownell, 1984). Thus, CP seems to have caused a reduction in the number of friends but perhaps, a greater network density.

Some participants also reported finding support in similar others (i.e., with CP) because they felt understood and accepted as a person with pain, which illustrates a greater homogeneity in their networks. It is not uncommon for people to relate to individuals who are comparable to them in terms of characteristics such as age, gender, race or health and disability status (Heaney & Israel, 2008). Evidence from peer-led support groups suggests that these may provide practical and significant emotional support for ICPs, while contributing to an increase in autonomy and agency (Arthur & Edwards, 2005; Cowan, 2012). The nurturing environment encountered in these support groups allows networking, learning and self-exploration, while minimizing pain-related talk (Finlay et al., 2018). Moreover, communal coping can be seen in these groups, with members giving support but still respecting the other individuals' boundaries and autonomy (Finlay et al., 2018), which has been found to promote quality of life, longevity and well-being (Post, 2005; Weinstein & Ryan, 2010). Therefore, friends that have similar chronic illnesses can be a source of empathy, comfort and information that only similar others with similar problems can provide (Gallant et al., 2007).

In this study the individuals who reported resorting to support from pain forums or similar others in pain associations, mentioned that this type of support was mostly online. This situation poses the question of whether or not this online support is enough to fulfill their friendship needs, how is it able to do so and if the aforementioned benefits of these support groups are felt by these participants. This is especially important because effective support is most likely to stem from similar others that have experienced identical stressors or events (Thoits, 1995). In sum, it seems that having stronger ties in a smaller, denser network with high homogeneity is useful to maintain a social identity and consequently, well-being and health (House et al., 1988).

Overall, these results seem to provide some insight into the friendships of ICPs, and how the support displayed by their friends may impact their adjustment to CP, as well as, how this condition can also affect their friendships directly, since most reported a reduction or more difficulty in interacting with friends after the onset of CP.

4.3. Limitations, implications and directions for future research

Even though these results are an important step in understanding the influence of friendships on the adaptation to pain, as well as, to a lesser extent the influence of CP on friendships, there are some limitations that should be highlighted. First, most of the participants were females, which hinders the representation of males in the data. Future research should target men to have an better understanding of possible gender differences that may exist regarding the influence of friends on the adaptation to CP (Glynn et al., 1999; Klauer & Winkeler, 2002).

Second, this study only interviewed individuals with CP but not their friends, which limits our understanding of the impact of CP on friendships. It also does not provide insight into the reasons for certain behaviors or attitudes from friends towards the relationships, as well as, the possible impact of CP on friends' psychological well-being. Therefore, the experiences of friends of the ICPs is warranted to obtain a greater comprehension of the influence of CP on friendships and if the impacts on psychological well-being studied for family members (Romano et al., 1989) are similar for friends. Moreover, understanding how they perceive their friends' CP situation may provide insights to design interventions to improve ICPs pain related adaptation. Longitudinal studies are also warranted to help determine the pain related outcomes for those with more positive friendships versus those with less.

Third, in this study some ICPs reported to take more refuge in their family and view their extended family as friends and that most of their friendship losses were within a described group of casual friends. It is unclear if this was a change after the onset of pain or was already a salient aspect of their relationships, which may provide confusing results since these individuals do not have a clear distinction between family members and friends in their lives. Therefore, exploring the possible variations between different life stages regarding their friendships and its' influence on the adaptation to CP, would shed some light on the importance attributed to friends throughout the life cycle. In particular the role of friendship in the adaptation to a chronic disease, and why some individuals reported not noticing differences in their friendships after the onset of pain while others did.

Lastly, given that this study was based in Portugal, it is possible that studies in other cultures and countries could yield different results regarding the perspectives of ICPs. So, replicating this study in other settings would help to understand possible variations that may be related to how culture many influence friendships effects on CP.

Despite these limitations, this study provides insights into the specific role of friends on the adaptation to CP in the adult population and identified gaps that provide suggestions for future research. It would be fruitful to relate existing theoretical models, which are mostly applied to romantic partner and ICP dyads to friend-ICP dyads. Since these frameworks may offer an interesting pathway to better understand the particular role of friends in the adjustment to CP. For instance, the social communication model of pain and empathy considers both the pain sufferer and the observers' views. Cognitions and social interactions (Goubert et al., 2005) from both can affect communication skills (e.g., expression of pain or attribution of meaning to responses) and consequently, influences individual interpretation of potential pain threats or elicit SS (Clark et al., 2018). In this study, empathic responses from friends made ICPs feel valued and cared for.

The intimacy process model (Reis & Shaver, 1988) can be used to highlight how emotional disclosure may increase intimacy when the recipient is responsive to it. In fact, this could be a way to explain the validation of emotional responses of the ICPs, as well as, the invalidation, in which the first increases intimacy and the latter disturbs emotion regulation (Reis & Shaver, 1988). Friends can recognize ICPs experiences and provide validation of their feelings without agreeing with them or having beliefs about its' accuracy (Clark et al., 2018). Therefore, when friends are, for instance, flexible and non-judgmental it provides emotional validation to ICPs and may assist in the emotion regulation.

From an interventional standpoint, we could argue that given the results, there is a necessity for individual, interpersonal and community level strategies. At the individual level, psychological support that assists ICPs in the adaptation to CP and allows the person to better understand their condition could potentially be beneficial not only to the individual but also to their friendships. A better understanding of their condition could provide ICPs the necessary tools to explain their condition to their friends. At an interpersonal level, and similarly to what is already being done with ICP and partner dyads (Smith et al., 2019), friend and ICP interventions could optimize and improve friendship quality by involving the close friends in the management of the condition. These improvements could translate into a better adjustment to pain, to a better comprehension of the ICP situation by the friend and ultimately strengthen the friendship bonds. At the community level, pain associations could promote more awareness of chronic painful conditions with a greater diffusion of information to the general public, since participants reported not only feeling misunderstood by friends but also from strangers or acquaintances.

These results contribute to the understanding of the influence of friendships on the adaptation to CP, and to a lesser extent the impact of CP on friendships. Future research should focus on the impact of CP on friendships including the perspectives of friends about CP. Studies should employ multiple different approaches to provide a holistic view of these relationships and possibly to better interventions designs that include not only the ICP, but also the friend(s).

Conclusion

The general aim of this study was to explore the reciprocal relationship between adult friendships and CP experiences. More specifically, we wanted to investigate the possible influence of friendships on the adaptation to pain, and for that we collected information pertaining the attitudes and behaviors of friends that ICPs deemed helpful and unhelpful to their adjustment to pain. We also intended to explore how CP could possibly influence the adult friendships, and for that we asked participants if pain has affected their friendships and if so, how.

Findings suggest that friends can play a promoting or hindering role in an ICP adjustment to CP, and is congruent with the existent literature (Affleck et al., 1988; Forgeron et al., 2011, 2013; Holtzman et al., 2004; La Buissonnière-Ariza et al., 2018; López-Martínez et al., 2008; Nabors et al., 2015; Park et al., 2017). Additionally, CP also appears to exhibit an influence on friendships. The impact of CP on friends' reactions towards the relationship with the ICPs, seemed to be mostly negative. The impact of CP on ICP's reactions towards their friendships were mostly comprised of actions they reported taking to avoid feeling like a burden or misunderstood, with some exceptions of participants reporting still trying to maintain active engagement with their friends. Furthermore, these results highlight the necessity of individual and community interventions to assist the ICPs in better conveying what they are feeling and to give tools to friends for a better and effective provision of SS to their friend with pain. Finally, yet important, even though this study had some limitations, future studies that employ different methodologies, longitudinal studies and friendship dyads, would provide further knowledge about the influence of friends on the adaptation to CP, and would also contribute to the design and testing of strategies for ICPs to maintain and strengthen their friendships.

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ANNEXES

Annex A

CONSENTIMENTO INFORMADO

O presente estudo surge no âmbito de uma dissertação de mestrado a decorrer no ISCTE – Instituto Universitário de Lisboa. Este estudo incide sobre a influência das amizades na adaptação a dor crónica e pretende perceber quais as principais consequências da dor nas relações de amizade e em que medida é que estas relações facilitam ou dificultam o processo de adaptação a dor.

O estudo é realizado por Inês Almeida (inesfnalmeida@gmail.com), que poderá contactar caso deseje colocar uma dúvida ou partilhar algum comentário.

A sua participação, que será muito valorizada, consiste em responder a algumas questões abertas que visam perceber a sua experiência de vida enquanto portador ou portadora de dor crónica e poderá durar cerca de 45 minutos. Não existem riscos significativos expectáveis associados à participação no estudo. Ainda que possa não beneficiar diretamente com a participação no estudo, as suas respostas vão contribuir para uma melhor compreensão da importância dos amigos na adaptação a dor crónica e que benefícios são atribuídos a estes, que parceiros românticos ou familiares não conseguem dar.

A participação neste estudo é estritamente voluntária: pode escolher participar ou não participar. Se escolher participar, pode interromper a participação em qualquer momento sem ter de prestar qualquer justificação. Para além de voluntária, a participação é também confidencial, apesar das suas respostas serem gravadas em áudio para posterior transcrição, estas serão analisadas em conjunto com as respostas de outros participantes e em nenhum momento do estudo precisa de se identificar.

Se aceitar participar, por favor indique verbalmente que aceita. A resposta as questões que vou colocar presume que compreendeu e que aceita as condições do presente estudo, consentindo participar.

ACEITO ☐ NÃO ACEITO ☐

Data: ___________________

Annex B

Exploratory and Alternative Questions of the Interview Guide

Exploratory	Alternative
1. Can you tell me a bit about your pain?	• How did the pain start? How is it nowadays? • Do you know the cause (etiology/diagnose) of the pain? • In terms of frequency would you say you have pain every day, every other day…? • In terms of intensity in how much would you rate your average pain on a scale from 0 to 10? • What are the most common locations where you feel pain? • What are some of the coping strategies you use to deal with pain?
2. Has your pain affected or does it currently affect your relationships with friends? If so, how?	• What positive influences did you get from that experience? • And negatives? • Other questions that may arise from the answers (regarding changes in quantity and quality of the interactions)
3. Did your friendships influenced or continue to influence your pain experiences? If so, how?	• What positive influences did you get from that experience? • And negatives?
4. How do your friends react when you are in pain?	• How does it make you feel?
5. Can you tell me about a situation that your friends tried to help you when you were in pain and you felt that action was helpful?	• How did it make you feel? • Why did you consider those behaviors helpful?

6. Can you tell me about a situation that your friends tried to help you when you were in pain and you felt that action was not helpful?	• How did it make you feel? • Why did you consider those behaviors unhelpful? • In this situation what would you like they had done?
7. Can you tell me about a situation where you felt your friends did not support you at all?	• How did it make you feel? • In this situation what would you like they had done?
8. Is there anything we have not talked about in relation to your friendships that you think it is important?	