

## IUL School of Social Sciences and Humanities Department of Social and Organizational Psychology

Healthy ageing despite chronic pain: the role of formal social support for functional autonomy and dependence

#### Marta Alexandra Osório de Matos

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# Doctor in Psychology Specialty in Clinical and Health Psychology

- Ph.D. Rosa Esteve Zarazaga, Full Professor at Department of Personality, Assessment and Psychological Treatments, Faculty of Psychology, University of Malaga, Spain

  Ph.D. Jaime de Curbo Prance, Full Professor et NOVA Medical School. Faculdade de
  - Ph.D. Jaime da Cunha Branco, Full Professor at NOVA Medical School Faculdade de Ciências Médicas, Universidade Nova de Lisboa, Portugal
- Ph.D. João Manuel Monteiro da Silva Moreira, Assistant Professor at Faculty of Psychology, Universidade de Lisboa, Portugal
  - Ph.D. Sibila Fernandes Magalhães Marques, Post Doctoral Researcher at Centro de Investigação e Intervenção Social, ISCTE Instituto Universitário de Lisboa, Lisboa, Portugal
  - Ph.D. Liesbet Goubert, Full Professor at Department of Experimental-Clinical and Health Psychology, Ghent University, Ghent, Belgium
  - Ph.D. Sónia Gomes da Costa Figueira Bernardes, Assistant Professor at ISCTE Instituto
    Universitário de Lisboa, Lisboa, Portugal
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#### **Abstract**

Chronic pain is prevalent and bears a toll on older adults' lives. Pain-related disability is the major cause of functional disability amongst older adults, and (formal) social support may play a central role in overcoming the detrimental effects of pain experiences. The literature on the effects of pain-related support on pain-related disability has shown inconsistent results. It is this thesis contention that the extent to which pain-related formal social support (e.g., received from caregivers at day-care centres, nursing homes) constitutes a protective or a risk factor regarding pain-related disability depends on the extent to which it promotes functional autonomy (perceived promotion of autonomy) or dependence (perceived promotion of dependence). In order to provide empirical support to such contention, a measure of these concepts – the revised Formal Social Support for Autonomy and Dependence in Pain Inventory- was developed and validated (study 1). Then, the direct association between perceived promotion of autonomy/dependence and pain-related disability and its behavioural and psychological mediating mechanism were investigated (studies 2 and 3). Finally, the buffering/amplifying effects of perceived promotion of autonomy/dependence on the effect of pain intensity on pain-related disability were analysed (study 4). Findings confirmed that perceived promotion of autonomy has a protective role and perceived promotion of dependence is as risk factor to pain-related disability. Also, these two functions of social support act through different pathways. This thesis provides insight on the role of pain-related support and bears important practical implications by informing formal caregivers' practices on which support actions can lead to better outcomes.

Key-words: formal social support, chronic pain, older adults, functional autonomy, functional dependence, healthy ageing.

#### **PsycINFO Codes:**

2226 Health Psychology Testing

2860 Gerontology

3360 Health Psychology & Medicine

3365 Promotion & Maintenance of Health & Wellness

3373 Community and Social Services

#### RESUMO

A dor crónica é prevalente e representa uma grande sobrecarga na vida das pessoas idosas. A incapacidade associada à dor é a maior causa de incapacidade funcional no grupo das pessoas idosas e o suporte social (formal) pode desempenhar um papel central na superação dos efeitos negativos associados à experiência de dor. A literatura sobre os efeitos do suporte na incapacidade associada à dor tem demonstrado resultados inconsistentes. O argumento desta tese é o de que o suporte social formal na dor (e.g., recebido pelos cuidadores nos centros de dias e os lares) constituiu-se como um fator protetor ou de risco para a incapacidade associada à dor na medida em que promove autonomia funcional (perceção de promoção de autonomia) ou dependência funcional (perceção de promoção de dependência). No sentido de dar suporte empírico a este argumento, desenvolveu-se e validou-se uma medida para estes conceitos – a Escala de Suporte Formal para a Autonomia e Dependência na Dor (estudo 1). De seguida, a associação direta entre a perceção de promoção de autonomia/dependência e a incapacidade associada à dor, e os mecanismos comportamentais e psicológicos que medeiam essa relação foram investigados (estudo 2 e 3). Finalmente, os efeitos de amortecimento/amplificação da perceção de promoção de autonomia/dependência no efeito da intensidade da dor na incapacidade associada à dor foram analisados (estudo 4). Os resultados confirmam que a perceção de promoção de autonomia tem um papel protetor e que a perceção de promoção de dependência é um fator de risco para a incapacidade associada à dor. Também, estas duas funções de suporte social operam através de diferentes mecanismos. Esta tese fornece uma visão sobre o papel do suporte social relacionado com a dor e tem importantes implicações práticas, informando as práticas dos cuidadores formais sobre quais as ações de suporte que podem conduzir a melhores resultados.

**Palavras chave:** suporte social formal, dor crónica, pessoas idosas, autonomia funcional, dependência funcional, envelhecimento saudável

#### **PsycINFO Codes:**

2226 Medição em Psicologia da Saúde

2860 Gerontologia

3360 Psicologia da Saúde & Medicina

3365 Promoção e manutenção da saúde e do bem-estar

3373 Serviços Comunitários e Sociais

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# Chapter BACKGROUND AND INTRODUCTION

#### Ageing and pain

People are living longer. In 2050, worldwide, it is estimated that the percentage of people over 60 years old (*i.e.*, older adults; United Nations, 2013) will have grown from 12% to 22% (World Health Organization [WHO], 2015). For each individual, the possibility of living longer could be synonym of having more and new prospects and experiences. Also, societies can benefit from older adults' knowledge and experiences. However, the benefits of population' ageing are quite dependent on individual health and physical functioning. Therefore, living in good health is a way to live meaningfully and to play a part in family and in community life. Indeed, a *healthy ageing process* encompasses the possibility of developing and maintaining the functional ability that enables well-being in later life (WHO, 2015). However, sometimes, ageing involves decreased physical capacity, which poses challenges to the individuals, their families, but also for health and social systems (WHO, 2015). Indeed, many health-related issues are commonly associated with ageing such as: hearing and visual loss, diabetes, depression, dementia and musculoskeletal pain (*e.g.*, back pain, neck pain, osteoarthritis) (WHO, 2015).

#### Chronic pain in older adults: prevalence, comorbidities and burden.

In the European population, the prevalence of chronic pain (persistent or intermittent pain for more than 3 months; Merskey & Bogduk, 1994) is 19% (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). However, it varies from 12% in Spain and approximately 40% in Italy, France and Ukraine (Breivik, Eisenberg, & O'Brien, 2013). In Portugal, more than one third of the population (36.7%) reported suffering from chronic pain (Azevedo, Costa-Pereira, Mendonça, Dias, & Castro-Lopes, 2012). Chronic pain translates into high healthcare and socioeconomic costs, both direct (*e.g.*, hospitalization) and indirect (*e.g.*, work absenteeism, social benefits as disability allowance and unemployment) (Breivik et al., 2013). For example, in Portugal, indirect costs of back and joint pain alone reached, in 2010, a total of €738 millions in Portugal - 0.43% of the gross domestic product (Gouveia & Augusto, 2011).

Chronic pain is known to affect more frequently individuals from specific groups, such as older adults (Azevedo et al., 2012). Indeed, chronic pain is known to increase with age (*e.g.*, Blyth, 2001; Cimmino, Ferrone, & Cutolo, 2011; Jakobsson, Hallberg, & Westergren, 2004; Johannes, Le, Zhou, Johnston, & Dworkin, 2010; van Hecke, Torrance, & Smith, 2013). Epidemiological studies showed that chronic pain affects the lives of more than 50% of older adults in community settings and more than 85% in institutional settings (*e.g.*, Azevedo, et al., 2012; Boerlage et al, 2008; Dellaroza, Pimenta & Matsuno, 2007; Ferrell, 1995; Helme & Gibson, 1997; 2001; Pereira et al, 2004). Musculoskeletal chronic pain (*i.e.*, pain in muscles, ligaments, tendons, joints and/or bones)

is one of the most prevalent chronic pain conditions among older adults. Miranda and colleagues (2012) have shown a prevalence of 86% in community-dwelling and institutionalized older adults.

Besides being highly prevalent, especially in institutionalized older adults, chronic pain has a huge toll on older adults' lives. Ageing in pain is associated with a decrease in healthy ageing (Wilkie, Tajar, & McBeth, 2013) and has been associated with depression, sleep disturbances and decreased social interactions (*e.g.*, O'Brien & Breivik, 2012; Parmelee, Katz, & Lawton, 1991; Power, Perruccio, & Badley, 2005). Furthermore, pain in old age is often associated with less control over life (*e.g.*, Turk, Okifuji, & Scharff, 1995; Willman, Petzäll, Östberg, & Hall-Lord, 2013).

In sum, chronic pain is a very prevalent condition worldwide and more so among older adults. Moreover, living with chronic pain has a toll on older individuals, by seriously interfering in many of their daily life activities and, hence, being often associated with high levels of pain-related disability. When chronic pain disrupts the life of older adults the support provided by formal caregivers (e.g., in day-care centres, nursing homes, assisted living facilities; Gauler & Kane, 2001; Lafrenière, Carrière, Martel, & Bélanger, 2003) might be a stepping-stone in overcoming the functional disability caused by chronic pain. Indeed, being in pain often restricts older adults interactions with others; and sometimes support provided by formal caregivers is the only regular source of support (Mort & Philip, 2014). Actually, as people age, and as a result of a greater life expectancy, the increase of social isolation and the decrease of informal networks emphasise the relevance of formal support networks in providing care to older adults (Capucha, 2005; Roy, 2006; Vaz et al., 2004). The spouse is often reported to be the most important source of support. However, very frequently older adults are single, divorced or widowed (e.g., Roy, 2006) – therefore they often live alone. Older adults without spouses or sons/daughters tend to rely more on formal networks (Shields, Sherr, & King, 2003). Therefore, formal social support networks may play a central role in protecting older adults against the deleterious effects of pain experiences, influencing positively their ageing process by promoting their ability to live an independent and fulfilling life (Shields et al., 2003). Therefore, generally, the present thesis aims to investigate the role that formal social support processes may play in minimizing (or amplifying) the impact of chronic pain on older adults' functional disability and ageing processes.

#### Pain-related disability: disrupting older adults' daily living

Chronic pain is the most important cause of functional disability in older age groups (Cimmino et al., 2011). *Pain-related disability* refers to the extent to which pain interferes with the performance of daily activities (*e.g.*, Cleeland, 2009; Helme & Gibson, 1997; Mobily, et al., 1994;

Reyes-Gibby, Aday, & Cleeland, 2002; Tait, Chibnall, & Krause, 1990; Thomas et al., 2004) and influences the reduction of valuable activity (Alschuler, 2011). Research indeed shows that older adults with chronic pain are less physically active than others without chronic pain (*e.g.*, Haneweer, Vanhees, & Picavet, 2009; Hendrick, Milosavljevic, & Hale, 2011; Stubbs et al., 2013).

Some theoretical models have been proposed to address the determinants of pain-related disability. Biomedical models of pain have focused exclusively on its neurophysiological features (*e.g.*, pain severity), only for diagnosis and treatment purposes (Bendelow, 2013). However, these models do not consider the influence of psychological and psychosocial variables in health and disease (Turk & Monarch, 2013). Therefore, we adopt the view of biopsychosocial models of pain, which assume that pain is determined by the interaction of biological, psychological (cognition, affect, behavior) and social factors (social and cultural contexts) (Asmund & Wright, 2004). Specifically, we describe below the operant conditioning and the fear-avoidance models, which have provided the main theoretical basis for the present thesis.

The operant conditioning model (Fordyce, 1976; Fordyce, Shelton, & Dundore, 1982): This model contends that pain behavior (e.g., limping, moaning and avoiding activity) can be reinforced by others, hence, increasing pain-related disability. The reinforcement of pain behaviors may include attention and help, the provision of medication, the reinforcement of rest and avoidance of activities – solicitous responses. Conversely, well behaviors (e.g., activity, working) may not be sufficiently reinforced. Therefore, according to this model, pain behaviors would be more rewarding than well behaviors (e.g., Itkowitz, Kerns, & Otis, 2003; Turk, Wilson, & Swanson, 2012). Moreover, the provision of solicitous support can be a reaction to pain and disability, which in turn will contribute to create or maintain disability (Ginting, Tripp, Nickel, 2011a). Indeed, patients with more severe symptoms and disability may present more opportunities for solicitous responses (Schmaling, Smith, & Buchwald, 2000). However, pain behaviors (activity avoidance) can be decreased and well behaviors (activity engagement) can be increased by verbal reinforcements (e.g., Doleys, Crocker, & Patton, 1982). One of the most threatening consequences of solicitous support might be the decrease and avoidance of activity that may lead to deconditioning, increased disability and functional decline (e.g., Pister et al 2012; Schmaling, Smith, & Buchwald, 2000). Indeed, many empirical studies stress the detrimental influence of solicitous responses on pain outcomes. In particular, solicitousness has been associated with chronic pain sufferers' higher pain-related disability, increased pain behavior, higher pain intensity and decreased activity (e.g., Boothy et al., 2004; Kerns et al. 1991; Newton-John, 2002; Pence, Thorn, Jensen, & Romano, 2008; Raichle et al., 2011; Romano et al., 2009; Schmalig et al., 2000).

The fear-avoidance model (Lethem et al., 1983; Vlaeyen et al., 1995; Leeuw et al., 2007): This model depicts the pathways to pain-related disability and to confrontation, identifying key

determinants. The first portrayed pathway indicates that after injury and the pain experience, negative affectivity and threatening illness information may lead to pain catastrophizing (*i.e.*, negative and exaggerated focus on pain). This increases pain-related fear (*i.e.*, fear of pain, physical activity or (re)injury), that would influence activity avoidance that leads to disuse, depression and higher pain-related disability. On the opposite pathway, individuals who do not develop pain-related fear after injury/pain experience would perform confrontation behaviors (activity engagement) that would lead to recovery (low pain-related disability). Accumulating evidence has shown that catastrophizing, pain-related fear and avoidance behaviors are associated with increased pain-related disability (Crombez, Vlaeyen, Heuts, & Lysens, 1999; Vlayen, Kole-Snijders, Boeren, & van Eek, 1995; Vlaeyen, & Linton, 2012).

These models have addressed some behavioral and psychological determinants of painrelated disability. The fear-avoidance model exclusively addresses psychological mechanisms (catastrophizing, pain-related fear) that influence the behavioral mechanisms (activity avoidance and confrontation) that unfold after the pain experience and that lead to pain-related disability. The operant conditioning model addresses the influence of significant others' actions as potential reinforcers of pain behaviors, which may lead to pain-related disability. Although the latter model implies that pain experiences are influenced, to some extent, by the social context, the construct of social support has not been fully addressed as a potential determinant of pain-related disability. Since social support has been traditionally described, by health psychology, as a key resource for people with chronic health problems (Willman, Petzäll, Östberg, & Hall-Lord, 2013) and we argue that formal social support might be a stepping stone to older adults in overcoming pain-related disability, it is our contention that social support may have an important role in influencing older adults' pain-related disability. Since social support is the central construct of this work, we will begin, in the next section, by identifying several features of social support that are relevant for the present thesis. Then we review the role of social support in explaining health outcomes. Finally, we review research on the role of social support in the context of pain, clarifying its implications for the aims of the present work.

#### **Social support**

The term *social support* is often broadly used to describe the processes through which social relationships influence health and wellbeing (Cohen, Gottlieb, & Underwood, 2000). However, social support can be divided into structural and functional social support. Structural social support is defined by social integration, which encompasses the structural and objective features of the

social networks (e.g., number of people, number of interactions; Rascle et al., 1997). When in need, the individual might turn to his/her social network (Barrera, 1986) and social integration might be a quantitative measure of the resources available to the individual (e.g., Wills & Ainette, 2012). However, in the present work we are interested in the functional (features of) social support, that refer to one's representations about the quality and function of social relationships in fulfilling one's needs (Shwarzer & Knoll, 2007; Rascle et al., 1997) regardless of the number of connections (Wills & Ainette, 2012). According to the functional perspective, social support can be divided into: a) prospective representations about the social resources that are perceived to be available and quality of social support in case of need (e.g., Rascle et al., 1997; Schwarzer & Knoll, 2007) – perceived (availability of) social support; b) or retrospective representations about supportive actions of others received in a given time, when in need (e.g., Lakey & Cohen, 2000; Schwarzer & Knoll, 2007) – *received social support*. Furthermore, social support can have different functional types, dependent on the content of support that is perceived to be available or received (e.g., Cobb, 1976; Rascle et al., 1997; Wills, 1985): a) emotional: sense of security, safety or love in times of need; b) esteem: sense of confidence about ones' ability and value to overcome adverse situation; c) instrumental: material or behavioural assistance to overcome a difficult time; d) informational: advice, suggestions and useful information to overcome adversity. Finally, social support can also be divided according to the source (e.g., Gauler & Kane, 2001, Lafrenière et al., 2003) that provides it: a) informal support: family and friends; b) formal support: health professionals and social service workers.

#### Social support and health

Social support has shown to have a protective role within the context of health – both physical and mental (*e.g.*, Bekele et al., 2013; Cobb, 1976; Cohen & Wills, 1985; Cohen et al., 2015; Uchino, 2004; 2006; Uchino, Bowen, Carlisle, & Birmingham, 2012; Thoits, 2011). Below, we will describe theoretical models outlining the processes involved in the influence of social support on health-related outcomes – direct effects, indirect effects and buffering effects. Subsequently, we highlight some of the theoretical frameworks that are relevant for the present work.

*Direct effects of social support:* This model argues that social support influences health outcomes directly, irrespective of the level of stress (Cohen & Syme, 1985), without the involvement of any other mechanisms or processes (Wills & Ainette, 2012). Higher levels of social support have been widely associated with lower levels of mortality, cardiovascular disease and

lower probability of infection (e.g., Berkman, Glass, Brissette, & Seeman, 2000; Holt-Lunstad et al., 2010; Uchino, 2012).

*Indirect effects of social support*: This model suggests that intermediate processes are involved in the effect of social support on health outcomes (Wills & Ainette, 2012). Indeed, much literature on this subject has indicated that various paths can exist in explaining such effects. That is to say, that the effect of social support on health outcomes may be accounted for by: emotions (e.g., positive affect), cognitions (e.g., self-efficacy, self-esteem, appraisals), behaviors (e.g., adaptive/maladaptive behaviors) and skills (e.g., coping) (e.g., Cohen, 1988; Cohen, 2004; Cohen & Syme, 1985; Schwarzer & Knoll, 2007; Shaw, Krause, Chatters, Connell, & Ingersoll-Dayton, 2004; Symister & Friend, 2003; Uchino et al., 2012). Definitely, social support might be more than a "protective cushion" against environmental demands (Benight & Bandura, 2004, p. 1134) and it might constitute a vicarious experience in dealing with a stressor, thus fostering individuals' skills to deal with adversity (Schwarzer & Knoll, 2007). Clarifying the mechanisms that link social support to health outcomes should be a priority for theoretical and intervention purposes (e.g., Reis, Collins, & Berscheid, 2000), because when aiming for improvements in health outcomes, relevant mechanisms should be targeted (Wills & Ainette, 2012). Some mediating mechanisms have been identified as accounting for the positive influence of social support on health outcomes. For instance, such mechanisms are the increase of self-esteem and self-efficacy, or the decrease of anxiety, distress and threat appraisals (e.g., Atienza, Collins, & King, 2001; Russell & Cutrona, 1991; Shaw et al., 2004; Symister & Friend, 2003).

Buffering effects of social support: According to this model, social support buffers the impact of a stressor on health outcomes (Wills & Ainette, 2012). The perception of having available or receiving a greater amount of social support might alleviate the appraisal and reaction to a stressful event by reducing the physiological response, prevent maladaptive behavioural responses and improve coping (e.g., Cohen & Willis, 1985; Cohen et al., 2000; House, 1981; Lakey & Cohen, 2000; Thoits, 1986). For instance, the mere presence of others has been shown to reduce the physiological reactivity associated with psychological stress (e.g., Karmarck et al., 1990).

The models described above predict a positive influence of social support on health. However many studies show that, sometimes, social support is not associated with better health (e.g., Cohen & Willis, 1985; Uchino et al., 2012; Schwarzer & Leppin, 1989; Thoits, 2011). The idea that social support not always has positive effects is more salient in the literature on the role of

social support on pain experiences. Next, we review the role of social support on pain-related disability.

#### The role of social support in accounting for pain-related outcomes

Research examining the relationship between social support and pain outcomes (*e.g.*, pain intensity, disability, activity, distress) has mostly focused on its direct and buffering effects.

On one hand, social support has been found to be associated with less severe pain, lower levels of pain-related disability, less pain-related distress and less avoidance of activity (*e.g.*, Boothy, Thorn, Overduin & Ward, 2004; Campbell et al., 2011; Cohen & Wills, 1985; Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003; Hughes et al., 2014; Jamison & Virts, 1990; Kerns et al., 1991; Kerns, Rosenberg, & Otis, 2002; Raichle et al., 2007; Raichle, Romano, & Jensen, 2011; Roberts, Klatzkin & Mechlin, 2015; Turk, Kerns, & Rosenberg, 1992, Zyrianova et al., 2006). On the other hand, another cluster of research – focusing on solicitous support (*i.e.*, providing constant help and attention in response to pain behaviors) from significant others – has shown that social support can increase pain-related disability, pain behaviors, dependence, catastrophizing and decrease wellbeing (*e.g.*, Coty & Wallston, 2010; Kerns et al. 1991; Raichle et al., 2007; Romano et al., 1995; Romano, Jensen, Turner, Good, & Hops, 2000; Romano, Jensen, Schmaling, Hops, & Buchwald, 2009). In sum, research on the direct effects of social support on pain-related outcomes has retrieved quite inconsistent results (*e.g.*, Campbell, Wynne-Jones, & Dunn, 2011; Matos & Bernardes, 2013).

The buffering effect of social support on pain-related outcomes has been much less investigated and has focused particularly on the relationship between pain (*e.g.*, intensity, disability) and depression. Although some studies did not find significant buffering effects (*e.g.*, Pjanic et al., 2013), others showed that social support buffered the effects of pain disability on depression in people with end-stage joint disease (Roberts, Mtecjyck, & Anthony, 1996), and of the effects of physiological stress responses on experimental pain sensitivity during the cold pressure task (Roberts, Klatzkin, & Mechlin, 2015). In addition, pain-related support buffered the impact of low self-appraised problem solving competence on depressive symptoms, among individuals with chronic pain (Kerns et al., 2002). Finally, other studies (Ginting, Tripp, & Nickel, 2011a; Ginting, Tripp, Nickel, Fitzgerald, & Mayer, 2011b) suggested that different types of pain-related support responses may play different roles: distracting responses buffered the negative impact of pain intensity on pain disability and on mental quality of life; while solicitous responses amplified the detrimental effect of pain intensity on pain disability. These latter studies were very innovative in

showing that pain-related support can buffer as well as amplify the (already) deleterious relationship between pain intensity and pain disability.

In sum, this body of research indicates that pain-related support has the potential to influence pain-related outcomes positively as well as negatively, through direct and buffer/amplifying pathways. The apparent inconsistencies in the direct effect literature and evidences on different buffering/amplifying roles of pain-related support suggest that there might be unexplored functions of pain-related support. Could such functions account for the incongruent effects of social support on pain experiences? It was, indeed, our contention (Matos & Bernardes, 2013) that the extent to which pain-related social support might constitute a protective or risk factor to pain-related disability would depend on whether social support was promoting *functional autonomy* (*i.e.*, the ability to perform activities of daily living without assistance; *e.g.*, Pinsonnault et al., 2003) versus *functional dependence* (*i.e.*, the need for assistance in accomplishing activities of daily living; *e.g.*, Katz et al., 1963). In the following sub-section we present such argument and its theoretical background.

## Formal pain-related support for functional autonomy and dependence: a new conceptualization and operationalization

The previous argument was anchored on: (1) the *operant conditioning model* (Fordyce, 1976) that established the idea that help received form others can reinforce (pain and well) behaviors and activity (avoidance and engagement); and on (2) the *fear avoidance model* (*e.g.*, Vlaeyen et al., 1995; Leeuw et al., 2007) that highlighted the detrimental effects of avoidance behaviors on pain-related disability and the positive influence of confrontation on recovery. Therefore, the reasoning was that formal social support for functional autonomy (henceforth, perceived promotion of autonomy) could motivate towards activity engagement, whereas formal social support for functional dependence (henceforth, perceived promotion of dependence) could reinforce activity disengagement.

Indeed, some previous research, drawing upon the operant model of pain, had acknowledged that significant others' responses could reinforce either pain behaviours and disability, or activity engagement and well behaviours (*e.g.*, McWilliams et al., 2014; McCraken, 2005; Pence et al., 2008; Romano et al., 1995; Schwartz, Jensen, & Romano, 2005). Responding with positive reinforcement to well behaviors is, however, not the same as providing support for functional autonomy when a patient displays pain behaviors. Therefore, the conceptualization proposed by Matos and Bernardes (2013) of two different functions of formal pain-related support was

theoretically and methodologically innovative. From a theoretical point of view, the conceptualization of the promotion of functional autonomy and dependence as different functions of formal pain-related support aimed to account for the inconsistent effects of social support on chronic pain, by proposing that different functions might bear different implications to older adults' pain experiences. Furthermore, the conceptualization of such new functions of formal social support raised the need to measure them. However, at that time, and to the best of our knowledge there was not a valid and reliable instrument that ensured the measurement of such functions of social support, especially within a formal support context. Therefore the first step, to explore the effects of perceived promotion of autonomy and dependence, was to develop and validate an appropriate instrument.

The development and preliminary validation study of the Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN; Matos & Bernardes, 2013) resulted in an instrument that allowed differentiating the formal pain-related support functions of the promotion of functional (1) autonomy and (2) dependence in older adults in pain. Within each one of these major functions, we also considered two classical functions of social support (*e.g.*, Cobb, 1976; Rascle et al., 1997; Sherboune & Stewart, 1991; Wills, 1985), due to their prevalence in formal settings aiming at supporting older adults: (1) emotional/esteem support and (2) instrumental support. Therefore, on one hand, perceived promotion of autonomy was conceptualized as the perceived frequency of support actions that either provided tangible help (instrumental support) or reinforced self-esteem and self-confidence (emotional/esteem support) to keep on going despite pain. On the other hand, perceived promotion of dependence was conceptualized as the perceived frequency of actions of support that either provided tangible help by substituting the person in his/her activities (instrumental support) or, by being overly understanding and empathic, reinforced lower self-efficacy to keep on going because of pain (emotional/esteem support).

The FSSADI\_PAIN showed reasonable psychometric qualities and its preliminary validation study (Matos & Bernardes, 2013) also provided partial empirical support to the argument that pain-related support could have different implications for pain outcomes. Indeed, perceived promotion of dependence was positively associated with pain severity and disability, for older adults with chronic pain. However, and against what we expected (Matos & Bernardes, 2013), perceived promotion of autonomy was not significantly associated with (better) pain outcomes. This study had its merits by proposing a new conceptualization and operationalization of two different functions of formal pain-related support, and also by pointing out important lines for future research (Matos & Bernardes, 2013). Namely in pointed the need to further improve the psychometric properties of the FSSADI\_PAIN in order to extend the investigation of the (direct, indirect, buffering and amplifying) effects of perceived promotion of autonomy and dependence on pain-

related disability in older adults with chronic pain. Generally, these were the main aims of the present thesis. The specific aims and outline of this work is described below.

#### Aims and outline of the present thesis

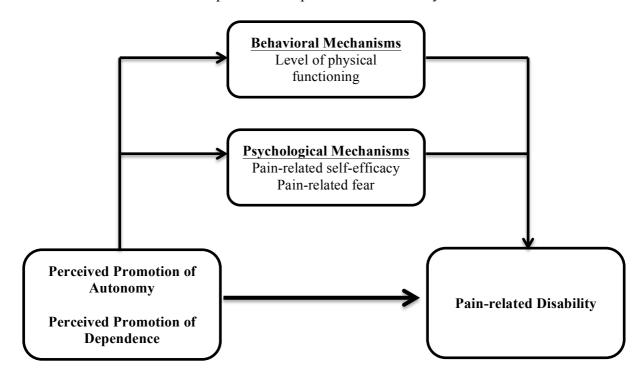
Although the FSSADI\_PAIN had shown reasonable psychometric qualities (Matos & Bernardes, 2013), the preliminary validation study showed some limitations that have set the path for the first study of this thesis. Therefore, the *first aim* of the present thesis was to revise and improve the Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN; Matos & Bernardes, 2013). The study of further development and validation of the revised FSSADI\_PAIN is presented in detail in **Chapter 2**.

Then, the *second aim* was to further examine the direct effects of perceived promotion of autonomy and dependence on pain-related disability (see Figure 1). This was first done with a cross-sectional study – reported in **Chapter 3** – and then with a longitudinal study – reported in **Chapter 4**. In both studies it was expected that perceived promotion of autonomy was associated with/predicted less pain-related disability and perceived promotion of dependence was associated with/predicted higher pain-related disability.

Thereafter, the *third aim* was to investigate some behavioural and psychological mechanisms that could potentially account for the influence of perceived promotion of autonomy and dependence on pain-related disability (see Figure 1). To the best of our knowledge pain research has not yet considered mediating mechanisms on the influence of pain-related support on pain-related disability. Accordingly, we explored the indirect effects of perceived promotion of autonomy and dependence on pain-related disability through behavioural (physical functioning) and psychological (pain-related self-efficacy and fear) pathways. The rationale behind the choice of such mediating factors is presented in Chapters 3 and 4. In Chapter 3, this model was partially tested through a cross-sectional design. More specifically, and since we were first departing from a behavioural point of view, anchored on the operant conditioning and fear avoidance models, only the behavioural path was tested. In **Chapter 4**, the full model – with both behavioural and psychological mediating pathways – was tested (Figure 1) with a longitudinal design. Overall, regarding the behavioural path it was expected that: (1) perceived promotion of autonomy would be associated with/predicted lower pain-related disability, by influencing higher levels of physical functioning; and (2) perceived promotion of dependence would be associated with/predicted higher pain-related disability by influencing lower levels of physical functioning. As for the psychological

path, it was expected that: (1) perceived promotion of autonomy would predict lower pain-related disability, by influencing higher pain-related self-efficacy and lower pain-related fear; and (2) perceived promotion of dependence would predict higher pain-related disability, by influencing lower pain-related self-efficacy and higher pain-related fear.

Figure 1 – Direct and indirect influence of perceived promotion of autonomy and dependence on pain-related disability

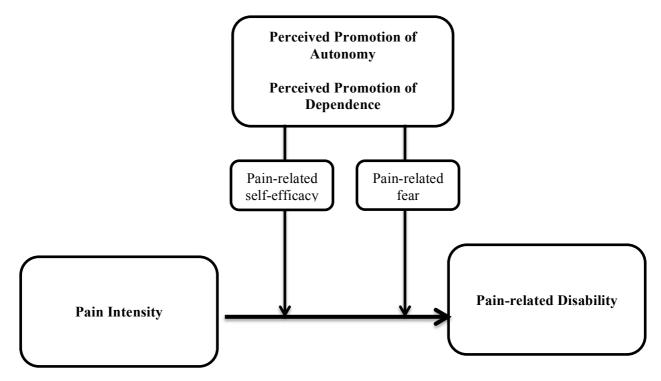


So far, we have been proposing the interaction of social, psychological and behavioral mechanisms in influencing pain-related disability. However, such interaction might be dependent on the physical features of the individual pain experience, like pain duration and pain intensity - biological features of the pain experience. For example, it has been suggested that the influence of interpersonal contexts on pain-related outcomes might be stronger in the initial phases of chronic pain experiences (*e.g.*, Cano, 2004). Likewise, it was expected that (3) people with more recent (and eventually less severe) pain experiences might be more permeable to the influence of pain-related support. To the best of our knowledge, this contention had not been investigated. Therefore, in **Chapter 4**, we also aimed to investigate whether the previously described mediating processes (depicted in Figure 1) would be moderated by pain duration and intensity.

Finally, the *fourth aim* was to explore the buffering and amplifying effects of pain-related support. **In Chapter 5**, the buffering effects of perceived promotion of autonomy and the amplifying effects of perceived promotion of dependence on the relationship between pain intensity

and pain-related disability were tested through a longitudinal design, as depicted in Figure 2. It was expected that: (1) perceived promotion of autonomy would buffer (decrease) the impact of pain intensity on pain-related disability; and that (2) perceived promotion of dependence would amplify (increase) the impact of pain intensity on pain-related disability. Moreover, there was the need to further investigate the psychological mediating mechanisms through which such effects unfold (Thoits, 2011; Uchino et al., 2012). Therefore, it was expected that (3) pain-related self-efficacy and fear could account for the buffering/amplifying effects of pain-related support. The rationale for choosing such mechanisms is explained in Chapter 5.

Figure 2 – Buffering effect of perceived promotion of autonomy and amplifying effect of perceived promotion of dependence on the influence of pain intensity on pain-related disability



Finally, in **Chapter 6**, after the empirical chapters, a general discussion of the main findings is provided with reflections on theoretical and practical implications of the present thesis.

# Chapter 2

# DEVELOPMENT AND VALIDATION OF THE revised FSSADI\_PAIN

**This chapter is based on the paper:** Matos, M., Bernardes, S.F., Goubert, L., & Carvalho, H. (2015). The revised Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN): Confirmatory factor analysis and validity. *The Journal of Pain*, *16*(6), 508-517.

#### **Abstract**

Pain among older adults is common and generally associated with high levels of functional disability. Despite its important role in older adults' pain experiences, social support has shown inconsistent effects on their functional autonomy. This suggests a moderator role of two recently conceptualized functions of pain-related support: perceived promotion of dependence versus autonomy. The present study aimed at revising and further validating the Formal Social Support for Autonomy and Dependence in pain Inventory (FSSADI PAIN), which measures these two functions of pain-related support, among institutionalized older adults in pain. Two hundred fifty older adults (Mage=81.36, 75.2% women) completed the revised FSSADI PAIN along with measures of physical functioning (SF-36) and informal social support (SSS-MOS). Confirmatory factor analyses showed a good fit for a two-factor structure: 1) Perceived promotion of autonomy (n=4 items;  $\alpha$ =.89); 2) Perceived promotion of dependence (n= 4 items; $\alpha$ =.85). The revised FSSADI PAIN showed good content, discriminant and criterion-related validity; it discriminated the perceived frequency of painrelated support by male and female older adults, and also of people with different levels of physical functioning. In conclusion, the revised FSSADI PAIN showed to be an innovative, valid and reliable tool that allows us to assess two important functions of pain-related support, which may play a relevant role in the prevention and reduction of pain-related physical disability and functional dependence among institutionalized older adults.

#### Introduction

As mentioned in the previous chapter, chronic pain affects 50 to 80% of older adults (*i.e.*, aged 60 or above; UN, 2013) in community and institutional settings (Ferrell, 1995; Helme, & Gibson, 2001) which represents an obstacle to active and healthy aging, by hindering older adults' functional autonomy (Cobos, 2008; Helme, & Gibson, 1997; Reyes-Gibby et al., 2002) – *i.e.*, the ability to independently perform physical, cognitive and social activities (Hébert, Guilbault, Desrosiers, & Dubuc, 2001).

Social support has been identified as a key factor in overcoming pain-related disability, but has also shown deleterious effects on pain-related disability (*e.g.*, Evers et al., 2003; Turk et al., 1992), mobility and daily activities' performance – *i.e.*, physical functioning (Cohen & Wills, 1985; Kristensen, 2015; Ledoux, Dubois, & Descarreaux, 2012; Podsiadlo, & Richardson, 1991; Wilkie, Peat, Thomas, & Croft, 2007). We argued that the impact of pain-related support on pain outcomes might depend on the extent to which it is promoting

functional autonomy versus dependence (Matos & Bernardes, 2013). Our contention was based on the assumptions that: 1) avoidance behaviours represent a main predictor of functional disability in chronic pain, as postulated by fear-avoidance (Leeuw, et al., 2007; Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen et al., 1995); 2) pain-related support, by promoting functional autonomy or dependence, may influence the extent to which individuals engage in activity avoidance versus engagement. The need to test this contention led to the first aim of this thesis – to revise and improve the Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN; Matos & Bernardes, 2013).

The FSSADI\_PAIN was developed to measure the (perceived) frequency of pain-related support actions for functional autonomy and/or dependence (perceived promotion of autonomy/dependence), provided by formal networks (*e.g.*, day-care centres, nursing homes) as promoting functional autonomy (perceived promotion of autonomy) to older adults when in pain. The FSSADI\_PAIN has previously shown reasonable psychometric qualities (Matos & Bernardes, 2013). Moreover, perceived promotion of dependence (but not perceived promotion of autonomy) was moderately and positively associated with pain severity and disability among older adults with chronic pain, highlighting the importance of differentiating these functions of support in the context of chronic pain.

However, the preliminary validation study pointed out some limitations (Matos & Bernardes, 2013), setting the path for the present study. First, because inter-judge reliability (Cohen K=.80) showed room for improving content validity, we aimed to revise some of the original items. Second, exploratory factor analysis extracted two factors – perceived promotion of autonomy and perceived promotion of dependence – which showed, unexpectedly, a moderate positive correlation, raising the need for the confirmation of the underlying factor structure. Consequently, we aimed to test the fit of three alternative models: 1) perceived promotion of autonomy and perceived promotion of dependence as independent factors; 2) perceived promotion of autonomy and perceived promotion of dependence as correlated factors; 3) pain-related support as a second-order factor with perceived promotion of autonomy and perceived promotion of dependence as first-order factors. Third, instead of using proxy measures of functional autonomy (presence of chronic pain and attendance to nursing home/day-care centre) we used a self-reported measure of physical functioning to assess the level of (dis)ability in performing daily activities. We expected that self-reported physical functioning would be positively related with perceived promotion of autonomy (H1) and negatively related with perceived promotion of dependence (H2).

Further, we aimed at exploring differences in perceived promotion of autonomy and dependence between men and women, which was not possible previously (Matos & Bernardes, 2013) due to sampling limitations. Stereotypical representations of masculinity have been associated with autonomy and pain-related stoicism, whereas femininity has been associated with dependence and pain-related expressiveness (Bernardes, Keogh, & Lima, 2008; Burgess, & Borgida, 1999; Deaux, 1993; Schreiber, Nora, Stage, Barlow, & King, 2006). Pain-related gender representations influence (wo)men's pain experiences, but also the way others act towards them (Bernardes et al., 2008). As such, caregivers may be more prone to promote men's autonomy and women's dependence. Likewise, wo(men) would elicit and be more receptive of gender congruent support (*i.e.*, men/autonomy; women/dependence). Consequently, assuming that perceptions of received support may, to some extent, reflect provided support, we hypothesized that men would perceive higher perceived promotion of autonomy than women and women would perceive higher perceived promotion of dependence than men (H3). Finally, we aimed to re-test FSSADI\_PAIN discriminant validity, expecting low correlations with a measure of informal social support (H4).

#### Method

#### **Participants**

Two hundred and fifty older adults were recruited to participate in this study, from seven day-care centres and nursing homes in Lisbon. Inclusion criteria were that people would be formally retired from work activities and were users of a day care-centre or nursing home for more than 6 months. Also, we only included people who were actually able to read and write autonomously (despite years of education) and who did not present any kind of cognitive impairments (information provided by clinical staff of the institutions).

#### Instruments and Validation Plan

The revised FSSADI\_PAIN. The FSSADI\_PAIN is an instrument originally developed in Portuguese that aims to measure formal pain-related support for autonomy and dependence in pain (Matos & Bernardes, 2013). The revised version of the FSSADI\_PAIN is presented in Appendix A. It was developed to assess two main dimensions, perceived promotion of autonomy and perceived promotion of dependence, both including items reflecting instrumental and emotional/esteem functions of social support (Matos & Bernardes, 2013).

Regarding perceived promotion of autonomy, instrumental support actions consisted of tangible/behavioural help that allows people in pain to accomplish their daily tasks by themselves; while emotional/esteem support actions reinforce peoples' self-esteem, self-confidence to keep on functioning and to keep engaged in social/physical activity. As for perceived promotion of dependence, instrumental support actions consisted of tangible/behavioural help that substitute the person in pain in his/her activities; while emotional/esteem support actions reinforce lower self-efficacy to keep on functioning and to avoid social/physical activity.

Revision of the item pool. For the development of the FSSADI\_PAIN, ten items were originally created for each of the dimensions (20 items in total), mainly based upon expert consultation on support actions reflecting each dimension and existing questionnaires (*e.g.*, Health Related Formal Social Support Questionnaire [Questionário de Suporte Social Institucional na Saúde] (Calheiros & Paulino, 2007), Social Support Inventory (Timmerman, Emanuels-Zuurveen, & Emmelkamp, 2000). Within each dimension, half of the items reflected instrumental support and the other half reflected emotional/esteem support (Matos & Bernardes, 2013).

For the revised version of the FSSADI\_PAIN, presented in this paper, items that previously had low factor loadings were revised (12 items) and the ones that presented high inter-item correlations were eliminated to avoid redundancies (2 items). Further, five new items were created. Generally, when revising the items, experts' input was taken into account in order to make the notions of autonomy and dependence promotion more explicit and clear and to include items related to physical exercise/activity. Table 1 summarizes the changes made in the item revision process.

In sum, participants were presented with twenty-three items. In the dimension of perceived promotion of autonomy, five items measured instrumental support and six items measured emotional/esteem support. In the dimension of perceived promotion of dependence, five items measured instrumental support and seven items measured emotional/esteem support.

Table 1 - Summary of item revision process.

(sub) scale	Original Item	Revised Item		
	Help me to arrange transportation to take care of my affairs	Help me to arrange transportation to take care of my affairs by myself		
Perceived Promotion of Autonomy-	Help me contact other entities to solve my personal problems	Help me contact other entities so I can solve my personal problems autonomously		
Instrumental Support	Take care of social outings	Help me to deal with practical aspects (e.g., transportation, reservations, tickets) so I can participate in activities/social outings		
Perceived Promotion of	Encourage me to participate in activities	Encourage me to participate in leisure and fun activities		
Autonomy- Emotional/ Esteem Support	Help me to arrange transportation to take care of my affairs  Help me contact other entities to solve my personal problems  Take care of social outings  Encourage me to participate in activities  Encourage me to participate in activities  Substitute me in solving my personal affairs  Arrange transportation for me to go home to rest  Ask family members and friends for help on my behalf  Ask others to help me in my tasks  Are understanding when I am worried  Advise me not to participate  Understand that I need help from others to cope with my pain	Motivate me to exercise		
	problems Substitute me in solving my	— Solve for me my personal affairs		
Perceived Promotion of	Arrange transportation for me to	Take care of practical aspects for me to go to home to rest.		
Dependence- Instrumental	Ask family members and friends	Contact for me my family/friends to solve my problems or chores.		
биррогі	Ask others to help me in my tasks	Take care of tasks that usually are my responsibility		
		Bring me everything I need so I do not need to move		
	•	Show they understand that pain is awful and I feel that it overwhelms me		
Perceived	Advise me not to participate	Encourage me to avoid any kind of activity		
Promotion of Dependence-		Tell me that I need help to cope with my pain		
Emotional/ Esteem Support		Advise me to stop whatever I am doing  Tell me not to push myself when I feel unable of handling certain issues		
		Discourage me to exercise.		

Answering scale. In the revised version, the answering scale was simplified to a 5-point Likert-scale, given that in our previous study many older adults reported experiencing trouble understanding a 7-point scale (Matos & Bernardes, 2013). Hence, participants were asked to assess the perceived frequency of each type of support action on a rating scale from 1 (not at all frequent) to 5 (extremely frequent).

*Pre-test.* Four older adults (2 women and 2 men, aged between 74 and 83 years) assessed the clarity of the items and their opinions were taken into account when revising the items.

### Scale validation plan.

Content validity. Ten independent judges (6 women and 4 men, aged between 27 and 58 years old) were asked to assess the face validity of the revised FSSADI\_PAIN items. This sample included two directors of a nursing home, two directors of day care centres, one expert on older adults' physical exercise and functional training, three nurses experienced in formal caregiving and two laypeople with no experience in older adults' caregiving. All independent judges were asked to analyse the conceptual definitions of the (sub)dimensions of the measure (see above) and to place the twenty-three items in the corresponding one.

Criterion-related validity. Two criteria were used to assess the revised FSSADI\_PAIN concurrent validity: participants' sex and their self-reported physical functioning. Regarding the latter, the Portuguese version of the Physical Functioning Scale of the Medical Outcome Study Short Form – 36 (MOS-SF-36) was used to measure older adults' (dis)ability to perform activities of daily living (Ferreira, 2000a; 2000b). Only items that were relevant to the daily routines of this age group in a nursing home/day care centre were presented to participants (5 out of 10), namely, the items assessing older adults' ability to a) do moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf; b) climb one flight of stairs; c) bend, kneel, or stoop; d) walk one block; e) bathe or dress. Rating scale was from 1 to 3 (1=yes, limited a lot; 2=yes, limited a little; 3=No, not limited at all). Afterwards, for each participant, items' scores were summed and transformed into a 0-100 range, to get a single and final score for physical functioning (Ferreira, 2000a; 2000b). A principal axis factor analysis (oblimin rotation) was conducted with the 5 items [KMO=.888; Bartlett's  $\chi^2$  (10)=1102.319, p<.001]. Based on the Kaiser criterion, one factor was extracted, accounting for 75.4% of the total variance and with excellent internal reliability ( $\alpha$  = .937).

Discriminant validity. In order to assess the discriminant validity of the revised FSSADI PAIN, participants were asked to complete some of the tangible and emotional support items from the Portuguese version of the Social Support Scale of Medical Outcomes Study (SSS-MOS; Pais-Ribeiro & Ponte, 2009). In line with our previous study (Matos & Bernardes, 2013), we only chose three items with the highest loadings on the factors of perceived tangible and emotional support, respectively. Participants were asked "How often is each of the following kinds of support available to you if you need it? Items for tangible support were: someone to help you if you were confined to bed; someone to prepare your meals if you were unable to do it yourself; someone to help with daily chores if you were sick. Emotional support items were: someone to share your most private worries and fears with; someone who understands your problems; someone to confide in or talk to about yourself or your problems. A principal axis factor analysis (oblique rotation) was conducted with the 6 items [KMO=.738; Bartlett's  $\chi^2_{(15)}$  = 1844.588, p<.001]. Based on the Kaiser criterion, the two predicted factors were extracted, accounting for 89.5% of the total variance: 1) perceptions of emotional support (n=3 items,  $\alpha$ =.98) and 2) perceptions of tangible support  $(n=3, \alpha=.95).$ 

### **Procedure**

This study followed the ethical guidelines established by the ethical review of research at the host institutions (CIS-IUL, 2013). Furthermore, it also complied with the code of conduct of psychologists concerning research (American Psychological Association, 2010) and with the ethical standards as set out in the 1964 Declaration of Helsinki and its later amendments. Also, boards of all the participating institutions (where data collection took place) approved the research protocol. Participants were approached at the institution they attended and were requested to collaborate on a study on pain-related support.

After individual consent to participate, the data collection protocol was individually administered, including the revised FSSADI\_PAIN, and the Portuguese versions of the SF-36, and the SSS-MOS (Appendix B). Furthermore, present pain experience was assessed by yes-or-no questions, following the methodological strategy of several (chronic) pain epidemiological studies (*e.g.*, Torrance, Smith, Bennett & Lee, 2006) by yes-or-no questions. More specifically, the questions were the same as those used in our previous study (Matos & Bernardes, 2013). Participants were asked: (1) 'Have you ever had constant or intermittent

pain for more than three consecutive months?' (2) 'Did you feel this pain during the last week?' and (3) 'Did you feel any pain in the last week? According to yes-or-no answers to these questions, when participants answered positively to questions 1 and 2 were categorized as having present chronic pain; when answering positively only to question 3 were categorized as having present acute pain; when answering no to question 2 and 3 were categorized as having no present pain. Only for participants with present pain experience, pain intensity was assessed using the pain severity subscale of the Brief Pain Inventory (Cleeland, 1989).

Also, participants' sociodemographic characteristics were collected and the anonymity and confidentiality of their data guaranteed. Finally, all participants and institutions were thanked and debriefed.

### Data analysis

First, we started by verifying the absence of missing data and analysing item distribution for the total sample (N=250). Second, an exploratory factor analysis (EFA) was conducted with a random sub-sample of about half of the original sample (*n*=122) using SPSS v20. Due to previous factor correlations (Matos & Bernardes, 2013), we started by conducting a principal axis factor (PAF) analysis with an oblique rotation with all items. However, given that in the present sample no significant correlations between the factors were found, we finally conducted a PAF with an orthogonal rotation to explore the factor structure. Items with high cross-loadings (difference between the loadings on at least two factors below .30) and with the lowest communalities (<.50) were progressively eliminated. Given the non-normality of most item distributions, in order to validate the PAF, a non-linear Principal Components Analysis for Categorical Data (CatPCA) was conducted in order to validate PAF results. In CatPCA all items were imputed as ordinal variables.

Subsequently, confirmatory factor analysis (CFA) was performed using maximum likelihood (ML) estimation with the second random sub-sample (n=128) using AMOS v20, with no missing data. CFA was ran to test the underlying structure of the revised FSSADI\_PAIN and, more specifically, to test the fit of three alternative models: 1) perceived promotion of autonomy and perceived promotion of dependence as independent factors; 2) perceived promotion of autonomy and perceived promotion of dependence as correlated factors; 3) pain-related support as a second-order factor with perceived promotion of autonomy and perceived promotion of dependence as first-order factors. Multiple fit indexes

were chosen reflecting different features of model fit (Hooper, Coughlan, & Mullen, 2008). Therefore, absolute fit indexes -  $\chi^2$  and Root Mean Square Error of Approximation (RMSEA) were used to determine how well the *apriori* model fit the data (McDonald & Ho, 2002). Also, incremental fit indexes - Incremental Fit Index (IFI), the Normed Fixed Index (NFI) and the Comparative Fit Index (CFI) indicated the fit of the model when compared to the baseline model (Hooper, Coughlan, & Mullen, 2008). Criteria for good fit were established by CFI>0.9; NFI>0.9; RMSEA<0.05 (Hu & Bentler, 1999; Maroco, 2010; Schreiber, Nora, Stage, Barlow, & King, 2006). Finally, a non-parametric method (bootstrap) with 5000 subsamples was used in order to validate the results obtained by the parametric method (ML).

Subsequently, using SPSS v20, we explored the relationship between perceived promotion of autonomy/dependence and participants' sociodemographic characteristics. Only participants' years of education were significantly positively associated with perceived promotion of dependence therefore we controlled for this variable in subsequent analyses. Then, we tested the association between perceived promotion of autonomy/dependence and physical functioning with Pearson correlations. To explore sex-related differences in perceived promotion of autonomy and perceived promotion of dependence we ran a t-test and a univariate analysis of covariance with years of education as a covariate, respectively. Finally, Pearson correlations were run to ascertain the relationship between the subscales of the FSSADI\_PAIN and SSS-MOS.

### **Results**

### Participant characteristics

Two hundred and fifty older adults (75.2% women), aged between 53 and 99 years (M=81.36, SD=8.54) participated in this study. This was a multicentre study: participants were recruited from four different day-care centres (46.8%) and three nursing homes (53.2%) in Lisbon. Regarding marital status, 67.2% of the participants were widowed, 14% were married, 10.4% were single and 8.4% were divorced. Years of education ranged from 0 to 20 (M=4.71, SD=3.93). Almost half of the participants (47.2%) reported experiencing chronic pain (i.e., persistent or intermittent pain for more than 3 months; Merskey & Bogduk, 1994), 17.2% reported acute pain (i.e., having felt pain during the previous week), and 35.6% reported no current pain. Participants who reported present pain experiences (n=161) also rated pain intensity (min=0, max=10, M=4.02, SD=2.23). Finally, there were significant sex-

related differences in pain experiences ( $\chi^2(2)=9.254$ , p=.010); a higher percentage of women reported chronic pain (52.7%) than men (30.6%); men reported more acute pain (21% vs. 16% in women) and more absence of current pain (48.4% vs. 31.4% in women). Also, 27.6% of the participants reported no physical limitations in performing daily tasks and 16% reported to be fully physically restricted in performing such tasks (min=0, max=100, M=42.0, SD=36.0).

### Content validity

Ten independent judges assessed the content validity of the 23 items, by matching each one to the respective sub-dimension of the FSSADI\_PAIN. The inter-judge reliability index was very good (Cohen's K=.9).

### Item descriptive analysis and sensitivity

The analysis of the distribution of the items on the total sample (N=250) showed that participants' responses covered the scale range for every item (min=1 and max=5). The means ranged between 1.46 and 3.00, and standard deviations ranged between .87 and 1.50 (Table 2). Most of the items did not present a normal distribution, showing high levels of skewness (skewness/SE skewness > |1.96|) and kurtosis (kurtosis/SE kurtosis > |1.96|).

Table 2 - Descriptive analysis of the items for the global sample (N=250).

Item	M	SD	Kurtosis/SE kurtosis	Skewness/SE skewness
Encourage me to participate in leisure and fun activities	2.91	1.50	08	-4.65
Encourage me to socialize	3.00	1.46	75	-4.29
Encourage me to trust in my ability to keep on going	2.46	1.40	2.60	-3.87
Help me to deal with practical aspects so I can participate in activities/social outings	1.97	1.27	5.93	-1.72
Advise me to stop doing whatever I am doing	1.46	.87	13.42	12.97
Bring me everything so that I don't need to move	1.68	1.20	10.55	4.38
Tell me that I need help from others to cope with my pain	1.51	.94	12.28	9.10
Tell me not to push myself when I feel unable of handling certain issues	1.62	1.04	9.74	3.82

### Construct validity and Reliability

Exploratory factor analysis. The sampling adequacy was guaranteed (KMO = .713; Bartlett's  $\chi 2$  (28) = 587.064, p<.001). Based on the Kaiser criterion, two factors were extracted accounting for 62.3% of the variance: (1) perceived of promotion of autonomy (n = 4 items) and (2) perceived of promotion of dependency (n = 4 items) (see Table 3). A CatPCA also corroborated this two-factor structure; both factors accounted for 72.9% of the explained variance and the loadings distribution was very similar to the one presented in Table 3. Finally, it should be noted that both factors showed very good internal reliability.

Factor descriptive analysis and sensitivity. The perceived promotion of autonomy factor presented a mean value (M=2.58, SD=1.19), corresponding to a moderate perceived frequency of autonomy promotion. Total scores did not have a normal distribution, but showed an acceptable level of skewness (.844), whereas the kurtosis (- 3.63) level evidenced a flatter than normal distribution (*i.e.*, platykurtic; Tabachnick, 2013).

The perceived promotion of dependence factor presented a low mean value (M=1.57, SD=.83), showing that participants perceived low promotion of dependence. This factor presented a rather skewed (10.29) and leptokurtic distribution (6.30) (Tabachnick, 2013)

Table 3 – EFA factor loadings and internal reliability (n=122).

Item	Factor Lo	Factor Loadings		
When I am in pain, in general, the employees at this institution	PPA	PPD		
Encourage me to participate in leisure and fun activities	.963	031		
Encourage me to socialize	.912	.009		
Encourage me to trust in my ability to keep on going	.748	.004		
Help me to deal with practical aspects so I can participate in activities/social outings	.593	.092		
Advise me to stop doing whatever I am doing	135	.810		
Bring me everything so that I don't need to move	.068	.747		
Tell me that I need help from others to cope with my pain	.092	.740		
Tell me not to push myself when I feel unable of handling certain issues	.051	.714		
Cronbach \alpha	.88	.83		

Confirmatory factor analysis. The first model tested was the one obtained from the previous EFA – the two independent factors model (Model 1; Figure 3). The latent variables' variance was constrained to 1 and maintained uncorrelated, errors were kept fixed, observed variables were free and df > 0. The model was identified and included two latent variables: perceived promotion of autonomy and perceived promotion of dependence. Four items were associated to each latent variable (standardized coefficients provided in Figure 3).

In order to examine the fit of the first model, five maximum likelihood-based fit indexes were chosen. The CFI (.953), the NFI (.915) and the IFI (.954) were all higher than the established cut-off of 0.9 (Hu & Bentler, 1999; Maroco, 2010; Schreiber, Nora, Stage, Barlow, & King, 2006), which showed a very good fit. Also, the RMSEA (.092) showed an acceptable fit to the data. Finally, we concluded that there was an acceptable fit between the model and the observed data ( $\chi^2$  (20)=41.382, p=.003). Subsequently, two alternative models were tested – a) two correlated factors model (model 2); b) one second-order factor of general pain-related support linked to two first-order factors (perceived promotion of autonomy and perceived promotion of dependence; model 3).

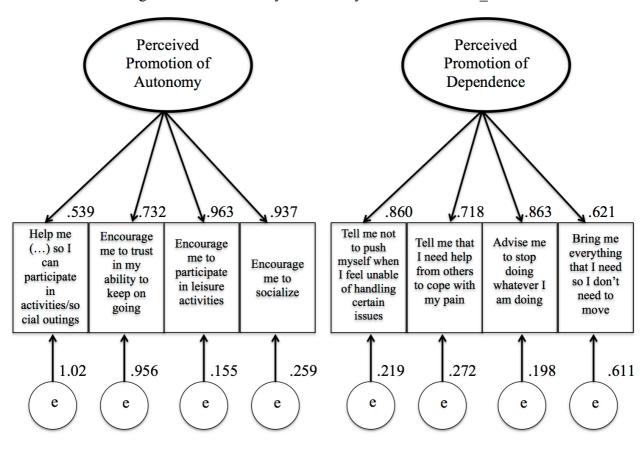


Figure 3 – Confirmatory factor analysis of the FSSADI PAIN.

As shown in Table 4, the fit indices of model 2 and model 1 were quite similar, due to the lack of significant covariance (p=.13) and correlation (r=-.156) between both latent variables. Model 3 showed the worse fit to the data. As shown in Table 4 none of the alternative models improved the data fit.

Table 4	- Fit inc	dexes con	iparison b	etween l	hypot	hesised	and	alterna	tive mod	els.

Structural models	Description	$\chi^2$	df	$\chi^2/df$	CFI	NFI	IFI	RMSEA
Hypothesised model	Figure 1	41.38	20	2.07	.953	.915	.954	.092
Alternative model 1	Figure 1 plus correlation between factors	39.01	19	2.05	.956	.920	.957	.091
Alternative model 2	One second-order factor of general perceived formal social support linked to two first-order factors	217.78	22	9.90	.574	.553	.579	.265

Due to underlying non-normality of the items, a non-parametric method (bootstrap) was subsequently used in order to validate the results obtained by the parametric method (maximum likelihood). As it can be seen in Table 5, the bias between the two methods was minimum.

Table 5 – Comparison of the estimates obtained from maximum likelihood and bootstrap methods.

Items	Maximum likelihood standardized estimates	Bootstrap standardized estimates	Bias
Help me to deal with practical aspects so I can participate in activities/social outings	.485	.483	001
Encourage me to trust in my ability to keep on going	.701	.701	.000
Encourage me to participate in leisure and fun activities	.909	.909	.000
Encourage me to socialize	.923	.924	.001
Tell me not to push myself when I feel unable of handling certain issues	.786	.786	001
Tell me that I need help from others to cope with my pain	.724	.726	001
Advise me to stop doing whatever I am doing	.775	.766	010
Bring me everything so that I don't need to move	.690	.683	007

### Criterion-related validity

The relationship between perceived promotion of autonomy/perceived promotion of dependence and self-reported physical functioning.

Self-reported physical functioning was positively correlated with perceived promotion of autonomy (r=.274, p<.001) and negatively with perceived promotion of dependence (r=.248, p=.002).

The relationship between perceived promotion of autonomy/perceived promotion of dependence and participants' sex.

Tests (ANCOVA) showed that participant's sex only had a significant effect on perceived promotion of dependence ( $F_{(1, 247)}$ =7.223, p=.008,  $\eta^2$ =.028), indicating that females perceived higher promotion of dependence (M=1.62; SD=.879) than males (M=1.39; SD=.648). No significant differences were found between women (M=2.63; SD=1.237) and men (M=2.46; SD=1.016) for perceived promotion of autonomy ( $t_{(248)}$ =.959, p=.339).

### Discriminant validity

No significant correlations were found between perceived promotion of autonomy/perceived promotion of dependence and the SSS-MOS' instrumental subscale (r=.052/.012, p=.410/.856) or emotional subscale (r=.081/-.074, p=.200/.243).

### **Discussion**

The present study aimed to revise and improve the psychometric features of a previously developed measure of pain-related formal support for the promotion of functional autonomy (perceived promotion of autonomy) versus promotion of dependence (perceived promotion of dependence) of older adults in pain – the FSSADI\_PAIN (Matos, & Bernardes, 2013).

The results of the preliminary validation study (Matos & Bernardes, 2013), its implications and limitations have set the path for the present work. More specifically, the present aims were to: (1) improve FSSADI\_PAIN content validity, by revising some of its original items; (2) test the underlying factorial structure of the revised FSSADI\_PAIN; (3) assess its criterion-related validity, by exploring its relationship with participants' sex and self-reported physical functioning; and (4) reassess its discriminant validity, by exploring its relationship with a measure of informal social support.

### Content validity

In order to improve the instrument's content validity, items were revised taking into consideration former results, namely, item factor loadings and correlations (Matos & Bernardes, 2013) and experts' input (*e.g.*, day-care centre and nursing home directors/other employees and nurses). As a result, two original items were dropped, twelve were revised and

five were newly created, resulting in a total of twenty-three items. These items were presented to a broader and more heterogeneous sample of expert judges, in terms of their background. The revised FSSADI\_PAIN (Appendix A) showed very good content validity. Moreover, the revised FSSADI\_PAIN showed a higher inter-judge reliability index (Cohen's K=.9) than its original form (Cohen's K=.8) (Matos & Bernardes, 2013). This suggests that the revised items are better representatives of the underlying conceptual (sub)dimensions of the instrument.

### Construct validity and reliability

As in our former study on the development and preliminary validation of the FSSADI PAIN (Matos & Bernardes, 2013), two factors were extracted by an exploratory factor analysis, showing good levels of internal reliability -1) perceived promotion of autonomy and 2) perceived promotion of dependence. The fact that, in our previous study (Matos & Bernardes, 2013), both factors unexpectedly showed a moderate and positive correlation (Matos & Bernardes, 2013), suggesting the presence of a general underlying factor of pain-related support, raised the need to confirm the instrument's underlying structure by a confirmatory factor analysis. Consequently, in the present study we aimed at testing and comparing the fit of three alternative models: 1) perceived promotion of autonomy and perceived promotion of dependence as independent factors; 2) perceived promotion of autonomy and perceived promotion of dependence as correlated factors; 3) pain-related support as a second-order factor with perceived promotion of autonomy and perceived promotion of dependence as first-order factors. The confirmation of two independent factors (model 1) ruled out the possibility of an underlying second order factor of general formal pain-related support. This finding suggested that perceived promotion of autonomy and perceived promotion of dependence are independent functions of pain-related support, which may bear different influences on older adults' pain experiences. As argued, this may actually account for the inconsistent effects of pain-related support on pain-related disability (Cobos, & Almendro, 2008; Deaux, 1993; Jamison, & Virts, 1990; Turk et al., 1992), although this contention still remains to be directly tested. We believe that the higher content validity of the current revised scales might have accounted for the fact that perceived promotion of autonomy and perceived promotion of dependence showed no significant correlation in the present study as opposed to the positive correlation found in our former study (Matos & Bernardes, 2013).

As for the instrument's reliability and sensitivity, both factors showed very good internal consistency indices and were sensitive to participants' differences concerning perceived promotion of autonomy and perceived promotion of dependence. It should be noted that, as in our former study (Matos & Bernardes, 2013), older adults showed, on average, lower perceived promotion of dependence than perceived promotion of autonomy. Indeed, participants' perceived promotion of dependence was again much more skewed to the lower end of the scale (low perceived frequency), where most item distributions deviated from normality. However, despite item non-normality, our results were validated by the use of a non-parametric approach, which indicated a robust solution for the factorial structure confirming a good fit to the data. Hence, we may conclude that perceived promotion of dependence item asymmetry may be somehow related with the nature and/or meanings of what is being measured, instead of reflecting poor item/factor quality. First, low perceived promotion of dependence may either be reflecting older adults' reluctance to report support behaviours that, by emphasizing lack of functional autonomy, may hinder self-esteem. Second, low perceived promotion of dependence may also be accounted for by the fact that our sample showed, on average, a reasonable level of physical and cognitive functioning, thus, not eliciting as much promotion of dependence as highly disabled older adults would. Finally, it may also reflect good quality practices in the seven participating institutions. Of course, one could argue for a selection bias, *i.e.*, only institutions with very good practices would give permission to run the study. However, given that none of the institutions that were approached refused to participate, we believe this interpretation is unwarranted.

### Criterion-related validity

As expected, self-reported physical functioning was positively correlated with perceived promotion of autonomy (H1) and negatively correlated with perceived promotion of dependence (H2). These results are congruent with fear-avoidance (Leeuw et al., 2007; Lethem et al., 1983; Vlaeyen et al., 1995) that postulates a positive association between avoidance and disability, on one hand, and confrontation and recovery, on the other hand. Nevertheless, it should be noted that the cross-sectional nature of this study restrains us from assuming a causal relationship between perceived promotion of dependence/disability and perceived promotion of autonomy/recovery. Indeed, it is possible that older adults with worse self-reported physical functioning might display more cues eliciting support behaviours that promote dependence, accounting for the higher perceived promotion of dependence. On the

other hand, older adults with better self-reported physical functioning might display more cues eliciting support behaviours that reinforce their ability to function autonomously, accounting for the higher perceived promotion of autonomy. Further research will be needed to explore the causal relationship between perceived promotion of autonomy/perceived promotion of dependence and self-reported physical functioning.

Also, the current study aimed at exploring differences in perceived promotion of autonomy/perceived promotion of dependence between men and women. We hypothesized that men would report higher perceived promotion of autonomy than women; and women would report higher perceived promotion of dependence than men (H3). Our expectation was only partially met, since only for perceived promotion of dependence (but not perceived promotion of autonomy) there were significant differences between men and women (females scored higher than men). Although the reasons explaining the lack of sex-related differences in perceived promotion of autonomy are unclear. The fact that stereotypical representations of femininity are widely associated with dependence (Burgess, & Borgida, 1999; Cohen & Wills, 1985; Robinson, Riley, & Myers, 2000) may well have accounted for differences in perceived promotion of dependence. It is possible that women, by feeling more comfortable eliciting and accepting dependence promotion support than men, turn out to receive more of this type of support from caregivers.

### Discriminant validity

In line with previous findings (Matos & Bernardes, 2013), no significant relationship was found between the revised FSSADI\_PAIN and SSS-MOS scales. This may be accounted for by the fact that these instruments measure different sources of support - informal support provided by family/friends vs. formal support provided by formal caregivers. However, both instruments include emotional and instrumental functions of social support. But, as indicated by the confirmatory factor analysis, as opposed to the SSS-MOS, the revised FSSADI\_PAIN structure does not revolve around the emotional/instrumental functions. This might also account for the low relationship between these measures. As such, we conclude that the revised FSSADI\_PAIN shows good discriminant validity.

### Limitations, implications and directions for future research

The findings demonstrate that the revised FSSADI\_PAIN is an innovative instrument in conceptualizing and operationalizing perceived promotion of autonomy and perceived

promotion of dependence, as different functions of pain-related support. Also it is a valid, reliable and sensitive tool to measure older adults' perceived support for autonomy/dependence in (chronic) pain. However, some limitations should be addressed. First, participants' reluctant willingness to report perceived promotion of dependence rather than perceived promotion of autonomy raises the need to explore, with a qualitative methodology, the meanings associated to perceived promotion of dependence/perceived promotion of autonomy. Also, this result highlights the relevance of considering the influence of social desirability in participants' responses, especially when the scales are being administered inside the institutions they attend.

Second, the direction of causality between perceived promotion of autonomy/perceived promotion of dependence and pain-related functioning remains to be tested with longitudinal designs.

Third, although the revised FSSADI\_PAIN is a valid and reliable measure of the frequency of perceived promotion of autonomy/perceived promotion of dependence, it does not provide information about older adults' support preferences. Not knowing about whether participants prefer autonomy vs. dependence promotion, when in pain, may constraint our knowledge about the influence of (chronic) pain relevant-support (Lugt, Rollman, Naeije, Lobbezoo, & Visscher, 2012). It is possible that preferences for the promotion of autonomy or dependence might moderate the effects of perceived promotion of autonomy/perceived promotion of dependence on pain experiences. For example, will the effects of perceived promotion of autonomy on pain and pain-related disability be the same for older adults who prefer promotion of autonomy than for the ones who prefer promotion of dependence? This is a question that remains unanswered. Hence, in line with other authors (Lugt et al., 2012), focusing on preferences for pain-related support could be a future line of research.

Furthermore, two important challenges to the generalization of our findings lie in participants' low educational level and high physical/cognitive functioning. Regarding educational level, since our results showed that years of education were positively correlated with perceived promotion of dependence, it would be reasonable to expect that a more educated sample would report higher perceived promotion of dependence, than present sample. In fact, a more heterogeneous sample in terms of level of education could, eventually, increase the variance of perceived promotion of dependence items and, consequently, minimize skewness. Hence, future studies should include older adults with higher educational levels. Low levels of perceived promotion of dependence might also be accounted for participants' high levels of physical/cognitive functioning, which also raise the

question of whether such results could be generalized to a more disabled sample of older adults. Future studies should, at least, strive to include older adults with different physical functioning status.

Finally, regarding sex-related differences in perceived promotion of dependence, the small effect size may raise some questions regarding its clinical significance. Future studies will be needed in order to further explore the role of sex and gender on perceived promotion of dependence and perceived promotion of autonomy to understand whether such differences may, to some extent, account for the sex-related differences in pain experiences.

Relevant implications can be drawn from the validation of the revised FSSADI\_PAIN. At a theoretical level, the conceptualization and operationalization of perceived promotion of autonomy and perceived promotion of dependence, assumes that pain-related support might not always translate into positive pain-related outcomes. Specifically the identification of perceived promotion of autonomy and perceived promotion of dependence as orthogonal dimensions, as opposed to two opposite poles of one dimension, suggests that pain-related support in pain is not a homogeneous construct with linear implications on pain experiences. Also, and as we have argued (Matos & Bernardes, 2013), this feature allows the identification of individuals that perceive ambivalent (high perceived promotion of autonomy and high perceived promotion of dependence) and undifferentiated support (low perceived promotion of autonomy and low perceived promotion of dependence) for the promotion of functional autonomy/dependence in pain. These findings are central to our contention that pain-related support, by promoting functional autonomy/dependence, might influence individual's engagement/avoidance in/of activities, therefore being less/more disabled.

From a practical perspective the development of the revised FSSADI\_PAIN might be useful for caregivers, institutions and policy makers because there is a lack of instruments measuring formal social support, especially, pain-related support; it might help promoting good practices of providing support to older adults suffering from (chronic) pain. For example, institutions may be able to signal at-risk individuals, namely, older adults with low physical functioning, high perceived promotion of dependence and low perceived promotion of autonomy. In conclusion, the FSSADI\_PAIN is an innovative, useful, valid and reliable tool to measure the promotion of autonomy/dependence as functions of pain-related support of older adults with pain. Its inclusion in future research will contribute to unravel the role of close interpersonal contexts on the promotion of active ageing among older adults with (chronic) pain.

This first study, by accomplishing the development of a valid and reliable tool, was fundamental for pursuing the other aims of the present thesis. More specifically, it became possible to measure the perceptions of received formal social support for functional autonomy and dependence when in pain. In the following chapters both theoretical models – depicted in Figures 1 and 2 (Chapter 1, pages 13 and 14) – will be tested using the revised FSSADI\_PAIN.

# Chapter 3

### (IN)DIRECT RELATIONSHIP BETWEEN PAIN-RELATED SUPPORT AND DISABILITY: A CROSS-SECTIONAL STUDY

**This chapter is based on the paper:** Matos, M., Bernardes, S. F., & Goubert, L. (2016). The relationship between perceived promotion of autonomy/dependence and pain-related disability in older adults with chronic pain: the mediating role of self-reported physical functioning. *Journal of behavioral medicine*, *39*(4), 704-715.

### **Abstract**

Chronic pain is prevalent among older adults and is usually associated with high levels of functional disability. Social support for the promotion of functional autonomy and dependence has been associated with pain-related disability and self-reported physical functioning. Nevertheless, these relationships need further inquiry. Our aims were to investigate: (1) the relationship between perceived promotion of autonomy/dependence and pain-related disability and (2) the extent to which self-reported physical functioning mediated these relationships. 118 older adults (Mage=81.0) with musculoskeletal chronic pain completed the Portuguese versions of the revised Formal Social Support for Autonomy and Dependence in Pain Inventory, the pain severity and interference scales of the Brief Pain Inventory, and the physical functioning scale of the Medical Outcomes Study-Short-Form 36 v2. Higher levels of perceived promotion of autonomy were associated with lower painrelated disability; this relationship was partially mediated by self-reported physical functioning (B=-.767, p<.001 decreasing to B'=-.485, p<.01). Higher perceived promotion of dependence was associated with higher pain-related disability; this effect was also partially accounted for by self-reported physical functioning (B=.889, p<.01 decreasing to B'=.597, p<.05). These results highlight the importance of perceived promotion of autonomy and dependence for managing older adults' experience of chronic pain.

### Introduction

We have previously argued (Matos & Bernardes, 2013; Chapter 2) that the impact of social support on pain-related disability might depend on the extent to which it promotes functional autonomy (*i.e.*, the ability to perform activities of daily living without assistance; *e.g.*, Pinsonnault et al., 2003) versus functional dependence (*i.e.*, the need for assistance to carry out activities of daily living; *e.g.*, Katz et al., 1963). Our argument was based on the assumption that pain-related social support might influence pain-related functioning, namely by supporting physical/social activity (dis)engagement (Fordyce, 1976; Vlaeyen et al., 1995). More specifically, social support for functional autonomy could reinforce activity engagement, whereas social support for functional dependence could reinforce activity disengagement. In addition, according to the Fear Avoidance Model (*e.g.*, Leeuw et al., 2007; Vlaeyen et al., 1995), avoidance behaviours increase pain-related disability while confrontation behaviours lead to recovery. Thus, activity engagement might be a crucial factor in suppressing pain-related disability and a facilitator of recovery; whereas activity

disengagement would increase pain-related disability and inhibit recovery. In sum, our contention was that with regard to pain-related disability, the extent to which pain-related social support might constitute either a risk or a protective factor would depend on whether it is promoting functional autonomy or dependence.

In a previous study (Matos & Bernardes, 2013), it was found a positive association between perceived promotion of dependence and pain-related disability among older adults with chronic pain; however, no significant relationship was found for perceived promotion of autonomy. Although these findings provide preliminary support for our assumptions, further inquiry into the association between perceived promotion of autonomy and dependence and pain-related disability is necessary. As such, the first goal of the present study was to further investigate the relationship between perceived promotion of autonomy and dependence and pain-related disability. In particular, we hypothesized that: (H1) higher perceived promotion of autonomy would be associated with lower pain-related disability and, that (H2) higher perceived promotion of dependence would be associated with higher pain-related disability.

In addition, it is important to investigate the mechanisms that might mediate the relationship between perceived promotion of autonomy and dependence and pain-related disability. To date, a large body of research has identified cognitive (e.g., catastrophizing, pain-related self-efficacy), affective (e.g., pain-related fear) and behavioural (e.g., activity dis/engagement) determinants of pain-related disability (e.g., Arnstein, 2000; Costa et al., 2011; Hasenbring et al., 2006; Nicholas, 2007; Nielson et al., 2001; Philips & Rachman, 1996; Vlaeyen et al., 1995). The extent to which these determinants may act as mediators of the influence of perceived promotion of autonomy and dependence on pain-related disability is yet to be explored. However, since we depart from a behavioural perspective by arguing that social support could influence pain-related disability by reinforcing functional autonomy/dependence, we chose to start by exploring the mediating role of a proxy of the latter, namely, self-reported physical functioning. In our previous work (Chapter 2), we established that the self-reported ability to perform daily activities – physical functioning – was positively associated with perceived promotion of autonomy and negatively associated with perceived promotion of dependence. As low physical functioning has been associated with pain-related disability (e.g., Leeuw et al., 2007; Lethem et al., 1983; Vlaeyen et al., 1995), we wanted to investigate whether the level of physical functioning could be a mechanism through which perceived promotion of autonomy and dependence would be related to pain-related disability. Thus, the second goal of the present study was to explore the mediating role of self-reported physical functioning in the relationship between perceived promotion of autonomy and dependence and pain-related disability, in older adults with chronic pain. Accordingly, we hypothesized that: (H3) the negative association between perceived promotion of autonomy and pain-related disability would be mediated by self-reported physical functioning; and, (H4) the positive relationship between perceived promotion of dependence and pain-related disability would be mediated by self-reported physical functioning.

### Method

### **Participants**

The present sample (N=118) consisted of a sub-sample taken from a larger pool of individuals (N=250) who had participated in a previous study (Chapter 2), where the inclusion criteria were: (1) having attended a day-care centre or a nursing home for at least six months; (2) being able to read and write autonomously; and (3) not presenting any kind of cognitive impairment (information provided by the institutions' clinical staff). More specifically, for the present study, a sub-sample of one hundred and eighteen participants (83.9% women) were selected based on the criteria of having reported continuous or intermittent pain for more than 3 months – chronic pain – felt in the last week. Older adults who did not report current pain or only reported acute pain were excluded from the present sample.

The 118 participants were users of four day-care centres (45.8%) and three nursing homes (54.2%) in the Lisbon area. All participants were retired and were aged between 53 and 95 years (Mage=81.0 SD=8.61). The vast majority had been widowed (71.2%), 14.4% were married, 9.3% were single and 5.1% were divorced. The participants' number of years of formal education ranged from 0 to 20 (M=4.81; SD=4.33).

### Instruments

Social Support for Autonomy and Dependence in Pain. The revised Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN) is a measure, originally developed in Portuguese that assesses the perceived frequency of formal social support actions for autonomy and dependence when in pain. Confirmatory factor analyses (reported in Chapter 2) have shown that this instrument comprises two underlying dimensions — Perceived Promotion of Autonomy (4 items; e.g., When I am in pain, the employees at this

institution...: ...help me to deal with practical aspects so I can participate in activities/social outings; ...encourage me to participate in leisure and fun activities) and Perceived Promotion of Dependence (4 items; e.g., When I am in pain, the employees at this institution...: ...bring me everything so that I don't need to move; ...advise me to stop doing whatever I am doing). Participants rated the perceived frequency of functional autonomy and dependence support actions when in pain on a Likert scale, ranging from 1 (not at all frequent) to 5 (extremely frequent).

Both factors have shown very good internal consistency indices, in the original  $(\alpha_{Perceived\ Promotion\ of\ Autonomy} = .88;\ \alpha_{Perceived\ Promotion\ of\ Dependence} = .83;\ Chapter\ 2)$  and in the present sample  $(\alpha_{Perceived\ Promotion\ of\ Autonomy} = .86;\ \alpha_{Perceived\ Promotion\ of\ Dependence} = .80)$ . The scores for perceived promotion of autonomy and dependence were obtained by computing the average of the corresponding four items. Higher scores represented higher perceived promotion of autonomy and dependence.

Pain Disability and Severity. Participants were presented with the pain interference and pain severity scales of the Portuguese version of the Brief Pain Inventory (BPI; Azevedo et al., 2007). Our initial intention was to use the pain interference scale to measure pain-related disability and, also, to assess and control for pain severity, which is often highly correlated with pain disability (e.g., Arnstein et al., 1999; Denison et al., 2004). Both scales of the Portuguese version, have shown good psychometric properties ( $\alpha_{pain severity}$ =.98;  $\alpha_{pain}$ interference=.84; Azevedo et al., 2007). It should be noted, however, that only some of the items on these subscales were presented. Given the clinical and sociodemographic characteristics of our sample (e.g., participants' low educational level), we reduced the length of the data collection protocol by including the items with the highest factor loadings in previous studies. Also, items that were not relevant for the daily contexts and routines of institutionalized adults (e.g., pain interferes with housework) were excluded. Therefore, participants were asked to rate pain severity at its worst and on average, from 0 (no pain) to 10 (pain as bad as you can imagine) during the last week. Then, they were also asked to rate how pain had interfered with: a) their general activity, b) mood, c) walking ability and d) sleep, from 0 (does not interfere) to 10 (completely interferes).

To assess the psychometric properties of these scales in the present sample, an exploratory factor analysis (principal axis factor analysis with oblique rotation) was conducted [KMO=.83; Bartlett's  $\chi^2$  (15)=456, p<.001]. Based on the Kaiser criterion, only one factor was extracted (n=6 items; with pain interference items scoring higher) accounting

for 61.2% of the total variance. This factor also showed a very high internal reliability ( $\alpha$ =.90). Based on these results, we decided to use this factor as our outcome variable and termed it – pain disability/severity. The score for pain disability/severity was obtained by averaging all item scores, with higher scores reflecting a higher degree of chronic pain disability and severity.

Self-reported Physical functioning. To measure older adults' self-reported ability to perform daily physical activities, participants were presented with five items on the physical functioning scale of the Portuguese version of the Medical Outcomes Study - Short Form 36v2 (Ferreira, 2000a; 2000b). The Portuguese version of this scale has good psychometric properties ( $\alpha$ =.87; Ferreira, 2000b). Only the five items (out of 10) that were relevant to older adults' daily context and routines at nursing homes/day-care centres were administered. Participants were asked about their ability to a) do moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf; b) climb one flight of stairs; c) bend, kneel, or stoop; d) walk one block; e) bathe or dress. They answered on a scale ranging from 1 to 3 (1 = yes, limited a lot; 2 = yes, limited a little; 3 = No, not limited at all). An exploratory factor analysis (principal axis factor with oblimin rotation) was conducted [KMO=.85; Bartlett's  $\chi^2$  (10)=466, p<.001]. Based on the Kaiser criterion, one factor – selfreported physical functioning - was extracted, accounting for 72% of the total variance (5 items, α=.93). Following Ferreira's guidelines (Ferreira, 2000a), participants' answers to the items were transformed into a final score that ranged from 0 (lowest ability) to 100 (highest ability) to perform daily physical activities.

### Procedure

This study followed the ethical guidelines established by code of conduct of psychologists concerning research (American Psychological Association, 2010) and with the ethical standards as set out in the 1964 Declaration of Helsinki and its later amendments. Also, boards of all the participating institutions (where data collection took place) approved the research protocol.

First, four day-care centres and three nursing homes were invited to collaborate. No institution refused or disapproved the research protocol. Second, all participants were informed about the purpose of the study, informed consent was obtained from all individual

participants included in the study, and they were guaranteed anonymity and confidentiality. No participants refused to take part in the study.

Prior to data collection, participants were screened for present pain experiences. Screening followed the methodological strategy of several (chronic) pain epidemiological studies (*e.g.*, Breivik et al., 2006; Torrance et al., 2006), by using yes-or-no questions. More specifically, the questions were the same as those used in our previous studies (*e.g.*, Matos & Bernardes, 2013; Chapter 2): (1) 'Have you ever had constant or intermittent pain for more than three consecutive months?' (2) 'Did you feel this pain during the last week?' and (3) 'Did you feel any pain in the last week?'. Participants were deemed to have current chronic pain if they answered positively to questions 1 and 2. Participants who only answered positively to question 3 were considered as having current acute pain. Finally, all participants who answered negatively to questions 2 and 3 were considered as having no current pain. Only participants that reported present chronic pain were included in the present study.

The data collection protocol (Appendix B) included several questionnaires in the following order: the revised FSSADI\_PAIN, the Portuguese versions of the pain severity and pain interference sub-scales from the BPI; the Portuguese version of the physical functioning scale of the MOS-SF-36 v2 and, finally, sociodemographic questions (sex, marital status, age, former profession, cohabitation status, years of formal education and how long participants had attended the institution).

The protocols were mostly applied individually and in face-to-face interviews. This was done in order to facilitate the participation of people with a low level of education, visual impairment and, often, at the request of participants. Few participants read it and filled it out by themselves (2.5%). Data collection took place at the institutions the participants were attending, and generally in a quiet and isolated location. All participants and institutions were thanked and orally debriefed. Debriefing was an opportunity to provide participants and institutions with simple and relevant information about the subject and the nature of the study (APA, 2010; CIS-IUL, 2013).

### Data Analysis

First, using IBM SPSS v20, we analysed the descriptive statistics of the sample and the distribution of the variables in the model to be tested (perceived promotion of autonomy, perceived promotion of dependence, self-reported physical functioning and pain disability/severity).

Second, we tested the relationship between the variables in the model and sociodemographic variables, using t-tests and Spearman correlations. By using the Bonferroni correction, in order to control for Type I error, a lower significance level was adopted (p= .05/12=.004). Since no significant relationships were found, sociodemographic variables were not included in the remaining analyses.

Third, two mediation models were tested, using 1) perceived promotion of autonomy and 2) perceived promotion of dependence, as predictors respectively; pain disability/severity as the criterion variable; and self-reported physical functioning as the mediator. Due to the lack of a normal distribution for most variables (see Table 6), a non-parametric approach (bootstrap) was used to test the mediation models. Preacher and Selig (2012) state that the benefits of using a bootstrapping approach are the inexistence of assumptions regarding distributions and its applicability to small samples. In this approach the effects are tested directly, rather than step-by-step (like the traditional approach of Baron & Kenny, 1986), by using a confidence interval derived by bootstrap that allows the significance of the effects to be inferred without the assumption of a normal distribution. Therefore, both mediation models were investigated by directly testing the significance of the indirect effect of the predictors (perceived promotion of autonomy and perceived promotion of dependence) on the criterion variable (pain disability/severity) through the mediator (self-reported physical functioning). Following Preacher and Hayes' (2008) guidelines, a bootstrapping approach was used to test indirect effects from a 5000 estimate and 95% percentile-based confidence intervals, using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution. The indirect effects were considered significant when the interval did not include zero.

### **Results**

### Descriptive analysis and distribution

As shown in Table 6, participants reported a moderate level of perceived promotion of autonomy and this score showed a near normal distribution. Participants reported low perceived promotion of dependence; this score was particularly skewed and did not follow a normal distribution. Older adults reported moderately disabling/severe pain, with pain disability/severity normally distributed. Finally, participants reported having a low level of self-reported physical functioning; the distribution of this score was highly skewed and deviated from normality.

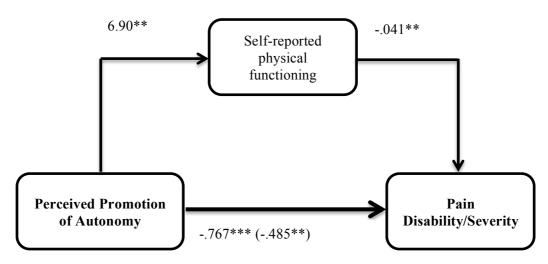
Table 6 – Descriptive statistics and distribution of perceived promotion of autonomy, perceived promotion of dependence, pain-related disability/severity and self-reported physical functioning (n=118).

Variable	Min-Max	M	SD	Kurtosis/SE kurtosis	Skewness/SE skewness	K-S
Perceived Promotion for Autonomy	1-5	2.80	1.17	-2.55	17	.021
Perceived Promotion for Dependence	1-5	1.66	.84	2.37	5.73	.000
Pain disability/ severity	.17-9.33	4.46	2.58	-2.31	.48	.200
Self-reported Physical functioning	0-100	33.2	33.2	1.41	3.07	.000

## The relationship between perceived promotion of autonomy and pain disability/severity: the mediating role of physical functioning

Figure 4 represents the mediation model in which perceived promotion of autonomy is the predictor, pain disability/severity is the criterion variable, and self-reported physical functioning is the mediator. As can be seen in Figure 4, perceived promotion of autonomy is negatively associated with pain disability/severity and it accounts for 11.3% of its variance  $(R_{adj}^2 = .11, F(1, 117) = 15.9, p < .001)$ , as hypothesized in H1. This relationship was partially mediated by self-reported physical functioning, as shown by the decrease in the unstandardized regression coefficients (B=-.77, p<.001 to B=-.49, p<.01), corroborating H3. The percentile-based confidence interval of the empirical distribution [-.483;-.060] corroborated the significance of the indirect effect. More specifically, perceived promotion of autonomy was positively associated with self-reported physical functioning which, in turn, was negatively associated with pain disability/severity. The mediation model accounted for 37% of the explained variance in pain disability/severity ( $R_{adj}^2 = .37$ , F(2, 117) = 35.2, p<.001).

Figure 4 –The relationship between perceived promotion of autonomy and pain disability/severity, partially mediated by self-reported physical functioning

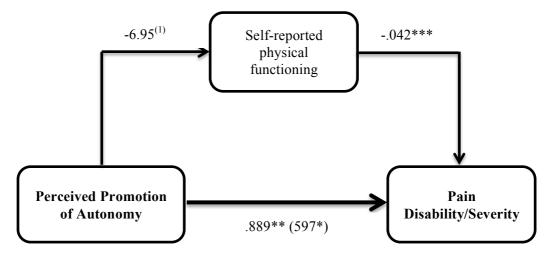


Note. Values in the figure are unstandardized regression coefficients, \*\*\* $p \le .001$  \*\* $p \le .01$ 

# The relationship between perceived promotion of dependence and pain disability/severity: the mediating role of physical functioning

Figure 5 represents the mediation model in which perceived promotion of dependence is the predictor, pain disability/severity the criterion variable and self-reported physical functioning the mediator. As can be seen in Figure 5, perceived promotion of dependence was positively related to pain disability/severity, accounting for 8% of its variance  $(R_{adj}^2 = .08, F(1, 117)=10.5, p<.01)$ , as hypothesized in H2. This relationship was partially mediated by self-reported physical functioning, as shown by the decrease in the unstandardized regression coefficients (B=.89, p<.01 to B=.60, p<.01), hence, corroborating H4. More specifically, perceived promotion of dependence was negatively associated with physical functioning. The percentile-based confidence interval of the empirical distribution [.023;.593] allowed us to sustain the significance of the indirect effect. In addition, self-reported physical functioning was negatively associated with pain disability/severity. The mediation model accounted for 36% of pain disability/severity ( $R_{adj}^2 = .36$ , F(2, 117)=33.82, p<.001).

Figure 5 –The relationship between perceived promotion of dependence and pain-related disability/severity, partially mediated for by self-reported physical functioning.



Note. Values in the figure are unstandardized regression coefficients, \*\*\* $p \le .001$  \*\* $p \le .05^{(1)} p = .058$ 

### **Discussion**

In this study, the first goal was to investigate, with a cross-sectional design, the relationship between perceived promotion of autonomy and dependence and pain-related disability among older adults with chronic pain, who attended day-care centres or nursing homes – which pertained to the second goal of this thesis

We hypothesized that (H1) higher perceived promotion of autonomy would be associated with lower pain-related disability; and (H2) higher perceived promotion of dependence would be related to higher pain-related disability. The second goal was to explore the mediating role of self-reported physical functioning in the relationship between perceived promotion of autonomy and dependence and pain-related disability – which partially responded to the third aim of the thesis by addressing the behavioural path of the hypothesized model (Figure 1, page 13). It was expected that (H3) the positive relationship between perceived promotion of autonomy and pain-related disability would be accounted for by self-reported physical functioning. The negative relationship between perceived promotion of dependence and pain-related disability would also be accounted for by self-reported physical functioning (H4).

Concerning the first goal, our findings confirmed that higher perceived promotion of autonomy was associated with lower pain disability/severity, and that higher perceived promotion of dependence was associated with higher pain disability/severity. Thus, the first

two hypotheses were confirmed. These results support our contention that pain-related social support may be associated with different pain-related outcomes, depending on whether it promotes functional autonomy or dependence (Matos & Bernardes, 2013). More specifically, this pattern of findings – by supporting this direct association – indicates that perceiving the social context as providing pain-related support for functional autonomy is associated with less disabling/severe pain. In contrast, when support for functional dependence is perceived, it is related to more disabling/severe pain. These findings come partially in line with our previous results, which showed a significant association between higher perceived promotion of dependence and higher pain-related disability but a non-significant association between the latter and perceived promotion of autonomy (Matos & Bernardes, 2013). The difference between the previous and the present results might be accounted for, on one hand, by the usage of different versions of the FSSADI PAIN. For the present work, we used the revised version of the FSSADI PAIN (Chapter 2) rather than the preliminary version used in Matos and Bernardes (2013). On the other hand, there is also the possibility that the direct association between pain-related disability and perceived promotion of dependence might be more consistent than the association with perceived promotion of autonomy. Indeed, our findings on the role of perceived promotion of dependence come in line with accumulating evidence on the deleterious effects of solicitous support on pain-related disability (e.g., Boothy et al., 2004; Kerns et al., 1991; Raichle et al., 2011; Romano et al., 2009). However, the lack of current empirical evidence on the role of a more adaptive function of pain-related social support, like perceived promotion of autonomy, does not allow us to draw any firm conclusions on the nature of its relationship with pain-related disability. If anything, our findings highlight the need to further explore the role of perceived promotion of autonomy on pain-related disability.

The second goal of the present study was to uncover underlying processes of the relationship between pain-related support for functional autonomy and dependence and pain-related disability, by testing the mediation effect of self-reported physical functioning. In line with our previous study (see Chapter 2), in the present sub-sample of older adults with chronic pain, higher perceived promotion of autonomy was associated with higher self-reported physical functioning, and higher perceived promotion of dependence was associated with lower self-reported physical functioning. Like other studies, these findings show that social support is an important predictor of physical functioning, within the context of chronic diseases (*e.g.*, Luszczynska, Sarkar, & Knoll, 2007; Shen, McCreary, & Myers, 2004). Furthermore, following the predictions of the Fear Avoidance Model (*e.g.*, Leeuw et al.,

2007; Vlaeyen et al., 1995) and as shown in previous research (Crook & Moldofsky, 1994; Vlaeyen et al., 1995), self-reported physical functioning was significantly associated with pain-related disability. Finally, our findings have shown that self-reported physical functioning partially accounted for the relationships between perceived promotion of autonomy and dependence and pain disability/severity, thus supporting H3 and H4.

This pattern of findings could possibly be an indication that perceptions about pain-related support might act as reinforcement of physical functioning, hence, they may lessen pain disability/severity. If this were so, it would show that social support might influence health-related outcomes by influencing individuals' behaviours, like physical activity (*e.g.*, Cohen & Syme, 1985). It would also indicate that social support provides more than just a "protective cushion" against stress (Benight & Bandura, 2004, p.1134). Indeed, as put forward by Schwarzer & Knoll (2007), (received) social support might constitute a vicarious experience in dealing with a stressor, thus enabling individuals' skills to deal with adversity.

Our findings also show that pain-related social support may be either adaptive or maladaptive. In a chronic pain context, support for functional autonomy seems to be adaptive by being associated with higher physical functioning and lower interference of pain in older adults' daily lives. Conversely, support for functional dependence seems to be maladaptive by being associated with lower physical functioning and higher pain disability/severity. It should be noted, however, that the extent to which these two functions of social support might be adaptive could depend on the specificities of pain experiences. For example, as we have argued before (Matos & Bernardes, 2013), it is possible that at the start of an acute pain episode, the most adaptive social response could be to promote functional dependence to hasten healing and recovery. Clearly, more research is needed to identify in which circumstances pain-related social support for functional autonomy and dependence is adaptive or maladaptive.

It should also be noted that due to the cross-sectional nature of the present study, we should also consider the possibility that the level of pain disability/severity or physical functioning might have influenced the kind of pain-related support received. As we have previously discussed (Matos & Bernardes, 2013), it is possible that people with higher disabling pain or lower physical functioning would display more pain behaviours, therefore eliciting more support actions promoting dependence instead of autonomy. This idea is congruent with Sullivan et al's (2004) Communal Coping Model of Catastrophizing showing that the presence of others might act as a cue to elicit pain behaviours, which in turn, would

lead to more solicitous social responses. However, the impossibility of clarifying the causal relationship between these variables stresses the need to interpret our findings with caution.

Nevertheless, these results stress the importance of social support within the context of pain-related functioning, indicating that it can fulfil different functions and have different repercussions on behaviours and pain-related outcomes. Furthermore, present results corroborate the negative association between solicitous social support and higher pain-related disability/severity (*e.g.*, Boothy et al., 2004; Kerns et al., 1991; Raichle et al., 2011; Romano et al., 2009), by showing the association between perceived promotion of dependence and higher pain disability/severity. Moreover, our findings add a more positive view of the influence social support has on pain by showing the association between higher perceived promotion of autonomy and less pain disability/severity.

### Limitations, implications and directions for future research

Some limitations of this study should, however, be pointed out. First, given the cross-sectional nature of the design, no conclusions can be drawn regarding the direction of causality. In future research, longitudinal studies should examine the impact of pain-related support on pain-related outcomes, over time (see Chapter 4).

A second limitation relates to the use of a self-report scale to measure physical functioning. Self-report measures only give information about participants' perceived ability to perform certain daily tasks. Despite the importance of measuring participants' views about their ability, this measure might be biased by recall or social desirability. More importantly, it does not provide information about actual/observed physical functioning concerning mobility, agility or strength to accomplish physical tasks. Indeed, perceived physical functioning might be poorly linked to real activity levels (Stubbs et al., 2013). In future research, physical functioning should also be assessed using observational measures (see Chapter 4).

Third, since self-reported physical functioning only accounted for part of the relationship between perceived promotion of autonomy and dependence and pain disability/severity, it would be interesting to explore other potential mediation mechanisms in future research, namely, cognitive and affective mediators. For example, one potential mediator could be fear of movement/(re)injury, which has been shown to be a strong predictor of pain-related disability in chronic pain patients (*e.g.*, Vlaeyen et al., 1995); another potential mediator could be an individual's activity patterns (*e.g.*, avoidance,

overdoing and pacing), which also plays an important role in the development and maintenance of chronic pain (Hasenbring et al., 2006; Nielson et al., 2001; Philips & Rachman, 1996); a final potential mediator could be pain-related self-efficacy, which has been associated with lower levels of pain intensity, disability, depression and anxiety (*e.g.*, Arnstein, 2000; Costa et al, 2011; Nicholas, 2007). Indeed, from a biopsychosocial perspective on chronic pain (*e.g.*, Gatchel, 2013; Turk & Monarch, 2013) the present study only addresses how social and physical variables influence pain disability/severity. In future research, it would be interesting to explore the relationship between pain-related social support and cognitive and affective mechanism that have been shown as important predictors of pain-related disability (*e.g.*, Turk & Monarch, 2013). This new avenue of research would also contribute to the integration of a social and interpersonal dimension to the dominant models on pain-related disability, like the Fear Avoidance Model (*e.g.*, Leeuw et al., 2007; Vlaeyen et al., 1995) – see Chapter 4.

A fourth limitation relates to the measurement of pain-related disability in this study. The original pain severity and pain interference subscales were only partially presented. As a consequence, the extracted factor – pain disability/severity – included items related to pain severity and pain interference in daily activities. In future work, we ought to measure pain severity and disability independently and with more extensive measures, since they represent two different dimensions of the pain experience which, despite being highly correlated, might have different associations with perceived promotion of autonomy and dependence.

Lastly, concerning the generalization of the results, there are two features of the present sample that should be discussed. First, the participants' low educational level was one of the reasons for collecting data in face-to-face interviews. This, however, may have led to social desirability having a greater influence on participants' responses. Second, because all participants lived in urban areas, with family and friends generally living nearby, informal support might have higher relevance than in rural areas. That is to say, urban older adults might rate lower with regard to pain-related support received from formal sources because they may be getting more support from informal sources. These features might raise the question of whether such results could be generalized to a more heterogeneous sample of older adults. Therefore, future research should include older adults living in rural areas, with more years of formal education.

Despite its limitations, this work has several theoretical and practical implications. Firstly, from a theoretical perspective, its results highlight that pain-related social support, depending on whether it promotes functional autonomy or dependence, is associated with

different pain-related outcomes for older adults living with chronic pain. Our contribution is innovative in that it proposes two different functions of social support that are specific to pain contexts. Furthermore, we show that these functions may have different associations with pain experiences, resulting in lesser or worse pain disability/severity. In other words, in a chronic pain context, pain-related social support might be adaptive as well as maladaptive, depending on the extent to which it promotes functional autonomy or dependence. We also begin to uncover one of the possible mechanisms that account for the relationship between pain-related support and pain-related outcomes.

From a practical point of view, in order to reduce pain-related disability, we could argue that autonomy and dependence promotion are functions of formal social support that could be targeted in training programs for the staff of day-care centres or nursing homes. For example, interventions could be developed to increase formal caregivers' knowledge and skills regarding which kinds of supportive behaviours are more adaptive for older adults with chronic pain. Thus increasing supportive behaviours that promote functional autonomy rather than functional dependence. Indeed, such supportive behaviours may even help promote older adults' physical activity, which is an important non-pharmacological strategy for managing chronic pain in older adults (*e.g.*, Haneweer et al., 2009; Hendrick et al., 2011; Stubbs et al., 2013).

Nonetheless, this is a line of research that it is still in its infancy and many features of pain-related support should stimulate future research and enlighten future interventions. Besides further exploring the mediating mechanisms of the relationship between perceived promotion of autonomy and perceived promotion of dependence, future research should also identify potential moderators of such relationships. Individuals' preferences for pain-related social support, the extent to which support actions are (in)visible or how the intentions behind those actions are perceived by the recipient are just some examples of potential moderators. Studies have shown that individuals' responses to social support actions may depend on the extent to which these actions address their needs or preferences (e.g., Maisel & Gable, 2009). Therefore, the relationship between perceived promotions of autonomy and dependence and pain disability might depend on the extent to which older adults' prefer receiving pain-related support for autonomy or dependence (Bernardes, Matos & Goubert, under review). Research carried out by Bolger and colleagues (2000; 2007) showed that invisible support is far more beneficial than visible support. Further to that, and because receiving support has an emotional cost, the most effective support is that which is not perceived as support (Bolger et al., 2000). In our present work, we are only assessing visible support for promotion of

autonomy and dependence. We feel, however, that it would be interesting to explore whether part of the support provided by staff at institutions is not being perceived, and the extent to which such invisible support may also have an effect on older adults' pain-related disability. Finally, would perceived promotion of autonomy still have a positive association with pain-related outcomes if older adults' considered such support behaviours neglectful or demanding? More research is needed to explore the moderating role of perceived intentions of support actions on the relationship between perceived promotion of autonomy/dependence and pain-related disability.

In conclusion, perceived promotion of autonomy and dependence are two important features of social support when managing older adults' chronic pain experiences. Future research on such functions of social support, but more specifically on perceived promotion of autonomy, can contribute towards preventing/reducing the deleterious effect of chronic pain on older adult's healthy ageing process. In the next chapter, a longitudinal study will be presented that will contribute to disentangle the temporal relationship between these two functions of formal social support and pain-related disability and further test the behavioural and psychological mediating mechanisms of such relationship.

# **Chapter**

# THE (IN)DIRECT EFFECT OF PAIN-RELATED SUPPORT ON DISABILITY: A PROSPECTIVE STUDY

**This chapter is based on the paper:** Matos, M., Bernardes, S. F., & Goubert, L. (submitted). A moderated mediation analysis of pain-related support for functional autonomy versus dependence in older adults with chronic pain. *Pain*.

## **Abstract**

Pain-related support has been shown to differentially relate to pain outcomes depending on whether it promotes functional autonomy or dependence (e.g., Chapter 3). However, there is the need to confirm longitudinally its effects according to a biopsychosocial perspective, rather than only relying on a behavioural standpoint. The present, longitudinal study aims at investigating (1) the direct effects of perceived promotion of autonomy/dependence on painrelated disability; (2) the mediating role of physical functioning, pain-related self-efficacy and fear; and (3) the moderating role of pain intensity and pain duration. One hundred and seventy older adults ( $M_{age}$ =78.3;  $SD_{age}$ =8.7) participated in a 3-months prospective design, with three moments of measurement, with a 6-week lag in-between them. Participants completed the Formal Social Support for Autonomy and Dependence in Pain Inventory, the Brief Pain Inventory (Cleeland, 1989), the 36-SF Health Survey, behavioural tests from the Senior Fitness Test, the Pain Self-Efficacy Questionnaire and the Tampa Scale for Kinesiophobia. Moderated mediation analyses showed that: 1) perceived promotion of dependence (T1) predicted an increase in pain-related disability (T3); 2) mediated by selfreported physical functioning (T2) and by pain-related self-efficacy (T2); 3) at short to moderate duration of pain and at low to moderate levels of pain intensity. Present findings stress the implications of different functions of pain-related social support. It emphasizes that promoting functional dependence is a risk factor, influencing behavioural and psychological mechanisms, in predicting worse pain outcomes. Upon this research, future interventions should raise awareness about the detrimental effects of promoting functional dependence to older adults with chronic pain, aiming to increase practices that promote a healthy ageing and well being in older age, despite chronic pain.

# Introduction

As aforementioned, this thesis argues that social support may be a risk or a protective factor within the context of chronic pain. Indeed, the help that people perceive to be available or that has been received when needed (Cohen et al., 2000) has been shown to influence pain-related outcomes, both positively (*e.g.*, Boothy et al., 2004; Evers et al., 2003; Hughes et al., 2014; Kerns et al., 2002; Raichle et al., 2007; Raichle, Romano & Jensen, 2011) and negatively (Coty & Wallston, 2010; Raichle et al., 2007; Romano et al., 2000; Romano et al., 2009). Drawing upon operant conditioning (Fordyce, 1976) and fear-avoidance models (Vlaeyen et al., 1995; Leeuw et al., 2007), we have argued that the extent to which pain-

related social support promotes individuals' functional autonomy (*i.e.*, the ability to perform activities of daily living without assistance; Pinsonnault et al., 2003) versus dependence (*i.e.*, the need for assistance in accomplishing activities of daily living; Katz et al., 1963) may account for such inconsistencies (Matos & Bernardes, 2013; Chapter 2; Chapter 3). More specifically, pain-related support can either reinforce pain and avoidance behaviours or well behaviours and activity engagement, which are crucial factors accounting for pain-related disability (*e.g.*, McWilliams et al., 2014; McCraken, 2005; Pence et al., 2008; Romano et al., 1995; Schwartz et al., 2005).

Previous cross-sectional studies with older adults with chronic musculoskeletal pain support this contention (see Chapters 2 and 3). Findings have shown that formal pain-related support (*i.e.*, provided by staff at day-care centres) that promotes functional autonomy (*i.e.*, perceived promotion of autonomy) was directly associated with lower levels of pain-related disability. On the other hand, pain-related support that promotes functional dependence (*i.e.*, perceived promotion of dependence) has been directly associated with higher pain-related disability. Of interest, older adults' self-reported physical functioning partially accounted for the relationship between perceived promotion of autonomy/dependence and pain-related disability (Chapter 3).

Although the findings described in Chapters 2 and 3 highlight the relevance of differentiating these two functions of pain-related support, they bear some limitations that have set the path for the present study. First, cross-sectional designs prevent inferences on causality, calling for the use of longitudinal designs. Therefore, in the present study our first goal was to investigate, with a longitudinal design, the hypotheses that perceived promotion of autonomy would predict a decrease in pain-related disability, while perceived promotion of dependence would predict an increase in pain-related disability.

Second, previous studies (see Chapter 2 and 3) were limited by the sole use of self-report measures of physical functioning, which could be biased by recall or social desirability. Therefore, the second goal of the present study was to investigate the longitudinal mediating role of *self-reported* and *observed* physical functioning in the relationship between perceived promotion of autonomy/dependence and pain-related disability.

Third, the exclusive focus on behavioural mediating mechanisms (physical functioning) in Chapter 2 and 3, called for the investigation of the mediating role of two psychological factors that also have been shown as important predictors of pain-related disability (*e.g.*, Gatchel, 2013; Newton-John, 2002; Turk & Monarch, 2013) – pain-related

self-efficacy and fear. For instances, self-efficacy has often been found as a mechanism through which social support operates upon health outcomes (Berkman et al., 2000), for example, by influencing health behaviours (e.g., increasing treatment adherence, healthier behaviours; Duncan & McAuley, 1993; Gulliver et al., 1995; Maeda et al., 2013). Ones' selfefficacy beliefs determine which activities to engage, the amount of effort and persistence in face of aversive situations (Bandura, 1997). Pain-related self-efficacy is the degree of selfconfidence to function despite pain (Nicholas, 2007) and it has been associated with efforts to actively deal with pain and with lower pain-related disability (e.g., Arnstein, 2000; Costa et al., 2011; Ferreira-Valente, Pais-Ribeiro, & Jensen, 2014; Nicholas, 2007; Sardá et al., 2007; Schulz et al., 2014; Stubbs et al., 2010; Turk & Okifuji, 2002; Woby et al., 2005). Moreover, pain-related fear, which refers to fear of pain, physical activity or (re)injury is an important predictor of avoidance behaviour and disability (e.g., Kori, Miller, & Todd, 1990; Leeuw et al., 2007; Lethem et al., 1983; Vlaeyen et al., 1995). However, the relationship between social support and pain-related fear is, to the best of our knowledge, to be explored. Therefore, we aimed to explore the link between pain-related support and pain-related fear in predicting pain-related disability. Consequently, our second goal was to investigate whether pain-related self-efficacy and fear (psychological path) longitudinally mediated the relationship between perceived promotion of autonomy/dependence and pain-related disability.

Finally, some previous studies suggested that the influence of the interpersonal contexts on pain-related outcomes might be stronger in the initial phases of chronic pain experiences. For example, Cano (2004) showed a stronger association between catastrophizing and partner support responses among individuals with shorter pain duration. These findings raise the possibility that specific dimensions of the pain experience (*e.g.*, pain duration, severity) may moderate the influence of pain-related social support on pain disability. Indeed, it would be reasonable to expect that people with more recent (and eventually less severe) pain experiences might be more permeable to the influence of others' supportive actions. To the best of our knowledge, this contention has not been investigated. Therefore, our final goal was to investigate whether the previously described mediating processes would be moderated by pain duration and intensity.

# Method

# Study Design and Participants

This study consisted of a 3-months prospective design, with three moments of measurement, with a 6-week lag in-between them. Participants were recruited according to the following inclusion criteria: a) having constant or intermittent musculoskeletal pain for at least three months (Merskey & Bogduk, 1994); b) being able to read and write autonomously; c) not presenting any kind of cognitive impairment; and d) being day-care centre users for at least 6 months.

One hundred and seventy older adults (67.6% women), who were users of nine day-care centres in Lisbon' metropolitan area, participated in this study at Time 1. Their ages ranged between 50 and 99 years old (*M*=78.3; *SD*=8.7). Five participants under 60 years old were included because they fulfilled all the inclusion criteria and because suffering from musculoskeletal chronic pain caused their early retirement. Participants' years of education ranged from 2 to 20 years (*M*=4.9; *SD*=2.6). They were users of the institution from 6 months to 30 years (*M*=4.5 years; *SD*=5.5). Regarding their marital status, 60.6% were widowed, 22.4% were married, 11.8% were divorced and 5.3% were single.

Participants reported having pain on 1 to 5 pain locations (M=1.5; SD=.8), with women (M=1.57; SD=.89) reporting more pain sites than men (M=1.22; SD=.534),  $t_{(168)}$ =2.669, p=.008. The most frequent pain location was joints (39.4%), followed by bones (27.1%), muscles (20.6%), tendons (2.4%) and ligaments (1.2%).

At T2, 152 individuals participated in the second wave of data collection. Eighteen dropouts occurred: two participants refused to collaborate and sixteen were unreachable due to disease. The sample at T2 did not differ from the T1 sample in terms of socio-demographic characteristics (67.1% women;  $M_{\rm age}$ =78.0;  $SD_{\rm age}$ =9.1) nor in clinical and pain-related characteristics.

At T3, 135 individual participated in the third wave of data collection. Since T2, seventeen dropouts occurred: twelve participants were absent due to disease, three refused to participate and one person had died. Also, at T3 the sample (69.6% women;  $M_{\rm age}$ =78.2;  $SD_{\rm age}$ =9.1) did not significantly differ from the samples at T1 and T2, concerning sociodemographic, pain-related and clinical variables.

## Measures

## Predictors.

Social support for functional autonomy and dependence in pain. To measure the perceived frequency of staffs' social support actions for functional autonomy and dependence when in pain, participants filled out the revised Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI PAIN; Chapter 2) at Time 1, 2 and 3. This instrument has two sub-scales: 1) Perceived Promotion of Autonomy (4 items), which describes emotional/esteem and instrumental support actions that aim to help older adults to function despite pain (Matos & Bernardes, 2013). E.g.: When I am in pain, the employees at this institution...: ... Encourage me to trust in my ability to keep on going ... Help me to deal with practical aspects (e.g., transportation, reservations, tickets) so I can participate in activities/social outings.; 2) Perceived Promotion of Dependence (4 items), which describes emotional/esteem and instrumental support actions that aim to substitute and overprotect the older adult in his/hers daily functioning because of pain (Matos & Bernardes, 2013). E.g.: When I am in pain, the employees at this institution...: ...bring me everything so that I don't need to move; ... Tell me not to push myself when I feel unable of handling certain issues. The rating scale ranged from 1 (not at all frequent) to 5 (extremely frequent). The revised FSSADI PAIN presented very good psychometric properties ( $\alpha_{PPA}$ =.88;  $\alpha_{PPD}$ =.83; Chapter 2). In this study, both factors presented excellent internal consistency at all measurement points (all alphas above .95). The scores for perceived promotion of autonomy and perceived promotion of dependence were calculated by computing the average of the respective four items. Higher scores represented higher perceived promotion of autonomy/dependence.

# Mediators.

# Physical functioning.

Self-reported physical functioning. To measure self-reported ability to perform daily physical activities, participants answered five items of the physical functioning scale of the Medical Outcomes Study - Short Form 36v2 (SF-36v2; Ware & Sherbourne, 1992), validated for the Portuguese population by Ferreira (2000a, 2000b), at Time 1, 2 and 3. Only the five items (out of 10) that were relevant to older adults' daily context and routines at day-care centres were administered. Participants were asked about their ability to: a) do moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf; b) climb one flight of stairs; c) bend, kneel, or stoop; d) walk one block; e) bathe or dress. Items were

answered on a scale ranging from 1 to 3 (1 = yes, limited a lot; 2 = yes, limited a little; 3 = No, not limited at all). The Portuguese version of this scale has good psychometric properties ( $\alpha$ =.87; Ferreira, 2000b). In this study, this sub-scale presented good internal consistency at all measurement points (all alphas above .93). Participants' answers to the items were transformed into a final score that ranged from 0 (lowest ability) to 100 (highest ability) to perform daily physical activities.

# Observed physical functioning.

Level of lower body strength. To measure lower-body strength, participants performed the physical task "30-s chair stand" from the Senior Fitness Test (Rikli & Jones, 1999; 2013). This physical task involved performing full stands in thirty seconds with the arms folded across the chest. The total number of full stands corresponded to the final score. Higher number of full stands represented higher levels of lower-body strength.

Level of agility. To measure the level of agility, participants performed the physical task "8-foot up-and-go" from the Senior Fitness Test (Rikli & Jones, 1999; 2013). This task involved getting up from seated position, walk 8 feet ( $\approx$  2 meters and 44 centimetres), turn, and return to seated position, on the chair. The score is obtained by the time, in seconds, needed to walk the 8 feet. Higher scores represented more time elapsed and lower level of agility.

# Pain-related self-efficacy.

To measure pain-related self-efficacy, participants were presented, at T2 and T3, with the Pain Self Efficacy Questionnaire (PSEQ; Nicholas, 2007), validated for the European-Portuguese population by Ferreira-Valente, Pais-Ribeiro, and Jensen (2011). Participants were asked to rate their pain-related self-efficacy beliefs to engage in daily activities despite pain (*e.g., I can enjoy things, despite pain; I can cope with my pain in most situations*), on a scale from 0 (not at all confident) to 6 (completely confident). The Portuguese version presented good psychometric properties ( $\alpha$ =.88). In the present sample the scale showed very good internal consistency, at both measurement points (all alphas above .96). Scale scores were obtained by the sum of the scores of the 10 items (ranging from 0 to 60). Higher scores indicated stronger self-efficacy beliefs.

# Pain-related fear.

In order to measure pain-related fear, participants were presented, at T2 and T3, with the Tampa Scale for Kinesiophobia (TSK; Miller, Kori, & Todd, 1991), validated for the Portuguese population by Cordeiro and colleagues (2013). The TSK is a 13-item scale assessing the excessive and debilitating fear of physical movement and activity (*i.e.*, kinesiophobia; Kori, Miller, & Todd, 1990). Participants were asked to rate their agreement with pain-related fear beliefs (*e.g., My body is telling me I have something dangerously wrong; it's really not safe for a person with a condition like mine to be physically active) on a 4-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree). The Portuguese version of the TSK has good psychometric properties (\alpha=.88). The scale showed excellent internal consistency in the present sample at both measurement points (all alphas above .96). A total score was calculated by averaging all item scores; higher scores indicated higher fear of movement/(re)injury.* 

# Moderators.

*Pain duration.* To measure pain duration, participants were asked "For how long have you felt this pain?". Participants' answers were transformed into months.

Pain intensity. To measure pain intensity, participants were presented, at T1, T2 and T3, with the pain severity subscale of the Brief Pain Inventory (BPI; Cleeland, 1989), validated for the Portuguese population by Azevedo and colleagues (2007). Participants were asked to rate their pain severity on a scale from 0 (no pain) to 10 (pain as bad as you can imagine), on the previous week: e.g., Please rate your pain by circling the number that best describes your pain at its: a) worst, b) least, c) average and d) at the moment. The Portuguese version has good psychometric properties ( $\alpha$ =.98). In this study, the pain severity scale showed good internal consistency indices at all measurement points (all alphas above .88). The scores for pain intensity were obtained by averaging all item scores; higher scores reflected higher pain intensity.

## Outcome variable.

*Pain-related disability*. To measure pain-related disability, participants were presented, at T1, T2 and T3, with the pain interference subscale from the Brief Pain Inventory (BPI; Cleeland, 1989), validated for the Portuguese population by Azevedo and colleagues (2007).

Participants were asked to rate how pain had interfered with their general activity/mood/walking ability/normal work/relations with other people/sleep/enjoyment of life, from 0 (does not interfere) to 10 (completely interferes), on the previous week. The Portuguese version has good psychometric properties ( $\alpha$ =.84). In this study, the pain interference scale showed good internal consistency indices at all measurement points (all alphas above .86). The scores for pain-related disability were obtained by averaging all item scores; higher scores reflected higher levels of pain-related disability.

# **Procedure**

The data presented in this chapter is part of a large-scale study on the effects of pain-related support on older adults' chronic pain-related disability. Other parts of these findings are reported in chapter 5.

The present study followed the ethical principles and code of conduct of psychologists concerning research (American Psychological Association [APA], 2010; Ordem dos Psicólogos Portugueses [OPP], 2011) and the ethics guidelines of the hosting institution - Centro de Investigação e Intervenção Social, Lisboa, Portugal (CIS-IUL, 2013). Furthermore, the boards of all the institutions that hosted the data collection approved the research protocol.

Eleven day-care centres were invited to participate in the study, but only nine accepted the invitation. One refusal was due to the length of the protocol and the other to the fact that the institution had, very recently, hosted a disruptive data collection procedure.

After the institutional boards' consent, at each day-care centre, participants were recruited (according to the inclusion criteria) with the help of the clinical staff. The clinical staff listed older adults who: were able to read and write autonomously; neither presented nor were diagnosed with any kind of cognitive impairment; and were users of the institution for at least 6 months. Afterwards, the listed older adults were individually screened, by the investigator, for the presence of: current chronic pain (*i.e.*, felt last week) and musculoskeletal pain. The screening for chronic pain followed the methodological strategy of several (chronic) pain epidemiological studies (*e.g.*, Breivik et al., 2006; Torrance et al., 2006), by using yes-or-no questions. More specifically, the questions were: (1) 'Have you ever had constant or intermittent pain for more than three consecutive months?' (2) 'Did you feel this pain during the last week?' and (3) 'Did you feel any pain last week?'. In addition,

the presence of musculoskeletal pain was assessed by asking older adults if their pain(s) were felt on at least one of the following body locations: muscles, ligaments, tendons and/or bones.

After ensuring all of the above-mentioned inclusion criteria, older adults were invited to participate on a study on the topic of pain-related support. After their acceptance, they were requested to sign an informed consent form, where anonymity and the confidentiality of the data were guaranteed. Then, data collection (Appendix C) occurred on three different time points, with a 6-week lag in-between. At time 1, all participants completed the revised version of the FSSADI\_PAIN, the Portuguese version of the BPI and a questionnaire on their sociodemographic and clinical characteristics. At times 2 and 3, participants filled out the revised FSSADI\_PAIN and the Portuguese versions of the BPI, the PSEQ and the TSK, the SF-36 and performed the physical tasks. To facilitate the participation of seniors with low levels of education and/or visual impairments, the data collection protocols were applied individually and in face-to-face interviews in a quiet room of the participating institution. On average, each interview took about 35 minutes. After the data collection, all participants and institutions were thanked and orally debriefed.

# Data Analysis

First, using IBM SPSS v22 (IBM Corp., 2013), we analysed the descriptive statistics of the sample and the distribution of the variables in the models to be tested. Since none of the variables in the models presented a normal distribution (see Table 7, a non-parametric bootstrapping approach was used in the mediation and moderated-mediation analyses (Preacher & Selig, 2012).

Second, we analysed Spearman correlations between the variables in the hypothesised models. Furthermore, using t-tests and Spearman correlations we tested the relationship between participants' socio-demographic characteristics and the variables in the models. Since no significant relationships were found, sociodemographic variables were not included in the remaining analyses.

Third, using the PROCESS macro (Hayes, 2013) in IBM SPSS v22 (IBM Corp., 2013), two multiple longitudinal mediation models were tested: Model 1) representing the behavioural pathway (physical functioning variables) and Model 2) representing the cognitive and affective pathway (pain-related self-efficacy and fear). A bootstrapping approach was used to test the indirect effects from a 5000 estimate and 95% bias corrected confidence intervals, using the cut-offs for the 2.5% highest and lowest scores of the empirical

distribution. The indirect effects were considered significant when the interval did not include zero.

Finally, also using the PROCESS macro (Hayes, 2013) in IBM SPSS v22 (IBM Corp., 2013), moderated-mediation analyses were conducted using pain intensity and pain duration as the moderators, respectively. This procedure retrieved the index of moderated mediation, which allows confirming the relationship between the indirect effect and the moderator of that effect; if the confidence interval did not include the zero, the conclusion was that a moderation of the indirect effect exists (Hayes, 2015). Also the B estimates (unstandardized regression coefficients) of the indirect effects at different values of the moderator (*i.e.*, –1SD, Mean, +1SD) were provided; and their significance was inferred by the observation of the bias corrected confidence interval using the cut-offs for the 2.5% highest and lowest scores. When the interval did not include zero, the parameter was deemed significant. All variables were centred for the analyses of moderated mediation models in order to facilitate the interpretation of the parameter estimates.

## **Results**

# Descriptive analysis and distribution

Table 7 shows the descriptive statistics and distribution of all variables in the study. Regarding the predictors, participants reported moderate levels of perceived promotion of autonomy and low levels of perceived promotion of dependence. Concerning the mediators, participants showed low levels of self-reported and observed physical functioning, namely, low lower-body strength and agility, moderate levels of pain-related self-efficacy and low to moderate levels of pain-related fear. As for the moderators, participants reported low mean levels of pain intensity and an average pain duration of 7.33 years. Finally, as for the outcome variable, participants reported, on average, a low level of pain-related disability.

Regarding the distributions, none of the variables in the models followed a normal distribution; therefore, a non-parametric bootstrapping approach was used in the following mediation and moderated-mediation analyses. In fact, some variables – perceived promotion of dependence, pain duration, pain intensity, self-reported physical functioning, lower-body strength, agility and pain-related disability – showed a quite asymmetric distribution (skewness/SE of skewness > 1.96) indicating that participants' answers concentrated on the lower end of the rating scales. Other variables – perceived promotion of autonomy, pain-related self-efficacy and pain-related disability – showed a flat distribution (kurtosis/SE of

kurtosis <-1.96). Finally, pain duration, lower-body strength, agility and pain-related fear showed a leptokurtic distribution (kurtosis/SE of kurtosis > 1.96).

Table 7 – Descriptive statistics and distribution of all variables in the models.

		Min	Max	Mean	SD	Skewness/SE skewness	Kurtosis/SE kurtosis	K-S
Predictors T1	Perceived Promotion of Autonomy	1	5	2.87	1.33	-1.12	-3.28	.000
	Perceived Promotion of Dependence	1	5	1.80	.91	4.94	0.41	.000
Moderators T1	Pain Duration	3	624	88	120.58	13.87	18.70	.000
	Pain Intensity	0	10	3.01	1.96	4.55	1.40	.000
Mediators T2	Self-reported physical functioning	0	100	32.6	32.9	3.85	-1.70	.000
	Lower body strenght <sup>1</sup>	0	20	4.49	3.55	5.97	5.61	.000
	Agility <sup>2</sup>	3.14	54.6	14.6	6.6	12.7	31.6	.000
	Pain-related Self-efficacy	0	60	33.80	19.13	-1.20	-3.18	.000
	Pain-related fear	1	4	2.29	.58	10	3.04	.000
Outcome T3	Pain-related disability	0	10	3.87	3.10	2.55	-2.37	.000

<sup>&</sup>lt;sup>1</sup>24 participants were not able to perform lower body strength task; <sup>2</sup>27 participants were not able to perform agility task.

# Spearman correlations

Table 8 shows that, except for perceived promotion of autonomy (T1), all other variables were significantly correlated with pain-related disability (T3). Therefore, perceived promotion of autonomy was not included in following mediation models (Tabachnick & Fidell, 2006). As a consequence, perceived promotion of dependence was the only predictor to be tested. The outcome variable – pain-related disability – showed moderate positive correlations (Cohen, 1988) with perceived promotion of dependence and pain intensity; large positive correlations with agility and pain-related fear (Cohen, 1988); and large negative correlations with self-reported physical functioning, lower-body strength and pain-related self-efficacy (Cohen, 1988).

Table 8 – Spearman correlations between all variables in the models.

	1	2	3	4	5	6	7	8	9
1. Perceived Promotion of Autonomy T1									
2. Perceived Promotion of Dependence T1	.48**								
3. Pain duration T1	.19*	11							
4. Pain intensity T1	.19*	.33**	15*						
5. Self-reported physical functioning T2	08	29**	08	48**					
6. Lower-body strength T2	07	13	10	38**	.57**				
7. Agility T2	14	.03	05	.26**	60**	70**			
8. Pain-related Self-Efficacy T2	07	26**	04	42**	.71**	.47**	45**		
9. Pain-related Fear T2	05	.12	.07	.14	32**	27**	.27*	36**	
10. Pain-related disability T3	.04	.22*	.04	.39**	61**	50**	.45**	67**	.42**

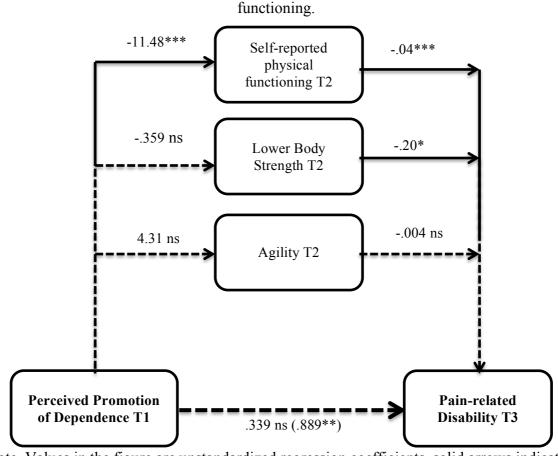
<sup>\*\*\*</sup>p≤.001 \*\*p≤.01 \*p≤.05

# The relationship between perceived promotion dependence and pain-related disability: the mediating role of physical functioning

Figure 6 represents the longitudinal mediation model in which perceived promotion of dependence (T1) was the predictor, pain-related disability (T3) the outcome and self-reported and observed physical functioning (lower-body strength and agility) were the mediators (T2). As it can be seen, higher perceived promotion of dependence at T1 predicted higher painrelated disability at T3, accounting for 6.9% of its variance ( $F_{(1,126)}$ =9.29, p=.003). This relationship was fully mediated by self-reported physical functioning (T2) only, as shown by the decrease in the unstandardized regression coefficients and the loss of significance of the effect of perceived promotion of dependence on pain-related disability (B=.889, p=.003 to B =.339, p=.184). The indirect effect of perceived promotion of dependence on pain-related disability through self-reported physical functioning (B=.493) was corroborated by the bias corrected confidence interval of the empirical distribution [.247; .828]. More specifically, higher perceived promotion of dependence at T1 predicted a higher level of pain-related disability at T3 by decreasing older adults' self-reported physical functioning at T2. The level of lower-body strength, B=.072; [-.029;.224] and agility, B=-.016; [-.192; .064] were not significant mediators of the role of perceived promotion of dependence on pain-related disability, since the indirect effects were not significant.

Overall, this mediation model accounted for 39% of the variance of older adults' pain-related disability at T3 ( $F_{(4, 123)}$ =19.672, p<.001).

Figure 6 - Longitudinal model of the relationship between perceived promotion of dependence and pain-related disability, mediated by self-reported and observed physical



Note. Values in the figure are unstandardized regression coefficients, solid arrows indicate significant relationships and dashed arrows indicate non-significant relationships, \*\*\* $p \le .01$  \* $p \le .05$  ns – non significant.

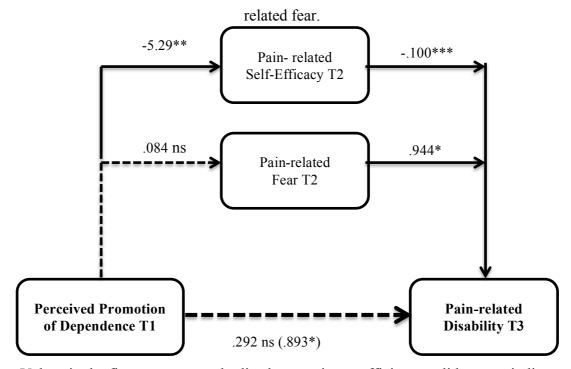
# The relationship between perceived promotion of dependence and pain-related disability: the mediating role of pain-related self-efficacy and pain-related fear

Figure 7 represents the mediation model in which perceived promotion of dependence (T1) was the predictor, pain-related disability (T3) was the criterion and pain-related fear and pain-related self-efficacy (T2) the mediators. As it can be seen, the relationship between perceived promotion of dependence (T1) and pain-related disability (T3) was fully mediated by pain-related self-efficacy (T2), as shown by the decrease and loss of statistical significance of the unstandardized regression coefficient (B=.893, *p*=.002 to B=.292, *p*=.192). The indirect effect of perceived promotion of dependence on pain-related disability through the level or pain-related self-efficacy (B=.523) was corroborated by the bias corrected confidence interval of the empirical distribution [.195;.920]. More specifically, higher perceived promotion of dependence predicted a higher level of pain-related disability by decreasing

older adults' pain-related self-efficacy. Pain-related fear, however, was not a significant mediator of the effect of perceived promotion of dependence on pain-related disability, since its indirect effects was not significant, B=.079; [-.012;.241].

Overall, this mediation model accounted for 48.9% of the variance of pain-related disability ( $F_{(3,131)}$ =41.718, p=.000).

Figure 7 – Longitudinal model of the relationship between perceived promotion of dependence and pain-related disability, mediated by pain-related self-efficacy and pain-



Note. Values in the figure are unstandardized regression coefficients, solid arrows indicate significant relationships and dashed arrows indicate non-significant relationships, \*\*\* $p \le .01$  \* $p \le .05$  ns – non significant.

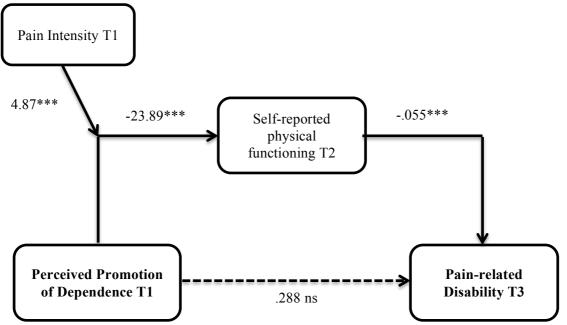
# Moderating effects of pain duration and intensity on the mediating role of self-reported physical functioning

First, pain duration (T1) was included, as the moderator of the longitudinal mediation model depicted in Figure 8. However, pain duration did not prove to be a moderator of the indirect effect of perceived promotion of dependence on pain-related disability through self-reported physical functioning.

Second, as shown in Figure 8, pain intensity (T1) was included, as the moderator of the longitudinal mediation model. The analysis showed that moderated mediation occurred by the interaction effect between the moderator (pain intensity) and the predictor (perceived

promotion of dependence) on the mediator (self-reported physical functioning), while self-reported physical functioning still had an effect on pain-related disability. More specifically, the indirect effect of perceived promotion of dependence on pain-related disability through self-reported physical functioning was significant at low (-1SD; B=1.042, SE=.257 [.573;1.59]) and average levels of pain intensity (Mean; B=.503, SE=.157 [.216; .827]) but not at higher levels of pain intensity (+1SD; B=-.037, SE=.160 [-.39;.24]). The moderator effect of pain intensity was corroborated by the index of moderated mediation (B=-.269, SE=.072 [-.43;-.14]).

Figure 8 – Pain intensity as moderator of the mediating role of self-reported physical functioning on the effect of perceived promotion of dependence on pain-related disability.



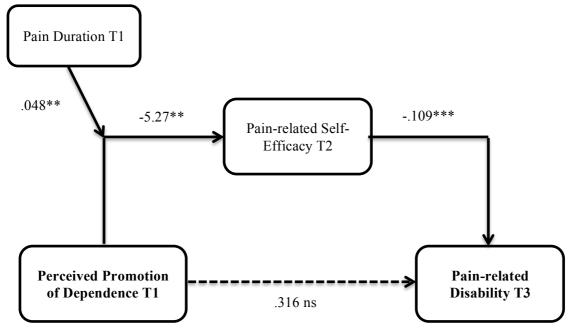
Note. Values in the figure are unstandardized regression coefficients, solid arrows indicate significant relationships and dashed arrows indicate non-significant relationships,  $***p \le .001$  ns – non significant.

# Moderating effect of pain duration and pain intensity on the mediating role of pain-related self-efficacy

First, pain duration (T1) was included as moderator of the longitudinal mediation model depicted in Figure 9. The analysis showed that moderated mediation occurred by the interaction effect between the moderator (pain duration) and the predictor (perceived promotion of dependence) on the mediator (pain-related self-efficacy), whilst pain-related self-efficacy still had an effect on pain-related disability. More specifically, the indirect effect

of perceived promotion of dependence on pain-related disability through pain-related self-efficacy was significant at shorter (-1SD; B=1.064, SE=.261 [.60;1.62]) and moderate levels of pain duration (Mean; B=.605, SE=.200 [.244; 1.02]) but not at longer pain duration (+1SD; B=-.050, SE=.317 [-.65;.63]). The moderated mediation is corroborated by the index of moderated mediation (B=-.005, SE=.002 [-.10;-.002]).

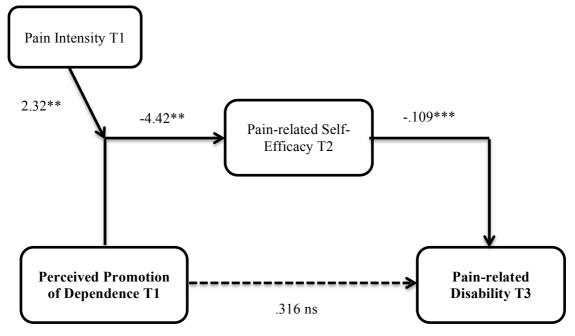
Figure 9 – Pain duration as moderator of the mediating role of pain-related self-efficacy on the effect of perceived promotion of dependence on pain-related disability.



Note. Values in the figure are unstandardized regression coefficients, solid arrows indicate significant relationships and dashed arrows indicate non-significant relationships, \*\*\* $p \le .001$ \*\* $p \le .01$  ns – non significant.

Second, pain intensity (T1) was included as moderator of the longitudinal mediation depicted in Figure 10. The analysis showed that moderated mediation occurred by the interaction effect between the moderator (pain intensity) and the predictor (perceived promotion of dependence) on the mediator (pain-related self-efficacy), while pain-related self-efficacy still had an effect on pain-related disability, B=-.253, SE=.093 [-.44;-.07]. More specifically, the indirect effect was significant at lower (-1SD; B=.990, SE=.295 [.41;1.57]) and moderate levels (Mean; B=.482, SE=.243 [.103; .867]) but not at higher levels of pain intensity (+1SD; B=-.026, SE=.243 [-.50;.45]). The moderator effect of pain intensity was corroborated by the index of moderated mediation (B=-.253, SE=.093 [-.44;-.07]).

Figure 10 – Pain intensity as moderator of the mediating role of pain-related self-efficacy on the effect of perceived promotion of dependence on pain-related disability.



Note. Values in the figure are unstandardized regression coefficients, solid arrows indicate significant relationships and dashed arrows indicate non-significant relationships, \*\*\* $p \le .001$  \*\* $p \le .01$  ns – non significant.

# Discussion

In line with the second aim of the present thesis, this study sought to test, with a longitudinal design, the hypotheses that perceived promotion of autonomy (T1) would lead to a decrease in pain-related disability (T3), while perceived promotion of dependence (T1) would lead to an increase in pain-related disability (T3). First, in contrast to our expectations, perceived promotion of autonomy did not predict older adults' pain-related disability after twelve weeks. In previous cross-sectional studies, the negative association between perceived promotion of autonomy and pain-related disability was indeed inconsistent (Matos & Bernardes, 2013; Chapter 3). This inconsistency might suggest, for instance, that the direct effects of perceived promotion of autonomy on pain-related disability might be dependent on other factors, *e.g.*, the needs of the recipient (*e.g.*, Maisel & Gable, 2009), his/her desires for support (*e.g.*, Brock & Lawrence, 2009) or support preferences (*e.g.*, McWilliams, Saldanha, Dick, & Watt, 2009; McWilliams, Higgins, Dick, & Verrier, 2014). For example, the protective direct effect of perceived promotion of autonomy on pain-related disability might only exist for people who have higher preferences and desires for this type of support, but not for others. Other possible explanation, for these inconsistent results, might be that perceived

promotion of autonomy, rather than influencing pain-related disability through (in)direct pathways, might act as a buffering mechanism – as described by the stress-buffering hypothesis of social support. This model portrays that social support buffers the impact of a stressor on health outcomes (*e.g.*, Cohen & Willis, 1985; Cohen et al., 2000; House, 1981; Lakey & Cohen, 2000; Thoits, 1986; Wills & Ainette, 2012). Indeed, it has been shown that distracting responses buffered the negative impact of pain intensity on pain disability (Ginting et al., 2011a; Ginting et al., 2011b). Thus it might be reasonable to expect that perceived promotion of autonomy might act as a buffer within pain experiences.

Second, as expected, higher perceived promotion of dependence (T1) predicted older adults' higher pain-related disability after twelve weeks (T3). This result confirms, longitudinally, former cross-sectional results (Matos & Bernardes, 2013; Chapter 3). Also, these results are congruent with (cross-sectional) research on solicitous support that has shown its relationship with higher pain-related disability (*e.g.*, Kerns et al. 1991; Romano, et al., 1995; Romano et al., 2000; Romano et al., 2009). Taken together, these results indicate that pain-related support, by promoting functional dependence, is able to increase pain-related disability. To the best of our knowledge, most research has not investigated these relationships using longitudinal designs. Thus, this study provides support to the detrimental influence of pain-related support, when it promotes functional incapacity of the person in pain.

Also, in line with the thesis' third aim, this study aimed to investigate behavioural and psychological mechanisms that could potentially account for the influence of perceived promotion of autonomy and dependence on pain-related disability. Therefore, we investigated the role of behavioural (physical functioning) and psychological (pain-related self-efficacy and fear) mechanisms in accounting for the detrimental influence of perceived promotion of dependence on pain-related disability. First, as expected, higher perceived promotion of dependence predicted higher levels of pain-related disability through the decrease in older adults' (self-reported) physical functioning. This corroborates previous cross-sectional results (see Chapter 3). Also, these findings are congruent with other studies that have demonstrated associations between solicitous support and lower self-reported functioning (Romano et al., 2009); and with studies in which social support predicts the level of physical functioning, in the context of chronic disease (e.g., Luszczynska et al., 2007; Shen et al., 2004). Furthermore, these results are in line with the operant conditioning model (Fordyce, 1976) that argues that support from others can reinforce pain behaviours and activity avoidance, and with the fear-

avoidance model (*e.g.*, Vlaeyen et al., 1995; Leeuw et al., 2007), that establishes that avoiding activity has detrimental effects on pain-related disability.

However, the level of agility and of lower-body strength, were not explaining mechanisms of the influence of perceived promotion of dependence on higher pain-related disability. The lack of effects of these variables might be accounted by the fact that these were poor indicators of what is actually pain-related physical functioning, by being performed out of the normal context of the individual. In other words, these measures might not have been ecological valid. In the future, observational measures should be applied within the person's context performing natural and daily activities.

Also, within the second goal, we explored the role of psychological mechanisms, in accounting for the detrimental effects of perceived promotion of dependence on pain-related disability. As expected, higher perceived promotion of dependence at T1 predicted a higher level of pain-related disability at T3, by decreasing older adults' pain-related self-efficacy. This is consistent with the argument that social support can have detrimental effects on health-related outcomes by disenabling one's self-efficacy beliefs (Benight & Bandura, 2004). Furthermore, decreases in pain-related self-efficacy can result in less behavioural efforts and task persistence when in pain (*e.g.*, Turk & Monarch, 2013). Therefore, it is reasonable to assume that perceived promotion of dependence, by decreasing pain-related self-efficacy, has led to less confidence to engage in activity.

Pain-related fear did not prove to be an explaining mechanism of the negative influence of perceived promotion of dependence on pain-related disability. Pain-related fear (T2) was not influenced by perceived promotion of dependence (T1). However, pain-related fear (T2) was associated with pain-related disability six weeks later (T3), which is congruent with previous research (Council, Ahern, Follick, & Kline, 1988; Philips, 1987; Vlaeyen et al., 1995; Kori et al., 1990; Sorbi et al., 2006). One possible explanation for the lack of effects of perceived promotion of dependence on pain-related fear, might be related to the fact that older adults who participated in this study generally reported pain for a long time. Since pain-related fear is an important predictor of how acute pain transforms into chronic (by avoiding activity), perhaps the influence of pain-related support on pain-related fear might be important on older adults acute pain experiences. For now, we can only conclude that pain-related support that promotes functional dependence did not have the potential to increase pain-related fear and hence, influence pain-related disability.

As for the final goal, we aimed to explore whether the effect of perceived promotion of dependence through the decrease in self-reported physical functioning and pain-related

self-efficacy were different for older adults with varying levels of pain duration and intensity. The findings showed that the detrimental effects of perceived promotion of dependence on pain-related disability, through the decrease of pain-related self-efficacy, only existed for older adults who presented (in this sample) with shorter (3 months) to moderate (7 years) pain duration, but not for those who reported longer duration (17 years). In other words, for older adults with more than 17 years of pain duration, perceived promotion of dependence had no influence on pain-related self-efficacy or the level of pain-related disability. For people that live with chronic pain for such long time, pain-related support is not a determinant of pain experiences and other factors may play a role. Since people are living longer and the proportion of older adults is growing, the odds are that the people will live with chronic pain for many decades. Therefore, research should focus on the consequences of pain duration and on the protective factors of pain-related disability for people with longer pain duration. Furthermore, the detrimental effects of perceived promotion of dependence on pain-related disability, through the decrease of self-reported physical functioning and of painrelated self-efficacy, were only true for older adults that reported low and moderate levels of pain intensity, but not for those with high levels of pain intensity. This indicates that for older adults who reported a level of pain intensity higher that 4.97 (on a scale form 0 to 10), perceived promotion of dependence did not reduced the level of self-reported physical functioning, of pain-related self-efficacy or pain-related disability. These results demonstrate that for people with shorter and less/intense pain experiences, perceived promotion of dependence is a risk factor and that social factors do not have the power to influence painrelated disability, when pain is more intense and/or longer. These results are congruent with research that found a stronger association between catastrophizing and partner support responses among individuals with shorter pain duration (Cano, 2004). Perhaps, for people with more severe pain experiences other factors might be important to deal with pain-related disability, like for example acceptance-based psychological interventions (e.g., McCracken, 2005). However, people with longer duration and worst levels of pain intensity might be receiving social support from other sources (e.g., hospitals, pain units, continued care units or even informal sources) that were not taken into account in the present study. These results stress the importance of psychosocial factors in influencing pain experiences at more recent and less intense pain experiences.

# Limitations and directions for future research

This study aimed to examine the prospective effects of perceived promotion of autonomy and dependence on older adults' pain-related disability. However, some limitations should be pointed out in order to inform further research on the topic. First, the physical tasks used to measure physical functioning were not associated with pain-related support, as discussed above. Future research should incorporate observational measures, within older adults' living contexts, that allow measuring the actual level of physical functioning, for example by means of ambulatory activity monitoring (*e.g.*, Bussmann, Ebner-Priemer, & Fahrenberg, 2009). Second, not including distress measures (*e.g.*, depression, anxiety) might constitute a limitation because: it would have left out part of the experience of living in pain; and because distress might influence perceptions about the receipt of support (Bolger & Ecknerode, 1991). Therefore, further research on psychosocial determinants of pain-related disability should incorporate distress measures. Third, the present sample was comprised of older adults attending day-care centres, who lived at home and might have a relevant informal support network. The present study did not measure the importance of such relationships in providing pain-related support.

As an input for future research, the lack of consistent results on perceived promotion of autonomy raises the need to further explore its role, because it might be dependent on the role of older adults desires or preferences for support (*e.g.*, Maisel & Gable, 2009; Bernardes, Matos & Goubert, under review) or even that it has a buffering effect, rather than a direct role (*e.g.*, Cohen & Willis, 1985; Cohen et al., 2000; Ginting et al., 2011a, 2011b; House, 1981; Lakey & Cohen, 2000; Thoits, 1986; Wills & Ainette, 2012). The absence of strong empirical evidence on the role of perceived promotion of autonomy calls out the need to further investigate about a positive and adaptive function of pain-related support.

# Theoretical and practical implications

Theoretical implications of the present research are linked to the innovative conceptualization of different functions of pain-related social support, by further stressing that promoting functional dependence is a risk factor that predicts worse pain outcomes. The present study also adds to the literature by its longitudinal design that allows to draw conclusions about the causality of the relationships of perceived promotion of dependence in increasing pain-related disability, by reducing the level of self-reported physical functioning and pain-related self-efficacy. Furthermore, this study has the merits of including behavioural

and psychological pathways as explaining mechanisms of the effect of perceived promotion of dependence on increasing pain-related disability.

From an intervention perspective, present findings have the potential to inform future training programs with caregivers. Such intervention should raise awareness about the detrimental effects of promoting functional dependence to older adults with chronic pain. Present results also stress, that pain-related support has higher relevance for shorter and less severe pain experiences. This finding might be very useful for caregivers, so they can develop individual and tailored care provision that aims to maintain the level of functioning and physical/social activity engagement in order to prevent higher levels of pain-related disability.

Due to the great prevalence of musculoskeletal chronic pain in older adults using formal care social services it is of utmost urgency to increase the quality of care provision in order to promote a healthy ageing and well being in older age, despite chronic pain.

In this chapter we presented a longitudinal study investigating the (in)direct effects of perceived promotion of autonomy and dependence on pain-related disability (Chapter 1, Figure 1, page 13). In the following chapter the same set of data will be used to explore another model (Chapter 2, Figure 2, page 14), where the buffering /amplifying roles of pain-related support for functional autonomy and dependence will be investigated.

# Chapter 5

# BUFFER OR AMPLIFIER? SUPPORT FOR FUNCTIONAL AUTONOMY AND DEPENDENCE ON OLDER-ADULTS' PAIN EXPERIENCES

**This chapter is based on the paper:** Matos, M., Bernardes, S. F., Goubert, L., & Beyers (submitted). Social support for autonomy buffers against the negative effects of pain intensity on pain-related disability: a longitudinal study in older adults with chronic pain. Health Psychology

## **Abstract**

This longitudinal study aimed to investigate: (1) the moderating role of formal social support for functional autonomy versus dependence on the relationship between pain intensity and pain-related disability among older adults with chronic pain, and (2) the mediating role of pain-related self-efficacy and pain-related fear in this moderation. One hundred and seventy older adults ( $M_{age}$ =78.0; SD=8.7) with chronic musculoskeletal pain participated in a 3-month prospective study, with three measurement moments. Participants filled out the Formal Social Support for Autonomy and Dependence in Pain Inventory, the Portuguese versions of the Brief Pain Inventory, the Pain Self-Efficacy Questionnaire and the Tampa Scale of Kinesiophobia. Using Structural Equation Modelling, it was found that perceived promotion of autonomy, at Time 1, moderated the relationship between pain intensity (T1) and painrelated disability (T2); this moderation was fully mediated by pain-related self-efficacy (T2). Perceived promotion of dependence was not a significant moderator. These findings highlight the importance of social support for functional autonomy in buffering the impact of pain intensity on older adults' pain-related disability. Also, they clarify the role of pain-related self-efficacy in this effect. Implications for the development of intervention programs, with formal caregivers, to reduce the impact of chronic pain, on older adults' healthy ageing process, are discussed.

# Introduction

Most research on the relationship between social support and pain-related disability has investigated its direct effect, with inconsistent findings (*e.g.*, Campbell et al., 2011). Our research (see Chapter 2, 3 and 4), begins to show that pain-related support is directly associated with different pain-related outcomes, depending on whether it promotes functional autonomy or dependence.

However, research on social support in pain contexts has focused much less on the stress-buffering hypothesis. While some studies did not find significant buffering effects (*e.g.*, Pjanic et al., 2013), a few others showed that social support buffered the effects of: physiological stress responses on experimental pain sensitivity during the cold pressure task (Roberts et al., 2015) and the effect of pain disability on depression in people with end-stage joint disease (Roberts et al., 1996). Moreover, recent studies (Ginting et al., 2011a, 2011b) showed that different types of pain-related support responses may play different roles: distracting responses buffered the negative impact of pain intensity on pain disability and on

mental quality of life; while solicitous responses amplified the detrimental effect of pain intensity on pain disability. In sum, the evidence on the buffering role of social support in a pain context is scarce and inconsistent. Its inconsistency might, in part, be related to the fact that some studies have used general measures of social support rather than measures of pain-related social support (*e.g.*, Pjanic et al., 2013). However, the studies by Ginting and colleagues (2011a; 2011b) measured pain-related support responses from others and were very innovative in suggesting that certain types of support responses may have a buffering role while other types may amplify the deleterious relationship between pain intensity and pain disability. Knowing that pain intensity is one of the main predictors of pain disability (*e.g.*, Arnstein et al., 1999; Denison et al., 2004), in the present study, we aimed to examine the buffering versus amplifying effects of different types of pain-related support on such relationship. More specifically, we hypothesized that: (H1) perceived promotion of autonomy would act as a buffer against the negative effect of pain intensity on pain-related disability and (H2) perceived promotion of dependence would amplify the negative impact of pain intensity on pain-related disability.

Besides investigating whether different types of pain-related social support act as stress buffers or amplifiers, there is also the pressing need to further investigate the psychological mechanisms through which such effects unfold (Thoits, 2011; Uchino, 2012). Therefore, the second aim of the present study was to investigate the extent to which pain-related selfefficacy and fear could account for the buffering/amplifying effects of pain-related support. In the health psychology literature, self-efficacy has often been found as a mechanism through which social support operates upon health outcomes (Berkman et al., 2000), for example, by increasing treatment adherence (e.g., Maeda et al., 2013) and healthier behaviours (e.g., Duncan & McAuley, 1993; Gulliver et al., 1995). This relationship, however, has been mainly studied as a direct one. Namely, social support has been described as a potential (dis)enabler of self-efficacy, which in turn would lead to positive or negative health outcomes (Benight & Bandura, 2004). Pain-related self-efficacy is a key determinant of pain behaviours and has been described as the degree of self-confidence to function despite pain and in expending efforts to persist in face of obstacles and aversive experiences (Nicholas, 2007; Turk & Monarch, 2013). High levels of pain-related self-efficacy have been associated with efforts to actively deal with pain (e.g., Turk and Okifuji, 2002) and lower levels of pain intensity, disability, depression and anxiety (e.g., Arnstein, 2000; Costa et al., 2011; Nicholas, 2007; Denison et al., 2007). Furthermore, it has been shown that pain intensity reduces pain-related self-efficacy, leading to higher levels of pain-related disability

(*e.g.*, Costa et al., 2011; Schulz et al., 2015). Based on these findings, we hypothesized that pain-related self-efficacy would mediate for the buffering/amplifying effects of perceived promotion of autonomy/dependence on the impact of pain intensity on pain-related disability (H3/4).

Another mechanism that could account for the moderator effect of pain-related social support is pain-related fear, i.e., fear of pain, physical activity or (re)injury (Kori et al., 1990). Pain-related fear is a key concept in the fear-avoidance model (e.g., Leeuw et al., 2007; Lethem et al., 1983; Vlaeyen et al., 1995), that postulates that low levels of pain-related fear lead to confrontation and recovery, while high levels of pain-related fear are associated with avoidance of physical and social activities, thereby increasing disability. Research has indeed shown that pain-related fear is associated with higher levels of pain-related disability (e.g., Kori et al., 1990; Vlaeyen et al., 1995) and maladaptive pain behaviours (i.e., avoidance of activity), and has been described as more disabling than pain itself (Waddell et al., 1993). Studies have found that social support has a beneficial effect on pain-related outcomes by inhibiting avoidance of physical and social activities (e.g., Uchino et al., 1996) but to the best of our knowledge, the relationship between pain-related support and pain-related fear is yet to be explored. We propose that perceived promotion of autonomy might be associated with less pain-related fear, by promoting higher persistence and ability to function despite pain. On the other hand, perceived promotion of dependence might be associated with higher levels of pain-related fear, by reinforcing avoidance and low ability to function with pain. As such, we hypothesized that pain-related fear would mediate the buffering/amplifying effect of perceived promotion of autonomy/dependence on the impact of pain intensity on pain-related disability (H5/6).

These hypotheses will be tested using a longitudinal approach. This will contribute to clarify the causal relationships between these variables, since most research on the topic has relied on cross-sectional approaches.

# Method

# Study Design and Participants

This study consisted of a prospective design, with three moments of measurement, with a 6-week lag in-between them. The time duration and lags were assumed appropriate, as longer lags might have resulted in increased dropout rates, considering participants' physical fragility. One hundred and seventy adults (67.6% women), who had participated in a previous

study (Chapter 4), aged between 50 and 99 years old (*M*=78.3; *SD*=8.7), attending nine day-care centres in urban areas in and around Lisbon, participated in this study at Time 1 (T1). Sample inclusion criteria were that participants: a) had constant or intermittent pain for at least three months; b) presented musculoskeletal pain; c) were able to read and write autonomously; d) did not present any kind of cognitive impairment; e) were users of a day-care centre for at least 6 months. Five adults aged less than 60 years old were included in our sample because they fulfilled all the inclusion criteria and had had an early retirement due to chronic pain.

Participants' years of formal education ranged from 2 to 20 years (M=4.9; SD=2.6) and 60.6% of them were widowed, 22.4% were married, 11.8% were divorced and 5.3% were single. Most participants lived alone (54.7%), and were users of the institution(s) for a duration of 6 months to 30 years (M=4.5 years; SD=5.5). All participants reported current musculoskeletal chronic pain, with a duration ranging from 3 months to 52 years (M=7.3 years; SD=10.1) and on 1 to 5 pain locations (M=1.5; SD=0.8). Women (M=1.57; SD=.89) reported a higher number of pain locations than men (M=1.22; SD=.534),  $t_{(168)}$ =2.669, p=.008. Joints (39.4%) were the most frequently reported pain location, followed by bones (27.1%), muscles (20.6%), tendons (2.4%) and ligaments (1.2%). On average, participants reported low levels of pain intensity (M=3.0, SD=1.9) and pain disability (M=3.8, SD=3.3), on a scale ranging from 0 to 10. Participants, however, reported rather low levels of ability to perform daily activities (e.g., climb stairs, walk, bathe and dress; M=35.4 out of 100; SD=34.2). Furthermore, 11.8% of the individuals were medically advised not to exercise, 42.9% reported having chest pain or dizziness on a frequent basis and 18.2% had high blood pressure.

At Time 2 (T2), two participants refused to participate and sixteen participants were unreachable due to disease (18 dropouts). Hence, 152 individuals participated in the second wave of data collection; they did not differ from the first sample in terms of their sociodemographic characteristics (67.1% women;  $M_{\rm age}$ =78.0;  $SD_{\rm age}$ =9.1) nor clinical and pain-related characteristics. At Time 3 (T3), twelve seniors were absent due to disease, three refused to participate and one person had deceased (17 dropouts). The sample at T3 (n=135; 69.6% women;  $M_{\rm age}$ =78.2;  $SD_{\rm age}$ =9.1) did not significantly differ from the samples at T1 or T2, regarding sociodemographic, pain and clinical characteristics.

# **Instruments**

Formal Social Support for the Promotion of Functional Autonomy and Dependence.

Participants were presented with the revised Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI PAIN) at T1, T2 and T3. The revised FSSADI PAIN measured the perceived frequency of social support actions, received from the staff, for functional autonomy and dependence when in pain (Chapter 2). The first subscale – perceived promotion of autonomy (4 items) - assessed instrumental support actions [that] consist of tangible/behavioral help that allows people in pain to accomplish their daily tasks by themselves, (...) [and] emotional/esteem support actions [that] reinforce people's self-esteem, their self-confidence to keep on functioning, and social/activity engagement (Chapter 2). E.g.: When I am in pain, the employees at this institution...: ..."help me to deal with practical aspects so I can participate in activities/social outings"; ... "encourage me to participate in leisure and fun activities". The second subscale – perceived promotion of dependence (4 items) – assessed instrumental support actions [that] consist of tangible/behavioral help that substitute the person in pain in his or her activities, (...) [and] emotional/esteem support actions that reinforce lower self-efficacy to keep on functioning and activity/social avoidance (Chapter 2). E.g.: When I am in pain, the employees at this institution...: ... "bring me everything so that I don't need to move"; ... "advise me to stop doing whatever I am doing". Participants were asked to rate each item on a rating scale from 1 (not at all frequent) to 5 (extremely frequent). The revised FSSADI PAIN presented very good psychometric properties ( $\alpha_{PPA} = .88$ ;  $\alpha_{PPD} = .83$ ; Chapter 2). In this study, both factors presented excellent internal consistency at all measurement points (all alphas above .95). The scores for perceived promotion of autonomy and perceived promotion of dependence were calculated by computing the average of the respective four items. Higher scores represented higher perceived promotion of autonomy respectively dependence.

# Pain Intensity and Disability.

At Time 1, 2 and 3, participants completed the pain severity and interference subscales of the Brief Pain Inventory (BPI; Cleeland, 1989), validated for the Portuguese population by Azevedo and colleagues (2007). Participants were asked to rate their pain severity in the last week on a scale from 0 (no pain) to 10 (pain as bad as you can imagine): *e.g.* "Please rate your pain by circling the number that best describes your pain at: a) its worst, b) its least, c)

its average and d) the moment (...). Also, they were asked to rate how pain had interfered with their: a) general activity, b) mood, c) walking ability, d) normal work, e) relations with other people, f) sleep and g) enjoyment of life, from 0 (does not interfere) to 10 (completely interferes). The Portuguese version showed good psychometric properties ( $\alpha_{pain \ severity} = .98$ ;  $\alpha_{pain \ interference} = .84$ ; Azevedo et al., 2007). In the present study, both factors presented good internal consistency indices at all measurement points (all alphas above .88). The scores for pain intensity and for pain-related disability were obtained by averaging all item scores for each subscale; higher scores reflected higher pain intensity and higher pain-related disability.

# Pain-related Self-Efficacy.

Participants were presented, at Time 2 and 3, with the Pain Self-Efficacy Questionnaire (PSEQ; Nicholas, 2007). The PSEQ has been validated for the European-Portuguese population by Ferreira-Valente, Pais-Ribeiro & Jensen (2011), and includes 10 items assessing participants' self-efficacy beliefs to engage in daily activities despite pain (*e.g.*, I can enjoy things, despite pain; I can cope with my pain in most situations), on a scale ranging from 0 (not at all confident) to 6 (completely confident). The Portuguese version presented good psychometric properties (α=.88; Ferreira-Valente, et al., 2011). In the present sample the scale showed very good internal consistency indices at T2 and T3 (all alphas above .96). Scale scores were obtained by the sum of the 10 items (ranging from 0 to 60). Higher scores indicated stronger self-efficacy beliefs.

# Pain-related fear.

Participants were presented, at Time 2 and 3, with the Tampa Scale for Kinesiophobia (TSK; Miller, Kori, & Todd, 1991). The TSK was validated for the Portuguese population by Cordeiro and colleagues (2013), and assessed the excessive and debilitating fear of physical movement and activity (*i.e.*, kinesiophobia; Kori, et al., 1990) with good psychometric properties (α=.88; Cordeiro et al., 2013). This version is a 13-item questionnaire (*e.g.*, My body is telling me I have something dangerously wrong; it's really not safe for a person with a condition like mine to be physically active), answered on a 4-point Likert scale, ranging from 1 (strongly disagree) to 4 (strongly agree). The scale showed excellent internal reliability in the present sample at T2 and T3 (all alphas above .96). A total score was calculated by averaging all items; higher scores indicated higher levels of fear of movement/(re)injury.

## Procedure

The data presented in this paper is part of a larger study on the effects of pain-related support on older adults' chronic pain-related disability (see Chapter 4). This study followed the ethical principles and code of conduct of psychologists concerning research (APA, 2010; OPP, 2011) and the ethics guidelines of the hosting institution - Centro de Investigação e Intervenção Social, Lisboa, Portugal (CIS-IUL, 2013). Eleven day-care centres in Lisbon metropolitan area were approached to collaborate in the study. Two declined the request; one institution justified their denial due to the protocol length and the other declined immediately on the first contact because they had recently hosted a data collection procedure that had been very disruptive. Nine day-care centres accepted to participate and their respective board of directors approved the study protocol.

Participants were recruited with the help of institutions' clinical staff, who identified older adults who: were able to read and write autonomously; neither presented nor were diagnosed with any kind of cognitive impairment; and were users of the institution for at least 6 months. Afterwards, the identified older adults were individually screened for the presence of: current chronic pain (*i.e.*, constant or persistent pain for more than 3 months felt last week) and musculoskeletal pain (*i.e.*, pain on muscles, ligaments, tendons and/or bones). Older adults meeting all the inclusion criteria were invited to participate. They signed a written informed consent, and their anonymity and confidentiality of the data were guaranteed. Then, data collection occurred on three different time points. At T1, all participants filled out the revised FSSADI\_PAIN, the Portuguese version of the BPI and a questionnaire on sociodemographic characteristics (Appendix C); at T2 and T3, participants filled out the revised FSSADI\_PAIN, the Portuguese versions of the BPI, the PSEQ and the TSK (Appendix E). At T3, all participants and institutions were thanked and debriefed by providing them with simple and relevant information about the subject and nature of the study (APA, 2010; CIS-IUL, 2013; OPP, 2011).

# Data Analysis

First, using IBM SPSS v22 (IBM Corp., 2013), analyses were performed on the descriptive statistics and the distribution of the variables of the models to be tested (perceived promotion of autonomy, perceived promotion of dependence, pain intensity, pain-related disability, pain related self-efficacy and pain-related fear) and the sociodemographic and clinical variables. Second, missing data was analysed. Missing estimations were ran using an

estimating method [Little's MCAR test chi-square=609.250, df=547, p=.033; normed chisquare = 1.11 (so <2)] that led to the conclusion that missing data was most likely at random (MAR). Therefore, missing imputation was performed using maximum likelihood estimations. Subsequently, four longitudinal moderation models, with centered predictors and moderators, were tested using M-Plus 7.1 (Muthén & Muthén, 1998–2012). First, the interaction effects of pain intensity with PPA, measured at Time 1, on pain-related disability at Time 2 and Time 3 were examined. Second, the interaction effect of pain intensity with PPD, measured at Time 1, on pain-related disability at Time 2 and Time 3 were tested. The reason for testing the interaction effects pain intensity x perceived promotion of autonomy/dependence on pain-related disability in time 2 (6 weeks after T1) and 3 (12 weeks after T1) was to confirm if the effect persisted after a longer lag. Finally, the mediational effects of pain-related self-efficacy and pain-related fear were tested, in the significant moderation models. Mediated moderation models were tested using maximum likelihood parameter estimates with standard errors and a chi-square test statistic that are robust to nonnormality – Maximum Likelihood Robust (MLR). Also, overall fit was assessed using established fit indexes – comparative fit index (CFI), the Tucker-Lewis index (TLI) and root mean square of approximation (RMSEA). Criteria for good fit were established by CFI>0.9; TLI>0.9; IFI>0.9; RMSEA <0.05 (Hu & Bentler, 1999; Schreiber, Nora, Stage, Barlow, & King, 2006). Furthermore, in order to corroborate the results, bootstrap confidence intervals were used from 5000 estimates, using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution. A bootstrapping approach was useful due to its inexistence of assumptions regarding distributions (Preacher & Selig, 2012). The test of the mediated moderation models followed the procedure proposed by Muller, Judd, & Yzerbyt (2005):

Step 1 – Check for significant interaction effects of pain intensity x perceived promotion of autonomy/perceived promotion of dependence on the mediators (pain-related self-efficacy or pain-related fear), and for significant effects of the mediators on pain-related disability.

Step 2 – Check for significant interaction effects between the moderators (perceived promotion of autonomy or perceived promotion of dependence) and each mediator (pain-related self-efficacy or pain-related fear) on pain-related disability, and for the significant effect of pain intensity on the mediator (pain-related self-efficacy or pain-related fear).

Step 3 – Check if the overall moderation effect was reduced, when at least one of the mediating processes described in step 1 and/or 2 were significant and controlled for.

## **Results**

# Descriptive statistics

As shown in Table 9, participants reported low levels of pain intensity (3.01 < M < 3.53); the predictor) and pain disability (3.80 < M < 3.28); the outcome) across the three measurement times. Regarding the moderators, participants reported moderate levels of perceived promotion of autonomy (2.84 < M < 2.96) and low to moderate levels of perceived promotion of dependence across all measurement times (1.80 < M < 2.05). As for the mediators, participants reported moderate levels of pain-related self-efficacy at T2 and T3 (32.41 < M < 33.80) and high levels of pain-related fear at T2 and T3 (2.29 < M < 2.39).

Regarding the distributions, none of the variables in the hypothesized models followed a normal distribution – which is accounted in further analyses. In fact, some variables – pain intensity, pain-related disability and perceived promotion of dependence – showed a quite asymmetric distribution (skewness/SE of skewness>1.96) indicating that participants' answers concentrated on the lower end of the rating scales. Other variables – pain-related disability, perceived promotion of autonomy and pain-related self-efficacy – showed a flat distribution (kurtosis/SE of kurtosis <-1.96).

Table 9 – Descriptive statistics and distributions of all variables at all measurement times.

	Variable	Time	Mean	SD	Min	Max	Kurtosis/SE kurtosis	Skewness/SE skewness
Predictor	Pain intensity	T1	3.01	1.96	0	10	1.40	4.55
		T2	3.35	2.28	0	10	92	3.12
		T3	3.53	2.40	0	10	8	2.62
Outcome	Pain-related - disability -	T1	3.80	3.28	0	10	-2.65	2.59
		T2	3.84	3.23	0	10	-3.41	1.77
		T3	3.87	3.10	0	10	-2.37	2.55
	Perceived	T1	2.87	1.33	1	5	-3.29	-1.12
	promotion of	T2	2.84	1.31	1	5	-3.33	63
Moderators	autonomy	T3	2.96	1.27	1	5	-2.90	-1.30
Moderators	Perceived	T1	1.80	.91	1	5	.41	4.95
	promotion of	T2	1.99	.95	1	5	1.25	4.70
	dependence	T3	2.05	.96	1	5	.64	4.06
Mediators	Pain-related self-	T2	33.80	19.13	0	60	-3.18	-1.20
	efficacy	T3	32.41	20.32	0	60	-3.36	85
	Pain-related fear-	T2	2.29	.58	1	4	3.04	10
		T3	2.39	.60	1	4	1.83	.22

# Simple Moderation Models: Perceived promotion of autonomy and dependence as moderators.

Pain intensity at T1 significantly predicted higher levels of pain-related disability at T2 and T3 (see Tables 10 and 11). Perceived promotion of autonomy at T1 did not have a direct effect on pain-related disability at T2 or T3, but significantly moderated the impact of pain intensity at T1 on pain-related disability at T2 (but not at T3). At higher levels of perceived promotion of autonomy (+1SD), the impact of pain intensity (T1) on pain-related disability (T2) was weaker (B=.819,  $t_{(169)}$ =5.571,p≤.001) than at lower levels of perceived promotion of autonomy (-1SD; B=1.067,  $t_{(169)}$ =7.671, p≤.001).

Table 10 – Perceived promotion of autonomy (T1) as moderator of the relationship between pain intensity (T1) and pain-related disability (T2 and T3).

Outcome variable: Pain-related disability (T2)									
	В	SD B	β	p-value	CI				
Dain intensity (T1)	.943	.100	.573	.000	0.739;				
Pain intensity (T1)					1.145				
Perceived promotion of autonomy (T1)	.074	.137	.030	.590	-0.199;				
	.074				0.347				
Pain intensity (T1) * Perceived promotion	124	0.059	101	.035	-0.246;				
of autonomy (T1)					-0.002				
Outcome variable: Pain-related disability (T3)									
	В	SD B	β	p-value	CI				
Pain intensity (T1)	.575	.118	.363	0.000	0.342;				
			.303	0.000	0.809				
Perceived promotion of autonomy (T1)	109	.164	046	0.507	-0.437;				
referred promotion of autonomy (11)					0.219				
Pain intensity (T1) * Perceived promotion	138	.084	116	0.099	-0.310;				
of autonomy (T1)					0.034				

Note. CI – bootstrap confidence intervals using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution; values in bold indicate significant *p-values* 

With regard to perceived promotion of dependence, Table 11 shows that it independently predicted higher pain-related disability at Time 3 (as described on chapter 4) but not at Time 2. Finally, perceived promotion of dependence did not significantly moderate the relationship between pain intensity and pain-related disability.

Table 11 – Perceived promotion of dependence (T1) as moderator of the relationship between pain intensity (T1) and pain-related disability (T2 and T3).

				-							
Outcome variable: Pain-related disability (T2)											
В	SD B	β	p-value	CI							
.895	.108	.545	0.000	0.677;							
				1.114							
.448	.245	.127	0.068	<b>-</b> 0.043;							
				0.938							
otion of109	9 .085	068	0.200	-0.290;							
				0.072							
Outcome variable: Pain-related disability (T3)											
В	SDB	β	p-value	CI							
.488	.120	.308	0.000	0.248;							
				0.728							
.635	.279	.186	0.023	0.081;							
				1.190							
165	110	107	0.160	-0.413;							
	165	103	105	3 .11810	.118	.118	.118	.118	10/	10/	0.100
	B .895 .448109 -related di B .488 .635	B       SD B         .895       .108         .448       .245        109       .085         -related disability       B       SD B         .488       .120         .635       .279	B     SD B     β       .895     .108     .545       .448     .245     .127      109     .085    068       -related disability (T3)     B     SD B     β       .488     .120     .308       .635     .279     .186	B         SD B         β         p-value           .895         .108         .545 <b>0.000</b> .448         .245         .127         0.068          109         .085        068         0.200           -related disability (T3)         B         SD B         β         p-value           .488         .120         .308 <b>0.000</b> .635         .279         .186 <b>0.023</b>							

Note. CI – bootstrap confidence intervals using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution; values in bold indicate significant *p-values* 

### Mediated moderation models: Pain-related self-efficacy and fear as mediators.

The mediating mechanisms of pain-related self-efficacy and pain-related fear were only tested in the significant moderation model described above, i.e. the model in which perceived promotion of autonomy (T1) significantly moderated the relationship between pain intensity (T1) and pain-related disability (T2).

### Pain-related self-efficacy

As shown in Table 12, the first step for testing a mediated moderation model (Muller et al., 2005) was met: perceived promotion of autonomy (T1) significantly moderated the relationship between pain intensity (T1) and pain-related self-efficacy (T2, the mediator) ( $\beta$ =.177, p≤.01), and pain-related self-efficacy (T2) significantly predicted pain-related disability (T2) ( $\beta$ =-.567, p≤.001). The simple slope analysis of the interaction effect shows that higher levels of pain intensity (T1) strongly decreased older adults' pain-related self-efficacy (T2), but this relationship was stronger for older adults with low perceived promotion of autonomy (-1SD; B=-5.283, t(169)=-5.331, p≤.001) than for older adults with high perceived promotion of autonomy (+1SD; B=-2.697, t (169)=-2.708, p≤.010).

The second step was not fully confirmed because perceived promotion for autonomy (T1) did not significantly interact with pain-related self-efficacy (T2) on pain-related

disability (T2); but pain intensity (T1) significantly predicted lower pain related self-efficacy at Time 2 ( $\beta$ =-.410, p $\leq$ .001). Finally, the third step was met - the overall moderator effect of perceived promotion of autonomy on the relationship between pain intensity and pain-related disability disappeared in the presence of the interaction effect.

In sum, a mediated moderation exists because the first and third steps, established by Muller et al. (2005) were met. Specifically, a significant interaction effect of pain intensity x perceived promotion of autonomy on pain-related self-efficacy was found; pain-related self-efficacy was significantly associated with pain-related disability; and the overall moderation effect was reduced. Furthermore, the fit of the mediated moderation model to the data was excellent ( $\chi$ 2=.072, p=.788, df=1,  $\chi$ 2/df=.072; CFI=1.0, TLI=1.1, RMSEA=.000).

Table 12 – Pain-related self-efficacy (T2) mediates the moderator effect of perceived promotion of autonomy (T1) on the relationship between pain intensity (T1) and pain-related disability (T2).

Outcome variable: Pain-related self-efficacy (T2)							
	В	SDB	β	p-value	CI		
Perceived promotion of autonomy (T1)	.938	1.013	.065	0.354	-1.047; 2.923		
Pain Intensity (T1)	-3.990	.740	410	0.000	-5.441; -2.539		
Perceived promotion of autonomy (T1)*Pain intensity (T1)	1.293	.505	.177	0.011	0.303; 2.284		
Outcome variable: Pain-related Disability (T2)							
	В	SDB	β	p-value	CI		
Pain-related self-efficacy (T2)	096	.010	567	0.001	-0.116; -0.075		
Perceived promotion of autonomy (T1)	.172	.104	.071	0.096	-0.043; 0.387		
Pain Intensity (T1)	.575	.096	.350	0.001	0.380; 0.771		
Perceived promotion of autonomy (T1)*Pain intensity (T1)	033	.062	027	0.595	-0.163; 0.097		
Perceived promotion of autonomy (T1)*Pain-related self-efficacy (T2)	007	.006	055	0.253	-0.020; 0.006		

Note. CI – bootstrap confidence intervals using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution; values in bold indicate significant *p-values* 

### Pain-related fear

As shown in Table 13, the first step to test a mediated moderation model was not fully confirmed: perceived promotion of autonomy did not significantly interact with pain intensity on pain-related fear ( $\beta$ =.028, ns); though, pain-related fear was significantly associated with higher pain-related disability ( $\beta$ =.251, p<.001).

Moreover, the second step was also not fully confirmed since perceived promotion of autonomy did not interact with pain-related fear on pain disability ( $\beta$ =.027, ns); but, pain

intensity had a positive effect on pain-related fear ( $\beta$ =.307, p≤.001). In sum, the mediated moderation model was not significant

Table 13 – Pain-related fear (T2) as mediator of the moderator effect of perceived promotion of autonomy (T1) on the relationship between pain intensity (T1) and pain-related disability (T2)

Outcome variable: Pain-related fear (T2)							
	В	SD B	В	p-value	CI		
Perceived promotion of autonomy (T1)	070	.037	159	0.057	-0.142; 0.002		
Pain intensity (T1)	.091	.027	.307	0.001	0.037; 0.146		
Perceived promotion of autonomy (T1)*Pain intensity (T1)	.006	.022	.028	0.778	-0.038; 0.050		
Outcome variable: Pain-related Disability (T2)							
	B	SDB	В	p-value	CI		
Pain-related fear (T2)	1.384	.381	.251	0.000	0.608; 2.160		
Perceived promotion of autonomy (T1)	.164	.138	.068	0.232	-0.115; 0.442		
Pain intensity (T1)	.815	.105	.496	0.000	0.600; 1.030		
Perceived promotion of autonomy (T1)*Pain intensity (T1)	145	.068	118	0.018	-0.287; -0.003		
Perceived promotion of autonomy (T1)*Pain-related fear (T2)	.102	.237	.027	0.563	-0.395; 0.599		

CI – bootstrap confidence intervals using the cut-offs for the 2.5% highest and lowest scores of the empirical distribution; values in bold indicate significant *p-values* 

### **Discussion**

In line with the fourth aim of the present thesis, this study examined the buffering effects of perceived promotion of autonomy and the amplifying effects of perceived promotion dependence on the relationship between pain intensity and pain-related disability, as depicted in Figure 2 (Chapter 2, page 14).

### Perceived promotion of autonomy/dependence: buffers or amplifiers?

The first goal of this study was to test the buffering/amplifying effects of perceived promotion of autonomy/dependence on the relationship between pain intensity and older adults' pain-related disability. First, perceived promotion of autonomy at T1 buffered the deleterious effect of pain intensity (T1) on pain-related disability at T2, confirming the first hypothesis (H1). Indeed, at higher levels of perceived promotion of autonomy, the impact of pain intensity (T1) on pain-related disability (T2) was weaker than at lower levels of

perceived promotion of autonomy. This result is consistent with Ginting and colleagues' (2011a, 2011b) findings, which showed that significant other distracting responses buffered the negative impact of pain intensity on pain disability and on mental quality of life of chronic pain patients. On the whole, these findings suggest that pain-related support that aims at the distraction and encouragement to function despite pain can be a protective factor of the detrimental effects of pain intensity on pain-related disability. It seems that, in order to be effective in its protective function, this type of support needs to be perceived by the person in pain as very salient and/or frequent. This idea may also account for the fact that, in the present study, this buffering effect was no longer significant from T1 to T3, indicating that it may dissolve as time goes by. In other words, to be effective, pain-related support for functional autonomy may need to be consistently and openly provided to pain sufferers.

Second, the present study aimed to explore whether perceived promotion of dependence amplifies the effect of pain intensity on pain-related disability, therefore being a risk factor (H2). This hypothesis was not confirmed. Similarly, the role of solicitous support as enhancing the effects of pain on pain-related outcomes has also not been consistently supported (Badr & Milbury, 2011; Ginting et al., 2011a, 2011b). Indeed, the idea that social support may amplify the effect of a stressor is at odds with the dominant theoretical models, where social support is mostly described as having a protective role and to buffer the harmful impact of aversive situations (*e.g.*, Thoits, 2011; Uchino, 2006). It seems that empirical findings, so far, favour the stress-buffering hypothesis.

However, rather than being an amplifier, perceived promotion of dependence influenced pain-related outcomes directly, as postulated by the direct effect hypothesis that states that social support influences health outcomes regardless of the levels of stress (*e.g.*, Wills & Ainette, 2012). The present study not only replicated the negative association between perceived promotion of dependence and pain-related disability, found in previous cross-sectional studies (Matos & Bernardes, 2013; Chapter 3), but also clarified the causal relationship between these constructs, by using a longitudinal design (see also Chapter 4). These findings are in line with research on solicitous support from significant others that has consistently shown a relationship with higher pain-related disability, pain behaviours and decreased well being (*e.g.*, Coty & Wallston, 2010; Kerns et al., 1991; Romano et al., 1995, 2000, 2009).

In sum, present findings suggest that pain-related support for functional autonomy and dependence – perceived promotion of autonomy and perceived promotion of dependence – influence pain-related disability in opposite directions and, also, through different pathways.

On one hand, perceived promotion of autonomy consists of an adaptive function of pain-related social support by being a buffer against the detrimental effects of pain intensity on pain-related disability. On the other hand, perceived promotion of dependence consists of a maladaptive function of pain-related social support, which directly and negatively influences pain-related disability, regardless of pain intensity.

## Pain-related self-efficacy mediates the buffering effects of perceived promotion of autonomy

The second aim of this study was to investigate the mediating role of two psychological mechanisms – pain-related self-efficacy and pain-related fear – in accounting for the buffering effects of perceived promotion of autonomy. First, pain-related self-efficacy totally accounted for the buffering effect of perceived promotion of autonomy on the impact of pain intensity on pain-related disability, thus confirming H3. More specifically, the mechanism that accounted for such effect was the buffer effect of perceived promotion of autonomy on the negative impact of pain intensity on pain-related self-efficacy. In other words, for older adults who reported higher levels of perceived promotion of autonomy pain intensity had a weaker negative effect on their pain-related self-efficacy, which, in turn, accounted for the weaker impact of pain intensity on pain-related disability. This result is partially in line with previous findings showing that pain intensity reduces pain-related self-efficacy, leading to worse pain-related disability (e.g., Costa et al., 2011; Schulz et al., 2015). However, and to the best of our knowledge, our study is one of the first showing that perceived promotion of autonomy might buffer the effect of pain intensity on pain-related self-efficacy, which in turn buffers the impact of pain intensity on pain-related disability.

Second, pain-related fear did not account for the buffer effect of perceived promotion of autonomy on the impact of pain intensity on pain-related disability, thus not confirming H5. Still, pain-related fear at T2 was significantly predicted by pain intensity at T1 and associated with higher pain-related disability at T2, which is congruent with previous research (*e.g.*, Arnstein, 2000; Costa et al., 2011; Kori et al., 1990; Vlaeyen et al., 1995). However, perceived promotion of autonomy was not a buffer of the negative effect of pain intensity on pain-related fear or of pain-related fear on pain-related disability. Although pain-related support can convey the belief that activity might or might not be dangerous to the person in pain, it is more likely that direct activity experiences are more effective in reducing pain-related fear (*e.g.*, Vlaeyen & Crombez, 1999). Therefore, perhaps a behavioural

intervention, rather than an interpersonal intervention based on the provision of pain-related support for functional autonomy, may be more effective in reducing the impact of pain intensity on pain-related disability.

Finally, it should be noted that our findings are in line with other studies (*e.g.*, Costa et al., 2011) that highlight the higher impact of pain-related self-efficacy (vs. fear) in predicting better pain-related outcomes, and stress that interventions should aim at increasing the former rather than decreasing the latter.

### Limitations and directions for future research

This study is innovative by exploring the buffering and amplifying effects of two types of pain-related support – perceived promotion of autonomy and dependence. It has its merits by using longitudinal data with structural equation modelling, which allows withdrawing conclusions about the causality of these relationships. Nevertheless, some limitations should be pointed out, which may indicate directions for future research. First, participants were all attendants at day-care centres in urban areas, only using formal social support facilities in part time. This means that other sources of support (e.g., family, friends, neighbours) that are not being considered might also play an important role. Therefore, further investigations could be conducted on the role of informal pain-related social support on older adults' pain experiences. Second, measures of distress (e.g., depression and anxiety) were not included. This might have left out a significant part of older adults' pain experiences since both pain and social support are often linked to distress (e.g., Pjanic et al., 2013). It is known that receiving social support might lead to worse psychological outcomes, by undermining individuals' sense of efficacy, self-esteem and autonomy and causing feelings of indebtedness and inequity (e.g., Bolger et al., 2000; Rafaeli & Gleason, 2009). This most often occurs when support signals that the recipient is incapable of coping independently with a stressful situation and is dependent on the provider for help (Rafaeli & Gleason, 2009), i.e., when support promotes functional dependence. In other words, perceived promotion of autonomy and dependence could also be differentially associated with distress. This hypothesis is yet to be tested.

Third, data collection was done by interviews inside the institutions, which might have increased social desirability bias, eventually accounting for the very low levels of perceived promotion of dependence that may be perceived as less socially desirable. In future research,

research protocols should be filled out autonomously by older adults in other settings outside the institution (for example at home).

### Theoretical and practical implications

The present findings confirm that different types of pain-related social support, depending on whether it promotes functional autonomy or dependence, are associated with different pain-related outcomes (Matos & Bernardes, 2013; Chapters 2 and 3). Findings also show that these different functions work through different pathways. Perceived promotion of autonomy is a protective factor and has a buffering role, while perceived promotion of dependence is a risk factor and directly influences higher pain-related disability. Promoting functional autonomy encompasses providing behavioural help and emotional/esteem support that aims to increase one's confidence to keep on functioning and to engage in (social and physical) activity despite pain. The present findings provide support to the argument that pain-related support for functional autonomy, within the context of chronic pain in older adults, is a more adaptive path in order to reduce the toll of chronic pain experiences. As such, it has the potential to contribute for a more positive living and to enable older adults' healthy ageing process, despite pain. On the other hand, promoting functional dependence is maladaptive within a chronic pain context, since it has been consistently associated to higher pain-related disability.

From a practical perspective, these findings could inspire the development of training programs with formal caregivers. Such training program could aim to raise caregivers' awareness about present practices, increase their knowledge and skills to promote functional autonomy and to minimize the promotion of functional dependence among older adults with chronic pain. Also, regarding interventions with older adults with chronic pain, should aim to increase individual's knowledge and self-management skills to rely on others support to improve functional autonomy, in order to endure in physical and social activities despite pain.

In sum, due to the high prevalence of musculoskeletal chronic pain in older populations, formal caregivers are important sources to help older adults overcome the functional obstacles posed by pain. Social support for functional autonomy despite pain is a way to promote healthy ageing and well being in latter life.

# Chapter 6 GENERAL DISCUSSION

This thesis was motivated by the need to find protective factors of older adults' healthy ageing despite chronic pain, within the context of formal support. Since musculoskeletal chronic pain is highly prevalent and disruptive of older adults' healthy ageing process, we aimed to contribute with research on the protective/risk factors for older adults' pain experiences, within the context of formal social support.

Literature on the role of social support on pain experiences has shown inconsistent results, leaving unanswered which features of pain-related support are beneficial or detrimental. Accordingly, the main research goal of the present thesis was to explore whether and how pain-related support might be a protective or risk factor of pain-related disability. More specifically, such protective or risk roles would depend on whether pain-related support was promoting functional autonomy versus dependence. In order to answer to the main research goal, several specific aims were outlined. The *first aim* pertained to the improvement of the psychometric properties of the Formal Social Support for Autonomy and Dependence in Pain Inventory (FSSADI\_PAIN; Matos & Bernardes, 2013). This was a stepping-stone to explore the effects of perceived promotion of autonomy and dependence on pain-related disability. After the validation of the scale, the following aims were theoretically anchored on the main models on the effects of social support on health outcomes, namely the (in)direct effects and buffering effect models (*e.g.*, Cohen et al., 2000; Cohen & Willis, 1985; Cohen & Syme, 1985; Wills & Ainette, 2012).

Therefore, the *second aim* was to explore if, indeed, perceived promotion of autonomy was related to less pain-related disability in older adults with chronic pain; and if perceived promotion of dependence was associated with higher levels of pain-related disability (see Figure 1, Chapter 2, page 13). Afterwards, the *third aim* was to explore if the relationship between perceived promotion of autonomy and dependence and pain-related disability could have been accounted for by behavioural and psychological mechanisms, namely, physical functioning and pain-related self-efficacy and fear (see Figure 1, Chapter 2, page 13). We also aimed to investigate if these relationships were dependent on pain duration and intensity. Finally, the *fourth aim* was to explore whether perceived promotion of autonomy would be a buffer and reduce the impact of pain intensity on the level of pain-related disability in older adults with chronic pain; and if perceived promotion of dependence would be an amplifying mechanism and, therefore, would increase the effect of pain intensity on pain-related disability (Figure 2, Chapter 2, page 14). Moreover, we aimed to investigate the extent to which pain-related self-efficacy and fear could account for the buffering/amplifying effects of pain-related support.

These aims were accomplished through the conduction of four studies, presented from chapters 2 to 5. Next, we briefly present the main findings and discuss how they contributed to answer to the main research question(s) – can pain-related support be a protective or risk factor depending on the extent it promotes functional autonomy or dependence? If so, how do these effects unfold?

### The development and validation of the revised FSSADI PAIN

In **Chapter 2**, it was confirmed that the revised FSSADI\_PAIN was composed by two independent factors – 1) perceived promotion of autonomy and 2) perceived promotion of dependence. Overall the instrument proved to be reliable and sensitive, and both factors showed very good internal consistency indices. Overall this study demonstrated that the revised FSSADI\_PAIN is an innovative instrument in conceptualizing and operationalizing perceived promotion of autonomy and perceived promotion of dependence, as different functions of pain-related support within the context of formal support. Indeed, although a few previous instruments had addressed the role of others in reinforcing pain and well behaviours (Kerns, Turk, & Rudy, 1985; Schwartz, Jensen, & Romano, 2005) these were circumscribed to informal relationships – specifically spousal relationships; and did not address the promotion of functional autonomy when the patient displayed pain behaviours.

### The direct association between pain-related social support and disability

In **Chapter 3**, the relationship between pain-related social support and disability was tested with a cross-sectional design; and in **Chapter 4**, it was tested with a prospective design.

As for the relationship between perceived promotion of autonomy and pain-related disability, taken together our findings were inconsistent. In the cross-sectional study, perceived promotion of autonomy was associated with lower pain-related disability. However, in the longitudinal study, perceived promotion of autonomy did not directly influence the level of pain-related disability after six and twelve weeks. Indeed, this latter result is consistent with our previous correlational findings (Matos & Bernardes, 2013), in which perceived promotion of autonomy was not directly associated with lower pain-related disability. This might suggest, for instance, that the direct effects of perceived promotion of autonomy on pain-related disability might be dependent on other factors, like the recipients'

needs, desires or preferences for support (*e.g.*, Brock & Lawrence, 2009; McWilliams et al., 2009; McWilliams et al., 2014; Maisel & Gable, 2009). Maybe perceived promotion of autonomy is a direct protective factor only for people who prefer this kind of support. Moreover, it is also possible that the role of perceived promotion of autonomy might be a buffer rather than having a direct positive effect; which is indeed a contention supported by our findings as discussed below.

Concerning the direct association between perceived promotion of dependence and pain-related disability both cross sectional and longitudinal studies supported our hypothesis of a negative association (Figure 11). This finding stressed the negative influence of painrelated support on functional dependence by increasing the level of disability caused by chronic pain in the life of older adults. This is congruent with cross-sectional research on solicitous support (e.g., Kerns et al. 1991; Romano, et al., 1995; Romano et al., 2000; Romano et al., 2009). Since, to the best of our knowledge, pain-related support literature lacks in addressing this relationship with longitudinal designs, this finding allows us to assume a causal relationship between perceived promotion of dependence and pain-related disability. Findings on the direct association between perceived promotion of autonomy/dependence on pain-related disability are partially supportive of our contention that pain-related social support may be associated with different pain-related outcomes, since only perceived promotion of dependence proved to be directly related with higher painrelated disability. However confirming the expectation that pain-related support would be associated with increases in pain-related disability called for a deeper search about the underlying mechanisms of such relationship.

### The indirect effects of perceived promotion of dependence on pain-related disability: the mediating role of behavioural and psychological mechanisms

In **Chapters 3 and 4**, we investigated the role of behavioural and psychological mechanism in accounting for the detrimental effect of perceived promotion of dependence on pain-related disability. Overall, findings showed that lower levels self-reported physical functioning proved to be a behavioural mechanism accounting for the effect of perceived promotion of dependence on pain-related disability. Meaning that perceived promotion of dependence increased pain-related disability by decreasing the level of physical functioning (Figure 11). The influence of perceived promotion of dependence in decreasing physical functioning is consistent with cross-sectional research that has shown that solicitous support

was associated with lower self-reported functioning in patients within chronic pain or other chronic diseases (*e.g.*, Luszczynska et al., 2007; Romano et al., 2009; Shen et al., 2004). Moreover, this finding is congruent with the theoretical assumptions of the operant conditioning (Fordyce, 1976) and the fear avoidance models (*e.g.*, Vlaeyen et al., 1995; Leeuw et al., 2007), as it corroborates that pain-related support influences lower behavioral performance, that in turn results in higher pain-related disability.

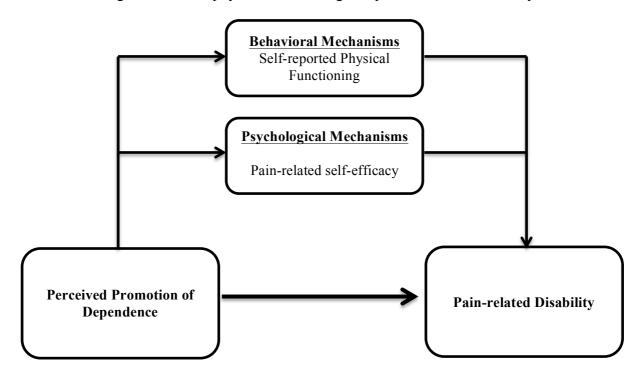
It should be noted, however, that this mediating mechanism was only found for self-reported but not observed physical functioning. The lack of results was, probably, related to the fact that the performance of these physical tasks was not influenced by pain-related support. Perhaps these measures lacked in ecological validity, because these were behaviours performed outside of the normal context and pain-related support had no influence in these tasks. Also, these physical tasks may be better indicators of physical capacity than pain-related functioning.

Concerning the psychological mediating mechanisms, only pain-related self-efficacy beliefs (but not fear) accounted for the effect of perceived promotion of dependence on pain-related disability (Figure 11). Meaning that perceived promotion of dependence increased pain-related disability by decreasing older adults' self-efficacy beliefs to function when in pain. This finding corroborates, within a chronic pain context, the assumption that social support can have detrimental effects on health-related outcomes by disenabling one's self-efficacy beliefs (Benight & Bandura, 2004).

Moreover, these findings only existed for older adults who presented shorter and less intense pain experiences. This finding showed that perceived promotion of dependence is a risk factor for shorter and less severe pain experiences and that social factors do not have the power to influence pain-related disability, when pain is more intense and/or longer. This is congruent with research that found a stronger association between catastrophizing and partner support responses among individuals with shorter pain duration (Cano, 2004). These results stress the importance of psychosocial factors in influencing less severe pain experiences and at earlier stages of development.

Pain-related fear did not prove to be an explaining mechanism of the negative influence of perceived promotion of dependence on pain-related disability. The lack of results might be related to the fact that participants of the present sample reported experiencing pain for a long time. Since pain-related fear is an important predictor of how acute pain becomes chronic, perhaps the influence of pain-related support on pain-related fear might be more important on older adults' acute pain experiences.

Figure 11 - Direct and indirect influence of perceived promotion of on pain-related disability through the level of physical functioning and pain-related self-efficacy.



In sum, the findings on the behavioural and psychological pathways add to the main research question by showing which mechanism are at place when perceived promotion of dependence is influencing higher levels of pain-related disability, in older adults with chronic pain. Therefore, these findings corroborate that pain-related support for functional dependence is a risk factor for older adults' pain experiences, by promoting lower physical functioning abilities to perform daily activities and lower beliefs on individuals' ability to keep on functioning when in pain. This pattern of findings is more striking among older adults with more recent and less severe pain experiences, which stresses the role of perceived promotion of dependence as a serious risk factor for the development of persistent pain.

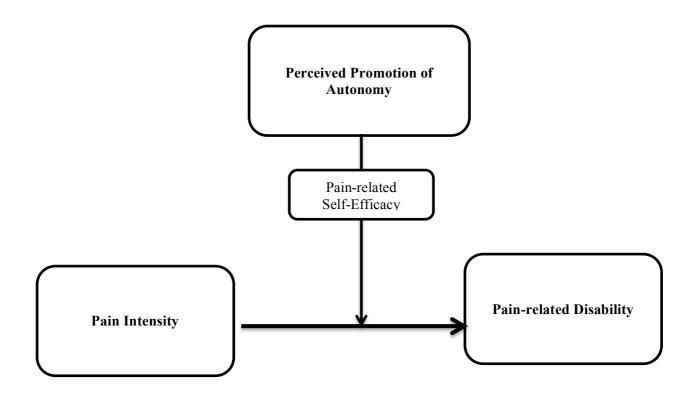
### The buffering and amplifying effects of pain-related support

In **Chapter 5**, we investigated whether perceived promotion of autonomy/dependence could have buffering/amplifying effects on the impact of pain intensity on pain-related disability. We sought to unravel how such buffering and amplifying effects would work. Our findings showed that perceived promotion of autonomy buffers the negative effect of pain intensity on pain-related disability, by protecting older adults' pain-related self-efficacy against the hindering effect of pain intensity (Figure 12). However this buffer effect did not

sustain across time, which might indicate that pain-related support for functional autonomy has to be frequently and continuously provided in order to be effective. In other words, these findings highlight that pain-related support for functional autonomy has a double protective role of the negative impact of pain intensity; it protects pain-related self-efficacy and pain-related disability against the negative impact of pain intensity. This result is consistent with research that has shown that pain intensity reduces pain-related self-efficacy, leading to worse pain-related disability (*e.g.*, Costa et al., 2011; Schulz et al., 2015). However, present findings are innovative in showing that perceived promotion of autonomy is a buffer of the effect of pain intensity on pain-related self-efficacy, which in turn buffers the impact of pain intensity on pain-related disability. Although perceived promotion of autonomy did not prove to (in)directly decrease pain-related fear, it is encouraging and an optimistic outcome that perceived promotion has a double protective role of the effect of pain intensity. This is in line with other research (*e.g.*, Costa et al., 2011) that has shown the higher influence of pain-related self-efficacy (vs. fear) in predicting pain-related outcomes.

Moreover, perceived promotion of dependence was not an amplifying mechanism of the effect of pain intensity on pain-related disability. Indeed, as previous research, solicitous support has not been consistently an amplifier (Badr & Milbury, 2011; Ginting et al., 2011a; Ginting et al., 2011b). In fact, social support has been predominantly described as having a protective role against the harmful impact of aversive situations (*e.g.*, Thoits, 2011; Uchino, 2006).

Figure 12 – Buffering effect of perceived promotion of autonomy on the influence of pain intensity on pain-related disability accounted for by pain-related self-efficacy.



In sum, present findings suggest that pain-related support for functional autonomy and dependence – perceived promotion of autonomy and perceived promotion of dependence – influence pain-related disability in opposite directions and, also, through different pathways. On one hand, perceived promotion of autonomy consists of an adaptive function of pain-related social support by being a buffer against the detrimental effects of pain intensity on pain-related disability (Figure 12). On the other hand, perceived promotion of dependence consists of a maladaptive function of pain-related social support, which directly and negatively influences pain-related disability (Figure 11).

### Limitations and directions for future research

This thesis contributes with innovative insights on the role of different functions of pain-related support in influencing older adults' chronic pain experiences. However, some limitations could be pointed out, informing further research on the topic. Specific limitations of each study are discussed in each chapter, therefore in the present section we will point out to overall limitations that ought to help future research endeavours.

First, all the data was collected, by interviews, inside the institutions in which the participants were attendants. This issue might have increased the influence of social desirability. This might have accounted for the generally low levels of reported perceived promotion of dependence and pain intensity; these are features that might strike as less desirable. Indeed, it has been shown that some older adults are reluctant to complaint about pain (Gagliese & Melzack, 1997; Gibson & Helme, 1995; Lansbury, 2000). It was never possible to overcome this limitation, because interviewing older adults inside the institution they were attending was more convenient for them. It should be stressed that it was very difficult to involve older adults in research and arrangements were needed in order to get them engaged – like collect data in interview form and inside the institutions. For older adults in nursing homes, this aspect was impossible to overcome, since they lived in the institution.

Second, all the studies in the present thesis used older adults' self-reported measures of pain-related support. This means that only the perspective of older adults was taken into account to explore the role of pain-related support. Further research should include caregivers' views on the topic and observational measures, because, self-report measures can be biased by social desirability, recall or even it is possible that individual factors (*e.g.*, personality, mood, distress) might blur perceptions about the support actually received (*e.g.*, Lehman et al., 2011).

Third, future studies should investigate the role of preferences for support since it might be an important moderator of the influence of pain-related support. It might be possible that the effects of perceived promotion of autonomy/dependence might be different for people who prefer promotion of autonomy/dependence.

Fourth, participants' general low educational level and the fact most were living in urban areas raises questions about the generalizability of these findings. Older adults with more years of education might be more sensitive, reactive or even more demanding of some types of support. Indeed, in the first study (Chapter 2) participants' years of education were positively correlated with perceived promotion of dependence, raising the hypothesis that a more educated sample could report higher perceived promotion of dependence. Although this was a limitation in every study, it was difficult to overcome since the educational level of Portuguese older adults remains very low. Indeed, in 2011, 31.4% of Portuguese older adults had not completed the basic education (Instituto Nacional de Estatística, 2012). Of course, future generations of older adults will have more education years and this limitation will be easily overcome. Moreover, since participants all lived in urban areas they might have had been receiving support from family and friends, which decreases the need of formal pain-

related support. The influence of formal pain-related support might be different among older adults who live in rural areas and have less availability of informal support.

Finally, not including distress might have left out a significant part of older adults' pain experiences since both pain and social support are often linked to distress (*e.g.*, Pjanic et al., 2013). Moreover, since receiving social support might lead to worse psychological outcomes, (*e.g.*, Bolger et al., 2000; Rafaeli & Gleason, 2009) it will be useful that future research controls for the level of distress and ascertain the costs of receiving pain-related support.

### Theoretical and practical implications of the present findings

Regarding the *theoretical implications*, the present thesis contributes with the conceptualization of new and different functions of pain-related support. Such conceptualization originated from the need to explain inconsistencies on the relationship between social support and pain outcomes. First, the development of the revised FSSADI\_PAIN is useful due to the lack of instruments measuring formal pain-related support. Furthermore, present findings are supportive of the main argument that pain-related support for functional autonomy would be a protective factor of the pain experiences; and that pain-related support for functional dependence would be a risk factor when in pain. These findings are also relevant by adding the conclusion that pain-related support is not always associated with positive outcomes. Moreover, this thesis showed that pain-related support can act through different pathways – direct, indirect, buffer, amplifier – and through different mechanisms – behavioural and psychological. These findings are meaningful by providing insight about many different ways in which social support is able to influence pain-related outcomes, but they also bear important practical implications.

The idea that pain-related support has different functions and different implications is especially important regarding its *practical implications* and how it really can influence older adults' pain experiences. Knowing that pain-related support has the potential to influence directly and indirectly pain-related disability provides information on what kind of support (not) to offer. Furthermore, this research gives insight on which mechanisms are better influenced by formal pain-related support and which have better outcomes. This research should translate into the field of formal networks, providing insight on which kind of support actions would lead to better outcomes. An intervention with caregivers should aim their knowledge and beliefs about chronic pain in older adults, and their skills on providing

support for functional autonomy and dependence. Also, interventions should be developed with older adults with chronic pain informing about the positive effects of maintaining functional autonomy, rather than functional dependence, and on raising physical ability and self-efficacy to function despite pain.

This thesis embodied the perspective of healthy ageing, as a desirable and natural process, fulfilled with freedom, dignity and functional autonomy. We aimed to contribute to such positive process of ageing of individuals with chronic pain, because it has the most important detrimental effect on an independent living, of older populations. Also, we believe that the formal support networks should provide the best care and be a stepping-stone for people in need to overcome aversive situations. This thesis leaves its contribution by bringing new insight about how pain-related support can be a protective or risk factor for older adults' pain experiences.

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#### APPENDIX A - The revised FSSADI\_PAIN

Durante toda a vida, a maior parte das pessoas sente dor de vez em quando. A dor pode ser uma experiência que dificulta o nosso dia-a-dia e a realização de várias tarefas quotidianas. Nestas circunstâncias, o apoio recebido nas instituições, como os Lares e Centros de Dia, pelas pessoas que aí trabalham pode ter um papel muito relevante no auxílio aos utentes com dores. No presente questionário, estamos interessados em conhecer a sua noção sobre a frequência com que, no geral, os funcionários desta instituição lhe prestam assistência quando têm dores. Não existem respostas certas ou erradas. Não estamos interessados em avaliar a sua instituição ou as pessoas que aí trabalham. Estamos apenas interessados na sua noção sobre o apoio que recebe quando tem dores. Abaixo estão indicadas diferentes situações de apoio prestadas em contextos de dor. Por favor, para cada situação, faça um círculo num dos números de 1 a 5, mostrando com que frequência os funcionários desta instituição lhe dão o tipo de ajuda que é descrita. Muito obrigada pela sua colaboração!

#### Quando eu estou com dores, no geral, os/as funcionários/as desta instituição...

	Nada	Pouco	Moderadamente	Muito	Extremamente
	Frequente	Frequente	Frequente	Frequente	Frequente
1. Incentivam-me a participar nas actividades de lazer e diversão.	1	2	3	4	5
2. Incentivam-me a conviver socialmente.	1	2	3	4	5
3. Incentivam-me a confiar na minha capacidade para continuar a funcionar.	1	2	3	4	5
4. Ajudam-me a tratar de aspectos práticos (ex., transporte, reservas, bilhetes) para que consiga participar em actividades/saídas sociais.	1	2	3	4	5
5. Aconselham-me a parar tudo o que estou a fazer.	1	2	3	4	5
6. Trazem-me tudo o que eu necessito para que não precise de me mexer.	1	2	3	4	5
7. Dizem-me que eu preciso da ajuda de outros para lidar com a dor.	1	2	3	4	5
8. Dizem-me para não insistir quando não me sinto capaz de tratar de alguns problemas.	1	2	3	4	5

#### APPENDIX B – Data collection protocol from studies 1 and 2

#### Part I

#### **Questions about present pain experiences**

1. Gostaríamo	os que nos falasse um pouco mais so	bre a sua dor:	
Já alguma vez	z teve dor, constante ou intermitente	, por mais de 3	3 meses consecutivos?
Sim	Não		
Sentiu essa do	or durante a semana passada?	Sim	Não
Se respondeu	que não à última questão: Diga se s	entiu alguma o	lor na semana que passou
Sim	Não		

## Part II (Preliminary version of the) Formal Social Support

#### for Autonomy and Depedence in Pain Inventory

Durante toda a vida, a maior parte das pessoas sente dor de vez em quando. A dor pode ser uma experiência que dificulta o nosso dia-a-dia e a realização de várias tarefas quotidianas. Nestas circunstâncias, o apoio recebido nas instituições, como os Lares e Centros de Dia, pelas pessoas que aí trabalham pode ter um papel muito relevante no auxílio aos utentes com dores.

No presente questionário, estamos interessados em conhecer a sua noção sobre a frequência com que, no geral, os funcionários desta instituição lhe prestam assistência quando têm dores.

Não existem respostas certas ou erradas. Não estamos interessados em avaliar a sua instituição ou as pessoas que aí trabalham. Estamos apenas interessados na sua noção sobre o apoio que recebe quando tem dores.

Abaixo estão indicadas diferentes situações de apoio prestadas em contextos de dor. Por favor, para cada situação, faça um círculo num dos números de 1 a 5, mostrando com que frequência os funcionários desta instituição lhe dão o tipo de ajuda que é descrita. Muito obrigada pela sua colaboração!

Quando eu estou com dores, no geral, os/as funcionários/as desta instituição...

Quando eu estou cor					
	Nada	Pouco	Moderadamente	Muito	Extremamente
	Frequente	Frequente	Frequente	Frequente	Frequente
1. Ajudam-me com					
algumas tarefas (ex.,					
preencher impressos,					
obter informações,					
usar o telemóvel) de	1	2	3	4	5
maneira a que eu	1	2	3	4	3
consiga tratar dos					
meus assuntos					
pessoais por mim					
próprio/a.					
2. Motivam-me para	_	_	_	_	_
fazer exercício físico.	1	2	3	4	5
3. Reconhecem que					
eu não sou capaz de					
lidar com a minha	1	2	3	4	5
dor.					
4. Auxiliam-me no					
contacto com					
entidades (ex: banco,					
segurança social) para	1	2	3	4	5
que consiga resolver					
os meus problemas					
pessoais					
autonomamente.					
5. Resolvem por mim					
os meus assuntos					
pessoais (ex.,		_	_		_
preenchem impressos,	1	2	3	4	5
contactam					
instituições, obtêm					
informações).					
6. Desaconselham-me	_	_			_
a realizar exercício	1	2	3	4	5
físico.					
7. Felicitam-me					
quando realizo as	1	2	3	4	5
actividades de forma	1		3	•	
autónoma.					
8. Tratam de todos os					
aspectos práticos para	1	2	3	4	5
eu poder ir descansar.					
9. Dizem-me para não					
insistir quando não					
me sinto capaz de	1	2	3	4	5
tratar de alguns					
problemas.					
10. Ajudam-me a					
~					
arranjar transporte	1	2	3	4	5
para eu poder ir tratar	_	_		·	
dos meus assuntos por					
mim próprio/a.					

-	•				
11. Contactam por					
mim aos meus					
familiares/amigos		_	_		_
para resolverem os	1	2	3	4	5
meus problemas ou					
tarefas.					
12. Incentivam-me a					
realizar de forma	1	2	3	4	5
autónoma as minhas	1	2	5		3
tarefas diárias					
13. Dizem-me que eu					
preciso da ajuda de					
outros para lidar com	1	2	3	4	5
a dor.					
14. Ajudam-me a					
tratar de aspectos					
práticos (ex.,					
transporte, reservas,	1	2	2	4	5
bilhetes) para que	1	2	3	4	5
consiga participar em					
actividades/saídas					
sociais.					
15. Incentivam-me a					
confiar na minha	1	2	3	4	5
capacidade para					
continuar a funcionar					
16. Incentivam-me a	1	2	3	4	5
conviver socialmente.	1	2	3	4	3
17. Aconselham-me a					
parar tudo o que estou	1	2	3	4	5
a fazer					
18. Encarregam-se da					
realização das tarefas					
-	1	2	2	4	E
que habitualmente são	1	2	3	4	5
da minha					
responsabilidade.					
19. Incentivam-me a					
participar nas	1	2	3	4	5
actividades de lazer e	1	2	3	4	3
diversão.					
20. Ajudam-me a					
carregar os meus					
pertences para que eu	1	2	3	4	5
me consiga deslocar					
sozinho/a com maior					
facilidade					
21. Incentivam-me a					
evitar qualquer tipo	1	2	3	4	5
de actividade.					
22. Trazem-me tudo o					
que eu necessito para					
que não precise de	1	2	3	4	5
me mexer.	1	2	2	A	<i>-</i>
23. Demonstram que	1	2	3	4	5

compreendem que a			
dor é horrível e me			
ultrapassa			
completamente.			

# Parte III Pain Severity and Pain Interference Sub-scales of the Brief Pain Inventory (Cleeland, 1989; Azevedo et al., 2007)

Tendo em conta a sua dor na passada semana:

Por favor, classifique a sua dor assinalando com um círculo o número que melhor descreve a sua dor **no seu máximo durante a última semana**.

Sem Dor										A pior dor que se
Selli Doi										pode imaginar
0	1	2	3	4	5	6	7	8	9	10

Por favor, classifique a sua dor assinalando com um círculo o número que melhor descreve a sua dor em média durante a última semana.

Sem Dor										A pior dor que se
Selli Doi										pode imaginar
0	1	2	3	4	5	6	7	8	9	10

Assinale com um círculo o número que descreve em que medida é que, durante a última semana, a sua dor interferiu com a sua/seu:

Actividade geral

Não interferiu										Interferiu
Não interferiu										completamente
0	1	2	3	4	5	6	7	8	9	10

Disposição Interferiu Não interferiu completamente Capacidade para andar a pé Interferiu Não interferiu completamente Sono Interferiu Não interferiu completamente 

Parte IV

Physical functioning scale of the Medical Outcomes Study - Short Form 36v2 (Ware & Sherbourne, 1992; Ferreira, 2000 a; 2000 b)

As perguntas que se seguem são sobre actividades que executa no seu dia-a-dia. Será que a sua saúde o/a limita nestas actividades? Se sim, quanto?

	Sim, muito limitado/a	Sim, um pouco limitado/a	Não, nada limitado/a
a) Actividades moderadas, tais como deslocar uma mesa ou aspirar a casa.	1	2	3
b) Subir um lanço de escadas.	1	2	3
c) Inclinar-se, ajoelhar-se ou baixar-se.	1	2	3
d) Andar várias centenas de metros.	1	2	3
e) Tomar banho ou vestir-se sozinho/a.	1	2	3

<u>Part VI</u> <u>Social Support Scale of Medical Outcomes Study (Sherbourne and Stewart, 1991;</u> <u>Pais-Ribeiro, & Ponte, 2009)</u>

Com que frequência dispõe de cada um dos seguintes tipos de apoio quando precisa?

	Nunca	Raramente	Às vezes	Quase Sempre	Sempre
a) Alguém que o/a ajuda, se estiver de cama.	1	2	3	4	5
b) Alguém com quem partilhar preocupações e medos.	1	2	3	4	5
c) Alguém para preparar as suas refeições se não as puder fazer.	1	2	3	4	5
d) Alguém que compreenda os seus problemas.	1	2	3	4	5
e) Alguém que o/a ajude nas tarefas diárias se ficar doente.	1	2	3	4	5
f) Alguém que confie para falar de si ou dos seus	1	2	3	4	5

#### <u>Parte V</u> <u>Socio-demographic questions</u>

#### **Dados Pessoais** Quantos anos de Sexo F M escolaridade tem? Estado civil Casado/a ou União de Há quanto tempo Facto frequenta a Instituição Viúvo/a Divorciado/a ou Separado Solteiro/a, nunca casou Modo de preenchimento do questionário Idade Auto-preenchimento Com quem vive? Entrevista Sozinho Cônjuge ou companheiro/a Familiares ou amigos Profissão anterior à reforma

#### APPENDIX C - Data collection protocol from studies 3 and 4

**Part I Questions about present pain experiences** 

1. Critérios de Inclusão/Exclusão no Estudo	Sim	Não
Já alguma vez teve dor, constante ou intermitente, por mais de 3 meses consecutivos?	DC	
Se sim. Sentiu essa dor durante a semana passada?	DC presente	
Está aconselhado a não fazer exercício pelo médico?		
Tem dor no peito ou tonturas?		
Tensão arterial > 160/100		

2. Alguma vez lhe foi diagnosticado/a alguma das seguintes doenças?

	Sim	Não
Artrite		
Reumatóide		
Artrite		
Inflamatória		
Osteoatrite		
Osteoporose		
Fibromialgia		
Doenças na		
coluna		
Sindroma do		
túnel cárpio		

Em caso de todas as respostas serem negativas seguir para a próxima pergunta:

3. A dor que referiu está relacionada com:

	Sim	Não
Um acidente grave		
Uma fractura de		
osso		
Dor nos ossos		
Dor nas		
articulações		
Dor nos músculos		
Dor nos tendões		
Dor nos		
ligamentos		

Em caso de todas as respostas serem negativas não continuar o questionário.

### Part II Socio-demographic questions

SSexo F M	Familiares ou amigos
Estado civil Casado/a ou União de Facto	Profissão anterior à reforma  Quantos anos de
Viúvo/a	escolaridade tem?
Divorciado/a ou Separado	Há quanto tempo frequenta a Instituição
Solteiro/a, nunca casou  Idade	
Idade	Modo de preenchimento do questionário
Com quem vive?	Auto-preenchimento
Sozinho	Entrevista
Cônjuge ou companheiro/a	]

Data de nascimento	Local	

#### Part III

#### Revised FSSADI\_PAIN (Matos, Bernardes, Goubert, & Carvalho, 2015)

Durante toda a vida, a maior parte das pessoas sente dor de vez em quando. A dor pode ser uma experiência que dificulta o nosso dia-a-dia e a realização de várias tarefas quotidianas. Nestas circunstâncias, o apoio recebido nas instituições, como os Lares e Centros de Dia, pelas pessoas que aí trabalham pode ter um papel muito relevante no auxílio aos utentes com dores.

No presente questionário, estamos interessados em conhecer a sua noção sobre a frequência com que, no geral, os funcionários desta instituição lhe prestam assistência quando têm dores.

Não existem respostas certas ou erradas. Não estamos interessados em avaliar a sua instituição ou as pessoas que aí trabalham. Estamos apenas interessados na sua noção sobre o apoio que recebe quando tem dores.

Abaixo estão indicadas diferentes situações de apoio prestadas em contextos de dor.

Por favor, para cada situação, faça um círculo num dos números de 1 a 5, mostrando com que frequência os funcionários desta instituição lhe dão o tipo de ajuda que é descrita.

Muito obrigada pela sua colaboração!

Quando eu estou com dores, no geral, os/as funcionários/as desta instituição...

	Nada	Pouco	Moderadamente	Muito	Extremamente
	Frequente	Frequente	Frequente	Frequente	Frequente
1. Ajudam-me a tratar de aspectos práticos (ex., transporte, reservas, bilhetes) para que consiga participar em actividades/saídas sociais.	1	2	3	4	5
2. Incentivam-me a confiar na minha capacidade para continuar a funcionar.	1	2	3	4	5
3. Incentivam-me a conviver socialmente.	1	2	3	4	5
4. Incentivam-me a participar nas actividades de lazer e diversão.	1	2	3	4	5
5. Dizem-me para não insistir quando não me sinto capaz de tratar de alguns problemas.	1	2	3	4	5
6. Dizem-me que eu preciso da ajuda de outros para lidar com a dor.	1	2	3	4	5
7. Aconselham-me a parar tudo o que estou a fazer	1	2	3	4	5
8. Trazem-me tudo o que eu necessito para que não precise de me mexer.	1	2	3	4	5

#### Parte III

## Questions about pain duration and localization and Pain Severity and Pain Interference Subscales of the Brief Pain Inventory (Cleeland, 1989; Azevedo et al., 2007)

	Agora, gos	staria de	e saber u	m pouce	mais so	obre a si	ia dor:				
	Há quanto	tempo	sente ess	sa dor? _					(=		meses)
	Qual a loc	alização	dessa d	lor?							
Qual a localização dessa dor?  DIREITA  ESQUERDA ESQUERDA  DIREITA  Tendo em conta a sua dor na passada semana:  a) Por favor, classifique a sua dor assinalando com um círculo o número que melhor descreve a sua											
	dor <b>no seu</b>	1 111 <b>4 XIII</b> 1	2	3	11111a SCII 4	папа. 5	6	7	8	9	10
Sen	n dor							·		-	A pior dor que se pode imaginar
	b) Por favo dor <b>no seu</b> 0		-				n um cí	rculo o r	número 8	que me	elhor descreve a sua
Sen	n dor	1					0	/	8	<u> </u>	A pior dor que se pode imaginar
	dor em mé	dia du	rante a	última s	emana.					-	elhor descreve a sua
	0	1	2	3	4	5	6	7	8	9	10
Sen	n dor										A pior dor que se pode imaginar

d) Por fav dor <b>neste</b>		_		assinala	ındo coı	m um cí	rculo o	número	que mell	hor descreve a sua
0	1	2	3	4	5	6	7	8	9	10
Sem dor										A pior dor que se pode imaginar
Assinale of sua dor in				o que de	screve 6	em que r	medida é	é que, du	irante a i	última semana, a
a) Activid										
0	1	2	3	4	5	6	7	8	9	10
Não interferiu										Interferi completament
b) Dispos	ição									
0	1	2	3	4	5	6	7	8	9	10
Não interferiu										Interferi completament
c) Capaci	dade par	a andar	a pé							
0	1	2	3	4	5	6	7	8	9	10
Não interferiu										Interferi completament
d) Traball	no norma	al (inclu	i tanto ti	abalho d	domésti	co como	trabalh	o fora de	e casa)	
0	1	2	3	4	5	6	7	8	9	10
Não interferiu										Interferi completament
e) Relaçõ	as com o	nutras na	55025							
c) Kelaçol	1	2	3	4	5	6	7	8	9	10
Não interferiu				<u> </u>						Interferi completament
f) Sono										
0	1	2	3	4	5	6	7	8	9	10
Não interferiu										Interferi completament
g) Prazer 0	de viver 1	2	3	Л	5	6	7	8	9	10
Não	1	<u></u>	3	4	<u> </u>	6	/	0	<u> </u>	Interferi
interferiu										completament

# Part IV Pain Self-Efficacy Questionnaire (Nicholas, 2007; Ferreira-Valente, Pais-Ribeiro & Jensen (2011)

Por favor, classifique o quanto está confiante, neste momento, de que consegue fazer as seguintes coisas, apesar da dor. Para indicar a sua resposta, desenhe um círculo à volta do número que melhor descreve a sua resposta, considerando que (0) indica nada confiante e (6) totalmente confiante. Lembre-se que este questionário **não** pergunta se tem ou não feito estas coisas, mas sim **o quanto confiante está de que consegue fazê-las neste momento, apesar da dor**.

	Nada						Totalmente
	Confiante						Confiante
1. Consigo apreciar as coisas, apesar da dor.	0	1	2	3	4	5	6
2. Consigo fazer a maior parte das tarefas domésticas (por exemplo, arrumar a casa, lavar pratos, lavar o carro, etc.), apesar da dor.	0	1	2	3	4	5	6
3. Consigo continuar a conviver com os meus amigos e familiares com a mesma frequência que antes, apesar da dor.	0	1	2	3	4	5	6
4. Consigo lidar com a dor na maior parte das situações.	0	1	2	3	4	5	6
5. Consigo fazer alguns trabalhos, apesar da dor (inclui o trabalho doméstico, e o trabalho remunerado e não remunerado).	0	1	2	3	4	5	6
6. Ainda consigo fazer muitas das coisas de que gosto, tais como actividades de tempos livres ou de lazer, apesar da dor.	0	1	2	3	4	5	6
7. Consigo lidar com a dor sem tomar medicamentos.	0	1	2	3	4	5	6
8. Ainda consigo alcançar a maior parte dos meus objectivos na vida, apesar da dor.	0	1	2	3	4	5	6
9. Consigo ter uma vida normal, apesar da dor.	0	1	2	3	4	5	6
10. Consigo ser cada vez mais activo(a), apesar da dor.	0	1	2	3	4	5	6

<u>Parte V</u>

<u>Tampa Scale for Kinesiophobia (Miller, Kori, & Todd, 1991;</u>

<u>Cordeiro and colleagues, 2013)</u>

Por favor, responda às seguintes questões de acordo com a escala da direita. Responda, por favor, de acordo com o que verdadeiramente sente, e não de acordo com o que as outras pessoas pensam que devia sentir. Não se trata de um teste sobre conhecimentos médicos, queremos apenas saber a sua opinião. Faça um círculo em volta do número que melhor corresponde ao que sente.

	Discordo Plenamente	Discordo	Concordo	Concordo Plenamente
1. Tenho medo de me magoar se fizer exercício	1	2	3	4
2. Se tentasse ultrapassar a dor a intensidade dela iria aumentar	1	2	3	4
3. O meu corpo está a dizer-me que tenho algo de errado e grave	1	2	3	4
4. As outras pessoas não levam o meu estado de saúde a sério	1	2	3	4
5. O acidente que sofri colocou o meu corpo em risco para o resto da vida	1	2	3	4
6. A dor significa sempre que me magoei	1	2	3	4
7. Tenho medo de magoar-me acidentalmente	1	2	3	4
8. Tentar não fazer movimentos desnecessários é a melhor coisa que posso fazer para evitar que a dor se agrave	1	2	3	4
9. Não sentiria tanta dor se não se passasse algo de potencialmente grave no meu corpo	1	2	3	4
10. A dor avisa-me quando devo parar de fazer actividade física, evitando assim que me magoe	1	2	3	4
11. Não é seguro para uma pessoa com a minha condição física ser fisicamente activa	1	2	3	4
12. Não posso fazer tudo o que as outras pessoas fazem porque me magoo muito facilmente	1	2	3	4
13. Ninguém deveria ter que fazer actividade física quando sente dor	1	2	3	4

#### Parte VI

# Physical Functioning measures: Physical functioning scale of the Medical Outcomes Study - Short Form 36v2 (Ware & Sherbourne, 1992; Ferreira, 2000a; 2000b); 30-s chair stand and 8-foot up-and-go from the Senior Fitness Test (Rikli & Jones, 1999; 2013).

As perguntas que se seguem são sobre actividades que executa no seu dia-a-dia. Será que a sua saúde o/a limita nestas actividades? Se sim, quanto?

	Sim, muito limitado/a	Sim, um pouco limitado/a	Não, nada limitado/a
1. Actividades moderadas, tais como deslocar uma mesa ou aspirar a casa.	1	2	3
2. Subir um lanço de escadas.	1	2	3
3. Inclinar-se, ajoelhar-se ou baixar-se.	1	2	3
4. Andar várias centenas de metros.	1	2	3
5. Tomar banho ou vestir-se sozinho/a.	1	2	3

Tareta	Score
1. Levantar e sentar na	
cadeira	
2. Sentado, caminhar 2,44m	
e voltar a sentar	

#### 1. Levantar e sentar na cadeira

Objectivo: avaliar a força e resistência dos membros inferiores.

<u>Instrumentos:</u> cronómetro, cadeira com encosto e sem braços, com altura de assento de aproximadamente 43 cm.

<u>Organização dos instrumentos:</u> por razões de segurança, a cadeira deve ser colocada contra uma parede, ou estabilizada de qualquer outro modo, evitando que se mova durante o teste.

<u>Posição do avaliado:</u> sentado na cadeira com as costas encostadas no encosto e pés apoiados no chão.

Posição do avaliador: próximo ao avaliado, segurando a cadeira.

Procedimento: o participante cruza os braços com o dedo médio em direcção ao acrómio. Ao sinal o participante ergue-se e fica totalmente em pé e então retorna a posição sentada. O participante é encorajado a completar tantas acções de ficar totalmente em pé e sentar quanto possível em 30 segundos. O analisador deverá realizar uma vez para demonstrar o teste para que o participante tenha uma aprendizagem apropriada. O teste deverá ser realizado uma vez. Pontuação: a pontuação é obtida pelo número total de execuções corretas num intervalo de 30 segundos. Se o participante estiver no meio da elevação no final dos 30 segundos, deve-se contar esta como uma execução.



2. Sentado, caminhar 2,44m e voltar a sentar <u>Objectivo:</u> avaliar a mobilidade física – velocidade, agilidade e equilíbrio dinâmico.

<u>Instrumentos:</u> cronómetro, fita métrica, cone (ou outro marcador) e cadeira com encosto a uma altura de aproximadamente 43 cm, até o assento.

Organização dos instrumentos: a cadeira deve ser posicionada contra a parede ou de forma que garanta a posição estática durante o teste. A cadeira deve também estar numa zona desobstruída, em frente coloca-se

um cone (ou outro marcador), à distância de 2,44 m (medição desde a ponta da cadeira até a parte anterior do marcador, cone). Deverá haver pelo menos 1,22 m de distância livre à volta do cone, permitindo ao participante contornar livremente o cone.

<u>Posição do avaliado:</u> o avaliado começa em uma posição sentada na cadeira com uma postura erecta, mãos nas coxas e os pés no chão com um pé levemente na frente do outro.

<u>Posição do avaliador:</u> o avaliador deve servir como um marcador, ficando no meio do caminho entre a cadeira e o cone, pronto para auxiliar o avaliado em caso de perda de equilíbrio.

<u>Procedimento:</u> ao sinal indicativo, o avaliado levanta da cadeira (pode dar um impulso nas coxas ou na cadeira), caminha o mais rapidamente possível em volta do cone, retorna para a cadeira e senta. Para uma marcação confiável, o avaliador deve accionar o cronómetro no movimento do sinal, quer a pessoa tenha ou não começado a se mover, e parar o cronómetro no instante exacto que a pessoa sentar na cadeira.

Lembre ao avaliado que o cronómetro não será parado até que ele esteja completamente sentado na cadeira.

<u>Pontuação:</u> o resultado corresponde ao tempo decorrido entre o sinal de "partida" até o momento em que o participante está sentado na cadeira. O tempo registado será o score utilizado para avaliar o desempenho.

Observação: lembre ao avaliado que este é um teste de tempo e que o objectivo é caminhar o mais rapidamente possível (sem correr) em volta do cone e voltar para a cadeira.