#### Received: 12 January 2023

DOI: 10.1002/nop2.1881

Check for updates

EMPIRICAL RESEARCH QUALITATIVE

• WILEY

# Helpful social support for chronic pain in long-term care residents: "With a little help I manage on my own"

Marta Osório de Matos 💿 🕴 Sónia Figueira Bernardes

Iscte-Instituto Universitário de Lisboa and Centro de Investigação e Intervenção Social (CIS\_Iscte), Lisbon, Portugal

#### Correspondence

Marta Osório de Matos, Iscte-Instituto Universitário de Lisboa and Centro de Investigação e Intervenção Social (CIS\_Iscte), Avenida das Forças Armadas, 1649-026, Lisbon, Portugal, Email: marta.matos@iscte-iul.nt

#### **Funding information**

Fundação para a Ciência e a Tecnologia, Grant/Award Number: CEECIND/00392/2017 and UIDB/03125/2020

## Abstract

Aims and Objectives: To understand older adults' experiences of receiving formal pain-related social support and to identify which caregivers' responses are perceived as (un)helpful to chronic pain adjustment.

Background: Chronic pain is highly prevalent in long-term care residents, negatively impacting their psychological, physical and social functioning. However, research has lacked to address the extent to which residents' experiences with staff responses, to their pain, may influence chronic pain outcomes.

Design: Qualitative study.

Methods: Twenty-nine older adults (7 men, 22 women,  $M_{age}$  = 87.7) were interviewed online through semi-structured interviews, and a thematic analysis was conducted. COREQ guidelines were followed.

Results: Two main themes emerged: (1) support during a pain crisis aiming at its relief and (2) support with daily activities because of pain to overcome pain interference. Findings indicate pain-related support is helpful when residents feel their psychological and functional autonomy is protected, and the interactions convey connection and intimacy. Furthermore, residents actively try to shape the support to be received. Also, gender roles and expectations seem to influence pain-related supportive interactions. Conclusion: Pain-related social support may contribute to the maintenance of older adults' health status and autonomy, ensuring a fulfilling and healthy aging process despite chronic pain.

Relevance to Clinical Practice: Findings can inform effective pain-related care practices in long-term care, regarding (1) how residents can shape the support they need; (2) which kind of support should be provided, and (3) how caregivers and organizations should provide pain-related support.

Patient or Public Contribution: Older adults who participated in the study were recruited from 3 long-term care facilities in Lisbon, in which they resided for longer than 3 months, had persistent/intermittent pain for more than 3 months; were able to maintain a conversation, recollect real episodes, and to fully provide informed consent to participate.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2023 The Authors. Nursing Open published by John Wiley & Sons Ltd.

KEYWORDS chronic pain, formal caregivers, long-term care facilities, social support

# 1 | INTRODUCTION

Chronic pain is a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components, present for more than 3 months (Raja et al., 2020). In long-term care facilities, up to 90% of the residents suffer from highly disabling chronic pain which prevents them from independently accomplishing activities of daily living and from social interactions (Resnick et al., 2019). Despite its high prevalence and impact on long-term care residents, chronic pain is often underreported, underrecognized, under-assessed and undermanaged. Indeed, multilevel factors have been identified accounting for this (for a review Knopp-Sihota et al., 2019). However, research has lacked to address interpersonal factors, namely the extent to which residents' experiences with staff responses to their pain may be contributing to such chronic pain outcomes. This study focuses on residents' experiences with pain-related interactions with formal caregivers in long-term care, due to the influence that social interactions play on pain outcomes. Indeed, pain behaviours can be reinforced by others' responses (Fordyce, 1977), and communicating catastrophizing thoughts about pain can be a form of eliciting support from others (Sullivan et al., 2001); and communication about pain, when validated, leads to increased intimacy (Cano & Williams, 2010). However, research on pain-related interpersonal dynamics has been focusing mainly on romantic couples (Bernardes et al., 2017). This body of research has shown that solicitousness and negative/distractive responses influence both pain outcomes and individuals' willingness to disclose pain and pain-related distress, which helps or hinders chronic pain adjustment (Burns et al., 2018; Newton-John & Williams, 2006). In the present paper, we focus on pain-related interactions between older adults and their formal caregivers in long-term care facilities, through the lens of social support - as it refers to one of the main processes through which social relationships influence health outcomes (Cohen & McKay, 2020).

# 2 | BACKGROUND

The effectiveness of received social support may depend on several factors: such as the extent to which it matches individuals' needs, preferences and goals; or its invisibility, as explicit support provision might create a sense of indebtedness or reduce the recipient's self-esteem (Cutrona & Russell, 1990; Uchino et al., 2011; Zee & Bolger, 2019). Furthermore, research on older adults with chronic pain has shown that the association between pain-related social support and chronic pain adjustment may depend on the promotion of individuals' functional autonomy or dependence. Indeed,

social support for functional dependence (help that allows the person in pain to avoid physical/social activity because of pain) is associated with lower physical functioning, pain-related self-efficacy and higher pain-related disability in older adults with chronic pain (Matos, Bernardes, & Goubert, 2016; Matos et al., 2017). Conversely, formal caregivers' support for functional autonomy (help and encouragement to accomplish daily activities autonomously despite the pain) is associated with older adults' higher physical functioning, pain-related self-efficacy and lower pain-related disability (Matos, Bernardes, & Goubert, 2016; Matos et al., 2017).

# 3 | THE STUDY

The research avenue of understanding why and how social support from formal caregivers to older adults with chronic pain is associated with better/worse pain adjustment is still in its infancy. Quantitative studies have proven the usefulness of approaching interpersonal dynamics as potential promoters of functional autonomy/dependence. However, there is still a gap in understanding inter and intrapersonal mechanisms that catalyse such positive/negative outcomes (Matos et al., 2017; Matos et al., 2016). Indeed, exploring older adults' phenomenological experiences of receiving pain-related social support will contribute to understanding which makes receiving pain-related support more (un)helpful. These insights might translate into clinical, professional and organizational practices, which would promote the quality of pain-related interactions, as a key path to reducing disabilities in an aging population with chronic pain. Yet, to the best of our knowledge, no previous studies have sought to explore the subjective and idiosyncratic experiences of long-term care residents with chronic pain-related interactions with their formal caregivers.

## 3.1 | Aims and objectives

Therefore, the present study aims to: (1) investigate residents' subjective experiences of receiving pain-related social support and (2) identify which caregivers' responses are perceived as helpful or unhelpful to pain adjustment.

# 4 | METHODS AND METHODOLOGY

This study was approved by Iscte-Instituto Universitário de Lisboa ethical review board (#34/2020) and the participating institutions (3 long-term care facilities in Lisbon). COREQ guidelines were used to design, implement and report the present study.

## 4.1 | Design

This is a qualitative study: data were collected through online individual semi-structured interviews and analysed through thematic analysis.

#### 4.2 | Methodological framework

WILEY\_NursingOpen

The present research methodology was informed by a phenomenological orientation (the phenomenon is the experience of receiving pain-related support). Thematic analysis was chosen due to its usefulness and richness to provide an interpretative thread across a set of semi-structured interviews. We aimed to unravel experiences (e.g. perspectives, practices and behaviours) related to receiving formal pain-related social support. A mixed inductive and deductive approach was used. The inductive part lies in the emergence of data about the features of (un)helpful pain-related assistance. The deductive part is linked to the social support nomenclature (e.g. elicited and received support, emotional and instrumental support), that assisted in organizing the interpretation of participants' reports.

#### 4.3 | Sampling and recruitment

Three long-term care facilities were invited based on the following criteria: provided skilled health services with 24-hour personal care assistance for activities of daily living, organized physical, cultural, and leisure activities, and provided psychosocial assistance. The potential participants were identified and listed by the nursing director at each long-term care facility, according to the inclusion criteria presented below. Then, the potential participants were approached by the institution's psychologist who made liaison with the research team. An informed consent form was handed to potential participants, where a full explanation of the study was provided. Participant recruitment stopped after 3 waves of interviews because the same contents were continually appearing in interviews, at some point no novelty was appearing—data saturation was achieved.

#### 4.4 | Sample size

Six residents declined the invitation to participate in the study, 31 agreed to participate and 2 of whom dropped out during the interview; overall, 29 participants were included in the study. Not wanting to talk with someone unfamiliar was the main reason for declining/withdrawing from the study.

#### 4.5 | Inclusion and exclusion criteria

The potential participants were recruited, according to the following inclusion criteria: (a) they had persistent/intermittent pain for more

than 3 months; (b) they were a resident for more than 3 months; (c) they were able to maintain a conversation and recollect real episodes; and (d) they were able to fully decide for themselves and could provide consent to participate.

#### 4.6 | Data collection

Data were collected through online individual semi-structured interviews, via the Zoom platform, between September 2020 and March 2021. Interviews were collected through video due to the pandemic context at that time. Both audio and video were recorded. Interviews took from 3 to 26 minutes (M = 10.0, SD = 6.0). Two participants were interviewed twice to explore key aspects (the emotional ambivalence of receiving help), due to the richness of their first interview. The interview guide aimed to capture the subjective experiences of receiving pain-related social support and to identify which caregiving responses were being received and considered (un)helpful: Q1: When you are in pain what kind of help do you usually get? (Probe questions: Was it offered/asked? How was it for you?); Q2: Why/How is that (un)helpful? (Probe questions: What would you prefer?).

Participants provided information regarding their age, the presence, location, duration of chronic pain and for how long they were residents in the long-term care facility. The interviews were conducted by the first author (female, Ph.D. in Clinical and Health Psychology experienced with this population and research topic), who had no previous relationship with the participants. In one longterm care facility, there were arranged several moments for the interviews to take place: in this institution, the interviews were done in a quiet and private room where a computer, camera and speakers were. In the other two institutions, residents were interviewed on tablets, and they were reached by the research team at a designated time and day; the interviews took place in residents' private areas during peaceful times. This procedure, at these two institutions, was similar when residents met online with their family and friends (due to restrictions in visits during COVID-19). At the beginning of each interview the purpose of the study, its expected duration, and procedures were presented. Residents were informed about their right to decline or to withdraw from participation without any consequences. Moreover, participants were free to call for assistance in case of difficulties during the interview (e.g. connection difficulties, audio or video malfunctioning) or to end the interview whenever they needed.

# 4.7 | Data analysis

A thematic analysis was undertaken following Braun and Clarke's guidelines (Braun & Clarke, 2006), using NVivo 12. The familiarization with the data, the initial coding, defining and naming of the themes, and producing the report were initially done by the first author. The second author discussed and provided input on initial

coding, in reviewing and naming the (sub)themes, along with the first author, and provided feedback on how quotes were accurately attributed to themes/sub-themes and on data interpretation and report. Disagreements (e.g. [sub]themes names and quotes coding) between the coders were solved collaboratively in meetings, through discussion until consensus was reached. (Sub)themes were identified, using an inductive approach (features of [un]helpful painrelated support) and a deductive approach (drawing upon social support theories and constructs, e.g. elicited/received/available social support).

## 4.8 | Ethical considerations

The confidentiality of the individual files was kept all the time; therefore, any kind of personal information that was not central to the research object was not shared with the research team. Informed consent was obtained by (a) having provided a written form of the consent upon first invitation that was (b) read over at the beginning of the interview session with the first author, (c) clarifications were provided and (d) confirmation of consent to participate and to record audio and video was obtained by participants signing the written consent forms. Interviews were archived offline in a storage hard drive; participants and institutions were anonymized.

#### 4.9 | Rigour

To ensure credibility, discussions were held with participants and professionals on (sub)themes and their interpretations. As for transferability, we looked to warrant heterogeneity regarding participants and institutions (age, pain location, time at the longterm care). Regarding dependability, discussions with professionals (Personal Care Assistants and Psychologists) helped to confirm that certain features of the support provided might be related to how long-term care is globally managed and was not institution specific. As for confirmability, all interviews were digitally recorded and transcribed verbatim, and raw data, data reduction and extracts were kept.

# 5 | FINDINGS

#### 5.1 | Participants

Table 1 has a detailed description of the participants' characteristics. Participants (N=29; 7 men, 22 women) were aged between 66 and 100 years old (M=87.7), residing in 3 different long-term care facilities in Lisbon from 3 months to 12 years (M=3 years and 7 months). All participants suffered from chronic pain in multiple sites with a moderate to high level of interference with their daily life, locomotion, sleeping and mood.

E 1 Participants' sociodemographic and

NursingOpen

# TABLE 1 Participants' sociodemographic and clinical characteristics.

#	Sex	Age	Pain location	Time in LTCF
1	Woman	82	Head	10 years
2	Woman	85	Back and knees	1.5 years
3	Man	94	Legs	6 months
4	Woman	80	Low back and hands	1.5 years
5	Woman	88	Legs	3 years
6	Woman	87	Neck	3 years
7	Woman	89	All body	1 year
8	Woman	87	Heels and shoulder	12 years
9	Woman	84	Leg	2 years
10	Man	74	Leg	5 years
11	Woman	94	Abdomen	1.5 years
12	Woman	88	Shoulder, leg and knee	2 years
13	Woman	66	Hands and shoulder	1 year
14	Woman	88	Legs	3 months
15	Woman	87	Legs	2 years
16	Man	83	Muscles	7 years
17	Woman	86	Head	2 years
18	Woman	100	Leg	2 years
19	Woman	75	Back	2 years
20	Woman	95	Knee, spine	2 years
21	Woman	100	Leg, face, spine	3 years
22	Man	89	Leg, arms, lungs	3 years
23	Man	81	Ankle	2 years
24	Man	66	Feet, knees	2 years
25	Man	99	Legs and feet	3 years
26	Woman	95	Back	12 years
27	Woman	74	Legs	1 year
28	Woman	90	Knee, shoulder	3 years
29	Woman	85	All body	1 year

# 5.2 | Findings

Two main themes emerged: (1) effective support during a pain crisis and (2) effective pain-related support in daily activities.

#### 5.2.1 | Helpful support during a pain crisis

The first theme consists of helpful support, elicited and/or received, to reduce pain severity during pain flares. This theme unfolded into three subthemes. The first sub-theme: When in pain I ask for a pill—consists of verbal requests for pain medication to nurses when/while residents are in pain. The second—When available, massages and physiotherapy are great—consists of non-pharmacologic support received because of pain, mostly provided by physiotherapists. Both types of support were perceived as effective and received because of pain behaviours (verbal complaints and requests for medication). Finally,

6330

WILEY\_NursingOpen

concerning the third sub-theme—If I move around, I will feel better—it was identified as a helpful and preferred helping action, although not always available/offered. In this theme, there were no striking differences between men's and women's speeches. Only one man reported an episode of not being helped after asking for it during a pain crisis.

#### When in pain I ask for a pill

When in pain, residents requested pain medication verbally that effectively reduced their pain:

I ask for the pill, and they give me... and the pain goes away.

(#9 Woman 84)

Indeed, a third of participants reported asking for pills/medication when in pain. However, some residents reported delaying asking for medication until the pain was severe:

> I tell them that something is hurting, and then they give me a pain pill. But it is rare for me to complain. I only complain when the pain is really strong. (#7 Woman 89)

All reports on pharmacologic pain control indicate that medication is always provided by nurses, even if sometimes personal care assistants make the liaison between the resident and the nurse. Most of the reports show that receiving pain medication relies on residents' verbal elicitation (*I ask*), and one resident reported that they are encouraged to ask for it.

(...) they are always telling me that I need to ask (for pain medication).

(#6 Woman 87)

It is uncommon for residents to have medications with themselves, therefore taking pain medication (pharmacologic pain control) is totally dependent on interacting with staff. This lack of autonomy may be experienced along with feelings of loss of control over pain medication as expressed by one resident:

When I was at home, I had everything; now here, I have nothing. I do not have a pharmacy; I do not have anything. So, look, I just let it go.

(#15 Woman 87)

Nonetheless, a male participant shared an episode in which he asked for pain relief that was not provided, influencing his future intentions to express his needs:

Once at night, I was in pain and rang the bell. They came to me, and they did not give me anything (...) After that episode, I never asked for anything again. (#16 Man 85) When available, massages and physiotherapy are great Some participants reported receiving massages, heat application and physiotherapy sessions when in pain. This was reported as highly effective to reduce pain and highly valued:

> Since I started the physiotherapy, the pain improved a lot. (#5 Woman 88)

> It felt good. I thanked him so much. I was very grateful. (...) I felt so relieved by the help he gave me. (...) it was a good help.

> > (#6 Woman 87)

It seems that it is more demanding to provide non-pharmacologic pain relief, than medication, as it is more dependent on the institution's resources. Also, it is more dependent on staff availability and more time-consuming.

> If the physiotherapist is nearby, he gives me a special tummy massage. If he is not around, they would give me some pain pills

> > (#11 Woman 94)

That is up to them, from time to time they come to massage me and put on some patches

(#21 Woman 100)

Sometimes I get a massage here on my hip and knees with the gel

(#24 Man 66).

#### If I move around, I will feel better

One-quarter of participants referred to help with ambulation as a helpful and preferred support action:

Now my knee and leg hurt, and I've been walking with a walker. I have been walking and I am better (#9 Woman 84).

(...) I have rheumatism, I need to walk (...) for me, it is very important to move around

(#13 Woman 66).

A male participant, with severe locomotion difficulties, reported his will to move around to manage pain and the staff's unavailability is implicit in his speech:

> When I am in pain I try to walk around, but I cannot do it on my own. I get help to bathe and dress. However, when I am in pain, the help that I want is that they [staff] would help me to walk around [but staff does not do it] ... so the medication is good help

**NursingOpen** 

Such inner conflicts seem to be solved by residents accepting the 'just enough amount' of support to meet their specific needs. Indeed, participants' reports indicate a negotiation process between residents and staff that results in residents' 'shaping' the type and the extent of help to be provided: Due to my shoulder, it is more difficult to get dressed [but] I only ask for help to pull my pants up and not all the clothes. An expressive example of actively 'shaping' support is a female resident with knee arthrosis who felt unsafe standing while showering:

I told them [the staff] that I had never asked for help before and that I shower by myself and that I get dressed without help (...) I do all that, but I was afraid to stand in the shower! If I had a bar to hold on to. I would not need assistance to shower. Then I came up with the idea for them to install a shower grab bar, which they did. Still, they wanted to send someone to assist me during the shower, but I said 'no,' since now I have the bar.

(#20 Woman 95)

(#8 Woman 87)

These negotiation processes allowed residents to maintain their functional autonomy as much as they could. As many were fearful of functional dependence and felt pride in accomplishing daily tasks without help.

> With a little help. I manage on my own (#23 Woman 81).

> Partially I do not want to bother people, but I also feel that if I get helped, I will always need help and will not be able to do things on my own, so I do not stop ... It took me a lot to lift my arm to get dressed but I did it myself, I did not ask for help.

> > (#6 Woman 87)

Reports of staff rushing while providing support were frequent. Despite support being available, providing it in a rush (or portraying a sense of rush) conveys the opposite message, which might reinforce the sense of being a burden to others.

> They have a lot of things to do and people to take care of, they are always rushing.

> > (#15 Woman 87)

They have no time, they have a lot of work, and they do not have time to chat. Everything is in a rush. There are people here that are a lot worse than me.

(#14 Woman 88)

Once again medication is described as a last resort when other strategies are not available, but the first to be mentioned.

# 5.2.2 | Helpful pain-related support in daily activities

The second theme mostly refers to instrumental pain-related support received from personal care assistants, for activities of daily living because of pain interference:

> Due to herniated discs in the spine, I get a lot of pain and I cannot undress by myself, so they help me. (#2 Woman 85)

Two sub-themes have emerged. The first-from the bliss of the availability of support to the ambivalence towards receiving it—reflects the oscillation between the (positive) appraisal of perceiving help as available whenever needed; and the emotional ambivalence towards receiving support, related to residents' inner conflicts regarding needing/receiving help. The second sub-theme-good helpillustrates the helpful features of social support that make it more welcoming. Also in this theme, male and female participants did not present profound differences in their experiences. Nonetheless, in the second sub-theme (as in the first theme) only a man reported having asked for help with activities of daily living and not having received it.

From the bliss of the availability of support to the ambivalence towards receiving it

Perceiving support to be available when needed was generally associated with a sense of safety and empowerment:

> It feels nice, to know that someone supports us if we need it. (...) I am glad, I feel supported.

> > (#13 Woman 66)

However, most residents stressed that receiving support for activities of daily living was experienced with ambivalence. Residents experienced sadness and shame for needing support due to pain interference-as it negatively impacts their sense of autonomy. They also expressed gratitude for getting help.

> (...) My legs were hurting a lot. I had to ask [help to put on the socks]. I do not like to bother other people. I am a very active person. I want to do everything by myself. I get very sad about asking for help, but I had to. Pride would not get us anywhere. When they help me, I stay alright. I understand that I cannot reject their help because I need it, right? If someone helps me, I feel thankful and stay alright.

> > (#14 Woman 88)

# The good help

Some features of support made receiving help, for activities of daily living, more welcomed. These features were signalled by feelings of safety, relief and interpersonal connection. Being the same care provider facilitated accepting the support, because there is mutual knowledge, and it increases the responsiveness of care.

In general, it is always the same person, which makes it easier [to accept the help].

(#8 Woman 87)

Good help is described as sensitive and responsive to residents' needs. Support is also more welcomed when provided calmly and respectfully—which is also a form of responsiveness.

> Our body is not always the same. Because I was not like this. Now I have other needs and they are always ready. [...] She (...) is very patient with me, she waits for enough time for me to get ready

(#9 Woman 84).

Also, 'small talk' during care provision was perceived as highly satisfactory. It seems to provide a sense of normality, as it reframes the interaction by not focusing the attention on residents' pain and needs for help and stressing the strengthening of a trusting relationship between staff and residents.

I like that we chat about the weather if it is good if it is cold if there was traffic

(#8 Woman 87).

One man, who was recovering from a leg fracture, stressed that good help came in the form of collaboration. This notion of 'collaboration' implied reciprocity, and the active role of the resident in the interaction, which was perceived as empowering and optimistic.

I feel happy because it is a collaboration. We must face this 'scheme' in the best way.

(#10 Man 74)

In this sub-theme only, a man reported to have needed help and not getting it.

I sometimes ask, but some ladies turn a blind eye and go away and do not help.

(#24 Man 66)

# 6 | DISCUSSION

The present study explored the subjective and idiosyncratic experiences of long-term care residents with chronic pain-related interactions, with their formal caregivers. This paper brings new insights by adopting the residents' perspective and by looking, into this phenomenon, through the lens of social support.

# 6.1 | The experience of receiving pain-related social support: What kind of support is being received?

First, findings indicate that helpful support during a pain crisis consists of receiving pain medication from nurses, and non-pharmacologic strategies (such as massages, physiotherapy sessions, heat application and ambulation) mostly from physiotherapists. Pharmacological support was received upon explicit request, although some participants delayed reporting pain/help-seeking for pain relief until the pain was severe. This was consistent with other research on community-dwelling older adults where delayed help-seeking behaviour was associated with greater pain severity (Cornally & McCarthy, 2011). Reluctance to report pain, and to ask for medication, is common in long-term care residents, mainly because of medication concerns, stoicism, worries about staff reaction and perceiving staff to be too busy (Knopp-Sihota et al., 2019). Still, one participant referred to the lack of autonomy/control over having/ taking pain medication, compared to the time she was at home. This illustrates the 'power' of the institution over residents' daily life, which embodies an ageistic approach of residents not being able or willing to strive for autonomy (Wikström & Emilsson, 2014). Also, during pain crises, non-pharmacologic support for pain relief (massages, physiotherapy and ambulation) was much less offered than pharmacologic relief. This imbalance might be accounted for by a lack of awareness/resources for multidisciplinary pain treatment. Indeed, non-pharmacologic strategies are as cost-effective as pain medication and associated with better pain outcomes (Shropshire et al., 2018).

Secondly, findings show that *helpful pain-related support in daily activities* consists of residents receiving pain-related instrumental support for activities of daily living. This is an innovative result that stresses that people need help to deal with pain interference, beyond pharmacologic pain treatment (to reduce pain intensity).

# 6.2 | Caregiver-resident interactions: What makes pain-related social support (un)helpful?

First, *helpful support during a pain crisis* meets residents' needs and wants (e.g. requests for pain relief), as postulated by the optimal matching hypothesis (Cutrona & Russell, 1990). Second, pain-related social support is helpful when it is embedded in physical and emotional connectedness, which might explain the satisfaction with massages/physiotherapy. Indeed, the range of affective and relational meanings that come with the physical touch of the body to overcome the pain, may play a fundamental role in building a trustful connection with others, meeting a fundamental need for connectedness (Ryan, 2000).

The second theme-helpful pain-related support in daily activitieshighlights that perceiving pain-related support to be available in case of need was highly reassuring and satisfactory. Indeed, perceiving support to be available buffers the negative impact of stressors (e.g. pain-related physical disability) by boosting residents' self-confidence (Cohen & McKay, 2020). Conversely, receiving help with daily activities is with emotional ambivalence and some resignation around the idea of I need therefore I must accept it. Indeed, it is known that explicit help might be felt as disempowering and undermining, working best when the receiver is unaware of the help provided (Merluzzi et al., 2016). In addition, pain-related support was better accepted when the resident was in control of the extent of help received to accomplish daily activities autonomously despite pain. That is to say that helpful pain-related support warrants psychological and functional autonomy (Ryan, 2000). Indeed, reports indicate that residents can be the 'gatekeepers' of their functional/psychological autonomy. This was illustrated by participants' efforts to 'shape' received support. This 'shaping process' resembled a negotiation, in which the resident identifies his/her needs and informs the care provider about enough amount of help they need so they keep on functioning, autonomously despite the pain. This 'shaping process', in which the receiver plays a pivotal function, appears to be a guarantee that the support matches residents' needs. Contrary to ageist conceptions (Wikström & Emilsson, 2014), residents prefer support that promoted functional autonomy rather than functional dependence, as previous quantitative findings have indicated (Bernardes et al., 2017). Along with a few reports on staff's support for functional dependence, these findings are uplifting given the importance of support for functional autonomy in buffering the impact of pain intensity on older adults' pain-related disability (Matos et al., 2017). Other features were pointed out as facilitators of helpful support, namely when provided by the same person, calmly, responsively and attentively to the residents' needs. Present results suggest that residents strive for connection and intimacy with their formal caregivers. This may influence their pain outcomes, as validating and empathic responses to pain-related distress have been shown to build intimacy and connection in informal relationships (Cano & Williams, 2010).

Some female participants appraised positively the use of 'small-talk' (trivial communication not central to task completion) during care provision. 'Small-talk' can be interpreted as a distractive response, taking away the focus from pain and care. This kind of strategy can be emotionally uplifting, as it might induce the feeling of being in a familial and affective relationship. A noteworthy observation was that only women referred to the importance of 'small-talk' during care provision whereas, one male participant referred to the optimistic and empowering idea of receiving support as a *collaboration*. Hence, traditional gender roles and identities seem to be able to shape supportive interactions in long-term care. Women, by being more communal, focus on the relational dimensions of care, whereas men, being more agentic, focus on instrumental/ task-related dimensions (Samulowitz et al., 2018).

How support is provided also accounts for its unhelpfulness. 'Rushing' is unhelpful because it conveys the sense of being a burden, instilling a sense of incompetence, hence, eroding a fundamental psychological need that must be met for healthy functioning—feeling <u>Nursing</u>Open

competent (Ryan, 2000). Some participants justified staff rushing with them because others were worse or needed more than them. This resembles a cognitive self-enhancement strategy—downward social comparison. Appraising others' situations as worse is a way to feel better about one's situation (*it could be worse*) (Pomery et al., 2012), to cope with the negative affect associated with the sense of being a burden.

Finally, only two men reported not getting pain-related support when asked (medication and help with daily activities). Whether this is a spurious finding, or it reflects gender bias in pain care, is still to be pursued in future research. However, it is possible that gender role expectations lead caregivers to respond differently to men's and women's pain. Indeed, men are expected to display more stoicism and be more pain tolerant whereas women are expected to be more expressive (Samulowitz et al., 2018). Indeed, in the present study, female participants used more words to describe their experiences than male participants.

#### 6.3 | Strengths and limitations of the work

Present research brings novel contributions because, by taking the care receiver perspective, provides insights on enabling practices to inform formal caregivers' pain-related communication and helping behaviours. However, some limitations ought to be discussed to inform future research. First, although data saturation was reached after three waves of data collection, the interviews were guite short. This should be pointed out as a limitation since it might reflect difficulties in building a trusting relationship between the participants and the researcher. Ultimately this translated into short interviews and more focused communication. Even though online interviews have been appraised as cost-effective, user-friendly and a facilitator of rapport in gualitative research, it might account for this limitation. Thus, it is possible that having conducted online interviews with longterm care residents to collect sensitive information (i.e. their appraisals on received pain-related care) might have been counterproductive regarding depth and duration. Probably, with this population face-toface interviews would be a better choice in future research, which might lead to longer interviews and the emergence of new/deeper content. Second, participants were mostly women and the experience of receiving help might not be the same for men and women. It is possible that enrolling more men in this kind of research might bring new information that will allow us to further explore gender roles. Moreover, these findings must be understood as embedded in a sociocultural context that is characterized by a collectivistic culture, with (generally) low levels of formal education in the generation under study. This might account for a certain benevolence with caregivers and institutions that is reflected in our findings.

## 6.4 | Recommendations for future research

Future research could further explore gender-related dynamics surrounding pain-related care in long-term care facilities.

# 7 | CONCLUSION

Chronic pain is a growing and disempowering and disabling condition among older adults in long-term care. It is possible to improve the lives of older adults with chronic pain, by improving the provision of formal social support. Effective formal pain-related social support may contribute to maintaining older adults' health status and autonomy, ensuring a fulfilling and healthy aging process despite chronic pain.

# 8 | RELEVANCE FOR CLINICAL PRACTICE

Present findings can be translated to the context of long-term care of residents with chronic pain in three dimensions-(1) how residents can shape the support they need; (2) which kind of support should be provided and (3) how caregivers and organizations should provide pain-related support. These conclusions can be translated for clinical practice through the empowerment of residents' skills to be verbal on their needs, not only concerning what but also concerning how they need/wish to be helped. Also, there should be a time to discuss the support needed, residents' preferences and goals. Regular moments of discussion regarding needs, preferences and goals should lead to a 'shared prescription' of support to be provided, which would translate into more effective helping behaviours from caregivers. Moreover, caregivers should promote the resident's functional autonomy (help and encouragement to accomplish daily activities autonomously despite the pain); be empathetic and validating of the resident's needs, preferences and goals. This is important to provide tailored help that is well received and to build interactions that are safe and satisfactory. This would account for residents shaping the support to be received and would inform the caregiver/institution about what support should be provided and how. As the findings point out, caregivers' verbalizations about support availability and their readiness to help should be frequent. Finally, provider and organization-level interventions could be developed so that care provision could be done without portraying a sense of rush and residents' need for connectedness could be met. In this domain, management evaluations should be frequent to confirm if the time allocated for providing care is enough and if solutions should be found. Moreover, training regarding knowledge, attitudes and behaviours should be available to caregivers working with this population.

#### ACKNOWLEDGEMENTS

The authors wish to acknowledge the colleagues that provided input on the research design (Health4All research group at CIS\_Iscte), the professionals that contributed as consultants on the interpretation of the interviews and psychologist trainees that assisted with technical aspects of the research (i.e. interview transcriptions and conduction).

#### FUNDING INFORMATION

This work was supported by Fundação para a Ciência e Tecnologia [Science and Technology Foundation] [grant number CEECIND/00392/2017; UIDB/03125/2020].

#### CONFLICT OF INTEREST STATEMENT

None to declare.

# DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### ORCID

Marta Osório de Matos 🕩 https://orcid.org/0000-0002-6673-2082

#### REFERENCES

- Bernardes, S. F., Forgeron, P., Fournier, K., & Reszel, J. (2017). Beyond solicitousness: A comprehensive review on informal pain-related social support. *Pain*, 158(11), 2066–2076. https://doi.org/10.1097/j. pain.00000000001033
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101.
- Burns, J. W., Post, K. M., Smith, D. A., Porter, L. S., Buvanendran, A., Fras, A. M., & Keefe, F. J. (2018). Spouse criticism and hostility during marital interaction: Effects on pain intensity and behaviors among individuals with chronic low back pain. *Pain*, 159(1), 25–32.
- Cano, A., & de C Williams, A. C. (2010). Social interaction in pain: Reinforcing pain behaviors or building intimacy? *Pain*, 149(1), 9-11. https://doi.org/10.1016/j.pain.2009.10.010
- Cohen, S., & McKay, G. (2020). Social support, stress and the buffering hypothesis: A theoretical analysis. In *Handbook of psychology and health* (Vol. IV, pp. 253–267). Routledge.
- Cornally, N., & McCarthy, G. (2011). Chronic pain: The help-seeking behavior, attitudes, and beliefs of older adults living in the community. *Pain Management Nursing*, 12(4), 206–217. https://doi. org/10.1016/j.pmn.2010.12.006
- Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching.
- Fordyce, W. E. (1977). Behavioral methods for chronic pain and illness. LWW.
- Knopp-Sihota, J. A., Dirk, K. L., & Rachor, G. S. (2019). Factors associated with pain assessment for nursing home residents: A systematic review and meta-synthesis. *Journal of the American Medical Directors Association*, 20(7), 884–892.e3. https://doi.org/10.1016/j.jamda.2019.01.156
- Matos, M., Bernardes, S. F., & Goubert, L. (2016). The relationship between perceived promotion of autonomy/dependence and painrelated disability in older adults with chronic pain: The mediating role of self-reported physical functioning. *Journal of Behavioral Medicine*, 39(4), 704–715.
- Matos, M., Bernardes, S. F., Goubert, L., & Beyers, W. (2017). Buffer or amplifier? Longitudinal effects of social support for functional autonomy/dependence on older adults' chronic pain experiences. *Health Psychology*, 36(12), 1195–1206. https://doi.org/10.1037/ hea0000512
- Matos, M., Express, A., Gerais, T., Cidade, C., & Santa, L. (2016). Preço: Dados para pagamento. 5–6.
- Merluzzi, T. V., Philip, E. J., Yang, M., & Heitzmann, C. A. (2016). Matching of received social support with need for support in adjusting to cancer and cancer survivorship. *Psycho-Oncology*, 25(6), 684–690.
- Newton-John, T. R., & de C Williams, A. C. (2006). Chronic pain couples: Perceived marital interactions and pain behaviours. *Pain*, 123(1–2), 53–63. https://doi.org/10.1016/j.pain.2006.02.009

Pomery, E. A., Gibbons, F. X., & Stock, M. L. (2012). Social comparison.

Raja, S. N., Carr, D. B., Cohen, M., Finnerup, N. B., Flor, H., Gibson, S., Keefe, F. J., Mogil, J. S., Ringkamp, M., Sluka, K. A., Song, X. J., 

- Resnick, B., Boltz, M., Galik, E., Holmes, S., Vigne, E., Fix, S., & Zhu, S. (2019). Pain assessment, management, and impact among older adults in assisted living. *Pain Management Nursing*, 20(3), 192–197. https://doi.org/10.1016/j.pmn.2019.02.008
- Ryan, R. M. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *The American Psychologist*, 55(1), 68–78.
- Samulowitz, A., Gremyr, I., Eriksson, E., & Hensing, G. (2018). "Brave men" and "emotional women": A theory-guided literature review on gender bias in health care and gendered norms towards patients with chronic pain. *Pain Research and Management*, 2018, 1–14. https://doi.org/10.1155/2018/6358624
- Shropshire, M., Stapleton, S. J., Dyck, M. J., Kim, M., & Mallory, C. (2018). Nonpharmacological interventions for persistent, noncancer pain in elders residing in long-term care facilities: An integrative review of the literature. Nursing Forum, 53(4), 538–548. https://doi. org/10.1111/nuf.12284
- Sullivan, M. J. L., Thorn, B., Haythornthwaite, J. A., Keefe, F., Martin, M., Bradley, L. A., & Lefebvre, J. C. (2001). Theoretical perspectives on

6335

'II F \

Uchino, B. N., Carlisle, M., Birmingham, W., & Vaughn, A. A. (2011). Social support and the reactivity hypothesis: Conceptual issues in examining the efficacy of received support during acute psychological stress. *Biological Psychology*, *86*(2), 137–142.

NursingOpen

- Wikström, E., & Emilsson, U. M. (2014). Autonomy and control in everyday life in Care of Older People in nursing homes. *Journal of Housing* for the Elderly, 28(1), 41–62. https://doi.org/10.1080/02763893. 2013.858092
- Zee, K. S., & Bolger, N. (2019). Visible and invisible social support: How, why, and when. Current Directions in Psychological Science, 28(3), 314-320. https://doi.org/10.1177/0963721419835214

How to cite this article: de Matos, M. O., & Bernardes, S. F. (2023). Helpful social support for chronic pain in long-term care residents: "With a little help I manage on my own". Nursing Open, 10, 6326–6335. https://doi.org/10.1002/nop2.1881