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Chronic pain issue

Thomas Fuller
editor

The International Association for the Study of Pain (IASP) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey & Bogduk, 1994, p.212). Pain usually signals that immediate protective action is required to prevent further actual or potential injury. In the context of chronic pain, the cause of the pain is often unknown and it is often not apparent that further harm or damage is actually occurring to the body. Although there are many options for pain management, in many situations there is simply no cure for chronic pain. This is not information that people like to hear when seeking help for a condition that just will not go away.

Chronic pain has been specifically defined or described as pain that lasts longer than otherwise would be expected for a condition to heal (Bonica, 1953). Chronic pain – a symptom of conditions such as fibromyalgia, complex regional pain syndrome, headache, lower back pain - affects millions of people throughout Europe and the rest of the world (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Breivik, Eisenberg, & O'Brien, 2013; Fayaz, Croft, Langford, Donaldson, & Jones, 2016; Vos et al., 2012), and has an enormous personal, social, emotional and economic impact (Goldberg & McGee, 2011). You will notice that this definition of chronic pain avoids the often contentious issue of specifying how long “chronic” should be before considered “chronic” –some suggest three months, others six, and others simply that the pain has been present for longer than expected. In research contexts criteria concerning duration can be important for participant selection and subsequently for the synthesis of study results into systematic reviews and meta-analyses. For patients worrying about the distinction of time related criteria is less important. For them, the pain is part of a daily experience and if it cannot be cured, then the hope is to limit the interference in daily activities and mood (to name a few sequelae) by utilising interventions such as graded exposure.

A biopsychosocial understanding of chronic pain has slowly gained wider acceptance and has in essence been the main foundation on which cognitive behavioural interventions have been developed. Within this context, learning mechanisms e.g. operant conditioning (Fordyce et al., 1973) and models such as the Fear Avoidance Model, (Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen & Linton, 2000, 2012) have evolved and contributed to the application of, for example, exposure therapy for chronic lower back pain. The evidence base for psychological interventions has steadily grown over the past 20 years and features diverse study designs such as experimental single-case series (e.g. (de Jong et al., 2008; Flink, Smeets, Bergbom, & Peters, 2015), randomised controlled trials (Cherkin, Sherman, Balderson, & et al., 2016) and systematic reviews with meta-analysis (e.g. (Eccleston, Palermo, et al., 2014). In fact there is considerable evidence for the effectiveness of CBT for children and adolescents (Eccleston, Palermo, et al., 2014), adults (Williams, Eccleston, & Morley, 2012) and mindfulness for chronic low back pain (Cherkin et al., 2016) amongst others.

While there is evidence to indicate that pain related disability is redu0d by CBT .and mindfulness for low back pain respectively, the evidence base, effect sizes and effects on secondary (but related) outcomes such as depression, varies depending on the type/source of chronic pain. Similarly, the amount and level of evidence that exists for providing web-based CBT for chronic pain management is, while promising, also relatively limited (Eccleston, Fisher, et al., 2014; Garg, Garg, Turin, & Chowdhury, 2016). Some researchers have also noted a relative lack of qualitative research relating to chronic pain and argue that this can capture important elements of patients' experiences not otherwise captured by other study designs (Osborn & Rodham, 2010).

The articles contained in this issue of the European Health Psychologist reflect the diversity and richness of study designs and issues faced in chronic pain research. Kai Karos writes an evocatively titled review paper (Hell is other people: on the importance of social context in pain research) about social factors involved in the modulation of pain; Maria Karekla and colleagues introduces the ambitious Algea project; and, Beatriz and Sanchez explore the impact of chronic pain on sexual behaviour in a sample of Brazilian women living with Fibromyalgia.

Karos (this issue) draws attention to some of the key theories and models underpinning predominantly experimental research into social factors related to the experience and expression of pain – an area that appears rich in unexplored research hypotheses. A finding of particular interest and with clear clinical relevance relates to peoples' invalidation and stigmatisation of patients' pain. Other issues covered in the review concern the controversial topic of social pain and concept of justice in pain experience.

Karekla and colleagues in their article "In Search of novel and more effective psychological treatments for chronic pain: The Algea Research Project" describe five ongoing projects that aim to address different issues related to the assessment and treatment of chronic pain. Specifically, they discuss: the translation and validation of two well-known pain related questionnaires into Greek; a cross-sectional study examining theoretically derived mediating and moderating factors in the adaption to living with chronic pain; and, two randomised controlled trials testing interventions. The Algea project is still in development and addresses the important and often neglected issue of translating research findings into practical resources for psychologists.

From a review paper, to a large international collaborative project, this issue is bookended by a piece of qualitative research conducted and reported by Centurion and Peres - The impact of chronic pain on the sexuality of women with fibromyalgia: a clinical-qualitative study. Linking nicely with the review on how social factors can affect pain, Centurion and Peres also examine the role that partners of participants play. Although the study was conducted in Brazil, their findings and conclusions resonate with the recently revised European Guidelines for the assessment and treatment of fibromyalgia (Macfarlane et al., 2016).

Finally, for interested clinicians and researchers there is a wide range of resources available from the IASP http://www.iasp-pain.org/index.aspx. To name a few, the resources include: educational materials, measurement scales, information about grants and funding opportunities, professional membership and clinical guidelines.

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commentary

Hell is other people: On the importance of social context in pain research

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The Social in Biopsychosocial

Pain is a universal form of human distress and functions to protect the body from harm. It is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (IASP, 1994). Despite its protective function, pain can persist beyond healing time and become chronic. Chronic pain has become a major public health concern worldwide, with an estimated 19% of European adults suffering from chronic pain (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006). Chronic pain has a destructive impact on psychological and physical well-being, often resulting in unemployment and deteriorated social functioning (Hadjistavropoulos et al., 2011).

Despite the great burden that pain poses, it frequently remains unrecognized, underestimated and undertreated (Craig, 2009). Clearly, a better understanding of factors that can modulate pain is vital to develop new treatments or improve existing ones. The biopsychosocial perspective on pain is widely accepted as a framework to better understand both acute and chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Hadjistavropoulos et al., 2011). While research into the biological underpinnings of pain has long dominated the field, there is an increased understanding of psychological processes that modulate pain such as cognitive appraisal (Moseley & Arntz, 2007; Vancleef, Peters, & De Jong, 2009; Vlaeyen & Linton, 2012), motivation (Claes, Karos, Meulders, Crombez, & Vlaeyen, 2014; Van Damme, Crombez, & Eccleston, 2008) and mood (Hanssen, Peters, Vlaeyen, Meevissen, & Vancleef, 2013).

However, although pain is subjective and personal, it always occurs within an interpersonal context. Pain is continuously communicated to and perceived by others (e.g., clinicians, family, and strangers). Yet, research into social factors modulating pain is sparse. Most research has focused on the role of social support, which has been shown to alleviate both experimental and clinical pain (see Brown, 2003 for a review). Although social context can be a source of strength and resilience, it can also be a source of threat and dysfunction. In other fields, threatening interpersonal experiences have been linked to increased psychopathology and decreased physical health (e.g., Gini & Pozzoli, 2009; Williams, 2007). Considering that patients suffering from chronic pain are frequently confronted with distressing social interactions (e.g., invalidation, ostracism, stigmatization) (Sullivan et al., 2008; Waugh, Byrne, & Nicholas, 2014) it is crucial to understand how pain and social context interact.

To this end, the present narrative review will highlight research that has investigated the effects of threatening interpersonal interactions and their modulation of pain-relevant outcomes. In addition, possible future directions and gaps in the current literature will be discussed.

Theoretical Considerations

The leading model describing the complex dynamics of pain in an interpersonal context is the social communication model of pain (Craig, 2009; Hadjistavropoulos et al., 2011), which primarily focuses on how pain is encoded and decoded in an interpersonal environment. The model states that each step of the pain communication process – the experience of pain, the encoding of pain into behavior, and the decoding of pain behavior by others – is subject to biological, psychological, and social influences. While this model has highlighted the importance of social context in pain research in recent years, it does not create specific, testable hypotheses of threatening social contexts. Other models, such as the communal coping model (CCM) of pain catastrophizing (Sullivan, Martel, Tripp, Savard, & Crombez, 2006; Sullivan & Adams, 2004) link pain behavior to specific personality characteristics, but again do not incorporate the importance of different social contexts and their effect on actual pain experience. A recent meta-analysis proposed a free energy framework to the study of social context in pain (Krahé, Springer, Weinman, & Fotopoulou, 2013). According to this view, the interpersonal context serves as a predictive signal of contextual safety or threat and influences the salience of (painful) stimuli within that context. In the context of this review, the model would predict that a threatening social context might signal increased salience and threat of pain, thereby increasing pain sensitivity.

In sum, while there are several theoretical accounts highlighting the importance of social context in pain research, specific theoretical predictions about the effect of a threatening social environment on pain are currently lacking.

Invalidation and Stigmatization

Patients suffering from chronic pain frequently report experiencing invalidation by others, including family members and clinicians (Kool et al., 2010; Waugh, Byrne, & Nicholas, 2014). Especially because chronic pain is often paired with lack of physical pathology and / or medical explanation, patients are often confronted with suspicion or even allegations of malingering. Paired with the finding that pain is commonly underestimated by others (Kappesser, Williams, & Prkachin, 2006), patients suffering from chronic pain frequently experience hallmarks of stigmatization such as alienation, social withdrawal and discrimination.

How do such experiences affect pain? Perceived stigmatization and invalidation were shown to be related to lower self-esteem, decreased pain self-efficacy, decreased perceptions of control over pain and greater tendency to catastrophize about pain (Waugh et al., 2014). Another series of studies (De Ruddere et al., 2011; Ruddere, Goubert, Stevens, Amanda, & Crombez, 2013) found that pain in the absence of a medical explanation was associated with less likability of the patient and increased suspicion for deception, which in turn lead to invalidation of the pain. In sum, such responses might further alienate patients, impede rehabilitation and lead to improper treatment of pain, further escalating the problem.

“Social Pain”

Another line of research has investigated the effect of social exclusion on the experience of pain. In a typical paradigm, participants are socially excluded, for instance using the cyberball paradigm (Williams & Jarvis, 2006) and subsequently have to undergo a pain task (e.g., a cold pressor test). An influential study by Eisenberger, Lieberman and Williams (2003) showed that the experience of social exclusion activates similar brain areas as the experience of physical pain. The authors interpreted the findings as evidence for psychophysiological overlap between physical pain and “social pain,” a term which has raised some controversy (for a review, see Eisenberger, 2015). Nevertheless, several studies have found that experiences of social exclusion can in fact influence the perception of pain and vice versa: Patients suffering from chronic pain seem to be more sensitive to experiences of exclusion, and those who are more sensitive to experiences of exclusion report more somatic symptoms, including pain. Moreover, experiences of early social trauma are associated with greater likelihood to experience physical pain later in life. For example, being a victim of bullying leads to psychosomatic and psychosocial health problems (Fekkes, Pijpers, Fredriks, Vogels, & Verloove-Vanhorick, 2006). Additionally, an experimental study showed that experiences of social exclusion lead to increased pain sensitivity (Bernstein & Claypool, 2012).

Taken together, these studies show that negative social interactions can directly affect the perception of physical pain, in the majority of cases increasing pain sensitivity. These findings are especially relevant for clinical practice, considering that many patients suffering from chronic pain experience alienation and ostracism on daily basis.

Intentional Harm and Perceived Injustice

In some cases, pain might be the result of (un)intentional harm by others. Torture and direct aggression are extreme examples of intentional harm, whereas injury following someone else's negligence or error (e.g., a car accident) would be considered unintentional harm. There is experimental evidence that intentional harm by someone else leads to increased pain severity compared to unintentional harm (Gray, 2012; Gray & Wegner, 2008) and seems to make the pain more threatening (Karos, Meulders, Goubert & Vlaeyen, in prep). One study even found that while intentional harm increases pain reports, actual pain expression is reduced, possibly creating a "double burden" for the sufferer: Increased pain perception, but also increased risk for underestimation of pain by others (Peeters & Vlaeyen, 2011).

The degree to which the sufferer experiences the pain to be just is also important. The experience of suffering as a result of another's actions are likely to give rise to the perception of injustice. An experimental study showed that recalling an episode of injustice negatively impacts pain and anxiety in the lab (McParland, Knussen, & Murray, 2016). Similarly, another study found that an experimental violation of justice resulted in elevated pain intensity, but only in participants with high just world beliefs (Trost et al., 2014). Cross-sectional studies in clinical settings also support this conclusion: Perceptions of injustice following a traumatic injury were related to greater pain intensity, depression and PTSD symptoms (Trost et al., 2015) and to increased pain catastrophizing, fear of movement and depression. Interestingly, perceived injustice also predicts poor rehabilitation and prolonged work disability (Sullivan, Scott, & Trost, 2012).

In conclusion, intentional harm results in more severe perception of pain than unintentional harm. In addition, pain can be perceived as unjust, including but not limited to cases of intentional harm by others. If pain is perceived as unjust, pain is perceived as more severe and rehabilitation is hampered.

Conclusion and Future Directions

Based on the limited research, we can conclude that social context impacts both pain-related and pain-unrelated constructs which are clinically relevant. First, a threatening social context detrimentally affects pain-related outcomes: Pain is perceived as more severe and threatening, rehabilitation from pain is impeded, work disability is extended and catastrophic thinking about pain increases. Second, social context also impacts pain-unrelated constructs that are clinically relevant. In particular, a threatening interpersonal environment increases the risk for general psychopathology such as depression, anxiety and PTSD. In addition, negative social experiences such as trauma and bullying can become risk factors for chronic somatic illness later in life.

Clearly then, pain research and clinical practice should consider interpersonal factors when studying and treating pain. Especially in clinical practice there is an increased need to create a safe and validating environment for patients that facilitates understanding and recovery from pain, rather than leading to a vicious cycle of alienation and psychological and physical deterioration of health. Acknowledging the effect that social context can have on pain appraisals, clinical practice should harness and incorporate these mechanisms into treatment by identifying dysfunctional social environments and transforming them into a source of support and resilience. Moreover, for pain scientists, greater attention should be devoted to contextual factors that shape an individual's pain experience and communication, be it social, motivational or otherwise (Wiech & Tracey, 2013).

Where do we go from here? There is still a long way to go. Research into social factors modulating pain is still in its infancy. We begin to understand that social experiences might play a crucial role in the development and maintenance of chronic pain complaints (Fekkes et al., 2006; Karos, Meulders, & Vlaeyen, 2015) and that they can facilitate or impede recovery from pain (Sullivan et al., 2009; Trost et al., 2015). One important direction for continuing this line of inquiry is the development of a theoretical model encompassing the social context in pain experience. Such a model should engender specific, testable predictions regarding social modulation of pain that take into account the diverse and often complex interactions between various contextual demands and individual differences and predispositions. A first step might be to incorporate contextual factors into existing models of chronic pain such as the fear-avoidance model (Crombez, Eccleston, Van Damme, Vlaeyen, & Karoly, 2012), pain communication models (Hadjistavropoulos et al., 2011) or evolutionary accounts of pain (Williams, 2016). An additional direction for future research concerns the development of a theoretically-based taxonomy of different kinds of social contexts. Such a taxonomy can help to organize various social contexts in terms of theoretical mechanisms (e.g., the personal needs that are threatened, their effect on motivational processes etc.) and highlight similarities and differences between different contexts. Ultimately, it should be our goal to predict which factors in the social domain facilitate recovery and resilience and which ones impede it.

Despite the aforementioned challenges and the complexity of the task, it should be clear that pain is both an intra- and interpersonal experience and if we are to fully understand and successfully treat it, we require an understanding of both those facets and their interactions.

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original article

In Search of Novel and More Effective Psychological Treatments for Chronic Pain: The "Algea" Research Project

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The aim of this paper is to present the objectives and current state of an ongoing multilevel collaborative research project for the study of pain. "Algea", the pain and suffering deity in ancient Greek mythology, was the name given to this project, which aims to investigate critical factors involved in the experience of pain, and suffering. Moreover, the project will examine the effects of a novel approach to treatment based on Acceptance and Commitment Therapy. This is a collaborative project between the University of Cyprus, the University of Crete, and the Cyprus Institute of Neurology and Genetics. Algea is the first systematic effort to examine pain related parameters and evaluate a novel therapeutic approach aimed at alleviating the suffering and interference in living experienced by individuals with one or more chronic pain conditions (e.g., rheumatoid arthritis). The specific objectives of the "Algea" project include: a) understanding the contributing factors involved in the experience of pain in individuals with chronic pain (CP) conditions, their dyadic interactions with their partners, and differences with individuals suffering from other chronic illnesses not involving pain; b) designing a culturally sensitive intervention based on new empirical findings stemming from third-wave CBTs for use in clinical settings (i.e., CP organizations, CP rehabilitation and outpatients units, etc.); c) evaluating via randomized clinical trials the acceptability and effectiveness of this intervention especially in reducing suffering, interference of pain and medical utilization in various chronic pain conditions; d) training interested health professionals in this new approach and widely disseminating it into clinical settings; and e) translating the intervention into a digitally-based intervention so as to be more accessible and reach a wider audience of CP sufferers.

The project employs an integrative bio-psychosocial and functional contextualistic perspective (theoretical view emphasizing "the importance of predicting and influencing psychological events (including thoughts, feelings, and behaviors) with precision, scope, and depth, by focusing on manipulable variables in their context"; Hayes, Barnes-Holmes, & Roche, 2001) by focusing on alleviating suffering and the full range of social and psychological consequences involved in the experience of pain (Turk & Gatchel, 2002). To this end, the project assimilates previous illness adaptations models, such as Leventhal's self-regulation model (Leventhal et al., 1997), with more modern frameworks, such as the Psychological Flexibility model (McCracken & Morley, 2014) and the therapeutic approach of Acceptance and Commitment Therapy (ACT; Hayes et al., 2011). The ultimate goal of the project is not the direct reduction of pain symptoms but instead the facilitation of better pain adjustment, less suffering and life interference associated with CP (see McCracken &Vowles, 2014, for a review). The resulting digitalized intervention aims to make use of innovations in technology and digitalized health care so as to deliver effective services to all patients who may have difficulty to attend traditional (i.e., face-to-face) treatment modes.

The Algea project (http://ucyweb.ucy.ac.cy/algea) aspires to create a more patient-centered care context in which Physicians, Clinical Health Psychologists, caregivers and/or significant others along with the CP sufferer, work collaboratively to achieve the common goal of better pain adjustment and living a valued life, even if pain is a reality.

To this end, five interrelated research studies comprised this project. The first study involved the Greek validation of various pain-related measures of interest to this project, including the Chronic Pain Acceptance Questionnaire (CPAQ; see Vasiliou, Karekla, Michaelides, & Kasinopoulos, 2017) and the Psychological Inflexibility in Pain scale (PIPS-II; see Vasiliou, Karekla, Michaelides, & Kasinopoulos, submitted). The second study investigated mechanisms related to CP adaptation. Specifically, it examined mediating and moderating factors drawn from third-wave CBT approaches (e.g. pain acceptance) between self-regulation related pathways (e.g. "illness representations–beliefs–pain interference") and adaptation to CP (e.g., physical and psychological functioning). It also compared CP patients with individuals suffering from other chronic conditions not involving pain (e.g., respiratory or cardiovascular problems) on the various constructs of interest (e.g. pain coping responses) so as to gain a better understanding of the pain experience and its mechanisms. Further, it examined the CP dyad "patients-spouses interaction" and its impact on the CP experience. Results from these studies will contribute to the tailoring and improvement of existing treatments for the management of CP and its resulting consequences.

Studies III, IV and V included the development of new treatment protocols developed from the findings of the previous steps and based on third-wave CBT approaches. These studies included randomized control trials (see clinical trials.gov registry reference: NCT02734992) in order to: a) examine the effectiveness and efficacy of these protocols across different pain conditions (e.g. rheumatoid arthritis, migraine headaches etc.); b) explore the proposed mechanisms of change (i.e., those stemming from the psychological flexibility model) in mediating the resulting outcomes. In the process of conducting these trials, numerous health and mental health care providers received training and supervision in working and delivering such interventions.

The treatment protocols, which were developed for the purposes of our studies, followed recent research evidence suggesting that attempts at modifying internal pain related experiences (e.g., thoughts, feelings, sensations) in order to achieve pain alleviation are only short-lived and may in the long-run lead to more pain and suffering (see McCracken & Vowles, 2014). Acceptance and Commitment Therapy, employed in the creation of the specified protocols, targets valued based living via the acceptance of all internal pain-related experiences and regards them for what they are (e.g., see thoughts as thoughts, "I have the thought that my pain will get worse if I go out") and not for what the person believes they may be (e.g., thoughts as the absolute truth, "I am sure that my pain will get worse if I go out, so I better stay home"). Techniques utilized included mindfulness, acceptance, cognitive defusion, self-compassion, values exploration, and committed action.

Even though the division 12 of the American Psychological Association (APA, Division 12, 2012) recommends ACT for CP as an empirically supported treatment for the management of general CP conditions, very few RCTs exist to investigate ACT and compare it to other treatments and only a handful of trials have been conducted for specific categories of chronic pain (e.g. chronic headaches). Even fewer studies exist that examine the specific mechanisms of action implicated in treatment outcome findings. As a way to expand this literature, studies III & IV examined not only the effectiveness of the proposed approach in achieving valued living with chronic pain, but it also examined the mechanism involved in any noted treatment change. Given the dearth of ACT based studies for the management of head pain, despite ACT being considered an empirically supported treatment for headaches, Study IV examined the efficacy of an ACT-based intervention for patients with primary headaches in a randomized clinical trial (clinical trials.gov registry reference: NCT02734992).

Finally, Study V involves the development and implementation of an online web-based intervention and a smartphone application, named "ALGEApp" (www.algeapp.com, in Greek). CP patients are faced with surmountable problems, such as dexterity issues, lack of access to specialized care centers, mobility difficulties, financial barriers, and even the cultural stigma of seeking psychological treatment in remote areas or small communities. The development of focused digitalized (web-based) psychological interventions, especially when these are grounded in solid theory and empirical evidence, can be of particular use for CP sufferers as they may promote behavioural changes and facilitate CP management (Brouwer et al., 2010; Brug et al., 2005; De Nooijer et al., 2005; Cuijpers, Straten, & Andersson, 2008).Very few studies have so far investigated the effectiveness of web-based ACT interventions on CP management (Buhrman et al., 2013; Trompetter, et al., 2015). Also, none of these programs have utilized the Persuasive System Design (PSD) methodology in creating attractive content that would capture the user and aid in treatment engagement, which was a major aim of this study. Thus, we believe that an intervention such as the “ALGEApp” promises great potential for users who will be able to conveniently access effective material on demand and at their own time, location, and pace.

In conclusion, the Algea project aims to build a new patient-centered environment for the management of chronic pain aiming at valued living (i.e., living in according to ones’ stated values (e.g., having close and loving relationships) even when pain is present) in all pain sufferers. Currently, the data from studies I and II, which are completed, are being analyzed and the initial findings are submitted for publication. The intervention studies (studies III – V) are still under way and soon we will have the first results. Our hope is that in the near future we will be able to conclude the entire Algea project and present the final findings and outcomes of this endeavor.

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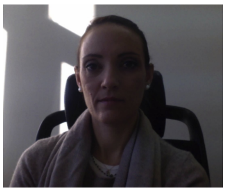

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original article

The impact of chronic pain on the sexuality of women with fibromyalgia: a clinical-qualitative study[1]

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Fibromyalgia is a rheumatologic syndrome characterized by the presence of chronic, non-inflammatory and widespread musculoskeletal pain, predominantly affecting middle-aged women. It is generally accompanied by memory, attention, mood and sleep disorders, as well as fatigue and headaches. According to the criteria proposed by the American College of Rheumatology (ACR) in 2010, its diagnosis is based on the presence of the following conditions for more than three months: (1) pain in at least seven out of 19 pre-established anatomic sites, while the patient has to score at least five points on a scale of associated symptoms – among which are depression and anxiety – or (2) pain between three and six sites and at least nine or more points on the scale of associated symptoms (Wolfe et al., 2010).

Considering that chronic pain is the primary symptom of fibromyalgia, there is an expectation that it will affect the sexual lives of patients. We performed a literature review (Centurion & Peres, 2016) including empirical studies on the topic, and found that most of the studies report that fibromyalgia is associated with many sexual problems in women, including reduced sexual desire and satisfaction. The utilization of quantitative methodology and self-report instruments addressing sexual dysfunction were predominant in these studies, as exemplified by Blazquez et al. (2015), and Burri, Lachance and Williams (2014). Sexuality, however, has subjective aspects that are not easily be apprehended by the quantification of certain occurrences – related, for example, to the presence of symptoms of sexual dysfunction.

Therefore, qualitative research that focuses on sexuality from a broader perspective – this is, a perspective not limited to sexual dysfunction – can contribute to the advancement of current knowledge on this topic, as such data collection strategies allow participants to express themselves more freely and attempt to both describe and interpret the meanings held by fibromyalgia patients regarding sexuality. To our knowledge, there is only one previous qualitative study in this area, which was conducted by García-Campayo and Alda (2004) who found that decreased sexual desire was related to a fear of experiencing musculoskeletal pain after sexual intercourse. Thus, we conducted a qualitative study aiming to understand how women with fibromyalgia experience sexuality. This paper is part of this study and more specifically addresses the impact of chronic pain on sexuality from the participants' perspective.

Better understanding concerning the impact of chronic pain on patients' sexuality is still needed to support multidisciplinary interventions intended to address this problem more directly, a problem that is usually neglected or relegated to a secondary plan in therapeutic regimes (Bazzichi et al., 2012). Additionally, it is interesting to note that, according to updated guidelines for fibromyalgia management from the European

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[1] Support: Coordination for the Improvement of Higher Education Personnel (CAPES).

League Against Rheumatism (EULAR), treatments should be tailored to the specific needs of individuals and involve psychological therapies (Macfarlane et al., 2016). These recommendations highlight the relevance of this paper's topic to a European audience.

Method

Research design

This study followed the assumptions of the clinical-qualitative methodology. Originally proposed in Brazil by Turato (2003), the clinical-qualitative methodology is defined as a refinement of qualitative methodology arising from the human sciences but directed to life experiences in health contexts. Also, according to Turato, the clinical-qualitative methodology favors the interpretation of meanings related to the health-disease continuum from the perspectives of patients, family members, or health professionals. Hence, as in any type of qualitative study, the researcher seeks to deepen understanding regarding the object of study in a specific social group, regardless of the numerical representation of participants.

Participants

Eight women who met the following criteria were included in the study: (1) having a diagnosis of fibromyalgia for at least six months; (2) being 40 to 60 years old, since the prevalence of fibromyalgia is higher in this age group; and (3) being literate, as participants were requested to write and then read to the group a story about a woman with fibromyalgia, in order to encourage them to express how fibromyalgia impacts their daily lives. There were no restrictions regarding social class, occupation, marital status, sexual orientation or any other aspects. Most were married, homemakers, and were 50 years old on average. Their level of education (from primary school to high school) varied and time since diagnosis ranged from 2 to 21 years. It is important to note that the participants composed a convenience sample and were recruited from a Brazilian non-governmental organization, Associação de Reumáticos de Uberlândia e Região (ARUR).

Data collection

The setting in which data collection took place was a psychoanalytic discussion group. This type of group presents the following basic characteristics: (1) meetings begin with some activity proposed by the coordinator – for example, a debate on the possible meanings of song lyrics that refer to the theme selected by the coordinator for that particular meeting – to induce associations, and at the same time, to limit the issue to be addressed; (2) has a time limitation; and (3) ideas are shared without any kind of judgment among the participants (Emílio, 2010). A total of four meetings that lasted approximately one hour and 30 minutes each were held on days and times scheduled according to the participants' availability. The meetings took place at the ARUR's headquarters and were audio recorded with the participants' consent.

Data analysis

The audio recordings were transcribed verbatim and analyzed afterwards according to the content analysis procedures recommended by Bardin (1979). Therefore, data analysis proceeded as follows: (1) free-floating reading – that is, an attitude in which none of the discursive elements are privileged a priori – was used to read data and establish initial hypotheses (pre-analysis); (2) data were grouped into preliminary categories (exploration of data); and (3) categories were established, latent and manifested content were differentiated and inferences were elaborated (treatment of results). The categories correspond to the grouping of the participants' reports, organized by the researchers using frequentist inference, based on numerical repetitions, or by categorical analysis, based on the identification of equivalences or similarities. In this study, we adopted the second. Note that from an epistemological point of view, content analysis is compatible with the clinical-qualitative methodology because it values the analysis of data from the participants' perspectives.

Results and Discussion

Various categories emerged from the content analysis. Considering this study's objective, only one category was addressed here, the one including reports that, directly or indirectly, refer to the impact of chronic pain on sexuality from the participants' points of view. We verified in these reports that this impact was considered invariably negative. For most participants, their pain significantly decreased sexual desire or even eliminated it entirely, as Excerpts 1 and 2, respectively, show. As a consequence, the participants reported they usually refuse to have sexual intercourse with their partners, as portrayed in Excerpt 3.

> Excerpt 1: "It changed everything [sexual desire after fibromyalgia] because [...] some days there's no stimulus, only pain; it sucks" (Participant S.)
>
> Excerpt 2: "I totally lost it [sexual desire]" (Participant R.)
>
> Excerpt 3: "Then you say [to the partner when he is interested in sex] 'would you go to sleep, for God's sake' " (Participant N.)

In general, the studies by Blazquez et al. (2015) and García-Campayo and Alda (2004) report similar results as they identify many women with fibromyalgia as presenting low frequency of sexual activity and high levels of sexual avoidance and also complain of marked decrease in sexual desire after syndrome onset due to chronic pain. This study's participants, however, indicated that despite the chronic pain, they would be more willing to have sex if their partners were more affectionate and attentive throughout the day, not just when they were interested in sex, as Excerpts 4 and 5 show.

> Excerpt 4: "[...] but I guess that, if it was done with love, you'd even have intimacy everyday, it's [...] good, but you don't get a little kiss during the day, you are not hugged [by the husband], but then at night, he wants to "screw"! Everything is going to hurt!" (Participant A.)
>
> Excerpt 5: "[...] During the day, there's no sign of affection, no attention, on the contrary, he fights with you, is mean to you for some reason. Then, at night he [husband] thinks you're ok (Participant N.)

This result is consistent with one of the conclusions reached by Burri et al. (2014), according to which dissatisfaction with the affective relationship stands out as the main predictor of sexual problems among women with chronic and widespread pain. The authors, however, do not clarify the reason for such dissatisfaction. Perhaps, this lack of clarification may be explained by the fact that only one question addressed this issue during data collection ("How satisfied are you with your current relationship?"). It is precisely in regard to current knowledge concerning this aspect that we believe this study can contribute. This is so because the aforementioned result suggests that the perceptions of women with fibromyalgia regarding their partners' behaviors is that their manifestations of companionship and affection, not related to sexual interest, may minimize the negative impact of chronic pain on sexuality.

Conclusions

Through the innovative utilization of a psychoanalytic discussion group as the setting of the data collection in a clinical-qualitative study on sexuality among fibromyalgia patients, the obtained results reveal that, from the participants' perspectives, the negative impact of chronic pain on sexuality may be minimized by factors that ultimately are related to the engagement of their partners in the affective relationship, such as spontaneous expressions of affection on diverse occasions. It is interesting to take this result into account when addressing women with fibromyalgia within the healthcare system, especially considering the EULAR updated guidelines for fibromyalgia management. Since the results reported here were collected from a very specific convenience sample, we are limited to naturalistic generalizations rather than statistical generalizations. We emphasize, however, that the use of more open data collection strategies stands out as potentially useful for new studies addressing this topic.

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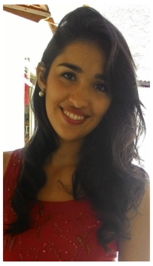

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commentary

United Nations University Dialogue: Exploring ties between science and policy making

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The United Nations University (UNU) of Tokyo is a global think tank functioning as a bridge between the international academic community and the United Nations institutions. The mission of the UNU is to contribute through collaborative research and education to finding innovative solutions to global issues of development and welfare that are of interest to UN Peoples and Member States. Throughout October the UNU, Tokyo organized a Sustainable Development Goals (SDG) Dialogue Series which I found particularly poignant given the current stage of the EHPS's relations with the Economic and Social Council (ECOSOC) at the UN. In April 2015 the EHPS was granted special consultative status which allows members of the EHPS-UN committee to actively attend UN/NGO meetings and discussions at the DPI and ECOSOC and connect with other professional psychological societies who are associated with the United Nations. However the EHPS is now at a stage where it's looking to contribute more actively by responding to policy recommendation calls and discussion panels such as the one announced for April 2017 "Promoting wellbeing in 21st century". In order to increase the effectiveness of our contribution it is important that EHPS communications reach both academic and non-academic audiences.

The Science, Policy & Capacity Building session brought together researchers and practitioners from different fields (behavioral science, engineering, policy research) to discuss how the 2030 Agenda for Sustainable Development and the Sustainable Development Goals can be translated into regional and national priorities in the Asia Pacific region. Regional organizations have been recognized as vital in reconciling the global vision of SDG-s with specific regional priorities. A coherent approach is necessary to address increasingly complex challenges (social disparities, climate change, health challenges). Over the course of the discussion panelists identified the lack of a effective science–policy interface and insufficient capacity as major challenges undermining integrated implementation of the SDG agenda.

There are several findings that the EHPS in its current position could potentially benefit from. Firstly, it's important to understand that the contribution of scientists in discussing and formulating SDGs should not end with the formulation of SDGs. Scientists' engagement is needed in implementation, continuous monitoring and reassessment of SDGs. Dr Katinka Weinberger, chief of the Environment and Development Policy Section of the UN Economic and Social Commission for Asia and the Pacific, has highlighted the issue of scientists engagement in SDG's and suggested that regional science-policy interfaces could be strengthened through, the creation of regional networks of academic institutions and think tanks. Secondly, Hein Mallee (Research Institute for Humanity and Nature) has stressed that the SDGs offer a unique opportunity for local and international science communities to reorganize their questions and research to complement an effort towards sustainable policies. Norichika Kanie (Keio University, UNU-IAS) concluded by emphasizing the role of regional nodes such as the Asia Pacific Forum – as a platform for science-policy exchange and at the same time calling for more research on the institutional landscape, including how informal networks of scientists can be linked to formal networks.

This dialogue series comes in the era of so called post fact politics mirroring growing distrust in institutions and policy makers [1]. WHO Chief Scientist representative to the EU, Roberto Bertollini emphasizes the following challenges for knowledge brokering: Evidence is not communicated effectively (wrong targeting); evidence is not available when policy makers need it and in a form that they can use it; policy makers lack the capacity to find and use evidence and lack opportunities to discuss system challenges with researchers. One way of addressing these challenges would be to include a new way of doing science that is solution oriented, holistic and closely involves stakeholders as partners at the research/action interface. Cooperation and joining forces is necessary in order to achieve the SDGs. Academia should be closely involved in supporting actions for sustainable development from measuring implementation to testing solutions and identifying risks. Integration of natural sciences with social and human sciences is important for policy making in order to evaluate the 'implementability' of policy options and to form well-rounded policy decisions that take into account the local cultural context. Additionally, the interdependence between SDGs (braking the 'silos mentality' to sustainable development) enforce an interdisciplinary scientific approach that would help identify critical trade-offs between policies targeting specific SDGs and would propose synergy solutions that could mitigate these trade-offs.

There is a widely accepted consensus that policy making benefits greatly from behavioral science. Whether policy-makers aim at changing behavior or designing better regulations, greater knowledge on how people are likely to behave and adhere to policy regulations is an obvious benefit. The UK government has pioneered connecting policy making with behavioral science in a formal way by commissioning the Behavioral Insights Team in 2010 to test public policy interventions through randomized control trials. Their research has demonstrated ways to increase tax compliance, home energy conservation, and charitable giving through social and behavioral inducements. The US Government went a step further when president Obama signed an executive order in 2015 directing federal agencies to incorporate more behavioral science into their activities and services by formally establishing a federal Social and Behavioral Science Team (SBST) (https://sbst.gov/) , a group of experts in behavioral science tasked with translating scientific findings into improvements in federal programs. In such a way federal agencies will have to develop, test and evaluate strategies for applying behavioral science insights to ease Americans' access to federal programs through such methods as simplified communications and options that are made clear and user-friendly. Health psychologists are an intricate part of this academic team as psychological science have a proven efficacy in tackling social sustainability and examining the psychological effects of globalization.

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