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Suffered life, hard life: adverse experiences in childhood of people with chronic musculoskeletal pain

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Vida sofrida, vida difícil: experiências adversas na infância de pessoas com dor musculoesquelética crônica

Vida sufrida, vida difícil: experiencias adversas en la infancia de personas con dolor musculoesquelética crónica

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ABSTRACT

Objective: To analyze the adverse experiences lived in the childhood by people with chronic musculoskeletal pain, based on psychoanalytic psychosomatics.

Methods: Qualitative research, developed with 20 people with chronic musculoskeletal pain and who were receiving physiotherapeutic treatment at a clinic in the countryside of the state of São Paulo. The data were collected during the months of June and July 2018, through semi-structured interviews. This article refers to one of the resulting themes of reflexive thematic analysis: Suffered life, hard life.

Results: When talking about their lives, people living with chronic musculoskeletal pain revealed themes associated with some adverse childhood experiences such as parental deaths, neglect, economic hardship, family violence, physical and psychological violence.

Final considerations: The analysis of adverse experiences lived in childhood by people with chronic musculoskeletal pain shows presence of intense suffering revealed in people's speech when associated with perceived physical pain.

Keywords: Patient-centered care. Psychosomatic medicine. Adverse childhood experiences. Chronic pain. Musculoskeletal pain.

RESUMO

Objetivo: Analisar as experiências adversas vividas na infância por pessoas com dor musculoesquelética crônica, com base na psicossomática psicanalítica.

Métodos: Pesquisa qualitativa, realizada com 20 pessoas com dores musculoesqueléticas crônicas e que estavam recebendo tratamento fisioterapêutico em clínica do interior do estado de São Paulo. Os dados foram coletados entre junho e julho de 2018 mediante entrevistas semiestruturadas. O presente artigo se refere a um dos temas resultantes de análise temática reflexiva: Vida sofrida, vida difícil.

Resultados: Ao falar sobre suas vidas, pessoas que vivem com dores musculoesqueléticas crônicas revelaram temas associados a algumas experiências adversas da infância como mortes dos pais, negligência, adversidade econômica, violência familiar, violência física e psicológica.

Considerações finais: A análise das experiências adversas vividas na infância por pessoas com dor musculoesquelética crônica demonstra presença de sofrimento intenso revelado na fala das pessoas ao associar com a dor física percebida.

Palavras-chave: Assistência centrada no paciente. Medicina psicossomática. Experiências adversas da infância. Dor crônica. Dor musculoesquelética.

RESUMEN

Objetivo: Analizar las experiencias adversas vividas em la infancia por personas con dolor musculoesquelética crónica, con base en psicosomática psicoanalítica.

Métodos: Investigación cualitativa, realizada con 20 personas con dolor musculoesquelética crónica y que estaban recibiendo tratamiento de fisioterapia en una clínica del interior de São Paulo. La recopilación de datos se llevó a cabo entre junio y julio de 2018 a través de entrevistas semiestructuradas. Este artículo hace referencia a uno de los temas emergidos del análisis temático reflexivo: Vida sufrida, vida difícil.

Resultados: Al hablar de sus vidas, las personas que viven con dolor musculoesquelética crónica revelaron temas asociados con algunas experiencias adversas de la niñez como muerte de los padres, abandono, adversidad económica, violencia familiar, violencia física y psicológica.

Consideraciones finales: El análisis de las experiencias adversas vividas en la infancia por personas con dolor musculoesquelética crónica demuestra presencia de sufrimiento intenso mostrado en las palabras de las personas al asociar con el dolor físico percibido.

Palabras clave: Atención dirigida al paciente. Medicina psicosomática. Experiencias adversas de la infancia. Dolor crónico. Dolor musculoesquelético.

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INTRODUCTION

Adverse experiences in childhood refer to experiences of abuse, neglect, violence, testimony of family violence, commercial exploitation, economic hardship, parental mental disorder, suicide attempt or death in the family, conflicting separation of parents and imprisonment of a family member. Such experiences are potentially traumatic and can interfere with the children's sense of security, bond and stability, especially if they occur between 0 and 17 years old, and these events can be emotionally painful, stressful and persist for years[1–2]. It is estimated that 62% of North American adults have experienced at least one adverse experience in childhood and approximately 24% have reported three or more experiences[3].

Chronic musculoskeletal pain in adulthood has been associated with adverse experiences that occurred in childhood. Physical and/or sexual abuse, in addition to dysfunctional environments, where various adversities can occur, are considered important precursors of chronic back and neck pain, headaches and pain caused by arthritis in adulthood[2,4]. Early loss or psychopathology of parents presented themselves as enhancers in the development of arthritis, low back pain, neck pain and any other type of chronic pain in adults[4].

It was observed that people who suffered simultaneously from various adversities such as physical and verbal abuse, threats, sexual assault and neglect were twice as likely to develop musculoskeletal disorders such as chronic back pain compared to those without child victimization experiences[5].

Early traumatic experiences, in addition to biological, genetic, cultural and social norms, are involved in somatic presentations even when symptoms are specific, such as localized pain, and these types of somatic presentations can be understood as expressions of authentic and personal suffering, regardless of whether or not they are described in medical terms[6]. In this sense, the recent suggestion that classifies chronic pain as a diagnostic entity and not just as symptom can reduce the stigma present in many cultures and, at the same time, cover those people who have chronic pain that do not fit into known etiologies and, thus, improving care for people living with these pains[7].

In the context of chronic musculoskeletal pain, the search for rapprochement between life history and pain may include a historical path from childhood that makes it possible to know, supported by theoretical constructions of psychoanalytic psychosomatics[8–11], subjective aspects of life histories and meanings for these pains from the perspective of the people who suffer these pains and, thus, start and conduct the therapeutic process of greater amplitude. Due to the privileged place of Nursing in the reception and initial evaluation of users of health services, this discussion is essential, enabling the construction of better and effective care plans for people living with chronic pain[12].

Thus, the aim of this study was to analyze the adverse experiences lived in childhood by people with chronic musculoskeletal pain, from the perspective of psychoanalytic psychosomatics.

METHOD

Cross-sectional study and qualitative nature anchored by the theoretical framework of psychoanalytic psychosomatics, with emphasis on the concepts of operative thinking, alexithymia and contemporary theoretical constructions that brought new contributions to the understanding of psychosomatic complaints and symptoms[8–11].

The research was developed in a physiotherapy clinic in the countryside of the State of São Paulo, linked to the Unified Health System (SUS), which performs an average of 3,000 consultations/month in many specialties. The reason for choosing this research site was due to the high number of people with chronic pain referred by the Basic Health Units. Thus, people were invited for convenience and selected through the inclusion and exclusion criteria. People aged 18 years or over who were undergoing physiotherapeutic treatment due to chronic musculoskeletal pain were included in the research. People with cancer disease or pain classified as neuropathic were excluded. To apply the inclusion and exclusion criteria, the researcher evaluated the patients' records.

After a first approach to the field to meet the clinic physiotherapists and talk about the research, the main researcher, who has a background in Physiotherapy, introduced himself, explaining that he was interested in deepening knowledge about people with chronic pain. Thus, 22 people were invited, but as one refused to sign the Free and Informed Consent Form (FICF) and another had to leave during the interview, 20 people participated in the study, who were identified by the letter P for participant, followed by Arabic numerals in the order of the interviews P(1) to P(20) in order to guarantee anonymity.

The script of semi-structured interview questions, prepared by the first researcher together with the last two authors of this study, was guided by the following questions: I would like you to tell me a little about yourself and your life so I can know you a little; What were the most memorable events in your life? Could you tell me when and how your pain started?

All participants authorized the recording of the interviews. After full transcription for further analysis, the statements were stored in HD by the researcher and the study supervisor, and the recordings on mobile devices were erased.

After five initial interviews with the purpose of verifying the coherence of the script, training and fine-tuning the researcher's contact with the participants, it was observed that there was no need for adjustments in the content of the questions. Thus, the proposed semi-structured script was maintained, and data collection took place between June and July 2018.

The single-meeting interviews took place face to face with the exclusive presence of the researcher and the participant, always in an isolated room. The interviews lasted between twelve minutes and forty-one seconds (12:41) to forty minutes and forty-nine seconds (40:49).

The delimitation of the number of participants in this study was determined by the saturation of meanings, by the discussion among researchers from the moment they considered that the collected data provided depth, richness and complexity that allowed a comprehensive understanding and that responded to the research objectives[13].

The methodological framework adopted for data analysis was reflective thematic analysis, an interpretive method that advocates both deep reflection on the collected data and the researcher's subjectivity during the coding process[14].

The first phase of the analysis provides a closer familiarization with the data, from data collection, interview transcription, reading and re-reading routines to a draft of initial ideas about what is suggested and what is interesting about these data. In the second stage, initial codes were generated, which identify a latent or semantic content from the data. After coding, done manually, the data are combined with each other. The next step involves classifying the initial codes into potential themes and grouping important parts into the themes under construction. The fourth step is dedicated to the refinement of themes, that is, some candidate to themes may not be, themes will have to be divided or even separate themes can be joined until a common pattern between the data of a theme is verified and there is clear differences between one theme and another[14]. As shown in figures 1, 2 and 3, there was a need to work until the researchers got a final thematic map.

The first configuration consisted of four themes and several subthemes.

In second configuration, the codes were grouped into three themes and subthemes.

After regrouping the codes, the final configuration resulting from the reflexive thematic analysis was composed by two themes and two subthemes.

In the next step, a new analysis was performed to identify the specificities and the story told by each theme. In the last step, vivid and convincing examples of the extract were chosen to produce an analysis report in relation to the research question[14].

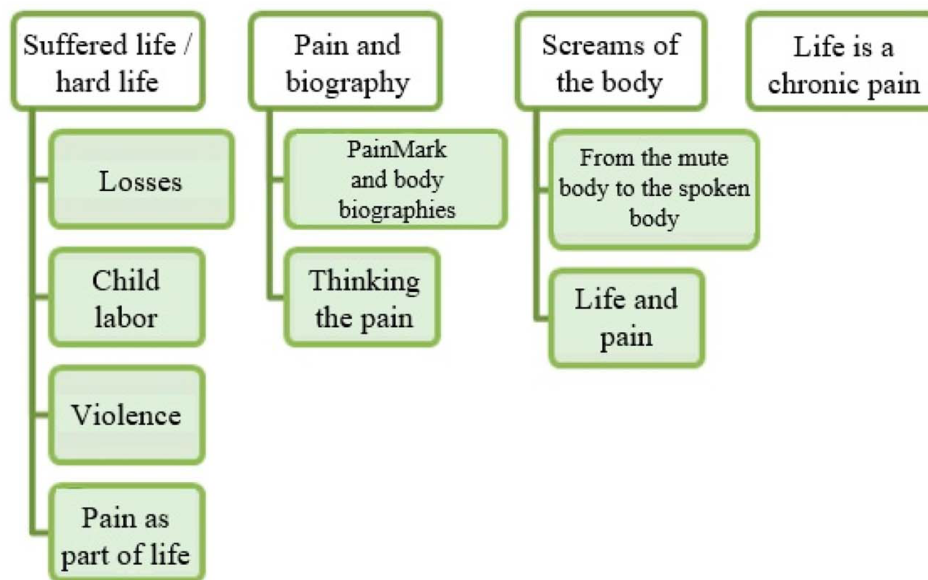

Figure 1 – Initial thematic map
Source: The Authors, 2018.

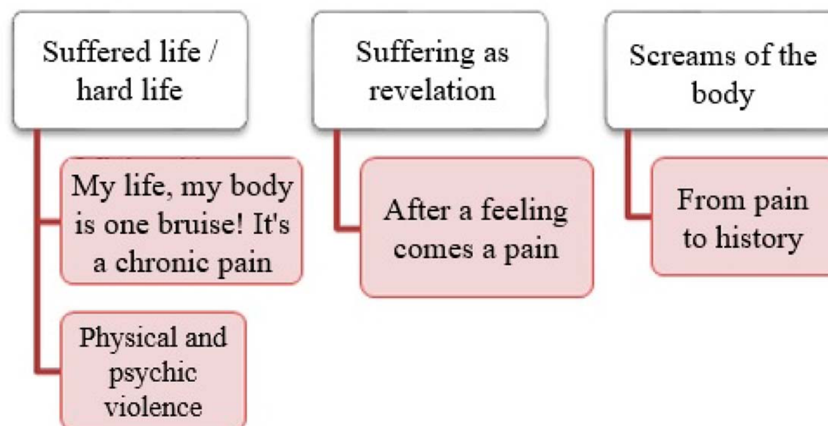

Figure 2 – Intermediate thematic map
Source: The Authors, 2018.

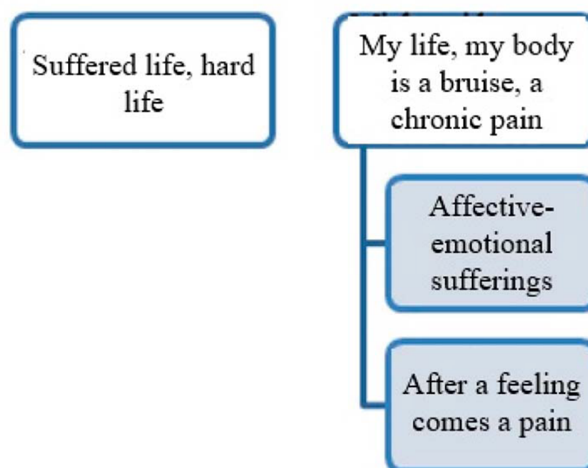

Figure 3 – Final thematic map
Source: The Authors, 2018.

All the process of data analysis was performed by the researcher together with the last two authors, seeking to carry out a richer reading of the data and a more homogeneous interpretation.

This research followed the national recommendations for research with human beings of the National Health Council. It was approved by the opinion nº 2,636,384 on 5/4/2018 by the Research Ethics Committee of the *Universidade Federal de São Carlos* (UFSCar).

RESULTS

Predominantly female (85%), participants had a mean age of 55.95 years, ranging from 18 to 82 years. In 60% of participants, pain had been present for at least 5 years. The profiles of the participants are shown in Chart 1.

From the reflective thematic analysis of the data, two themes emerged, however, this article refers to the first: Suffered life, hard life. It encompassed reports of physical efforts, heavy work, parental death, cases of physical and psychological violence, neglects, experienced in the family nucleus of origin expressed by the participants when they were invited to talk about themselves and their life trajectory.

Experiences of child labor as a way to help the family survive. Some participants recalled this period with resignation and acceptance, as something natural to the local way of life:

Participant	Gender	Age (years)	Occupation	Education	Marital Status	Diagnostic Hypothesis	Time of Pain
P1	F	71	Retired	Complete High school	Single	Bilat. Gonart.	+15 years
P2	F	74	Housewife	Incomp. Middle School	Widow	Hands Arthrosis	2-3 years
P3	F	47	Maid	Incomp. Middle School	Divorced	Spine Arthrosis	+ 3 years
P4	F	37	Cleaner	Complete High school	Married	Dorsopathy	10 years
P5	F	18	Student	Complete High school	Single	Scoliosis	1 year
P6	F	59	Reviewing and folding	Complete High school	Widow	Bilateral Gonarthrosis	6 years
P7	M	41	Warehouse Manager	Complete High school	Married	Pubalgy	11 months
P8	F	69	Retired	Incomp. Middle School	Widow	Bilateral Gonarthrosis	3 years
P9	F	64	Retired	Complete High school	Single	Bilateral Gonarthrosis	5 years
P10	F	62	Housewife	Incomp. Middle School	Married	Fibromyalgia	6 years
P11	F	63	Unemployed	Incomp. Middle School	Divorced	Low Back Pain	4 years
P12	M	72	Retired	Incomp. Elem. School	Married	Hip Arthrosis Left Hip.	6 years
P13	F	82	Maid	Complete Elem. School	Single	Low Back Pain and Left Shoulder Rotator Cuff Injury.	2 years
P14	F	62	Seamstress	Complete High school	Divorced	Cervical arthrosis and bilateral glenoum	4 years

Chart 1 – Profile of study participants. Ribeirão Preto/SP, Brazil, 2018

Participant	Gender	Age (years)	Occupation	Education	Marital Status	Diagnostic Hypothesis	Time of Pain
P15	F	32	Unemployed	Complete High school	Single	Left Patella Recurrent Dislocation.	14 years
P16	F	21	Administrative Assistant	Complete High school	Single	Scoliosis	10 years
P17	F	52	Withdrawn	Elem. School	Divorced	Fibromyalgia	13 years
P18	F	56	Withdrawn	Elem. School	Widow	Fibromyalgia	9 years
P19	F	74	Retired	Complete Higher Educ.	Single	Spine Arthrodesis and Fibromyalgia	28 years
P20	M	63	Retired	Complete Elem. School	Married	Bilateral Gonarthrosis	12 years

Chart 1 – Cont.
Source: Research data, 2018.

[...] I was eight, nine years old, fetched water from the dams, took some big barrels [...] at the age of twelve I took care of six nephews, fetched water from the cistern, washed clothes, made food, fed them, sweep the yard, then I went to the cerrado to fetch firewood[...] at the age of thirteen I came to the city to work as a maid and then my life went to work until four years ago. (P12 – 63 years – Low back pain – 4 years of pain).

[...] works, works and works a lot, always, since the age of fourteen! I really stopped studying to go to work [...] always helping father and mother[...] I carried a lot of weight, we always did that [...] I think my pain comes from all these efforts in my life! (P6 – 59 years – Bilateral gonarthrosis – 6 years of pain).

Some participants complained timidly while others highlighted suffering associated with feelings of dissatisfaction, displeasure, fear of violence and economic exploitation as described in the following statements:

[...] I had no leisure, I had nothing! I didn't study! I was never one to play with little friends [...] we had to help the parents, help take care of the house. From the age of seven, eight, I started working. (P13 – 72 years – Left Coxarthrosis – six years of pain).

[...] from the age of seven, my father put me to work. I had to pick up cotton, if I stopped, I was beaten [...] worked among the thorns, wearing flip-flops, without long pants [...] one day he took a hoe handle to beat me for a candy. I couldn't get anything [...] even when I was 16 years old, working as a maid, I had to hand over all the money to him. (P8 – 69 years – Bilateral gonarthrosis – three years of pain).

Experiences involving emotional, material, violence and negligence needs were also revealed:

[...]I had problems because I lost my father at the age of six [...] my mother had nine children. (P20 – 79 years – Spine Arthrosis and fibromyalgia – twenty-eight years of pain).

[...] I left when I was fourteen, I went to work in a family home [...] there were fights at home between father and mother [...] we always listened and was kind of scared! (P3 – 47 years old – Spine Arthrosis – more than three years of pain).

[...] my childhood was such a precarious childhood [...] at the age of 14, I had tuberculosis, I had to stay six months at the hospital, away from the family [...] since I was five years old, he (father) abandoned us! My older sister

who bore the responsibilities. (P9 – 64 years – Bilateral gonarthrosis – five years of pain).

[...] my childhood was practically alone, my mother had to work [...] the memories I have of him (father) is always drunk [...] with affection and fondness, then I don't have that! I didn't have from my father! (P7 – 41 years – Pubalgy – eleven months of pain).

[...] he's my cousin, we're practically brother [...] none of us has a father, they're actually gone [...] we don't want to know these days either! It was never missed in my life. (P5 – 18 years – Scoliosis – one year of pain).

Experiences involving the parent figure, such as alcoholism, early death and mental disorders, emerged:

[...] I lost my mother very early, I was very young [...] my father drank a lot, we had a lot of difficulty, a very suffered life when I was a child, of material things. (P1 – 71 years – Bilateral gonarthrosis, more than fifteen years of pain).

[...] since I was a kid I was raised by my grandmother. I had a mother, but she was a bit confused in the head, it doesn't matter if she had children or not! [...] my grandmother got sick, I went to live with a person she worked for who just raised me. (P14 – 82 years – Low back pain and left shoulder rotator cuff injury. Two years of pain).

Several adverse experiences such as neglect, economic hardship, family violence, physical and psychological violence experienced simultaneously:

[...] I had no contact with my father, nor his relatives [...] at the age of 15 he suddenly appeared [...] he didn't pay child support, he was arrested. We went through a lot of difficulties, what we earned was not enough [...] I was four years old or so, his hand (stepfather) closed in my face, my mouth started to bleed [...] he said that if we stayed there, he would kill everyone. (P17 – 21 years old – Scoliosis – ten years of pain).

The interview allowed the participants to talk about important situations in their lives that were accompanied by emotions and feelings.

DISCUSSION

The look at people living with chronic musculoskeletal pain from the perspective of psychosomatics seeks to rebuild bridges, so often lost, between psychic and body expression[15].

In the statements about themselves and their lives, the participants of this study revealed several adverse experiences that happened in childhood. Many initial statements referred to childhood work experiences which, although meeting the family's economic needs, also seemed to have caused suffering such as the suppression of childhood experiences such as playing, having friends, and even preventing them from attending school. In some reports, these experiences represented a burden, due to the obligation, feelings of injustice and economic exploitation. Others revealed experiences of parents' death very early, triggering emotional and/or economic suffering, as well as experiences of parents who left the family, imprisoned parents, neglects, including with the health care of their children, fights between parents, children who suffered physical and psychological aggressions from an early age, parents without mental conditions to care for their child.

It must be considered that such results are repeated in the literature for the context of chronic diseases; one study sought to describe the prevalence of exposure to adverse childhood experiences and the risks of chronic illness and disability in 53,998 people with chronic illnesses in the United States. It was identified that 60% of respondents experienced at least one adverse situation in childhood. In addition to the high prevalence, the chances of reporting several chronic conditions increased proportionally to the number of adversities experienced in childhood. The authors concluded that the risk for chronic diseases and disabilities can be as early as childhood[16]. A scope review demonstrated that risk factors for the development of cancer, such as obesity, smoking and alcohol abuse, are related to adverse childhood experiences[17].

It is important to highlight that recently the IASP (International Association for Study of Pain) published the new concept of pain as "an unpleasant sensory and emotional experience, associated or similar to that associated with an actual or potential tissue injury". Complementary notes point out the need to assess pain holistically, where each life experience can influence the biopsychosocial sphere and the perception of pain; the authors also emphasize that personal reports must be always respected[18].

Although we did not use instruments to quantitatively assess the presence of alexithymia in the participants of this study, it was observed that, when talking about their pain and their lives, emotions were expressed and feelings were identified and communicated[8–9] which perhaps allows us to to infer that, at various times during data collection, operative functioning and alexithymia were not present.

Adverse events that occur in childhood, such as family violence, generate excitement that, by surpassing the child's ability to psychically elaborate or tolerate such events, produce unbearable thoughts and fantasies that can be manifested through somatization[11,15]. Such aspect reinforces the importance of building safe and stable environments for children[17].

Associated with the understanding that behind somatization there may be a lack of ability to deal with adverse experiences, new psychoanalytic theoretical constructions on psychosomatic issues have considered that somatic presentations themselves can be seen as manifestations of a hidden history of the subject's life which, until then, was unable to be represented, for himself and for someone else, so the (re)construction of this lost history could help make sense of somatization[19].

Without excluding biological aspects, psychoanalytic psychosomatics also considers the interest in the subjective aspects contained in the particularities of the person's life, the remarkable events, affection, and the valuation of the bond. Thus, affection and subjectivity should not be dissociated from the patient's discomfort and physical suffering[20].

Therefore, when describing their significant experiences lived from the initial family nucleus, it is imperative that these stories and the stories of their sufferings, physical and/or psychological, are listened to, respected and also, that a space for closer human relationship be built where this listening and the affections present are welcomed[20].

In the analysis of the study results, it should be considered as a limiting factor that the participants were selected in a single institution, in which users of the Unified Health System (SUS) are exclusively assisted, which incurs in a very specific context, and there should not be a generalization of the conclusions brought here.

The fact that the participants were selected from a single institution, in which users of the Unified Health System (SUS) are exclusively attended to, is a limitation of this study, as it can determine a very specific context.

FINAL CONSIDERATIONS

The analysis of adverse experiences lived in the childhood by people with chronic musculoskeletal pain demonstrates the presence of intense suffering revealed in people's speech when associated with perceived physical pain. The present study reveals the possibility that adverse childhood experiences may have negative impacts on psychological and somatic health in adulthood, including regarding chronic pain.

This study suggests that health professionals should consider the life history of people with chronic musculoskeletal pain and their possible suffering when conducting the therapeutic process, in addition to only the objectivity of symptoms.

It must be highlighted the prominent role of the nurse in this process, a professional who often performs the initial reception in primary health care. Thus, Nursing can present itself as an active agent of excellence in the care of these people, whether in assistance, care management and teaching. In the first, the nurse must include in their care process the collection of data on the life history of these people; listening, by itself, already enables a therapeutic alliance and is a space for healing, in addition, it enables the nurse to assess pain through the biopsychosocial model, and with that, to plan care based on this model. In the second sphere, the management of care for people with chronic pain should be focused on heading the health team's view on the implication of these aspects of people's lives through actions of permanent education and organization of services and protocols that favor this listening, in addition to enabling necessary referrals to different professionals. With regard to nursing education, there is a need to focus on students in training that excellent pain care is provided by listening and collecting data on the history of life and pain in order to be able to see the biopsychosocial model in the assessment and management of chronic pain.

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