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VIVÊNCIAS RELATADAS POR PACIENTES COM DOR CRÔNICA NÃO ONCOLÓGICA SOB TRATAMENTO EM AMBULATÓRIO ESPECIALIZADO DE HOSPITAL UNIVERSITÁRIO: UM ESTUDO CLÍNICO-QUALITATIVO

A QUALITATIVE STUDY ON THE LIFE EXPERIENCES REPORTED BY NON-ONCOLOGICAL PAIN OUTPATIENTS UNDER TREATMENT IN A BRAZILIAN PUBLIC HOSPITAL

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Tese apresentada à Faculdade de Ciências Médicas da Universidade Estadual de Campinas como parte dos requisitos exigidos para a obtenção do título de Doutora em Ciências Médicas, área de concentração Ciências Biomédicas.

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ORIENTADOR: PROF. DR. EGBERTO RIBEIRO TURATO

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DEDICATÓRIA

Ao meu filho, Heitor.

O real significado, o verdadeiro aprendizado.

Às minhas irmãs, Josy e Luciana.

A maior herança que minha mãe poderia ter deixado.

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Mas a dor não é um lugar fácil para se deixar para trás.
Habitamos a dor. A dor nos habita.
Dolor dictat.
Escrevemos sobre a dor, mas a dor
nos reescreve.

Melanie Thernstrom

Não existem duas coisas que estão presentes na vivência, não vivemos o
objeto e, ao lado deste, o ato intencional que se refere a ele;
não se trata de duas coisas no sentido da parte e do todo
que o abarca; pelo contrário, é uma só coisa o que
está presente, a vivência intencional, cujo caráter
descritivo é precisamente a intenção
relativa ao objeto.

Husserl

RESUMO

Uma dor que dure mais de três meses é considerada incapacitante e afeta vários níveis de atividade do sujeito, bem como sua interação social e, consequentemente, seu bem-estar. Assim, a dor crônica como processo de adoecimento não pode ser entendida como necessariamente localizada em determinada parte do corpo: ela se relaciona com um conjunto de dificuldades físicas, psicossociais, espirituais e sociais. O objetivo deste estudo foi compreender, do ponto de vista psicológico, os significados atribuídos por pacientes não oncológicos, em tratamento especializado, a suas experiências pessoais com a dor crônica. Foi utilizado o método clínico-qualitativo, por meio de entrevistas semidirigidas de questões abertas, realizadas em ambulatório especializado de hospital universitário na região sudeste do Brasil. A amostra de sujeitos foi concluída pelo critério de saturação e os dados foram tratados nos seguintes passos: transcrição na íntegra das entrevistas, releituras flutuantes para desvelar núcleos de sentidos nas falas dos entrevistados, categorização em tópicos para discussão e análise qualitativa de conteúdo. A análise revelou cinco categorias dentre as 16 entrevistas consideradas: 1. *Metáforas como expressão do sentido particular*; 2. *Resignação à fatalidade*; 3. *O encontro entre corpo e mente*; 4. *A satisfação com o tratamento apesar de sua limitação*; 5. *Dores além da dor crônica*. As falas dos indivíduos destacam dores adicionais que eles experimentam em seu processo de adoecimento e sua necessidade de que as particularidades de seu sofrimento sejam valorizadas. Para além das críticas à visão unidirecional da intervenção biomédica e das limitações já conhecidas dos tratamentos de dor crônica, os pacientes deste estudo demonstram receber no ambulatório alguma atenção também às suas questões simbólicas. Acreditamos que essa atenção contribui para o sucesso do procedimento, reforçando a ideia de que a compreensão do contexto do paciente no momento dos atendimentos e o acolhimento de sua expressão podem ser atitudes positivas para a evolução do tratamento, pois o contexto de vida e a expressão do indivíduo também são aceitos como demandas e manejados adequadamente.

Palavras-chave: Pesquisa Qualitativa, Dor Crônica, Ambulatório Hospitalar, Estresse Psicológico, Meio Social.

ABSTRACT

A pain that lasts for more than three months is considered disabling and affects individuals' activities at different levels, as well as their social interaction and consequently their well-being. Therefore, chronic pain as a process of falling ill cannot be understood as confined to a certain part of the body: it is related to a set of physical, psychosocial, spiritual, and social difficulties. The objective of this study was to understand, from a psychological perspective, the meanings that non-oncological patients who receive specialized treatment attribute to their personal experience with chronic pain. The clinical qualitative method was used, with semi-directed interviews with open questions conducted at the specialized outpatient clinic of a teaching hospital in the southeastern region of Brazil. The sample of subjects was completed according to the saturation criterion and data were treated as follows: complete transcription of interviews, text skimming to unveil cores of meaning in the interviewees' narratives, categorization in topics to be discussed, and qualitative analysis of content. The analysis revealed five categories in the sixteen interviews considered: 1. *Metaphors as expression of personal meanings*; 2. *Reluctant acceptance of fate*; 3. *The encounter of body and mind*; 4. *Satisfaction with treatment despite its limitations*; 5. *Pains beyond the chronic pain*. The subjects' narratives emphasize the other pains they experience during their processes and their need for having the particulars of their suffering valued. Beyond criticism against the unidirectional view of the biomedical intervention and the well-known limitations of chronic pain treatments, the patients in this study show that, at the outpatient clinic, they are also receiving some attention to their symbolic issues. We believe that such attention contributes to successful procedures, reinforcing the idea that understanding the patients' context at the moment of treatment and welcoming their expression may be positive attitudes in the evolution of treatment, since both the patients' life context and their expressions are also accepted as demands and managed accordingly.

Keywords: Qualitative Research, Chronic Pain, Life Experiences, Psychosocial Effects of Disease, Psychological Stress, Psychological Adaptation.

TABELAS E FIGURAS

ARTIGO 2 - Psychosocial meanings of life experiences of patients with non-oncologic chronic pain: a literature review

ARTIGO 3 - Pains beyond life experiences with non-malignant chronic pain: a qualitative study of Brazilian outpatients

SIGLAS E ABREVIATURAS

AAINH	Analgésicos anti-inflamatórios não-hormonais
CAPES	Coordenação de Aperfeiçoamento de Pessoal de Nível Superior
CEP	Comitê de Ética e Pesquisa
DC	Dor Crônica
FCM	Faculdade de Ciências Médicas
HC	Hospital de Clínicas
IASP	*International Association for the Study of Pain*
LPCQ	Laboratório de Pesquisa Clínico-Qualitativa
SUS	Sistema Único de Saúde
TCLE	Termo de Consentimento Livre e Esclarecido
UNICAMP	Universidade Estadual de Campinas

SUMÁRIO

1. INTRODUÇÃO

> *A dor é qualquer coisa que a pessoa que a experimenta diz que é,*
> *e existe sempre que a essa pessoa diz que existe.*
>
> Margo McCaffery

1.1 A dor como doença

A dor é, provavelmente, uma das formas universais e mais remotas de estresse e um dos mais primitivos sofrimentos do homem. Compreendê-la é uma das grandes preocupações da humanidade; entretanto, apesar dos esforços e de a dor ser tão antiga quanto a própria humanidade, ela ainda não foi completamente compreendida nem pode ser completamente controlada (1, 2).

Os compêndios internacionais e os mais variados artigos científicos sobre dor são unânimes em relatar a dificuldade em definir o que é dor e ressaltam a dificuldade em se tratar as dores crônicas (3-7).

Considerada parte integrante da vida, a dor sempre esteve presente ao longo do desenvolvimento do ser humano, exercendo função protetora para o organismo. Associada a doenças, processos inflamatórios, acidentes e procedimentos médicos ou cirúrgicos, funciona como um alarme indicador de que algo não está bem. Esse aspecto adaptativo é de grande valor para a sobrevivência, já que é a partir da sensação de dor que os indivíduos têm motivação para se afastar do fogo, de objetos pontiagudos ou procurar cuidados para determinada sintomatologia. Indivíduos portadores de um transtorno genético chamado *insensibilidade congênita à dor*, apesar de conseguirem distinguir sensações táteis, como temperatura e pressão, não possuem a dor em seu campo de experiências e, por isso, são mais suscetíveis a acidentes, podendo não chegar a atingir a fase adulta (8).

Com o efeito didático de categorização e para o uso de uma terminologia que facilite a comunicação entre pesquisadores, equipes de saúde e pacientes, alguns sistemas de classificação da dor foram desenvolvidos. A classificação mais utilizada e a que é relevante para o presente estudo considera a dor de acordo com sua duração, incluindo dor aguda e crônica (9-11).

A dor aguda tem duração relativamente curta, que vai de alguns minutos até semanas. Decorre de lesões teciduais, processos inflamatórios ou moléstias (4, 12). É sentida em algum momento da vida pela maioria dos indivíduos e possui significado positivo por ser o indicativo de lesão ou doença. Alguns exemplos são as dores ocorridas no pós-operatório ou associadas a procedimentos médicos em geral, as advindas de arranhões, traumatismos extensos, algumas cefaleias, infarto agudo de miocárdio, no trabalho de parto e em muitas outras situações clínicas. A experiência desse tipo de dor é um processo complexo que ativa uma série de mecanismos neurofisiológicos, hormonais e psicológicos, caracterizando uma reação de alarme e preparando o organismo para a ação de luta e fuga (1).

No entanto, há um tipo de dor que, mesmo tendo surgido associada a um processo de doença ou a uma lesão, permanece após o tratamento (4, 13). Essa modalidade de dor deixa de ser entendida como sintoma, passa a ser considerada em si uma doença e é chamada de dor crônica (DC) (4). Bem mais abrangente que um sintoma prolongado, constitui uma situação complexa em termos fisiopatológicos, diagnósticos e terapêuticos. Pessoas que sofrem de DC dificilmente apresentam melhora, independentemente dos recursos terapêuticos usados, pondo em xeque o conhecimento e a paciência do médico (13). É comum que acabem se submetendo a uma série de tratamentos, sendo até submetidas a cirurgias desnecessárias, e sua peregrinação por vários consultórios constitui uma característica universal (14-16).

A presença constante e a duração prolongada da dor, em geral, são muito perturbadoras. Torna-se o foco principal de atenção do indivíduo e dificulta grande parte de suas atividades. O indivíduo acaba por ter alterada, muitas vezes, sua mobilidade, seu sono, sua vida sexual, seu humor; podendo apresentar também, baixa autoestima, pensamentos negativos, apreciação desesperançada da vida, alterações em suas relações familiares, de trabalho e de lazer (17).

Pode ser altamente destrutiva para o bem-estar psicológico e social do paciente, que, pela falha dos mecanismos biológicos de autocura, as mal sucedidas tentativas de autocontrole e os frequentes fracassos dos tratamentos médicos, pode ficar seriamente debilitado e em situação grave de estresse (12). Quanto mais tempo a dor persiste, maior a probabilidade de o indivíduo se tornar deprimido, arredio, irritado e, cada vez mais, preocupado e persistente na busca por alívio.

São exemplos de DC a que acompanha a artrite reumatóide, a dor fantasma e a dor associada a doenças crônicas progressivas, como a dor do câncer (13). Esta última, inclusive, compõe, para determinados autores, uma categoria específica: a dor crônica progressiva (18-20). Isso acontece por ser decorrente de uma doença crônica progressiva e surgir apenas em determinado momento do avanço da doença, ou ser derivada de quadros pós-operatórios ou de lesões esportivas.

As dores crônicas também podem ser classificadas, de acordo com a presença ou ausência de lesão tecidual, atual ou pregressa, em *orgânicas* ou *emocionais*. As dores orgânicas podem ser *nociceptivas*, quando há um estímulo doloroso periférico originado em vísceras ou tecidos somáticos, ou *neuropáticas*, se resultam de lesão em algum nível do sistema nervoso central ou periférico. Nas dores ditas emocionais, não se reconhece a existência de estímulos neuropáticos ou nociceptivos (21).

Estima-se que os gastos em tratamentos de pacientes com dores crônicas podem superar os gastos somados de tratamentos de pacientes com cardiopatias, câncer e AIDS (22). A dor prolongada está entre as principais causas de absenteísmo ao trabalho, licenças médicas, aposentadoria por doença, indenizações trabalhistas e baixa produtividade. É um problema de saúde pública, pela prevalência, alto custo e impacto negativo que pode causar na qualidade de vida de pacientes e de suas famílias (23).

São escassos os estudos sobre a prevalência de dor na população geral; entretanto, estima-se que 2% a 40% da população mundial adulta sofra de DC (24, 25). É importante considerar nesses estudos possíveis variações e inadequações nos desenhos de pesquisas, a diversidade de conceitos de DC, os critérios utilizados para sua identificação, a patologia de base e os aspectos culturais, algo que justifica a disparidade dentre os dados divulgados.

Pesquisa realizada em 16 países da Europa e em Israel revelou que 19% da população investigada sofria de dor moderada ou grave havia pelo menos seis meses (26). Segundo o *Mayday PainLink Report,* realizado nos Estados Unidos, 40 milhões de pessoas sofrem de dores duradouras, causadas principalmente por problemas na coluna, artrite, câncer, lesões por esforço repetitivo e cefaleias, dentre outros (8). Afeta mais indivíduos do que diabetes, doenças do coração e câncer combinados, e é a principal causa de incapacidade até os 45 anos (27). Nesse mesmo país, aproximadamente 89 bilhões de dólares são gastos anualmente com tratamentos, compensações trabalhistas e litígios envolvendo doentes com DC (6).

No Brasil, também são poucos os estudos que têm sido realizados, e a maioria deles tem sido conduzida em populações específicas (idosos, trabalhadores), com tipos específicos de dor ou em ambulatórios (28). Estudo realizado pela Organização Mundial da Saúde revelou alta prevalência na América do Sul, tendo o Brasil apresentado o índice de 31%, com dados da cidade do Rio de Janeiro (29). Em outro estudo, este realizado em Salvador, a DC foi encontrada em 41,4% da população (28). Neste país, as dores mais comuns em adultos são as epigastralgias e outras dores abdominais, disúrias, cefaleias, artralgias, lombalgias, dores torácicas e dores nos membros (6).

1.2 A evolução na compreensão da DC

Em várias culturas, antes da entrada na Idade Média, a dor era percebida como resultado da influência de entidades que estavam além do corpo. Os males físicos, de forma geral, eram entendidos na Mesopotâmia como pecado ou impureza. A enfermidade era o castigo ordenado pelos deuses e poderia recair sobre toda a família ou sobre o próprio pecador (30). No Antigo Egito, achava-se que a dor era causada pela incorporação de espíritos de mortos no corpo dos acometidos. Na Grécia clássica, com Hipócrates, e na Roma antiga, com Galeno, os primeiros passos foram dados em busca de uma explicação racional para a dor (31).

A Idade Média foi marcada pelo prolongamento da hegemonia do galenismo, como um sistema perfeitamente coerente cobrindo todos os problemas da medicina, e pela importância da medicina árabe de Avicena. Nessa época, a dor passa a ter um papel importante no prognóstico das doenças e também indica o local acometido (32).

Entretanto, só com a chegada do século XVIII há mudança significativa em relação à sua compreensão. O crescimento do conhecimento médico e científico foi alavancado pelo desenvolvimento do microscópio e pela utilização de técnicas de dissecação em autópsias, que contribuíram para a compreensão do funcionamento do corpo humano. Foi também nesse período que se deu o aprimoramento de substâncias capazes de controlar a dor. O uso do clorofórmio, do óxido nitroso e do éter como anestésicos para cirurgias, da cocaína como analgésico regional (33), e a identificação dos receptores neuronais e da transmissão dos impulsos nervosos fazem com que a dor passe a ser tratada como fenômeno exclusivamente biológico, explicado fisiologicamente (34).

Nesse contexto, se estabelecem percepções de dor classificadas por Turk e seus colaboradores (35) como pertencentes às Teorias Restritivas, dentre as quais se destaca a Teoria da Especificidade (36). De acordo com essa teoria, um sistema especializado de transmissão carregaria mensagens de receptores exclusivos de dor na pele até um centro de dor no cérebro. A dor seria uma sensação específica, com equipamento sensorial próprio e independente dos outros sentidos, o que resultaria em uma relação direta e sem possibilidade de variação entre o estímulo físico e a sensação percebida pelo indivíduo; portanto, a intensidade da dor seria proporcional à extensão do dano tecidual (4, 37, 38).

Essa proposição do mecanismo da dor como uma reação estímulo-resposta foi feita inicialmente por René Descartes, em 1644, tendo chegado ao refinamento descrito acima com o que foi aprimorado nos séculos seguintes por Muller e Von Frey (35). Essa teoria apresentava lacunas por não conseguir explicar dores que não estavam associadas necessariamente a uma lesão ou que permaneciam após serem tratadas - como a dor fantasma e as neuralgias periféricas – já que não admitia a atuação de componentes além dos mecânicos no processo. Entretanto, essa mesma teoria foi responsável pelo surgimento de diversos métodos cirúrgicos na manipulação da DC, por meio do seccionamento de nervos, que são utilizados até hoje com o objetivo de bloqueio da sensação dolorosa (2).

A partir da chegada do século XX e com o surgimento de novas correntes de pensamento, o dualismo cartesiano e a própria ciência passaram a ser questionados. É nesse século que ocorre um corte epistemológico na história da ciência ao se refutar a visão de mundo reducionista, mecanicista e determinista da física newtoniana e do pensamento cartesiano, dominantes desde o século XVII.

Admite-se então, aos poucos, a interferência de questões emocionais na origem do adoecimento, considerando-se este como a exteriorização de um conflito interno com o mundo externo (39) ou a influência dos mesmos, bem como de aspectos sociais, na aderência e evolução dos tratamentos.

O século XX também marca a evolução no conceito de dor. Com as lacunas da Teoria da Especificidade, a Teoria da Comporta ou *Gate Control*, de Melzack e Wall, publicada em 1965 (36), ganhou credibilidade por sua abrangência. Essa teoria afirma que a dor é regulada por uma "comporta" que pode se abrir ou fechar por meio de impulsos provenientes dos nervos periféricos ou do sistema nervoso central, aumentando ou diminuindo a dor percebida. Esse mecanismo de comportas poderia ser influenciado por uma série de fatores, como estado de humor e estímulos ambientais, induzindo as comportas nos feixes de fibras nervosas da medula espinhal a abrir-se para permitir que os impulsos de dor cheguem ao cérebro ou fechar-se para interrompê-los. Apesar de carecer de comprovação científica, essa teoria revolucionou os conhecimentos sobre o tema por trazer à tona outros elementos envolvidos no processo, como o estado emocional do indivíduo, e pela integração de novas abordagens terapêuticas, ao invés de explicar a dor simplesmente como uma experiência sensorial aferente (40).

A partir de formulações como essa, a dor é hoje considerada pela *International Association for the Study of Pain* (IASP) “uma experiência sensorial e emocional desagradável associada a um dano real ou potencial dos tecidos, ou descrita em termos de tais danos” (41). Admite-se nessa definição a presença da subjetividade do indivíduo e, por consequência, seu caráter particular de expressão. Como descrito por Lima e Trad, a dor está no corpo, na mente, na história de vida, no cotidiano, ou seja, é multidimensional (42). De acordo com Harding e colaboradores, a DC é uma experiência complexa influenciada pelo ambiente sociocultural do indivíduo, por suas crenças, expectativas, atitudes e pelo significado que atribui a sua dor, assim como por fatores biológicos (43).

Dessa forma, pode-se concluir que a DC não existe de forma isolada: existem indivíduos que manifestam DC, e que, para que ela seja compreendida, há de se observá-la a partir da perspectiva desse indivíduo. Também não se pode pensar em uma única forma de manifestação desse processo, já que cada indivíduo é único, e sua forma de apreender, significar e expressar são, também, singulares. Para compreender a dor, é necessário dar voz à experiência do paciente (44).

1.3 Alguns aspectos psicológicos e psiquiátricos

Os aspectos psicológicos envolvidos na experiência dolorosa crônica podem se sobrepor aos sensitivos (45). Esses componentes emocionais são diversos e muito particulares, tendo relação com os significados que os indivíduos atribuem a essas suas vivências. Desse modo, estão presentes em sua gênese, manifestação e tratamento; podendo atuar como facilitadores ou complicadores de cada uma das fases desse complexo processo (46).

Dentre as múltiplas possibilidades de interferência nociva de questões psicológicas, podemos exemplificar que uma dor pode ser reflexo de problemas emocionais, pode servir de recurso para expressar alguma necessidade particular do indivíduo, ou ser um meio para atrair atenção e afeto (47, 48). Podem ainda associar-se ao estímulo nociceptivo desencadeando ou agravando quadros psicopatológicos (12, 49).

A história do sujeito e suas características pessoais são determinantes nesses processos (48). É a partir de experiências da infância que o sujeito vai construindo um repertório de comportamentos e reações à dor, na medida em que vai acumulando experiências pessoais e observando os outros, principalmente a família. Esses comportamentos vão sendo moldados também pela cultura, que pode ser responsável, inclusive, pela cristalização de padrões comportamentais, como a tolerância à dor (32). Interferem particularmente nestes padrões o sistema de crenças sociais, científicas e religiosas (48).

Portanto, ambiente familiar e social têm papel fundamental no modo como o indivíduo expressa sua dor. Sua expressão depende de reforços recebidos do ambiente e podem contribuir para sua manutenção mesmo na ausência do estímulo. Por essa perspectiva o comportamento de dor pode ser reflexo e símbolo do sofrimento do doente em outras áreas da sua vida, como a vivência de outras situações existenciais difíceis ou conflitos familiares (12). Assim, a personalidade do indivíduo torna-se um dos determinantes de como ele lida com seu quadro de DC.

Por isso, informações sobre o jeito de ser do paciente antes da manifestação álgica facilitam o entendimento de sua reação ao adoecimento (48, 50).

No que concerne a presença de transtornos mentais nesses pacientes a literatura aponta prevalências altas, sendo mais frequentes os diagnósticos de transtornos de ansiedade, do humor e somatoformes (6, 49). Cada uma dessas psicopatologias guarda aspectos específicos em sua relação com a DC, podendo a dor estar presente no desencadeamento dessas condições, ser resultado delas ou apresentar-se concomitantemente. Alguns autores afirmam que em indivíduos mais vulneráveis a desenvolverem quadros psicopatológicos, o estresse associado à dor pode estimular tais quadros e, no sentido inverso, uma psicopatologia pode intensificar a experiência de dor (49, 51). Fato que acaba por evidenciar a impossibilidade de se abordar essas ocorrências em separado (49).

Em pacientes com transtornos de ansiedade há um alto nível de preocupação com questões somáticas e por isso uma possibilidade de maior percepção de dor. Esses quadros, da mesma forma, podem acentuar a tensão muscular e atuar nos mecanismos de estresse de modo a aumentar a ocorrência de dor (52). A ansiedade diminui ainda o limiar de sensibilidade e tolerância dolorosa e está associada ao exagero no autorrelato dessa sensação (49).

A depressão é um diagnóstico frequente em pacientes com DC e 60% dos indivíduos deprimidos relatam sintomas álgicos como cefaleia, lombalgia, dor torácica e musculoesquelética crônica (52). Pacientes deprimidos e com DC referem maior intensidade de dor, têm menor capacidade de controle da sua vida e menor capacidade de desenvolver estratégias positivas de enfrentamento da situação dolorosa, o que resulta em um maior impacto das limitações acarretadas por ela em seu cotidiano (53).

Em indivíduos que sofrem de transtornos somatoformes a dor pode ser a exteriorização de conflitos psicológicos. Nestes casos há a evidencia de fatores emocionais levando à condição dolorosa e a ausência de patologia orgânica que justifiquem a gravidade do quadro doloroso (54). Distúrbio de dor psicogênica, um dos distúrbios descritos neste transtorno pelo DSM-IV, talvez seja o diagnóstico psiquiátrico mais comum em pacientes com DC (49).

Essas expressões psicológicas, bem como os sintomas psicopatológicos, devem ser considerados e tratados com cautela para que não sejam percebidos pelos que têm contato com esses indivíduos como manifestações estereotipadas ou de tentativas de manipulação (54). Muitos pacientes não têm consciência desses aspectos subjetivos, da possível ocorrência de uma psicopatologia, nem do modo como interferem em seu adoecimento, cabendo a membros especializados da equipe de cuidado a identificação e o manejo dessas situações.

1.4 Manejo do paciente com DC

Partindo da premissa de que a dor é sempre uma experiência subjetiva e particular, constituindo um fenômeno complexo e multidimensional (55), compreendemos que as diversas práticas a serem utilizadas para sua investigação e controle componham um “quebra-cabeça” a ser articulado pelos profissionais de saúde (56).

A investigação da dor é fundamental para que se compreenda sua magnitude e origem, para definição da terapêutica a ser implementada e verificação de sua eficácia (57). Suas etapas compreendem essencialmente o exame clínico e o uso de técnicas para a aferição das características da dor e de sua repercussão na vida do indivíduo. Em relação ao exame clínico, valoriza-se a história da doença, o exame físico, bem como exames laboratoriais de imagem (57). Para a avaliação de suas características, os métodos utilizados nesses casos são basicamente inferenciais e dependem do relato do paciente (58). Atualmente, existem instrumentos de avaliação que, de acordo com os profissionais que os utilizam, facilitam a comunicação do paciente e permitem comparações individuais e grupais (57-59).

A avaliação da *intensidade* da dor pode ser realizada através de diversos instrumentos que se se utilizam de escalas numéricas, de categorias de palavras, escala visual analógica, ou expressões faciais (58). Estas escalas apresentam itens que indicam sofrimento crescente e solicitam o registro do paciente sobre a magnitude de sua queixa álgica. As *características sensitivas e afetivas* podem ser conhecidas através da solicitação para que o doente descreva espontaneamente sua dor, ou também por meio de inventários padronizados, como o “Questionário para dor McGill". Este questionário compreende 78 descritores, organizados em grupos, para que o paciente os indique na tentativa de identificar sua dor (60). A preocupação em conhecer os comportamentos alterados pela vivência dolorosa são indícios da gravidade do quadro. Para acessar *incapacidades* e *prejuízos* acarretados pela doença são utilizadas também escalas numéricas ou de frequência de ocorrência (57).

No que se refere à terapeutica da DC, o controle da dor é mais que um cuidado ao sintoma, ele torna-se o objetivo do próprio tratamento (56). Dentre as intervenções farmacológicas habituais, podem ser empregados o uso de analgésicos anti-inflamatórios não-hormonais (AAINH), analgésicos morfínicos, corticosteroides, antidepressivos, neurolépticos, anticonvulsivantes e bloqueadores de receptores hormonais. Além disso, pode ser necessária também a realização de procedimentos anestésicos ou neurocirúrgicos (61). Como métodos adjuvantes são recomendados procedimentos de medicina física, que podem proporcionar alívio da dor com pouca ou ausência de efeitos colaterais e reduzir a necessidade de analgésicos (62).

Entretanto, além das possibilidades farmacológicas e de medicina física, há uma gama de intervenções psicossociais que podem ser determinantes para a evolução positiva desses quadros crônicos. O conhecimento em relação ao cotidiano do indivíduo, seu contexto familiar e profissional, e a determinados aspectos subjetivos, podem fornecer elementos, que além de ajudarem na avaliação da magnitude do quadro, permitem aos profissionais a elaboração de intervenções específicas para cada um destes setores. Com isso obtém-se maior controle da patologia e a reabilitação global dos doentes incapacitados pela dor, já que atuam em suas condições resultantes e nas afecções nosológicas responsáveis por sua instalação (45, 63, 64).

Teixeira e colaboradores consideram que o tratamento da dor deve adaptar-se à sua natureza complexa, exigindo a adoção de várias modalidades de intervenção e demandando a individualização dos planos terapêuticos (45). No que se refere a isso, vários estudos apontam que a atuação multidisciplinar no cuidado ao paciente com DC é significativamente mais eficaz, já que permite melhor precisão de diagnóstico e amplitude de tratamento, se comparada a profissionais que atuam separadamente (65-68). Pacientes com quadros álgicos crônicos quando acompanhados por esses serviços especializados podem apresentar até 75% de melhora em relação aos que seguem tratamentos clássicos (68). Além disso, as perdas econômicas e gastos com tratamentos de doentes com DC atendidos por equipes multidisciplinares é de um sexto do valor do atendimento realizado em clínicas não especializadas (45).

Em relação aos procedimentos psicossociais, o comprometimento de todos os membros da equipe em exercer atitudes encorajadoras e esclarecedoras em relação ao tratamento e a patologia para os pacientes e cuidadores, contribuem para maior confiança nas condutas, maior autonomia e melhor adesão ao tratamento (45). Devem também ser foco da atuação multidisciplinar intervenções mais específicas, como o reforço dos potenciais preservados do paciente, o desenvolvimento de sua autoconfiança, o encorajamento para a execução das tarefas, o incremento da independência dos doentes em relação ao sistema de saúde e sua adaptação para o desempenho de outras atividades, o cuidado aos desajustamentos familiares, sociais e profissionais. Importante ainda atenção e cuidado a questões simbólicas e de saúde mental presentes em relação ao adoecimento (12, 45, 48, 68).

1.5 Motivações para o estudo

Mesmo considerando as tradicionais orientações clínicas sobre a necessidade de uma abordagem integral no cuidado ao doente de DC, e mesmo sendo reconhecido o empenho dos profissionais de saúde nesse sentido, parece existir uma desorientação sobre como direcionar a atenção para captar essa integralidade (42, 69-71). Compreendemos que, a despeito das extensas elaborações teóricas sobre o tema, no âmbito das intervenções assistenciais e do contato com o paciente, a atenção à identidade do indivíduo doente está longe da prática (71-74).

A falta de relevância desse tipo de entendimento pode ser um dos entraves na criação de intervenções e serviços mais eficientes no tratamento de pessoas que sofrem de dor por períodos prolongados (42, 75, 76), o que justifica a estimulação de contínuos questionamentos e reflexão. A lacuna citada instiga consideração sobre esse contraste, e foi o que motivou a composição do presente trabalho.

Coincidentemente, o Hospital de Clínicas (HC) da Unicamp, instituição onde a pesquisadora trabalhou e foi o campo de sua pesquisa de mestrado, possui ambulatório específico para o tratamento de pessoas com DC. Logo, somando-se à motivação inicial, percebemos que vários usuários desse ambulatório são encaminhados ao serviço especializado ambulatorial da psiquiatria do mesmo hospital. Isso aumentou o interesse por uma investigação qualitativa dessa população, bem como fez emergir as primeiras hipóteses sobre a experiência do tratamento médico desses pacientes que são acompanhados por um serviço acadêmico exclusivo para eles.

Acreditamos, além de tudo, que esta pesquisa adequa-se a um programa de doutorado por seu caráter inédito. Ainda são poucas as pesquisas utilizando metodologia qualitativa com pacientes com dor crônica no Brasil e não se conhece nenhum estudo que reflita sobre as vivências desse tipo de paciente realizado no Hospital de Clínicas da Unicamp.

Esperamos com este estudo que a expressão da voz, dos múltiplos significados atribuídos ao processo vivencial desses indivíduos, possa fornecer subsídios aos profissionais, especialmente àqueles formados no modelo biomédico, intencionados em atingir a esfera psicossocial do problema como complemento potencializador do tratamento.

2. HIPÓTESES

O presente estudo parte dos seguintes pressupostos em relação aos indivíduos que pretende investigar:

- São pacientes que têm a experiência de vida de afrontar uma DC, a qual lhes traz limitações diversas, dentre as quais:
    - *problemas na execução de tarefas rotineiras;*
    - *diminuição na esfera de interações sociais;*
    - *dificuldades nas atividades sexuais.*
- Passam a ter uma percepção dos próprios sintomas dolorosos, ainda que de natureza não-oncológica, como fenômeno carregado de sentidos, tais como:
    - *tratar-se de uma situação patológica para a qual chegou a ser necessário um tratamento de 'fim-de-linha';*
    - *tratar-se de uma condição humana que levará a uma sobrevida menor.*
- Passam, desse modo, a representar psicologicamente o caráter dessa sensação física intensa, cotidiana e sem registro de remissão no passar dos anos, como algo:
    - *Que se torna o centro da vida em torno do qual os campos pessoais devem gravitar;*
    - *que organiza um discurso naturalmente predominante em suas conversações.*

3. OBJETIVOS

3.1 Objetivo geral

i. Realizar pesquisa de campo para compreender, do ponto de vista psicológico, significados atribuídos por pacientes não oncológicos, em tratamento especializado em ambulatório de hospital universitário, às experiências pessoais relatadas sobre sua DC.

3.2 Objetivos específicos

i. Realizar investigação conceitual e de bibliografia no recorte teórico da pesquisa de campo com discussão crítica do material levantado para elaboração de trabalho teórico para divulgação acadêmica e servir como subsídio para articular com a investigação empírica subsequente.

ii. Compreender significados emocionais relatados em entrevistas semidirigidas sobre a presença vivenciada do fenômeno da dor por pacientes em seguimento médico ambulatorial.

iii. Compreender conteúdos psicossociais mencionados nessas entrevistas que vierem informados como possivelmente relacionados ao processo do adoecimento e do tratamento clínico, com repercussão nos âmbitos de relações amorosas, familiares, religiosas, laborais, sociais, recreativas e afins.

4. RECURSOS METODOLÓGICOS

Minha mãe achava estudo
a coisa mais fina do mundo.
Não é.

A coisa mais fina do mundo é o
sentimento.
(...)

Adélia Prado

4.1 Sobre o método e sua escolha

De acordo com os objetivos relatados para o estudo empírico, que é apresentado como Artigo 3 nos “Resultados” desta tese, o desenho de investigação escolhido foi do enfoque qualitativo, especificamente o Método Clínico-Qualitativo.

Os métodos qualitativos foram criados e têm sido usados genericamente no campo das Ciências Humanas. De acordo com Minayo (77), em seu ponto de vista sociológico, os métodos qualitativos são aqueles:

> [...] capazes de incorporar a questão do significado e da intencionalidade como inerentes aos atos, às relações, e às estruturas sociais, sendo essas últimas tomadas tanto no seu advento quanto na sua transformação, como construções humanas significativas.

A mesma autora firma ainda:

> [...] aplica-se ao estudo da história, das relações, das representações, das crenças, das percepções e das opiniões, produto das interpretações que os humanos fazem a respeito de como vivem, constroem seus artefatos e a si mesmos, sentem e pensam.

Esses métodos distinguem-se particularmente por não se direcionarem à busca dos chamados “fatos”, mas à busca dos significados dos fenômenos apreendidos pelos indivíduos. Turato lembra que os significados dos eventos exercem um papel estruturante para os seres humanos: as vivências dão molde à vida das pessoas. Do mesmo modo, os significados das ocorrências são partilhados culturalmente e organizam o grupo social com suas representações (78).

Enquanto particularização e refinamento dos métodos qualitativos em geral, o Método Clínico-Qualitativo volta-se especificamente para os *settings* assistenciais onde se relatam as vivências nos processos de saúde-doença. Busca compreender os significados de natureza psicológica e sociocultural expressos por indivíduos, relacionados aos múltiplos fenômenos pertinentes ao seu problema, tendo como foco o indivíduo - pacientes ou outras pessoas envolvidas no processo, como familiares, profissionais de saúde ou pessoas da comunidade (78, 79). O conhecimento dos significados dos fenômenos nessas circunstâncias é essencial para se compreender aprofundadamente certos sentimentos, ideias e comportamentos de doentes, seus familiares e equipe de saúde, e, consequentemente, para melhora da qualidade das relações entre esses sujeitos. É importante para promover maior adesão de pacientes e da população a tratamentos individuais ou a medidas implementadas coletivamente (78).

4.2 Características do campo de pesquisa

O presente estudo foi realizado no Ambulatório de Dor do Hospital de Clínicas da Faculdade de Ciências Médicas da Universidade Estadual de Campinas (Unicamp). Trata-se de um hospital público universitário de nível terciário, totalmente conveniado ao Sistema Único de Saúde (SUS). Está localizado na região de Campinas, interior do estado de São Paulo, cobrindo uma população de quatro milhões de habitantes.

O Ambulatório de Dor existe desde o ano de 1984 e é coordenado pelo Departamento de Anestesiologia. Funciona às terças-feiras pela manhã atendendo pacientes com dor de origem oncológica, e às quintas-feiras à tarde dedica-se ao atendimento de pacientes com outros tipos de dores crônicas. Conta com uma equipe de médicos anestesiologistas, docentes e residentes, além de profissionais de enfermagem.

O atendimento é realizado por médico em residência supervisionado por docente. O ambulatório recebe pacientes de dor oncológica encaminhados de diversos serviços de saúde do município, entretanto, em relação aos pacientes com dor não oncológica, só são aceitos pacientes encaminhados de outras clínicas do próprio hospital e com diagnóstico já confirmado. Além disso, o ambulatório limita seu atendimento a patologias fora da especialidade dos outros serviços do HC.

4.3 Processo de aculturação

É importante considerar que a fase de entrada do pesquisador no campo requer um período de tempo variável para ambientação e aculturação. Para Turato (79), a *ambientação* consiste na “adaptação pessoal a um determinado espaço funcional e à rotina de trabalho e hábitos que nele as pessoas ‘nativas’ desenvolvem”. O autor considera a *aculturação* um fenômeno mais amplo e profundo que o anterior, por tratar-se de um processo de assimilação de ideias e costumes do ambiente para o qual migra o pesquisador. É uma empreitada científica de ordem psicossocial, na qual é necessário transpor barreiras culturais (79). É o desafio, além da adaptação às condições espaciais e temporais do campo, de se compreender e respeitar a linguagem, os hábitos e os conceitos da população que se deseja investigar.

No caso desta pesquisa, o processo de aculturação iniciou-se antes da chegada da pesquisadora ao campo, antes da ambientação. Seu desconhecimento em relação ao funcionamento do ambulatório rendeu alguns contatos telefônicos, trocas de *e-mails* e visitas ao local antes do início oficial do estudo de campo, ocasiões em que puderam ser registradas as impressões iniciais no diário de campo.

Após oficializada a entrada, seguiu-se de imediato a indicação de sala para a realização das entrevistas e o convite para participar dos atendimentos realizados pela equipe médica. Desse modo, pôde-se perceber a dinâmica de funcionamento do serviço e realizar entrevistas preliminares, que serviram para instigar questionamentos teórico-práticos e aprimorar o roteiro semidirigido. As idas ao ambulatório foram interrompidas três semanas após seu início por conta de reforma ocorrida no prédio, seguida de um período de licenciamento da pós-graduação. As idas ao campo foram retomadas depois de um ano e meio e perduraram por três meses.

A entrada oficial no serviço ocorreu em setembro de 2011; foi convencionado com a equipe que os pacientes que passariam pelo atendimento médico naquelas tardes seriam encaminhados, em seguida, à pesquisadora, que faria a apresentação e o convite para participação no projeto.

4.4 Construção da amostra e inclusão dos sujeitos

De acordo com Turato (79), amostra, na linguagem científica das pesquisas com seres humanos, designa “uma parcela selecionada segundo determinada conveniência, e extraída de uma população de sujeitos, consistindo assim num subconjunto do universo”.

Para este estudo, os critérios de inclusão dos sujeitos foram:

- possuir diagnóstico de DC não oncológica;
- estar em tratamento no Ambulatório de Dor do Hospital de Clínicas da Unicamp;
- concordar em participar do estudo e assinar o Termo de Consentimento Livre e Esclarecido (TCLE, Apêndice II);
- apresentar condições intelectuais, emocionais e físicas para expressar-se durante a entrevista, garantindo assim informações válidas.

Deste modo, constituiu-se uma amostragem não probabilística e por conveniência, tendo sido acessados os pacientes mais disponíveis a participar do estudo. O fechamento dessa amostra se deu por critério de saturação, quando, após repetidas entrevistas, possíveis dados novos não acrescentaram informações substancialmente originais aos já obtidos, segundo a crítica dos pesquisadores e pares-revisores (80). A autonomia do pesquisador em interromper a coleta de dados quando acha conveniente não constitui de ação arbitrária; ao contrário, ele conta, além da crítica de seus pares-revisores, com a avaliação cuidadosa de que os elementos colhidos atenderão à discussão para atingir os objetivos trazidos no projeto (79). Assim, a amostra foi concluída com 17 participantes, tendo ocorrido uma exclusão por limitações técnicas de registro. As características dos 16 entrevistados restantes são apresentadas na Tabela 1 do Artigo 3.

4.5 Coleta de dados

O contato com os sujeitos deu-se através dos médicos do ambulatório onde o estudo foi realizado. Após a consulta, os pacientes eram brevemente informados a respeito da pesquisa e, caso concordassem, encaminhados até a entrevistadora, que lhes dava informações detalhadas e novamente a possibilidade de escolha em participar do projeto.

Esse encontro obedecia a algumas etapas, também sugeridas pelo método clínico-qualitativo, em que inicialmente se procurava estabelecer um *rapport* através da apresentação entre entrevistador e entrevistado, seguida da descrição detalhada dos objetivos da entrevista. Em seguida era realizada a leitura do termo de consentimento e sua explicação em linguagem coloquial, ressaltando: os ganhos da pesquisa para a ciência e para a comunidade, duração e dinâmica da entrevista, uso do gravador, preservação do anonimato, dentre outros. Depois disso, dados pessoais de identificação do entrevistado eram anotados, e iniciava-se a entrevista semidirigida de questões abertas.

Esse modelo de entrevista funciona como um roteiro para o encontro, abrangendo tópicos relacionados aos objetivos do estudo. Os tópicos são apresentados através de questões abertas que propiciam ao sujeito a oportunidade de expressão o mais livre possível em relação ao que foi proposto, dando ensejo ao surgimento de achados originais. De acordo com Fontanella (81), a entrevista semidirigida consiste em instrumento da exploração de problemas novos para a ciência, já que objetiva fazer emergir significados atribuídos aos fenômenos frutos das experiências singulares dos pacientes e tem a capacidade de produzir fenômenos inéditos e relevantes a partir da relação entrevistador-entrevistado.

Para esta pesquisa, um roteiro de questões básicas foi estruturado e utilizado em todas as entrevistas (Apêndice I). Alguns aspectos relacionados ao comportamento dos entrevistados que chamaram a atenção da entrevistadora foram anotados em seu diário de campo, assim como suas reações emocionais. Posteriormente, as entrevistas foram transcritas na íntegra, formando o chamado *corpus* transcrito. Os encontros com os pacientes para a coleta de dados foram realizados em salas de atendimento reservadas para esse fim no próprio ambulatório.

4.6 Técnica de tratamento de dados

A análise de dados deste estudo foi realizada pelo processo de análise de conteúdo, através das etapas sugeridas pela literatura de pré-análise, com a execução de leituras flutuantes, a constituição do *corpus* e a formulação de hipóteses; a exploração do material através da categorização dos tópicos emergentes; chegando finalmente à etapa de tratamento dos resultados e interpretação (82).

As entrevistas transcritas, seus áudios e as anotações do diário de campo foram analisados mantendo a atenção tanto ao que era objetivamente dito e expresso, quanto a possíveis conteúdos implícitos, buscando captar os fenômenos das vivências dos participantes do estudo. Para Bardin (82), nesse momento é importante que o pesquisador estabeleça contato com o material em análise, procurando conhecê-lo e deixando-se invadir por impressões e orientações.

A partir da apropriação dos conteúdos emergentes, em busca de núcleos de significados, os principais temas foram assinalados e organizados seguindo critérios de prevalência e relevância. De acordo com Minayo (77), a exploração do material consiste em uma operação classificatória na busca pelo núcleo de compreensão do texto. Através de categorização, processo de redução do texto às palavras e expressões significativas, o conteúdo do *corpus* deve ser organizado. As categorias findam por abranger vários temas que, por meio de sua análise, podem expressar significados importantes que atendam aos objetivos do estudo e propiciem uma visão diferenciada sobre eles (83). A ordenação dos temas não é feita necessariamente por sua frequência, mas também por sua relevância, caso em que, embora não haja repetição dentre os relatos, o pesquisador identifica riqueza de significados relacionados aos pressupostos de seu estudo, o que é de grande potencial para o aprofundamento no fenômeno estudado e consequente desenvolvimento de novos conhecimentos (79, 84).

A fase seguinte, de interpretação, é caracterizada pela realização de inferências sobre o material apreendido. A leitura feita pelo pesquisador de seu material não é simplesmente uma leitura do que é claro e evidentemente comunicado, é antes a busca de um sentido que subjaz em segundo plano (82). O intuito de quem analisa os dados aqui é duplo, como descreve Bardin (82): compreender o que é objetivamente comunicado e, principalmente, desviar a atenção para outra mensagem vislumbrada através ou ao lado da mensagem primeira.

A interpretação dos dados deste trabalho considera a multiplicidade de sentidos atribuídos pelos sujeitos que vivenciam os fenômenos em estudo, como preconizam Campos e Turato (83). A discussão leva em consideração o olhar da pesquisadora, sua imaginação e criatividade, aspectos valorizados em análises como esta (77, 79, 82), sendo em seguida relacionada à literatura.

4.7 Validação

De acordo com Minayo (77), a questão preponderante quanto à validade e à verificação em pesquisas qualitativas está no questionamento de “até que ponto o investigador conseguiu compreender a lógica interna do grupo estudado ou dos textos analisados?”. Nesse sentido, Turato (79) aponta que o processo de validação dos dados obtidos em pesquisas clínico-qualitativas deve atender a critérios internos ao pesquisador e externos a ele.

A validação interna diz respeito aos rigores pessoais do pesquisador em relação ao seu objeto de estudo e aos recursos internos que possui, que garantem que a apreensão do fenômeno esteja em conformidade com o real. O autor ressalta que toda a formação do pesquisador, seu conhecimento teórico, suas experiências e seu domínio de técnicas e procedimentos de pesquisa são considerados e constituem a estrutura da condução bem-sucedida de seu trabalho. Afirma ainda que este *backgroud* pode facilitar a configuração de um ambiente positivo para a realização das entrevistas, na medida em que promove uma atmosfera de confiança e respeito na relação, o que incentiva o entrevistado a se pronunciar de modo mais autêntico (79).

Neste caso, a formação da pesquisadora como psicóloga clínica e hospitalar, com participação em outras pesquisas conduzidas também em ambientes hospitalares, facilitou o contato com os pacientes sujeitos da pesquisa, na acuidade da observação de suas expressões e na articulação teórica no momento de trabalho com os dados.

O processo de validação externa, igualmente importante para a validação de pesquisas qualitativas, ocorre no espaço interpessoal, nas trocas com os membros da comunidade acadêmica, na interação com juízes e pelos pares (79, 83). Minayo (77) pontua a intersubjetividade como procedimento fundamental de crítica e julgamento científico. Para a autora, a submissão do produto do conhecimento às discussões permite lançá-las à pluralidade de perspectivas, que podem clarificar focos anteriormente obscuros ou, ainda, romper o que anteriormente foi estabelecido. Turato (79) propõe que o trabalho seja submetido a supervisões com o orientador do projeto ou pesquisador sênior de seu grupo e que seja discutido com sua rede de interlocutores, pares de grupo de pesquisa.

O rigor metodológico desta pesquisa foi garantido por exame frequente e minucioso de todo o material ao longo de seu desenvolvimento, em contínua supervisão do professor orientador e através do processo de validação pelos pares do grupo de pesquisa ao qual a pesquisadora é afiliada – membros do Laboratório de Pesquisa Clínico-Qualitativa (LPCQ). Esse grupo localiza-se no Departamento de Psicologia Médica e Psiquiatria da Faculdade de Ciências Médicas da Unicamp, está credenciado à Plataforma *Lattes* e é composto por pesquisadores de graduação, mestrado, doutorado e pós-doutorado, além de pesquisadores seniores.

As "trocas de ideias acerca dos resultados preliminares feitas com as audiências qualificadas em eventos científicos", como afirma Turato (79), também são consideradas parte do processo de validação, que, no caso desta pesquisa, conta com quatro apresentações em congressos internacionais, quatro em congressos nacionais e uma publicação – extensivamente discutida com avaliadores internacionais.

4.8 Cuidados éticos

O projeto desta pesquisa teve aprovação do Comitê de Ética em Pesquisa da Faculdade de Ciências Médicas da Universidade Estadual de Campinas, homologado em 22 de novembro de 2011, sob o parecer de número 1136/2011, CAAE 1036.0.146.000-11 (Anexo). Foram considerados pelo estudo somente indivíduos que consentiram sua participação após a explicação dos termos da pesquisa e assinaram o Termo de Consentimento Livre e Esclarecido (TCLE, Apêndice II).

Antes do início de cada uma das entrevistas, foram fornecidos esclarecimentos relacionados à justificativa do estudo, aos seus objetivos e procedimentos e à garantia do sigilo. Assegurou-se ainda aos entrevistados a possibilidade de desistir de participar do estudo a qualquer momento, de recusar-se a falar de tema que não considerasse adequado e a participar da pesquisa, sem que isso levasse a qualquer tipo de penalização ou prejuízo ao seu tratamento na instituição. Todas as dúvidas apresentadas foram esclarecidas pela entrevistadora.

A apresentação do TCLE era realizada em seguida, e só participou do estudo o indivíduo que concordou com suas condições e assinou o documento. Os participantes receberam uma cópia também assinada pela pesquisadora.

Os procedimentos que envolveram esta pesquisa não apresentavam risco aos participantes; entretanto, sabe-se que o tipo de entrevista utilizado pode levar à mobilização emocional. Diante dessa possibilidade, a entrevistadora estava preparada para dar o suporte psicológico imediato e informar à equipe médica qualquer intercorrência significativa, para que os devidos encaminhamentos fossem realizados. Contudo, não houve necessidade de encaminhamento em nenhum dos casos.

As entrevistas foram realizadas em sala do ambulatório designada para esse fim. Os sujeitos foram identificados no estudo por uma codificação, e seus demais dados omitidos do estudo para garantir sigilo e privacidade.

Nenhuma ajuda financeira ou benefício foi concedido aos participantes.

5. RESULTADOS

Compõem os resultados desta pesquisa três artigos cujos resultados respondem aos objetivos elaborados inicialmente.

Artigo 01

Título: *The phenomenological-existential comprehension of chronic pain: going beyond the standing healthcare models.*

Situação: publicado em janeiro de 2014 no periódico *Philosophy, Ethics, and Humanities in Medicine:* http://www.peh-med.com/content/9/1/2

Artigo 02

Título: *Psychosocial meanings of life experiences of patients with non-oncologic chronic pain: a literature review.*

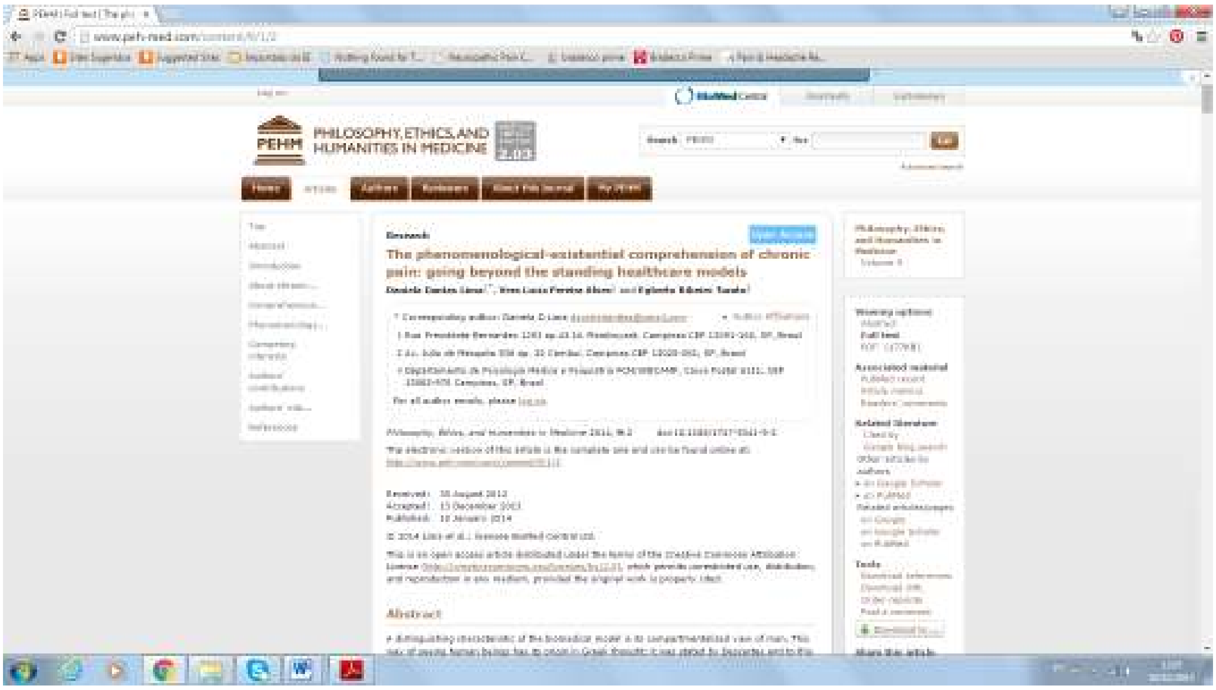
Situação: submetido em 10 de dezembro de 2015 ao periódico *Qualitative Research.*

Artigo 03

Título: *Pains beyond life experiences with non-malignant chronic pain: a qualitative study of Brazilian outpatients.*

Situação: em revisão final para submissão ao periódico *Pain*.

Artigo 01



PEHM PHILOSOPHY, ETHICS, AND HUMANITIES IN MEDICINE

Research

The phenomenological-existential comprehension of chronic pain: going beyond the standing healthcare models

Abstract

Artigo 01

THE PHENOMENOLOGICAL-EXISTENTIAL COMPREHENSION OF CHRONIC PAIN: GOING BEYOND THE STANDING HEALTHCARE MODELS

Authors: Daniela Dantas Lima, Vera Lúcia Pereira Alves, Egberto Ribeiro Turato.

ABSTRACT

A distinguishing characteristic of the biomedical model is its compartmentalized view of man. This way of seeing human beings has its origin in Greek thought; it was stated by Descartes and to this day it still considers humans as beings composed of distinct entities combined into a certain form. Because of this observation, one began to believe that the focus of a health treatment could be exclusively on the affected area of the body, without the need to pay attention to patient's subjectivity. By seeing pain as a merely sensory response, this model was not capable of encompassing chronic pain, since the latter is a complex process that can occur independently of tissue damage. As of the second half of the twentieth century, when it became impossible to deny the relationship between psyche and soma, the current understanding of chronic pain emerges: that of chronic pain as an individual experience, the result of a sum of physical, psychological, and social factors that, for this reason, cannot be approached separately from the individual who expresses pain. This understanding has allowed a significant improvement in perspective, emphasizing the characteristic of pain as an individual experience. However, the understanding of chronic pain as a sum of factors corresponds to the current way of seeing the process of falling ill, for its conception holds a Cartesian duality and the positivist premise of a single reality. For phenomenology, on the other hand, the individual in his/her unity is more than a simple sum of parts. Phenomenology sees a human being as an intending entity, in which body, mind, and the world are intertwined and constitute each other mutually, thus establishing the human being's integral functioning. Therefore, a real understanding of the chronic pain process would only be possible from a phenomenological point of view at the experience lived by the individual who expresses and communicates pain.

Key words: Intractable pain, Psychosomatic, Hospital Out Patient Clinic, Psychological Stress, Social Environment

RESUMO (Portuguese)

Uma característica marcante do modelo biomédico é a visão de homem compartimentalizada na qual se embasa. Esta forma de ver o ser humano teve origem no pensamento grego, foi afirmada por Descartes e permanece até hoje como sendo este ser composto por entidades distintas que se combinam em determinada sorte. Como fruto desta constatação passou-se a acreditar que o foco da atenção de um tratamento de saúde poderia ser dado especificamente à área do corpo acometida, sem que fosse necessária atenção à subjetividade do doente. Compreendendo a dor como mera resposta sensorial, este modelo não pôde alcançar o que seria a dor crônica, por esta se tratar de um processo complexo podendo existir independente de lesão tecidual. A partir da segunda metade do século XX, quando se torna impossível negar a interferência entre psique e soma, surge a compreensão de dor crônica que se tem hoje: de uma experiência individual, resultado de uma soma de fatores físicos, psicológicos e sociais, não podendo por isso ser abordada de modo desvinculado ao indivíduo que a expressa. Este entendimento permitiu um grande avanço de ponto de vista por ressaltar sua característica de vivência particular. Entretanto, a compreensão de dor crônica enquanto soma de fatores faz jus ao modo atual de compreensão do o adoecimento mantendo em sua concepção a dualidade cartesiana e a premissa positivista de se voltar a uma única realidade. Para a fenomenologia, em contra partida, o indivíduo em sua unidade é mais que a mera soma de partes. Entende o ser humano como *entidade intenciona*l, onde corpo, mente e mundo são entrelaçados e constituem-se mutuamente, estabelecendo, assim, um tipo de funcionamento completamente integral do ser humano. Deste modo, o real entendimento de um processo de dor crônica só seria possível a partir de um olhar fenomenológico da experiência como vivida pelo indivíduo que a expressa e comunica.

Palavras-chave: Dor Intratável, Psicossomática, Ambulatório Hospitalar, Estresse Psicológico, Meio Social.

INTRODUCTION

This paper is the result of a theoretical collaboration carried out by professionals from the field of psychology in its interface with health, who base their interventions on the phenomenological model.

This is a critique of the way chronic pain processes have been understood by health sciences and through phenomenological thinking it draws attention to the proposal of articulating and strengthening the phenomenological perspective with health sciences.

Chronic pain is a complex object that cannot be understood based on the biomedical paradigm, because it is an individual experience and involves aspects other than the physical ones [1]. Today, pain is seen as the sum of physical, psychological, and social factors and, for this reason, it cannot be approached separately from the individual who expresses it.

The comprehension of chronic pain as a sum of factors corresponds to the current way of seeing the process of falling ill, which reflects the western view of man. This compartmentalized way of seeing the individual has its origin in Greek thought, was stated by Descartes, and remains to this day viewing the human being as composed of distinct entities combined into a certain form. As a result of this observation, one began to believe that the focus of a health treatment could be exclusively on the affected area of the body, without the need to pay attention to the individual's identity – who and how the patient could be –, a feature of the biomedical model of health.

However, not even models founded on holistic alternatives succeeded in their aim to understand what the experience of this type of pain could be. The expansion of this understanding into the psychological and social factors of the ways of falling ill represented by psychoanalysis – and later by psychosomatics – and the proposition of a different health model – the biopsychosocial – holds a Cartesian duality and the positivist premise of pursuing a single reality based on natural science methods [2].

This can be observed especially in the definition of pain in use today, proposed by IASP (International Association for the Study of Pain): "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" [3]. However, in spite of the mind-body split still present in its concept, this understanding has allowed a significant improvement in its perspective, for emphasizing that pain is a private, individual experience. Pain cannot be expressed through diagnosis technology, it is what it means for the subject that experiences it.

In the experience of living with pain, the individual's world is affected and the experiences that constitute this individual also define the origin and expression of his/her pain. The indivisible world of a patient includes his/her pain, but from the point of view of health it continues to be compartmentalized.

At heart, phenomenology tries to retrieve precisely the understanding of this individual who, in his/her unity, is more than a simple sum of parts. The individual seen as an intending entity would not be a mere product of the influences of the world, but rather a part of it, in which body, mind, and the world would be intertwined and constitute each other mutually, thus establishing the human being's integral functioning.

Therefore, to get a fuller understanding of a chronic pain process a phenomenological outlook is hard to be avoided.

The path outlined in this introduction is based on the connection between the evolution of knowledge about pain and the development of medicine, in an attempt to discuss the efforts of objectifying and subordinating pain to science in the history of both pain and science, from supernatural interferences to the focus materialized on the body. Concurrently, there is a critique of how models to understand health – products of this evolution – were not capable of achieving a real understanding of chronic pain. The next section introduces the first records about pain as an expression of something that transcends the physical body, analyzing the influence of the divided man of Cartesian thought and the attempts to retrieve a subjectivity that has been underestimated for centuries. These attempts failed, because they continued to be objectified and distant from the individual. Following, we introduce phenomenological thought as an effort to retrieve a view of man closer to reality and as the possibility of understanding what suffering from chronic pain would be. In this topic, we also discuss how distant the phenomenological perspective is from both theory and practice with regard to health.

ABOUT CHRONIC PAIN

Pain is probably one of the oldest and most universal forms of stress and one of the earliest sufferings of humankind. Understanding it is one of the major concerns of humanity; however, despite the efforts and the fact that it is as old as humanity itself, pain neither has been completely understood nor can be totally controlled [4, 5].

International compendiums and the most different scientific articles about pain are unanimous about the difficulty to define it and emphasize how hard it is to treat chronic pain [6-10].

Considered as an integral part of life, pain has always been present throughout the development of the human being, exerting a protective function on the body. Associated with diseases, inflammatory processes, accidents, and medical or surgical procedures, pain functions as a warning sign indicating that something is not well. This adaptive aspect is of great value for survival, because it is based on the sensation of pain that individuals are motivated to move away from fire and pointed objects or to seek treatment for certain symptoms. Individuals with a genetic disorder called *congenital insensitivity to pain*, although able to distinguish tactile sensations such as temperature and pressure, do not have pain among their experiences and, for this reason, are more prone to accidents and may not reach adulthood [11].

Some systems of pain classification have been developed with the didactic aim of categorizing pain and creating a terminology to facilitate communication between researchers, healthcare teams, and patients. The most common classification used today considers pain according to its duration and includes acute and chronic pain [12-14].

Acute pain has a relatively short duration, from some minutes to some weeks. It derives from tissue damage, inflammatory processes, or illnesses [7, 15]. It is felt at some moment in life by the majority of the individuals and has a positive meaning, because it indicates injury or illness. Some examples are post-operative pains, pains associated with medical procedures in general, pains derived from scratches or extensive trauma, some headaches, acute myocardial infarction, labor, and many other clinical conditions. The experience of this type of pain is a complex process that activates a series of neurophysiological, hormonal, and psychological mechanisms, characterizing an alarm reaction and preparing the body for the fight and flight response [4].

However, there is a type of pain that, even having been associated with disease or injury, persists after treatment [7, 16]. More specifically, according to the American Pain Society and the International Association for the Study of Pain, it is the pain that persists beyond the usual time for tissue cicatrization, for a period of more than three months [17, 18]. This type of pain is no longer seen as a symptom, it is considered an illness in itself, called chronic pain [7]. Much more comprehensive than a persistent symptom, it is a complex physiopathological, diagnostic, and therapeutic situation. Individuals who suffer from chronic pain hardly show any improvement, regardless of the therapeutic resources used to treat it, putting in check physicians' knowledge and patience [16]. It is typical of chronic pain patients to submit to a series of treatments, and even to unnecessary surgeries, and their pilgrimages to several doctor offices is universal [19-21].

In general, the constant presence and the long duration of pain are deeply disturbing. Pain becomes the focus of the individual's attention and makes a large part of his/her activities more difficult. Frequently, the individual ends up with altered mobility, sleep, sexual life, and humor, and can also show low self-esteem, negative thoughts, a hopeless perception of life, and changes in his/her family, work, and leisure relationships [22]. Gooberman-Hill and colleagues [23] state that pain that lasts more than three months is considered disabling, affecting several levels of the subject's activity, as well as his/her social interactions and, consequently, his/her well-being.

Craig [15] states that pain can be highly destructive of the psychological and social well-being of a patient, who can become seriously debilitated and under severe stress caused by failures in self-healing biological mechanisms and unsuccessful attempts of self-control and medical treatments. The longer pain lasts, the higher the individual's probability to be depressed, aloof, irritated, and more and more worried and persistent in his search for relief.

Rheumatoid arthritis, postherpetic neuralgia, degenerative spine conditions, osteoarthritis, AIDS, migraine, diabetic neuropathy, and phantom pain are examples of chronic pain action [16, 20, 24] as well as cancer, in which, for some authors, pain refers to a specific category: progressive chronic pain [25-27]. The chronification of pain may derive from a progressive chronic disease and emerge only at a certain moment of disease development, or derive from postoperative symptoms or sports injuries.

Chronic pains can also be classified as *organic* or *emotional*, according to the presence or absence of current or previous tissue damage. Organic pains can be *nociceptive*, when there is a peripheral painful stimulus originating from viscera or tissues, or *neuropathic*, when resulting from damage at any level of the central or peripheral nervous system. In the so-called emotional pains, the existence of neuropathic or nociceptive stimuli is not acknowledged [28, 29].

In the economic sphere, it is estimated that the cost to treat patients with chronic pains exceeds the total cost to treat patients with heart disease, cancer, and AIDS [30]. Prolonged pain is among the major causes of absence from work, sick leaves, disability retirement, severance pay, and low productivity. It is a problem of public health for its prevalence, high cost, and negative impact on the quality of life of patients and their families [31].

COMPREHENSIONS OF PAIN AND THE THEORETICAL MODELS OF HEALTH

From supernatural to submission to science

According to Rey [32], the beginning of medicine is related to pain relief, and there would be no medical art without its search for effective remedies or its effort to interpret pain with the purpose of naming the organ affected or predicting the cure for the disease. Therefore, it was in contemporary medicine that chronic pain became a medical object derived from a historical and epistemological construction [1]. This development encourages reflection on the origin of this process and on how the biomedical reasoning itself is structured.

At its emergence, medical science was closely linked to witchcraft, from which it separates when it becomes able to explain for itself the causes of diseases and to propose their cure [33, 34].

In many cultures, before the beginning of the Middle Ages, pain was perceived as a result of the influence of entities that were outside the body. Physical ailments in general were seen in Mesopotamia as sin or impurity. Disease was punishment inflicted by gods and could claim either the sinner or his/her whole family [35] . In Ancient Egypt, pain was thought to be caused by the spirits of the dead residing in the body of the individual affected by pain. In Classical Greece, with Hippocrates, and in Ancient Rome, with Galen, the first steps were taken to explain pain rationally [36]. However, the Greek tragedy of the fifth century B.C. valued a brutal and concrete interpretation of pain, contributing in a certain way to provide an irreplaceable testimony of particular expressions [32].

The Middle Ages were marked by the extended hegemony of Galenism, as a perfectly coherent system that covered all problems of medicine, and by the importance of the Arabic medicine of Avicenna. At that time, pain begins to play an important role in the prognosis of diseases, besides indicating the site affected [32].

The end of the Dark Age is marked by the use of a new class of chemical agents to control pain and the eventual recognition of the power of opium [36]. However, the changes in conceptions from Antiquity were small. It was necessary to wait for the construction of another model of science, with different demands, to see changes in the foundations of knowledge [32].

At the onset of the eighteenth century, the growth of medical and scientific knowledge was levered by the development of the microscope and by the use of dissection techniques in autopsies, which contributed to the understanding of the human body functioning. It was also in this period that it was discovered that certain diseases were caused by microorganisms, which fostered the development of antiseptic and anesthetic techniques and the progress of surgery [37].

Thus, the new science that takes shape in the Classical Age tends to abandon occult forces, beliefs and purely nominal explanations permanently: *"In this context (...) medicine itself tried to envisage the human body as a complex machine which could be compared to an ensemble of ropes, levers, and pulleys. It tried to reason in a 'geometric fashion', i.e. by rigorously stringing together all its propositions and accepting only that which could be proven"* [32] (p. 99).

It is in this period that there is an improvement in the substances used to control pain. The use of chloroform, nitrous oxide, and ether as anesthetic in surgeries, of cocaine as a regional anesthetic [38], and the identification of neuronal receptors and nervous impulses transmission eventually make pain to be treated as an exclusively biological phenomenon, to be explained physiologically [39].

Deriving from these advancements in the medical field, and based on the belief that mind and body function separately, a model of conceptualizing health and disease emerges, the so-called biomedical model. This model proposes that all diseases or physical disorders can be explained by disturbances in physiological processes, which, on their turn, can be explained by biochemical imbalance, viral or bacterial infections [37, 40, 41]. Disease would be an exclusively bodily ailment, independent of psychological and social processes. This conception was broadly accepted during the nineteenth and twentieth centuries and represents to this date the prevailing view in the medical field [42].

The divided man: the biomedical model

In much the same way as in the historical development of medicine, knowledge related to pain was deepened and approaches physical suffering separately from emotional and social events [35, 37].

The view that mind and body function separately is reinforced as knowledge improvements bring evidence that the causes of diseases and the possibilities of cure are in the body itself. The body deprived of its identity would suffice and became the object of medicine. In this context arises the biomedical model.

However, the idea of separation between body and mind is not simply a consequence of this scientific evolution process. Since the first writings about health and disease, which date back to 500-300 B.C., mind and body are seen as separate and unrelated entities [42]. Hippocrates and his students devoted efforts to eradicate the vestiges of the magical-religious way of thinking about the human body. As a challenge to healers, Hippocrates taught physicians (*iatros*) to treat only what was observable or palpable [43].

Although this tradition has its origin in Greek thought, it was the philosopher and mathematician René Descartes (1596-1650) who formulated more clearly the ideas that immediately precede the contemporary biomedical concepts about the human body [43] and that became a landmark of modern rationality [44]. For Descartes, man was composed of two substances: the soul (abstract, spiritualistic, thinking, and indivisible) and the body (the physical part, concrete, divisible). Soul was different from body in such a way that it could exist independently. The only interaction between both was through the pineal gland, regarded as the seat of the soul [45]. Likewise, since religious matters were mainly related to the issues of human soul, from that moment on it was clear that science and religion would also be set apart [46].

According to Leder [47], Descartes had a profound interest in immortality and thought the main objective of his studies was the development of a new medicine, one that could overcome diseases, postponing the arrival of death. For years, the investigation methodology chosen by Descartes was the dissection of animal bodies, with the objective of understanding their functioning, since he believed that body's life was modeled on the workings of an inanimate machine [47]. Consequently, this human body deprived of life eventually became a mark of Cartesian metaphysical and scientific explorations.

In this way Descartes, a devout Catholic, was able to preserve the soul as the domain of theology and to legitimate the body as the domain of science. The so-called Cartesian dualism thus freed biology to pursue a radically materialist thinking, but withdrew the mind (soul) from clinical practice for the next 300 years [43].

In an attempt to show that modern medicine is deeply rooted in Cartesian thought, Leder [47] reviews how the development of medicine maintained its focus on an inanimate body, the corpse: “Medical education still begins with the dissection of a cadaver, just as the clinical case ends in the pathologist’s lab” (p. 121). With medical technology, diagnostic instruments such the use of stethoscope, blood tests, and image tests allow an access to the living body similar to that achieved only by corpse dissection.

Leder points out that patients are frequently treated as corpses during physical examinations, when they are asked to assume the pose of a dead body: flat, passive, mute, and naked; if they are called upon to express themselves, it is always in search for their mechanical functioning. The knee is tapped to provoke reflexes, the abdomen is poked to see if pain ensues, and the patient is asked to breathe deeply to hear whether the lungs produce audible sounds. As in the Cartesian conclusion that the living body can be treated as a machine, medicine proposes forms of treatment that are mechanical as well: to a cardiac patient, a drug that will bring physiological changes; exercises may be recommended to strengthen the heart muscle; and, in case surgery is necessary, the body will be opened up and some vessels will be replaced. The physician uses means to alter body functioning, as one would do with a mechanical thing, replacing parts and regulating processes [47].

In this context are established perceptions of pain that Turk [14] and colleagues classify as belonging to the Restrictive Theories, among which the Specificity Theory stands out [48]. According to this theory, a specialized transmission system carries messages from exclusive skin receptors for pain to a pain center in the brain. Pain is regarded as a specific sensation, with its own sensory equipment, independent of other senses, which would result in a direct relation, with no possibility of variation between the physical stimulus and the sensation perceived by the individual; therefore, pain intensity would be proportional to the extension of tissue damage [7, 49, 50].

This proposition for the mechanism of pain as a stimulus-response reaction was initially made by René Descartes himself, in 1644, and has reached the refinement described above through improvements made by Muller and Von Frey in the following centuries [51]. This theory had significant gaps, since it was not able to explain pains not necessarily associated with injury or those that persisted after having been treated – such as phantom pain and peripheral neuralgia – and it did not admit the action of components other than the mechanical ones in the process. However, this same theory was responsible for the emergence of several surgical methods to manipulate chronic pain by nerve sectioning, which are still in use to block pain sensation [5].

The twentieth century and the attempts to connect the human machine parts: the biopsychosocial model

From the beginning of the twentieth century and with the emergence of new schools of thought, Cartesian dualism and science itself began to be questioned. It was in that century that an epistemological break occurs in the history of science, when the reductionist, mechanicist, and determinist view of the world of Newtonian physics and Cartesian thought, prevailing since the seventeenth century, is refuted.

Moreover, because of treatment improvement, disease pattern has also changed. With the advancement of medicine, the main health problems, previously associated with infectious diseases, began to be related to chronic diseases. External ailments, which would have earlier caused the individual's death, became treatable and curable. Thus, it was observed that treatment success is increasingly dependent on patient's behaviour [37].

Therefore, the interference of emotional issues is gradually admitted at the origin of the process of falling ill. This interference is seen as the exteriorization of an internal conflict with the external world [52] or as the influence of emotional and social aspects on treatment adherence and evolution. These conceptions were not considered by the biomedical model to understand health and disease processes.

Freud’s revolutionary ideas, gathered under the name of *psychoanalysis*, call attention to and also mark this epistemological break [39]. Freud’s work on conversion hysteria with patients who showed symptoms of physical diseases without organic cause attracts the curiosity of physicians and researchers to the study of the interaction of emotional and bodily processes [37]. It also contributes to understand the circumstances that culminate in the concretization of suffering in a psychological or somatic manifestation based on the investigation of the conflict origin [53]. However, Freud has never written about psychogenesis [54]. Well before him, in 1818, Heinroth coined the term *psychosomatics*, which soon fall into disuse. It was retrieved only a century later, as *psychosomatic medicine* by Felix Deutsch [55]. The main concern of this new branch of medicine was to find the symbolism of some diseases and elements to understand the relation between emotional states and organic symptoms.

Consequently, psychosomatics has been involved with the comprehension of the relation between social and psychological factors, biological and physiological functions, as well as with the development of several physical diseases, encouraging research development and emphasizing psychoanalytical interpretations about specific health problems. For such, psychosomatics was based on Franz Alexander’s idea about basic conflicts typical of diseases such as ulcers, migraines, asthma, hypertension, cancer, and others, and sometimes on the concept of psychological profiles coined by Flanders Dunbar, who considered that there were specific personal profiles predisposed to specific diseases [37, 56].

However, in spite of considering the interaction of psychological and social processes in disease states, emphasizing the individual’s history, psychosomatics is now a model susceptible to be questioned. Its concept carries a heavy semantic load rooted in the philosophical dualism of Cartesian thought – as the view of man that is being discussed here –, which have spread through modern rationality to the concept of disease as a whole. To think of psychosomatics is to assert – as in its own definition, the connection of psyche and soma – the existence of two separate entities, disregarding the notion of man as a unity; it is to treat pathologies as processes of organic or psychological order, and not as results of the interaction of an integral body, in which mind and body are one, which makes this concept redundant [44, 57].

Therefore, psychosomatics, as Turato [58] states, carries an idea of monodirectionality, a dichotomic emphasis, and induces to an impervious individualization. It thus fails to encompass an understanding of the person, to seek his/her totality and his/her form of expression, because it remains committed to search explanations based on causes or factors and on stimulus and response [56].

The twentieth century also marks the evolution of the concept of pain. Because of the gaps in the Specificity Theory, Melzack and Wall's Theory of the Gate Control, published in 1965 [48], has gained credibility for its comprehensiveness. This theory holds that pain is regulated by a "gate" that can be opened or closed by impulses from peripheral nerves or from the central nervous system, increasing or decreasing perceived pain. This mechanism of gates would be influenced by a series of factors, such as mood states and environmental stimuli, which would induce the gates of the bands of spinal cord nerve fibers to open, so that pain impulses could reach the brain, or to close, with the aim of blocking them. The physiological description of this mechanism would not be appropriate here, because there is no scientific evidence of its functioning and because it is probably incorrect; however, this theory has revolutionized knowledge about pain, for eliciting other elements of the process, such as the individual's emotional state and the integration of new therapeutic approaches, rather than being explained simply as an afferent sensory experience [59].

Based on formulations such as this one, pain is now considered by the International Association for the Study of Pain (IASP) as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" [3]. This definition admits the existence of the individual's subjectivity and, consequently, of his/her particular way of expression. As described by Lima and Trad [1], pain is in the body, in the mind, in life-history, in the everyday, in the lifeworld, *i.e.*, it is multidimensional. According to Harding and colleagues [60], chronic pain is a complex experience influenced by the individual's sociocultural environment, by his/her beliefs, expectations, attitudes, and the meaning he/she assigns to his/her own pain, as well as by biological factors.

It is in this same context, in which body, mind and social environment are partners in the process of falling ill, that the biopsychosocial model emerges. This model is understood as a humanistic approach that studies behaviors and experiences, aiming at uncovering underlying meanings and interpretations, and that acknowledges the uniqueness and complexity of the human experience [2]. For this reason, it demands a multidimensional evaluation of the individual, taking into account the aspects of the disease itself; the patient's behavior; the social, cultural, and family context in which he/she lives; and the health system itself [61].

However, we perceive that, as in psychosomatics, in spite of valuing the individual's emotional aspects and social context, this model continues to reproduce a model of thought based on Cartesian dualism. For Traverso-Yépez [2], the biopsychosocial model shares with the biomedical model the positivist premise of pursuing a single reality to be uncovered by the methods of natural science, which denotes a merely palliative stance in relation to the biomedical perspective. The biopsychosocial model adds psychological and social dimensions to the understanding of the process of falling ill more as rhetoric than as a legitimate practice [62, 63].

Consequently, so far, it seems there is no theoretical model for the processes of falling ill – especially for the experience of chronic pain – which includes the object of which it speaks: the individual. Therefore, a new way of thinking and understanding the human being is needed.

PHENOMENOLOGY AND THE INTENTIONALITY OF THE BODY THAT HURTS

The person in pain

It is based on the concept of *intentionality*, which Brentano [64] has retrieved from the Scholasticism and was later enunciated by thinkers such as Husserl and Merleau-Ponty, that we propose a way of seeing the individual opposed to the Cartesian model.

Husserl's appropriation of the concept of intentionality describes this principle as consciousness that is invariably consciousness of something, and that consciousness of something is consciousness only when directed to an object. In the same way, the object can only be defined in its relation with consciousness, it is always object-for-a-subject. An object only exists and has meaning for a certain consciousness [65]. Intentionality is each and every relation between the individual and his world; it is not in the individual nor in a certain object, but in the relation between both.

Likewise, Merleau-Ponty's philosophy proposes that, for understanding the relationship of man with the world, we must transcend dichotomies. Merleau-Ponty approaches a model of man that is not inserted in the western dualist thought either, but speaks of a subject constituted by the world, which constitutes the world, and that one does not exist exclusively for the other, but is part of the other. Man's boundaries with the world are "blurred", denying the dichotomy subject-object [66, 67].

For Merleau-Ponty, intentionality is the meaning that emerges from the contact of the individual with the world and the others in a dialectical relationship. It is a type of primordial – not rational, carnal, or bodily – perception. The intending consciousness establishes a type of integral functioning of the individual, in which body, mind, and the world are intertwined and constitute themselves mutually.

The singularity of Merleau-Ponty's understanding of intentionality is in showing that the relationship subject-world is essentially mediated by the body: "I am conscious of the world through my body" [68] (p. 122). This philosopher introduces a new way of understanding the body, which he calls *lived body*, because it is through this body that man opens himself to the world and, therefore, perceives this world and himself [68].

Thus, we understand that the *lived body* is an intending entity [47]. From the perspective that each and every relationship of the individual with his/her world is intentional and that all contact of the individual with his/her world is mediated by his/her body, we conclude that an individual is always a human being in this living body, which is permanently in relation with the world around him/her and that it is only based on this interaction that he/she constitutes his/her own world, with his/her own meanings and perspectives.

Drew Leder [47] states that the body is a material entity constituted of organs that function in a specific way, but that it also plays a subjective role. Retaking the term used by Merleau-Ponty, Leder reaffirms that the lived body is an intertwining between perception and what is perceived, it is intentional and material. When he opposes to the Cartesian paradigm, and once again echoing Merleau-Ponty, Leder affirms that the body is not simply an object in the world, but an intending entity in which the world emerges. If the body is alive, it is related, and the individual is made of these relations.

The way of seeing man described here is clearly opposed to the model deprived of intentionality and subjectivity proposed by Descartes. Understanding pain exclusively from an anatomopathological perspective, as something situated in a certain part of the body, is to not understand what feeling pain is in human terms. The body that hurts is an individual constituted by the world that surrounds him/her, influences him/her, and is influenced by him/her at every moment, and it has unique characteristics – which, without attention, may limit therapeutic intervention.

Viewed in this light, pain, when it occurs, calls the individual's attention to the affected part of his/her body and may control him/her as no other bodily experience. According to Leder [69], because of pain the individual's time and space experiences change. Perception turns to the sensation of the moment, with a focus on the site of pain. Moreover, pain can limit locomotion and eliminate interest in other stimuli. Whereas a healthy individual is able to explore the past through memories and fantasize the future, for a person who suffers from chronic pain, his/her past of pain is all that he/she wants to forget, and a future without pain is impossible to conceive [69].

As a process of falling ill, chronic pain can thus be understood as a way of being in the world, and it is not necessarily located in a certain site [70]. However, it affects the individual as a whole, for seizing his/her attention, raising questions, causing suffering, changing his/her role in the family, changing his/her work situation, limiting his/her possibilities of leisure, and so on.

The perspective brought about by phenomenology seems essential to understanding the point of view we want to achieve today to comprehend the ways of falling ill and the constitution of chronic pain – its origin and presence – in the reality of individuals.

It is not possible to reduce an individual's experience of pain to a number on a scale (as usually requested in some patient evaluations), just as one does not overcome a state of chronic pain solely by interventions based on experience or on the most recent scientific discoveries. It is not possible to provide quality help to a person whose history is unknown. To understand pain, it is necessary to give voice to the patient's experience [71].

Thus, we can conclude that chronic pain does not exist in isolation: there are individuals who manifest chronic pain, and to understand it, we need to observe it from this individual's perspective. In addition, we cannot think of a single form of process manifestation, since each individual is unique and his/her ways of understanding, signifying, and expressing are singular as well.

In Madjar's words [71]:

> To understand pain we need to understand the person in pain and a phenomenological gaze can help us to do that. The key is our attentiveness to the lived experience of the person in pain, and our willingness, individually and as members of health care teams, to work as much *with* as *on* our patients. The cognitive and technical work of pain diagnosis and treatment needs to go hand in hand with the supportive, and the affirming acts that make possible for the patient's voice to be heard and to be valued (pg. 275).

A perspective to be affirmed

The phenomenological perspective associated with healthcare, although addressed by authors such as Baron [70], Leder [69], Toombs [72] and Svenaeus [73], among others, is still rare in scientific publications.

In a survey (carried out on April 24, 2013) of the electronic database PubMed to write this paper, the association of the terms *phenomenological* and *pain* retrieved 129 studies, which are listed as material published in important medical sciences journals in the past five years. However, among these papers, just five include discussions from a phenomenological perspective; most (112) are related to research carried out from traditional health perspectives and use qualitative phenomenological methodology. The remaining twelve articles did not match our search terms: they concerned the general use of the term *phenomenological* or were related to psychological pain. Consequently, we conclude that phenomenology is present and is rather common in the field of health as a research methodology, but not as a way of theoretical articulation, of new possibilities of seeing the human being.

Within the scope of healthcare interventions and contact with patients, the phenomenological understanding of the individual is also away from professionals' practice. In these settings, we observe that the biologicist etiology, the fragmented conception of health, and the imperative and ruling character of a positivist view of science continue to be favored, overlooking the relevance of social, psychological, and ecological aspects as mediators in health-disease processes [2]. And even more distant is the understanding of these factors as intertwined. Lima and Trad [74], in an attempt to comprehend the senses and meanings assigned to chronic pain by the physicians of the pain management service of two large university hospitals in Brazil, point to a still unidimensional view of the constitution of chronic pain.

Although acknowledging the importance of psychological intervention in the process, it is only when medical understanding cannot pinpoint and explain pain that the psychologist is mentioned in the process. It is only when known physiological mechanisms are not detected that attention is given to the psychological and social determinants of pain [1]. There is a gap between health professionals' point of view and the experience lived by the patient. Professionals try to separate pain from anxiety, depression, suffering, and from other emotional reactions, to the point of assigning these aspects of the human experience to different expertise [71]. Patients, on the other hand, do not experience pain as a pure sensation; for them, pain "arrives as a complete package... painful, miserable, disturbing..." [75] (p. 149).

FINAL REMARKS

In its attempt to understand, explain, and intervene in the ways of falling ill – particularly of chronic pain –, the reductionist view of the current models of health is not able to grasp the complexity of such phenomena. With the advancement of medical sciences and the observation of physical determinants in some illnesses, in addition to the parallel cultural strengthening of Cartesian thought and positivist science, we observe an excision of all other influence on the body beside the physical, visible ones.

In face of recent evidence, based on the emergence of new theories and clinical observation, health professionals begin to understand how the determinant for adherence to and efficacy of modern treatments proposed depends more on the individual's psychosocial context than on medical technology. Then, they begin to conceive a new form of thinking about their patients, considering that, beyond patients' physical complaint, there is something subjective that interferes in the origin, expression, and management of their illnesses.

However, in the daily routine of health services, they still think of a divided individual, composed of the sum of biological, psychological, and social parts, to the detriment of a unified view. In practice, this individual is treated by different professionals in specialized walk-in services and ends up suffering from interventions that still favor his/her physical complaints or overvalue certain aspects of his/her subjectivity.

Based on what was proposed, we understand that the phenomenological thought enables a way of thinking that goes beyond what has already been theoretically structured. Reaffirming the individual's functioning as integral, unthinkable or unmanageable in separate instances, this perspective sees a human being constituted of the world in which he/she lives and of his/her experiences, who expresses in the experience of chronic pain who he/she is.

As the understanding of chronic pain is a challenge to science in its tireless attempts to objectify pain, we understand that this type of pain can be easily described in phenomenological terms, since the only way to understand the other's pain is through his/her communication of his/her subjective experience. According to

Scarry [76] (p. 13), “to have pain is to have *certainty*; to hear about pain is to have *doubt*”. It is in the phenomenological gaze that lies the possibility of understanding experience as it was lived by the individual who communicates it [71].

However, this philosophical point of view is not directly related to the theories and interventions of health psychology disciplines; it falls to healthcare professionals and researchers to reflect to articulate what the theory may affirm and what it can do for their practice, besides how to combine such theory with an already present theoretical restlessness to overcome psychosomatic theories and the biopsychosocial model.

Therefore, our intention is to provoke a critical look at the theories correlated to models of understanding health, as well as at professional interventions, services, and stances, in addition to providing suggestions of new theoretical and intervention models. We raise here the possibility of using the foundation proposed by phenomenology to structure a new model, a new way of thinking about health.

Authors’ contributions

DDL is responsible for the conception, protraction and drawing up of the article. VLPA is responsible for the drawing up and critical revision of the article. ERT is responsible for the critical revision of the article. All authors read and approved the final manuscript.

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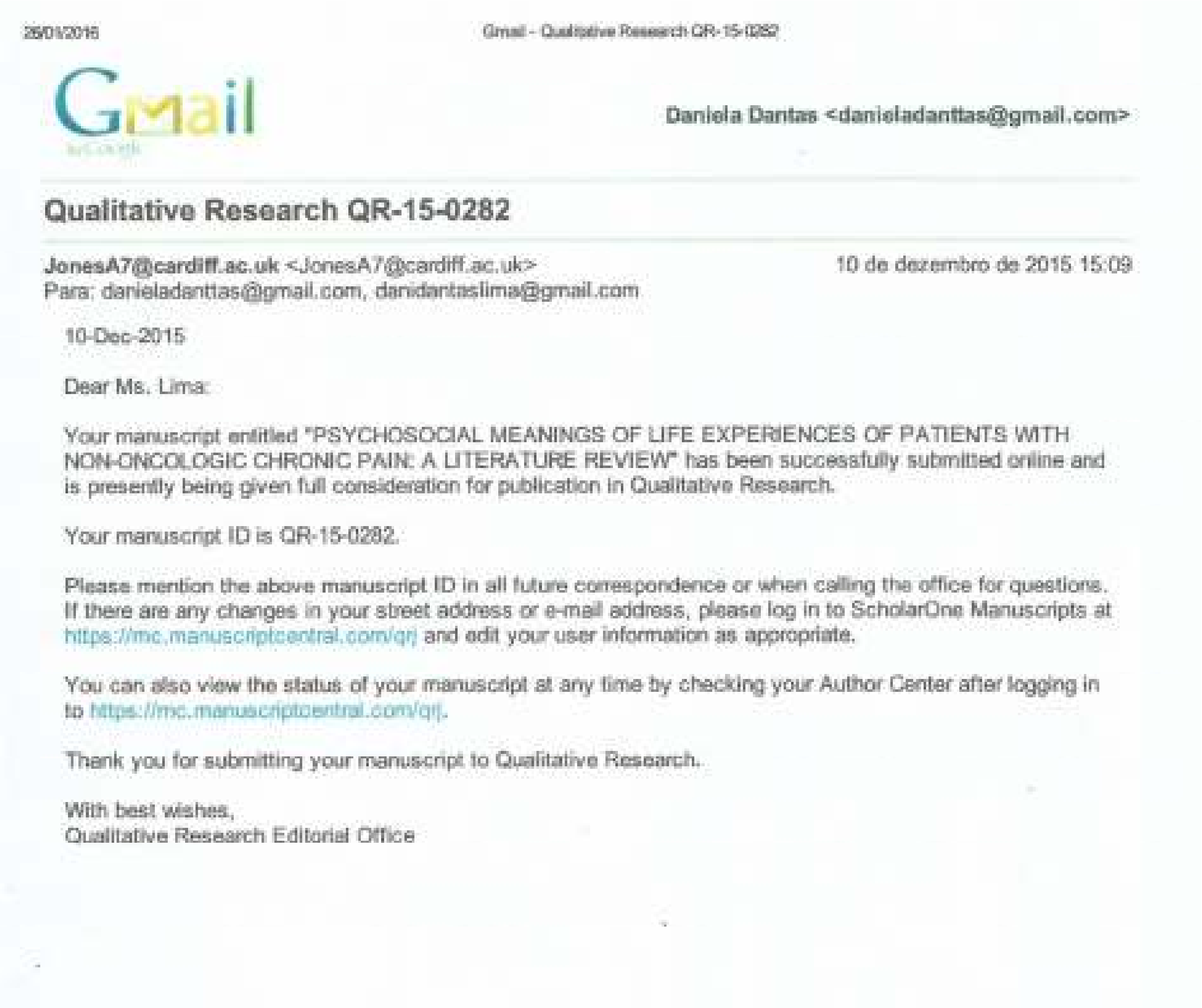
Artigo 02



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Artigo 02

PSYCHOSOCIAL MEANINGS OF LIFE EXPERIENCES OF PATIENTS WITH NON-ONCOLOGIC CHRONIC PAIN: A LITERATURE REVIEW.

Authors: Daniela Dantas Lima, Vera Lucia Pereira Alves, Cristina Aparecida Arrivabene Caruy, Egberto Ribeiro Turato.

ABSTRACT

Chronic pain (CP) is currently seen as a multidetermined phenomenon involving the interaction of physical, social, cultural, and psychological factors. This makes clear how important it is for scientific research related to this matter to go beyond isolated reflections on body, mind, and social environment to be able to provide an integrated view of the meanings of CP patients' lived experiences. Among the research methodologies in use, those that offer qualitative perspectives bring about a suitable way to explore the meanings of life experiences. Our work aimed to provide an overview of reflections on the life experiences of individuals with CP based on qualitative research studies published as scientific articles over a five-year period. A bibliographic survey of the database *PubMed* was conducted associating the terms *chronic pain*, *life experience*, and *qualitative*, considering articles published between October 2008 and October 2013. After this survey, we could confirm the impact the onset of CP has on patients' lives, which may result in a total life restructuring that includes even the individual's own identity. Among the difficulties patients faced in this restructuring process, reported in the articles under analysis, we perceived as fundamental their attempts to adapt to their new condition, as well as their suffering for not feeling understood by family members and healthcare teams. We also observed the articles analyzed tend to focus on certain aspects of CP patients' life experiences and fail to understand these individuals' actual and complete experience.

Keywords: Chronic Pain, Psychology, Psychosocial Effects of Disease, Life Experiences, Psychological Stress, Psychological Adaptation.

INTRODUCTION

The concept of the mechanism of pain as a stimulus-response reaction was first proposed by René Descartes in the seventeenth century. Since then, it has contributed significantly to the evolution of the treatment of patients with chronic pain (CP). For decades, this theory has laid the foundation for interventions with a biomedical focus and been responsible for the introduction of several surgical methods to manipulate chronic pain and for the development of drug therapies still used to block painful sensations [1, 2]. However, this concept of pain as a specific sensation, with its own sensory equipment, independent of other senses, was not able to handle the complexity of CP patients' experiences [3].

As the biomedical sciences evolved and the perspective on the sick changed, favored by the gaps left by the previous proposition, a new theory arose in the beginning of the twentieth century, bringing a revolutionary view: the theory of the Gate Control [4]. This theory brought to light other elements at play in the process of pain, such as the individual's emotional state and the inclusion of new therapeutic approaches, instead of explaining pain as a predominantly afferent sensory experience [5].

Thus, 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 [6].

Although some authors regard it as a proposition that does not demonstrate a satisfactory understanding about a person with CP [4], pain is now seen as a multidetermined phenomenon that involves the interaction of physical, social, cultural, and psychological factors [7, 8]. This relationship between psychological factors and CP has been extensively discussed over the past decades [9, 10]. Therefore, psychological and social factors are implicated in the etiology, persistence, and aggravation of pain conditions [11, 12].

Consequently, CP as a process of falling ill cannot be understood as necessarily situated in a certain part of the body. It is related to a series of physical, psychosocial, spiritual, and social struggles [13, 14] and affects people as a whole, calling their attention, assailing them with doubts, making them suffer, altering their family roles, changing their ability to work, limiting their chances of leisure. As Leder [15] emphasizes, pain calls people's attention to the affected part of the body and may control them as no other bodily experience. Pain is so intense that it is not possible to understand its process without understanding the patient's individual context as well. To understand CP, we need to give voice to the patient's experience [16].

Considering that, we perceived how important it is for scientific research related to this topic to go beyond the isolated interferences from the psychological and social spheres – encompassing more than symptoms and physical effects – to provide an integrated view of the meanings of these individuals' life experiences. Based on investigations which use qualitative methodologies, we can explore these aspects, given that one of the main characteristics of such methodologies is searching for meanings in what individuals say about the experiences they lived.

Research demonstrates the value of describing pain verbally [17, 18] as opposed to studies which classify diseases more linearly, according to pain assessment scales. This methodological approach, characteristic of biomedicine, is limited, because it does not capture the intensity of the experience this type of patient undergoes [19].

The relevance of qualitative studies on patients' life experiences also points to conclusions whose aim is to improve therapy. Knowing who the patients with CP are may produce more effective therapies [20]. An example is that of drug interventions only partially efficient to relieve pain. They often lead patients to use non-pharmacological strategies developed individually in their search for what they think is adequate to their cases [21, 22]. Thus, knowing who these individuals are and how they manage their own pain may enrich healthcare service strategies [20].

Taking into account the mentioned scientific relevance of studies on the life experiences of individuals with CP, this paper aims to provide an overview of what has been produced and published about the topic over a five-year period. We intend to present the researchers interested in the subject with organized information about the complexity of CP patients' life experiences reported in the literature.

MATERIAL AND METHOD

This is a literature review carried out using PubMed, a database that covers leading journals in the field of biomedical and allied sciences. To conduct our survey of Pubmed, we combined the search terms "chronic pain", "life experience" and "qualitative", considering the five-year period from October 2008 to October 2013. The steps taken were the following:

- First, we combined the terms "chronic pain" and "life experience" to focus on the theoretical aspect of our project on the lived experiences of CP patients; then, in a parallel subproject, the results of this first search will be used to contextualize our field research with CP patients. As mentioned in the Introduction, the term "qualitative" was chosen because it represents the methodology we believe to be adequate to an investigation into individuals' life experiences. This is the methodology used in our field study, in line with the approach adopted by the research group to which the authors of this article are affiliated.

- Second, we critically examined 51 articles. Of this total, we excluded 37 for one the following reasons: they explored life experiences focusing either on the process of falling ill or on treatments, and not on the CP experience itself; their participants were health professionals or patients' relatives, and not patients themselves; or they applied mixed qualitative and quantitative methodologies.

- Third, we read the fourteen remaining articles carefully, focusing on their findings and looking, at the same time, for thematic similarities among them.

- Finally, we faced the methodological challenge of establishing relationships among the similarities found in the material we extracted from the articles, organizing these similarities in topics to be discussed, and building a harmonious relationship among them.

Although the researchers of the Laboratory of Clinical-Qualitative Research, to which the authors are affiliated, have monitored all four steps, the last one, that of classifying the results in topics, required several debates and rounds of peer-reviewing.

RESULTS

The articles chosen for our study are from different countries: two from the United States; two from New Zealand; one from Spain; one from Ireland; two from Sweden; three from the United Kingdom; two from Australia; and one from Canada. All have been published in English, except for the one from Spain, which was published in Spanish. These articles focus on individuals with CP, independently of the type of the pain they have or of specific types of CP, such as fibromyalgia, neuropathic pain, chronic low back pain, chronic knee pain, or chronic pelvic pain.

Regarding their objectives, the studies by Soklaridis *et al*. (2011), Persson *et al*. (2011), Ong *et al*. (2011), Löfgren & Norrbrink (2012), Traska *et al*. (2012), Dow *et al*. (2012), West *et al*. (2012), and Robinson (2013) intend to explore a particular aspect of life experiences, for example: type of patients' discourses; strategies used to cope with pain; the frustration experienced; the meaning of resilience; or how individuals reconstruct their biographies after experiencing chronic pain. The research by Clarke *et al*. (2012), Budge *et al*. (2012), and Ferrer & Pera (2013), besides investigating life experiences, aim to provide information to healthcare professionals. The others – Denny (2009), Crowe (2010), and Lin *et al*. (2012) – have as their only purpose to explore life experiences. Table 1 details this information.

The results of these studies make clear for us that the onset of pain in the life of an individual has an impact that can produce a total life change. This process of change is marked by patients' attempts to adapt and by their suffering, caused by lack of empathy on the part of family and healthcare providers.

Our understanding resulted from our readings, and we introduce it here as four categories: (1) *The impact;* (2) *The coping*, (3) *Non-legitimate suffering*; and (4) *Identity change*.

Reference	Year	Author	Type of CP	Aims	Results
26	2013	Robinson, K; Kennedy, N; Harmon, D.	Chronic pain	To investigate the discourses used by people with chronic pain.	Participants rejected a biomedical discourse by proposing their own explanatory models of pain, resisting psychosocial understandings of pain, criticizing medical professionals and healthcare services, and challenging medical expertise, professionalism, and power.
32	2013	Ferrer, MCO; Pera, MPI.	Fibromyalgia	To show the experience of people suffering from fibromyalgia through ethnography and narrative, and a reflection to raise and question the direction of professional care.	Highlight the stress generated in the waiting time to diagnosis and the vital break which means the disease, the difficulty of sharing with family and friends, the conflict with health system and the limited presence of nurses, the interest to remain active at work and personal life although tightly constrained by the pain and discomfort, treatment adherence, aids association representing, and thinking the present and little for the future.
20	2012	Löfgren, M; Norrbrink, C.	Neuropathic pain	To explore and obtain increased knowledge about (i) strategies and treatments used by individuals with neuropathic pain following spinal cord injury (SCI) for handling long-term pain, and (ii) their experience, needs and expectations of SCI neuropathic pain management.	A model with four categories emerged: "Pain is my main problem" explained the impact of pain in the informants´ everyday life; "Drugs: the healthcare solution" described the informants´ experiences of pain management; "The gap in my meeting with healthcare" described the discrepancy between what the informants wanted and what health care could offer. "But… this works for me" described treatments and strategies, which the informants found helpful for pain control and pain relief.
27	2012	Lin, IB; O´Sullivan, PB; Coffin, JA; Mak, DB; Toussaint, S; Straker, LM.	Chronic low back pain	To achieve an in-depth understanding of the CLBP experience from the perspective of Aboriginal people living with the condition.	The experience of CLBP was found to be multidimensional, impacting on activities of daily life, employment, sport and family participation, emotional and cultural well-being.
17	2012	Clarke, A; Anthony, G; Gray, D; Jones, D; McNamee, P; Schofield, P; Smith, BH; Martin, D.	Chronic Pain	To gain insight into how older adults with chronic non-cancer pain describe their pain, with a view to informing professional approaches to its assessment.	Qualitative individual interviews and one group interview were undertaken with 23 older adults. Following analysis, the following main themes emerged: diversity in conceptualizing pain using a simple numerical score; personalizing the meaning of pain by way of stories, similes and metaphors; and, contextualizing pain in relation to its impact on activities.
25	2012	Budge, C; Carryer, J; Boddy, J.	Chronic Pain	To learn more about people's experience of pain in the context of long-term illness, in order to inform primary health care practice.	Three main themes, which were common to all authors' analyses and are considered most relevant to practice, are presented and discussed. These themes were labeled 'medication concerns', which encompasses side-effects, reluctance to take pills and pain medication as a choice; 'coping with pain', including acceptance, pacing yourself and non-pharmaceutical pain relief; and 'seeking help for pain', which included negative and positive experiences and lack of care continuity.
29	2012	Traska, KT; Rutledge, DN; Mouttapa, M; Weiss, J; Aquino, J.	Fibromyalgia	To describe how persons with fibromyalgia manage their lives given the multiple symptoms they experience, in particular how they use non-pharmacologic strategies, or how they incorporate these strategies along with pharmacologic agents.	Participants reported many strategies to cope with fibromyalgia symptoms and manage their lives. Main strategies included: 'pacing/planning', 'distraction techniques', 'coping with touch sensitivity', 'putting on the mask' and 'medications'. In addition, 'social support' from others with fibromyalgia and from family members was reported to be very important.
23	2012	Dow, CM; Roche, PA; Ziebland, S.	Chronic Pain	To improve understanding of the sources of frustration for people with chronic pain and consider the potential influence of frustration on the chronic pain experience and relationships with health professionals.	Frustration is a multi-faceted emotion and its effects are cumulative. Sources of frustration include interference with everyday activities, the interruption of life goals and roles and the unpredictability of pain; here we focus on the frustrations associated with the invisibility of chronic pain and the perceived limitations of diagnosis and pain management (both related to the perceived legitimacy of the condition). Several of the participants who had lived with chronic pain for many years described overcoming, or managing, their frustrations.
33	2012	West, C; Stewart, L; Foster, K; Usher, K.	Chronic Pain	To explore the meaning of resilience, or adaptation in the face of adversity, to people living with chronic pain.	The findings from this study revealed that while living with chronic pain is generally a negative experience, the participants also told positive stories around the following themes: (i) Recognizing individual strength; (ii) Looking for the positives in life; (iii) Accepting the pain; and (iv) Learning to accept help.
31	2011	Soklaridis, S; Cartmill, C; Cassidy, D.	Chronic Pain	To explore how injured workers living with work-related chronic pain rethink and reconstruct their biographical experience.	Analysis of the focus groups revealed the impact that chronic pain has on the social components of an injured worker's life; particularly their sense of self, their relationship to others and how they perceive themselves in social situations.
30	2011	Persson, D; Andersson, I; Eklund, M.	Chronic pain	To investigate how people with chronic pain experience their daily doing, with a special focus on possible adjustment to pain and altered life conditions in order to cope with pain and maintain well-being.	The findings showed that along with the grief of having to abandon jobs and former social networks, the participants coped with their everyday lives in ways that opened up the use of imagination and improvisation and the valuing of non-material and altruistic behavior. An occupation was generally given up when aches (participants' term) became worse, except for when the occupations were so enjoyed that the pain was put out of focus.
28	2011	Ong, BN; Jinks, C; Morden, A.	Chronic knee pain	To examine how people live with knee pain, giving focus on the meaning and enactment of self-management in everyday life and the hard work associated with devising and maintaining routine adaptive strategies.	It emerged that self-management could be based on implicit and incremental learning from experience or on explicit evaluation of actions. Either way, embodied and emotional hard work was involved in maintaining a daily life that allowed people to fulfill social roles and relationships.
24	2010	Crowe, M; Whitehead, L; Gagan, MJ; Baxter, GD; Pankhust, A; Valledor, V.	Chronic low back pain	To investigate peoples' experiences of the impact of chronic low back pain.	Four main themes were identified: the unpredictability of the pain, the need for vigilance, the externalization/objectification of the body and the alteration to sense of self.
19	2009	Denny, E.	Pelvic pain (endometriosis)	To explore women's experience of living with endometriosis.	Uncertainty exists around diagnosis, the course of the disease, and the future. It is argued that the way in which the pain of endometriosis is interpreted and managed by women and health professionals is integral to this uncertainty.

Table 1: List of articles analyzed for this literature review

1) The Impact

The literature analyzed mentions that the onset of pain in the life of individuals may impact the simplest everyday activities, and eventually make them permanently unable to accomplish their daily activities or fulfill their social roles, causing emotional damages. This impact is emphasized and refers to CP traits from the beginning: invisibility, unpredictability, limiting character, and negative feelings.

CP invisibility make it hard to be communicated to and recognized by others [23]. In one of the studies analyzed [19], the authors identified the struggle of female patients with chronic pelvic pain, often mistaken for a common period pain.

Other study points out that, for its female participants, one of the major impacts of pain is related to the fact that they do not know when or how it will come and which actions will exacerbate it [24]. This confirms CP unpredictability, supposedly a life experience so significant that one of the studies focuses on the uncertainty that involves the experiences of patients with endometriosis [19]. The authors discuss their patients' uncertainties about diagnosis, the course of the disease, and the future.

One of the articles calls attention for the fact that their interviewees' stories often focus on the restrictive or totally disabling character of CP [17]. Pain invariably affects the daily activities of the interviewees, restricting or disabling them completely. For the participants, the severity of pain is related to gains and losses in physical and social activities. Other studies also discuss how the everyday life – activities and relationships – of an individual with CP is affected [17, 25-30]. Löfgren and Norrbrink's [20] interviewees consider pain as the worst problem in their lives.

The feeling of frustration is the subject matter of one of the articles under discussion [23]. The authors perceive in participants' discourses that life experiences associated to CP processes, such as those described before, trigger a frequent feeling of frustration. These authors identify frustration in the narratives of their interviewees about CP invisibility and diagnosis and management limitations. They state that frustration, in these cases, is cumulative. Other studies also identify the feeling of frustration in their interviewees' accounts [31, 27].

The emotional cost, although little explored, is apparent. Lin *et al*. [27] mention that CP emotional consequences are widespread among their subjects, especially the most debilitated. The authors describe what they call negative feelings in these individuals, for instance: anger, depression, fear, or anxiety. Mood swings, irritability, worthlessness, fear, shame, inadequacy, and emasculation are also feelings identified and discussed by Soklaridis [31].

2) The Coping

The authors of the studies under analysis mention that research subjects try to develop means to adapt to their reality and remain active. They develop their own ways to relieve pain and accomplish their activities, in an attempt to adapt to increasing pain in their lives. The studies we analyzed discuss this type of action separately, addressing either the action related to coping with pain itself or the action related to coping with daily activities.

Concerning actions to relieve painful sensations, these studies state that it is while experiencing pain that people find out and/or create alternatives to cope with it. The adjustments individuals make in their lives are based on what they have learned through experience and experimentation [28, 19, 29]. Individuals with CP develop their skills by "trial and error", and become experts at dealing with their problem [26, 19, 20]. Therefore, each individual develops his/her own treatment.

One of the studies identifies amusement and holistic techniques as some of the resources to relieve pain. Listening to music or white noise, taking a bath or shower, relaxing the muscles, taking a leisurely walk, singing, etc. are resources used by this study's participants as a way of taking the focus off of pain and discomfort [29]. In the same vein, other study points out that its interviewees found and used non-pharmaceutical methods [25]. Having good ergonomic furniture, such as a good chair to rest, is considered very important; the warmth derived from a bath or shower, from a blanket, mattress or heat package is also often mentioned, as well as massages, physiotherapy, lying down, and listening to music.

Other authors observed in their patients' narratives a strategy they call *daydreaming* as another way of getting distracted from pain [30]. Daydreaming concerns thinking of desired occupations for the future, such as a trip. Reading a book is an activity some individuals consider positive, whereas others speak only of the value of "doing something" to not focus on their pain, without referring to any particular occupation. Using equipment, music, and movement techniques, changing position, taking breaks, stretching, amusing themselves, and resting are aspects mentioned in another study [26].

The importance of getting distracted from pain to relieve it is clear; however, some pleasant activities – which take the focus off of pain – are mentioned as potential aggravators, for example: taking care of grandchildren, doing sport activities, and going on vacation [30, 28].

According to this literature, for some individuals pain is so severe and limiting that getting through the day is a challenge and requires detailed planning. Pacing activities is considered in these studies as another way of mitigating pain derived from physical exertion. This is a strategy frequently used by the participants of one of the studies analyzed, as well as reducing speed when walking, getting up, and doing daily activities [28].

About coping with practical daily living, one of the studies draws attention to the fact that the daily presence of pain forces individuals to think about the implications of all their actions. It illustrates this understanding with the story of one of its interviewees, who stated that simply parking his car would become a worry for him, because of his chronic knee pain [28].

Frequent or occasional difficulties in self-care, such as getting dressed and looking after personal hygiene, as well as doing household tasks, are often stressed in the studies analyzed. In some cases, the individual cannot get out of bed because of the severity of pain, which varies from day to day [27]. Research participants also state that there are days when they cannot bathe or even move [29]. They say they are sensitive to touch and that even the contact of clothes with their skin can be painful [29]. Therefore, routine activities become challenges, and patients report difficulties walking, cycling, walking the dog, going to the post office or to the mall, cleaning the house, cooking, washing clothes, gardening... [17, 30]. Becoming unable to work can also be a consequence for those living with CP [27].

Some studies [25, 26, 29, 30] identify countless research participants who attempt to remain productive. Their main way to manage daily living and increase chances of accomplish important tasks, with the aim of mitigating pain, is described by one of the studies as *pacing their activities* [29]: “Pacing has involved consistently planning ahead, balancing activities over time, and allowing others to assist them in completing important tasks”. The authors explain that individuals become cautious about the amount of effort dedicated to an activity and about the amount of activities they can do. The authors consider it a learning process, because, on the days the pain is not so intense, the individuals tends to do more, and the more they do, the more intense the pain comes back, making them suffer for days afterwards. Therefore, even when patients feel better, they remember that there is a limit for their actions.

This strategy was also reported in other study as *slower pace and performance of daily doing* [30]. In this study, women – who are in general responsible for household tasks – tell they split up their duties over the week, doing a task a day or an activity at a time, with no hurry. This attitude of moderation is also reported by other study’s participant, who says he does everything he used to do, but it takes him longer [25]. Along the same lines, the following strategies for accomplishing activities are highlighted: using medication, resting, taking breaks, changing position, prioritizing, having targets, doing things differently, and getting assistance [26].

3) Non-legitimate suffering

The studies analyzed here discuss the difficulty CP patients have to communicate their suffering and to see it recognized by their families and healthcare teams. One of the studies stresses that these individuals report they are seen by others as whiners, hungry for privilege or attention. They perceive that other people doubt their problems and are not interested in them [26].

The participants of another study complain that CP is an invisible condition. They point out that this fact makes pain difficult to communicate and prove [23]. Patients say they wish pain were visible (identifiable by others), making them look bluish or showing a letter “P” on their foreheads. In this way, others would not doubt the pain is there. These participants also complain that family and friends do not believe in them or seem to forget they have a problem.

The interviewees of other study state that the only people able to understand those who live with CP are other CP victims [29]. Another research, whose subjects are women with chronic pelvic pain, highlights that both family and healthcare professionals are perceived as those who make patients think they have some kind of moral flaw, since they cannot face their period pain as other women do [19]. One of the participants reports being accused by her doctor of overstating her pain when the site of her endometriosis was taken into account. Such accusation derives from the fact that this kind of CP is associated with a tissue lesion that can be seen through imaging tests.

As to healthcare professionals, patients complain that healthcare teams are not interested in their experiences, nor in the knowledge they have acquired of their own pain, nor in the way they cope with it. Patients say there is no interest and no support for any issue besides medication [20].

The relationship between healthcare professionals and patients with fibromyalgia is highlighted as often frustrating in one of the studies [32]. The authors report that the participants complain that their healthcare teams do not believe in them. These patients state that healthcare professionals do not recognize their diseases and do not give them adequate attention. Complaints also appear frequently in another study, which points out that patients are not heard by their doctors, who are not interested in patients with pain. From patients’ perspective, health professionals get tired of frequent complaints and give up on treatments, as they no longer know which procedures to adopt. The article also discusses the participants’ suspicion that their doctors assume patients pretend to feel pain [25].

One patient describes the double challenge of coping with her problem and making an effort to legitimate it before her doctors [23].

4) Identity change

According to the studies analyzed, after significant life changes that alter activities, feelings, perspectives, and relationships, individuals with CP start to perceive themselves differently, and may eventually come to the conclusion that they are no longer who they used to be.

The new situation of these individuals' existence is understood in one of these studies as an *alteration to sense of self* [24]. The authors highlight in their research subjects' discourses how their "sense of self" had altered since they had experienced chronic pain problems. The researchers state that the experience of chronic pain altered not only lifestyles, but also the way their patients used to see themselves.

Other authors have also identified the alteration to sense of self as something relevant in their interviewees' reports. Soklaridis *et al*. [31] observed their subjects – workers with CP – had lost the sense of who they were. These patients compared who they were before and after the lesion that triggered the chronic pain and perceived that their "real" selves have been interrupted at some point before the onset of CP. They report difficulties in knowing their identities and understanding who they are now and who they will be in the future. In another study, the authors draw attention to a biographical interruption in their subjects' lives: the difficulties they face to adapt to the limits of a formerly active time at work and at home, in which disease represents a rupture with their previous lives [32].

Other studies analyzed here also point to an alteration in participants' values [33, 30]. A revision of values or the adoption of new values may happen as a result of changes in patients' lives. The new values come as a way of resignifying a lifestyle that became more restrict. Doing things on their own, as well as enjoying moments of more independence, are examples of how some people start to face the social restrictions of which they are victims. Finding meanings in non-material values, enjoying what is simple, learning to see the funny side of things, imagining that the situation could be worse, and hoping it improves are also aspects derived from CP experience considered as positive in many studies.

Therefore, changes of perspective that culminate in the acceptance of a new condition may improve well-being and quality of life. The acceptance of pain is identified by Budge *et al.* [25] in their interviewees' stories as an adjuvant aspect in coping with the problem. The authors observe pain becomes, for some people, an important part of who they are. In the same vein, West *et al.* address the tolerance to pain described by their patients as a learning process, a way of adapting to pain as part of their lives [33]. Accepting pain, for many of their interviewees, was a long process that involved assimilating the changes that occurred in their lives and redefining their identities.

DISCUSSION

We think our findings point to the importance of understanding CP as inseparable of individual contexts: who the subjects who experience CP are; with whom they relate; and what the environment where they live is. This helps us understand the origin of this process of falling ill, the way it is expressed, and how it is managed. The studies analyzed have reports that go beyond the mere complaint about the physical discomfort of pain. In their narratives, patients emphasize how pain spreads, affecting negatively their whole existence. Pain is not situated in the organ attacked; it affects the whole life of a human being.

According to these research studies, the impact of CP experience seems to exceed the uncomfortable feeling of frequent pain. It is aggravated by its effects in individual contexts and it is not merely the single impact of living with the frequent feeling of pain, but, rather, of pain plus the difficulty of communicating it, the unpredictable way it affects everyday life, and the limitations to accomplish daily activities. The intensity of these events generates a series of negative feelings expressed by the individuals who experience them.

Therefore, the impact of CP on the life of an individual can be so significant that it is compared to devastating events such as the death of loved ones, and can even be considered the worst event ever in someone’s life [34].

The literature analyzed states that individuals with chronic illnesses face moments of crisis because they experience adverse situations related to their illnesses [35-37]. A disease affects the dynamics of a person’s development, generating an inner disagreement. The disease breaks people’s dynamics and relationships with themselves and the world, emerging as an enemy to be found, studied, and fought [38].

A permanent disease makes individuals experience loss in social and financial relations, physical abilities, leisure, and so on. These losses derived from the constant presence of pain may result in low self-esteem and lead to social isolation. In addition, constant challenges to individuals’ integrity, such as the feeling of being stigmatized, the loosening of social bonds, and personality changes may lead individuals to experience negative emotions that are difficult to eliminate and that can hinder their rehabilitation processes [39].

The impact of these new life experiences causes the whirlwind of emotions described in the studies discussed. The whole of the negative experiences interfering with the practical and emotional life of patients may cause mental health problems. Maybe this is one of the reasons why anxiety and depression are so common in CP patients [40].

The results of the studies analyzed highlight patients’ limitations caused by CP and patients’ attempts to not let these restrictions affect their daily activities. The narratives of research subjects often focus on attempts to overcome pain and its limiting character. Some studies focus specifically on aspects of their participants’ discourses that show the methods they use to change the situation in which they are living, caused either by pain or by the limitation pain imposes.

As to coping with painful sensations, other studies confirm the idea discussed in the articles analyzed. These studies conclude that through experimentation individuals develop specific ways – alternative to traditional medicine – to relieve their pain [41-43]. Similarly, with regard to coping with daily activities, it is already known how important work and autonomy are for an individual’s health and well-being [44, 45]. In some studies on CP, patients’ accounts stress how important it is for them to remain engaged in their occupations, despite the pain [46-48], in an attempt to not give up to CP.

In a study on women with CP, there are narratives based on metaphors for fighting, describing how these women carry on despite their pain and how they complete what they perceive as their duties or social obligations [49]. May *et al*. underline the notion of “hard work” related to the effort individuals have to make to remain active in spite of their disease [50, 51]. According to Belgrave [52], for CP patients, their struggle can be time-consuming and requires effort, leaving them with little time and inclination to do other things. Yet, pain patients do not consider this focus on daily activities as something extraordinary or deserving special attention. On the contrary, “hard work” does not even emerge as something planned [53], it tends to be obscured.

On the other hand, in the studies analyzed, patients do not report any kind of benefit derived from their processes of falling ill, such as financial gain or change in family roles. Likewise, there are no stories of specific aspects of individual suffering and failure without a subsequent description of attempts to change the situation.

Robinson *et al*. identify a moral aspect in their interviewees’ narratives, related to the effort they make to show they behave properly. According to these authors, an immoral behavior for people with CP would be to pretend, to overstate, or to give up to pain to obtain “rewards” such as financial help, leaves of absence from work, or attention. These individuals describe themselves as honest people going through real pain, with no intention to burden others, trying to accomplish their activities and fulfill the requirements of their social roles, despite the pain [26]. The emphasis on this moral aspect is also highlighted in other qualitative studies, in which participants describe their attempts to demonstrate how efficiently they fulfill their obligations in order to be considered people of high moral standards. They reject the idea that the onset of pain is related to personality or individual weakness, or that pain is a call for attention or an excuse to avoid working [54, 55].

The studies analyzed do not include subjects' narratives about the possibility of getting something from their processes of falling ill, nor show stories of suffering itself. Similarly, they do not favor these aspects as the core of their investigation. Their interest is invariably focused on how individuals cope with and try to overcome pain and not on how they suffer from it.

Concerning patients' narratives about the difficulty of having their suffering recognized by others, we observed that aspects related to family involvement in CP patients' disease processes are mentioned in various other studies besides those discussed in this review. It is known that CP consequences affect not only patients' lives, but also the lives of their partners and family [56]. This interference can be so significant in the family environment that it may produce affective and sexual changes in family relationships. Family roles change, as well as family perspectives for the future, which eventually can change the family dynamics completely [57, 58].

Nevertheless, we did not find in any study on families reports showing they do not believe in the sick family member. Quite the reverse, when these studies stress the negative feelings expressed by CP patients' relatives, these feelings are pacified by their feeling of guilty and their responsibility for the family member who is sick [59, 58]. West *et al*. [58] identify anger when addressing the negative feelings of families toward an individual with CP. However, anger is described as related to CP and not to the sick family member. Consequently, these studies approach aspects of the stoic and committed attitude of families and partners. Some families even exhibit a symbiotic dynamics, in which family functioning focuses on the individual with CP [59, 60].

Similarly, theoretical discussions about the perception of individuals with CP concerning lack of understanding on the part of families are rare. Smith and Friedemann [59] discuss this topic briefly and conclude that the perception of these individuals may be related to a supposed difficulty of people with CP to express and share their feelings.

Even rarer are studies on how healthcare professionals perceive patients with CP. It seems that little has been explained about the lack of understanding on the part of healthcare professionals mentioned by CP patients. This unfavorable and stereotyped view of certain types of CP emerges only in patients' complaints reported in studies such as the ones analyzed in this review, but it is still little discussed [61].

However, we question whether this event is related to the well-known difficulty of biomedical model in understanding and managing CP. Lima *et al*. [4] state that, because of cultural influences and isolated scientific evidence, it is a characteristic of the biomedical model to direct attention specifically to that "part of the body" affected by the disease. It means that this type of intervention can be successful, even when no attention is given to the patient's identity. Because the situation opposes to this one and is complex in terms of physiopathology, diagnosis, and therapeutic management, the process to treat CP is extremely consuming not only for patients, but also for the professionals who take care of them [62].

Lima and Trad [63] explain that, in many senses, CP escapes the biomedical paradigm and creates situations that threaten knowledge and practice in the field of professional healthcare. For these authors, CP transgresses the background of empiricist rationality, because it is not necessarily situated in a "part of the body" and because it is not simply a problem of nervous transmission. It then becomes an enigma. Moreover, CP victims hardly improve, independently of the therapeutic resources used, putting in check doctors' knowledge and patience [62].

The data discussed here show how appalling is the lack of studies on families and healthcare teams addressing their negative feelings toward individuals with CP. These feelings are clearly perceived by the participants of several investigations, and the studies that intend to examine families and healthcare teams specifically are emphatic when they mention the difficulties both of them face in the care of a CP patient. However, these difficulties are not expressed as something that affects the professional or the family negatively, but as something that motivates caregivers to change themselves and to be more efficient in the care they provide. The focus of discourses and investigations turns to morally appreciated aspects of life experience meanings.

Another aspect identified in the studies analyzed refers to the possible identity change individuals go through. Living with a chronic condition is an experience in which daily life structures and its guarantees are deeply disturbed and require a fundamental rethinking of a person's biography. The onset of a chronic illness in someone's life can be understood as a "disruptive event", since it affects personal life, its meanings and expectations, that is, one's personal "biography" [64-66].

Corbin and Strauss [67] use the expression *biographical work* when they refer to patients' struggle to adapt to their new condition after being diagnosed with a chronic illness. Several studies have demonstrated that individuals with chronic illnesses become innovators in the face of their condition, because they have to create new meanings and values for their lives. Besides managing their illness, these individuals have to negotiate their social roles actively, face the problem of stigma every day, and try to resume their lives, which have been interrupted by a fatality [68, 69].

Changing the routine according to their limitations and the feelings aroused in the process of falling ill generates modifications not only in the way people organize their practical lives, but also in the way they start to perceive themselves while they go through the process. Thus, it is expected that chronic illnesses will alter the self; it is expected that an individual's identity will change.

The ability of CP to change one's identity is addressed in some studies [70-72]. For Aldrich and Eccleston [70], one of the defining characteristics of pain is its intrinsic ability to modify the self. In other study, Eccleston [55] states that the fundamental and threatening challenge to the identity is central in the experience of prolonged suffering.

FINAL CONSIDERATIONS

From a general perspective, the studies analyzed here show the impact of pain on people's lives, depending on its magnitude, can affect their most basic daily activities to the point of preventing individuals from working and fulfilling their social roles and changing their way of behaving and thinking.

The impact of the onset of pain is marked by generalized losses and causes intense suffering. The constant presence of pain ends up affecting directly the accomplishment of everyday activities. Pain constrains its victims to think about the implication of all their acts. However, it seems these people, despite the pain, insist on remaining active and try, also despite the pain, to adapt to the tasks to be accomplished. Moreover, they make an effort to show they can be successful and try to keep their functioning as close as possible to what it used to be.

As part of this process, patients also suffer for not feeling understood by their families and healthcare providers. In face of such a significant life change, which alters activities, feelings, perspectives, and relationships, the individuals start to perceive themselves differently and see they are no longer who they used to be. At this point, they stop asking for help and believing in treatments. It is then that frustration yields to resignation and a change of identity occurs.

We also confirmed that the scientific literature related to the topic is not scarce. However, we observed in this literature a tendency to narrow the focus of investigation, thus missing what might be understood about the real and integral experience of an individual with CP. These studies, despite valuing patients' narratives, instead of collecting data through instruments, maintain a perspective subordinate to the biomedical model, which emphasizes limited aspects of life experiences, such as patients' type of discourse; the strategies they use to cope with pain; the presence of certain feelings; the way they reconstruct their biographies after the experience, etc. These studies' methodology and understanding do not reflect an integral view of the human being. They seem to focus less on what patients suffer or experience in general and more on their chances of improvement.

On the other hand, the moral aspect identified in patients' accounts can make them co-responsible for this research focus. Not only do individuals with pain direct their narratives towards morally appreciated aspects, but also probably their families and healthcare teams, since we did not find discussions about personal difficulties related to coping with CP.

Therefore, patients, families, professional healthcare teams, and researchers seem to focus on what is understood as positive by common sense, making a tacit agreement to take only a superficial look at what they propose to discuss. Narratives and investigations focus on morally valued aspects, giving up on a real contact with patients' life experiences and, consequently, on going more deeply into their meanings.

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Compliance with Ethical Standards

We declare we do not have any kind of conflict of interest related to this material.

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Artigo 03

PAINS BEYOND LIFE EXPERIENCES WITH NON-MALIGNANT CHRONIC PAIN: A QUALITATIVE STUDY OF BRAZILIAN OUTPATIENTS

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ABSTRACT

Introduction: A pain that lasts for more than three months is considered disabling and affects individuals' activities at different levels, their social interactions, and consequently their well-being. Chronic pain as a process of falling ill cannot be understood as confined to a certain part of the body; it relates with a set of physical, psychosocial, spiritual, and social difficulties. **Objective:** To understand the range of meanings the outpatients of a specialized service of a teaching hospital in the state of São Paulo, Brazil, attribute to their chronic pain experiences and the impact these experiences have on their lives. **Method:** The qualitative method was used, with semi-directed interviews with open questions. The sample size was completed according to the saturation criterion and data were treated as follows: complete transcription of interviews, text skimming to unveil cores of meaning in the interviewees' narratives, categorization in topics to be discussed, and qualitative analysis of content. **Results:** Sixteen interviews were conducted, whose analysis revealed five categories: 1. *It seems a bug is eating you:* metaphors as expression of personal meanings; 2. *I learned to get used to it:* reluctant acceptance of fate; 3. *It hurts when I get nervous:* the encounter of body and mind; 4. *I wonder if I hadn't come here how I would feel now:* satisfaction with treatment despite its limitations; 5. *Am I getting to explain it right or am I talking much more about me than about the pain?:* pains beyond the chronic pain. **Discussion:** The subjects' narratives express pains beyond their chronic pain and reveal how much they need that their individual suffering become valued. **Conclusions:** Understanding patients' emotional state and the context in which they live when they come to health care, besides welcoming their expressions, may contribute to treatment evolution, since these expressions may be understood as demands and managed accordingly.

Keywords: Qualitative Research, Chronic Pain, Life Experiences, Psychosocial Effects of Disease, Psychological Stress, Psychological Adaptation.

INTRODUCTION

According to the International Association for the Study of Pain (IASP), chronic pain (CP) is today one of the most underrecognised, undertreated medical problems (1), despite affecting about 20% of the world's adult population (2, 3). A research carried out in 16 European countries and in Israel revealed that 19% of the population under study had been suffering from moderate or serious pain for at least six months (4). In the United States, pain affects more individuals than diabetes, heart disease, and cancer combined, and it is the main cause of disability among people up to 45 years of age (5). In Brazil, there is no epidemiological study including all regions; however, regional studies show prevalences ranging from 30% to 40% of the whole population (6, 7). Because it is so prevalent, disabling, and associated with economic impacts, CP is considered a serious public health problem.

According to IASP definitions, CP is the pain that persists beyond the normal time of tissue healing, lasting longer than three months, and that, when associated with illness or injury, remains after treatment (8-11). This type of pain is no longer understood as a symptom, and begins to be perceived as a disease (11). Much broader than a prolonged symptom, CP is a complex physiopathological, diagnostic, and therapeutic issue.

Individuals who suffer from CP hardly show any improvement, regardless of the therapeutic resources employed. They require state-of-the-art medical knowledge and occasionally cause problems in their relationships with healthcare services (10). It is usual that they eventually submit to a series of treatments, even to unnecessary surgery, and their visits to several different medical offices are a universal characteristic (4, 12, 13).

In general, the constant presence and long duration of pain are deeply disturbing, because they affect several levels of the individuals' activities, as well as their social interactions, and consequently their well-being (14). An individual with CP may be seriously debilitated and under severe stress derived from failures in self-healing biological mechanisms, unsuccessful attempts of self-control, and frequent failures in medical treatments. CP becomes the main focus of their attention and disrupts most of their activities, often altering their mobility, sleep, sexual life, and humor; individuals can also show low self-esteem, negative thinking, a hopeless look on life, and altered family, work, and leisure relationships (15). The longer the pain, the higher the probability of individuals to become depressed, aloof, irritated, and more and more worried and persistent in their search for relief (16).

Therefore, as a process of falling ill, CP cannot be understood as necessarily located in a certain part of the body; it is linked to a set of physical, psychosocial, spiritual, and social issues (17, 18). It affects individuals as a whole, seizing their attention, raising questions, causing suffering, altering family roles, changing work conditions, limiting leisure options. For its complexity, it is not possible to understand the CP process without understanding the patient's individual context as well. To understand CP, it is necessary to give voice the patients' experiences (19).

Some studies discuss that a fragmented conception of health, the biomedical perspective, is still privileged in healthcare settings, overlooking the relevance of social and psychological aspects as mediators in health-disease processes (20). In a research conducted in the outpatient pain clinics of two large Brazilian teaching hospitals, we identified a still unidimensional view of the constitution of CP, and only when the biomedical perspective could not find and explain pain other factors of the process of falling ill were mentioned (21). It was only when known physiological mechanisms were not detected that attention turned to the psychological and social determinants of pain (22).

Long standing clinical guidelines about the need for scope to approach CP patients and the knowledge of the literature about integral health assistance ensure the dissemination of a correct intention among healthcare practitioners' when they approach patients; however, we observed some confusion on how to direct attention, where to look to capture the whole. It seems that, despite extensive theoretical elaborations on the subject, in the scope of health assistance interventions and contact with patients, there is still a gap between theory and practice (23).

This gap favors old habits in health services and encourages a reflection on this contrast, which has motivated us to write this article, based on a qualitative research on CP patients. CP patients' voices, conveying the expression of the many meanings attributed to their experiences, may help the healthcare practitioners – especially those educated according to the biomedical model – who have the intention to reach the psychosocial domain of the problem as a potential treatment aid. We also point out that it is typical of qualitative research to widen the exploratory field and add to existing research, fostering opportunities for new studies, even those based on different research designs.

Therefore, the objective of this study is to understand the range of meanings the outpatients of a specialized service of a teaching hospital in the state of São Paulo, Brazil, attribute to their CP experiences, the impact CP has on their lives, and its psychological implications.

SUBJECTS AND METHOD

This research was conducted using the clinical qualitative method, a distinction and refinement of qualitative methods, especially designed for healthcare settings that encourage experiences in health-disease processes. It tries to understand the psychological and sociocultural meanings of patients' narratives related to the many phenomena their problems involve, always focusing on the individual – patients or other people who take part in the process, such as family, healthcare practitioners, or people from the community (24, 25). In these circumstances, knowing the meanings attributed to the phenomena is essential to understand thoroughly certain feelings, ideas, and behaviors of patients, families, and healthcare practitioners, and to improve the quality of the relationships among these subjects. Likewise, it is important to encourage patients' and population's higher adherence to individual treatments or collective measures (24).

Our data were collected through semi-directed interviews with open questions, which functioned as scripts during the meetings, including topics related to the study's objectives. The open questions are topics that gave subjects the opportunity to express themselves as freely as possible about what was proposed, opening the way for original findings to arise. The guiding question and topic of our interview was: "*How is it living with a pain that haunts you every day?"*.

The sample was completed according to the saturation criterion. After 17 interviews, new data did not add substantially original information to what had already been collected, based on our own and our peers' view (26). Of the interviews conducted, one was discarded due to recording technical limitations. Therefore, the study sample size was of 16 patients (Table 1) with non-oncological CP being treated at the Outpatient Pain Clinic of the Teaching Hospital of the State University of Campinas (Ambulatório de Dor do Hospital de Clínicas da Universidade Estadual de Campinas, UNICAMP). This is a public tertiary teaching hospital, located in the region of Campinas, state of São Paulo, with a population of four million inhabitants.

The interviews were conducted after the patients had read and signed an informed consent form, recorded with patients' permission, and later transcribed and examined according to a content analysis technique (27), which produced the categories described in this study. These categories have not been ordered by theme frequency, but especially by theme relevance. Although themes do not repeat in the narratives, they represent for the researcher a wealth of meanings related to the research assumptions, with great potential for deepening the study of the phenomenon and developing new knowledge (25, 28). We followed the seven steps recommended in the literature to conduct a qualitative content analysis, described in Figure 1 below:

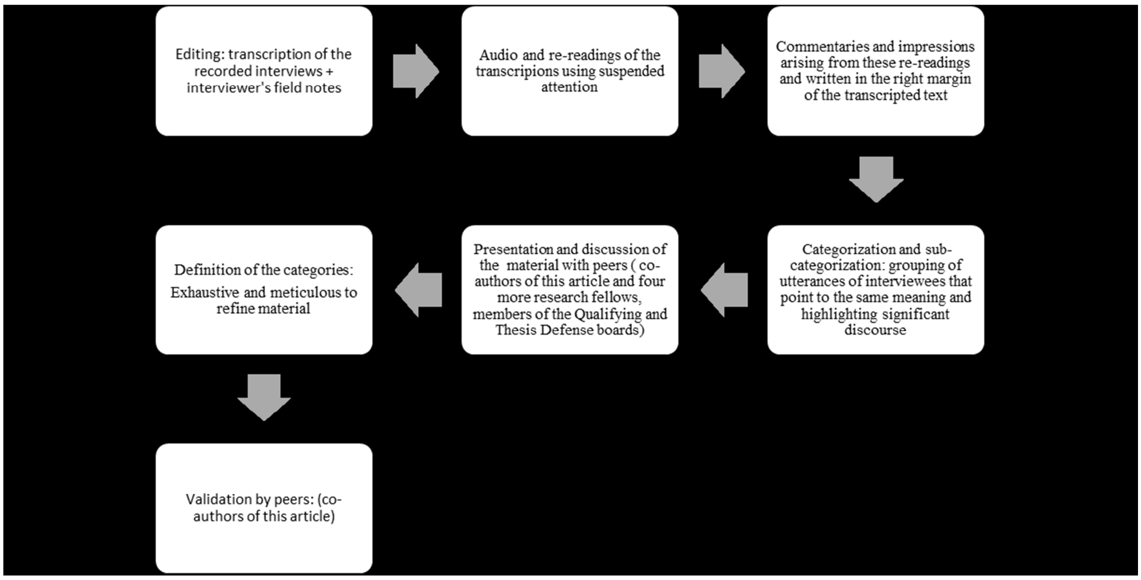

Figure 1: The Seven Steps in a QCA Flowchart - *Qualitative Content Analysis.* Faria-Schützer, Débora B.; Surita, Fernanda G. C.; Alves, Vera L. P.; Vieira, Carla M.; Turato, Egberto R. Emotional experiences of obese women with adequate gestational weight variation: a qualitative study. PLoS ONE. 2015; 10(11).

The categories selected, as well as the whole content of this study, were validated by peer-reviewers from the Laboratory of Clinical Qualitative Research, School of Medical Sciences, UNICAMP.

The research project was approved by the Research Ethics Committee of the School of Medical Sciences of UNICAMP.

RESULTS

The interviews confirmed the studies that describe patients' long journey through numerous medical services and successive and ineffective pharmacotherapic approaches and adjuvant clinical treatments. This was the reason for referring these patients to the specialized outpatient service of a high-complexity tertiary teaching hospital, where expert anesthesiologists examined them and gave them medication. In many cases, the patients followed a parallel treatment for other health problems in other outpatient clinics of the same hospital or in other institutions. These patients came from a low-income population with no other treatment option than that offered by the public health system.

The analysis of the interviews revealed five categories that demonstrate the patients' need for having the particulars of their suffering valued, together with the expression of other pains they experienced during the process, either directly linked to the CP process or related to special life situations. The categories also revealed some features specific to the outpatient care service that treats these patients, especially the value its practitioners give to the symbolic content of patients' different complaints. The categories are described and discussed below, namely: 1. *It seems a bug is eating you: metaphors as expression of personal meaning*; 2. *I learned to get used to it: reluctant acceptance of fate*; 3. *It hurts when I get nervous: the encounter of body and mind*; 4. *I wonder if I hadn't come here how I would feel now: satisfaction with treatment despite its limitations*; 5. *Am I getting to explain it right or am I talking much more about me than about the pain?: pains beyond the chronic pain.*

Participant	Age	Sex	Marital status	Occupation	CP onset	Diagnosis
E01	61	M	Married	Retired farmer	2002	Post-laminectomy pain syndrome; bone tuberculosis, treated; T8 root amputation; cardiopathy
E02	28	F	Single	Craftswoman	1987	Cervical pain after spinal fracture; mandibular osteomyelitis; mandibular osteonecrosis; chronic recurrent multifocal osteomyelitis; severe combined immunodeficiency; SAPHO syndrome
E03	55	M	Married	Salesman	2013	Postherpetic neuralgia; complex regional pain syndrome, left foot; chronic lymphocytic leukemia in remission; systemic arterial hypertension
E04	61	F	Single	Saleswoman	2000	Complex regional pain syndrome type II, right lower limb; hypothyroidism
E05	41	M	Divorced	Bricklayer	2010	Traumatic amputation, left lower limb; systemic arterial hypertension; hypothyroidism
E06	71	F	Single	Housemaid	2005	Chondroma of left knee; disc protrusion of L1,L5; arthropathy, right shoulder
E07	65	F	Single	Retired metalworker	1991	Cervical spondylitis with nerve root compression; chagasic megacolon; chronic anemia; arthralgia of the knees
E08	62	F	Divorced	Housewife	2005	Upper limb arthrosis; colon adenocarcinoma; bronchial asthma; chronic obstructive pulmonary disease
E09	47	F	Married	Housewife	2004	Left accessory nerve injury; squamous cell carcinoma on face+ cervical metastasis
E10	82	F	Widow	Retired housemaid	2013	Lumbar chronic pain; bilateral hip arthrosis; systemic arterial hypertension; congestive heart failure; hypothyroidism
E11	31	M	Single	Radiologist	2008	Neuropathic pain; Humeral and femoral bilateral osteonecrosis
E12	49	F	Married	Kitchen assistant	2011	Complex regional pain syndrome, left patella; spontaneous complex regional pain syndrome; systemic arterial hypertension; hypothyroidism
E13	53	F	Single	Retired production assistant	1988	Complex regional pain syndrome type II
E14	60	M	Divorced	Retired janitor	2003	Post-laminectomy pain syndrome; systemic arterial hypertension; diabetes mellitus type 2
E15	52	F	Married	Retired nursing technician	2005	Cervical post-laminectomy pain syndrome; arthrosis
E16	60	M	Married	Retired gas station manager	1992	Post-laminectomy pain syndrome; lumbar and lower limbs pain; hemophilia B

Table 1 – Some sociodemographic and clinical characteristics of the patients interviewed.

DISCUSSION

On talking about their CP experience, the patients, as expected, revealed their suffering belonged to a world filled with pain, a world that became limited, marked by losses derived from the limitations brought on by their painful sensations and characterized by the other pains they had. These patients emphasized they experienced other pains beyond the CP, unveiling other painful experiences in everyday life, making clear between the lines how adequate the outpatient service was to treat their specific problems.

1. *It seems a bug is eating you:* metaphors as expression of personal meaning

Pain was something patients found difficult to explain. They talked about the challenge of translating their sensation into words and, in an attempt to be understood and communicate their pain in a proper way, they eventually found unusual terms, not generally used to explain the condition. These expressions tended to be intense and convey powerfully the severity of pain:

> *When it's stronger, it's like a hammer hitting your bone. A very heavy hammer.* (E02)
>
> *It's something that would make you prefer getting knocked out by Anderson Silva*[1] *in the ring to feeling what I'm feeling.* (E03)
>
> *Oh, it's a terrible pain. It seems a... It seems a bug is eating you. (...) It seems an infection that makes like this* [pinching her arm quickly and repeatedly]. (E10)

Pain subjects are precisely the ones who cannot express their problem openly, because it is not merely physical, even when the sensation is physical. The pain is something that *seems to be*, it is *as if it were*. It is not defined primarily by its essence, but by its effect, by being bitten or hammered, by the invisible and the unobjectionable. The effect describes a symbolic dilaceration of an actual chronicity. Therefore, attention should be given to those in this fragile condition. Their inner world is in the metaphors: the infection, the bone – pain tears the inside apart. It is there, in the inner world, that pain needs attention and relief.

Thus, we perceive that the metaphoric language used by the patients we interviewed was adopted to express what they felt individually, reflecting their incarnated pain. On describing their pain with words like *biting, pricking, burning, nervous*, among others, they were trying to communicate a sensation, but, above all, they were inviting others to feel what they were feeling, looking for empathy: *a hammer hitting YOUR bone*. The expression through metaphors calls attention to the

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[1] Brazilian mixed martial arts fighter.

dimension of their suffering, and might be a way to legitimate the pain of these individuals.

On talking about their pain, the patients are expressing the elements tangled in their sensations. They talk about themselves, their constitution, their personality, their culture. They talk also about the difficulties they face during the process, about the physical suffering derived from intense and continuous pain, about experiencing limits, about pain chronicity. It is expected that they make an effort to express that in words, and the metaphors end up being a solution to communicate the intensity and quality of experiences that are unique. It is a way to show for those who listen to them the particulars of the pain they feel.

Because pain is an illness that diagnostic technology cannot reach, the metaphors can also help patients to face the additional challenge of legitimizing their pain. These people deal with what some authors call *double burden*, because, besides coping with the painful sensation itself, they meet obstacles to affirm the legitimacy of their pain before family and healthcare practitioners (29, 30). These are the two contradictory sides of the phenomenon of pain, which, on the one hand, shows vehemently through a frequent painful – sometimes excruciating – sensation that affects the whole individual's life, and on other hand, is dissimulated and deceiving, because it does not show to others, who eventually ignore or deny it (29). Pain shows only to those who feel it.

This way of expressing through metaphors proved to be the most appropriate for the patients interviewed, given the particulars of their illness; however, it may also be essential to the healthcare practitioners who follow them up. This category becomes even more important when we see that the outpatient clinic where these patients are treated manages their symptoms. Therefore, it is a space where people under treatment can talk about what they feel, instead of constructing narratives that remain within the limits of a specific diagnosis. It is an outpatient service that allows people to talk more about symbolic issues. We understand that mentioning a symptom favors the construction of a symbolic discourse more than mentioning the diagnosis, because the diagnosis is a medical construct and the symptom is a patient's construct. From this perspective, we think that the pain clinic, even inadvertently, invites individuals to speak about themselves and is a space for symbolization that becomes therapeutic in this sense as well.

2. *I learned to get used to it:* reluctant acceptance of fate

Living daily with pain makes pain familiar, and its treatment in a specialized clinic offers a rich source of information. Patients demonstrate they have learned about chronicity from their own pain and through information acquired during the process. We could also observe that, in some cases, the individuals seem to have become tolerant to pain. Yet, we cannot say that they accept this reality. Their narratives reveal dissatisfaction and traces of hope:

> *In the beginning, I never imagined I would be like this. (...) We have to accept. We have to come back down to earth and understand, but it's awful to accept it. But it's been a while, isn't it? (...) Then, it's something, as I said, that I think it's for good, you know?* (E13)
>
> *Here, the doctor also used to say: 'Mr. X, you have to get used to this pain, because there is no cure. There is no cure.' (...) No, the thing is to live with every bad thing that shows up, live with it and hope to live until the day God wants. (...) I'll tell you... I ended up getting used to it. Of course, nobody likes pain. (...) I take paracetamol every four hours. It gives a little relief, you know? It relieves a bit, and I can get along. I learned to get used to it, because it has no... Unless a miracle happens... a miracle.* (E16)

Experiencing the unusual every day makes us reflect on how *forever* will be. The need for attention falls on pain impacts on life, on the adaptations that will be necessary. Mitigating pain encourages hope in the possibility of a normal life, but within the reality of necessary adaptations. Learning helps patients to free themselves from *"I have to accept"*, and enjoy a chance to reconstruct themselves and reinvent their lives under different conditions.

It is important to observe that these patients have been diagnosed a long time ago, referred from other outpatient services, and, at the moment when this study was carried out, were searching for adequate management for their problems. Therefore, to understand how they assimilate this reality, we must consider that they were informed about the chronicity of their illness and do not disregard their long experience with it.

Thus, we perceived that this outpatient service contradicts what is culturally expected from ordinary healthcare services: the search for cure. The individuals interviewed for this study were already at a stage of their treatments in which it was obvious that this expectation was no longer realistic, which made us conclude that their wish for cure had been replaced by the expectation for pain management. On the other hand, their bet in a treatment at the outpatient clinic of a teaching hospital, with no other therapeutic options, did not characterize them as “end-of-line” patients, who, reconciled to the impossibility of a cure, would have surrendered to fate. Their effort to adhere to treatment shows how much they were engaged in a search for a better quality of life.

In the literature, discussions on the assimilation of pain into everyday life are frequent and, for some authors, becoming tolerant to pain may result from learning to adapt through individual experiences (31-33). The experience of living with pain would make individuals find ways to keep themselves functional in spite of it.

This attitude is known as functional adaptation and is familiar to individuals with CP, who usually are successful at adapting their routines. In addition, more than adjusting daily activities to pain, this adaptation process may help individuals to accept their condition and grow with it (31, 34-36). It can result from a change in values that occurs at the same time that the adjustments patients make in their routines, which often show gains derived from a change of perspective on negative experiences and feelings. An example is replacing the negative meaning of loneliness – originating from the social limitation imposed by the problem – with awareness about the importance of independence and self-directedness (34).

However, the individuals interviewed for this study followed a different path. They seemed to understand that a cure was impossible and demonstrated they had adapted their daily routines, but they also gave the impression of being far from accepting pain or identifying a positive value change related to it. In this case, it seems patients move on with the adequate discomfort provided by hope and by the search for an escape route.

We observed that pain was not welcomed, but it could not be banished either. Its presence causes troubles and anxiety, and comes to integrate individuals' lives, modulating intentions and possibilities, mediating relationships. It becomes part of how individuals judge life; they create expectations at the same time that they see pain as a tolerated intruder. Pain sufferers learned to subject to pain, as people used to do during war in old times: when it was impossible to defeat invading armies, peace agreements were made, and the nation invaded would pay taxes and subject to the invaders' living and survival conditions. Therefore, patients would entertain hopes of a peaceful and productive coexistence with pain.

Based on that, we can say that the outpatient service becomes a place of cure in a different sense: the political. It surpasses the physiopathological sense; it touches abilities to help individuals grow to live with their bodies, with the many services provided, with resignation, with what is possible, and such interventions are essentially therapeutic as well.

3. *It hurts when I get nervous:* the encounter of body and mind

We perceived that the patients interviewed tended to describe pain as something with its own existence, independent of the patient, as if it was an object. The same objectification happens to their own bodies. On talking about pain or other diagnoses, the patients also refer to the organ affected as an entity:

> *Sometimes I get up with it.* (E09)
>
> *When I make any effort, it [the arm] yells.* (E15)

However, in other moments, the patients link their pain to different experiences, either stating a possible cause or complaining about pain increase in emotionally difficult situations, or else about their pain affecting their emotional state:

> *This void that comes to me... (...) When this void comes to me, it seems that... You know? It seems even my teeth hurt. I can't even...* (E07)

> *I took only fluorexetine, because when it is the pain that makes me cry... I feel a... Even depression. (...) It hurts when I get nervous. I've already seen it. It hurts when I feel anxious about anything.* (E09)

> *It [the mother's death] really upset me. I don't know if it has something to do with it. Does it have anything to do with my arm? With what I feel?* (E13)

We thus confirmed how the theoretical division between mind and body, a token of our culture, shows in the patients' narratives, making them stereotyped. Their narratives correspond to the current approach to the process of falling ill, which reflects how the Western culture sees humankind. This compartmentalized way of seeing an individual has its origins in the Greek thought, was affirmed by Descartes, and to date understands human beings as composed of different entities combined into a certain form (37).

In addition, the very experience of pain may contribute to this perception of pain and body parts as external or objectified. This experience is able to take individuals out of their worlds, calling their attention to pain and to the affected part of the body, changing the way patients see themselves and, consequently, leaving them fragmented and with altered identities (35, 38-40).

However, these individuals eventually reveal a different, integrated perception when they reflect on what they feel. They suggest that their pain is linked to other experiences. Therefore, they seem to perceive their functioning in an integrated way, and report this splitting between the parts only when they speak, revealing that culture makes them express their perceptions mistakenly.

In their narratives, we observe that cultural traits and pain experience itself make individuals get out of their worlds, focus on the painful part of their bodies, and see themselves as fragmented. However, the dimension of integrated functioning is not totally lost. On the contrary, it may even function as a link between the body and the emotional experiences, giving patients the opportunity to question and reflect on how they fall ill and on their own existence. It is a way of reconciling the many painful stimuli that pain calls for within the individual. Physical pain as an expression of emotional pain; emotional pain, as a result of physical pain, and all adaptations it requires are the many aspects of a fragmented, but again unified individual, organized by the presence of pain.

4. *I wonder if I hadn't come here how I would feel now:* satisfaction with treatment despite its limitations

The condition of patients who suffer from persistent and long-lasting pain hardly improves and, when some improvement occurs, it is not permanent. Even so, we perceived in patients' narratives an expression of satisfaction concerning the treatment and the practitioners who followed them up in the outpatient clinic.

> *Thank God, I came here! If I had not come here, I don't know how I would feel. I couldn't no longer hold a fork with my hand. I couldn't sign my name. You have just seen my handwriting is not good, but I could write. I write two, three lines and have to pause.* (E13)

> *But Unicamp is the Sírio-Libanês*[2] *of the public health system, because the doctors treat... I've never met anybody who had treated me badly here. Thank God, all who treated me and all who I asked for help for other people have treated me well. You understand? And all of them had... So... They left the hospital feeling well, like me.* (E15)

The institution to which the outpatient clinic belongs is a referral hospital in the region, well-known in the community, where it is reputed as outstanding, especially among the low-income population it serves. The credibility assigned to the hospital allows these individuals to establish a relationship of trust in the institution in advance, often beyond actual contact or experience with the service.

In this sense, we perceived that our interviewees extolled the care received at the institution and, maybe as a consequence, established strong ties with the service and adhered to the treatment. We also observed that these patients admitted some evolution in their condition, even when pain was still a distress in their lives.

Patients perceived the health practitioners' effort to provide care and understood that the control of their illness was beyond treatment possibilities. They

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[2] Sírio-Libanês is a private hospital for patients from the top of the social pyramid. This comparison derives from a supposition made by this patient, who forms a picture about hospital services based on mass media and popular information. Mass media advertises service at the hospital mentioned above as elite, efficient, and supplied with the best resources.

thus seemed to tacitly make a distinction between treatment effectiveness and the quality of the care provided. In this case, it is clear how other elements in a caregiving relationship are important to consider it efficient and high quality: it is as important as symptom relief. Again, we confirmed that this specialized outpatient setting is a therapeutic space for symbolization whose action pass beyond the limits of pain symptoms and organs affected.

We understand that, as the interventions made in this setting are directed to symptom management, and no longer to diagnostic investigation, patients' narratives about their current situation are encouraged and valued. This brings about what we perceive as one of the most outstanding features of the service: a setting where complaints are valued, what makes of it a space that allows patients to express their innermost feelings. There, clinical listening is directed to the symptom, which is the very expression of a patient's existential anxiety.

As a space for symbolization, the outpatient clinic becomes a meeting place for patients and a welcoming service that frees patients' expression and encourages the construction of identification with healthcare practitioners and with other patients; they become allies in that setting to exchange information and to form ties that add up to the gains in physical relief and pain management, making up a comprehensive form of treatment.

Gaining satisfaction from treatment is the *sine qua non* of a clinical action to orientate and redirect the life of the resigned patient in pain. The treatment may please patients and help them cope with new situations. We believe that, consequently, the cases evolved positively and mainly subjectively, given the faith nurtured in the patients' imaginary as regards the institution and the empathic attitude of caregivers before patients' suffering. We already know that the opportunity of expression provided by the ability to listen and accept the individual's reality, translated as empathy, has the potential to enhance personal development (41). It reinforces how crucial the relationship between practitioner and patient is to treatment, with empathy as its driving element and one of its most important factors of success (42). We believe there is an empathetic attitude on the part of the outpatient clinic professionals that may also be generating positive clinical outcomes and patients' satisfaction.

We thus perceive how these professionals' attitude may interfere in patients' experiences with their own illness and question whether these professionals are aware of the fundamental role they can play in the patients' process of constructing meanings for the experience of falling ill.

5. ***Am I getting to explain it right or am I talking much more about me than about the pain?:*** pains beyond chronic pain

Following the initial question of the interview, the patients began to narrate what had been proposed, but their free speech eventually led them in different directions, bringing about themes other than the one that motivated the meeting. We observed that the narratives did not try to contextualize the experience of pain, but something different and impregnated with feeling. Something to which patients were automatically referred to when expressing the experience with their pain. Another pain was on focus:

> *My mother was very strict. My father left us when I was small, I don't even remember him. Now I see, I think that... That sadness of hers she transferred it to me. Then, I was the only one who kind of cared for her. She used to say that she didn't like me, that I wasn't a daughter, you know? (...) Am I getting to explain it right or am I talking much more about me than about the pain?* (E07)

On talking about their experiences from a broader perspective, the patients eventually brought about a question as part of a contextualization that seemed to be more motivating than CP itself at that moment, and they deepened it. Other themes became the focus of their narratives, such as the health problem that produced the CP, other health problems, emotional issues, or financial hardship.

> *But I don't sleep at night. Since the accident, I haven't slept a full night. (...) Every little thing upsets me after the accident. It changed... One changes... I changed a bit. I don't know if it was... If it was some... Even if all of you were treated to be cured, nobody would be cured.* (E05)

> *Everything was cut off here, even here in my mouth. It opened... (...) He said: "You'll need radiotherapy". But, when they referred me to this place to have radiotherapy, it came back. Then, I had to be there to cut it off again. Then, the doctor said: "You'll have to..." I didn't stay in the hospital; I think I stayed only three days. And my*

> *daughter was two years old. (...) My son was eight. I said: "I won't see my daughter grow up".* (E09)
>
> *I said: "But isn't there anything to do?". He said: "No. Besides, the resonance device is out of order. If you have the means, you can pay for a resonance". I said: "I can't afford that.". Then, there is no... Then, they prescribed this medicine that I couldn't take so far, because they are not distributing it for those with pain. They give it only for those who faint (...) Then, I couldn't take it yet. I couldn't afford to buy it.* (E14)

The condition that produced the pain motivated the patients, because it had been traumatic, such as the amputation of a limb, a severe illness, or a disease still demanding treatment, such as a chronic disease. Regardless of their relation to the CP, the patients with other diagnoses also superimposed their experiences with this problem on the core theme of the interview at the moment of their narratives. Something similar has been previously described by other researchers, who observed that their interviewees did not consider CP as a problem as important as their other chronic conditions. Pain was seen as "something else" to be endured, with no right to complaints, as part of everyday life (43).

Likewise, patients have delved into particular aspects of their emotional lives whenever they perceived some relation between CP and their mood, their personality, or previous experiences, even when they were not aware of it. Here, we emphasize a particular clinical look: physical pain makes another pain speak, the psychological pain, the sadness. The patients need to find an escape for inescapable pains. Those who find in physical pain an expression for psychological pain need physical relief, but they also need that their physical pain may channel their emotional conditions. Whenever the latter yells, the problem exceeds the somatic sphere and requires adequate care and psychological attention.

Another theme we observed to be superimposed on the expressions about CP was the financial hardship endured by patients, who, deprived of essential resources to their health and well-being, experienced difficulties sometimes more urgent than pain. Worse than that, they did not enjoy the relief that could be provided by a certain treatment, because they could not afford it. This emphasizes one of the particulars we observed in our interviewees when we took into account the experiences of patients with the same problem in developed countries. In the literature, it is usual to find narratives of CP patients living in different contexts who try all treatment options and, when they do not get good results, start to develop their own coping strategies (30, 33, 43). On the other hand, what we observed among this study's interviewees was that their financial situation was so difficult that, although having been treated for years, they did not have access to all treatment options available, because these options are not offered in public health services, and the patients cannot afford the cost on their own.

Moreover, we believe that the technique chosen to conduct the interviews has played a decisive role in the direction given to patients' narratives, since we have used a semi-directed interview with open questions, in which the interviewees could lead their narratives to reach the themes that motivated them, which was crucial for data collection.

Therefore, we understand that all this change in direction brought about the tangled sufferings caused by the different pains that are part of these patients' CP processes. Whenever asked to talk about their pain, probably unaware of it, they talked also about other pains. Their CP seems to affect them so completely that it confuses their whole life structure and relates closely to their other sufferings.

CONCLUSIONS

Besides discussing and questioning the distress experienced by CP patients already addressed in the literature, this study focuses on the way that outpatients under treatment search for a broad therapeutic intervention in the healthcare setting they visit so often. Patients eventually use the outpatient service as a domain for a liberating expression and for symbolization, functions that we observed that exist in this outpatient service and exceed the ones objectively offered.

Therefore, the specific and invisible features of the patients' suffering add up to the invisible particulars of the service. We observed that patients make efforts to communicate their subjectivity and, for this reason, use metaphors to describe not only their suffering, but also their perception of themselves, of others, of other pains beyond CP, and of their history. We understand that this type of expression enriches the material to be assessed by the healthcare practitioners who follow these patients up, since their interventions are directed to the way patients express their feelings.

Patients’ reluctant acceptance of the implications of everyday pain makes us aware of how they learn from their chronic problems and that their wish for cure has been replaced with an expectation for adequate management. Living permanently in pain may also mean an opportunity for individuals to perceive themselves emotionally and getting to know themselves better, since in their experiences CP calls attention to aspects that go beyond the physical aspects related to the process of falling ill, allowing patients to perceive themselves as more complex human beings.

These patients demonstrate that their treatments may evolve even with limited drug interventions, given the way they show a subjective evolution in their processes, produced by their positive relationship with healthcare practitioners. This relationship arises as an essential element in their experiences with their own pain and with treatment management.

Even considering the magnitude of the CP problem, it is not more severe than any other everyday misfortune these patients undergo. They show that the additional pains they have are as relevant as CP itself and call attention to them, indicating how the tangled events that make up each of them are also part of their CP.

We thus understand that these other pains are ways of expressing a single suffering experienced by the individual. Understanding the context in which patients live at the moment of treatment, their emotional state, and how this expression is received may be positive for treatment evolution, since they become accepted as demands and are managed accordingly. It does not mean that all healthcare practitioners should have the skills for psychosocial interventions, but that it is important to adapt their interventions to the individuals and not to a protocol.

Based on our observations about the particulars of the outpatient clinic functioning and about the possibility of involving its administrators with these particulars, and maybe the possibility that they are not aware of this tangled symbolic framework, we suggest that future studies bring information about healthcare practitioners' perspectives on these phenomena. We think of studies that could add to the existing studies on patients and widen the scope of the existential meanings of this outpatient setting.

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6. DISCUSSÃO

De que comparação vou me valer para explicar a dor a alguém que não a está sentindo?
Só sabe o que é a dor aquele que a está sentindo, no presente.
Enquanto a dor está doendo, meu corpo - não minha cabeça -
sabe o que ela é.

Rubem Alves

A motivação para iniciar a produção deste trabalho de doutorado, com a elaboração de artigo conceitual, partiu da tarefa de leituras introdutórias para a habitual elaboração do projeto de pesquisa. Igualmente, da consequente constatação da importância de se olhar para questões subjetivas do doente com DC, considerar sua identidade e de como, contrariamente, certos modelos de saúde vigentes pareciam não dar conta suficiente dessa abordagem. Tal motivação veio reforçada pela verificação coincidente de que pouco havia em termos de propostas sólidas para que essas perspectivas fossem pensadas.

Consideramos que são irrefutáveis os ganhos advindos de uma perspectiva biológica na evolução da compreensão e do tratamento da DC. Entretanto, sabemos das limitações de modelos que focam em uma única realidade, seja ela biológica, psicológica ou sociológica. Desse modo, consideramos que a Fenomenologia poderia oferecer modos de pensar que vão além do teoricamente construído e, assim, incrementar a compreensão desses processos.

Entretanto, compreendemos que o pensamento fenomenológico também não possibilita uma concepção final dos processos individuais de adoecimento. O objetivo de trazermos tal teoria à discussão foi tentar aproximar o que os distintos modos como descrevemos intelectual e didaticamente o funcionamento de um ser humano ao modo como, na realidade, nos percebemos. Uma tentativa de continuar a difusão de antiga discussão entre mente e corpo ainda presente em nossas práticas, e também na literatura, já que são raros os textos e artigos que propõem discussão entre os modelos vigentes de saúde. Também há pouco material suficientemente organizado em relação a críticas ao modelo biopsicossocial.

A realização de uma revisão de literatura, voltada ao tema específico sobre o qual se debruçava a pesquisa, levou a uma visão ampla em relação ao que se conhece sobre vivências de pessoas com DC e ao que vem sendo pesquisado a respeito disso com base, em particular, na metodologia qualitativa.

A partir dos artigos consultados para tal revisão, confirmamos que o impacto causado pela entrada da DC na vida dos indivíduos, dependendo de sua magnitude, pode repercutir nas mais simples atividades do dia-a-dia, chegando a impedi-los de exercerem atividades profissionais, papéis sociais, e modificar seu modo de agir e pensar. Entretanto, essas pessoas fazem questão de manterem-se ativas, esforçam-se para demonstrar que podem ser bem-sucedidas e procuram manter um funcionamento o mais próximo possível ao anterior. Como parte desse processo, os indivíduos sofrem também por não se sentirem compreendidos por seus familiares e profissionais de saúde.

Diante dessa significativa mudança de vida, tendo atividades, perspectivas, relações e sentimentos alterados, os indivíduos passam a perceberem-se de modo diferente, constatando não ser mais quem eram. Diminuem então os pedidos de ajuda e a crença nos tratamentos. É quando a frustração cede à resignação, ocorrendo, assim, uma mudança de identidade.

Os estudos enfatizam ainda como a DC se espalha e afeta de modo negativo toda a existência dos indivíduos, fazendo-nos compreender que não está “localizada” no órgão acometido, mas em toda a vida do paciente.

Em relação ao estudo de campo, sabemos obviamente que a realização de um único estudo não é capaz de alcançar a totalidade dos sentidos atribuídos pelos indivíduos às suas vivências. Entretanto, acreditamos que neste trabalho, a partir do método utilizado, conseguimos apreender o que de mais significativo emergiu no momento do encontro entre a pesquisadora e os pacientes entrevistados no Ambulatório de Dor.

Esses pacientes, como esperado em certo momento, trouxeram à tona as características percebidas no processo e as sensações que experimentavam. Suas falas deixavam transparecer, portanto, o sofrimento existente em seu mundo tomado pela dor, um mundo que passa a ser restrito, marcado por perdas advindas das limitações acarretadas pela sensação dolorosa. Essa percepção caracteriza “dores adicionais” experimentadas por eles. Os pacientes enfatizam essas “demais dores”, assim como revelam outras vivências dolorosas de seu cotidiano, deixando nas entrelinhas a existência de uma adequação do *setting* do ambulatório em foco às especificidades de seu problema.

Compreendemos que esse serviço clínico-assistencial, que se ocupa de tratar sintomas, consiste em um espaço onde acaba havendo valorização e acolhimento das queixas. Assim, os pacientes são convidados pelos médicos a falar do que sentem e lhes é permitido expressar o que é mais profundo, que são as simbolizações. A escuta clínica, atendendo ao sintoma, porta a própria expressão da angústia existencial do paciente. Sob essa perspectiva, pensamos que o Ambulatório de Dor, mesmo que inadvertidamente, acaba por constituir-se como espaço de simbolização, tornando-se terapêutico também nesse sentido.

Por sua vez, considerar achados da pesquisa de campo à luz das discussões apresentadas pelos trabalhos que compuseram nosso artigo de revisão permite-nos dizer que nossos entrevistados vivenciam, com todas as dificuldades trazidas pelo impacto da doença, as agruras cotidianas relacionadas à sua dor. Em seu enfretamento, é claro o esforço que fazem para manterem-se ativos. Isso fica evidenciado pela sua disposição em se manterem engajados em tratamento que não garante evolução significativa de seu quadro. Nossos entrevistados não demonstram aceitar a condição que lhes é imposta, algo oposto ao relatado nos estudos consultados. Talvez por isso, não relatem sobre mudanças positivas em sua identidade, também informadas pelos estudos. Isso nos faz compreender que essa disposição talvez seja alimentada justamente pela não aceitação de sua condição, e que essa mesma não aceitação é o motor para que não seja o paciente de “fim-de-linha” que pode ser, à primeira vista, considerado por não deter outras alternativas terapêuticas.

Os pacientes também não fazem menção à falta de empatia por parte dos profissionais de saúde ou familiares, como referem aqueles estudos. Contrariamente, dão sinais de compreensão em relação às limitações das intervenções e demonstram que a equipe de saúde responsável pelo seu cuidado foi capaz de ultrapassar a intervenção meramente física.

Os achados da pesquisa de campo sobrepõem-se aos da revisão de literatura e reforçam o que foi discutido em nosso artigo conceitual: a necessidade de comunicar aspectos particulares de sua dor, o modo como ela passa a fazer parte de suas vidas, a satisfação com a compreensão da equipe em relação ao seu problema e a expressão de outras vivências dolorosas associadas ao processo de adoecimento. Também as questões sociais e emocionais associadas ao impacto do advento da dor na vida dos indivíduos, o modo como passam a conviver com ela e manejam o tratamento, somados à dificuldade de terem seu sofrimento reconhecido e a consequente mudança estrutural de vida, e até de personalidade, por conta de tamanha interferência. Esses nossos achados unem-se ao que foi introduzido na discussão teórica e remetem-nos à questão que deu início a presente investigação: de que não é possível propor cuidado ao sujeito com DC sem que se considere seu contexto e sua identidade.

7. CONCLUSÕES

A dor física não tem voz, mas quando finalmente encontra uma voz ela começa a contar uma história.

Scarry

O presente trabalho buscou compreender os significados atribuídos por pacientes com DC em tratamento ambulatorial às suas vivências psicossociais. Acreditamos ter atingido os objetivos propostos e que a pesquisa de campo teve sua qualidade legitimada pela realização prévia do estudo conceitual e da revisão discutida de literatura.

A respeito da proposta de que o pensamento fenomenológico possa contribuir para a compreensão dos processos de DC, compreendemos que essa visão filosófica ainda não se relaciona de modo direto com teorias e intervenções da disciplina da Psicologia da Saúde. Caberia assim, aos profissionais da assistência e pesquisadores, realizar reflexões para a articulação do que essa teoria pode dizer e o que pode fazer por sua prática; além de como se pode aliar tal teoria à inquietação teórica, já existente, de superação das teorias ditas psicossomáticas e de modelo biopsicossocial.

Constatamos, com o estudo seguinte, que não é escassa a produção científica relacionada ao tema da DC. Entretanto, percebemos a tendência nos trabalhos publicados em direcionar o foco da investigação, perdendo-se o que pode ser compreendido da real e integral experiência do indivíduo. Os artigos parecem focar-se menos no que sofrem ou vivenciam, de modo geral, os indivíduos, e mais em sua possibilidade de superação e em outros aspectos moralmente valorizados dos discursos, abrindo mão de um contato real com as vivências dos indivíduos e do consequente aprofundamento nos significados a elas atribuídos.

A partir da pesquisa empírica, verificamos que os pacientes buscam uma ampla intervenção terapêutica no serviço que frequentam. Constatamos que os pacientes empregam esforços para comunicar sua subjetividade e, por isso, se utilizam de metáforas que qualificam não só seu sofrimento, mas a percepção de si, do outro, de outras dores além da DC, e de sua história. Entendemos que esse tipo de expressão enriquece o material a ser avaliado pela equipe de saúde que os acompanha, já que suas intervenções são voltadas para como os pacientes expressam se sentir. Às características particulares e invisíveis do sofrimento dos entrevistados se somam as peculiaridades invisíveis do serviço, tornando o ambiente de atendimento um território de expressão libertadora e simbolização, trazendo ganhos ao tratamento além dos previstos pela equipe de saúde.

A importância de se considerar os contextos subjetivo e social do indivíduo com DC é o aspecto que vincula os três artigos de resultados desta tese, procurando manter atual a antiga constatação que carrega e pretendendo instigar reflexões para o quanto algumas verificações podem manter-se desvinculadas da prática.

Nesse sentido, o estudo de campo nos diz além do que foi argumentado no Artigo 1. Apesar da crítica à visão unidirecional da intervenção biomédica, os pacientes mostram nas entrelinhas que seus cuidadores, mesmo mantendo foco nesse tipo de estratégia, parecem ir além do que intencionam objetivamente e de algum modo conseguem alcançar algo do mundo mais amplo de seus pacientes. Contudo, acreditamos que as intervenções podem ser ainda mais eficazes na medida em que a necessidade dessa ampla intervenção faça parte da crítica dos profissionais de saúde e esteja conscientemente presente em sua atuação, tornando-se aceitas também como demandas e manejadas adequadamente, seja embasando uma intervenção, seja levando o caso à discussão com outros profissionais. Pretendemos, portando, estimular o olhar crítico em relação às teorias correlatas aos modelos de compreensão de saúde, assim como em relação às intervenções.

A partir das constatações feitas sobre as peculiaridades do funcionamento do ambulatório estudado e da possibilidade de os profissionais que o conduzem serem envolvidos por essas especificidades e, talvez, não se darem conta do emaranhado arcabouço simbólico, esperamos que estudos futuros possam nos trazer informações sobre suas perspectivas a respeito desses fenômenos, perspectivas que complementem as dos usuários dos serviços e com ela possam dialogar.

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9. APÊNDICES

9.1 Apêndice I

ROTEIRO E INSTRUMENTO DE COLETA DE DADOS

Entrevista Nº _____

HC Nº: ___________

Data: ___ / ____ / ____

Início: ______ : ______ h. Término: ______ : ______ h. Duração em min.: _____ ________________

Entrevistador: _________________________________ Assinatura: _____________________________

A) Dados de Identificação Pessoal do Entrevistado:

Nome Completo: ____

Endereço para contato: ____

Sexo: _________________

Data de Nascimento: ________ / ________ / _________ Idade: _______ anos.

Profissão exercida / Ocupação: ____

Naturalidade: ____

Procedência / Há quanto tempo:____

Estado civil / Situação conjugal atual / Há quanto tempo: ____________________________________

Com quem mora: ____

Tem filhos? Quantos? Quais as idades? ____

Religião (denominação) / Religiosidades (prática): ____

B) Dados clínicos do paciente obtidos no prontuário e/ou com a equipe responsável:

Diagnóstico (físico): ____

Diagnóstico (transtorno mental): ____

Doenças secundárias: ____

Tipo de dor: ____

C) Questões iniciais sobre as vivências sob estudo relativas a aspectos da doença: (a ser aprimorado na fase de aculturação em campo, para futuras entrevistas semidirigidas de duração de cerca de 01 hora)

- Como é para você possuir uma dor que te acompanha cotidianamente, como você se sente com isso?
    - Você consegue descrever como é a dor que sente?
    - A dor interfere em seu cotidiano?
    - O que você pensa sobre o tratamento que está fazendo?
    - Você já buscou outras formas de tratar seu problema?
    - Há algo mais que você gostaria de comentar?

D) Dados da observação e auto-observação do entrevistador:

Apresentação pessoal do informante, seu comportamento global, expressões corporais, gesticulações, mímica facial, expressões do olhar, estilo e alterações na fala (silêncios, fala embargada, lapsos de língua e outros atos falhos, colocações inibidas e desinibidas, alterações no timbre e volume da voz, risos, sorrisos, choros e manifestações afins:

____

E) Outras observações:

____

9.2 Apêndice II

TERMO DE CONSENTIMENTO LIVRE E ESCLARECIDO PARA PARTICIPAÇÃO DE SUJEITOS EM PESQUISA CLÍNICO-PSICOLÓGICA

Instituição: UNICAMP / FCM / **Laboratório de Pesquisa Clínico-Qualitativa**

Projeto: ***Vivências relatadas por pacientes com dor crônica que se encontram sob tratamento num ambulatório de dor de hospital universitário - um estudo clínico-qualitativo.***

Pesquisador: Daniela Dantas Lima – aluna de doutorado – Depto. de Psicologia Médica e Psiquiatria

Orientador: Prof. Dr. Egberto Ribeiro Turato – Depto. de Psicologia Médica e Psiquiatria
Telefones: (19) 3521-7206 – Depto. de Psicologia Médica e Psiquiatria
(19) 3521-8936 – Comitê de Ética em Pesquisa da FCM/ Unicamp

O **objetivo** desta pesquisa científica é aprofundar a compreensão a respeito das influências psicológicas e sociais na gênese e manejo da dor crônica.

Para tanto, será realizada uma **entrevista** que poderá durar cerca de 01 (uma) hora e, se necessário, uma segunda entrevista de complementação. Na entrevista, você será convidado a falar sobre questões propostas pelo entrevistador para os objetivos deste estudo serem alcançados.

Os registros (gravações, anotações) feitos durante a entrevista ficarão em **sigilo**, não sendo divulgados nem aos profissionais de saúde que atendem neste local. Porém, alguns trechos dos relatos serão estudados, em reunião fechada, por pesquisadores do Laboratório de Pesquisa Clínico-Qualitativa (Departamento de Psicologia Médica e Psiquiatria – FCM/ Unicamp) que estuda diversas condições emocionais e sociais das pessoas frente a problemas de saúde. No entanto, não será revelada no grupo a sua identidade de informante. Esclarecemos que o relatório final, **com citações anônimas**, **estará disponível a todos**, quando o estudo for concluído, incluindo apresentação em congressos e publicação em revistas científicas.

Poderá não haver **benefícios** diretos ou imediatos para você, enquanto entrevistado deste estudo, além evidentemente da oportunidade de poder falar livremente de sua vida, das satisfações e preocupações. No entanto, futuramente poderá haver mudanças na melhora aos cuidados prestados aos doentes e à população, quando os profissionais de saúde tomarem conhecimento das conclusões deste trabalho.

Informamos que este projeto foi **aprovado** pelo Comitê de Ética em Pesquisa da Faculdade de Ciências Médicas da Unicamp, em Campinas SP, tendo sido homologado na reunião do dia 22/11/2011, protocolo número 1136/2011.

Este **TERMO**, em duas vias, é para certificar que eu, ___________________________ , *concordo* em participar na qualidade de voluntário do projeto científico acima mencionado, sem gastos ou ganhos financeiros diretos para nenhuma das partes. Por meio deste documento, dou *permissão* para ser entrevistado e para estas entrevistas serem registradas em gravador de voz.

Estou *ciente* de que as gravações ficarão em posse deste pesquisador para prosseguimento do estudo e também disponíveis a mim se eu quiser ouvi-las. As mesmas serão apagadas ao final de cinco anos. Sei que os resultados do estudo serão divulgados, considerando o conjunto das informações dadas por várias pessoas entrevistadas, sem que meu nome ou de nenhum outro participante apareça associado à pesquisa.

Estou *ciente* de que um técnico poderá fazer a transcrição das falas para texto de computador e que colegas do Laboratório de Pesquisa Clínico-Qualitativa poderão conhecer o conteúdo para discussão, mas todas estas pessoas estarão submetidas às normas do sigilo profissional.

Estou *ciente* de que não há riscos previstos para minha saúde, que sejam resultantes da participação nesta pesquisa. No entanto, estou ciente de que, durante a entrevista, poderei ter algumas recordações ou emoções, que talvez eu preferisse não lembrar ou sentir.

Estou *ciente* de que sou livre para recusar a dar alguma resposta a certas questões durante as entrevistas, bem como para retirar meu consentimento e terminar minha participação, a qualquer momento, sem que isso represente prejuízo aos atendimentos e tratamentos que recebo.

Estou *ciente* de que para obter qualquer outro esclarecimento ético posso entrar em contato como o Comitê de Ética desta instituição, cujo número de telefone encontra-se no topo deste documento.

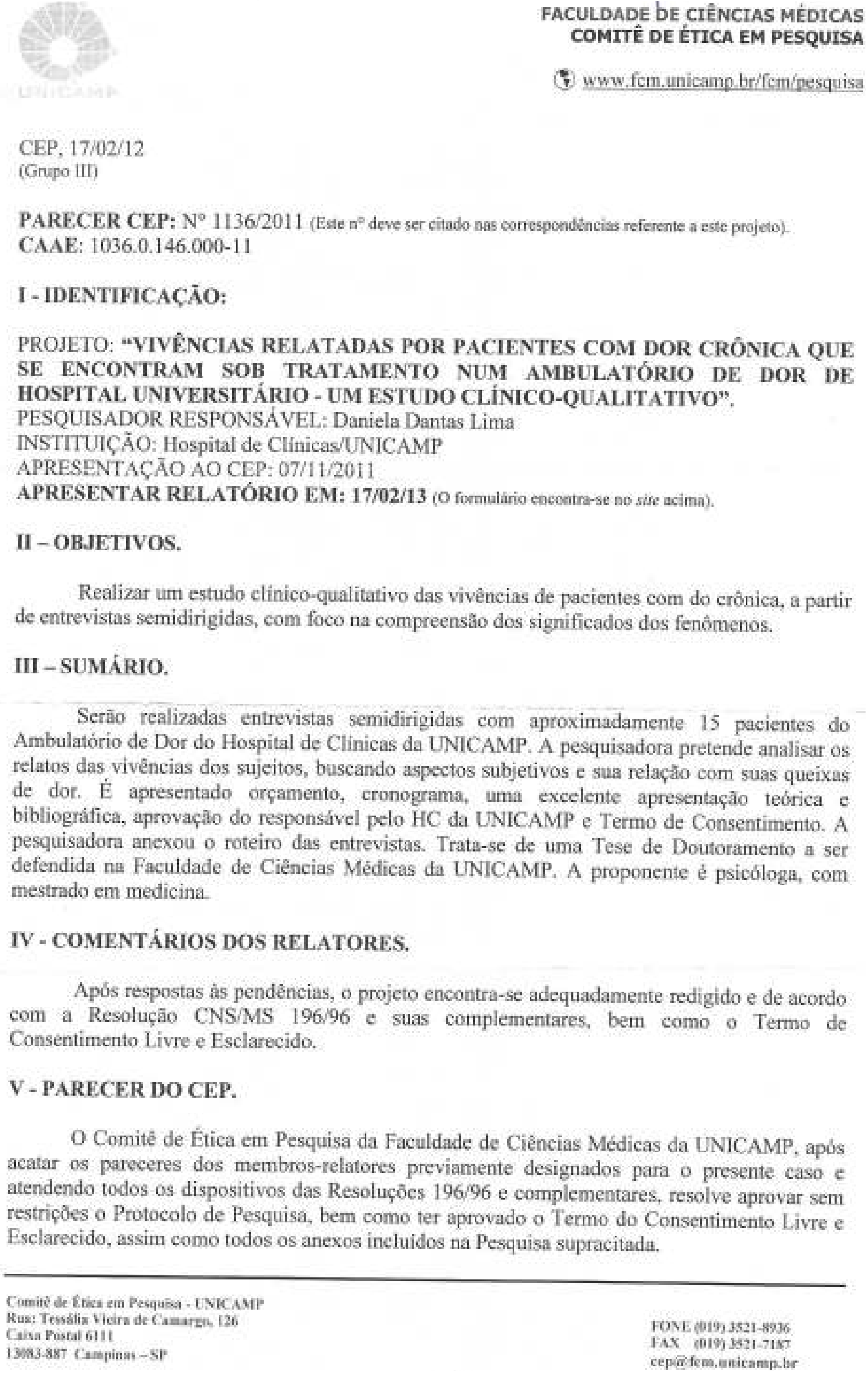
Por fim, estou *ciente* de que terei oportunidade para perguntar sobre qualquer questão que eu desejar, e que todas elas deverão ser respondidas, ao meu contento, ao final da entrevista.

	NOME:	**ASSINATURA:**
Pesquisador:	___________________________________	____________________________
Entrevistado:	____________________________________	____________________________

Entrevista nº _____ Local: ________________________ Data: ___ / ___ / ___

10. ANEXO

10.1 CARTA DE APROVAÇÃO DO CEP



FACULDADE DE CIÊNCIAS MÉDICAS
COMITÊ DE ÉTICA EM PESQUISA

www.fcm.unicamp.br/fcm/pesquisa

CEP, 17/02/12
(Grupo III)

PARECER CEP: Nº 1136/2011 (Este nº deve ser citado nas correspondências referente a este projeto).
CAAE: 1036.0.146.000-11

I - IDENTIFICAÇÃO:

PROJETO: **"VIVÊNCIAS RELATADAS POR PACIENTES COM DOR CRÔNICA QUE SE ENCONTRAM SOB TRATAMENTO NUM AMBULATÓRIO DE DOR DE HOSPITAL UNIVERSITÁRIO - UM ESTUDO CLÍNICO-QUALITATIVO".**
PESQUISADOR RESPONSÁVEL: Daniela Dantas Lima
INSTITUIÇÃO: Hospital de Clínicas/UNICAMP
APRESENTAÇÃO AO CEP: 07/11/2011
APRESENTAR RELATÓRIO EM: 17/02/13 (O formulário encontra-se no *site* acima).

II – OBJETIVOS.

Realizar um estudo clínico-qualitativo das vivências de pacientes com do crônica, a partir de entrevistas semidirigidas, com foco na compreensão dos significados dos fenômenos.

III – SUMÁRIO.

Serão realizadas entrevistas semidirigidas com aproximadamente 15 pacientes do Ambulatório de Dor do Hospital de Clínicas da UNICAMP. A pesquisadora pretende analisar os relatos das vivências dos sujeitos, buscando aspectos subjetivos e sua relação com suas queixas de dor. É apresentado orçamento, cronograma, uma excelente apresentação teórica e bibliográfica, aprovação do responsável pelo HC da UNICAMP e Termo de Consentimento. A pesquisadora anexou o roteiro das entrevistas. Trata-se de uma Tese de Doutoramento a ser defendida na Faculdade de Ciências Médicas da UNICAMP. A proponente é psicóloga, com mestrado em medicina.

IV - COMENTÁRIOS DOS RELATORES.

Após respostas às pendências, o projeto encontra-se adequadamente redigido e de acordo com a Resolução CNS/MS 196/96 e suas complementares, bem como o Termo de Consentimento Livre e Esclarecido.

V - PARECER DO CEP.

O Comitê de Ética em Pesquisa da Faculdade de Ciências Médicas da UNICAMP, após acatar os pareceres dos membros-relatores previamente designados para o presente caso e atendendo todos os dispositivos das Resoluções 196/96 e complementares, resolve aprovar sem restrições o Protocolo de Pesquisa, bem como ter aprovado o Termo do Consentimento Livre e Esclarecido, assim como todos os anexos incluídos na Pesquisa supracitada.

O conteúdo e as conclusões aqui apresentados são de responsabilidade exclusiva do CEP/FCM/UNICAMP e não representam a opinião da Universidade Estadual de Campinas nem a comprometem.

VI - INFORMAÇÕES COMPLEMENTARES.

O sujeito da pesquisa tem a liberdade de recusar-se a participar ou de retirar seu consentimento em qualquer fase da pesquisa, sem penalização alguma e sem prejuízo ao seu cuidado (Res. CNS 196/96 – Item IV.1.f) e deve receber uma cópia do Termo de Consentimento Livre e Esclarecido, na íntegra, por ele assinado (Item IV.2.d).

Pesquisador deve desenvolver a pesquisa conforme delineada no protocolo aprovado e descontinuar o estudo somente após análise das razões da descontinuidade pelo CEP que o aprovou (Res. CNS Item III.1.z), exceto quando perceber risco ou dano não previsto ao sujeito participante ou quando constatar a superioridade do regime oferecido a um dos grupos de pesquisa (Item V.3.).

O CEP deve ser informado de todos os efeitos adversos ou fatos relevantes que alterem o curso normal do estudo (Res. CNS Item V.4.). É papel do pesquisador assegurar medidas imediatas adequadas frente a evento adverso grave ocorrido (mesmo que tenha sido em outro centro) e enviar notificação ao CEP e à Agência Nacional de Vigilância Sanitária – ANVISA – junto com seu posicionamento.

Eventuais modificações ou emendas ao protocolo devem ser apresentadas ao CEP de forma clara e sucinta, identificando a parte do protocolo a ser modificada e suas justificativas. Em caso de projeto do Grupo I ou II apresentados anteriormente à ANVISA, o pesquisador ou patrocinador deve enviá-las também à mesma junto com o parecer aprovatório do CEP, para serem juntadas ao protocolo inicial (Res. 251/97, Item III.2.e)

Relatórios parciais e final devem ser apresentados ao CEP, de acordo com os prazos estabelecidos na Resolução CNS-MS 196/96.

VII- DATA DA REUNIÃO.

Homologado na XI Reunião Ordinária do CEP/FCM, em 22 de novembro de 2011.

Steiner
Prof. Dr. Carlos Eduardo Steiner
PRESIDENTE do COMITÊ DE ÉTICA EM PESQUISA
FCM / UNICAMP

10.2 Permissão do editor Artigo 1

Os direitos autorais do artigo já publicado da presente tese permanecem com os autores. Esta informação é de acesso público no site da revista, mesmo assim foi reiterada em comunicação com o editor e anexada aqui.

26/01/2016 Gmail - Authorization

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Daniela Dantas <danieladanttas@gmail.com>

Authorization

James Giordano <jg353@georgetown.edu> 21 de março de 2015 11:59
Para: Daniela Dantas <danieladanttas@gmail.com>
Cc: Sherry Loveless <editorial@peh-med.com>

Dear Dr Dantas-

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Sincerely,

JG
Editor-in-Chief
Philosophy, Ethics, and Humanities in Medicine

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