Life History of Women with Fibromyalgia: Beyond the Illness

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Abstract
Fibromyalgia is a chronic pain syndrome, which mostly affects middle age women and whose etiological factors remain unclear. Psychosocial aspects may have a relevant role as predisposing, triggering, and/or perpetuating factors for this syndrome, raising the interest about life history of patients with fibromyalgia. In this study, we interviewed 10 women with a diagnosis of fibromyalgia, who had identified a critical or very stressful life event before the onset of the syndrome. The interview about the life history comprises the whole life, before and after the onset of the syndrome, and the narratives were analyzed with interpretative phenomenological analysis. Nine themes emerged: struggle, focus on adversities, positive overlaps the negative, scars of unhappy childhood, help others, perfectionism and desire to achieve, unsatisfactory present, perception of injustice, and keep feelings inside. A difficult life history is prevalent in these women and the themes identified are discussed in their relation with other qualitative studies and their possible role as predisposing and perpetuating factors for fibromyalgia. The ability to value the positive side of things, despite the adversities these women emphasized, is highlighted as an aspect to explore in psychological intervention, to enable a better management of this syndrome.

Keywords
Chronic Pain, Fibromyalgia, Interpretative Phenomenological Analysis (IPA), Life History, Psychology

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Acknowledgements
This research was supported by grants from the Portuguese Foundation for Science and Technology.
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Fibromyalgia is a chronic pain syndrome, which mostly affects middle age women and whose etiological factors remain unclear. Psychosocial aspects may have a relevant role as predisposing, triggering, and/or perpetuating factors for this syndrome, raising the interest about life history of patients with fibromyalgia. In this study, we interviewed 10 women with a diagnosis of fibromyalgia, who had identified a critical or very stressful life event before the onset of the syndrome. The interview about the life history comprises the whole life, before and after the onset of the syndrome, and the narratives were analyzed with interpretative phenomenological analysis. Nine themes emerged: struggle, focus on adversities, positive overlaps the negative, scars of unhappy childhood, help others, perfectionism and desire to achieve, unsatisfactory present, perception of injustice, and keep feelings inside. A difficult life history is prevalent in these women and the themes identified are discussed in their relation with other qualitative studies and their possible role as predisposing and perpetuating factors for fibromyalgia. The ability to value the positive side of things, despite the adversities these women emphasized, is highlighted as an aspect to explore in psychological intervention, to enable a better management of this syndrome. Keywords: Chronic Pain, Fibromyalgia, Interpretative Phenomenological Analysis (IPA), Life History, Psychology

The syndrome of fibromyalgia is a chronic pain condition characterized by widespread muscle pain and also associated with fatigue, sleep and cognitive difficulties, anxiety and depressed mood (Smith et al., 2009). Fibromyalgia presents intense subjective complaints but no objective clinical findings, and although disruption of pain processing has been demonstrated at various levels in the nervous system, the lack of an objective test in the clinical setting to confirm a diagnosis makes this an uncertain condition (Fitzcharles & Yunus, 2012). It is much more common in women; the overall prevalence in the adult United States population was estimated at 2% and a survey in five European countries (France, Germany, Italy, Portugal, and Spain) found 2.9 % of fibromyalgia cases (Branco et al., 2010).

The lack of a clear explanation and comprehension about the causal mechanisms of this syndrome and the fact that psychological disorders are more prevalent in this population compared with normal population (Rose et al., 2009) enhances the interest about the links between physical and psychological aspects of this syndrome. Within a biopsychosocial perspective, several authors have claimed attention to the importance of psychosocial aspects, which could play a role as predisposing, triggering, and/or perpetuating factors for fibromyalgia (Eich, Hartmann, Muller, & Fischer, 2000; Van Houdenhove & Egle, 2004). Some of these aspects have been assessed mainly in quantitative studies, which have focused on childhood traumatic events and adversities as possible risk factors for fibromyalgia (Low,
& Schweinhardt, 2012; Olivieri, Solitar, & Dubois, 2013; Smith et al., 2009). Although there have been several qualitative studies about the experience of patients with fibromyalgia, most of them focus on the time period after the onset of the syndrome and issues as the impact of fibromyalgia and confrontation with diagnosis, living with the symptoms, the treatments and perceived quality of care (Cunningham & Jillings, 2006; Lempp, Hatch, Carville, & Choy 2009), and the biographical disruptions brought by the syndrome (Asbring, 2001; Rodham, Rance & Blake, 2010). Few qualitative studies include the whole life history, and, of these, the great majority is still very focused on the experience of the syndrome, with interview questions especially addressing fibromyalgia (Hallberg & Carlsson, 1998; Hughes, 1999; Tevens, 2003; Wentz et al., 2004). Concerning data analysis, most of them use grounded theory or narrative analysis and the most common emergent theme is about adverse childhood experiences.

For this reason, we wanted to analyze the life history of women with fibromyalgia, because we consider that the lack of knowledge about the syndrome enhances the interest of a complete qualitative approach, comprising the whole existence of these patients and not specifically concerned with the experience of the syndrome. We used a Life History Interview that has no specific question about fibromyalgia, or even about health and illness, and our purpose was to identify common themes that may help elucidate the characteristics and functioning of women with fibromyalgia. This may be important to help clarify some predisposing and perpetuating factors and, mainly, to improve the psychological comprehension and management of women with fibromyalgia, in a multidisciplinary approach. As a research group of psychologists and rheumatologist, fibromyalgia is a study topic that embodies the convergence between these two fields, being a syndrome that includes physical and psychological features and should be approached in a multidisciplinary level, either in the assessment and comprehension as in the intervention.

Method

Participants

The participants were 10 women with a diagnosis of fibromyalgia, as part of a larger sample from a previous quantitative study (Gonzalez, Baptista, Branco, & Ferreira, 2013). The inclusion criteria were being more than 18 years old, having a fibromyalgia diagnosis for at least 6 months, not having another rheumatic disease or painful condition, not having a psychiatric diagnosis, psychological/psychiatric counseling, and psychotropic medication. The whole sample from the previous study had been recruited with the help of the National Association against Fibromyalgia and Chronic Fatigue Syndrome (MYOS), which helped us to contact a great number of patients with a confirmed diagnosis of fibromyalgia, current or former associates. A total of 106 women with a diagnosis of fibromyalgia were contacted by telephone and asked about the inclusion criteria; 54 women met the criteria and of these, only 4 did not agree to participate, leading to a final sample of 50 women. We selected the participants of this qualitative study based on two important additional criteria, to get some homogeneity: symptoms duration and identification of a discrete critical or very stressful life event, within months to one year before the onset of the syndrome. Thus, we selected 11 patients whose symptoms duration was similar to the mean value of the whole sample, and who had identified a discrete event at the onset of fibromyalgia symptoms. Because one of the patients was not available, the final sample had 10 participants, ages between 29 and 59 years old (M = 47.10; SD = 8.50), living in the same geographical district. Four participants were high school graduates, three had a college degree, one had a master’s degree, one had a 9th grade education and another had a 6th grade education. Seven were working, one was retired, one was unemployed and one did not work as an option. All of them were married, except one,
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who was divorced. The mean duration of the fibromyalgia diagnosis, in years, was 5.40 years ($SD=2.75$) and the mean duration of symptoms was 12.40 ($SD=2.36$). The selected women were contacted by telephone, told about the goals of the study and asked about their availability to participate. All of them have had contact with the first author of this study, in one assessment session from the previous study, about 6 months earlier. At the beginning of each interview, the researcher explained again the context and the purpose of the life history study and reminded the interviewee of the right to withdraw at any point. The participants gave their written informed consent and were guaranteed confidentiality and an anonymous presentation of the findings.

Data Collection

We used the Life Story Interview (McAdams, 1995), which has nine sections (I. Life chapters; II. Critical events; III. Life challenge; IV. Influences on the life story: positive and negative; V. Stories and the life story; VI. Alternative futures for the life story; VII. Personal ideology; VIII. Life theme; IX. Other). In section II. Critical events, we asked the woman to describe in detail what happened, where it happened, who was involved, what she did, what she was thinking and feeling, the impact this event had in her life story and what this event says about who she is or was as a person. Accordingly to McAdams (1994) the life story is a psychosocial construction that takes the form of internalized narrative and integrates the reconstructed past, perceived present, and anticipated future.

The main researcher conducted the interviews individually, which took place in each patient’s home, in one sitting, being present the interviewer and the patient only. The interviews were recorded and had an average duration of approximately 120 minutes. The fact that the interviewer had have previous contact with these women, in the assessment session of the quantitative study, made it possible for them to be confident and totally open in this deep life interview.

Data Analysis

After the entire transcription of the interviews, we began the coding process using interpretative phenomenological analysis (IPA), a qualitative methodology that aims to explore in detail how participants make sense of their personal and social world and focus on the meanings particular experiences and events hold for participants. We did not intend to analyze the answers to each question in a factual manner, but rather to achieve units of meaning, in a more global approach. IPA involves detailed examination of the participant’s life-world, concerned with the individual’s personal perception, with no attempt to achieve objectivity. Thus, this is not a prescriptive methodology and although the researchers should follow a basic process (from descriptive to interpretative), the analysis is a personal, interpretative work the researcher does at each of the stages and may be adapted (Smith & Osborn, 2003). The centrality of researcher’s subjectivity means that traditional criteria for evaluating research quality (such as reliability) are inappropriate for this kind of studies, because the purpose is to offer one of the possible interpretations for the phenomenon (Touroni & Coyle, 2002). Namely, the inter-rater reliability limits the richness of the process and does not exclude the subjectivity of interpretation, being simply an interpretation agreed by two people (Yardley, 2000).

The first author of this study conducted the coding process, accordingly to the methodological frame presented by Smith and Osborn (2003): after reading the entire transcript with an open attitude, to get a grasp of the whole nature of each participant account, we began searching for units of meaning and annotating all the significant and interesting aspects of what the participant said, staying close to her own words. This process took place through repeated
readings of the interview. In the second step we went back to the beginning of the transcript and began giving titles to the units of meaning previously found, as emergent themes that capture the essence of the participant’s words; these themes are more abstract and correspond to a more interpretative level of analysis. Simultaneously, we kept going back to the text to assure that our interpretation was in line with the actual words of the participant, in an iterative analysis. Then, we searched for connections among the themes and grouped them in clusters, moving from a chronological order to a more theoretical one. Finally, we gave these clusters a title, achieving superordinate themes. To exemplify these steps, we present a short extract from a patient interview:

I think the biggest turning point was five years ago, a period in which my marriage was in rupture, and there was a time when we went apart from each other to think about our lives…we were going through a difficult phase and we even thought about getting divorced…and then I made a retrospective of many things that were happening because of me…I was very obsessive and perfectionist and I was living very much or the house, the domestic work…forgetting about myself and also neglecting my husband…I mean, not going out for dinner and that kind of stuff…and then I felt really guilty and I said to myself that things had to change, I had to start dedicating more to myself because maybe that is a way to give my marriage an opportunity.

In the first step, we made the following annotations in the left-hand margin of the transcript: Identifying a difficult phase in the marriage as a life turning point; making a retrospective; feeling guilty for the marriage crisis; identifying the need to lower the perfectionism; committing more to herself and to the marriage. In the second step, we extracted the following themes from these annotations: A retrospective analysis of own behaviors; to recognize the negative effects of perfectionism; to change for a better life. In the two last steps, we searched for connections among the themes found in the whole interview and grouped them in clusters, moving from a chronological order to a more theoretical one and finally giving them a title, thus achieving superordinate themes. In the particular case of this patient, we achieved 10 superordinate themes: Perfectionism and self-demand; fight against perfectionism; pessimism and insecurity; not wanting to burden other people; struggle and goals accomplished; to overcome pessimism; to take responsibility for others; difficulty in trust; perception of divine protection; difficult childhood as a driving force. We repeated this process with each individual interview and the final step was to look at all the superordinate themes and try to identify repeated themes in the whole sample, which correspond to common patterns. As a way to ensure trustworthiness of our work, the second author reviewed the final themes and how they were grounded in the transcripts, as a form of validation (Smith & Osborn, 2003); also, credibility has been sought by giving a faithful description of the participants’ experience using participants’ own words to describe their experience (Sandelowski, 1986), which relates to the criteria of transparency and clarity, at the level of presentation (Yardley, 2000).

In our final analysis, we defined the criteria of considering as relevant and indicator of homogeneity the themes that are present in at least 7 of the 10 patients, thus achieving nine main themes. These themes include sub-themes, which represent the specific nature of that aspect in our sample.
Results

The list of main themes and their subthemes is presented in table 1. We present extracts from the data set to illustrate our interpretations, as the criterion of persuasiveness by “grounding in examples” (Touroni & Coyle, 2002).

Table 1. Themes and subthemes that emerged from analysis of the interviews with women with fibromyalgia

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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<tbody>
<tr>
<td>Struggle</td>
<td>Overcoming adversities</td>
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<tr>
<td></td>
<td>Getting strength out of weaknesses</td>
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<tr>
<td>Focus on adversities</td>
<td>Victimization and unhappiness</td>
</tr>
<tr>
<td></td>
<td>Pessimism and insecurity</td>
</tr>
<tr>
<td>Positive overlaps the negative</td>
<td>Gratitude</td>
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<td></td>
<td>Imagining future happiness</td>
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<td></td>
<td>Accepting reality as it is</td>
</tr>
<tr>
<td>Scars of unhappy childhood</td>
<td>Violence and abuse</td>
</tr>
<tr>
<td>Help others</td>
<td>Family instability and lack of love</td>
</tr>
<tr>
<td></td>
<td>Preoccupation with others since childhood</td>
</tr>
<tr>
<td></td>
<td>Injustice as drive to help others</td>
</tr>
<tr>
<td>Perfectionism and desire to achieve</td>
<td>Intolerance, rigidity and self-exigency</td>
</tr>
<tr>
<td></td>
<td>Desire for learning and self-improvement</td>
</tr>
<tr>
<td>Unsatisfactory present</td>
<td>Disappointment and regret</td>
</tr>
<tr>
<td>Perception of injustice</td>
<td>A misunderstood syndrome</td>
</tr>
<tr>
<td>Keep feelings inside</td>
<td>Solitude as search for balance</td>
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<tr>
<td></td>
<td>Avoid burdening other people</td>
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<td></td>
<td>Denying emotions</td>
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Note: N = 10

Struggle

This theme, pertaining to the overcoming of repeated adversities throughout life, combines two aspects: in some of these women, struggle is presented as the facing of repeated challenges, including a sign of personal strength:

I could not continue my educational pathway, it was very hard to accept, I saw my world tumbling down but I thought “I will do what they want me to do but one day I will study again” and I could not rest my mind until I did it. I worked all day, I had my daughter to take care of, the money was never enough, but I did not quit. There were years of struggle, day after day.

In other women, struggle is presented more as survival and the need to get over past weaknesses: “When I decide something, although it may hurt me, I always move on. I may be scared, may feel I am falling down, but then my weaknesses turn into strengths and I just do what I have to do.”
Focus on Adversities

This theme focused on a strong reference to repeated obstacles, including potentially traumatic events, situations of fear and despair (e.g., hunger, war), unexpected disappointments, a negative past, insecurity and pessimism. The subtheme victimization and unhappiness focus on the perception of having suffered more adversities than most of the people:

Some time ago I was thinking about my family members that already died, because I have a co-worker that is about my age and last month she went to the second funeral within her family and I began to think that I went to 17 or 18 funerals of people in my family. Do you understand the comparison? I had more regrets in my life than most of the people.

The subtheme pessimism and insecurity expresses some kind of insecurity that is clearly present in some of the women and not apparent in other women, but reveals at some point. This insecurity is linked with a pessimistic approach that tends to expect and emphasize the negative outcomes:

When other people anticipate a very happy event, lots of joy, I am always expecting some failure, because I think that it is not possible that everything goes well. I may be pessimistic, but I never feel secure, I have learned that something will always come to end our happiness.

Positive Overlaps the Negative

This theme is based in valuing the positive side of experiences and situations, as having the power to compensate the great adversities that had been experienced. It includes several aspects, as the redemptive love of a child, which enlightens a sad existence; the effort to accept reality as it is, despite the negative features; the perception of having been loved and cherished and being grateful for this; the search for self-enhancement and the attempt to change personal characteristics which are considered as negative (e.g., pessimism, perfectionism, hostility, etc); the belief that future will bring happiness; the belief in protection from a “higher” force. Imagining future happiness refers to the attempt to foresee positive things in the future since they were children, despite having a difficult life, as a way to cope with the adversities:

Even as a child, with so many problems, I already had something, some ambition, some hope in the future. I knew one day I would be happy, I had the notion of happiness inside of me. I always had the power to see the light at the end of the tunnel.

The gratitude concerns the acknowledgment that there has always been someone to give them some help and attention in the most difficult times (whether he/she is a family member, a stranger, or even a “higher” spiritual force). Some of the women are now able to consider a past failure (namely, a professional challenge that went wrong) as a positive opportunity for a change and personal growth: “After all, I always had people helping me. There was always someone, in the worst situations, with all the confusions, someone that would give a hand. I must say and I must value that.”

Accepting reality as it is concerns to the need to overcome past expectations that cannot be achieved, realizing that this is the only way to focus on the positive side of situations instead
of focus on the negative things that would make them suffer. Some of these expectations cannot be accomplished because of limitations brought by fibromyalgia (to have a healthy and active life, professional success, travel) and others are not directly related to the syndrome (financial difficulties, the lack of a love partner):

I have always appreciated the simplest things. Being really thirsty and drinking a glass of water, I could get pleasure from that, you see? It took me time to understand that I must accept reality as it is, that is the secret, or I would always be unsatisfied.

Although this attitude is much more difficult for some of these women than for others, all of them stated that they had to learn how to value small things and little pleasures, for their own sake.

**Scars of Unhappy Childhood**

This theme includes the clear statement of having had a childhood marked by difficulties and instability, because of different aspects. Most of these women stated having had economical limitations that hindered their possibilities and their future, some of them even recalled lack of basic aspects as housing conditions, possibility to go to school and even food. The subtheme family instability and lack of love refers to the sense of insecurity these women felt in their childhood, because of frequent house changes, loss of family members, family conflicts or at least with one of the parents and, in some cases, psychiatric problems or substance abuse by a parent:

Having a mother like my mother, a really mean woman, it marks you forever. I never knew what to expect from her, how she would be. She was never caring and I remember that as a time of constant instability and confusion. I have no good things to recall.

Seven women reported having suffered some kind of violence and abuse, in childhood and/or adolescence, namely, physical and/or sexual abuse by a family member and/or being witness to physical violence within the family:

I was left with my grandparents. We lived in a very small house, I cannot even call it a house. We had no money, people were always coming in and out. My grandfather was always drunk and he was violent with everyone. No one ever protected me from the terrible things I had to experience.

**Help Others**

This theme refers to concerns with other people and with their well-being; these women reported feeling bad when they saw other people in a negative situation, their will to protect them and do something for them. This concern seems to be present since childhood and includes sympathy toward strangers and assuming responsibility for family members in need. They have the urge to help, mainly when they see injustices:

I remember being a teenager, I started working at a young age … and in my way to work I saw those little boys, homeless, and I had the impulse to grab them
and take them home. Of course I could not do it but sometimes I gave them what
I had, and that was not much.

Other participant said:

I was never able to tolerate any kind of injustices. I was still a child but I saw
that in that school we were treated differently depending on your family name
and how much money you had. I only wanted to stay with the poor ones, I gave
them lessons … or no one would care for them.

Perfectionism and Desire to Achieve

This theme represents two different kinds of aspects: one of them is the most prevalent
and reflects high sense of responsibility, self exigency and intolerance toward failures and
mistakes. Almost all of the women recognize that perfectionism is a main characteristic of their
personality, and, although they have some pride in this, many of them also say that they have
tried to reduce it, at least in the last years, because they realized that it hindered some aspects
of their life:

Today I try to be different, but at that time I was very, very exigent with myself,
maybe too much. I had to have everything perfect, in order, perfect in my job
and perfect in my home, and of course I expected the same from everyone else,
I hated clumsy people. Nowadays, I accept a little better that I am not
responsible for everything … and people may have different standards.

The other aspect of this theme reflects the valuing of constant learning, wanting to achieve their
goals and progress in professional life, emphasizing work and effort.

Throughout my life, I have always tried to learn something in all the places I
have been. Even in the way I present myself, the way I speak … I have always
tried to learn from the women to whom I worked, asked them for books … I
feel rewarded by being at my best.

Unsatisfactory Present

Beyond some questions pertaining to the negative impact of fibromyalgia, this theme
includes the sensation of not being fulfilled, because of frustrations, family conflicts,
intellectual aspirations not achieved, which are part of the subtheme disappointment an regret:
“When it seemed that the situation was going to get better, it all went wrong, I went right
back to the same financial situation. I started [at that job] and the good things ended … so
unfortunately success is not for me.”

Five of these women referred the vivid recall of past abuses, which sometimes become
an overwhelming burden:

I think many times about my past. Sometimes I feel outraged because I think
that the violence, the bad life I had, it all contributed to this disease. When I
have more pain it seems like I can feel all the cold I felt, it is like a ghost, those
memories still hurt.
Several women complained about the lack of understanding other people have toward fibromyalgia, not valuing their symptoms and sometimes not believing that they really feel bad, in pain and incapable of working and fulfill their obligations:

I have some days in a month, sometimes is less than that, when I feel pretty well, I feel like a normal person, it is just that … and people still do not understand how we feel. Sometimes the pain and the fatigue are the worst but other times what hurts the most is to know what some people think about us.

Perception of Injustice

This theme includes multiple references to the sensation of having suffered injustices in several moments of life. Mainly in childhood, they had the belief of having been neglected at some point, being treated worse than their siblings, being limited by an unfavorable social situation that hindered their educational pathway, and situations of active discrimination:

What I have always thought is why did I have to go live with him [the uncle], if the distance from my mother’s house was not that big? And my sisters could stay with my mother, why? It was so unfair and it marked my whole future.

Other participant stated:

I felt sorry for myself because it seemed like I could foresee what happened later [failing in school two years in a row]. Although I made a lot of effort and studied a lot, I felt it was not worth it. It was just a big injustice.

Keep Feelings Inside

Finally, this theme includes the tendency to enjoy being alone, to get comfort in solitude and having difficulties in revealing their feelings and thoughts. One aspect is looking for solitude as search for balance:

I like being with other people, my husband, my friends, but I have a need for solitude too. First of all, I need solitude to paint, because painting is an act of solitude and also because I get easily tired with the noise, it irritates me. I need to be alone to regain my inner balance. I have always been like that.

Other aspect is the tendency to deny emotions, which these women have to different extents, because they do not feel very comfortable exposing their emotions, especially the negative ones:

They never saw me crying, I have always had this shell. Even as a kid, when I was beaten, sometimes I left home crying tears of blood, as I call them, but when I arrived at the bus I had a smile on my face, so no one would suspect.

Finally, there was also present the tendency to not share the negative feelings, worries and needs, with the intention of not burden another people:

Although I knew I could count on her [an older cousin] if things were really difficult, I knew I was alone, I hated to ask for help. Maybe this relates to my
way of always trying to overcome all the obstacles on my own. Although I am married and have my husband, I always try to resolve the problems by myself, I do not like to depend on anyone, still nowadays.

Discussion

We begin the discussion by establishing relations among the themes we identified and those of the other few qualitative studies that address the whole life of patients with fibromyalgia. The theme scars of unhappy childhood is the most common theme identified in the qualitative studies with fibromyalgia patients, either as a theme/category exclusively concerning childhood or included in a broader category of several life stages. Thus, we refer to traumatic life history (Hallberg & Carlsson, 1998), childhood memories (Hughes, 1999), developmental stressors (Teven, 2003) and overstrained as a child (Wentz et al., 2004). The content of the theme focus on adversities is also quite present in the literature, namely in critical life events (Teven, 2003), unprotected adult self (Wentz et al., 2004) and broken life (Sallinen, Kukkurainen, Peltokallio, Mikkelsson, & Anderberg, 2012). Pertaining to the theme help others, the only study that also includes this theme as being present since childhood is Tevens (2003), with the aspect caregiving. In adulthood, we identify the aspects giving and doing for everyone else (Hughes, 1999), compensating strategies (Wentz et al., 2004) and desire to help and support others (Juuso, Skär, Olsson, & Söderberg, 2013), although the later respects to the period after the onset of fibromyalgia only. The theme perfectionism and desire to achieve relates to over-compensatory perseverance (Hallberg & Carlsson, 1998) and to aspects “hypomanic repair” and “strength/being in control” (Wentz et al., 2004). The contents of the theme struggle are present in several compensating strategies included in Wentz et al. (2004) and, although this theme is not explicitly represented in other studies, it tends to be connected in some way with the description of perfectionism and action to achieve goals and overcome obstacles. The theme keep feelings inside represents respects to a broad set of feelings and situations, throughout life and beyond the experience of fibromyalgia, therefore differing from most of the studies previously mentioned, which refer to isolation and hiding the pain and suffering caused by fibromyalgia only. We found some resemblance with the theme positive overlaps the negative in one study (Hughes, 1999), where the chapter healing journeys presents the desire of patients to value their physical and emotional well-being, to forgive people that hurt them in the past, the attempt to value the lessons brought by fibromyalgia and the sensation of being connected with a “higher” force. In a more recent study, Juuso et al. (2013) also found an active search for well being by the women in their sample, but it differs from our study in that they looked for it specifically in their past good moments. Pertaining to the theme perception of injustice, although this perception is present in several other studies, it pertains only to the injustice of having fibromyalgia and the feelings about the onset of the syndrome, which is much narrower than the meaning in our study. Finally, pertaining to the main theme unsatisfactory present, although this aspect is found in all of the studies previously mentioned and in almost all of the qualitative studies with fibromyalgia patients, it only includes the negative impact of the syndrome in everyday life. In the present study, this theme is much broader, going beyond fibromyalgia, the impairment and the attitudes of disbelief and criticism from others.

We confirmed a relevant predisposing factor identified in the quantitative and qualitative literature, because the theme scars of unhappy childhood includes adverse experiences and unfavorable conditions that could cause long-lasting psychological effects and damage the stress regulation system, reducing thresholds for pain perception and tolerance (Eich et al., 2000; Van Houdenhove & Egle, 2004). We may relate the theme struggle and, secondly, the theme perfectionism and desire to achieve to a high “action proneness” identified
by Van Houdenhove, Neerinckx, Onghena, Lysens, & Vertommen (2001) in fibromyalgia patients. This overactive lifestyle could hinder the health status and act as a predisposing, triggering and perpetuating factor, and the more actively these patients attempted to strive for achievement or perfection, before the onset of the syndrome, more difficulties in coping with the actual functional limitations they will have. Since these authors also state that this action proneness would be more prevalent in patients with childhood victimization experiences, as a way of coping, we mention again the theme scars of unhappy childhood, which corresponds to some kind of abuse and victimization in several women of our sample.

Pertaining to the other themes we found, we may only hypothesize that they may play a role as predisposing and/or perpetuating factors for fibromyalgia. With respect to the theme keep feelings inside, which has always been present in these women’s lives, we have known since the works of Pennebaker and colleagues that the failure to talk about significant negative experiences is associated with increased health problems, autonomic activity and ruminations (Pennebaker, 1995), because the inhibition or active holding back of thoughts, emotions or behaviors cause stress that can lead to disease, over time (Pennebaker, Kiecolt-Glaser, & Glaser, 1988). In this line, some studies have claimed that written emotional expression produces health benefits in fibromyalgia patients (Broderick, Junghaenel, & Schwartz, 2005; Gillis, Lumley, Mosley-Williams, Leisen, & Roehrs, 2006). The theme focus on adversities may be related to the concept of pessimism, which has been associated to negative outcomes in several studies; namely, in a sample with rheumatoid arthritis, pessimism was an independent predictor of negative experiences, as more negative daily mood, pain-related activity limitations, negative daily events and poorer sleep (Affleck, Tennen, & Apter, 2001). In a recent study, an hypothetical model confirmed a negative role of pessimism in chronic pain patients adjustment, though the relation between pessimism and passive coping which is related to higher levels of pain, anxiety and impairment and lower levels of functioning (Ramírez-Maestre, Esteve, & López, 2012).

We hypothesize that perception of injustice could act as perpetuating factor; it has been showed that perceived injustice, as a concept pertaining specifically to the unfairness of the illness, accounted for significant pain-related outcomes after controlling pain intensity and other variables (Rodero et al., 2013). Considering that in our study this perception of injustice is not only related to fibromyalgia and its symptoms, but to different other aspects and periods of these women lives, we establish a connection between perception of injustice and acceptance, a broad concept that goes beyond the better known concept of acceptance of pain (McCracken, & Zhao-O’Brien, 2010); they state that acceptance of a wide set of undesirable experiences chronic pain patients may encounter, such as other multiple physical symptoms and experiences of emotional distress, may have a unique role in the quality of life of these patients, as a general psychological acceptance. It may be that the intense perception of injustice, which in many cases seem to emotionally hurt these women, is somehow the opposite of a full acceptance of life, with its difficulties and frustrations, leading to more dissatisfaction. We consider it would be important to study the relation among these variables, in the scope of quality of life and illness behavior of patients with fibromyalgia.

Finally, the theme positive overlaps the negative is particularly worth noting, because it is not prevalent in the literature and patients with fibromyalgia are much more associated with negative aspects and complaints, even by health professionals. It is interesting that this theme coexists with themes that strongly focus on negative aspects of life, which is consistent with the view of optimism and pessimism as separate constructs, instead of opposite ends of a bipolar continuum (Affleck et al., 2001). We consider this ability to emphasize the positive aspects is a promising data to explore in the psychological intervention with these patients, which has confirmed positive impact in their physical well-being (Glombiewski et al., 2010);
this is even more important in that there is no single “gold standard” treatment for fibromyalgia that is effective for every patients (Fitzcharles & Yunus, 2012).

The main limitation we find in this study is the sample size; however, IPA studies are conducted with small and fairly homogeneous samples and have been published with samples of one, four and nine, in that the main aim is to say something in detail about the perceptions and understandings of the particular group (Smith & Osborn, 2003). This fact and the recognition that, in this qualitative approach, different interpretations of the data are possible, makes these results an illustration of patterns of living and meaning in this group of fibromyalgia patients, which cannot be generalized as such, but rather shed some light on this thematic.

We consider our study is one of the few studies that analyzes the whole life history of women with fibromyalgia and not only the experience of the syndrome, considering these women as individuals beyond being patients with fibromyalgia. These women declared having shared some personal information and reflect on some aspects of their lives for the first time, maybe because the previous contact they had with the interviewer made they more confident and open. Of course, preconceptions of the interviewer about these women could have hindered the analysis, but she tried to limit this through awareness and reflexivity at each step of the process, and the interpretations “grounding in examples” (Touroni & Coyle, 2002) is also a way to do it. Therefore, we consider this was more a strength than a limitation. These women had a mean score of disability due to the impact of fibromyalgia higher than the average fibromyalgia patient and close to the one that characterizes the severely affected ones (Linares et al., 2008); so, it is possible that this pattern of lives, with mention to multiple adversities and some dominant negative themes, would not be present in less disabled patients, as some studies have shown a positive relation between disability level and potentially traumatic events in childhood and adolescence (Spiess, 2003) and abuse and neglect in childhood (Filippon, 2013). Also, it would be relevant to compare these narratives with life narratives of fibromyalgia patients who do not identify any kind of event and, afterward, with patients with medically explained chronic pain.

References


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Acknowledgement

This research was supported by grants from the Portuguese Foundation for Science and Technology.

Article Citation