

Aging and chronic pain: a study of women with fibromyalgia

Maria Angelica Schlickmann Pereira Hayar¹, Arlete Camargo de Melo Salimene², Ursula Margarida Karsch³, Marta Imamura⁴

ABSTRACT

Objective: This study seeks to investigate the aging process of women affected by fibromyalgia, as well as its physical, personal, and social impacts. **Method:** Sixty-six (66) women participated who were diagnosed with fibromyalgia, aged from 30 to 68 years, living in Sao Paulo/SP. For qualitative research, a group of fifteen (15) out of the 66 women was selected at random: five (05) aged from 30 to 49 years; five (05) aged from 50 to 59 years; and five (05) aged 60 years and above. Individual, semi-structured interviews designed by the author were conducted, recorded, and later transcribed verbatim. The instrument sought to encourage the subjects to reflect in order to access social representations of pain, of the disease, and of aging with chronic pain. The methodology used for processing the qualitative research data was the Collective Subject Discourse technique. **Results:** Analysis indicated greater incidence of fibromyalgia among elderly women, but the impact on quality of life, as measured by the FIQ, was greater among the middle-aged group (50 to 59 years). There was a greater prevalence of the disease among women with poor levels of formal learning, but it was found that the impact of fibromyalgia was more significant for women with higher education. The presence of religiosity was very significant in this group of subjects. **Conclusion:** Primary care provided by public health programs, such as “Estratégia de Saúde da Família” (Family Health Strategy), requires the proper approach to a person suffering from such a peculiar chronic illness as fibromyalgia. This approach should be extended to the elderly, in observation to the policies for humanization of healthcare services seeking to promote health.

Keywords: Aged, Chronic Disease, Fibromyalgia, Women, Gender and Health

¹ Social Worker, PhD candidate, Post-Graduation Program in Social Work at the Pontifícia Universidade Católica de São Paulo

² Social Worker, Director of Social Services at the Physical Medicine and Rehabilitation Institute - HCFMUSP.

³ Social Worker, Professor, Post-Graduation Program in Social Services at the Pontifícia Universidade Católica de São Paulo

⁴ Psychiatrist, Coordinator of the Clinical Research Center at the Physical Medicine and Rehabilitation Institute - HCFMUSP.

Mailing address:

Centro de Pesquisa Clínica do Instituto de Medicina Física e Reabilitação
Maria Angelica Schlickmann Pereira Hayar
Rua Jandiatuba, 580
CEP 05716-150
São Paulo - SP
E-mail: angelicasphayar@gmail.com

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INTRODUCTION

The aging process happens in various societies and cultures and is conditioned by biopsychosocial determinants specific to different contexts. In 1950, life expectancy for humans was only 48 years. Currently, on average, this lifespan has increased to 68 years.¹ The World Health Organization (WHO) recognizes that this population phenomenon is an indicator of improvement in world health and human development, a result of increments to the policies for public health, social welfare, and housing. It is connected to the current low indices of fecundity, but also to the overcoming of values, behaviors, and stereotypes.

Life expectancy in Brazil has increased in the years between 1999 and 2009, with an increase of approximately three years, extending the average life span to 73.1 years of age. In the period evaluated, the life expectancy of the women went from 73.9 to 77 years, and of the men went from 66.3 to 69.4 years.²

Women live longer than men and constitute most of the elderly population, not only in Brazil, but all over the world. This characterizes a cross-reference of gender in the issue of aging. This phenomenon, referred to by scholars as the "feminization" of aging is happening in association with epidemiological projections that indicate an alarming prevalence of chronic pain in Brazil, especially among women.^{3,4} Studies show that women report chronic pain more frequently than men and that the prevalence of this type of pain among women is especially relevant among the elderly.⁴⁻⁷

Chronic pain has generated a growing interest in the last decades and, according to the Clinical Protocol and Therapeutic Directives for Chronic Pain CPTDCP/PCDTDC,⁸ there is no available data in Brazil on its prevalence in the general population. However, in 2007, Dellaroza & Matsuo made a study with 529 elderly subjects in the city of Londrina, state of Paraná, and found that 51.44% of them suffered from chronic pain.³

In Brazil, studies dedicated to aging with chronic pain are very few, and even scarcer are the studies that associate aging with chronic pain due to fibromyalgia, cross-referenced by the issue of gender. Thus, the aging process for women suffering from fibromyalgia and the impact of this pathology on the physical, personal, and social aspects, aggregated to the changes that it creates, has become the central theme of this study, through

the social historic focus that sought to go beyond the unilateral biophysical concept of diseases.

Social Representations

Pain, as any and all experience, pertains to a field of meanings developed collectively, and an individual's way to be and act, as well as his many experiences, are directly referred to the society to which that individual belongs. The expression of pain is ruled by cultural codes that are absorbed in the social environment from the first moments of socialization. The social place an individual occupies can influence his tolerance to pain, because within a society there are different sociocultural conditions that qualify the reality of pain in different ways. In addition, someone else's reaction to our pain is also related to the place we occupy in society, therefore, the form that pain takes needs to make sense to someone else, it must be contained in the symbolic matrix of that society to be understood, that is, become a representation that is socially shared.

Social representations are the knowledge that stems from common sense and are constructs developed by the social subjects, and these subjects interact and interconnect through the sharing of those representations. Lefèvre & Lefèvre point out that the individual has a positioning that he believes to be totally his, but that, in reality, it is a set of ideas derived from discursive matrices that are available in a specific sociocultural space and in a specific historical time. Thus, the individual adopts a collective opinion in a private way.¹⁰

Fibromyalgia

Fibromyalgia is a chronic disease that afflicts the musculoskeletal system and that causes great suffering to those who have it. Targino⁶ affirms that fibromyalgia has been seen as a generalized pain tolerance reduction syndrome that would originate from low levels of serotonin and high levels of substance P in the cerebrospinal fluid, probably due to a neurotransmitter dysfunction. It is the second most common rheumatologic disorder that triggers chronic musculoskeletal pain, surpassed only by osteoarthritis. Studies on the prevalence of the disease in the general population indicate frequencies between 1 and 4%, with women being afflicted up to eight times more than men.¹¹ Fibromyalgia has greater incidence in individuals between 45 and 64 years old, but can occur at any time of life and afflict even children and adolescents, in which case, it seems there is not a great

difference in the incidence between boys and girls.^{6,12} Fernandes¹³ bases his findings on the studies by Goldstein,¹⁴ for whom fibromyalgia has a genetic base as much as it is a consequence of alterations in the limbic system, stemming from childhood traumatic experiences, diseases, and accidents. Waddell points out that approximately half of the patients with fibromyalgia remember the beginning of the disease, relating it with complaints from other pains that expanded with time and manifested themselves in other parts of the body.¹⁵

OBJECTIVE

Main Objective

The main objective of this study was to unveil how the aging process associated with chronic pain provoked by fibromyalgia was perceived, felt, and lived by women participating in the study and what the impact was of this pathology in the physical, personal, and social aspects of their lives.

Secondary objectives

The secondary objectives of this study were to know the socioeconomic, cultural, and demographic profile of women with fibromyalgia who are served by the Unified Health System (SUS) in Brazil, to identify the possible alterations in the performance of their family and social roles influenced by the presence of fibromyalgia, and to know the social representations that these women present in aging with chronic pain provoked by fibromyalgia.

METHOD

The study, defined as descriptive, prospective, retrospective, bibliographic, quantitative and qualitative, had its project submitted to the Research Ethics Committee - CAPPesq that authorized it in October 17, 2012 under the No. 128.416. The study was carried out at the Hospital das Clínicas Clinical Research Center of the University of São Paulo School of Medicine, in the period between October of 2012 and February of 2013.

The universe of the study consisted of 66 women with clinical diagnoses of fibromyalgia, aged between 30 and 68 years, residing in the city of São Paulo, Brazil. The following instruments were used to collect data: the socioeconomic, cultural, and demographic profile of users from the *IMREA/HC FMUSP* Clinical Research Center,

Fibromyalgia Impact Questionnaire (FIQ), and oral reports from the patients.

For the quantitative research, the data from 66 women was analyzed, collected by social workers in one-to-one interviews inserted into the operational routine of the Clinical Research Center. The quantitative research was treated by statistical methods where the quantitative variables used were means, medians, and minimum and maximum standard deviations in order to indicate the variability of the data. The qualitative variables used were relative frequencies (%) and absolute frequencies (N).

For the qualitative study, a group of 15 subjects was selected randomly from the initial 66 women: 5 between 30 and 49 years old, 5 between 50 and 59 years old, and 5 aged 60 years or older. Individual interviews were made, recorded, and later transcribed in their entirety through the application of a semi-structured instrument developed according to the Collective Subject Discourse (CSD) methodology, in the form of a script with questions that had specific previously established objectives. The instrument sought to stimulate the subjects to reflect and make it possible to access the social representations of pain, disease, and aging with chronic pain.

The Collective Subject Discourse (CSD) technique was also used as methodological procedure to treat the data in the qualitative research. Through this technique the discursive matrices contained in the discourse of these women was investigated so that, based on them, the social representations that circulated within the group could be recovered.

While using the CSD to access social representations, we sought to distinguish the discursive matrix, through the subjects' reports. At the same time that this matrix helps the individual recover those thoughts, they are retrieved and help gather and form a matrix common to these individuals.

The CSD aggregates what is similar in the depositions and separates what is different in the thoughts of the individuals interviewed, maintaining the discursive matrix that is common to all of them.

RESULTS

The data indicates that the greatest incidence of fibromyalgia is among elderly women (Chart 1), showing compatibility with other studies that indicate that elderly women suffer from chronic diseases, among which there are the musculoskeletal ones, such as fibromyalgia.^{6,11,15}

Chart 1. Distribution according to age bracket and marital status

Age	N = 66
30 to 49 years	19.7%
50 to 59 years	37.9%
60 to 69 years	42.4%
Marital Status	N = 66
Married	47.0%
Single	24.2%
Divorced	7.6%
Separated	12.1%
Widow	7.6%
Legally Separated	1.5%

The fact that most subjects were living with a partner agrees partially with data from the CENSO 2010,¹⁶ that showed about a third of Brazilians were living in some type of relationship and an increase in consensual relationships, going from 28.6% to 36.4% when compared to the CENSO 2000.¹⁷

Chart 2 shows a higher frequency of women with four years of formal learning - 21.2%, followed by those who studied for 11 years - 18.2%, and of those who studied for only five years - 12.2%. The prevalence of subjects with poor levels of formal learning suggests the presence of functional illiteracy. According to the report from 2011-2012 by the Instituto Paulo Montenegro (IPM)¹⁸ on the Funcional Illiteracy National Index (*Índice Nacional de Analfabetismo Funcional - INAF*), there was increase in the number of functionally literate people in all the age brackets in Brazil. However, significant proportions of illiterate people are still present, especially among the elderly. Formal learning is an element of significant importance when examining access to health, for it can interfere in the communication with health professionals, especially the physician. Poor vertical communication with the health professional may effectively compromise the prevention and treatment of pains and other diseases related to the aging process, since the level of cognition of the patients and their understanding of the explanations given by the health professional may not achieve the expected results.

Regarding ethnicity (Chart 3), the results obtained corroborate those from the Brazilian Institute for Geography and Statistics¹⁶ that showed, in the 2010 CENSO, that 91 million people classified themselves as white (47.7%), approximately 82 million classified themselves as brown (43.1%), and 15 million people classified themselves as black (7.6%).

Asian-descended people reached almost two million (1.1%) and indigenous reached 817 thousand (0.4%). Experts in demography believe that the increase in the black population (black and brown) is due to the increase in the number of people that now declare themselves as brown and that before preferred to classify themselves as white. But this is also due to black women being still those with the most children within a general decrease in the fecundity rate of Brazilian women.¹⁹

Having a religion is predominant among these women. This is a strong Brazilian characteristic, confirmed by the 2010 CENSO,¹⁶ that also shows an increase in the diversity of religious groups in Brazil.

The predominance of religion in this group of women may indicate that their religion/spirituality functions as a strategy to face stressful situations, as is the case of living with chronic pain without any expectation of cure. A bibliographical review study by Siegel et al.²⁰ about religion in health and disease contexts indicated an association of religion with the more positive perception of efficacy in the facing of chronic diseases in the elderly and with lower indices of depression and anxiety in that population. Along those lines, another study by Ferraro & Kelley-Moore²¹ demonstrated that religion frequently plays a central role in the lives of elderly people and that, with time, it becomes an important source of emotional support, with significant repercussions in their physical and mental health.

As for welfare (Chart 4), the data indicates that 55.4% of the women are covered by Social Security, however 44.6% of them are not protected by this system. From the 44.6% of these women who are not covered, 69% are still of an economically active age, but are not working formally and, consequently, have no right to

Chart 2. Distribution according to level of formal learning

Formal Learning	N = 66
Illiterate	6.1
Incomplete elementary	10.6
Complete elementary	22.7
Incomplete junior high	18.2
Complete junior high	9.1
Incomplete high school	4.5
Complete high school	18.2
Incomplete college	4.5
Complete college	4.5

Chart 3. Distribution according to ethnicity and religion

Ethnicity	N = 66
White	47.0%
Brown	43.9%
Black	9.1%
Religion	N = 66
YES	95.50%
NO	4.50%

Chart 4. Distribution according to welfare

Welfare	N = 66
Disability pension due to illness	9.1%
Disability pension due to accident	1.5%
Regular Retirement Pension	19.7%
Retirement pension for Disability	13.6%
Widow's benefit/Death Pension	10.6%
LOAS*	1.5%

*LOAS - BENEFÍCIO DE ASSISTÊNCIA SOCIAL AO IDOSO E AO DEFICIENTE (Social Assistance Benefit to the Elderly and Disabled)

receive the benefits instituted by the welfare and work legislations. From those, 31% are already older than 60 years and do not receive any type of retirement pension, which translates into an old age permeated by difficulties.

Their families were mostly composed of up to four people - 75.7%, followed by those with up to six people - 24.2%. The income per capita is a relevant factor when observing the levels of consumption of a specific population. The average income per capita of the women in this study was of R\$ 437.50 (216.58 USD as of October, 2012 rates: 2.02 BRL = 1 USD) with a median of R\$ 569.77 (282.06 USD). It can be seen that in the average per capita, these women obtained less than the monthly minimum salary in effect in 2010: R\$ 510.00 (291.43 USD as of 2010 average rate: 1.75 BRL = 1 USD). This data corroborates the 2010 CENSO¹⁶ showing that, even with a tendency to decrease in the last few years, income inequality is still significant in Brazil.

Although the national average household income per capita was R\$ 668.00 (381.71 USD as of 2010 average rate: 1.75 BRL = 1 USD) in 2010, 25% of population received up to R\$ 188.00 (197.43 USD), and half of the Brazilian population received up to R\$ 375.00 (214.28 USD), which is less than the minimum monthly salary in effect for that year.²

Of those women, 26.7% showed a score in the FIQ above 80, indicating a significant negative impact on their lives, since the maximum score was close to 100 points and the average was above 70 (Table 1).

The subjects had lived an average of 15 years suffering the symptoms of fibromyalgia, with the shortest time referring to pain of five years and the longest, of 31 years.

It was seen that the Basic Health Units (Unidades Básicas de Saúde - UBSs) were the first place they looked for in the search for a diagnosis. After these consultations, they were forwarded to specialized care.

When giving the diagnosis, many times the specialist does not clarify or cannot explain clearly and objectively all the aspects of the disease. This may happen due either to consultations being brief or to lack of knowledge about the disease. When the health professional gives the diagnosis and does not offer all the information on the disease such as its chronic characteristics—that it is not fatal—and that it will not cause any physical deformities, those questions remain in the imagination of those patients. Depending on the social representation they have of the disease, the symptoms may even become worse. Nevertheless, the simplest explanation may be something that can comfort them when they are afflicted with the typical pains of fibromyalgia.

The physician is the professional who will make that pain legitimate, who will reveal the mysteries involving the disease, and enable these women to develop strategies to face it. Women who are aging with fibromyalgia need the legitimacy offered by this professional to have their rights guaranteed, because with guaranteed rights, that person is protected legally.

The representation of pain as imaginary causes frustration and anger, because it means that that person was unable to convey the magnitude of her suffering, and that constitutes a situation of prejudice and lack of credibility. Thus, the appropriate care at the proper time may not be offered, which, even while waiting to be treated, could make that pain become chronic and increasingly difficult to treat.

Another disease that existed before their fibromyalgia was determinant for these women to access the health system. It was from the implications stemming from those diseases that these women discovered that they also had fibromyalgia symptoms.

The previous diseases mentioned are infirmities that have socially-accepted markers and whose existence could be proven by exams. The social representation that exists in these cases is that it is necessary to treat the patient immediately, giving them care and treatment, exactly like when there is pain caused by a cut, a fracture, or even a disease like cancer (even when it was already in remission).

[...] The doctor from there said: Your problem is a disease called fibromyalgia. We don't know its cause or how to cure it" [...].

In this speech, the physician gives the diagnosis and situates science in relation to the disease and its treatment. The definition

Table 1. Fibromyalgia Impact Questionnaire (FIQ Scores)

		FIQ SCORES	AGE	YEARS OF FORMAL LEARNING	PEOPLE IN THE FAMILY	INCOME PER CAPITA
N	Valid	15	15	15	15	15
	Losses	0	0	0	0	0
Mean		70.55960	53.47	6.73	3.13	548.18
Median		70.03500	55.00	5.00	3.00	400.00
Mode		53.161	55	4	2	400
Standard Deviation		10.571129	9.738	3.918	1.302	495.364
Minimum Value		53.161	33	1	1	136
Maximum Value		85.519	65	14	5	1900
Percentile	25	66.83200	47.00	4.00	2.00	212.50
	50	70.03500	55.00	5.00	3.00	400.00
	75	81.12600	63.00	11.00	4.00	640.00

of their diagnosis and prognosis offers the patients the ability to organize their daily lives, making it possible to respect the needs of the body and to look for support in their social network, when needed.

From the Collective Subject Discourses, it can be seen that fibromyalgia and its symptoms, especially chronic pain, cause a very dramatic negative impact in the lives of all those women, which corroborates the results obtained in the FIQ and other studies that used the same research instrument.^{22,23} According to the survey by Targino,⁶ when compared to other rheumatologic diseases, fibromyalgia shows the highest levels of pain, functional disability, and psycho-affective stress. Martinez²⁴ and Kaplan²⁵ also indicated that fibromyalgia is one of the diseases that causes the greatest losses in quality of life, with great impact on daily routines, and causing serious ruptures in the routine of patients. According to these authors, patients with fibromyalgia have worse quality of life than patients with other chronic diseases, such as rheumatoid arthritis, chronic obstructive pulmonary disease, erythematous systemic lupus, and even cancer.

Many times, the intensity of pain makes it unviable to perform daily tasks and work. That triggers a series of conflicting events that permeate the daily life of these women, and they attribute the origin of the pain to such conflicts. These are the "[...] pains of sadness as much in the body as in the soul."

The women in the group studied showed common personality characteristics, especially a tendency to perfectionism. Maybe there is a need to control situations and, when this possibility is lost, the pain takes over their bodies.

I believe that's how the fibro started. It's one of the hardships of our life, isn't it?

In this speech, the representation of the disease is expressed as a lack of balance that affects not only the body, but also the soul. According to Minayo,²⁶ spiritual diseases refer to the set of anxieties and dissatisfactions caused by the difficulties of life. The author points out that understanding these "diseases of the spirit," "emotional disorders," is a great challenge to the biomedical model, because this model "has no frame of reference to deal with the sensations experienced in the body marked by the exclusion of the assets necessary to maintain their individual and social lives."

Women react to pain by developing strategies to face them focusing on the problem, on the pain itself. In search for ways to deal with it, they begin to control or deal better with this daily challenge that is to live with pain. In that sense, they face the adversity of their condition with active confrontation strategies in relation to the stressor (the pain itself) such as looking to solve immediate problems or looking for alternatives that make their lives easier.

I gloss over the pains and pretend I don't have anything, I try to distract myself, you know? I listen to the radio, watch TV, read a book. I try to forget that I'm feeling pain in order for me to do my things.

Women react to pain in one way or another. They learn to perform their tasks even feeling pains and "don't give up." In this behavior, a pro-active reaction is observed in relation to the limitations imposed by the condition they face, which presents a quality that psychology, borrowing the concept from physics, calls resilience.

CONCLUSION

The study showed that access to treatment began with the appearance of pre-existing pathologies such as cancer, depression, and back pain, among others. This finding reveals emphatically how much fibromyalgia is still associated with a great lack of knowledge on the part of professionals in health teams, which contributes to disqualify the health assistance in our reality. In addition, fibromyalgia, for not being a visible disease, tends to be discredited, causing insecurity, discomfort, frustration, low self-esteem, and feelings of guilt, in addition to triggering processes of social and family exclusion and isolation.

The social representation of fibromyalgia as a disease associated with psychosomatic or even nonexistent aspects may influence the difficulty of access to labor and welfare rights. It is a social representation that can have a discriminatory and exclusive role and it must be combated through the dissemination of information on the disease among health professionals, beginning in the academic environment.

The aging process, when associated with chronic pain, does not seem apparent for those women who experience it. The pain itself is what stands out the most, an "entity" that stays with these women every day and demands numerous strategies to face it. Strategies are dearly needed to face the sensations and emotions provoked by the insidious presence of pain; it is as if aging were passing by unnoticed. Many times, that can hide the presence of physical and psychological symptoms of some life stages inherent to the feminine condition, such as menopause, for example.

The current Brazilian model of health care is centered on the treatment of acute cases and does not efficiently address the current reality, in which chronic diseases have become an important health problem. The growth of the elderly population and the consequent increase of chronic diseases convey the need to surpass the predominant health model and adopt a long-term treatment, encompassing the entire course of life, promoting global health, to diminish the social vulnerabilities to which the elderly are exposed and, especially, the women who are the focus of this study, in the later phases of their lives.

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