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The meaning of the diagnosis in the illness trajectory of persons with rheumatic disease: From the uncertainty

El significado del diagnóstico en la trayectoria del enfermo reumático: De la incertidumbre a la disrupción biográfica

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ABSTRACT This article seeks to analyze the meaning of medical diagnosis in the biographies of people who suffer from a rheumatic disease. Based in the ethnographic method, in-depth interviews were carried out among fifteen informants affected by different rheumatic conditions from the City of Barcelona. These interviews make it possible to see how the symptoms, dysfunctions or limitations experienced up until an accurate diagnosis is issued, can finally be reinterpreted through a model that explains the condition and gives it a name, attributing new meaning to the symptoms and establishing certain care and coping strategies. After a period of uncertainty, this definitive medical diagnosis allows to decipher the enigma of the chronic condition that afflicts the ill person representing a turning point in the illness trajectory that is recognized as a biographical disruption that resignifies the past and future of the subject. However, it is often necessary for those affected to undergo a complex, erratic and uncertain itinerary to reach the definitive diagnosis, so that this moment is identified retrospectively as a milestone in the illness experience.

KEY WORDS Clinical Diagnosis; Rheumatic Diseases; Chronic Disease; Disabled Persons.

RESUMEN El interés de este artículo es analizar el significado del diagnóstico médico en la biografía de los sujetos que padecen alguna enfermedad reumática, a través de un trabajo etnográfico basado en entrevistas en profundidad realizadas a un grupo de quince informantes de la Ciudad de Barcelona afectados por distintos padecimientos reumáticos. Los relatos de los entrevistados permiten abordar cómo los síntomas, disfunciones o limitaciones, experimentadas hasta el momento en que se emite un diagnóstico certero, finalmente pueden ser interpretados a la luz de un modelo que explica esta condición, se reconoce cuál es la enfermedad, se resignifica la sintomatología y se establecen determinadas estrategias de atención y afrontamiento. En este sentido, el diagnóstico médico definitivo logra descifrar el enigma de la condición crónica que aqueja al enfermo y constituye así un punto de inflexión en la trayectoria de atención, que es reconocido como una disrupción biográfica que resignifica el pasado y futuro del sujeto. No obstante, con frecuencia los afectados recorren un complejo itinerario, a veces errático e incierto, para llegar al diagnóstico definitivo, por lo que este momento se identifica retrospectivamente como un hito en la experiencia del padecimiento.

PALABRAS CLAVES Diagnóstico Clínico; Enfermedades Reumáticas; Enfermedad Crónica; Personas con Discapacidad.

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INTRODUCTION

The results presented in this article form part of a larger study conducted in the city of Barcelona, the primary objective of which is the analysis of chronicity. This is defined as the sociocultural and subjective process that is constructed through the everyday experience of subjects who live, in a permanent or prolonged way, with a damage, disease, dysfunction or disability defined by its duration as "chronic." This study was structured around the various aspects of chronicity, which despite being inherently related, for analytical purposes can be organized into four topics: the illness experience in the context of subject's biography; the illness trajectory centered on the diagnostic and therapeutic itineraries; the main physical, social, psychological and economic consequences derived from the condition; and corporality and its impact on the patient's subjectivity.(1)

It is generally held that the onset of an illness may to a greater or lesser extent alter the patient's daily life, and that this depends on a number of aspects; these include (but are not limited to) the social or functional limitations associated with the condition, its severity, its duration, or the care strategies needed to manage it. Nonetheless, when an illness becomes a constant in the person's life and is accompanied by a professional biomedical diagnosis, the person is acknowledged or labelled as "chronically ill." This recognition constitutes a particularly significant event in the biography of the affected person, both because a cure is impossible or highly improbable, and because the duration and evolution of this condition may be uncertain. In some cases, the medical condition may be controllable and more or less stable, or to present periods of crisis and remission, while, in other cases, it may be marked by a degenerative process and even of lethal consequences. Whether of a mild or serious type, what has in common is its life-long character and the need for subjects to learn to live with (and in spite of) their chronic condition.

Chronically ill persons experience and learn to recognize a set of traces that are not only physical, but also emotional and social, that the illness inscribes in their body, in their identity, and their biographies. The ways in which each subject lives, copes with, and interprets their suffering not only shape their lifestyle or affect their social relationships, but also reconfigure their subjectivity. In this sense, the traces of illness are materialized – sometimes resoundingly – and allow us to analyze how chronicity shapes or structures the subject, is inscribed in the body both in a literal and metaphorical sense, and is embodied in the subject.(2)

In these conditions, medical treatment is oriented towards forms of maintenance, control, and limitation of damage. It also establishes secondary prevention guidelines or palliative care, in a therapeutic horizon whose extreme limits are between the control and death. A chronic condition defines a process in which the subject must learn to live with it, generating both individual and collective coping strategies.

The objective of this article is to describe and analyze the impact of the definitive medical diagnosis in the illness experience. Through the retrospective look of the affected subjects, the aim is to reconstruct how the diagnosis was received, how the set of symptoms, dysfunctions or limitations experienced up to that moment were re-signified. From that point, they could be recognized with a name that facilitated their understanding and opened a new way forward: the diagnostic moment is remembered by our interviewees as a turning point in the diagnostic itinerary leaving traces on their lives, as a point of arrival, and at the same time, as a beginning in their illness experiences.

RESEARCH CONTEXT AND INFORMANT CHARACTERISTICS

The ethnographic data presented in this article were collected as part of a study on the processes linked to chronicity that was carried out in the city of Barcelona from 2005 to 2012. Various phases of fieldwork were completed over the course of this period, which included work with different groups of chronically ill, in a situation of disability or physical dependence. The analysis was focused on the meaning attributed to the chronic condition and its consequences in the lives of these individuals and those around them.

The results presented in this article are taken from in-depth interviews conducted with a group of individuals suffering from rheumatic conditions. Contact with all 15 informants who participated in this study was established through an association of affected persons – all of whom were members of the association and to a greater or lesser extent participated in its activities. Additionally, interviews were conducted with healthcare professionals who had previously worked with this association. The majority of informants were interviewed in two to three sessions, and the average time devoted to each was about six hours. Informed consent was obtained from all informants, who were assured of the confidentiality and anonymity of their participation in the study.

Informants were diverse in terms of the type and duration of the rheumatic condition they suffered from, although they were similar in terms of socioeconomic status. Some young adults and some older, of both sexes, who had been affected by some type of rheumatic disease for at least five years and were willing to participate in the research were selected. Ten women and five men were interviewed. The age range was between 30 and 70 years, and the average age of the group was 48 years.

Nine of fifteen informants were married, two were widows, two were divorced and two were single women. Four of them were under 40 years old, had no children and had opted not to, a decision mainly derived from their condition. Thirteen of them lived with their families and two of them lived alone.

In terms of socioeconomic status, the interviewees belonged to the middle class; the majority had completed university studies or technical careers. Most of them had worked as professionals. Nonetheless, they had all since ceased to be economically active, as those who were previously employed had retired due to their condition. All informants had received some type of biomedical and legal certification of their partial or total inability to perform working activities, and therefore received pensions based on their condition. Male informants expressed greater concern regarding their economic situation because of their illness, given that they had gone from being the primary income earner in their households to being secondary suppliers, providing only their pensions to household spending, while their wives had had to participate in the labor market pressured by this situation.

Our informants suffered from different types of rheumatic conditions, in some cases associated with other chronic diseases. Four informants suffered from rheumatoid arthritis, two from scleroderma, three from ankylosing spondylitis (AS), three from fibromyalgia, two from lupus, and one from osteoarthritis. Diagnosed comorbidities included depression, blindness, diabetes, obsessive compulsive disorder, and stroke.

Both younger and older informants had extensive experience with their condition; one-third had had their condition for at least thirty years, roughly half had for fifteen to twenty-five years, three informants had their condition for approximately ten years, and only one informant had for five years. The person's age and the duration of their condition had particularly significant impacts on their biography. In six cases the person's condition appeared before they had reached the age of 20, and in the remaining nine, the condition appeared before they reached the age of 45. Given that all informants were affected at a young age, in the midst of their professional lives and at prime reproductive age, their condition drastically altered their careers or modified their plans for having children and their relationships with significant others, as was the case of four young women.

A significant aspect that needs to be made explicit about the profile of the respondents is that they all had some experience with participation in self-help groups and patient associations . some of them were even prominent activists – so they had time and space to reflect collectively about the problems arising from their suffering.

Belonging to an association of affected persons facilitated their ability to speak openly about their illness experience, as they had previous opportunities to introduce themselves to others as individuals affected by a rheumatic condition and to share their stories on multiple occasions. Therefore, informants' accounts were constructed within the scope and limitations of the biographical narrative as described by Bourdieu.(3) He points out that the narrator reconstructs the story as a biographical illusion, highlights relevant aspects that retrospectively stand out, while others topics are – consciously or unconsciously – minimized, forgotten, or denied, based on their own assumptions regarding the created or imagined expectations of the listener. From my point of view, the affected people were able to reconstruct their biographies more reflexively, in which the condition acquires a relevant aspect of their identities, not only due to the illness experience itself, but also because one of the strategies to cope with this condition was, precisely, active participation in the self-help group.

THE DIAGNOSTIC ITINERARY: FROM UNCERTAINTY TO BIOGRAPHICAL DISRUPTION

In this study, the term "diagnostic itinerary" refers to the phase of the care trajectory in which the first symptoms are identified, a causal explanation linked to a particular nosological entity is sought, and one or several health professionals are consulted. They may (or may not) be able to implement diagnostic tests and/or therapeutic prescriptions in order to establish some interpretations which permit a tentative or provisional diagnoses regarding the person's condition, until they are able to determine the correct or definitive diagnosis. Although this is an initial stage in the care trajectory, its duration tends to vary, given that it may be prolonged by multiple tentative, confusing, or mistaken diagnoses and/or treatments aimed at alleviating certain symptoms, but which are not always suitable.

Therefore, diagnostic itineraries may be short and accurate; however – as was the case for almost all of our informants – they can also become a difficult journey marked by the uncertainty of not knowing what is happening, consulting different specialists. The professionals observe only partial aspects of the condition without being able to accurately identify the nosological entity and *piece things together* in order to establish a definitive diagnosis. This process was described by informants as "a labyrinth in the darkness," "walking without knowing very well where the road is going," "blind attempts," and in addition to the physical discomfort they experienced uncertainty, anxiety, and distress.

Throughout this difficult trajectory, getting an accurate diagnosis can be a relief for the ill person, as it often eases their unrest and allows them to give a name to – to label – the set of symptoms that they had experienced with uncertainty and confusion up to that point. In certain stages of the disease, being able to establish a precise diagnosis can mean, finally, obtaining a consistent explanation of the symptoms, which provides the subject a framework with which to understand their bodily experience. Furthermore, they are able to reorient their search for medical treatment towards better-defined goals, perhaps with the hope that this way they will find a possible solution to their problems. Nonetheless, this newfound certainty can – in parallel – be taken as serious news, because knowing that their condition is chronic, incurable, or has a severe prognosis, may be interpreted as a "life sentence," that will "condemn" the subject to live, feel, and construct their world in relation to their illness.

The main significance of a definitive diagnosis is that it represents a turning point in the way that the subject understands the nature of their illness, finally able to give it

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a name. In some cases, they are unable to become fully aware of the condition's implications, while in others the labeling as "chronic" or "lifelong" is assimilated and they may proceed to act accordingly, either modifying their lifestyle to some degree, reflecting on their present or future circumstances, or at times even reassessing certain aspects of their identity. Therefore, a diagnosis of a disease allows to identify, validate, and normalize it; it represents a milestone, from which the subject recognizes their condition as permanent and lifelong.(4) In the majority of cases, the definitive diagnosis marks a before and after in the subject's life.

The establishment of a diagnosis can also be seen as a crucial moment in the biography of affected individuals, given that it is not only a medical diagnosis, but also that it may influence the reconfiguration of their own identity.(5,6) The impact of the diagnosis can vary greatly according to the subject's personal history. In some cases, this event may signify a continuity with the past, another step in the steady march towards an uncertain future; in others, it is an expected or even predictable result, consistent with the lifestyle that had been leading; in other cases, it represents a breaking point in the subject's personal history.

In this sense, I consider it relevant to raise one of analytical perspectives that have marked the theoretical debate about chronicity outlined by Michael Bury,(7) in his classic study on a group of patients suffering from rheumatoid arthritis. Bury posits that chronic diseases constitute a type of experience in which the structure of everyday life and the forms of knowledge that sustain them are disrupted, disturbed, or altered in their daily flow. He suggests analyzing chronic disease through the category of biographical disruption; rather than a rupture proper, it would mean an alteration of the normal flow of things, an inability to continue activities naturally.

The diagnostic label has also been analyzed as a disruption in the biography of the sufferer, as a turning point in their personal history, which often leads them to pose such questions as "*what is happening to me*," "*why is this happening*," "*what type of future will I have*," and "*what should I do now?*" Such questions symbolize the uncertainty, pain, and suffering that can take on a number of forms ranging from denial, desire to escape from reality, self-blame, or refusal to accept the new condition.

Bury identifies two stages in this process. The first refers to the beginning of the problem and the recognition of the new condition; it requires explaining what is happening, in which a disruption of the aspects or behaviors that up to that moment had been taken for granted from common sense. Additionally, this stage marks the beginning of conscious attention to bodily states and the decision of whether to seek help; it is considered a biographical shift from a perceived normal or predictable trajectory to one that is fundamentally atypical, uncertain, and harmful.(7)

Given that the onset of symptoms is often perceived as a nuisance, they are at times assessed as though they were the product of some atypical physical activity rather than being regarded as a possible warning sign. The onset of such conditions is uncertain, imperceptible, insidious, and often asymptomatic. It is likely that the person will not involve others close to them at this stage, but rather will wait until an advanced phase of disease. Bury points out that patients frequently hide their symptoms or disguise their effects for extended periods.(7,8) The decision to seek specialized professional care and the definitive diagnosis mark the end of this first stage. This creates a sense of relief as the person is able to give a name to the condition, although it can also generate feelings of disbelief or anxiety.

The second stage involves more profound disruptions in the explanatory systems that the person normally employs, leading to a fundamental re-thinking of their biography while causing them to mobilize resources in order to cope with this altered situation. This stage is characterized by the emergence of a disability, the problem of uncertainty about the impact and course of the disease, as well as questions regarding what should be the appropriate behavior in light of its effects.

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At this stage, there is a search for legitimacy and tolerance of others, which implies a re-evaluation of the relationship between the now-manifest illness, their identity, and sense of self. The definitive diagnosis provides the person with concrete information that they can use in order to relate to their new condition as well as to explain it to others. Nonetheless, the effectiveness of treatment regimens (which sometimes are based on trial and error) and the knowledge about the causes are limited, leading to conflicting feelings of fear, relief, and anxiety. At this point, it becomes necessary for the person to construct a bridge that links this information, the medical knowledge of the disease, with their total biography, which would allow them to find answers to the different questions they pose, and with which – through a biographical review – they can find a subjectively meaningful causality.(9) Along with this disruption of structures of explanation and meaning, it is also possible to observe modifications in the person's lifestyle, changes in their daily activities, and in their approach to managing their condition (in terms of both material and organizational resources). These involve a practical reorganization of their personal relationships and social support networks.(10) The disruption of friendship and community ties are not only brought on by functional limitations, but can also be attributed to the stigma, shame, or concealment that chronic conditions or disabilities produce. At times this can lead to the abandonment of certain social circles or even increased social isolation.(11)

Therefore, it is important to understand the different aspects that contribute to shaping the intensity and impact of these disruptions in the subject's life, such as the social representations about the disease (whether prior to their experience or derived from it), the presence or absence of a social support network (mainly within the family group), the contexts in which their social interactions and daily activities are carried out, their possibilities for legitimating changes in their behavior, and their resilience in the face of disability and stigma.(12,13)

The physical, psychological, social, and economic consequences that chronic diseases imply do not only alter the life of the patient, but also bring about changes in their surroundings. Alterations in their family dynamic may be positive, as their situation encourages the activation of care systems and solidary support, or they may be negative, at times serving to catalyze preexisting conflicts, which are exacerbated by the new condition. In any case, the usual rules of reciprocity and mutual support are modified due to the increased dependency of the patient.(6)

This framework for understanding biographic disruption has received diverse criticisms,(14,15,16,17) but it has also been buttressed by a number of studies that employ its analytical perspective,(8,18) which have become an obligatory point of reference in the literature studying chronicity.(19,20,21,22,23,24,25)

In our experience working with this group of rheumatic patients, biographical disruption is a topic that has consistently emerged from the conscious reflections of our interviewees, all of whom recognized the way in which the disease disrupted their biographies, activities, relationships, and personal projects. They spoke about how they were able to learn to live with their condition, assuming its limitations, generating coping strategies, adapting to their new lifestyle, and reconfiguring their own identity. They described a permanent learning process in order to recognize the progression of symptoms, to monitor their bodies, to acknowledge the increasing limitations produced, and to identify real or imagined risks that they should avoid.

I employ the concept of *embodiment* posited by Csordas(2) to refer to the forms in which the appropriation of an illness is expressed in the body and through the body; that is, the chronic condition becomes *incorporated* into the identity of the affected subject. A large part of their life and the lives of those around them are structured according to the demands of their condition, while their world is redefined in terms of what they are able to do (limitations) and what they should avoid (risks). They must learn to balance and control these two dimensions through certain coping strategies in a permanent process of adapting and monitoring their corporeality. Their daily routines include self-care and professional medical attention, both for therapeutic and rehabilitation purposes, in addition to dealing with the administrative proceedings necessary to obtain the social benefits provided by the State. These social management activities oblige them to navigate a complex network of institutions, legislation, and bureaucratic proceedings in order to obtain disability pensions, work leave, and official disability certification. These bureaucratic processes turned out to be time-consuming and mentally exhausting, both for the interviewees and for their families.

A retrospective look at the time of diagnosis

In this section, I am interested in discussing the way in which our interviewees retrospectively reconstruct their own diagnostic itinerary. Despite the time elapsed, this long process was recorded in the memory of our informants.

In some cases, the first identifiable symptoms included recurring pain or inflammation in some joints or other areas of the body, which became increasingly frequent and intense. The causal explanations for these symptoms (both by the patients and by the doctors consulted) were associated with a particular activity performed, an inadequate posture, or were simply considered to be of an "inexplicable" nature. These symptoms frequently persisted for an extended period of time, in which informants were unable to make sense of the condition affecting them. Imprecise or erroneous diagnoses were made, and the treatments that were prescribed – essentially anti-inflammatories and painkillers – had merely palliative effects:

> *I started having really intense pain at 17, one day I just woke up with a strong pain in my foot. From that point on I started seeing doctors because I started to feel pain in my whole body. First in my feet, then in my knee, then one day in my hands, a week later in my other knee, after a month in my shoulder. Since the pain started in my foot they told me that it was a sprain. I told them that was impossible because I hadn't done anything where I could have sprained my foot, but they insisted that that was what it was. But when I started having pain in different parts of my body – first in my knees, then in my shoulders – I told them it couldn't be, it wasn't a sprain. That was my general practitioner. That's how it began, with intermittent pain, going from doctor to doctor, alternative medicine, orthopedic surgeons, general practitioners, so many different specialists just to find out what I had. We ended up going to any type of doctor because we had no idea where to turn. After a while – I don't remember how long it took, maybe five or six months, I don't know – I was diagnosed with "arthritis." By that time, I was 18. It was after at least five months, something like that, but it was definitely less than a year.* (Lety, 32 years old. Juvenile rheumatoid arthritis).

The duration of the illness largely determines the way in which it is embodied in the identity of the patient. As in the case described above, for almost half of Lety's life she has had to cope with the (quite limiting) consequences of her illness. By recovering some reflections about the temporality of the condition, the establishment of a diagnosis involves a redefinition of the past, the present, and the future of their illness. However, it also led to a re-configuration of themselves as subjects; although their identity is much more complex than simply the label of a "chronically ill" person, this category can nonetheless play an important role in shaping their identity.

> *My disease struck when I was ten, the doctors treated me but I wasn't conscious of having a disease. I guess I thought of it as something that had*

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> *come up but that would eventually go away and I'd be cured. It started with an inflamed knee and I couldn't run or play so my parents took me to the doctor, and they told me to rest it and the inflammation would go away. It went on like this until I was 14 or 15, but it got worse and worse, the inflammation got more intense and lasted longer, until I had surgery on my right knee at age 16. No, they didn't say anything* (regarding a diagnosis). *They didn't know what it was. They thought it was some type of joint problem so their diagnosis was that I had a dark red mass in one of my joints, it was dark red like wine, gelatinous. So, they removed it. But this was all talk, I didn't have any reports and they sent me to do radiation therapy. I don't know if they thought it was cancer. They had made a few comments that it could be a white tumor, but I never understood what that was, not even if it was a good thing or a bad thing. Then it turned out that no, it wasn't that bone cancer. So then they started me on radiation therapy and my symptoms went away until I was 19.* (Pedro, 59 years old. Ankylosing spondylitis and blindness)

Several points for analysis emerge from these accounts. A period of uncertainty with respect to the diagnosis is common when dealing with rheumatic disease, given that a significant amount of time can go by before a definitive diagnosis is made. Additionally, because the diagnostic itinerary generally involves consultations with general practitioners, when the patient is first referred to a specialist it is commonly an orthopedist or traumatologist . In ideal circumstances, the patient is referred to a rheumatologist, who is generally able to make a more precise diagnosis.

It should be noted that the diagnostic itineraries were structured in a similar manner: diffuse symptoms imprecise diagnoses, and after a certain period and the prescription of diverse treatment options (painkillers, anti-inflammatories, or corticosteroids), more specific diagnostic tests were performed (for example, rheumatoid factor blood tests or radiographic imaging) making it possible to confirm or discard a diagnoses. In some cases, a definitive diagnosis was made in a relatively short amount of time due to a particularly acute manifestation, as in the following case:

> *It all started eight years ago when I was 29, I remember I started to notice something strange when my ankles started swelling. One day over the summer my ankles swelled up and I just thought it was because of the heat, but when by September the swelling didn't go away and I started having pain in my knees and joints I decided to go to the doctor. So I went to the doctor, and since it was joint pain I went to see an orthopedic physician, but they didn't find anything. Then I started spraining things all the time. If you go to orthopedics because you're in pain but they find that you haven't broken anything, it's a sprain, but that's not really what it was. Since they never found anything I started going to a rheumatologist.* [...] *Four or five months went by. I started having this pain around September, and I wasn't diagnosed until February or something like that. Over six months I started to have a lot of symptoms. It was like they were activated all of a sudden. The doctor first told me it was lupus, that's when I started experiencing all the symptoms and my skin got really rough. My skin started to get really rough and shortly after the episodes of Reynaud's started. At first, they had diagnosed me with lupus, because of that last symptom that appeared the rough patches of skin; they said it was lupus because as soon as they saw that my skin was like that they diagnosed me. The rheumatologist sent me to have some tests done or something like that. So, they hospitalized me for 15 days because I was working at the time so it would have been much quicker to do all the tests that way. They did one*

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> *test after another and by the time I got out of there they had diagnosed me with systemic diffuse scleroderma.* (Irma, 37 years old. Schleroderma)

Informants saw the confirmation of a definitive diagnosis as a turning point in the illness trajectory, and they processed this moment in a number of ways, from disregard or denial to extreme pessimism regarding what this information would mean for their future. The adjectives used by their doctors to describe their conditions – such as "chronic," "progressive," "incurable," "irremediable," "degenerative," "of unknown cause" – consistently appear in interviewees' recollections, as adjectives whose meaning was not fully understood at that moment, but only with the passage of time:

> *Once as I went to a rheumatology service, with a simple analysis, the rheumatologist diagnosed me as having polyarthritis. At that time the words he used were "a chronic and progressive polyarthritis." That was exactly how he put it. I didn't give much importance to the words "chronic" and "progressive." At that time, I didn't really understand the significance as throughout my life has had meaning. I almost did not know. I practically didn't know that a chronic disease could affect someone at age 22, and the fact that it was progressive didn't frighten me at that time, it wasn't until a few days later that I started to understand the significance of those words.* [The doctor was] *an extremely professional and humane person, blunt but human, in the sense that he did not deceive me. From the first day, he told me that I had arthritis, that it was chronic and that it would keep getting worse. At that time I didn't understand what was meant by "progressive," it wasn't until he explained it to me that I understood.* [...] *It was a relief to finally know for sure what I had. From the beginning the arthritis decided that it was going to have a quite important development, it was affecting both feet and I felt the symptoms in my right wrist and in my left knee.* (Jorge, 55 years old. Rheumatoid arthritis).

In some cases, there was short-term vision regarding the consequences of the diagnosis. Informants anticipated that the identification of the nosological entity would ensure the prescription of effective treatment strategies that would put an end to their symptoms and restore their health, reduce their pain, allow them to regain full mobility, and return to their normal activities. Less clear was their perception of what would occur in the medium or long term:

> *It was the first time that they told me what I had was rheumatoid arthritis, for the first time they told me that. A rheumatologist explained to me that with my knees, after a while the last option I would have, that there wouldn't be other alternatives, was knee replacement surgery in both knees* [...] *um, and she said that there was some risk that my leg would be stiff after the surgery. But she said that after a while you'll have to do it. I didn't know what to expect at that point. That was the first thing they told me. That was my diagnosis. I think it was better that way, if they had told me everything I would have to go through it would have been worse, I would have completely collapsed.* [...] *When they explained the disease to me, they said that no, there was no cure. They told me there was no remedy. That there was currently no cure or remedy for this disease. They explained to me the effects of arthritis, that it can take ten years off a person's life. I was in such bad shape that that was the least of my worries. I didn't care about how many years less I'd live, that was the least important thing to me. What I was more concerned about was if I'd be able to walk, if I'd be able to walk normally, it wasn't so much about if I'd have problems with stairs, because usually you have to go up or down just a few steps, but I was mostly worried*

> *about being able to walk. The thing is people would tell me that life expectancy, for example, is 75 years. I was so young at the time, I was 21 years old, and people would tell me that I would probably die ten years earlier at 65, but I didn't care, because I was already walking like a* yaya [grandmother], *like a little old lady. I always said that on the stairs I was already like a 90 or 100-year-old* yaya. *I was mostly worried about being able to walk, if I'd get me mobility back.* (Jacinta, 38 years old. Juvenile arthritis)

Moreover, the manner in which medical professionals communicate diagnoses – and in particular, the prognosis that they relate to the patient – is key in determining the impact that this information will have. The perceived severity of this information and its emotional impact depend on the sense of alarm or the relative composure with which it is communicated. It is important to note the clarity with which informants recalled the way that the name of their illness was communicated to them as well as how they processed this information in that moment.

> *They diagnosed me* [with spondylitis] *in a really harsh way, but maybe I should thank them for that because it changed me a lot. They told me that it was a disease that I wasn't going to die from, but that I would have it my whole life and that I would have to take care of myself because if I didn't I would end up in a wheel chair. They told me this when I was about 24 years old. It broke me...* [Felipe begins to cry] *but I had to keep working and keep living my life, keep moving forward. I have to thank them, because maybe if they would have told me not to worry about anything I wouldn't really have been so aware of what I had, that it was something serious. That's why I have to thank them... They give you the news... Yeah, I don't know, maybe they thought it was really that serious. Maybe they thought that that was how they'd get me to react, and if I didn't react to what they said I really could end up in a wheel chair... and the fact is I'm not because the surgery has really helped me a lot. Both of my hips are operated on and because of that I'm not in a wheel chair.* (Felipe, 55 years old. Ankylosing spondylitis)

One element that was consistently present in interviews was the fact that a definitive diagnosis allowed informants to name, understand, and take action with respect to their illness, which prior to that point was conceived of as an erratic or unknown entity. It is worth mentioning that informants reported long periods of uncertainty regarding the chronic disease that they were suffering from, and they received imprecise or erroneous diagnoses and were treated with palliative measures that only worked to calm the symptoms they were experiencing. In this sense, a definitive diagnosis can also represent a source of relief and certainty after a long and ambiguous journey, allowing them to visualize their future more clearly. This marks the beginning of another stage in the care trajectory, initiating a long grieving process which includes stages of denial, evasion, sadness, and resolution. People go through this process at their own pace – with periods of crisis, stability, adaptation – a product of their own illness experience.

> *A friend told me I should go see Dr. G at the General Hospital.* [...] *He was a really outstanding doctor, really outstanding. He helped me understand what I should be doing and what I shouldn't be doing.* [...] *I mean he really improved my well-being, it was the first time somebody told me what I had. He told me that I had a disease called Spondylarthritis, and that it was a chronic disease which meant that there was no cure, but that with proper treatment and doing the necessary exercises I could have a totally normal life. A work, family, sexual, normal life. At that time, I had been living with my condition for 17 years. He connected everything that*

> *had happened to me before, my knee problems, gluteal problems, the stiffness, the pain, he connected all of that.* [...] *If I had to describe what I felt at that moment* [...] *at that moment I understood that what I had was incurable. I started to become aware of the fact that I was going to have this disease my whole life, but at the same time I felt reassured that I was going to lead a normal and healthy life, that's the sense that I got. A feeling of relief... even, almost even happiness, because I found someone that would take care of me, who showed interest, who wanted to help me. He didn't even charge me. The first visit and all the times I went to see him after that, for six or seven years. He's really special, yes, yes. He's like a madman, like a person who is outside the social parameters, and* [...] *well, I mean, he doesn't do that with everyone, just with the people he considers really in need he does that.* (Pedro, 59 years old. Ankylosing spondylitis and blindness)

To some extent, the information provided by doctors when delivering a diagnosis may be sufficient with regards to what the patient can process at that time. However, over time additional questions and new uncertainties regarding their future may arise. Initial expectations regarding their perspective on attending to and reducing symptoms and returning to daily routines, after some time are recognized as a point of no return, a disruption in the subject's biography that is nonetheless linked to their previous story.

Medical professionals acknowledge the limits to available treatment options and the gaps in their own explanatory models. Therefore, they attempt to make it clear to patients that their condition is incurable, explain that treatments will have palliative effects aimed at reducing pain, and give meaning to the idea of chronicity as a new way of experiencing the illness. The patient must become accustomed to living with this condition, with resignation and stoicism, consoled by the fact that it will not be the cause of death.

Therefore, it is important to underscore the centrality of the doctor-patient relationship in all informants' narratives. The interviewees evaluated their physician's technical knowledge, however they give importance above all to their doctor's human qualities, the sensitivity or bluntness with which they communicated the information, the time dedicated to explaining the patient's medical condition, and what would be the possible prognosis or treatment options.

CONCLUSIONS

From the retrospective view of the people interviewed, a definitive diagnosis represents the central answer to the question "*what is happening to me?*" This is an issue that, in the case of rheumatic diseases, can involve a somewhat diffuse or erratic itinerary as well as palliative therapies addressing only certain symptoms. This period is recreated in the memory of our informants as a stage in which a mixture of uncertainty and anxiety is added to the discomfort derived from their condition.

In light of the years that had passed since that moment, the definitive diagnosis is identified as the starting point of a long trajectory, hence the relevance of applying the concept of biographical disruption to explain the alteration of the course and the difficulties to recover the normal course of life until then. Other turning points in the illness trajectory can be identified – such as prosthesis placement surgeries, infiltrations, hospitalizations, among others. Similarly, other points of no return were identified – like retirement from work, obtaining disability pensions, ending certain interpersonal relationships, discontinuing certain social or leisure activities that as result of their illness became lost over the time. By examining their illness trajectories, it was possible to distinguish the stage corresponding to the diagnostic itinerary and the multiple meanings attributed to the establishment of a definitive diagnosis in the subject's biography. In each of our interviewees'

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narratives, it is possible to approach the sensations, emotions, afflictions, and lessons derived from their experience with the diagnosis, which had often led them through extended periods of uncertainty, pain, and a search for answers and solutions.

The definitive diagnosis, understood as a disruptive moment, allows them to reinterpret the past of their condition – a period in which illness had no name or it was equivocal – and shift their attention to the future, being able to recognize it and name it within a nosological and therapeutic framework with which the ill person may be able to situate him/herself and generate coping strategies. Moreover, the definitive diagnosis also means a social label that will have repercussions for the subject's identity, their sense of self, and others' perceptions of him or her. This will have an impact on their self-image, the image that they project, and that which is reflected in the gaze of others, in an encounter of mirrors. The illness also influences social relations that are activated and those that are deactivated, as well as the social and cultural structure that compels the subject to opt for certain strategies and discard others, shaping their new lifestyle.

This study has focused on one stage in the illness trajectory, which illustrates the impact and significance of a definitive diagnosis as a moment of disruption in the subject's biography, a starting point for them to seek out new ways of dealing with their condition.

It is necessary to open spaces in which the voices of those affected – the sick and their families – can be heard, while at the same time raising awareness among the general population and ultimately promoting innovative ways to improve the quality of life of affected people, aiding them to live through chronicity.

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