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## Original Article

### «Living with rheumatoid arthritis» in an indigenous *qom* population in Argentina. A qualitative study<sup>☆</sup>



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#### ABSTRACT

**Introduction:** Rheumatoid arthritis (RA) is a chronic disease which impacts patients' quality of life. The prevalence of RA in the *qom* population was 2.4% and represented an aggressive and disabling disease. The study goal was to describe the experience of the indigenous *qom* community individual suffering from RA, along with their experience with the local health care system in the city of Rosario, Santa Fe, Argentina.

**Methods:** Qualitative Study using techniques of participant observation and semi-structured interviews; following a guideline developed by a multidisciplinary research group comprising anthropologists, rheumatologists, nurses, and psychologists. A triangulation strategy was implemented for the analysis. **Results:** A total of 33 interviews were conducted in 29 individuals with RA. The results showed a “normalization” of their symptoms and of their limitations in performing daily tasks. The individuals' relationship with the local health care system was complex and limited in several aspects (e.g. access to health care, continuity of treatment, complexity of medical care pathway and lack of cultural competence).

**Conclusions:** RA is a disease that has a negative impact on the daily lives of the *qom* people living in Rosario. Improving the relationship between this population and the local health care system as well as the implementation of multidisciplinary work should be priorities.

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### «Vivir con artritis reumatoide» en una población indígena *qom* en la Argentina. Un estudio cualitativo

#### RESUMEN

**Introducción:** La artritis reumatoide (AR) es una enfermedad crónica que impacta la vida de los pacientes. La prevalencia de AR en la población *qom* fue de 2,4% y representó una enfermedad agresiva y limitante. El objetivo del estudio fue describir la experiencia de los individuos de la comunidad indígena *qom* que sufrían de AR, y su experiencia con el sistema de salud local en la ciudad de Rosario, Santa Fe, Argentina.

**Materiales y métodos:** Estudio cualitativo de corte etnográfico utilizando técnicas de observación de los participantes y entrevistas semi-estructuradas; siguiendo una guía desarrollada por un grupo multidisciplinario de antropólogos, reumatólogos, enfermeras y psicólogos. Se realizó un análisis temático basado en las narrativas reconstruidas y una estrategia de triangulación entre investigadores.

##### Palabras clave:

Sistema de Salud

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**Resultados:** Se realizó un total de 33 entrevistas en 29 individuos con AR. Los resultados mostraron una "normalización" de los síntomas y de sus limitaciones al realizar tareas diarias. La relación entre los individuos y el sistema de salud local fue complejo y limitado en diferentes aspectos (por ej. acceso al sistema de salud, continuidad del tratamiento, complejidad en las vías de acceso a la asistencia médica y falta de competencia cultural).

**Conclusiones:** La AR es una enfermedad que tiene un impacto negativo en la vida diaria de la población qom que vive en Rosario. Mejorar la relación entre esta población y el sistema de salud, así como también implementar un trabajo multidisciplinario debe ser una prioridad.

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## Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory disease with articular and extra-articular involvement, which impacts patients' functionality and quality of life.<sup>1</sup> The overall prevalence of this disease varies between .3% and 1.2%, some ethnic differences are shown.<sup>2</sup> Prevalence in the indigenous population is heterogeneous; in North America the reported prevalence was 5%–7%,<sup>3</sup> while in Latin America (LA) a prevalence of .4%–1.6%<sup>4–7</sup> was estimated. The Latin American Study Group of Rheumatic Diseases in Indigenous Peoples (GLADERPO) conducted epidemiological, anthropological, and genetic studies in several indigenous populations in Argentina, Mexico, and Venezuela. The prevalence of RA in the Qom population in Argentina was the highest reported (2.4%).<sup>8</sup>

In Argentina, the Qom (also known as Toba) belong to the Guaycurú language family, who originally inhabited the northeast of the country in the provinces of Chaco, Formosa, and Salta. The process of assimilation of the population is relatively recent (around the 19th and 20th centuries). Deforestation of the original forests, appropriation of land and climatic catastrophes (significant flooding) have been forcing the Qom to migrate from the 1960s to the present day. The Qom population settled in the territories of the provinces of Buenos Aires and Santa Fe, with Rosario being one of the most densely populated cities in the province of Santa Fe.<sup>9</sup>

In 2008, the Argentine Health Research Forum,<sup>10</sup> highlighted the complex epidemiological profile of the indigenous population, as its rate of vulnerability and mortality is higher than that of the rest of the population.

The current complex situation of the indigenous population requires researchers to use a social and epidemiological strategy that combines both quantitative and qualitative techniques. A study conducted in the Mayan community in Mexico, and published by GLADERPO,<sup>11</sup> used a strategy that prioritized the experiences of individuals with RA as well as their relationship with the local health system.

This study took the same approach as the study in Mexico and aimed to describe the experience of Qom individuals with RA, and their experience with the local health system in the city of Rosario, Argentina.

## Materials and methods

**Qualitative ethnographic study.** The objective of this design is based on the theoretical concepts of the trajectory of experiencing the condition and seeking care, to describe and understand the journey of the Qom group in their experience of RA, as well as their experience with the health system. Experiencing the condition is defined as the interpretation and reconstruction of the cultural dimension of the disease by the patient and his/her family from their own specific context.<sup>12,13</sup> Care seeking trajectories refer to the followed by the individual to achieve treatment and rehabilitation for a health problem.<sup>14</sup>

To meet the objectives of the study, the techniques of semi-structured interviews and non-participatory observations recorded

in anthropologists' field diaries were used. Interview and observation guides were used, developed by a multidisciplinary group of researchers (anthropologists, rheumatologists, nurses, and psychologists). The aspects included in the guide were: daily life (daily activities, type of work undertaken, housing conditions, family relationships, dependence on others) and access to the health system (availability of biomedical resources and treatment), use of traditional resources and traditional medicine (Appendix B Annex 1).

This study is nested in a previous epidemiological study undertaken and published by the same team of researchers.<sup>8</sup>

### Participating population

Individuals with RA identified in the epidemiological study were invited to participate.<sup>8</sup> Thirty-three interviews were conducted; in four cases a second interview was deemed necessary due to the valuable information provided. Thirty-eight hours and 15 minutes of interviews were analysed.

The criterion strategy of information saturation was chosen for the sample.<sup>15</sup> Information was considered saturated when the data collected no longer provided new categories of analysis or when the relationship between the categories had been validated.

### Field work strategy

In all cases, the process included several visits to the homes of the individuals interviewed. A first visit was made to establish initial contact, introduce the interviewers, and obtain informed consent. The home visits began with a presentation given by the Qom cultural facilitator (a Spanish/Qom bilingual community member), who explained the purpose of the study, the confidentiality of participation, and the future use of the data. The individuals were invited to participate in the study and were given informed consent forms and time to read and understand them. If the individual was illiterate, the consent process was conducted verbally. Signing of informed consent took place in the presence of witnesses, a facilitator/translator, and a representative of the Provincial Ministry of Health. Most of the interviews were conducted in the participants' homes (n=30) and the remaining few at the local health centre (n=3). The participants' homes were preferred as the place for the interview to facilitate the individual's recollection of significant experiences for his or her narrative. In some cases, a subsequent meeting was necessary to complete the interview.

All interviews were conducted in Spanish, recorded, and then transcribed into Word documents and enriched with comments from the anthropologists' field diary observations, to complete the process of analysis.

### Analysis

A reconstruction of trajectories was carried out through the narratives of the participants and that observed by the team of anthropologists, a thematic analysis thereof was then undertaken.

The criterion of information saturation was used to define the richness and depth of the study themes.<sup>16,17</sup>

Two members of the research team read the reconstructed narratives several times to identify the themes and sub-themes. This analysis continued throughout the writing process. A triangulation strategy was implemented to analyse the consistency of the information (data triangulation), convergence of the analysis (researchers' triangulation) and complementarity of the techniques used, such as non-participatory observation, interviews and clinical information from the participating rheumatologists (methodology triangulation).<sup>18</sup>

### *Ethical approval*

The study was approved by the Research Ethics Committee of the Health Department of the Municipality of Rosario on 22 December 2010 (Resolution No. 1659/2009), with the support of the Ministry of Health (resolutions 1619/2010 and 0127/2011) and the Ministry of Social Development of the Province of Santa Fe, the Rheumatology Association of Santa Fe, the Faculty of Medical Sciences, National University of Rosario and representatives of local Qom organizations. The study was registered with the Provincial Bioethics Committee of the Province of Santa Fe on July 5, 2012 (registration order number: 13).

## **Results**

### *Context of the study*

The study was carried out in Rosario, province of Santa Fe, Argentina. Rosario is the most populated city in Santa Fe and the third most populated city in Argentina. At the time of the last census in 2010, Rosario had more than 1,190,000 inhabitants.<sup>19</sup>

There was no official data on the number of Qom individuals established in Rosario; therefore, it was necessary to conduct a population census and map the data collected. The sample included individuals who met the following inclusion criteria:  $\geq 18$  years of age, who identified themselves as Qom and who had at least six months' residence in the city of Rosario. The Qom population is located in three districts: North (Barrio La Travesía), Northwest (Barrio Pumitas) and West (Barrio Rouillón).

This population primarily comprises young, second or third generation Rosario-born people with communicative competence in Spanish, unlike the older population and recent immigrants who still speak Qomlaqtaq (their mother tongue) as their first language. The Qom undertake casual work and are employed informally in jobs that require extreme physical activity.

In terms of housing conditions, irregular sites mix with urban areas. The Qom have limited access to some public services: running water, irregular electricity supply, transport, and rubbish collection.<sup>9</sup>

The health system in Argentina is divided, historically, into three poorly integrated levels: public health, social security, and private health. The public health system is financed by the state budget and is administered by national, provincial, and local governments. This complex organisation is based on the principle that every citizen has the right to health care, regardless of whether they have social or private cover of any kind.<sup>20</sup> In Rosario, the public health system is structured in three levels, according to the primary healthcare strategy.<sup>21</sup> At primary level, healthcare is mainly provided by general practitioners, and at secondary and tertiary level by specialists, for example, rheumatologists.

A total of 29 individuals were interviewed, 25 (86.2%) of whom were women, with an average age of 40.8 (range 26–55) years and a mean (standard deviation) 5.1 (0.3) years of formal education. All

the individuals were beneficiaries of the public health system. The city of Rosario was the birthplace of 15 (51.7%) individuals, and the province of Chaco was the birthplace of 14 (48.2%) individuals. All the patients spoke Spanish and 20 (68.9%) also spoke Qom. Most of the participants live in the Barrio Rouillón (n = 22).

In relation to RA, all the patients met the 1987 RA classification criteria;<sup>22</sup> over 90% were found to be HIV positive and around 60% had radiological changes. Most patients had active and limiting disease.

The following issues were identified: 1) Living with RA: perception of pain, daily activities, type of work undertaken, housing conditions, family relations, use of traditional medicine, and 2) Relationship with the local health system: access to the health system, doctor-patient relationship, continuity of treatment and availability of medication.

### *Living with rheumatoid arthritis*

*Interpretation of symptoms.* Symptoms were both normalised and underestimated. The interpretation of symptoms could be one of the reasons for delay in consulting a doctor.

"I didn't really notice. I had a pain in my legs, my knee and I thought it was normal (...)" (woman, 41 years old, five years with RA).

"(...) I didn't attach any importance to it (...) neither did I tell the doctor about this (...)" (woman, 48 years old, three years with RA).

"(...) When I came to Rosario in 1980, I started working in 1995 and worked until 1996, when I couldn't go on any longer because it hurt too much (...)" (man, 55 years old, 18 years with RA).

*Work and rheumatoid arthritis.* Notably, most of the individuals, regardless of gender, undertook physically demanding work. The characteristics of the disease, therefore, have major impact on the productivity and livelihood of the individual and his or her family.

"(...) You know, now I can't even tear cardboard (...) even if the cardboard isn't very thick, I can't do it, because of my disease, I can't do anything that requires effort because my hands hurt" (man, 52 years old, seven years with RA).

"(...) Now, I don't work at home or with my family, because of the pain in my body and hands (...) I don't have the strength to do my job (...)" (woman, 46 years old, six years with RA).

*Dependence. Another consequence of rheumatoid arthritis.* The physical limitations of the disease and its consequences on daily routine affect family relationships, mainly due to dependence on others. A feeling of frustration and hopelessness can be perceived in the narratives, especially in the intonation.

"(...) It was then that I needed my daughter's help because I couldn't stop myself, I couldn't support myself (...) because of the pain in my hands. I couldn't even open the tap, or comb my hair, I depended on everyone (...)" (woman, 48 years old, three years with RA).

"(...) And I didn't say anything to my wife, how it was hurting me, nothing. I wanted to continue, to continue working (...). She helps me in my work (...)" (man, 55 years old, 18 years with RA).

### *Process of seeking help.*

*Traditional medicine.* In addition to using the public health system, groups of strategies were observed in the population to treat the disease according to their belief, value, and action systems, all of which are different from those of the health system. These strategies can be grouped into three categories: shamanism (practices primarily associated with the conception that illness is the result

of an 'evil'), religious healing in the context of native Pentecostal churches, and traditional pharmacopoeia (medicinal herbs).

#### *Shamanism.*

"(...) For him, it is as if you're operating on the disease, you're taking out the disease, it's not that it's (...) it's as if he's operating on the patient. And then he saw that the patient was covered by a white sheet, and they put a plate there (he touches his knees) (...) And, well, there you have everything, I don't know, the disease falls into the plate and he shows you what that disease is (...)" (man, 50 years old, seven years with RA).

#### *Religious healing.*

"(...) I never said anything, I pray, for my life, I ask the Lord to heal whatever I have, I have faith in God, nothing is impossible for God, He can do everything (...)" (man, 45 years old, four years with AR).

"(...) No, now it doesn't hurt much. This is why I told Dr G. the last time I went there last year, and he said: Are you taking something? I'm not taking anything now, I told him. Because I go to church, I said. And through the church, the people who are always praying for me, I can't take the pills anymore, I said. And now it's like it helps me (...) From the gospel to the doctors. It's like I have more faith in the gospel than in doctors, and healers don't (she laughs, she's referring to shamanism) (...) Even though they are doctors too (...)" (woman, 40 years old, four years with RA).

#### *Traditional pharmacopoeia.*

"(...) my grandmother, my grandmother, who lives in el Chaco, when I went there in May told me to take (...) She told me to drink alcohol, tobacco, but I don't know (...) I didn't do it. You mix all that into alcohol and every night you put it where it hurts. Not only where it hurts, but, (...) in the heads of the bones, in all that and if eases, it eases the pain a lot (...)" (woman, 42 years old, five years with RA).

### *Relationship with the local health system*

*Doctor-patient relationship.* Some disagreements arise in the relationship between patients and doctors. Patients complain about the little time they have to explain things, or about the lack of explanation. It is inferred from the analysis that what patients refer to as a lack of explanation is a way of expressing difficulty in understanding it, as well as the impossibility of building a doctor-patient relationship.

"(...) and the pain in your body, did the doctor tell you why you have that pain? When I ask the doctor, she always says: we'll talk later (...)" (woman, 31 years old, seven years with RA).

"(...) You know that doctor was so loved here, he attended you so naturally (...) because if you need a pill, he'd say: What happened? What do you need? (...) He would explain to people: Look, you have this, this, and this (...) he explained everything. But not this one!" (man, 52 years old, seven years with RA).

*About the medication.* Even though standard treatment is provided free of charge, some difficulties were observed in the continuity of treatment. After a follow-up visit to the specialist who originally prescribed the treatment, patients can receive medication on a monthly basis at the nearest primary care centre (PCC). It was noted during the fieldwork that many patients had problems taking the medication as prescribed due to lack of knowledge.

"(...) Look, I really don't know, I don't know. Because they gave me four pills, but I don't know which pill is for Chagas disease and which is for RA. I was treated by two doctors and I asked one of them about one of the pills I'm taking. It's for your bones,

he said. But this is a painkiller, it's not what's going to cure you (...) they're pain killers, when that pain gets hold of you, it's going to ease the pain" (man, 55 years old, 18 years with RA).

"(...) Yes, I have to stop taking one, but I don't know which one (...)" (woman, 45 years old, five years with RA).

*Access. Availability of appointments.* The difficulty in accessing medical appointments (long hours of waiting in the street exposed to different weather conditions) has a negative impact not only on the patient's health but also on the continuity of treatment, as patients lose interest and abandon treatment.

"(...) Yes, yesterday I had an appointment scheduled with the doctor, but I left. Why? There's not much time for medical visits. There are too many people. If you're late, they won't see you (...)" (woman, 46 years old, 13 years with RA).

"(...) I didn't have the X-ray (X-ray of the hands). I couldn't get it done the other day (...) I arrived and didn't ask and I was sure that they were going to take the X-ray, but when I arrived at CEMAR (the name of the health care facility), they told me that I should have had the X-ray at the hospital (...)" (woman, 48 years old, 3 years with RA).

As a result of these difficulties, patients adopt different strategies to speed up care, such as skipping the visit with the primary care physician at the PCC and going directly to secondary care. However, this strategy is not sufficient.

Most of the time, the Qom individuals combine both systems of care (traditional and biomedical) in seeking care for their disease.

## **Discussion**

This paper, from a qualitative perspective, is the first investigation of a chronic disease like RA and its impact on daily life conducted in Qom residents of the city of Rosario. The first finding was that most of those interviewed had an aggressive manifestation of the disease, which limited their daily and work activities. This was already described by GLADERPO<sup>23</sup> and coincides with the results presented by Alarcón et al.<sup>24</sup> and Callahan.<sup>25</sup> These authors highlighted that indigenous populations present a higher level of deterioration and more aggressive disease progression. Similarly, Barnabe et al.<sup>28</sup> described that indigenous patients have greater consequences of RA in relation to the magnitude of symptoms experienced, quality of life, limitations to activities of daily living and in reduced work possibilities.

The second relevant finding was that, despite living in an urban context and within the vicinity of a PPC, treatment compliance and continuity were not as high as expected. Low adherence to treatment by patients was observed in the abovementioned study.<sup>23</sup> In comparison with other studies that focus on the analysis of health system accessibility, most undertaken in rural contexts where geographical distances were a determining factor, low adherence to treatment was also observed.<sup>11,26–29</sup> In line with this finding, a review of the literature by Loyola-Sanchez et al.,<sup>30</sup> which describes arthritis healthcare utilisation by indigenous populations in Australia, Canada, New Zealand and the United States, noted that indigenous populations under-utilize specialist services while at the same time frequently using emergency services due to complications of the disease (i.e. hospitalizations). Free distribution of medication in the Qom population does not necessarily guarantee that it will get to the patient. The latter may be due to a lack of understanding or awareness of the mechanisms of medication provision and its requirements.

Another relevant point was the doctor-patient relationship. A high rate of professional staff turnover, as well as a lack of sensitivity to ethnic specifics, could affect the relationship between the

PCC and patients; facts observed in other studies.<sup>11,31,32</sup> A research study conducted in an indigenous community in Alberta, Canada,<sup>33</sup> in which patients with RA and local health service professionals were interviewed, found that the underutilization of specialist treatment was due to a lack of knowledge about how to access health care. The authors emphasised the need for a culturally sensitive health system. Similarly, a systematic review of the specialist literature, conducted by Fradgley et al.,<sup>34</sup> on the main barriers to specialist care experienced by individuals with chronic diseases, highlighted a lack of understanding of the health system and poor relationship between health professionals and communities as the most common obstacles. Lin et al.<sup>35</sup> described, in a recent review, that communication difficulties between health professionals and indigenous people were the main reasons why indigenous people did not access the health system.

Thus, we believe that the main anthropological contribution should be to facilitate mutual understanding between health professionals and their patients, improving their relationships and dispelling the common misconception that obstacles to healthcare are the result of failures on the part of the patients.

The main difficulties include language differences between interviewers and respondents. Another constraint was the well-known pattern of continuous movement between Rosario and the Qom communities in the Chaco region. This point was highlighted in the cohort of RA patients belonging to the Qom community.<sup>23</sup> Migration was the main cause of visits lost to follow-up.

The main strength of this paper was its multidisciplinary approach, guided by the fundamental objective of improving indigenous patients' access to the health system. The clinical and epidemiological understanding of this disease is complemented by the social approach of anthropology. The meeting of these different disciplines allows us to obtain a better understanding of the consequences of living with RA in this social group. The field work was and still is conducted by the same group of professionals, which has consolidated the relationship with the community.

We can conclude that RA is a disease that has a negative impact on the daily life of the Qom population living in Rosario. A new care strategy needs to be adopted, prioritising multidisciplinary work in which not only medical staff, but also other actors such as social workers, anthropologists, and community leaders, play a fundamental role.

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#### Conflict of interests

The authors have no conflict of interests to declare.

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#### Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.reuma.2020.04.006>.

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