

Narrative inquiry and quality of life in women with rheumatoid arthritis

Indagación narrativa y calidad de vida en mujeres con artritis reumatoide

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Abstract

Introduction: Rheumatoid arthritis (RA) has a strong impact on work capacity and quality of life. The prevalence of RA is higher in women in their third and fourth decades of life. In order to understand how RA patients perceive their quality of life, it is necessary to consider their experiences and the meanings they give to their condition as chronic patients. This process also provides relevant information for implementing strategies that contribute to solving their needs and improving their quality of life.

Objective: To describe the perceptions of women with RA about their quality of life.

Materials and methods: Qualitative descriptive study conducted on a sample of 36 women diagnosed with RA who were administered in-depth interviews. Data were organized using the AtlasTI program; on the other hand, the narrative inquiry and the interpretive analysis were carried out according to Ricoeur and Benner, respectively.

Results: The narrative inquiry of the participants' stories allowed them to describe their quality of life as a state of well-being despite being affected by the disease. The analysis of the narratives told by the participants made evident the need for social security and protection, considering the multiple difficulties faced by people with RA in the current Colombian health system.

Conclusion: The results of this study may be regarded as a contribution to the humanization of health service delivery since they will allow health professionals to reflect on how to approach quality of life from a psychosocial and humanistic perspective.

Keywords: Rheumatoid Arthritis; Life Quality; Qualitative Research (MeSH).

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Resumen

Introducción. La artritis reumatoide (AR) es una enfermedad que afecta la capacidad laboral y la calidad de vida; su prevalencia es mayor en mujeres entre la tercera y la cuarta década. Para comprender cómo los pacientes con AR perciben su calidad de vida, es necesario considerar sus experiencias y los significados que dan a su condición de enfermo crónico, además este proceso permite obtener información relevante para implementar estrategias que contribuyan a solucionar sus necesidades y mejorar su calidad de vida.

Objetivo. Describir las percepciones de mujeres con AR sobre su calidad de vida.

Materiales y métodos. Estudio descriptivo cualitativo realizado en una muestra de 36 mujeres diagnosticadas con AR a quienes se les realizaron entrevistas a profundidad. Los datos fueron organizados mediante el programa AtlasTI; la indagación narrativa y el análisis interpretativo fueron realizados de acuerdo con lo propuesto por Ricoeur y Benner, respectivamente.

Resultados. La indagación narrativa de los relatos de las participantes les permitió describir su calidad de vida como un estado de bienestar a pesar de que esta se ve afectada por la enfermedad. En el análisis de las narrativas se evidenció que la necesidad de protección y seguridad social es un fenómeno producto de las múltiples dificultades que las personas con AR afrontan en el actual sistema de salud de Colombia.

Conclusión. Los resultados reportados en este estudio pueden considerarse como un aporte para la humanización de la prestación de los servicios de salud, puesto que permitirán a los profesionales de la salud reflexionar sobre cómo abordar la calidad de vida desde un enfoque psicosocial y humanístico.

Palabras clave: Artritis reumatoide; Calidad de vida; Investigación cualitativa (DeCS).

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Introduction

For patients with rheumatoid arthritis (RA), quality of life is a relevant concept that is directly related to the level of satisfaction they have with their lifestyle, beyond the physical consequences of the disease.^{1,2}

RA affects the quality of life of the people who suffer from it, as well as their working potential and, therefore, their general well-being. In some cases, it can cause premature mortality, which is why it is considered a public health problem.² This disease is more common in women (with a female to male ratio of 3:1), particularly in their third to fourth decade of life.

Due to the great economic burden it generates for society, RA is considered a high-cost disease. In this regard, Birnbaum *et al.*³ reported that it had a direct cost of \$19.3 billion in the U.S. in 2005, money that was allocated to employers (33%), patients (28%), government (20%) and caregivers (19%).

Early diagnosis and timely initiation of treatment contribute positively to the quality of life and well-being of people with RA, as the perception of the disease improves, and life expectancy increases when the health condition is stable.⁴

Considering perceptions from a qualitative approach leads to comprehending the congruence or disparity between the opinions of the patient, the family, and the health care provider, which is useful to know the benefits and risks that are not detected using other study methodologies.^{4,5} Likewise, recognizing the experiences and meanings that people give to their chronic illness allows understanding life from their point of view and learning relevant information to implement processes that help solve their needs and, therefore, improve their quality of life.

Exploring the narratives that describe the experience of living with a chronic disease allows, on the one hand, to know the perception that this type of patients have about the quality of life and, on the other hand, to make contributions to the development of a comprehensive, worthy and humanized care, represented in socially responsible and people-centered care.⁶ In this sense, the objective of the present study was to describe the perceptions of women with RA about their quality of life.

Materials and methods

Qualitative descriptive study in which a narrative inquiry methodology was implemented. It was used to conduct a phenomenological analysis based on the understanding of the contexts, facts, and truths that people exposed when asked about their experience as RA patients.⁷

To select the participants, all women with a diagnosis of RA who attended the outpatient service of the reference center where the study was conducted (in Bogotá D.C., Colombia) and had a HAQ (Health Assessment Questionnaire) score of 3 at the time of the interview, that is, markedly impaired functional capacity, and no cognitive impairments, were considered.

Data was collected through in-depth interviews according to the following questions: What is the meaning of the experience of living with the disease? Based on your experiences with arthritis, what has happened to your quality of life? What are the most important needs you have in your everyday life after being diagnosed with arthritis? Similarly, during the administration of the

instrument, the participants were given a socio-demographic characterization card designed by the researchers so that they could fill it out and provide information on age, educational level, marital status, and occupation.

The interviews, which were conducted between March and September 2014, took between 18 and 60 minutes and were recorded, transcribed verbatim and transferred to the AtlasTi software. Immediately after the end of the interview, the researchers made a field journal reflection that was self-recorded and transcribed; at the end, 42 field journal notes were transcribed.

The interpretative analysis was carried out according to the method proposed by Benner⁸ and following the guidelines for content analysis⁹ and narrative inquiry¹⁰ described below:

1. *Transcription of interviews.* Each interview was recorded and transcribed verbatim, line by line and individually, to capture the meanings contained in the narratives.
2. *Thematic analysis.* The narratives were read and re-read in depth as many times as necessary to obtain a global interpretation and to establish the most relevant themes.
3. *Narrative analysis.* The life stories of the interviewees were considered for the interpretative analysis. All the narratives were included in a universe of perceptions where every situation shared by the participants was relevant. In addition, each patient's ideology, concerns, and opinions were deemed as the central input for narrative inquiry.
4. *Identifying patterns of meaning.* The aim was to discover the richness of the narrative meanings to understand the experiences of each patient.

The study followed the ethical principles for medical research on human subjects established by the Declaration of Helsinki¹¹ and the provisions on health research of Resolution 8430 of 1993;¹² in addition, it was approved by the Research Ethics Committee of the Faculty of Nursing of the Universidad Nacional de Colombia, as stated in Minutes No. 1 of January 24, 2011. Once patients were informed about the objective, possible risks, and procedures to be performed, and agreed to participate in the study, they signed an informed consent.

To keep the anonymity of the participants, each one was identified with the letter "p" and a number assigned according to the order in which they entered the project.

Finally, the authors report that this article derives from the doctoral thesis entitled *Calidad de vida y nivel de salud percibido en personas con artritis reumatoide* (Quality of life and perceived health level in people with rheumatoid arthritis).¹³

Results

The sample was made up of 36 women between the ages of 32 and 76, of whom 15 were married, 7 were divorced, 9 were single, and 5 were widowers. The majority (n=27) of the participants had basic education, 5 had some technical studies and 4 had university studies. With respect to their occupation, 11 women were retired, 3 were unemployed, 10 were housewives, 6 were employees, and 6 said they were freelancers.

The women interviewed expressed through their experiences what living with RA means to them. Based on the analysis of these narratives, the stories were

classified into three categories: "Perception of quality of life for women living with RA", "Perception of lack of protection and vulnerability when living with RA" and "Care needs of people with RA". The characteristics of each of these categories, which are supported by some of the participants' stories, are described below:

Perception of quality of life for women living with RA

According to their stories, the interviewees perceive their quality of life as an "optimal" state of well-being that allows them to live well despite the disability caused by RA. For these women, having a stable health condition, that is to say, having the disease under control, means not feeling pain, being able to handle the symptoms, facing crises in the best possible way, and feeling good and happy in spite of what they are going through.

"Sometimes I can't go out because of the pain, but I try to stay active in my house regardless of the symptoms" (p2).
 "When pain crises and digestive discomfort occur, it is very difficult to manage the disease, but that is my life story, it is up to me to face this" (p4).
 "Trying to be happy and thinking that things will get better. It is not (sic) all the time, only when I eat meat or when I do housework" (p19).
 "In this situation, I can say that my life is visiting doctors and hospitals" (p8).

Perception of lack of protection and vulnerability when living with RA

Lack of protection is perceived as a fact that represents the multiple difficulties faced by women with RA in the current health system. According to the interviewees, there is no timely, quality, and comprehensive treatment that considers this disease as a pathology that affects all aspects of the life of those who suffer from it.

"Going through so many medical services, tests, medications [...] every doctor looks at one part" (p5).
 "I could not use public transport again, people are not supportive, there are no mechanisms to facilitate access to a pension or support for the expenses generated by specialized care when living outside the city" (p31).

This category also includes the concept of vulnerability, which was described by the interviewees as the perception of fragility in the context of a chronic disabling disease that forces a change in routines and lifestyle in a struggle to preserve autonomy.

"This disease changes your life. You can no longer do the same things you did before; you have to learn to survive" (p33)

In this sense, suffering from this disease brings with it the perception of vulnerability at both the individual and social levels. Similarly, feeling as a burden to the family and not being able to accept reality are facts with which the interviewees live daily.

"It is not easy to get used to see the deformity of the hands. Sometimes I dream with my life before using the wheelchair, I would like to go back to that time" (p7).

"Not being able to exercise my role as a mother, losing my job, not having a pension, these things affect me a lot. It's like being broken" (p6).

Care needs of people with RA

Study participants expressed multiple care needs, which can be interpreted as a lack of social support, affection, disease management skills, and social protection and security. In this sense, social relationships, especially with family and friends, are regarded as a need to maintain a social bond to deal with the disease and the main support to address uncertainty.

"Talking or listening to my visiting relatives is very important [...] I don't leave the house much, but I am always communicating by phone or text" (p22).
 "The help and company of the family is fundamental to live with the disease every day" (p4).
 "I try to think calmly about my future, although I don't know what complications will happen later, or if one day I will wake up unable to get out of bed" (p17).

In addition to family and friends support, the interviewees talked about the need to be recognized as chronically ill and request help from the State.

"I have had many disabilities in my job and my bosses think very little of my situation. They have not changed my duties and only hope that I will retire soon [...] Because of the disabilities, I almost lost my job and now I have many economic difficulties" (p23).
 "I feel unprotected, without any support from the state, I only count on my mother and she is already an old person" (p29).

According to the stories analyzed, it was also evident that the interviewees need to feel supported and loved even though their health condition affects their physical image, that is, they feel the need for affection. It was also important for them to manifest and channel their feelings and, in this way, strengthen their emotional state and mental health.

"When I can, I vent to a neighbor. She is the only person I can talk to about my fear of being disabled [...] I am very concerned about my financial future, not being a productive person because of the damage to my hands" (p14).
 "When the days are of pain and inflammation, it takes time to assimilate that situation [...] it is a very overwhelming condition" (p9).
 "The company of my dog is fundamental [...] he accompanies me unconditionally" (p35).

Similarly, participants noted that, to participate in activities related to their health care, they must have appropriate and extensive knowledge of RA, its treatment, and the potential to improve their quality of life. In this regard, they stated, among other ideas, that they would like to participate in support groups to learn about the experiences of other people with the same disease, be aware of scientific advances in the treatment of RA and receive information on alternative therapies for its management.

"I would like to have a space to share with other sick people and learn tips so that the symptoms do not win" (p36).
 "I want to learn relaxation techniques and exercises to do at home [...] I am interested in learning how to handle crises with tranquility, do some therapy" (p32).
 "I would like to learn more about new treatments and medical advances" (p33).

Finally, in all the stories, the need for protection and social security perceived by the interviewees was evident, since these women have to face various difficulties to access health services in their daily lives, which evidences failures in the quality and timeliness of care.

"So many procedures that limit access [...] I always have to do lines again, they do not give me all the medications" (p8).
 "I am authorized to pick the medication in one place, and it is delivered in another. So many trips cause me fatigue and pain [...] Every time I am assigned a control appointment, I see a new specialist" (p36).
 "It is very frustrating when they do not authorize the appointment with a specialist, the continuity is lost. Medical appointments take more than four to six months" (p1).

Discussion

The narratives of the interviewees reveal the condition of vulnerability that people with RA experience. They also reflect the burden that a chronic disease entails in terms of changes in their lifestyles and the way they deal with the symptoms and disability resulting from the progression of the disease, as well as the socialization problems caused by this situation.¹⁴

Social impact is evident in the costs of medication and travel (difficulties in accessing public transportation) and in the decrease in income due to job instability. These situations increase the perception of feeling a burden on the family, as stated by one of the participants when she said that not being able to work or fulfill her role as a mother affects her greatly. In this regard, some studies agree that RA affects both patients and their families, as daily routines, financial burdens, and relationships between family members and their primary roles are altered.¹⁵⁻¹⁷

Interviewees said that they experience feelings such as fear, anger, frustration, uncertainty, and sadness, which they avoid expressing in front of their loved ones. In this regard, Fallatah & Edge¹⁸ point out that the scale of emotions experienced by both patients and families is not only evident during the diagnostic phase of the disease, but also when exacerbations and crises occur. For this reason, it is fundamental to explore this component and, in this way, generate spaces in which those suffering from RA can express what they are feeling and receive support for the resolution of their problems. The participants also expressed the need for more humanized care and invited to reflect on strategies that contribute to improving the quality of life from a humanistic perspective.

Concerning the perception of lack of protection, the impact of the difficult access to the health system¹⁹ and, particularly, specialized care services, is evident, as it may generate complications and reduce opportunities to treat and mitigate systemic effects and joint damage.²⁰⁻²² In summary, it is clear that there is a need for

more quality health services that provide more humane, timely, and comprehensive care.

Participants described quality of life as a state of well-being and happiness that allows them to "live well" despite the severity of their condition and the disabilities that can result from the disease.²³ According to them, in order to have proper care of the disease and meet their need for a better quality of life, active communication²⁴ between the treating health team and the patient is required.²⁵

Slade *et al.*²⁶ state that trust is a determining factor for adherence to therapies and that consultations should, therefore, be oriented towards patient perceptions and interpretation of suggested guidelines. Also, Rees & Williams²⁷ point out that patients should be able to discuss their own perceptions of care actions (including lifestyle management) with a professional who is willing to listen and has the time to do so.

Since a patient's autonomy is the most reliable and accurate source of information about their physiological function and symptoms, it is also the focus of self-management interventions.²⁸ This shows the importance of developing comprehensive care focused on the particular needs of each person.

The analysis of the reports obtained revealed some needs that, when solved, can facilitate the confrontation of RA and all that it entails, which coincides with what Fallatah & Edge reported.¹⁸ However, the multiple care needs involving social and emotional dimensions reflect the impact of coping with a chronic condition, a finding also reported by Withall *et al.*²⁹ Furthermore, the patients interviewed said that they are interested in participating in follow-up programs that strengthen their security and confidence, and in developing coping strategies with self-defined objectives.

According to the findings of this study, health care centers should consider people with chronic diseases as patients requiring continuous health care. Consequently, patients must move from a paradigm of individual health care to a comprehensive one, in which the capacities of each human being are recognized and strengthened, the difficulties resulting from the disease are mitigated, and not only the disease as such is valued but also the experience of each individual.

The limitation of this study is that it was conducted in a single rheumatology care center, which is why it is necessary to develop new research to expand knowledge about the experience of living with RA in a health system such as the Colombian system.

Conclusions

The results of this study show the complexity of the impact that RA has on women's lives and can be considered as a contribution to the humanization of health service delivery. They should encourage health professionals to reflect on how to approach quality of life from a psychosocial and humanistic approach, as well as to understand the needs for care and accompaniment in the process of coping with the disease.

The interviewees expressed their desire to feel more informed and involved in their symptom control process and in the search for alternatives to achieve self-management considering their health condition. Therefore, research efforts must be directed towards

comprehensive and participatory care that allows RA patients to live the reality of their disease from a positive perspective.

Conflicts of interest

None stated by the authors.

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