







Symptomatic perception of patients affected by chronic chikungunya: a qualitative perspective

Percepção dos sintomas de pacientes acometidos por chikungunya crônica: um olhar qualitativo

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Abstract

Objective: To understand the demands caused by chikungunya in the chronic phase and their impacts on patients' mental health and quality of life. **Materials and methods:** This is a qualitative study, performed from November 2019 to January 2020. Focus groups and deep interviews were carried out. Then, the Discourse Analysis was performed. **Results:** Chronic pain was the main clinical manifestation reported by the participants, being responsible for affecting aspects related to quality of life and mental health. As for psychological view, this study showed that chronic pain was also reported as one of the main symptoms related to anxiety and depression among research subjects. **Conclusion:** this study demonstrated how the chronic illness caused by Chikungunya impacted the subjects' perception in the domains related to quality of life and mental health. Furthermore, we seek to focus on the management of disease in a holistic way, putting the patients' own awareness of the impacts of the disease on their lives in a relevant level of their treatment.

Keywords: Quality of Life; Disease Management; Public Health; Chikungunya.

Resumo

Objetivo: Compreender as demandas causadas pela chikungunya em sua fase crônica e seus impactos na saúde mental e na qualidade de vida dos pacientes. **Métodos:** Trata-se de um estudo com abordagem qualitativa, realizado entre novembro de 2019 a janeiro de 2020. Inicialmente, foram realizados grupos focais e entrevistas em profundidade; seguidas da Análise do Discurso. **Resultados:** A dor crônica foi a principal manifestação clínica relatada pelos participantes, sendo responsável por afetar aspectos relacionados à qualidade de vida e saúde mental. Quanto ao aspecto psicológico, este estudo mostrou que a dor crônica também foi relatada como um dos principais sintomas relacionados à ansiedade e depressão entre os sujeitos da pesquisa. **Conclusão:** este estudo demonstrou como a doença crônica causada pela chikungunya impactou na percepção dos sujeitos em seus domínios relacionados à qualidade de vida e saúde mental. Além disso, procuramos centrar-nos na gestão da doença de forma holística, colocando a consciência dos próprios doentes sobre os impactos da doença nas suas vidas num nível relevante do seu tratamento.

Palavras-chave : Qualidade de Vida; Manejo Clínico; Saúde Pública; Chikungunya.

INTRODUCTION

Chikungunya disease (CHIK) is characterized by sudden onset polyarthralgia, which may present fever, headache, myalgia, and rash¹. The first outbreaks of CHIK were reported in the early 2000s, mainly in Asia and Africa². By 2004, the virus had spread throughout Europe and the Americas with the potential to spread to other regions^{3,4}. During 2005 and 2006, there were epidemics of magnitudes never recorded before, with emphasis on Reunion Island, with 266.000 people infected. This number represented 34% of the total local population⁵. In Brazil, the first notifications were confirmed in 2014, with more than 300,000 reported cases. The Northeast region had the highest prevalence of cases, especially in the state of Ceará, with about 195.993 between the years 2016 to 2017⁶.

The natural history of Chikungunya disease can be characterized in three stages, according to the evolution of symptoms: a) acute, with a course of fewer than 21 days of infection with a predominance of altralgic and febrile symptoms; b) post-acute, with extensive inflammatory reactions lasting longer than 21 days and; c) chronic, with the maintenance of important pain symptoms even after three months of infection^{7,8}. The CHIK chronification rate can reach 48% in some regions of Brazil^{6,9,10}. Several factors can contribute to the chronification of the disease: from individual characteristics such as genetic predisposition and immune status of patients to inappropriate pharmacological approaches adopted in the early stages of the disease^{11,12}.

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Recent research suggests that chronic pain in chikungunya patients may persist for several months or years after infection^{13,14}. The persistence of pain symptoms may be associated with neuropathic components¹⁵, requiring the use of medications that help to control this type of pain, such as those belonging to the classes of antidepressants and antirheumatics. In addition, the chronicity of pain symptoms associated with the absence of clear clinical protocols for the establishment of more efficient therapeutic approaches generates suffering and impacts people's Quality of Life (QoL) negatively. As a consequence of the debilitating condition resulting from the chronification of CHIK manifestations in a significant portion of the infected population, it is essential to develop more in-depth studies aimed at understanding the limitations in the dimensions of quality of life and mental health¹⁶.

However, researches related to the chronicity of chikungunya are still not enough, notably when its scope is related to the understanding of its impact on the physical and psychological dimensions¹⁷. Therefore, this manuscript aims to understand the demands on the quality of life and mental health of patients in the chronic phase caused by Chikungunya.

METHODS

This study has a qualitative approach, carried out with 19 people of both genders living in the city of Fortaleza, northeastern Brazil, whose signs and symptoms of CHIK have evolved into the chronic form of the disease. The survey was performed from November 2019 to January 2020 and the research subjects were recruited through virtual invitations, mostly social media, aiming to reach broader and more varied segments of the population and have been proposed as promising identification and recruitment tools of participants for clinical trials¹⁸. As participation criteria, we adopt patients with chronic pain by Chikungunya with more than three months post-infection.

The research technique adopted was a Focus Group (FG). This choice is justified by the greater sensitivity to apprehend concepts, feelings, attitudes, beliefs, experiences, and reactions in a group through the evidence of behaviors and reflections from the interaction with other actors involved in the process^{19,20}. Five focus groups were held.

After an attentive analysis of the qualitative material, gaps were identified that led us back to the empirical field to elucidate issues considered crucial for the good execution of the research. The objective was to further deepen the subjectivity of the participants about the manifestation of the disease and its impacts on daily life. Under these circumstances, the interviews were carried out due to the depth, density, and quality of the material produced through these meetings¹⁹.

Two theoretical categories were selected as guides for the analysis in this study: quality of life and mental health. Thus, for the analysis of the qualitative material, the technique of Analysis of Discourse (AD) was used. Such a relationship is due

to the ability that an AD has to explore the baggage between how the interlocutor's processes and the nuances of the text are explicit (in this case the speech) and the objective of the research itself²².

All ethical precepts of research involving human beings were followed under Resolution 510/2016 of the National Health Council of Brazil and approved by the Research Ethics Committee under number 2.959.677.

RESULTS AND DISCUSSION

Table 1 presents the socioeconomic characteristics of the research participants. Almost all of them were women (89.5%), with an average of 62 years of age. As for the level of education, most of them had incomplete elementary education. The year of diagnosis of the disease was predominantly between 2016 and 2017, which corroborates the period of the greatest magnitude of the outbreak in Fortaleza.

Table 1. Socioeconomic characteristics of the research participants interviewed in the city of Fortaleza, 2019/2020

Age	Marital Status	Schooling	Year that had CHIK	Sex	Live with a CHIK patient
54	Divorced	H.S. complete	2017	F	Yes
55	Married	H.S. incomplete	2017	F	No
65	Married	E.S. incomplete	2017	F	No
48	Married	E.S. incomplete	2017	F	No
65	Married	E.S. incomplete	2017	F	No
68	Married	E.S. complete	2015	F	No
12	Single	E.S. incomplete	2017	F	No
46	Divorced	U.E. incomplete	2017	F	Yes
83	Single	Illiterate	2017	F	No
90	Widowed	E.S. incomplete	2017	F	Yes
66	Married	H.S. incomplete	2017	F	Yes
56	Married	U.E. complete	2017	M	Yes
57	Single	E.S. incomplete	2017	F	Yes
94	Widowed	E.S. incomplete	2017	F	Yes
60	Married	U.E. complete	2017	F	Yes
53	Married	U.E. complete	2017	F	No
79	Widowed	Illiterate	2016	F	No
42	Married	H.S. complete	2017	M	No
67	Married	H.S. complete	2016	F	No

Subtitle: "F" - female; "M" - male; "E.S." - Elementary School; "H. S." - High School; "U.E." - University Education.

This study showed that chronic pain was the main clinical manifestation highlighted caused by CHIK by the research subjects, in addition to being responsible for important limitations related to the quality of life:

"To come to lunch, they needed to put me in a

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wheelchair to go to the table. [...] and to go to the bathroom, to take a shower. I didn't walk alone. I didn't do anything alone" (FG-3).

"It limits because when I'm in crisis, I can't go down a ladder, I can't wear heels anymore, I don't do that anymore. [...] I always liked high-heeled shoes a lot. Today I can't, I retired all my high heel sandals, I can only wear flats. I even try, but with time, the ankle seems to go away... And the joints are swollen" (FG-4).

The impairment in the quality of life of people affected by CHIK is considered an important public health issue, although little documented in the literature^{23,24}. As reported by the participant, a deficit in the ability to perform daily activities, such as descending a ladder was noticed, such variables are directly related to the quality of life since it is present in the main assessment questionnaires²⁵. It represents the enduring severity of impacts and their magnitude on the dimensions of social life. In addition, the present findings are in line with other studies that demonstrated a worsening in the quality of several physical and psychological domains when compared to non-infected²⁴.

Other complications resulting from the chronicity of CHIK were also identified in this study. The alteration of musculoskeletal structures and the disturbance of their functions were reported by the subject:

"I had all my joints swollen, I didn't close my hand, I didn't have the strength for anything. [...] I lost more strength in my hands due to chikungunya. I didn't close my hand and thought that I wouldn't even be able to close it anymore. It affected me a lot because I don't have the strength to pick something up with my hands anymore, I don't twist anymore" (FG-1).

"During the period of chikungunya disease, it got a lot worse... I had already injured my ankle and was very bad, but surgery was not necessary. I was one hundred percent good. But when I got the chikungunya, it was like I got injured again. [...] The wrist too [...], because I did too, it swelled a little and didn't move due to chikungunya" (FG-5).

Rheumatological symptoms such as stiffness, pain, and edema were three times more frequent in people with chronic manifestations of CHIK when compared to the general population not infected by the disease²⁶. Other studies have also identified frequent symptoms such as arthralgia and paresis, especially in the upper and lower extremities^{16,27}. This research demonstrates that, in addition to the losses in QoL, the chronicity of chikungunya negatively impacted participants' mental health:

"You are totally dependent on people, and you can't do anything on your own, and that [...] This is also what

affects the psychological the most. [...] At work, it was difficult because, in this case, there are three flights of stairs. The room is on one floor, one bathroom above and the other bathroom below, so you... So it was very difficult" (FG-3).

"It affected me, well... Because I was feeling more symptoms after it, much more. I'm not the same person I was before chikungunya, I'm not anymore, I'm not" (FG-5).

Studies carried out with individuals who evolved to the chronic stage of the disease have shown the presence of alterations in brain regions involved in the cognitive and emotional modulation of pain. This complex interaction may be associated with the development of psychic pathologies such as anxiety and depression²⁸. A study conducted by Queyriaux (29) with individuals suffering from chronic CHIK form concluded that 87.5% of the participants reported feeling psychologically affected after the infection.

Going deeper into the analytical dimension of this research for aspects related to mental health, we realized that chronic pain was associated with symptoms of anxiety and depression among participants:

"I became a more still person. I avoid many situations, the disease prohibits us from doing many activities for which there was a lot of disposition before. [...] Do you know what my anxiety is? It's wanting to do things and not being able to. Some days make me want to open that door and go away. I went to church every day, and there were days when I went twice. After that, it was over. So I can spend the day indoors, I keep doing things" (E-4).

"I got more depressed. We even have a change of mood... quickly. It is a cruel disease" (E-1).

The literature shows that the most important clinical manifestations associated with CHIK chronicity are related to rheumatic and musculoskeletal impairment characteristics. However, studies also demonstrate that a significant portion of the infected population complained of tiredness, insomnia, anxiety, and mild and moderate depression^{24,30}.

"I think that the worsening of the psychological state makes it a more painful disease... it blocks you, where you are not able to leave" (FG-4).

"I became more sensitive. Everything makes me cry" (FG-2).

"People feel depressed, with a feeling of impotence. Want to do something but you can't. Looks like you get old before your time." (FG-5).

Although the psychic complaints brought by this study

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have multifactorial characteristics, research increases their association with the chronicity of CHIK. According to the authors, persistent pain in these cases is one of the most important risk factors for depression, and mood disorders, in addition to gastrointestinal manifestations³¹. Thus, this study draws the attention of health professionals to the need to consider the elements of physical and psychic nature when preparing their therapeutic plans. With this, the aim is to promote a broader approach to the disease, able to take into account both the most apparent signs and symptoms of the disease without neglecting its possible impacts on the psychological dimension of patients.

The study has some limitations. Among them, we highlight the non-application of scales capable of assessing the mental health impairment of the research participants. On the other hand, we were more interested in delving into their perceptions, which do not always correspond to what was identified by other instruments.

CONCLUSION

This study operates in a field of the health-disease process that

still has gaps in the academic focus: qualitative content. There is a need to understand how dense the relationship between chronic CHIK patients with their daily lives can be. Such a qualitative approach puts us in a perspective of interpretation of the disease through each patient, articulating it, albeit dialectically, within its treatment.

We must discuss how chronic CHIK can interfere with the life of each affected person to make them aware of their limitations and physical and/or psychological pain. The patient's awareness of the impacts of the disease on their lives already reveals the need for health education in the clinical management of Chikungunya so that this management takes place more holistically.

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