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## Evaluation of the quality of life dimensions of individuals with visceral leishmaniasis: an exploratory study

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### ABSTRACT

**Objective:** To evaluate the quality of life of patients affected by visceral leishmaniasis according to social, clinical, and epidemiological aspects. **Method:** A descriptive, cross-sectional, and quantitative study. It was developed between July and October 2019 in a hospital in the state of Paraíba, Brazil. Probabilistic sample including individuals over 18 years of age, of both genders, and under treatment for visceral leishmaniasis. A social-demographic questionnaire was used alongside with the Medical Outcomes Survey Short-Form 36. **Results:** 23 patients participated in this research, most of them male, single, and between 18 and 80 years of age. There is a negative impact on all areas of quality of life, with lower scores on the emotional role, physical function, and social role. **Discussion:** Visceral leishmaniasis is a neglected disease that affects several human dimensions, which presupposes the insertion of the nurse in educational and assistance actions that can mitigate the effects of the disease and improve the quality of life of this population.

**Keywords:** Health-related Quality of Life; Visceral Leishmaniasis; Nursing.

## INTRODUCTION

Leishmaniasis lies within the scope of neglected diseases, characterized by an endemic zoonosis, mainly in the warmer weather tropics<sup>(1)</sup>. Caused by protozoans of the *Leishmania* genus, it is responsible for affecting human beings and can develop a cutaneous and visceral form<sup>(2)</sup>.

Visceral Leishmaniasis (VL), also known as kala-azar, is a systemic parasitic disease caused by the *Leishmania donovani* parasite, referred to as a species complex. It is estimated that approximately 500,000 new VL cases occur annually. It is characterized by fever, substantial weight loss, hepatosplenomegaly, and anemia in the most severe stages. When untreated, its mortality rate (mainly in developing countries) gets very high<sup>(3)</sup>.

It is one of the most neglected diseases in the world, affecting the poorest people in developing countries and can be associated with malnutrition related to poverty, weakness of the immune system, geographical displacement of the patient to endemic sites, inhospitable housing or areas of disease occurrence, illiteracy, gender roles played by the sick individuals, and lack of financial resources<sup>(4)</sup>. VL is a chronic, systemic condition characterized by long-term fever, weight loss, asthenia, adynamia, hepatosplenomegaly and anemia, among other clinical manifestations. When untreated, it can lead to death in more than 90% of the cases. It is highlighted that only a small portion of the infected individuals develop signs and symptoms from the disease. Following infection, if the individual does not develop the disease, it is observed that the tests for cellular or humoral immu-

nity remain reactive for a long time<sup>(5)</sup>.

Thus, the impact of infection and the therapeutic process, especially the need for hospitalization, can interfere with the quality of life of the patients which, according to the World Health Organization (WHO) is defined as the individuals' apprehension of their position in life in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards, and concerns. This definition considers the individuals' satisfaction regarding the physical, psychological, social interaction, environment and spiritual aspect dimensions of their life<sup>(3,6)</sup>.

The assessment of the health-related Quality of Life (HRQoL) has been used to determine the aspects associated with diseases or the established treatment, which, when they occur, modify the individuals' health state and may have repercussions on their quality of life<sup>(7)</sup>. Based on this discussion, the following question permeates this investigation: What dimension of the quality of life of individuals affected by VL has the greatest impact? In this sense, this study aims to evaluate the quality of life of patients affected by visceral leishmaniasis according to social, clinical, and epidemiological aspects.

## METHOD

A descriptive, cross-sectional, and quantitative study. The study was conducted at the Unit of Infectious and Parasitic Diseases (*Doenças Infecciosas e Parasitárias*, DIP) of a reference University Hospital in the care of individuals affected by leishmaniasis in the state of Paraíba, in the Northeast of Brazil. The sample was of the probabilistic type, obtained by means of

sample calculation, which was based on data from the Department of Informatics of the Brazilian Unified Health System (DATASUS) where, in Paraíba, between 2016 and 2017, 43 VL cases were notified in individuals over 15 years of age. Considering a significance level of 10% and a test power of 80%, the sample of this study was composed of 23 participants in the in-patient regimen.

The following eligibility criteria were considered to compose the sample of this research: individuals over 18 years of age, of both genders, who had a medical diagnosis of VL, and under treatment in the aforementioned service. Patients using psychotropic drugs and those with a noticeable physical or cognitive disability (evidenced by questions related to daily life, the place they are in, age, and day of the week) were excluded from answering the questionnaires used in the research.

For operationalization of data collection, a questionnaire containing sociodemographic and epidemiologic information of the participants was used, namely: gender, origin city, schooling, marital status, occupation, alcohol or drug use (whether licit or illicit), displacement within or outside the state, type of house, materials used for building the house, locality and proximity to woodlands rivers, as well as the presence of pets and/or wild animals in the surroundings. As for the clinical aspects, diverse information was addressed regarding the patient's main complaint when seeking the health service, the comorbidities present, and the laboratory tests taken to diagnose leishmaniasis.

To evaluate the participants' quality of life in this study, the Medical Outcomes Survey Short-Form 36 (SF-36) was used, which is an

instrument of a multidimensional character used for measuring QoL, composed of 36 items already validated and translated into Portuguese<sup>(8)</sup>. It addresses eight domains: functional capacity, physical aspects, emotional aspect, mental health, social aspects, vitality, pain, and general perception of health. The score ranges from 0 to 100, with higher values indicating better QoL<sup>(9)</sup>.

The patients seen at the DIP of the HULW-UFPB were invited to participate in the study, and the objectives of the research were explained, followed by the reading of the Free and Informed Consent Form in order to obtain the participant's consent and signature or fingerprint on the document. Later, in a private room, there was interaction with the research participant through questions guided by the QVRS data collection and measurement instruments. Data collection took place between July and October 2019.

The data from the participants' answers were tabulated in a 2010 *Microsoft Office Excel* spreadsheet and then transferred to the SPSS software, version 20. The Shapiro-Wilk test was conducted for each of the dependent variables in order to check the normality of the data. For data analysis, descriptive measures (frequency, mean and standard deviation) were used, as well as non-parametric statistical tests (*Mann-Whitney* for variables with only one category, and *Kruskal-Wallis* for variables with more than two categories). Under CAEE: 11309619.9.0000.5183, the present study has been approved by the Research Ethics Committee, according to Opinion No. 3,362,887, complying with the assumption of Resolution 466/2012 of the National Health Council.

## RESULTS

23 inpatients of the reference service for the treatment of leishmaniasis in the state of Paraíba participated of this research.

The sociodemographic characterization of the participants, described in Table 1, shows that 91.3% of the participants were male, with an age range between 18 and 80 years old, mean age of 36.83 years old ( $\pm 16.708$ ), the majority being aged up to 39 year old (69.6%), and with a mean family income of R\$ 1,311.78 ( $\pm$  R\$ 681.71). It is highlighted that, at the time of developing this study, the minimum wage in Brazil was R\$ 1,039.00.

Regarding marital status, the majority of the participants was single (60.9%) and was working in agriculture and cattle raising activities (52.2%). When asked about the use of alcohol and other substances (cigarette, marijuana, or cocaine), 65.2% of the participants reported the use of alcohol (either frequently - 52.2% or sporadically-13.0%), and 60.8% makes use of other substances (whether cigarettes - 34.8%, marijuana - 17.4% or cocaine - 8.7%).

Regarding displacement (inside or outside the state) in the last six months, 87.0% of those interviewed said they had not moved, 100% said they lived at their homes, 69.6% in their own property, in rural areas (60.9%) and in houses built with ceramic bricks (95.7%).

As for the characteristics of the property surroundings, 69.6% said they live near the woodlands, 60.9% said there are rivers near their houses, and 78.3% said there are no banana trees near their homes. Concerning the presence of animals in the property, 69.6% of the participants had pets at the

time of the research, of which 56.5% were dogs and 30.4% were cats; and 82.6% said there were no sick animals near their homes. Regarding the clinical data of the participants in this study, Table 1 illustrates that 91.3% of the patients sought the health service with an initial complaint of fever. As for the comorbidities presented by the patients admitted to the hospital for the treatment of VL, it was observed that 17.4% had diabetes. For the laboratory diagnosis of leishmaniasis, 65.2% of the patients were diagnosed by means of serology.

Regarding the domains of quality of life according to the SF-36 instrument, Table 2 shows, by the means of the scores, that there was a greater negative impact on the QoL of individuals with VL in the emotional role (8.70) domain, followed by the physical function (9.78) and by the social role (33.70) domains.

Based on inferential statistics regarding the impact of the sociodemographic, epidemiological, and clinical characteristics on the quality of life of the individuals affected by VL, it is observed in Table 3 that there was a statistical difference between the genders and the physical functioning ( $p$ -value: 0.036), body pain ( $p=0.012$ ), general health ( $p=0.016$ ), vitality ( $p=0.020$ ), social function ( $p=0.032$ ), and mental health ( $p=0.036$ ) domains. There was a statistical difference regarding the age of the participant and the physical functioning domain ( $p=0.017$ ) and between the general health domain and the patient's area of residence ( $p=0.015$ ).

There was no significant statistical difference when non-parametric tests were performed between the SF-36 domains and the comor-

**Table 1** - Distribution of the sociodemographic and clinical data of individuals with visceral leishmaniasis. João Pessoa, PB, Brazil, 2020 (n=23)

<b>Sociodemographic and clinical data of the participants</b>			
<b>Variable</b>	<b>Category</b>	<b>Patients with VL</b>	
		<b>n</b>	<b>%</b>
Gender	Male	21	91.3
	Female	2	8.7
Age group	Up to 39 years old	16	69.6
	40 years old or more	7	30.4
Marital status	Single	14	60.9
	Married	7	30.4
	Divorced/Separated	2	8.7
Profession	Agriculture and cattle raising activity	12	52.2
	Social activity	9	39.1
	Business activity	2	8.7
Consumption of alcoholic beverage	Frequently (1x/week)	12	52.2
	Does not drink	8	34.8
	Sporadically (1x/month)	3	13.0
Use of chemical substances	No	9	39.1
	Cigarettes	8	34.8
	Marijuana	4	17.4
	Cocaine	2	8.7
Displacement outside the state (in the last six months)	No	20	87.0
	Yes	3	13.0
Type of house	House	23	100.0
	Apartment	0	0.0
Condition of the property	Own	16	69.6
	Rented	7	30.4
Area of residence	Rural	14	60.9
	Urban	9	39.1
Construction material	Bricks	22	95.7
	Mud	1	4.3
Property next to the woodlands	Yes	16	69.6
	No	7	30.4
Property next to rivers	Yes	14	60.9
	No	9	39.1
Property next to banana trees	No	18	78.3
	Yes	5	21.7
Presence of pets in the home	Yes	16	69.6
	No	7	30.4
Cat	Yes	7	30.4
	No	16	69.6
Dog	Yes	13	56.5
	No	10	43.5
Sick animals	No	19	82.6
	Yes	4	17.4

### Clinical data of the participants

Variable	Category	Patients with VL	
		n	%*
Initial complaint	Fever	21	91.3
	Weight loss	15	65.2
	Paleness	8	34.8
	Splenomegaly	8	34.8
	Hepatomegaly	8	34.8
	Pain	5	21.7
	Diarrhea	3	13.0
Comorbidities	Diabetes	4	17.4
	Systemic Arterial Hypertension	3	13.0
	Rheumatic disease	1	4.3
	HIV and AIDS	1	4.3
	No comorbidities	14	61
Laboratory diagnosis of leishmaniasis	Serology	15	65.2
	Histopathological	6	26
	Polymerase Chain Reaction (PCR)	5	21.7

\* Number regarding the frequency of answers, not regarding the sample.  
 Source: Elaborated by the authors, 2020.

**Table 2** - Scores of the Medical Outcomes Survey Short-Form 36 domains for individuals with visceral leishmaniasis. João Pessoa, PB, Brazil, 2020 (n=23)

Domains	Patients with leishmaniasis		
	Mean	Median	Standard Deviation
Body pain	58.83	52.00	28.84
General health	45.83	42.00	23.52
Physical functioning	38.26	35.00	32.88
Mental health	44.52	44.00	24.16
Vitality	37.17	30.00	29.88
Social function	33.70	37.50	18.63
Physical function	9.78	0.0	25.83
Emotional role	8.70	0.0	28.81

Source: Elaborated by the authors, 2020

bidities presented by the individuals with VL, as shown in Table 4.

The Social function domain presented a statistical difference when related to the initial complaint of pain ( $p=0.032$ ). When referring to paleness, there was a statistical difference in the vitality domain ( $p=0.019$ ). Diarrhea showed a difference when compared to the

mental health domain ( $p=0.020$ ).

### DISCUSSION

The results of this research show that, of the total number of participants with VL infection, males are more affected, corroborating previously developed studies that have the same

**Table 3** - Scores of the Medical Outcomes Survey Short-Form 36 domains, according to the sociodemographic data of individuals with visceral leishmaniasis. João Pessoa, PB, Brazil, 2020 (n=23)

Sociodemographic variable	Physical functioning	Physical function	Body pain	General health	Vitality	Social function	Emotional role	Mental health
Gender (a)								
Male (n=21)	12.90	12.19	12.95	12.98	12.93	12.88	12.10	12.88
Female (n=2)	2.50	10.00	2.00	1.75	2.25	2.75	11.00	2.75
p-value	0.036(**)	1.000	0.012(**)	0.016(**)	0.020(**)	0.032(**)	1.000	0.036(**)
Age(a)								
Up to 39 years old (n=16)	14.19	12.88	12.34	12.09	13.59	12.34	12.44	12.81
40 years old or more (n=7)	7.00	10.00	11.21	11.79	8.36	11.21	11.00	10.14
p-value	0.017(**)	0.273	0.728	0.935	0.091	0.739	0.557	0.402
Area (a)								
Urban (n=9)	10.39	10.00	10.50	7.78	9.83	10.11	11.00	8.89
Rural(n=14)	13.04	13.29	12.96	14.71	13.39	13.21	12.64	14.00
p-value	0.374	0.127	0.409	0.015(*)	0.227	0.287	0.502	0.079
Profession <sup>(b)</sup>								
Agriculture and cattle raising activity (n=12) <sup>(1)</sup>	11.33	11.88	12.63	12.63	11.42	11.46	11.96	10.83
Social activity (n=9) <sup>(2)</sup>	11.44	12.61	10.89	11.67	12.33	13.00	12.28	14.56
Business activity (n=2) <sup>(3)</sup>	18.50	10.00	13.25	9.75	14.00	10.75	11.00	7.50
p-value	0.361	0.750	0.812	0.841	0.866	0.836	0.884	0.282

Significant results: (\*) p-value < 0.01 and (\*\*) p-value < 0.05.

<sup>(a)</sup>-Mann-Whitney Test

<sup>(b)</sup>-Kruskal-Wallis Test

<sup>(1)</sup>- Farmer and fisherman

<sup>(2)</sup>- Retired, welder, sanitation agent, endemic control agent, student, social worker, bricklayer and watchman

<sup>(3)</sup>- Merchant and entrepreneur

Source: Elaborated by the authors, 2020.

design of this research<sup>(4,10)</sup>. A similar situation is found in the inland of Paraíba where the number of men with VL was higher than in women<sup>(11)</sup>.

Regarding the age range of the individuals affected by Leishmaniasis, the present research points out similar data to the study developed in 2018 in the state of Rio Grande do Norte, showing that the mean age range

of infection by VL has been increasing (following the Brazilian national scenario) with a mean age of 21.7 years old in 2014. This characteristic is probably due to environmental changes and greater exposure of the adults to the leishmaniasis transmitting vector<sup>(12)</sup>. In another research study developed between 2015 and 2016 in Ethiopia with 590 individuals co-infected by VL and HIV, there

**Table 4** - Scores of the Medical Outcomes Survey Short-Form 36 domains according to the clinical data (comorbidities) of individuals with visceral leishmaniasis. João Pessoa, PB, Brazil, 2020 (n=23)

Variable	Physical functioning	Physical function	Body pain	General health	Vitality	Social function	Emotional role	Mental health
Diabetes (a)								
Yes (n=4)	9.38	12.63	10.13	12.38	10.25	10.88	11.00	14.75
No (n=19)	12.55	11.87	12.39	11.92	12.37	12.24	12.21	11.42
p-value	0.420	1.000	0.561	0.921	0.598	0.799	1.000	0.398
Rheumatic disease (a)								
Yes (n=1)	17.00	20.50	3.00	17.00	7.50	4.00	11.00	20.00
No (n=22)	11.77	11.61	12.41	11.77	12.20	12.36	12.05	11.64
p-value	0.652	0.174	0.391	0.652	0.696	0.304	1.000	0.391
Systemic arterial hypertension (a)								
Yes (n=3)	6.83	10.00	15.50	11.33	12.83	11.50	11.00	12.50
No (n=20)	12.78	12.30	11.48	12.10	11.88	12.08	12.15	11.93
p-value	0.173	0.807	0.365	0.880	0.861	0.878	1.000	0.916
HIV and AIDS (a)								
Yes (n=1)	8.50	10.00	21.00	10.50	19.00	18.00	11.00	15.50
No (n=22)	12.16	12.09	11.59	12.07	11.68	11.73	12.05	11.84
p-value	0.739	1.000	0.391	0.913	0.435	0.609	1.000	0.739

(a)- Mann-Whitney Test

Source: Elaborated by the authors, 2020.

**Table 5** - Scores of the Medical Outcomes Survey Short-Form 36 domains according to the clinical data (initial complaints) of individuals with visceral leishmaniasis. João Pessoa, PB, Brazil, 2020 (n=45)

	Physical functioning	Physical function	body pain	General health	Vitality	Social function	Emotional role	Mental health
Pain (a)								
Yes (n=5)	11.00	12.10	7.00	8.50	8.50	6.20	11.00	8.10
No (n=18)	12.28	11.97	13.39	12.97	12.97	13.61	12.28	13.08
p-value	0.730	1.000	0.061	0.204	0.205	0.032(**)	1.000	0.155
Fever (a)								
Yes (n=21)	12.79	12.19	11.71	11.55	12.62	12.33	12.10	12.74
No (n=22)	3.75	10.00	15.00	16.75	5.50	8.50	11.00	4.25
p-value	0.075	1.000	0.569	0.352	0.213	0.573	1.000	0.111
Weight loss (a)								
Yes (n=15)	11.73	11.57	11.40	10.90	11.93	12.43	11.77	12.17
No (n=8)	12.50	12.81	13.13	14.06	12.13	11.19	12.44	11.69
p-value	0.813	0.534	0.578	0.300	0.964	0.704	1.000	0.886
Paleness (a)								
Yes (n=8)	14.06	12.94	15.63	14.88	16.44	15.56	12.44	15.13
No (n=15)	10.90	11.50	10.07	10.47	9.63	10.10	11.77	10.33
p-value	0.299	0.423	0.061	0.143	<b>0.019(**)</b>	0.064	1.000	0.111
Splenomegaly (a)								
Yes (n=8)	15.50	13.13	13.44	13.06	15.00	14.13	13.88	14.69
No (n=15)	10.13	11.40	11.23	11.43	10.40	10.87	11.00	10.57
p-value	0.071	0.312	0.473	0.600	0.125	0.265	0.111	0.173



Hepatomegaly <sup>(a)</sup>								
Yes (n=8)	15.31	13.13	13.44	12.88	15.38	14.13	13.88	15.69
No (n=15)	10.23	11.40	11.23	11.53	10.20	10.87	11.00	10.03
p-value	0.089	0.312	0.473	0.669	0.081	0.265	0.111	0.057
Diarrhea <sup>(a)</sup>								
Yes (n=3)	13.00	13.50	7.67	14.50	11.83	14.83	11.00	20.17
No (n=20)	11.85	11.78	12.65	11.63	12.03	11.58	12.15	10.78
p-value	0.821	1.000	0.260	0.530	0.992	0.465	1.000	0.020(**)

Significant results: (\*\*) p-value < 0.05.

<sup>(a)</sup>- Mann-Whitney Test

Source: Elaborated by the authors, 2020.

was an age mean of 35 ( $\pm$  8.5) years old<sup>(3)</sup>, approximating to the findings of this study. Regarding the income of the individuals affected by VL, it is observed that the lower the purchasing power and schooling, the worse the housing conditions and the possibility of breeding sites of the vector, facilitating the spread of infection, which hinders actions of health education and prevention of VL transmission<sup>(13)</sup>.

Regarding the characterization of the participants' property surroundings in this research, proximity to woodlands, rivers, and banana trees is observed, with the presence of animals in the home, even with suspected diseases, which can be associated with the participants' getting infected. This study has shown that most of the patients affected by leishmaniasis live in the rural area, differing from the current epidemiological profile<sup>(14)</sup>.

VL must be compulsorily notified in the national territory due to its symptomatological severity, thus defining the importance of its fast and accurate diagnosis, which can be performed at an outpatient level of care by means of the clinical, differential, parasitological, and serological diagnostic method<sup>(13)</sup>. The scientific research studies on the subject indicate that leishmaniasis negatively

impacts on the quality of life of the affected individuals, in particular on the psychological dimension of human health, on general health, and on the physical dimension of these individuals<sup>(15)</sup>.

In this perspective, the term Health-Related Quality of Life (HRQoL) generally involves the perception of health and the impact of physical, social, psychological, and spiritual aspects on it, but leaves out other more generic aspects such as salary gain, freedom, and environment, among others<sup>(7,16)</sup>.

In this research, the results point out that the quality of life domains that are based on the SF-36 of the individuals infected by VL were affected, with lower scores in the emotional role, physical function, and social function domains. In a research study conducted in India using the SF-36 instrument, a negative impact on the quality of life of individuals with post-kala-azar leishmaniasis (a clinical dermal affection after a VL episode) is evidenced, particularly in the mental health, social functioning, body pain, and general health dimensions<sup>(4)</sup>.

Thus, the HRQoL of those affected by VL suffers interference in several dimensions, which limits us to use only generalized instruments for measuring the quality of life which may not be sufficient for bringing out

the particularities of this disease. In Brazil, a specific instrument was validated in 2018 to measure the quality of life of individuals with tegumentary leishmaniasis, thus observing the additional need for an instrument capable of permeating the particularities of the impact of VL on the HRQoL of those affected<sup>(17)</sup>.

When it comes to the analysis of the impact of VL on the quality of life of the participants regarding the sociodemographic and clinical data, there was possibly a worsening in the physical functioning, body pain, general health, vitality, social function, and mental health domains when related to the patient's gender and area of residence. In view of this, there is a difference in the current epidemiological pattern of leishmaniasis, which changed from an accidental zoonosis in human beings to a parasitic infection resulting from the increase of the disease in urbanized territories due to intense deforestation, which may be related to the adaptation of the mosquito to the environment<sup>(18)</sup>.

When the scores of the SF-36 domains were analyzed according to the initial complaint, the social function, vitality, and mental health domains presented impairments regarding pain, paleness, and diarrhea. As a systemic clinical entity, VL persists in the individual insidiously. Weight loss and long-term fever, lymphadenopathy, hepatosplenomegaly and anemia, hypoalbuminemia, edema, and a progressive weakness state are characteristics of this parasitic infection, which is divided into non-apparent/asymptomatic, initial, state, and final periods<sup>(5,11)</sup>.

It should be noted that VL is highly lethal in patients with an ineffective therapeutic regimen or with severe malnutrition, which is

aggravated when it occurs in individuals living with the human immunodeficiency virus<sup>(19)</sup>.

## CONCLUSION

In order to answer the question that permeated this research, the data presented express a considerable impact of visceral leishmaniasis on the quality of life of the affected individuals.

Regarding the quality of life dimensions affected by leishmaniasis, it is evident that there is a negative impact of the disease on all the scores in the SF-36 domains, especially in the emotional role, physical function, and social function domains. This evidences the need for immediate actions in order to mitigate the impact of this disease on the quality of life of these individuals.

Thus, nursing professionals may provide integral health care to the individuals exposed to or already affected by visceral leishmaniasis, aiming at meeting the care needs of these people, since it is observed that this neglected disease currently impacts negatively on several dimensions of the quality of human life, as evidenced in the present investigation.

Therefore, the nurse can be inserted in the promotion of health by means of educational actions for the prevention of the infection and of assistance actions, through the systematization of the Nursing Care targeted to the quality of life dimensions affected by the disease with activities of information on its aspects and characteristics, and the instituted therapy so that the negative impacts on the psychological dimension can be mitigated.

The limitation of this research was the absence of a validated instrument to inves-

tigate the impact on the quality of life of people with visceral leishmaniasis. Thus, it is suggested that new research may propose and validate a specific instrument for this population with a view to enhancing this measure in a refined way, considering the particularities of the individuals affected by the disease.

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