The knowledge of Primary Health Care professionals about the Human T-lymphotropic virus

O conhecimento dos profissionais da Atenção Básica em Saúde sobre o Vírus T-linfotrópico Humano

El conocimiento de los profesionales de la Atención Primaria de Salud sobre el virus linfotrópico T humano

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RESUMO

Objetivo: investigar o conhecimento de profissionais de saúde presentes em unidades básicas de saúde (UBS's) sobre o HTLV e as condutas tomadas em caso de infecção. **Método:** pesquisa quantitativa transversal de abordagem exploratória, sendo realizada por meio de entrevista, com preenchimento de formulário via Google Forms. Realizada em julho de 2023. **Resultados:** estudo composto por 33 profissionais de saúde, dentre os quais 39% afirmaram desconhecer o HTLV. Essa informação é preocupante, considerando que uma unidade de saúde representa a principal porta de entrada para os indivíduos em busca de atendimento à saúde. A maioria expressiva, representando 70%, demonstrou conhecimento sobre os meios de prevenção da doença. Porém, a vacinação não foi identificada pela maioria como um método de prevenção, destacando uma percepção menos difundida sobre o papel da vacina nesse contexto. **Conclusão:** é crucial divulgar pesquisas sobre o tema, criando oportunidades estratégicas para aprimorar tanto a compreensão clínica quanto a empatia no atendimento aos portadores do HTLV, contribuindo assim para a melhoria do diagnóstico, tratamento e qualidade assistencial. **Descritores:** Vírus Linfotrópico T tipo 1 Humano; Vírus Linfotrópico T tipo 2 Humano; Infecções; Atenção Primária em saúde.

ABSTRACT

Objective: To investigate the knowledge of health professionals present in primary health care units (BHUs) about HTLV and the procedures taken in case of infection. **Method:** cross-sectional quantitative research with an exploratory approach, carried out through interviews, filling out a form via Google Forms. Carried out in July 2023. **Results:** study composed of 33 health professionals, of which 39% said they were unaware of HTLV. This information is worrying, considering that a health unit represents the main gateway for individuals seeking health care. The significant majority, representing 70%, demonstrated knowledge about the means of preventing the disease. However, vaccination was not identified by the majority as a prevention method, highlighting a less widespread perception about the role of the vaccine in this context. **Conclusion:** it is crucial to disseminate research on the topic, creating strategic opportunities to improve both clinical understanding and empathy in the care of HTLV carriers, thus contributing to the improvement of diagnosis, treatment and quality of care.
Descriptors: Human T Lymphotropic Virus type 1; Human T Lymphotropic Virus type 2; Infections; Primary Health Care.

RESUMEN

Objetivo: Investigar el conocimiento de los profesionales de la salud presentes en las unidades de atención primaria de salud (UBS) sobre el HTLV y los procedimientos tomados en caso de infección. **Método:** investigación cuantitativa transversal con enfoque exploratorio, realizada a través de entrevistas, con la cumplimentación de un formulario a través de Google Forms. Se celebra en julio de 2023. **Resultados:** se realizó un estudio compuesto por 33 profesionales de la salud, de los cuales el 39% dijo desconocer el HTLV. Esta información es preocupante, teniendo en cuenta que un establecimiento de salud representa la principal puerta de entrada para las personas que buscan atención médica. La gran mayoría, que representa el 70%, demostró conocer los medios de prevención de la enfermedad. Sin embargo, la mayoría no identificó la vacunación como un método de prevención, lo que pone de manifiesto una percepción menos generalizada del papel de la vacuna en este contexto. **Conclusión:** es crucial difundir la investigación sobre el tema, creando oportunidades estratégicas para mejorar tanto la comprensión clínica como la empatía en la atención de los pacientes con HTLV, contribuyendo así a la mejora del diagnóstico, el tratamiento y la calidad de la atención.
Descriptores: Virus Linfotrópico T humano tipo 1; Virus Linfotrópico T humano tipo 2; Infecciones; Atención Primaria de Salud.

ORIGINAL

Introduction

The Human T-Lymphotropic Virus (HTLV) belongs to the Retroviridae family, genus Deltaretrovirus, and is responsible for infections that affect T cells, resulting in acute, chronic, and progressive immune imbalances. Discovered in 1977 in Japan in T cells from patients with cutaneous lymphoma[1], there are four subtypes of the virus: HTLV-1, HTLV-2, HTLV-3 and HTLV-4. However, only the HTLV-1 and HTLV-2 subtypes are related to the development of diseases, acting differently on TCD4+ and TCD8+ lymphocytes.[2] The HTLV-3 and HTLV-4 subtypes do not cause disease in humans, being identified only in cases of zoonotic infection of primates in sub-Saharan Africa[3].

HTLV transmission can occur vertically (childbirth and breastfeeding) as well as horizontally (unprotected sexual intercourse, blood transfusions, needle sharing)[4]. In some regions of the world, such as the Caribbean, Africa, Central America, South America, Japan, and Asia, the population's lack of knowledge has led to the neglect of the virus, making it endemic[5]. It is estimated that about 20 million people worldwide are infected, with Brazil having the highest incidence, especially in the North and Northeast regions[6].

HTLV, which is often asymptomatic, can take years to manifest symptoms, but when active, it can induce neurological complications, as well as inflammatory diseases such as uveitis and dermatitis[7]. Studies show that HTLV infection can mask the diagnosis of AIDS in HIV carriers, due to the increase in CD4+ T cells [8]. In addition, HTLV infection can accelerate the progression of liver disease in individuals with hepatitis B and C[9]. Two other diseases are also associated with the virus, Adult T-Cell Leukemia/Lymphoma and Tropical Spastic Paraparesis/Myelopathy, which, although rare, have a poor prognosis[10].

Available data are still scarce, and despite the high number of cases in the country, there are no effective programs to control the disease[11]. Identifying people living with the virus and adopting prevention and transmission measures is essential to reduce the impact on the Unified Health System[11,12]. Therefore, the knowledge of health professionals in Basic Health Units (BHUs) about HTLV plays a fundamental role in early detection, appropriate management, and prevention of the spread of this infection. Additionally, education about HTLV is essential to reduce the stigma and lack of awareness surrounding this infection, which often leads to late diagnosis.

Investing in the training and updating of health professionals in the UBS on HTLV is a crucial measure to improve patient care and contribute to the control of this neglected infection. In this context, the objective of the present study is to investigate the knowledge of health professionals present in basic health units (BHUs) about HTLV and the procedures taken in case of infection.

Method

This is a cross-sectional quantitative research with an exploratory approach, being carried out through interviews, with the completion of a form via Google Forms. The questionnaire, with objective questions, was directed and carried out in July 2023 with health professionals working in the Basic Health

Units of a municipality in the metropolitan region of Curitiba, after approval by the Research Ethics Committee (CEP).

The invitation to participate in the research was made available virtually, with a link to the electronic address. The dissemination was carried out through social networks (Instagram®, Facebook® and WhatsApp®) and the questionnaire was presented after the participants read and accepted the Free and Informed Consent Form (ICF).

Quantitative research investigates a well-defined problem and its theory corresponding to the object of the guiding question, i.e., understanding what one wants to study in the research, thus clarifying, through a quantitative method, what one wants to elucidate[13].

Cross-sectional studies describe situations or phenomena at an undefined point in time, i.e., they represent a photograph or instantaneous section of a population by means of a sampling.[14]

Inclusion and exclusion criteria

The following inclusion criteria were adopted: health professionals working in the primary care service, in the multiprofessional area, regardless of the time of professional experience or time of training in the area of activity. Exclusion criteria: professionals under 18 years of age, who work as interns.

Data analysis methodology

The data analysis was developed by the researchers through the tabulation of the data in an online spreadsheet (Google Sheets) with analysis of normality and homogeneity. Based on the results, parametric or non-parametric analyses were performed in order to demonstrate and compare the level of knowledge of professionals in relation to HTLV. All statistical analyses were performed using Excel.

Ethics Committee

The present study followed the guidelines for research procedures in a virtual environment, of February 24, 2021 of the National Research Ethics Commission (CONEP), the Executive Secretariat of the National Health Council (SECNS) and the Ministry of Health (MS), for the preservation of the protection, safety and rights of research participants involving the use of the internet and/or in a non-face-to-face manner, in accordance with the Resolutions of the National Health Council (CNS) – No. 466 of 2012 and No. 510 of 201615, addressing: the dignity, autonomy and integrity of research participants; application of the informed consent form in a clear manner; submission of the research to the IRB; protection of participants' privacy and confidentiality; ethical and scientific responsibilities of researchers; ongoing monitoring of the research and communication of any modifications or adverse events to participants and the Ethical Board.

The Ethics Committee plays a crucial role in protecting the rights, well-being, and dignity of research participants by ensuring that ethical standards are maintained throughout the research process. For the approval of the project by the CEP, the methodology and stages of the study were presented, as well as the form with the questions related to the theme, the informed consent form and the

authorization of the research site, being approved under the CAAE number: 69680523.0.0000.5539.

Results

This study was composed of 33 professionals, twelve nurses (36%), five physicians (15%), four community health agents (12%), four nursing technicians (12%), three nursing assistants (9%), two oral health agents (6%), two dentists (6%) and one nursing resident (3%) (Table 1). The age range ranged from: 31 to 40 years (39%), 41 to 50 years (27%), over 51 years (18%) and 18 to 30 years (15%). There was a predominance of females (82%).

At the UBS, the workload can vary predominantly between 20 and 40 hours per week, with 79% (n=26) of the participants working 40 hours, 9% (n=3) working 20 hours and 12% (n=4) with different workloads, such as Nursing Resident (60 hours), Physician (50 hours), Physician (24 hours) and Nursing Technician (36 hours).

Regarding the years of professional training, the category of nurse stood out with more than ten years of training (Table 1).

Table 1- Sociodemographic characteristics of the study participants (n=33), Paraná, 2023.

Profession	Participants		Training time			
	n	%	< 1 year	1 to 5 years	5 to 10 years	> 10 years
Nurse	12	36		3	1	9
Doctor	5	15	1	1	1	2
Community Health Worker	4	12		1		3
Nursing Technician	4	12		1	1	2
Nursing Assistant	3	9				3
Oral Health Agent	2	6			1	1
Dentists	2	6				2
Nursing Resident	1	3		1		
Age						
18-30 years old	5	15				
31-40 years old	13	39				
41-50 years old	9	27				
over 51 years	6	18				
Sex						
Female	27	82				
Male	6	18				
Working Hours						
20 hours	3	9				
40 hours	26	79				
Other	4	12				

The research was based on research on the knowledge of professionals from primary health care units about HTLV through a questionnaire. To the question: "Do you know or have heard about the HTLV virus?" the predominant answer was "Yes" with 61% (n=20) of the answers. Participants who reported "No" knowledge of the disease (39% n=13) ended their participation at this point in the study. Among these participants, most of them had more than ten years of professional training (Table 2).

Table 2- Answers No to the question: "Do you know or have you heard about HTLV?" in relation to the formative years, Paraná, 2023.

No	Years since graduation			
	< 1 year	1 to 5 years	5 to 10 years	> 10 years
Nurse				2
Doctor				
Community Health Worker		1		3
Nursing technician				
Nursing Assistant				3
Oral Health Agent			1	1
Dentistry				2
Nursing Resident				

Regarding the question: "How did you know about HTLV?", 50% (n=10) of the professionals answered that they learned about it during their academic training or in the technical course, 30% (n=6) reported hearing about the disease through television or the internet, and 15% (n=3) had contact with the theme in their daily work. In the aforementioned question, it is noteworthy that no professional stated that they had participated in educational actions on the subject, and 5% (n=1) stated that they had been approached about the disease during blood donation.

Regardless of the way in which knowledge about the disease is acquired, in the question: "Do you know the forms of transmission?", 95% (n=19) of the professionals stated that they know that the forms of transmission of the virus are through unprotected sexual intercourse, shared use of needles and syringes, via the placenta, and breastfeeding (Table 3).

To the question: "These are diseases that can affect HTLV patients, except", 65% (n=13) answered that Kaposi's Sarcoma is an opportunistic disease and that patients with HTLV cannot be affected by this disease, 20% (n=4) answered Lymphoma/Leukemia and 15% (n=3) of the professionals are unaware of the diseases associated with the STI in question.

In the question: "What are the forms of diagnosis?", all participants reaffirm that the blood test is the gold standard for detecting the disease. Regarding the follow-up of the disease, in the question: "Regarding treatment, please mark:", 50% (n=10) of the participants stated that there is no specific treatment for HTLV, 30% (n=6) believe that there is a possibility through the use of antivirals, 10% (n=2) immunosuppressants and another 10% do not know the appropriate type of treatment.

To the question: "They are forms of prevention, with the exception of:", the vast majority of the participants 70% (n=14) answered that vaccination is not a form of prevention of HTLV, 25% (n=5) stated that the use of condoms is not

effective against contagion and 5% (n=1) did not know how to answer. None of the participants reported the use of disposable syringes and needles.

In the question: "What was your greatest difficulty in caring for patients with HTLV?", 80% (n=16) answered that they had no difficulties during the care of these patients, the other 20% (n=4) answered respectively that the difficulty resulted from lack of knowledge of the pathology, lack of specific training about the disease, absence of symptoms and due to the theme being little addressed.

For the last question: "After answering the questions, do you consider it important and necessary to discuss and seek knowledge on the subject?", 95% (n=19) of the corresponding professionals believe it is important and necessary to discuss and seek knowledge on the subject.

Table 3- Level of knowledge of professionals in relation to the HTLV virus, Paraná, 2023.

	Participants	
Questions	**n**	**%**
Do you know or have you heard about HTLV?		
Yes	20	61
No	13	39
How did you hear about HTLV?		
In the day-to-day work	3	15
During academic training or technical course	10	50
Participated in educational actions about the disease	0	0
Television or internet	6	30
Other	1	5
Do you know the ways of transmission?		
I don't know	1	5
Unprotected sexual intercourse	19	95
Contact with sweat	0	0
By means of droplets	0	0
These are diseases that can affect HTLV carriers, except:		
I don't know	3	15
Myelopathy (HAM)	0	0
Lymphoma/Leukemia (ATLL)	4	20
Kaposi's sarcoma	13	65
What are the forms of diagnosis?		
I don't know	0	0
Blood test	20	10
Gynecological examination	0	0
Sputum examination	0	0
Regarding treatment, please tick:		
I don't know	2	10
Performed with antivirals	6	30
Antibiotics	0	0
Immunosuppressants	2	10
There is no specific treatment	10	50
These are forms of prevention, with the exception of:		
I don't know	1	5
Use of condoms	5	25

Vaccination	14	70
Use of disposable syringes and needles	0	0
What was your biggest difficulty in caring for the HTLV patient?		
Ignorance	1	5
Lack of specific training	1	5
Absence of symptoms	1	5
Topic little addressed	1	5
I didn't have any difficulties	16	80
After answering the questions, do you think it is important and necessary to discuss and seek knowledge on the topic?		
Yes	19	95
No	1	5

Discussion

To improve the presentation of the discussion, the data were categorized based on the variables contained in the questionnaire, namely: knowledge, difficulties in attendance, challenges and the importance of the theme. Based on this categorization, they were organized into their respective subheadings: health professionals' knowledge about HTLV; health professionals' knowledge of the diagnosis, treatment, and prevention of HTLV infection; Challenges, difficulties and importance of HTLV studies.

Healthcare professionals' knowledge of HTLV

Of the professionals who answered that they were unaware of HTLV (39% n=13), most are over 40 years of age, with more than 10 years of training and work 40 hours per week. The lack of knowledge about HTLV may be related to work overload, which limits the search for professional updates, often being replaced by leisure activities during free time[16].

The absence of continuing education is another relevant factor. A growing demand for skilled professionals requires the incorporation of learning as an integral part of the routine. To achieve quality care, it is necessary to understand the context in which these professionals work and implement effective teaching-learning strategies.[17]

It is noteworthy that all the community health workers consulted in the survey stated that they were not familiar with HTLV. These professionals play a crucial role as intermediaries between the community and health programs, making it essential to prepare them effectively for more assertive approaches in their field of activity, as recommended by the Ministry of Health.[18]

In addition, it is worrying that dentists and oral health agents have also admitted to being unaware of the disease. Given the nature of HTLV transmission through contact with contaminated blood, these professionals should be well informed about sterilization, infection and cross-infection prevention practices, in addition to the proper use of personal protective equipment[19]. The oncogenic capacity of HTLV also requires attention both in the dental field and in the diagnosis of possible associated diseases.

Of the professionals who reported knowing HTLV, 61% (n=20) were female, 75% (n=15) worked as nurses, 50% (n=10) had more than 10 years of professional experience and were aged between 31 and 40 years.

Although 50% (n=10) of these professionals acquired knowledge about the virus during their academic training or in technical courses, none of them occurred in specific educational activities about HTLV. Again, the importance of continuing education to promote technical improvement and involve health professionals in a reflexive way in decision-making in the face of identified challenges is emphasized.[20]

It is not relevant that only one of the specialized professionals acquired knowledge about HTLV during a blood donation. In many cases, the diagnosis of the disease occurs during blood donations due to the mandatory screening for the virus in this context. In Brazil, the scarcity of HTLV prevalence studies makes blood donors an important source of data.[21]

Regarding the forms of transmission, most professionals (95% or n=19) correctly answered that the virus can be transmitted through unprotected sexual intercourse, sharing needles and syringes, vertical transmission (from mother to child during pregnancy or breastfeeding). This high rate of inadequate knowledge about HTLV can be attributed to a lack of information both in the general population and among health professionals, often confusing HTLV with HIV.[22-23]

Although the routes of transmission of HTLV are similar to those of other sexually transmitted infections, such as HIV, the important differentiation lies in the longer exposure time and the greater amount of infected cells that can be transmitted for HTLV transmission. This is possible due to specialized mechanisms, such as virological synapse, in which the virus alters the normal physiology of T cells[3]. In addition, unlike HIV, HTLV does not cause clinical disease in most carriers, with symptoms appearing only in a small percentage of patients.[11]

Finally, it is noteworthy that the majority of participants (65% or n=13) correctly agree that Kaposi's Sarcoma is not associated with HTLV, but with the HIV virus. Although HTLV and HIV share some routes of transmission, they have specific biological characteristics[11]. It is relevant to mention that most people infected with HTLV remain asymptomatic for many years, with only a small percentage developing serious clinical conditions such as HAM/TSP or ATLL.[19]

Healthcare professionals' knowledge of the diagnosis, treatment, and prevention of HTLV infection

Regarding the diagnostic methods, all participants (n=20) correctly answered that the proper diagnosis of HTLV is obtained by means of blood tests. The diagnostic process consists of two distinct steps: screening and confirmation. In the first phase, seek the detection of specific antibodies through blood collection, and the ELISA method is widely used due to its high sensitivity and affordable cost. If the result is positive, a Western blot is performed, which confirms the infection and distinguishes between types 1 and 2 of the virus.[21-22]

It is essential to emphasize that the diagnosis of HTLV can be challenging, considering its latent phase, the absence of obvious clinical manifestations, and the lack of knowledge on the part of many health professionals. This often leads to a late diagnosis[23]. Because clinical diagnosis is rare, healthcare providers often do not suspect the presence of HTLV, resulting in patient referral to different specialists or inappropriate treatments based on misdiagnoses.

Since the discovery of HTLV in the 1980s, public policies have been broken, including mandatory screening in blood banks since 1993, mandatory testing of organ donors and recipients since 2009, and mandatory screening in assisted reproduction since 2011.[25] In 2020, HTLV was included in the Clinical Protocol and Therapeutic Guidelines for Sexually Transmitted Infections.[24] In 2021, the Ministry of Health launched the Clinical Management Guide for HTLV Infection to provide information to health professionals and managers, supporting preventive measures at all levels of care.[22,24]

Some Brazilian states, such as Bahia and Mato Grosso do Sul, maintain screening during prenatal care and report confirmed cases[10]. This screening is essential to prevent vertical transmission and during breastfeeding, ensuring adequate follow-up of infected mothers by a multidisciplinary team4. This allowed the identification and reduction of the transmission of the virus, highlighting the importance of team preparation, especially in primary care during prenatal care.

However, unlike other STIs, such as viral hepatitis and HIV, in which the tests are requested by SUS users and have mandatory mandatory notification, HTLV often goes unnoticed by both patients and health professionals.

HTLV is an incurable disease, and treatment varies according to the related clinical manifestations. To date, there is no proven effective therapy for TSP/HAM, since infection by the virus remains neglected and investments in the search for effective treatments are still limited[26]. In the present study, half of the interviewees, 50% (n=10) correctly answered that there is no specific treatment for HTLV.

Although half of the participants in this study answered correctly about the treatment of the disease, the other 50% (n=10) had no response or mentioned treatments with immunosuppressants or antivirals. This highlights the need to consider that even when there is knowledge about the pathology, many people are unaware of the appropriate therapeutic approaches for HTLV. People infected with HTLV should be followed up in specialized services, where they receive psychological support and special attention for the early diagnosis of the various clinical manifestations related to the infection.[3]

The majority of participants, 70% (n=14), correctly answered that the means of preventing the disease include the use of condoms and the non-use of shared syringes and needles, excluding vaccination as a method of prevention. For the prevention of HTLV, it is recommended to adopt already established methods to avoid other STIs, such as the use of condoms in all sexual intercourse and not sharing syringes and needles. In addition, breastfeeding is contraindicated, requiring the use of lactation inhibitors by the puerperal woman and the use of infant milk formulas for the newborn.[4,26] Although the infection is endemic in several parts of the world, there is still no effective prophylaxis method, such as a vaccine.

Public policies, including mandatory mandatory notification, awareness campaigns would be important allies to collect accurate data on the disease, outline coping and prevention strategies. It is essential that in health services, the approach is not limited only to assessing the risk of illness, but also including the prevention of transmission of the virus.[23-25]

Challenges, difficulties and importance of HTLV studies

Among those who answered that they had experienced difficulties during the management of the 20% HTLV patient (n=4), the following stand out: lack of knowledge about the disease, lack of specific training, absence of symptoms, and difficulty due to the theme being little addressed.

Therefore, it is essential to highlight the urgent need for awareness and deepening of studies related to this infection, since the lack of knowledge about the disease, evidenced by the participants who responded to the survey. The importance of continuous educational initiatives is emphasized. These should address not only the clinical aspects of the technique, but also its social and psychological ramifications[24].

This result is in line with studies carried out[25-26], in which health professionals who worked at an STI testing and counseling center reported their experiences in the care of HTLV patients. Among the discourses highlighted by the authors are: that of not having knowledge about the disease, having a deficit of information and limited content on the subject, and that of not having adequate training, but only a superficial approach to the subject in the training offered by the responsible agencies. This fact shows that there is a systematic gap in the training of health professionals. The superficiality of the theme in the training offered by the responsible agencies should be addressed through a critical review of these programs, ensuring the inclusion of updated and relevant information on HTLV[23].

The research also revealed that the absence of symptoms is a barrier to early recognition of HTLV, making it imperative to create efficient identification strategies. The lack of training specifically indicated by professionals highlights the need for robust and targeted training programs capable of filling existing knowledge gaps.[20]

For the last question of the survey, 95% (n=19) think it is pertinent to discuss the theme. The other 5% (n=1), who thought it was not necessary to seek knowledge, reported not knowing about the treatment of the disease or about the opportunistic diseases related to HTLV during the research. This fact can demonstrate that, despite knowing about the existence of the disease, professional updating is pertinent for the appropriate management of this patient.

In summary, it is vital to disseminate studies on the subject, so that there are strategic opportunities to strengthen not only clinical understanding, but also empathy and sensitivity in the care of HTLV patients. This approach not only improves the quality of care provided but also contributes to building a more informed and compassionate healthcare network.

Conclusion

A solid understanding of HTLV infection is essential, since the disease often remains asymptomatic, becoming clinically apparent only in advanced stages. Lack of knowledge can lead to late diagnoses, inappropriate treatments, and even the spread of the virus. Therefore, the training of healthcare professionals not only helps to identify HTLV cases more quickly, but also to provide adequate guidance to patients, ensuring proper follow-up and minimizing the risks of transmission.

In addition, knowledge about HTLV is crucial for public awareness and the implementation of effective health policies. Well-informed health professionals can play an active role in educating the community, identifying at-risk groups, and implementing targeted preventive measures. Therefore, investing in the continuous training of health professionals on HTLV not only improves patient care, but also contributes to a more comprehensive and effective approach in the fight against this disease.

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