

Medical confidentiality in the care of patients with HIV/AIDS

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Abstract

The life of the person who finds they are infected with the immunodeficiency virus is transformed after the diagnosis. And, given the stigma of the disease, confidentiality is the way to ensure privacy when facing this condition. Through an integrative review of the literature, this study aimed to identify how confidentiality has been addressed in the care of people with HIV/AIDS. Nineteen national and international scientific publications, published between 2010 and 2015, were selected in open access databases. Studies have pointed out that stigma, prejudice and discrimination permeate the lives of HIV-positive people, who are constantly living in fear of being discovered. In addition, it has been found that discrimination is present even among health professionals and that breaking confidentiality usually leads the patient to abandon treatment. Therefore, preserving the privacy and confidentiality of the person with HIV/AIDS is the duty of professionals and represents a challenge in the information age.

Keywords: HIV. Acquired immunodeficiency syndrome. Confidentiality. Bioethics. Ethics, professional.

Resumo

Confidencialidade médica no cuidado ao paciente com HIV/aids

A vida da pessoa que se descobre infectada pelo vírus da imunodeficiência se transforma após o diagnóstico. E, dado o estigma da doença, o sigilo é forma de garantir a privacidade nesta condição. Por meio de revisão integrativa da literatura, este estudo visou identificar como tem sido abordada a confidencialidade no cuidado à pessoa com HIV/aids. Foram selecionadas 19 publicações científicas nacionais e internacionais, publicadas entre 2010 e 2015, em bases de dados de livre acesso. Os estudos apontaram que estigma, preconceito e discriminação permeiam a vida dos soropositivos, que vivem constantemente com medo de serem descobertos. Além disso, constatou-se que a discriminação está presente inclusive entre profissionais da saúde e que romper o sigilo normalmente leva o paciente a abandonar o tratamento. Portanto, preservar a privacidade e a confidencialidade da pessoa com HIV/aids é dever dos profissionais e representa desafio na era da informação.

Palavras-chave: HIV. Síndrome de imunodeficiência adquirida. Confidencialidade. Bioética. Ética profissional.

Resumen

Confidencialidad médica en la atención del paciente con VIH/SIDA

La vida de la persona que descubre que está infectada por el virus de la inmunodeficiencia se transforma luego del diagnóstico. Y, dado el estigma de la enfermedad, el secreto es una forma de garantizar la privacidad en esta condición. Por medio de una revisión integrativa de la literatura, este estudio procuró identificar cómo ha sido abordada la confidencialidad en la atención de la persona con VIH/SIDA. Se seleccionaron 19 publicaciones científicas nacionales e internacionales, publicadas entre 2010 y 2015, extraídas de bases de datos de libre acceso. Los estudios señalaron que estigma, prejuicio y discriminación marcan la vida de los seropositivos, quienes viven constantemente con miedo a ser descubiertos. Además, se constató que la discriminación está presente incluso entre los profesionales de la salud y que romper el secreto normalmente conduce a que el paciente abandone el tratamiento. Por lo tanto, preservar la privacidad y la confidencialidad de la persona con VIH/SIDA es un deber de los profesionales y representa un desafío en la era de la información.

Palabras clave: VIH. Síndrome de inmunodeficiencia adquirida. Confidencialidad. Bioética. Ética profesional.

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Declararam não haver conflito de interesse.

In the 21st century, in the face of so many technological advances that allow us to intervene in the various peculiarities of human beings, in a world where the impossible is becoming extinct and the interpretation of social norms is becoming more flexible, distinguishing what is good from bad and setting ethical limits on people's actions is increasingly complex¹.

In the area of health, scientific development expands the set of information that enable care to be given to users of the services. Amongst this information, there are those of a confidential nature that, although they are the exclusive property of the patient, must be provided to professionals in order to make care effective. In this context, new technologies further increase the risk of misuse of such information^{2,3}.

Ethics are fundamental not only for good social interaction, but also for the practice of professionals, especially those who deal directly with human beings⁴. Among all the conditions that health professionals have to deal with in their daily practice, confidentiality is one of the most relevant from an ethical point of view, since it guarantees the privacy of technical and personal information. Maintaining professional confidentiality is one of the moral precepts in health⁵. Confidentiality should motivate professionals to develop appropriate conduct, avoiding embarrassment to users⁶. Privacy, therefore, would be a form of "individual protection"⁷.

The emergence of acquired immunodeficiency syndrome (AIDS) and its rapid spread has shaken the world, testing our ability to deal with a previously unknown disease⁸. Given the unknown and the mortality rates caused by the disease, the diagnosis of the human immunodeficiency virus (HIV) became a landmark in the lives of those infected⁹, since it also implied social discrimination. Consequently, in order to protect themselves against intolerance and aggression, people living with HIV/AIDS (PLWHA) often choose not to expose their health status¹⁰.

Because it is a communicable disease, AIDS leads the person to suffer some public interest implications, with the possibility of breaking the secrecy of their serology¹¹. In the face of such conflicting situations involving PLWHA, how can physicians maintain ethical behavior? Under what circumstances should professional secrecy be preserved, and what may or may not be said without characterizing breach of confidentiality? Under what circumstances should confidentiality be violated? What are the limits of the duty to preserve confidentiality? Are Rosenthal and Scheffer right to say that *there will be no ethics as long as prejudice prevails*?¹²

In view of all these issues, this study aims to identify how the confidentiality of PLWHA information has been addressed in scientific publications, specifically analyzing how the authors address issues related to confidentiality, the difficulties in maintaining it and the conflicts involving this information. Therefore, we start with the following guiding question: "How have authors been addressing the confidentiality of PLWHA in national and international scientific publications?"

Methodology

Characterized as an integrative review¹³, this study consulted publications available in the following databases: the Latin American and Caribbean Literature on Health Sciences (*Literatura Latino-Americana e do Caribe em Ciências da Saúde* - LILACS), Scientific Electronic Library Online (SciELO) and the Nursing Database (*Banco de Dados de Enfermagem* - BDEF). Based on the Health Sciences Descriptors (Descritores em Ciências da Saúde - DeCS), it was determined that the terms "HIV" and "acquired immunodeficiency syndrome" would be cross-referenced with "confidentiality", "bioethics" and "professional ethics" in Portuguese, English and Spanish. The following Boolean operators were used to increase the quality of the results: "HIV and confidentiality", "HIV and bioethics", "HIV and professional ethics", "acquired immunodeficiency syndrome and confidentiality", "acquired immunodeficiency syndrome and bioethics", "acquired immunodeficiency syndrome and professional ethics", generating a total of 40 associations.

The sample included studies available in full, online and free, published between January 2010 and December 2015. The search was carried out in January 2016, and titles and abstracts of the publications were first read, and then the texts in full. Articles that were duplicated, published outside the stipulated period, and that did not meet the research objectives were excluded.

Results

A total of 336 publications were obtained: 5 in BDEF, 211 in LILACS and 120 in SciELO. Of this total, 276 publications were excluded (4 from BDEF, 194 from LILACS and 78 from SciELO), with 60 articles remaining. After a new reading, 19 studies were selected, 9 from LILACS and 10 from SciELO, which gave rise to two categories: 1) confidentiality involving PLWHA and 2) breach of diagnostic confidentiality: an ethical dilemma. The specifications of the publications that made up the final sample are described in Table 1 at the end.

Table 1. Publications analyzed in the integrative review, ordered according to citation in categories

Author(s)	Title	Topic	Journal (database)	Vol. (n)	Study origin
Junges, Recktenwald, Herbert, Moretti, Tomasini, Pereira; 2016 ¹⁴	Confidentiality and privacy of information about patients treated by primary health care teams: a review.	Confidentiality and privacy of information about patients in primary health care	<i>Revista Bioética</i> (LILACS)	23 (1)	Brazil
Arrivillaga-Quintero; 2010 ¹⁵	Analysis of barriers to therapeutic adherence by Colombian women with HIV/AIDS: a matter of health rights	Obstacles to therapeutic adherence	<i>Salud Pública de México</i> (SciELO)	52 (4)	Colombia
García, Viñas, Rodríguez; 2013 ¹⁶	Life Condition of Children Infected with HIV/AIDS, in San Luis Potosí, Mexico.	Living Condition of Children with HIV/AIDS	<i>Revista Costarricense de Salud Pública</i> (SciELO)	22 (2)	Mexico
Herrera, Molina, Vásquez; 2011 ¹⁷	Children Affected with HIV/AIDS: Use and access to Health Services in five Colombian cities	Access to health services for children with HIV/AIDS	<i>Salud Uninorte</i> (SciELO)	27 (2)	Colombia
Kerr, Kendall, Pontes, Werneck, McFarland, Mello, Martins, Macena; 2011 ¹⁸	Selective participation in a RDS survey among MSM in Ceará, Brazil: a qualitative and quantitative assessment	Low participation of upper-class men who have sex with men in surveys	<i>Jornal Brasileiro de Doenças Sexualmente Transmissíveis</i> (LILACS)	23 (3)	Brazil
Paula, Silva, Zanon, Brum, Padoin; 2015 ¹⁹	Ethics in research on adolescents living with HIV/AIDS	Ethical aspects of the data collection stage performed with adolescents with HIV/AIDS	<i>Revista Bioética</i> (LILACS)	23 (1)	Brazil
Soares, Brandão; 2013 ²⁰	The non-return of individuals to know their HIV status at a Voluntary Counseling and Testing Service in the state of Rio de Janeiro.	Reasons for non-return of users to CTC; difficulties in accessing the service	<i>Physis Revista de Saúde Coletiva</i> (SciELO)	23 (3)	Brazil
Ferreira, Passos; 2012 ²¹	Factors associated with failure of clinical screening among blood donors who have altered serological results in the Centro Regional de Hemoterapia de Ribeirão Preto	Risk factors associated with blood donors with HIV; reasons for not being detected during screening	<i>Revista Brasileira de Hematologia e Hemoterapia</i> (LILACS)	34 (6)	Brazil
Mataboge, Peu, Chinuoya, Rikhotso, Ngunyulu, Mulaudzi; 2014 ²²	Healthcare workers' experiences of HIV testing in Tshwane, South Africa	Experiences of health professionals when they need HIV testing	<i>Curatationis</i> (SciELO)	37 (1)	South Africa
Cárdenas, Monteiro, Moreira; 2014 ²³	Expansion of HIV counseling and testing strategies: technical challenges and ethical-political tensions	Implementation of models for Voluntary Counseling and Testing, and HIV Testing and Counseling	<i>Salud Colectiva</i> (SciELO)	10 (2)	Brazil

continues...

Table 1. Continuation

Author(s)	Title	Topic	Journal (database)	Vol. (n)	Study origin
Araya, Bravo, Carrasco, Urrutia, Veja, Rubio, Lira; 2013 ²⁴	Facilitators and barriers to HIV testing: A literature review	ELISA test for the diagnosis of HIV in primary health care	<i>Revista Chilena de Infectología</i> (SciELO)	30 (6)	Chile
Sosa, Barrios; 2011 ²⁵	Bioethical approach of HIV-patients and of secondary care physicians and nurses on the HIV/AIDS	Bioethics approach of HIV patients and of health professionals	<i>Revista Cubana de Medicina General Integral</i> (LILACS)	27 (2)	Cuba
Domínguez, Lozano, Almagro, González; 2014 ²⁶	Bioethics and social approach of the Acquired Immunodeficiency Syndrome	The impact of ethical implications on HIV patients	<i>Humanidades Médicas</i> (LILACS)	14 (2)	Cuba
Rovaletti; 2010 ²⁷	Human rights, information society and risk society	The protection of the individual with HIV and the progress of the "information society"	<i>Acta Bioethica</i> (LILACS)	16 (2)	Argentina
Berenguera, Pujol-Ribera, Violan, Romaguera, Mansilla, Giménez, Almeda; 2011 ²⁸	Experiences about HIV/AIDS preventive-control activities: discourses from non-governmental organizations professionals and users	Experiences of professionals and users in non-governmental organizations for HIV/AIDS prevention and control	<i>Gaceta Sanitaria</i> (SciELO)	25 (3)	Spain
Feldmann, Moreira, Lucena, Melo; 2012 ²⁹	How to proceed when a HIV positive pregnant woman omits her status to the sexual partner?	Ethical and legal dilemmas experienced by health professionals who deal with infected pregnant women who omit their seropositivity to their sexual partner	<i>Femina</i> (LILACS)	40 (6)	Brazil
Luz, Miranda; 2010 ³⁰	The philosophical and historical bases of the care and the call of sexual partners in HIV/AIDS as a form to look after	The concept of care from the perspective of philosophy linking with the practice of the nurses	<i>Ciência & Saúde Coletiva</i> (SciELO)	15 (1)	Brazil
Bernal, Álvarez, Santos; 2010 ³¹	Bioethical problems coming out from health care of people living with HIV/AIDS. 2010	Bioethics in the process of caring for persons with HIV/AIDS	<i>Revista Médica Electrónica de Matanzas</i> (LILACS)	32 (2)	Cuba
Burger, Groenewald, Rossouw, Bradshaw; 2015 ³²	Medical certification of death in South Africa: moving forward	Qualification of medical certification and data on causes of death in South Africa	<i>The South African Medical Journal</i> (SciELO)	105 (1)	South Africa

Patient confidentiality

We analyzed 15 studies¹⁴⁻²⁸ in which the authors present different positions on the maintenance of the confidentiality of the serological result. In all of them, the major concern was the boundaries between maintaining the confidentiality of the diagnosis and revealing it in a way that did not cause the user embarrassment. Subjects of the study were women with HIV treated in primary care (PC), women with HIV and men who have sex with men (MSM) - all of whom were upper class - with a fear of social discrimination and a low percentage of anti-HIV testing; children with HIV discriminated by health professionals; confidentiality involving adolescents; people who were being attended at the Centro de Testagem e Aconselhamento - CTA (Counseling and Testing Center) and at the Regional Hemotherapy Center; stigma among colleagues in health services; expanding coverage of HIV testing; social discrimination as a barrier to the ELISA test; the advancement of information technologies in health services and the breach of confidentiality; and professionals, health services and Non-Governmental Organizations (NGOs) that advocate the confidentiality of the diagnosis to society.

Junges et al.¹⁴ highlighted the confidentiality and privacy dilemma regarding information from women assisted by *atenção básica* - AB (primary care) teams. In order to have multiprofessional responsibility for care, it is necessary to reveal the diagnosis of HIV to other professionals; however, the distrust regarding a breach of confidentiality leads HIV users not to reveal their diagnosis to PC professionals.

Failures have been observed in the specialized HIV/AIDS service, such as a lack of privacy to perform tests and collect results, and the use of vehicles identified with the STD/AIDS program, being that the notion of privacy in work processes is often limited only to non-disclosure of the name of the PLWHA. Arrivillaga-Quintero¹⁶ also points out in her research the fact that upper class women, motivated by fear of stigma and a breach of confidentiality, do their follow up with private services in order not to have their name registered in the Health System.

As for children with HIV, García, Viñas and Rodríguez¹⁶ point out that revealing the diagnosis causes embarrassment to parents or guardians themselves, due to the discrimination by health professionals. In cases where the situation was exposed, attending school and living in the community did not cause a discriminatory reaction, which shows that prejudice was present only in the health service.

The fear of stigma is what leads caregivers and health professionals not to reveal to children with HIV their serology status. In the study by Herrera, Molina and Vásquez¹⁷, 96.2% of the children with HIV did not

have access to their diagnosis due to the professionals' fear regarding possible psychological damages that these children would face if they accidentally disclosed their serology. However, failure to maintain confidentiality occurred, causing the diagnosis to go beyond the limits of the caregiver team and to reach the unit's security person. The authors concluded that the service contributed to the stigmatization of PLWHA by the family and the community.

Concern with diagnosis confidentiality and with prejudice is also present in the study by Kerr et al.¹⁸ regarding men who have sex with men (MSM) and who belong to the upper social class. The fact that they were homosexuals generated fear of prejudice, which led to the low percentage of testing compared to low and middle-class MSM. Respondents feared they would be discriminated against if the positive test result surfaced, especially if the test was performed at the health facility.

The question of confidentiality and privacy in research with adolescents was addressed in the study by Paula et al. As the diagnosis of HIV in adolescents is often limited to the family, the researcher must preserve confidentiality and have a respectful relationship with adolescents, in order to allow the emergence of topics that are fundamental to their study. It is essential to understand that the adolescent has the right to decide whether or not to disclose his/her diagnosis and that information can only be shared in case of consent or risk. Confidentiality, recognized as one of the essential elements of the patient-professional therapeutic relationship, is also fundamental in the researcher-PLWHA relationship.

When investigating why users did not return to a Centro de Testagem e Aconselhamento - CTA (Counseling and Testing Center) between 2008 and 2009, Soares and Brandão²⁰ found that only 1% of users did the test in a confidential manner. The study points out that the need to identify those who wish to perform or collect exams represents a failure of the service regarding anonymity. This factor can be referred to as the cause of the low return of users to the testing service.

Ferreira and Passos²¹ demonstrate how distrust in maintaining confidentiality leads blood donors from a regional hemotherapy center to omit relevant facts in the screening interview, which ultimately changes the serological results. For the authors, this fact highlights the importance of the institution conveying to its donors its commitment to privacy.

Mataboge et al.²² address the problem of breaches of confidentiality and the stigmatization by work colleagues in health services regarding HIV testing. The study shows that health professionals

are afraid to take the exam in their workplace, therefore seeking treatment, in case of a positive result, in other service units. Likewise, for fear that lack of confidentiality will prevent adequate support, practitioners refer nursing students to other reference services when diagnosing them with positive HIV serology.

A study by Cárdenas, Monteiro and Moreira²³ addressed extending the coverage of voluntary testing for HIV diagnosis, discussing the caution professionals need to apply so as not to produce programmatic vulnerability (which reproduces or increases the fragility of users)³³. The authors refer to international concern regarding informed consent in order to perform the test at the counseling stage, thereby assuring the user's confidentiality, explaining the risks (physical, emotional and social) and benefits of the test, as well as the right to decline consent. In the case of the young population, adherence to the test is conditional on the guarantee of the result not being communicated to family members. The adherence of women to actions that will reduce the vertical transmission of the virus depends on the recognition of women's rights regarding autonomy, physical integrity, non-discrimination and privacy. A final point highlighted by the authors²⁴ is the need for PLWHA's consent to communicate their diagnosis to their sexual partners.

According to Araya et al.²⁴, when offering and facilitating people's access to the ELISA test, health centers should disclose that testing is private and confidential, since such confidentiality is fundamental for patients' decision-making. When they believe that organizations and health professionals (who have access to their names) are not reliable, users tend to refuse to take the test.

Sosa and Barrios²⁵ studied the knowledge of physicians, nurses and patients with positive HIV serology on diagnosis confidentiality. The survey found that 67% of physicians, 44% of nurses and 100% of patients thought that the community should not be informed about who is affected by the HIV virus, since anonymity poses no danger. Regarding the institutional scope, for Domínguez et al.²⁶, privacy refers to the responsibility of professionals to maintain the confidential nature of personal information about the health of the users in clinics, hospitals and the formal health system units, also guaranteeing the security records (electronic or non-electronic).

Rovaletti²⁷ instigates reflection on how to protect data, information and human life itself in a borderless world, especially on issues surrounding the HIV/AIDS pandemic. The author suggests the use of closed communication networks, with the transmission of encrypted data and restricted access by means of

codes, in order to maintain the person's anonymity - this being the imperative for the development of an ethical and legal communication system.

Also according to the author²⁷, in the context of information ethics, the electronic transmission facilitates the manipulation of multiple data by information and communication technologies (ICT), which favors subjects' control and the comprehensive view, while creating the illusion that this information remains in constant anonymity. Eventually, these data are disseminated among family and friends, generating stigma and making evident the lack of care of some health professionals and employees regarding patient confidentiality.

Finally, Berenguera et al.²⁸ call attention to the good result of maintaining the confidentiality present in actions of NGOs that serve those who do not have access to health services, namely people with AIDS, MSM, injecting drug users, sex workers, persons deprived of their liberty and illegal immigrants. Health professionals working in these organizations establish horizontal relationships and links with people as a strategy to facilitate access to NGOs and reduce prejudice.

Breach of diagnosis confidentiality: an ethical dilemma

The studies in this category address the breach of professional confidentiality when the serological condition puts the health of third parties at risk, when there is a requirement to notify the health authorities or insurers, or to register this information on the death certificate.

Feldmann et al.²⁹ discuss whether physicians and other health professionals should disclose confidentiality in cases of users who omit their serostatus to the sexual partner, putting them at risk. The authors emphasize that PLWHA has a guarantee of secrecy and power over their privacy, and it is up to them to decide whether (or not) to inform people about their health. However, every health professional has the obligation to breach confidentiality whenever the health of others is put at risk under the possibility of criminal sanctions for irrational transmission of HIV. This justifies the breach of confidentiality, since maintaining secrecy is justified to protect PLWHA from social discrimination, but not to contribute to the spread of the virus.

However, the dilemma remains for health professionals working in CTA, while ensuring the confidentiality of the person seeking the HIV test and directing the health care of their sexual partners. After all, one cannot benefit one person over another³⁰.

According to Luz and Miranda³⁰, PLWHA have a duty to protect their sexual partners by

communicating their condition. If there is no collaboration, the professional can intervene by summoning these partners, in a type of action that requires extreme delicacy and resourcefulness. For this, the professional can develop a protocol that allows the monitoring of the cases.

From another perspective, Domínguez et al.²⁶ point out informed consent as a tool to guarantee confidentiality. For the authors, the HIV test should be performed only with the consent of the patient, except in situations of limited consciousness. The study reinforces that breaching confidentiality may discourage many people from cooperating in testing programs due to fear of discrimination.

Also according to Domínguez et al.²⁶, the emergence of AIDS highlighted the dilemma of confidentiality, since the risk to the lives of others establishes a moral and legal obligation to inform the spouse or partner, as well as the mandatory notification of health authorities. Therefore, although confidentiality is the right of the user, there are limitations to autonomy when it conflicts with the integrity of other people, as in the example in which the PLWHA refuses to reveal their serological condition to the partner.

Bernal, Álvarez and Santos³¹ assume that professional confidentiality is not an absolute value for the American Medical Association (AMA). As the physician is responsible for preventing the spread of contagious diseases, the association postulates relative confidentiality as long as the ethical obligation to recognize PLWHA's right to discretion and privacy is maintained.

For AMA, the physician is responsible for persuading the infected person to prevent third-party exposure to the disease. If the professional does not obtain results, he/she must inform the authorities, and if they do not take the appropriate measures, physicians themselves must inform and advise the third party involved. This premise, which is becoming popular, derives from the principle of justice, since it is intended to avoid unfair damages to third parties who are unconscious of the risk. Physicians start from the perspective that PLWHA have the same responsibility as society and the State³¹.

Another aspect highlighted by the authors³¹ refers to the discussion that is going on in the United States regarding the need for state laws to protect PLWHA. The government seems inclined to notify the national public health authorities of people's names with a view to protecting them. However, it is not appropriate to propose this measure simply because it is a public health tradition in the country,

since people may avoid testing for fear of being identified by the notification.

There is also the risk of a breach of privacy and confidentiality regarding a positive HIV diagnosis when the user contracts life insurance and consents to the insurer, in writing, access to all information necessary to establish the contract, especially at the time of death. Burger et al.³² also report the difficulty faced by many physicians in registering on the death certificate HIV infection as the underlying cause, given the need to notify the health authorities of the serological condition. According to the authors, this flow of information may compromise the confidentiality of the user. On the other hand, the underreporting of these data compromises the political decisions necessary for the adequate management of the disease, which affects not only those directly involved, but society as a whole.

Discussion

Based on the analysis of the studies presented here, the following key issues can be enumerated: PLWHA that fear stigma and discrimination due to fear of confidentiality breach; health professionals who disclose confidential information in an inadequate way; breach of confidentiality when facing risk to the health of third parties; guarantee of privacy of PLWHA information in medical records (electronic or otherwise); health professionals who defend the anonymity of PLWHA from public knowledge; and maintaining confidentiality as a way of building links between professional and patient.

When discussing issues related to HIV and AIDS, it is necessary to distinguish the terms "stigma", "prejudice" and "discrimination". Stigma is defined as *that which is considered shameful or dishonorable; an infamous brand*³⁴ that can stimulate forms of segregation. Prejudice is understood as *a concept or opinion formed before having the necessary knowledge about a particular subject*³⁵ or person. Discrimination, in turn, *is the act contrary to the principle of equality*³⁶, which segregates, excludes, restricts access to, or abuses the person who is a victim of prejudice.

In this way, everything that is unknown or "foreign" to society's standards incites pre-judgment and can lead to discriminatory acts. This process, which often occurs unconsciously, generates emotional fragility, damage to health, and social exclusion. In the case studied here, fear of stigma, prejudice and discrimination causes many PLWHA not to seek health services.

According to the Joint United Nations Program on HIV/AIDS (UNAIDS)³⁷, stigma, prejudice and discrimination are among the main obstacles to HIV prevention and treatment, and to PLWHA care. These adverse conditions directly confront the fight against the epidemic by generating in people the fear of arousing suspicions about their serological condition, preventing access to information that would allow, among other things, safer sexual practices.

Likewise, fear of stigma and discrimination causes people to stop seeking health services and undergoing the anti-HIV test, fearing the breach of confidentiality by professionals, as reported in the studies by Arrivillaga-Quintero¹⁵, Herrera, Molina and Vásquez¹⁷ and Kerr et al.¹⁸. Fear of violence also often discourages disclosure to family members and sexual partners, and impairs adherence to treatment.

Prejudice and discrimination against PLWHA also occur on the part of health professionals, as reported by Mataboge et al.²². In the same sense, Sadala and Marques³⁸ found that prejudice and intolerance to the “risk group” still persist. Although they are aware that this definition is no longer used, the authors use it to emphasize that, despite efforts to the contrary, the stigma about PLWHA remains, hindering the professional-user relationship.

According to these authors, in the specialized services these impasses were overcome, but in the general health services and hospitals PLWHA are still stigmatized. Prejudice also exists in medical schools, where it manifests itself when some procedures are not performed by different professionals from the team. Finally, Sadala and Marques³⁸ reflect on the medical limits regarding equality in the treatment of PLWHA, since, if they were granted privileges, they would be made different from the others. There is also the question: would providing assistance in a separate place to avoid discrimination, as in referral services, be a form of discrimination?

Prejudice and discrimination of health professionals may still occur when undergoing HIV testing. The Brazilian Ministry of Health states that it is the right of the professional to maintain the absolute confidentiality of their own examination results, as well as any subject discussed during counseling³⁹. When this is violated, the professional can be stigmatized by both co-workers and service users.

Regarding the maintenance of confidentiality, in establishing CTAs, the Ministério da Saúde - MS (Brazilian Ministry of Health) advocated the anonymity of serological diagnosis⁴⁰. Currently, confidentiality is maintained, but anonymity is optional⁴¹. In hemotherapy services, the Agência

Nacional de Vigilância Sanitária - ANVISA (National Health Surveillance Agency) provides in the Resolução da Diretoria Colegiada – RDC (Collegiate Board of Directors Resolution) 343/2012 that *the privacy of information provided by the donor before, during and after the blood donation process should be absolutely preserved*, including in serological screening⁴². When the outcome for HIV is positive, the hemotherapy service should refer the person to the referral service; it is not their role to define the diagnosis but only to discard the blood bag⁴³.

Apropos the health autonomy of adolescents, it should be specifically pointed out that, due to the stigma they may suffer, including in the family environment, it is foreseen by the Brazilian Ministry of Health that persons between 12 and 18 years of age who are mentally capable have the right to HIV testing without the consent of their legal guardians⁴¹. That is, adolescents have the right to privacy and the confidentiality regarding their diagnosis. However, due to the specific legal status of this population⁴⁴, the care provided still brings ethical, legal and social contradictions related to this right⁴⁵.

AIDS has raised important questions regarding bioethics. Topics previously undisputed, such as medical confidentiality, began to be rethought: on the one hand, the safeguarding of the patient; on the other hand, responsibility for the health of the community³⁹. Article 10 of the *Resolução CFM 1.665/2003* [CFM Resolution 1,665/2003] provides that *professional confidentiality must be strictly adhered to in relation to patients with the AIDS virus, except in cases determined by law, for just cause, or by express authorization of the patient*⁴⁵.

In the case of legal duty, the breach of confidentiality is made through the notification of the diagnosis to the health authorities and the fulfillment of the death certificate, and for just cause in cases of safeguarding the life of others. Conversely, Scheffer and Rosenthal¹² argue that the professional must fulfill the duty of confidentiality, pointing out that, although the PLWHA sexual partner has the right to know that he/she can be infected, such a right does not justify breaking the confidentiality of the professional-user relationship; the partner must be informed by means of examinations.

In this regard, AMA⁴⁶ directs physicians to comply with all disease notification laws, while safeguarding the confidentiality of the patient's condition, but at the same time preventing, within the limits of the law, PLWHA from infecting other persons. Thus, if a PLWHA poses a threat to another identifiable individual, the physician's duty ranges from notifying public health authorities to

communicating the risk to a third party without disclosing the identity of the person of origin.

Ethical dilemmas related to ICT refer to information technology as a resource that, while facilitating activities in the health service, can provide access to private information. Misuse of such systems may lead to breach of confidentiality and violation of patient privacy. Therefore, it can be seen that computer networks also allow improper access and alteration of information, threatening the well-being and even the life of the user⁴⁷.

Even after the death of the patient, in the case of notification of serological tests for death certificates, professional confidentiality must be strictly adhered to (except in cases of compulsory notification, situations involving risk to others and ill-treatment of minors⁵), since *patients have the right to dignity and respect, even after death*⁴⁸. Confidentiality is fundamental for the user to trust in the health professional, and this relationship, in turn, is a key part of creating bonds.

A point that was present in most of the studies analyzed should be highlighted: patients' distrust of confidentiality. The users of the services have the impression that their data will be communicated in some way, either by compulsory notification, by the care service being provided by a team, by the ease of access to the information, or by failures in the work processes.

This review clearly demonstrated that these issues drive users away from services, failing to submit to testing or to seek results. Therefore, a solution to the problem would be ongoing education at work in order to raise awareness and educate health professionals about the importance of confidentiality in PLWHA care, emphasizing situations in which diagnosis should be revealed or not, and to whom and when to reveal it.

Finally, Sadala and Marques³⁸ state that health professionals should use the best scientific knowledge in PLWHA care, without losing the perspective that they are dealing with human beings

who are suffering because of their health condition and require unique – and, why not affectionate care?

Final considerations

Data analysis confirmed that the fear of stigma, prejudice and discrimination ultimately determines the health-disease process because, in the face of this feeling, people stop seeking health services, performing HIV tests and adhering to treatment. In this context, breach of confidentiality not only violates the duty to maintain privacy regarding information obtained during professional practice, but reinforces the patient's fear of being socially excluded.

The studies presented different conflicts regarding confidentiality, according to the characteristics of the population and health services involved. All stressed that confidentiality creates trust, facilitates people's access to health services, and brings together users and the health team. Conversely, breaking it causes users to lose confidence in the professional and the health service, aggravating the damages resulting from their condition. In this way, preserving privacy and confidentiality - and not only of PLWHA - is a duty of health professionals, not merely because of respect for the Code of Ethics or the Hippocratic Oath, but because, when choosing the profession, they chose to care for human beings, not viruses.

To carry out a study like this generates the expectation of finding objective answers to the practical dilemmas. The existing legislation and the professional councils' regulations guide the professionals' work in the care of PLWHA, but each person is in a unique and distinctive situation, which makes care complex, requiring special analysis and continuous search by health professionals to perfect the practice. In view of this, the preservation of the privacy and confidentiality of an individual is fundamental, and its breach is acceptable only in case of risk to the health of the collective. After all, what are the limits of privacy and confidentiality?

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