DOI 10.18471/rbe.v37.50338
Original Article

ACCESSIBILITY AND USE OF HEALTH SERVICES: WOMEN LIVING WITH THE HUMAN IMMUNODEFICIENCY VIRUS

ACESSIBILIDADE E UTILIZAÇÃO DOS SERVIÇOS DE SAÚDE: MULHERES VIVENDO COM O VÍRUS DA IMUNODEFICIÊNCIA HUMANA

ACCESIBILIDAD Y UTILIZACIÓN DE LOS SERVICIOS SANITARIOS: MUJERES QUE VIVEN CON EL VIRUS DE LA INMUNODEFICIENCIA HUMANA

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How to cite this article: Kleinubing RE, Langendorf TF, Padoin SMM, Paula CC. Accessibility and use of health services: women living with the human immunodeficiency virus. Rev baiana enferm. 2023;37:e50338.

Objective: to analyze the access of women living with HIV to health care services. Method: qualitative, participant research, mediated by interview and observation with 14 women in the health services of a city in southern Brazil. Content analysis was developed, based on the theoretical categories of the structural and procedural elements of access according to Starfield. Results: the access of women living with HIV to Specialized Services and Primary Health Care occurred at the woman's own initiative. The link occurred mainly in the specialized service that best embraced and met their needs, regardless of the psychosocial relationships established, waiting time for care and geographic location of health services. Final considerations: several factors interfere positively or negatively in women's access to health policy, highlighting the lack of efficient communication between professionals from different services, which affects women's access to information and procedures.

Descriptors: Health Services Accessibility. Delivery of Health Care. HIV. Acquired Immunodeficiency Syndrome. Women.

Objetivo: analisar o acesso de mulheres vivendo com HIV aos serviços de atenção à saúde. Método: pesquisa qualitativa, participante, mediada por entrevista e observação com 14 mulheres nos serviços de saúde de um município do Sul do Brasil. Foi desenvolvida análise de conteúdo, pautada nas categorias teóricas dos elementos estrutural e processual do acesso segundo Starfield. Resultados: o acesso das mulheres vivendo com HIV aos Serviços Especializados e à Atenção Primária à Saúde ocorreu por iniciativa da própria mulher. O vínculo deu-se majoritariamente no serviço especializado que melhor acolheu e supriu suas necessidades, independentemente das relações psicossociais estabelecidas, tempo de espera para os cuidados e localização geográfica dos serviços de saúde. Considerações finais: há uma série de fatores que interferem positiva ou negativamente no acesso das mulheres à política de saúde,

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destacando-se a falta de comunicação eficiente entre os profissionais de diferentes serviços, o que afeta o acesso das mulheres à informação e procedimentos.

Descritores: Acesso aos Serviços de Saúde. Atenção à Saúde. HIV. Síndrome de Imunodeficiência Adquirida. Mulheres.

Objetivo: analizar el acceso de mujeres viviendo con VIH a los servicios de atención a la salud. Método: investigación cualitativa, participante, mediada por entrevista y observación con 14 mujeres en los servicios de salud de un municipio del Sur de Brasil. Se desarrolló análisis de contenido, pautado en las categorías teóricas de los elementos estructurales y procesales del acceso según Starfield. Resultados: el acceso de las mujeres que viven con VIH a los Servicios Especializados y a la Atención Primaria de Salud ocurrió por iniciativa de la propia mujer. El vínculo se dio mayormente en el servicio especializado que mejor acogió y suplió sus necesidades, independientemente de las relaciones psicosociales establecidas, tiempo de espera para los cuidados y localización geográfica de los servicios de salud. Consideraciones finales: hay una serie de factores que interfieren positiva o negativamente en el acceso de las mujeres a la política de salud, destacando la falta de comunicación eficiente entre los profesionales de diferentes servicios, lo que afecta el acceso de las mujeres a la información y procedimientos.

Descriptors: Accesibilidad a los Servicios de Salud. Atención a la Salud. VIH. Síndrome de Inmunodeficiencia Adquirida. Mujeres.

Introduction

The Joint United Nations Program on HIV/AIDS (UNAIDS) presents an action plan that includes strategic lines, such as expanding access to health services, to control Human Immunodeficiency Virus (HIV) infection with quality[1]. A study based on secondary data, also indicated by the program, aimed to evaluate the social determinants of access to HIV and syphilis diagnostic tests in 13 thousand users[2].

Due to the strengthening of HIV control programs and the qualification of attention to this population and, considering the simplification of treatment, infection with this virus began to present characteristics of a chronic condition, which implied the need to reorganize the care model, which was centered on Specialized Services (SS) and did not include Primary Health Care (PHC)[3]. Chronicity demands indicate the need for integration of services and composition of women's lines of care for sexual and reproductive health issues, in addition to HIV testing, and should consider both specialized and primary care services[4].

Although PHC services represent the preferred gateway to the health system for people living with HIV, including pregnant women, these actions are still insufficient. Access to primary care involves obstacles, and the difficulty of access is a factor that discourages users, due to the long waiting time between the appointment, the day of the consultation and the service process[5]. Obstacles present in the organization of PHC make users recognize in the SS, which have greater technological density and resolution, the source of safe care able to meet their health needs, regardless of the complexity of the problem. This hinders the understanding of the existence of a service network, which could be used as a resource option[3].

Historically, SS have been, and in many cases still are, regular search services for people living with HIV. The decentralization guideline is recent, being necessary to consider that, even in a situation with chronic care characteristics, issues such as stigma are relevant. Thus, testing for early diagnosis and health monitoring in primary care are not identified by society as decentralized actions for care and integration between PHC and SS, as indicated by the Ministry of Health[6], which converges with the theoretical framework of quality of health care, which discusses the attribute access[7].

A significant decrease in HIV transmission will not be achieved as long as permanence in treatment is not a priority for all health services[8]. In view of the epidemiological picture and

the repercussions of HIV infection, the stigma affecting the infected persons, the lack of cure and the lack of debate and knowledge on conditions for access to treatment and information by women, this study aims to analyze the access of women living with HIV to health care services.

Method

This is a descriptive study with a qualitative approach. For its writing, the Checklist Consolidated Criteria for Reporting Qualitative Research (COREQ) was used, in view of the transparent and accurate report of this research.

The study was conducted in a city in the central region of Rio Grande do Sul, Brazil, where the health care of women living with HIV is offered by primary and specialized care services. In PHC, there are 31 services, of which 18 are traditional Basic Health Units (BHU) and 13 consist of Family Health Strategy (FHS). The specialized services are two, one federal (university hospital) and another municipal.

Participant observation techniques were used, developed in both SS and two PHC units (one FHS and another BHU), from June to August 2017, totaling 45 hours. In this period, the component annotations of the Observation Notes (ON) were elaborated, empirical source for the analysis. During participant observation, semi-structured interviews were also conducted with women living with HIV, with a previously tested script. The inclusion criteria were: women living with HIV and who, at some point, accessed health services. The exclusion criterion was to have the service performed in a particular service.

The recruitment of participants occurred when women accessed the health service for some care (medical, testing, medication), and, at this time, the invitation to participate in the research was made. As this was the first contact, there was no previous relationship with the study participants. The convenience sample consisted of 14 women, ending the interviews when there was thematic saturation and the internal logic of the object of study was found[9]. The interviews were conducted in separate rooms in the services, in order to respect the privacy and confidentiality of the diagnosis, and conducted by the first author, who had experience in the theme and qualitative approach.

The analysis was performed after the triangulation of the information and obtained through the content analysis, of the thematic type[9], of the empirical material of the transcription of the interviews and the ON. In the pre-analysis, the initial selection of the material was carried out through the grouping of the transcribed interviews and the ON, through floating reading. In the exploration of the material for categorization, the data were grouped based on the theoretical framework of analysis[7], which was the guiding thread for the interpretation anchored in the categorized theoretical elements, considering the quality of health care according to the access attribute[7].

The theoretical categories of the structural and procedural elements of access, according to Barbara Starfield[7], are based on the principle that, in order to provide the health needs of individuals, the service must act in the first contact, promoting accessibility, characterized by structural elements: proximity between health services and the population assigned, availability of times and dates for attendance and flexibility in scheduling. Accessibility should consider: the psychosocial aspect of the relationships established within health services, such as language or cultural barriers, communication between professionals and users; the issue of geographical accessibility, regarding the adequacy of transportation and the distance to be traveled to the service; and the problem of time or temporal accessibility, involving the dynamics of care (availability of schedules)[7].

Regarding accessibility, the use of services (procedural element) is achieved whenever there is demand for health of individuals. This can be preventive or investigative, through a consultation or monitoring of a pre-existing problem. Sometimes, it occurs at the user's initiative, as in PHC services, as well as through guidance or professional referral or administrative

requirement, usually present in services of higher technological density[7].

The access attribute is composed of accessibility and use of services, inseparable elements of each other and mutually related, in view of the reflection of accessibility in the extension of the use of health services. This means that, if there is no guarantee of accessibility to a particular health service, its use is unfeasible.

The ethical precepts of Resolution n. 466/12 of the National Health Council were respected, and the research was approved by the Institutional Ethics Committee, under Opinion n. 1,635,237. For the anonymity of the participants, the code I (Interview) was used, followed by the corresponding interview number and the code ON, in addition to the service where the observation was developed.

Results

The women interviewed were on average 26 years old, mostly white. Regarding schooling, four had complete elementary school and one, incomplete; five with complete high school and two, incomplete; and two with incomplete higher education. As for the marital status, ten women reported having a partner, three were single and one, divorced.

The structural element accessibility is represented by the following categories: psychosocial, geographical and temporal[7]. The first one (psychosocial) also presents three subcategories: positive communication, cultural barriers and communication barriers.

The results indicate that, in the subcategory of positive communication, support, embracement and conversations were related to satisfaction with the service, reflecting access or return to the health service. The subcategory of cultural barriers related to the unavailability of wrong information and/or guidance and the divergence of information. Regarding communication barriers, the absence of diagnostic secrecy and prejudice weaken the link and access in both PHC and SS.

> *I found out* [the HIV diagnosis, at the PHC service]*, the nurse talked to me and I felt embraced, and I intend to return*. (I8).

> *Either the post or the emergency room* [are prepared to meet the demands of people with HIV]*, if you are seropositive, they ignore you* [...] (I3).

> *I suffered with prejudice and stopped treatment* [...] *a professional started to judge me. I saw that it was someone who was not prepared, so I did not go any further. I felt attacked.* (I8).

> *The doctor reduced the woman's desires and fears, resulting from misleading information received from a doctor who, according to the user's report, said that she was "producing tumors" due to HIV.* (ON - SS).

> *The municipal specialized service makes contact with people tested in other health services [*with rapid HIV reagent test]*, and invite you to attend the specialized municipal service.* (ON - SS).

> *The CO is responsible for the confidentiality of information, which is restricted to the medical record. The psychologist and social worker talk about issues such as HIV and confidentiality.* (ON Maternity).

The findings revealed the difficulty of working in a multidisciplinary team, the need for training of health professionals to meet the demands related to HIV infection and the absence of co-responsibility for the care of seropositive users in PHC services and their communication with the SS.

> *One year ago I was taking the HIV drugs he* [PHC doctor] *guided me.* [...] *my tests* [CD4 and CV done in the specialized service during pregnancy] *were horrible. The doctor said to change completely* [the way she was taking the ARV] [...] *She thought I had relaxed and I said: no* [...] *I am following what they said there* [in the PHC] [...] *and she* [the doctor] *said: "forget what they told you there* [in the PHC service]*, wait until your consultation here [in the specialized service] and ask your questions."* (I2).

> *It was good* [the viral load] [...] *they said* [in the health service of another municipality] *that I could have normal birth. But the doctor here* [of the specialized service] *told me to have Cesarean section.* (I12).

> *The nurse reported difficult communication between the specialized services, which makes the health team unsatisfied* [...] *the specialized health unit is currently responsible for assisting the pregnant women referred from the PHC.* (ON- SS).

Regarding the geographical component, the following factors, considered facilitators, were indicated as intervening in access: the proximity of PHC services and the availability of intercity transport from the health department of the municipality of residence to the SS. As for the temporal component, the study revealed that

the systems to schedule appointments and examinations can increase the waiting time to receive health care, especially in PHC services, and this may cause preference for a type of service in the health care network.

> *The health car always picked me up at my house, because if not, it would always be difficult* [to go to the specialized service], *because we are unable to go.* (I4).

> *For me* [the PHC service] *is closer to my house* [...] *that is why the post was easier for me.* (I10).

> *When the cases are not urgent and there are too many patients scheduled, the patients from the embracement are re-scheduled to another day in the week.* (ON - BHU).

> *The doctor* [PHC] *refers and the patient goes to a single line, by RHC, from which the patient is referred to the federal specialized service. He said that more urgent cases are preferential* [like cases of debilitated patients with more compromised health status due to the HIV], *however, sometimes there are unnecessary referrals, which are not urgency. Sometimes, patients that should be referred with urgency are not.* (ON - SS).

In the categorical analysis of the procedural element used in health services, the access of women to the PHC service occurred after a situation of exposure to HIV, demanding the search for the test and the discovery of the infection. Thus, the demand for care in PHC was evidenced by preferential initiative of the users. Moreover, the first contact with the PHC service occurred due to a health situation, through illness or pregnancy, motivating the search for the rapid HIV test.

When women who already have a previous diagnosis of infection sought SS, spontaneously or by transference (communication), they intended to confirm the diagnosis and maintain health monitoring. Nevertheless, in this service, the use was triggered more frequently by indication of the health professional, through the transfer between services. On these occasions, PHC was responsible for the demands not related to HIV, and SS, for cases of immunizations, tests and consultations for health problems that did not constitute urgency.

> *I had a strong flu and the rumors began, I sought the doctor* [...] *in the first test, I was diagnosed.* (I1).

> *I sought the post for the pregnancy rapid test. Then I did the rapid test [anti-HIV] and it appeared.* (I10).

> *I was in the prenatal care* [in the PHC service], *then the doctor told me: "you are infected and can't do the prenatal care, you have to go there"* [specialized service] [...] *to vaccinate.* (I14).

> *Nursing guidance is that pregnant women must maintain monitoring in the basic network, combined with the federal specialized service. The first consultations are scheduled via the 4th RHC together with the basic network.* (ON - SS).

> *The user must go to the PHC for the consultation with the doctor and to report any need. The doctor refers and the user goes to a single line, by RHC, and is referred to the federal specialized service.* (ON - SS).

The link to the service as a preferred source of care led participants to remain using the SS for receiving health care, such as tests, guidance, monitoring of old problems, consultations with specialists and multidisciplinary team and routine treatment. Therefore, women living with HIV have shown preference in choosing a service that welcomes and meets their needs.

> *I keep going to the post for the routine treatment.* (I5).

> *When I have doubts, I come to the municipal specialized service.* (I11).

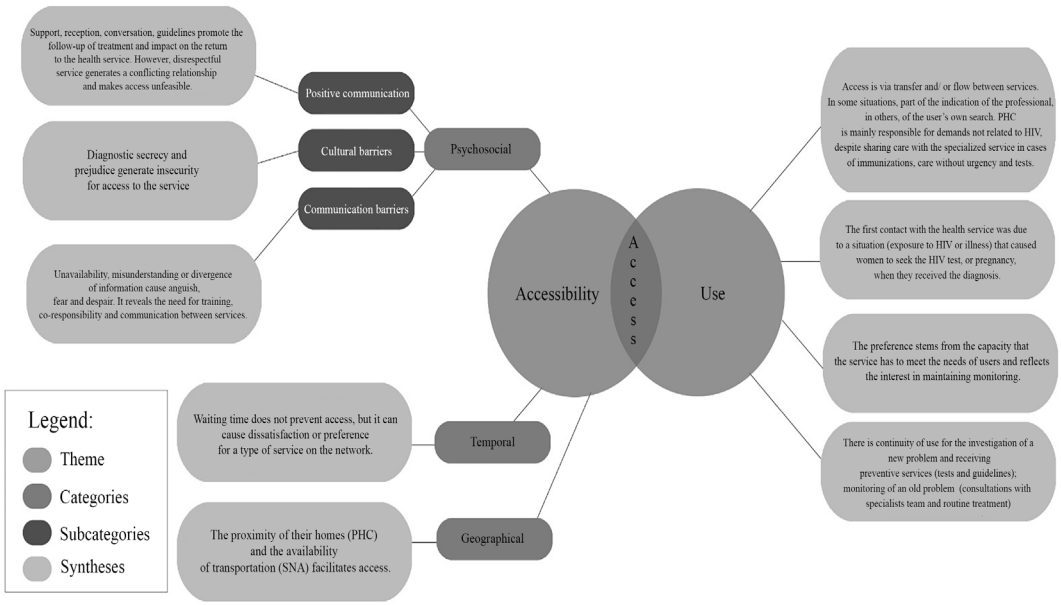
> *The follow-up is good* [in the PHC service] [...] *but [the specialized service] is better for me* [HIV] [...] *it has specialists for everything.* (I13).

> *The puerperal woman preferred prenatal care only in the FHS.* (ON - FHS).

> *The professional reported that women with HIV hardly attend the primary care service; they normally attend the federal or municipal specialized service.* (ON - FHS).

The triangulation of information obtained through interviews and participant observation culminated in the elaboration of Figure 1.

Figure 1– Synthesis of the analysis of women's experience applied to the theoretical categorization of the structural and procedural elements of access. Santa Maria, Rio Grande do Sul, Brazil – 2018



Source: created by the authors.

Discussion

Concerning PHC, despite the potential to assist pregnant women living with HIV, the lack of human resources makes access to prenatal care impossible[10]. Even if there is an incentive for this population to access PHC and SS services jointly, the inability of PHC to meet health demands provides that these women are linked to other services, especially specialized services[11].

The decentralization of the diagnosis of HIV infection, in order to expand the possibilities of access, has PHC as the preferred door for rapid testing, facilitating the transfer in HCN. However, by extending the range of services enabled to perform this testing, issues involving confidentiality and disclosure of diagnosis can generate conflicts between professionals and users[12].

To meet the health demands of women living with HIV, there is need to complement professional experience with the best scientific evidence and qualify the process of interpersonal and intersectoral communication, considering the existence of conflicting communication within the team and the different sectors[13]. Such actions promote accessibility to the quality of health care, and the psychosocial dimension minimizes cultural and communication barriers.

Thus, there is need to rethink the form of organization and management of work in health, aiming to give greater importance to the training and updating of professionals in the care of people living with HIV[14].

As for intersectoral communication, to make the disruption of the network possible, PHC, especially the FHS, should be co-responsible for the care of people living with HIV. This means, among other attributions, knowing the assigned population and taking responsibility for the care or monitoring of treatment, according to the territorialization or the needs of the users.

For PHC resolution, some characteristics, such as territory definition, are fundamental. This may interfere with access to health services, considering the organization of the population in families, and therefore these should be known by health services, which will imply geographical and temporal accessibility[15].

In the present study, geographical accessibility, through the availability of municipal transport, facilitated attendance to the specialized service. However, when the participant herself needed to bear the displacement, women living with HIV opted for care in PHC, according to the proximity of their homes.

The continuity of care during pregnancy and puerperium, without the pilgrimage between different locations and municipalities, depends, among other factors, on overcoming possible difficulties and access gaps related to the geographical location of health services. Under these conditions, many women living with HIV may leave the services and, due to the lack of recognition of the assigned population, PHC does not develop an active search[11].

Temporal accessibility refers to the waiting time to obtain consultations and diagnostic and therapeutic support services. In the present study, the delay in scheduling or receiving tests and care and dissatisfaction with the health service, pointed out by the interviewees as difficulties in the procedural element of the accessibility attribute, were revealed. Waiting time and scheduling modality for receiving care on specific days do not always represent the best access opportunities for users[14].

Access to health services is essential for the quality of women's health care, but a study conducted in all Brazilian federal units indicates concerns[16]. Some barriers shown by women were: the difficulty in scheduling the consultation, the adequacy of time for attendance with service professionals and the difficulty of transportation[17].

The organization of care, which often denies or postpones consultations because of the absence of service records or staff professionals, reveals the lack of an open door in the HCN, especially in PHC[11]. In this sense, regardless of the serological condition or the woman's life cycle, these factors represent obstacles to health monitoring, because the shorter the time for access to actions, the better the satisfaction of the users. Women living with HIV used health services for consultations, investigation of new health problems, monitoring of preexisting problems or receiving preventive services.

The anti-HIV test is the first step in responding to the epidemic. Many women discover that they are living with HIV during pregnancy, under the guidance of health professionals during prenatal consultations[15]. This signals the importance of disease screening and, in case of seropositivity, recommendations to avoid vertical transmission, treatment with antiretroviral drugs and other care during childbirth, postpartum and with the exposed child.

The proposition of the UHS for coping with the HIV epidemic was decentralization of care, which expanded the HCN and included PHC as the preferred gateway for people living with the virus. However, the structural problems faced by PHC, which include waiting time, low coverage of FHS, turnover of professionals and the use of fragile technologies of care for people with HIV, make these services develop occasional care for the distribution of prevention, immunization, gynecological or clinical consultation[12].

In HCN, the referral of these users should consider the ease of access and satisfaction with the care received. Nevertheless, a study showed that pregnant women with HIV are transferred exclusively to specialized services, often losing the link with PHC. This reveals the lack of coordination of actions and a flow of transfer, as well as the need to train health professionals in PHC to assist this population[10].

When considering vulnerable populations, such as women living with HIV, health actions are often restricted to the identification of seropositive pregnant women, in order to adopt measures focusing on the prevention of vertical transmission. This implies the health of women beyond the pregnancy-puerperal period, triggering the diagnosis of infection and early initiation of treatment[18].

To minimize this gap in care, decentralization and joint action between PHC services and specialized services is indicated, through interconnection and the transfer system (reference and counter-reference), to promote shared care. For the use of services, intersectoral

communication strategies, joint decision-making and co-responsibility between teams are necessary[19]. Similarly, it is necessary to consider the user's experience and perception of the recommended service. Therefore, the user will decide which location will be the most suitable for access to health care[12]. In some situations, this is believed to contribute to user's access to the service.

The choice and predilection for a particular health service represent an important indicator of quality, as it reflects the degree of service performance and satisfaction on the part of those who access it[9]. In addition, since health professionals represent the secondary support network for these women, embracement and link can contribute to this choice[12].

Thus, the SS needs to stimulate and guide the use of PHC, aiming at the degree of integration as a decision to guarantee access. The continuity of the use of services may occur by investigating a new problem or monitoring an old one, in a preventive and/or treatment scope[20].

A limitation of the research concerns its execution with exclusive focus on the users, which was minimized by participant observation in the services.

As contributions of the research, the components of geographical, temporal and psychosocial access, when positively analyzed by users, are related to satisfaction with care and thus reflect a link with the source of care, which will be their preferred source. To maintain the logic of care networks, teamwork shall be developed, sharing responsibilities between services to continue assistance.

Final Considerations

Regardless of the psychosocial relationships established, the waiting time for care and the geographical location of health services, the access of women living with HIV to SS and PHC occur at the woman's own initiative. Next, she continues the health actions in the service that best embraced and met her needs, mostly in the specialized service. This indicates a mismatch between the link of users and the recommendation of public policy on decentralization and territorialization.

The experience of women, their autonomy of choice and the link with professionals who develop care should be considered in order to qualify health actions and improve the access of those living with HIV to health services. The link and the resolution depend on a positive communication between the services and their professionals and of these with these women. To enable the establishment of cooperative relationships, it is essential to train health professionals in terms of qualification of communication within and between services.

Collaborations:

1 – conception and planning of the project: Raquel Einloft Kleinubing, Tassiane Ferreira Langendorf, Stela Maris de Mello Padoin and Cristiane Cardoso de Paula;

2 – analysis and interpretation of data: Raquel Einloft Kleinubing, Tassiane Ferreira Langedorf, Stela Maris de Mello Padoin and Cristiane Cardoso de Paula;

3 – writing and/or critical review: Raquel Einloft Kleinubing, Tassiane Ferreira Langendorf, Stela Maris de Mello Padoin and Cristiane Cardoso de Paula;

4 – approval of the final version: Raquel Einloft Kleinubing, Tassiane Ferreira Langendorf, Stela Maris de Mello Padoin and Cristiane Cardoso de Paula.

Competing interests

There are no competing interests.

Acknowledgements

The authors would like to thank the National Council for Scientific and Technological Development (CNPq), the Coordination for the Improvement of Higher Education Personnel (CAPES) and the Federal University of Santa

Maria (UFSM) for the possibility of carrying out this research.

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Received: July 28, 2022

Approved: September 13, 2023

Published: October 25, 2023