Coordination of care for people living with HIV in the prison system
Coordenação do cuidado às pessoas que vivem com HIV no sistema prisional
Coordinación del cuidado a las personas que viven con el VIH en el sistema penitenciario

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Confl  icts of interest: Manuscript extracted from the thesis “Care coordination during assistance to persons deprived of liberty living with HIV”, presented in 2019 to the Postgraduate Program in Public Health Nursing at the Ribeirão Preto College of Nursing, Universidade de São Paulo.

Abstract
Objective: To analyze the care coordination for people living with HIV according to the prison unit.
Methods: Cross-sectional study conducted in six prison units in the state of São Paulo. Eighty-five inmates living with HIV and six technical directors were interviewed. Coordination indicators were created from questions with a 1-5 scale and classified as satisfactory (>3.5 to 5.0), regular (>2.5 to 3.5) and unsatisfactory (1.0 to 2.5). ANOVA and Kruskal Wallis were used.
Results: The coordination was classified as unsatisfactory (mean 2.49). Unsatisfactory indicators: “Questioning side effects of antiretroviral therapy (ART)”; “Questioning the difficulties in ART intake”; “Observing ART intake”; “Requesting ART bottles/packages to monitor medication intake”; “Asking for explanations regarding the use of ART”; “Questioning the storage conditions of ART in the prison cell”; “Informing and discussing T-CD4 + and viral loading results”; “Informing the scheduling of consultation at the HIV reference service” and “Take to care for other medical specialties”. The following obtained regular classification: “Take to emergency medical care when needed” and “Not missing an appointment at the HIV reference service”. “Questioning the regularity of the use of ART” was the single worst indicator evaluated in the comparison between the prison units studied (p<0.05).
Conclusion: The performance of prison units does not differ in relation to most coordination indicators studied, which shows the need for improving the performance with regard to the development of actions to monitor the use of ART, inform and discuss test results with inmates and take them to care outside the prison unit.

Keywords
Prisons; HIV; Acquired immunodeficiency syndrome; Health service research; Comprehensive health care

Descritores
Prisões; HIV; Síndrome da imunodeficiência adquirida; Pesquisa sobre serviços de saúde; Assistência integral à saúde

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Coordination of care for people living with HIV in the prison system

People deprived of liberty (PDL), along with other population groups, are considered key and priority populations for health care due to the higher risk for HIV/AIDS infection. In 2017, the World Health Organization (WHO) highlighted that the incidence of HIV among key populations continued to increase and that between 40% and 50% of new infections by the virus occur in these populations and their partners. Although supported by laws within the list of health actions and services of the National Health System (Brazilian SUS), the prison population represents a segment widely exposed to unworthy conditions of confinement that make these people vulnerable both programmatically and individually to infections and/or illnesses. Associated with these conditions, there is the sharing of inputs for drug use, tattoos, unprotected sex and homosexual practices that expose individuals to HIV infection.

Health Care Centers (HCC) were created in this context. They represent Primary Health Care (PHC) services inside the prison system, are the gateway to the Care Network and a place for longitudinal monitoring that promotes the integration of actions and articulation with other health care points of the SUS aligned with the needs and demands of PDL. In addition, the National Policy of Comprehensive Health Care of PDL (Portuguese acronym: PNAISP) was instituted to ensure health care for PDL by guaranteeing actions for the promotion, prevention and management of recurrent and already installed diseases, with emphasis on HIV.

As a result, it is necessary to implement the PHC attribute of care coordination, since it presupposes guaranteeing continuity of care in articulation with members and resources within the service itself (horizontal integration) or with other points of the Care Network (vertical integration). This understanding is reinforced due to the segmentation and fragmentation of care that represent a challenge for the monitoring and continuity of care of chronic conditions such as HIV.

In view of the above, the aim of this study was to analyze the care coordination provided to people living with HIV in prison, according to the prison unit, based on the hypothesis of existing a difference between them in relation to the care provided.

Methods

Cross-sectional, quantitative study that is part of a larger study. The investigation scenario consisted of...
of six prison units in the region of Ribeirão Preto, where inmates awaiting trial are held in temporary detention centers (TDC), like those serving time in prisons. In order to ensure the teams’ privacy, the prison units were named according to the acronyms: UP-A; UP-B; UP-C; UP-D; CDP-E; and CDP-F. In 2015, these units were occupied by 1,767, 1,671, 1,922, 507, 882 and 1,091 inmates, respectively.

The monitoring and specialized follow-up of PDL living with HIV in the studied place was performed by specialized services of the public health network. In cases of complications, care was provided by two Emergency Care Units.

The study population included all PDL living with HIV/AIDS in the prison system in the region of Ribeirão Preto. Inclusion criteria were individuals who had been in custody for more than six months where data collection was performed.

An interview was also conducted with all six technical health directors of prison units that were part of the study. Both for PDL and health directors, the refusal to participate in the study was defined as an exclusion criterion. Note that none of them refused to participate in the study.

The interview was held from August to November 2015 with use of a data collection instrument from the larger project that was prepared based on the Recommendations of the National Plan for Highly Active Antiretroviral Therapy (HAART) in HIV-infected adults; on the Protocol of Primary Health Care in prison units of the state of São Paulo; and the Primary Care Assessment Tool (PCAT). The instrument developed was content validated by specialists, a pilot test for content and semantics analysis was done, and it was subsequently applied to PDL living with HIV and made available in the doctoral thesis from which the present article was extracted.

The final version included 44 variables distributed in six sections: I- Sociodemographic data; II- Sexual practice; III- Clinical and follow-up data; IV- Route in the prison system; V - List of actions and services offered by the prison unit to PDL with HIV/AIDS; and VI –Coordination and integration of health actions and services to care for PDL with HIV/AIDS. In the interviews conducted with the technical directors of health, was used a specific structured questionnaire comprising a “Script for the characterization of prison units” with information on the environment, structure and work routines.

For this study, variables related to the evaluation of care coordination of sections III and VI of the data collection instrument were used, as well as variables related to structure components and work routines of the prison unit characterization script. The variables were grouped according to the dimensions of care coordination: the capacity of prison health units in the care provided to PDL living with HIV; administrative and organizational structure; integration between health teams and services; informational continuity.

For data analysis, descriptive techniques were used and indicators relevant to the dimensions “horizontal integration”, “vertical integration” and “informational continuity” were built. These indicators corresponded to the average value of responses for each variable in a 1-5 Likert response scale arranged in a box plot with respective confidence intervals. The composite indicator for the care coordination was also calculated. These were classified as satisfactory (>3.5 to 5.0), regular (>2.5 to 3.5) and unsatisfactory (1.0 to 2.5).

Subsequently, the analysis of variance (ANOVA) was used with the Tukey’s test to compare the performance of the different prison units in relation to care coordination. This test was performed when the assumptions of homoscedasticity were met by the Levene’s test. Normality was not tested, since the population studied had an ‘n’ greater than 30. When there was a violation of criteria for the use of ANOVA, the Kruskall-Wallis test and the multiple comparison test were used. The level of statistical significance adopted in all tests was 5%.

This study was approved by the Research Ethics Committee of the responsible institution, according to CNS Resolution 466/12 under number 013/2017.
Results

During the data collection period, 102 inmates diagnosed with HIV were identified in the six prison units. Of these, ten did not meet the inclusion criteria, five refused to participate in the study and two were absent from the unit, which resulted in 85 study participants.

Regarding the clinical follow-up of PDL living with HIV, 43 (50.6%) subjects received the diagnosis of infection in the prison system; 72 (84.7%) were under medical supervision; 67 (78.8%) used antiretroviral therapy (ART); 13 (15.3%) interrupted medical follow-up at some point. In the current incarceration, 18 (21.2%) reported hospitalization because of HIV/AIDS and 23 (27.1%) reported occurrence of tuberculosis (Table 1).

At the time of data collection, the UP-A had 14 professionals, UP-B had 17, UP-C 20, UP-D 16, CDP-E 14 and CDP-F 11. The multiprofessional team inside prison units, the UP-B, UP-C and UP-D had at least seven professionals from different categories (doctor, nurse, nursing assistant/technician, dental surgeon, social worker, psychologist and health correctional officer). Of these professionals, the UP-A and CDP-D units did not have a doctor and the CDP-E did not have a doctor nor a dentist. The care to health demands was performed predominantly full time (83.0%).

The general composite indicator for care coordination during the care provided to the PDL living with HIV in prison units obtained an average of 2.49 (± 1.82), which classifies as unsatisfactory.

As for horizontal integration, the following indicators obtained satisfactory results: “No delay in the delivery of antiretroviral drugs (ARV)”; “Conducting blood collection at the prison unit”; “Guidelines on preparation for blood collection for exams”. The indicator “Questioning the regularity of the use of ARV drugs” was classified as regular. The other nine indicators were considered unsatisfactory, as shown in figure 1.

Table 1. Frequency distribution of clinical follow-up data of people deprived of liberty living with HIV in prison units of a health region in the state of São Paulo

<table>
<thead>
<tr>
<th>Clinical follow-up of HIV</th>
<th>PLH (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n(%)</td>
</tr>
<tr>
<td>Diagnosis performed in the prison system</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Undergoing HIV medical follow-up</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Use of ART</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Interruption of medical follow-up</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Hospitalization due to HIV/AIDS</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>No</td>
</tr>
<tr>
<td>HIV-related illnesses in the last incarceration*</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td></td>
<td>Pneumonia</td>
</tr>
<tr>
<td></td>
<td>Herpes Zoster</td>
</tr>
<tr>
<td></td>
<td>Oral candidiasis</td>
</tr>
<tr>
<td></td>
<td>Kaposis’s sarcoma</td>
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<tr>
<td></td>
<td>Toxoplasmosis</td>
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<tr>
<td></td>
<td>Cryptococcosis</td>
</tr>
<tr>
<td></td>
<td>Cytomegalovirus</td>
</tr>
</tbody>
</table>

* Since more than one answer alternative to these variables was possible, the percentage of answers exceeds 100%.

Figure 1. Means and confidence intervals of variables of the dimension of integration of health actions and services within the prison unit (horizontal integration) during care provided to people living with HIV in prison units of a health region in the state of São Paulo.
Still in relation to horizontal integration, six (100%) technical directors of health spontaneous demand; anti-HIV, Hepatitis and Syphilis testing; and collection of TCD4 +/viral loading in loco. Five (83.3%) prison units provided ART to inmates monthly and three (50.0%) informed the development of strategies to assess medication adherence.

In relation to vertical integration, the following obtained regular classification: “Taking to emergency medical care outside the prison unit in the presence of health problems” (average 3.09) and “Not missing an appointment with the infectologist in the specialized care service” (average 3.23). The indicator “Take to care in other medical specialties when necessary” was classified as unsatisfactory (average 2.43).

Still in vertical integration, five (83.3%) technical directors of health reported that the discussion of cases with HIV reference services occurred by e-mail and in four (66.6%), the discussion was by phone.

With regard to informational continuity, the indicator “Reinforcing the guidance given by the doctor monitoring your HIV treatment” was classified as regular (average 2.64). In this dimension, two (33.3%) technical directors of health reported that correctional officers inform about the procedures performed in specialized HIV services.

Regarding the performance of the different prison units, the indicator “Questioning the regularity of the use of ART” was better evaluated in the UP-C compared to the UP-D. Other indicators showed a statistically significant difference for ANOVA and the Kruskal-Wallis test, although the same did not occur in multiple comparison analyzes (Table 2).

### Discussion

Technical directors of health reported the diagnosis of HIV infection was routine at the time inmates were admitted to the prison system. Undertaking actions to carry out tests for HIV diagnosis within prison units reflects the valorization of international guidelines for controlling the virus spread in prisons, since one of the primary goals established by the UNAIDS was expanding the diagnosis of infection by 2020.(12)

The diagnosis represents one of the stages in the cascade of continuous HIV care and reflects access to health actions and services offered for the prevention and management of infection. International studies indicate that, after the institution of diagnosis, HIV treatment in incarceration has promoted significant improvement in the clinical conditions of inmates due to viral suppression and the link to therapeutic follow-up. This reinforces longitudinality and continuity of care as priority components of the care coordination of HIV/AIDS in the prison system.
Tuberculosis stands out among the HIV-related comorbidities identified. In a study conducted in Africa, although inmates had normal serologic status (T-CD4+ above 500 cells/mm3), the prevalence of TB/HIV co-infection was high. Another highlighted fact is that inmates are key/vulnerable populations for the development of both HIV and TB because of the risk behaviors they adopt, coupled with prison units conditions; overcrowded, with poor ventilation, among others.

As for horizontal integration, three indicators of this dimension were evaluated satisfactorily and show the responsibilities taken over by health teams of prison units regarding the provision of ART to inmates and the collection of tests for their clinical follow-up. The operationalization of these actions in prisons presupposes shared health care in coordination with specialized HIV services, medication dispensing units and the laboratory network.

Actions of surveillance and monitoring of the use of ART were classified as unsatisfactory, except for the indicator “Questioning the regularity of the use of ART”, classified as regular. Such results suggest these activities are not frequent in the dynamics of care provided in prison units, despite efforts to regularly deliver ART to inmates, and show a possible fragmentation of care and the transfer of responsibility to inmates regarding self-care and therapeutic adherence. The self-care should foster users’ autonomy, and have the support, encouragement and motivation of the team.

Regarding actions of monitoring ART use, three prison units reported the supervision of ART intake when inmates went to the wards, performance of monthly checks in prison cells and questioning of subjects. Given the structural limitations of the Brazilian prison system, these actions have specific and unsystematic characteristics in the dynamics of care provided and may go unnoticed by inmates.

Elements classified as unsatisfactory that could contribute to the process of building self-care with the support of prison unit teams are the dissemination and discussion of results of T-CD4+ tests and viral loading with inmates. This would allow the sensitization and empowerment of subjects in relation to clinical conditions and the need of adherence to treatment.

Regarding the composition of teams, 50% of prison units had seven professionals from different categories. However, in relation to the doctor, at the time of data collection, 50% of prison units did not have this professional. An incomplete human resources team interferes with the performance and resolution of prison units as PHC points and is in disagreement with the PNAISP recommendations. This situation and the overcrowding of the studied prison units are elements that generate work overload for the teams and consequently, reflect on the care provided. Thus, the units need to articulate with other points of care, which requires the transport of inmates from the prison unit, the mobilization of correctional officers, a vehicle and a police escort.

In the vertical integration, weaknesses were identified in the articulation with the other points of care and repeated difficulties were faced in the logistics required for transportation outside the prison unit, as also cited in another study. In the integration between prison units and services of the care network, health care implies the cooperation of several actors for the coordination and continuity of care and communication between health and justice/security teams. The technical directors of health indicated weaknesses in the integration between such teams, which compromises the integrality and resolution of care provided, according to the health needs and demands of PDL.

The indicator “Take to care for other medical specialties” was assessed as unsatisfactory because three prison units are located in a small municipality, and their reference institutions for secondary and tertiary care points involve transportation to other municipalities. The access requires availability of spaces, scheduling and multiprofessional integration between health services and public security services. Thus, the importance of assessing the Care Network available in the SUS of municipalities when building new prison units with the aim to guarantee the health access for PDL.

Other obstacles related to referrals include failures in formal communication when PDL are re-
ferred to health services external to prison units in situations of acute HIV.\(^{(21,22)}\) The articulating role of prison units is essential in the care coordination process, with the aim of shared healthcare management put into practice by formal and informal communication mechanisms. Shared information fosters clinical and therapeutic decisions capable of promoting continuity and effectiveness of healthcare\(^4\). In this perspective, correctional officers have a central role as interlocutors of information because they accompany inmates in situations of care outside the prison.

The team should guarantee information continuity by reinforcing the medical guidelines and conduct prescribed during the care provided at the specialized HIV service. However, this indicator was assessed as regular, and possible explanations for the work overload in prison units were the information shortage identified in health records of PDL and the centrality of information in health correctional officers. A study indicated that information continuity and interprofessional communication are precarious because of the lack of computerized medical records.\(^{(11)}\)

Regarding the performance of prison units in the coordination of HIV care, the indicator “Questioning the regularity of ART use” was better evaluated in the UP-C compared to the UP-D. To explain this finding, the UP-C offered full-time care and supervision of medication intake to inmates who sought the health team. Meanwhile, in the UP-D, care was restricted to the afternoon period and monthly checks were performed in prison cells to monitor the medication intake. There is also a greater number of nurses in the UP-C, with the view of a leadership role for this professional, since their skills qualify them for the recognition and embracement of the health needs and demands of PDL living with HIV, thereby contributing to the timely management of cases.

Note that populations of the prison units mentioned above are distinguished by sex, thus, health demands are differentiated and perceived differently by the subjects. There is a trend among female inmates to make comments and criticize health services, such as regarding the lack of a multidisciplinary team and the neglect of individual care.\(^{(23)}\) Women have a more acute self-perception regarding their own health needs and problems,\(^{(24)}\) so the evaluation of care received differs between sexes. In addition to these aspects, in some contexts, there is the invisibility of prisoner women, who end up neglected in relation to their health aspects.\(^{(25,26)}\)

Possible limitations of the study are the sample size, which may have made it impossible to identify differences in performance between prison units regarding variables of care coordination, in addition to possible memory and information biases.

**Conclusion**

The performance of prison units does not differ in relation to most coordination indicators studied. This shows that all units need improvements with regard to the development of actions to monitor the use of ART, inform and discuss test results with inmates and transportation for care outside the prison unit. The composition of human resources staff, the period of service offered by prison health teams, the adoption of different strategies for monitoring ART and the prison population served could explain this finding.

**Collaborations**

Cadamuro ACGA, Andrade RLP, Lopes LM, Neves LAS and Monroe AA contributed to the study design, discussion of data, article writing and approval of the final version of the manuscript. Cadamuro ACGA and Andrade RLP performed data analysis.

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