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Family characteristics of the prison population undergoing palliative care

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Abstract

The growing prison population in Brazil demands health policies aimed at incarcerated individuals, their families, and prison staff. The Penitentiary System Hospital Center launched a multidisciplinary palliative care service in 2015. In 2019, this study was initiated to conduct a descriptive analysis of data obtained from medical record reviews. Patients treated by the palliative care team between January 2018 and October 2019 were included. Sociodemographic data and family ties were analyzed. Most incarcerated individuals were young males with a high rate of estrangement from family relations, caused by incarceration itself, in addition to economic issues and the fragility of pre-existing ties. This study seeks to contribute to future health policies aimed at the incarcerated individuals and their families.

Keywords: Palliative care. Family. Family relations. Prisoners. Substance-related disorders.

Resumo

Características familiares de população privada de liberdade sob cuidados paliativos

O crescimento da população privada de liberdade no Brasil acarreta a necessidade de criar políticas de saúde voltadas a pessoas encarceradas, seus familiares e agentes penitenciários. O Centro Hospitalar do Sistema Penitenciário iniciou um serviço multidisciplinar de cuidados paliativos em 2015. Em 2019, foi iniciado o presente estudo para realizar análise descritiva dos dados obtidos da revisão de prontuários. Foram incluídos pacientes atendidos pela equipe de cuidados paliativos no período de janeiro de 2018 a outubro de 2019. Foram analisados os dados sociodemográficos e os vínculos familiares. Identificou-se o predomínio de população jovem e masculina, com alto índice de afastamento das relações familiares, provocado pela própria condição de privação de liberdade, além de questões econômicas e fragilidade dos vínculos preexistentes. O objetivo deste trabalho é contribuir em futuras políticas de saúde voltadas à população privada de liberdade e suas famílias.

Palavras-chave: Cuidados paliativos. Família. Relações familiares. Prisioneiros. Transtornos relacionados ao uso de substâncias.

Resumen

Características familiares de una población privada de libertad bajo cuidados paliativos

El aumento de la población privada de libertad en Brasil conlleva la necesidad de crear políticas sanitarias dirigidas a las personas encarceladas, sus familias y los agentes penitenciarios. El Centro Hospitalario del Sistema Penitenciario inició un servicio de cuidados paliativos multidisciplinarios en 2015. En 2019 empezó este estudio para realizar un análisis descriptivo de los datos obtenidos de la revisión de las historias clínicas. Se incluyeron pacientes atendidos por el equipo de cuidados paliativos en el período entre enero de 2018 y octubre de 2019. Se analizaron datos sociodemográficos y vínculos familiares. Se identificó el predominio de la población joven y masculina, con un alto índice de distanciamiento de las relaciones familiares provocado por la propia condición de privación de libertad, además de cuestiones económicas y fragilidad de los vínculos preexistentes. Se espera que este trabajo contribuya a futuras políticas sanitarias dirigidas a la población privada de libertad y sus familias.

Palabras clave: Cuidados paliativos. Familia. Relaciones familiares. Prisioneros. Trastornos relacionados con sustancias.

Research

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In 1990, Brazil had approximately 90,000 persons deprived of liberty (PDL). In June 2017, the number of PDL was 726,354 [1]. Therefore, there was a 707% increase in the prison population, while the general population grew by 41% [1]. In response to the continuous and significant increase in the population deprived of liberty in the prison system, the Brazilian State has improved social policies geared toward it. In 1984, the Criminal Enforcement Law [2] was enacted, which established the rights and duties of the convicted, with the objective of social reintegration, listing what is considered the minimum necessary to preserve respect for persons deprived of liberty and their autonomy. For the first time in Brazil, this document mentions health as one of the basic needs to be provided to citizens in situation of deprivation of liberty [3,4].

In 2003, a joint work of the Ministries of Justice and Health concluded the National Health Care Plan for the Prison System (PNSSP) [5], which organized the health care of the prison population in prison units and integrated it into the Brazilian Unified Health System (SUS) [6,7]. In 2014, more in-depth discussions led to the implementation of the National Comprehensive Health Care Policy for Persons Deprived of Liberty in the Prison System (PNAISP) [8], which expanded access to health care for provisionally incarcerated populations and those in a semi-open and open regime, which had not been included in the PNSSP. It also included the population allocated to federal prisons. Health promotion and disease prevention initiatives now included family members of this population group and prison system staff.

Despite the policies instituted, the provision of health care services in the penitentiary system in Brazil is still very precarious, as described by Pinheiro and collaborators [9], who report the situation of PDL in the Pau dos Ferros Regional Penal Complex, in the state of Rio Grande do Norte. In this study, the precariousness of prison facilities is evident, which leads to the occurrence of diseases or the worsening of already weakened health conditions, the lack of human resources in health care (physicians, dentists, nursing teams and pharmacy teams), in addition to the lack of resources for transportation of the most needy for care in external health care institutions. This situation also affects several other Brazilian prisons.

The state of São Paulo, despite representing about 21.6% of the Brazilian population in 2017, was responsible for 31.5% of the PDL that year, with an imprisonment rate of about 508 people for every 100,000 inhabitants [1]. This high rate of imprisonment led the state to launch, in 2009, the Penitentiary System Hospital Center (CHSP) [10]. The CHSP currently has 142 beds in operation, includes four simple inpatient units and a special and semi-intensive care unit with 12 beds. It has a surgical center, a clinical pathology laboratory, a diagnostic imaging sector (with simple radiology and ultrasound) and an outpatient clinic. It serves patients in the areas of medical clinic, cardiology, infectiology, surgery (general, head and neck, proctology, plastic, thoracic and urology surgery), orthopedics, physiatry, gynecology and obstetrics, psychiatry and clinical neurology. It also has a multidisciplinary team, composed of nursing, psychology, social work, occupational therapy, speech therapy, motor and respiratory physiotherapies, pharmacy and nutrition. It is a secondary-size referral center for outpatient care, elective hospitalizations, small and medium-sized surgeries and long-term hospitalizations for all penal institutions in the state.

In January 2015, due to the intense suffering of patients deprived of liberty admitted to the CHSP at an advanced stage of life-threatening diseases and the lack of adequate planning to manage this stage, there was the creation of the Palliative Care Group (PCG). Since then, the PCG, through referral or active search, evaluates, discusses and follows up, in an interconsultation format, patients, their families and the professional caregivers responsible for them in the CHSP.

Over time, the PCG traced characteristics that are peculiar to PDL. The most notable characteristic is family estrangement. People with a disease that threatens the continuity of life have as main caregiver, in general, a closer family member, who constitutes, with the health care team, the core of palliative care. Through communication, the health care team can understand the history of the patient. The family and the patient, in turn, can better understand the disease and its possible evolutions. This joint work aims to establish a health care plan.

Family estrangement or absence requires the team to seek the individual's history through

their own means. This is difficult when there are neurological or oncological diseases that compromise communication. In addition, the fear of dying within the prison system—associated with the hope of receiving humanitarian pardon or sentence progression allowing recovery of freedom—hinders frank conversations about the process of dying. Maschi, Marmo and Han [11], in a literature review published in 2014, report that one of the main barriers to the provision of palliative and end-of-life care in prison is distrust in the relationship between patients and prison staff.

The family also has important functions in the process of penal enforcement, rehabilitation and return of the incarcerated person to community life [12,13]. Visits can be both positive—supporting and helping to cope with the suffering of prison—and negative—worsening the feeling of frustration and guilt of the person deprived of freedom. In positive cases, persons who receive visits exhibit better mental health during the prison period, better adaptation to prison rules [14] and more success in reentering social life, that is, decreased recidivism into crime after release [15]. The number of new convictions after returning to social life tends to be lower when these people are compared with those who did not receive visits or received few visits when incarcerated.

This study aims to trace sociodemographic characteristics of incarcerated people and their families, as well as to quantify the successful contacts and face-to-face meetings with family members. In cases of non-occurrence of family meeting, an attempt is made to understand the reasons for the failure. The expectation is to enrich the discussion on the quality of familial relationships and help in the design of social policies with a view to fostering the rapprochement of persons deprived of liberty with their loved ones.

Method

Descriptive statistical analysis of the data obtained from the review of medical and social records. Patients treated by the PCG between January 2018 and October 2019 and who died in the CHSP during follow-up were included. Patients who were discharged from hospital for return to prison or by release permit and/or those whose guardian did not authorize the use of data for the project were excluded.

To request authorization from those responsible for the patients, the research ethics committee (REC) of the ABC Foundation required at least two attempts at telephone contact. Data collection from those responsible for the patients was performed by the PCG social worker, based on social records. The contact was conducted by the authors of this study. In cases of unsuccessful contacts, the ethics committee waived the consent form.

We collected the following data: name and telephone number of the family member/guardian of the person deprived of liberty contained in the social record; age and gender of the incarcerated person; degree of kinship or relationship of the family member/guardian with the person deprived of liberty and their gender; number of incarcerated people with a history of psychoactive substance abuse. Family members/guardians who were contacted were asked how many were able to organize for a family meeting at CHSP and what were the alleged reasons for not attending a meeting.

All collected data were transferred to an Excel spreadsheet accessed exclusively by Paulo Cintra Antonacio. Data such as name, medical record number, date of birth and dates of hospitalization and death were omitted in the submission of this research, to prevent the identification of patients and guardians. Only the data necessary for the study are included.

Results and discussion

Between January 2018 and October 2019, 54 patients were treated by the PCG at CHSP. Of these, 13 were discharged from hospital. Other 41 patients died at the institution and were eligible for the study. The author conducted, between March 15 and 30, 2022, two attempts to make telephone contact with those responsible for the patients, as recommended by the ABC Foundation REC. Only five replied, of which two refused to participate in the study. Therefore, in total, we analyzed the medical records of 39 patients who met the inclusion criteria, given the waiver of informed consent by the REC in cases where there was no contact after two attempts.

Of the 39 people, 36 (92.3%) were men and 3 (7.7%) were women. The mean age was 51 years for men, ranging from 25 to 76 years, and 53 years for women, ranging from 41 to 66. The higher mean age and prevalence of males are distinct characteristics of this population when compared with those served by other palliative care services in medium-complexity community hospitals in Brazil. Marcucci and collaborators [16], when reporting the implementation of the palliative care service at the State Hospital Dr. Anísio Figueiredo, in Londrina, Paraná, between May 2016 and April 2017, found that, of the 129 patients followed, 57% were women and with a mean age of 80 years. Bravalhieri and collaborators [17] analyzed the data of patients followed by the palliative care group in the long-term care unit of Hospital São Julião, in Campo Grande, Mato Grosso do Sul, between April 2017 and April 2018 and found, in the 31 medical records evaluated, a mostly female population (55%), with a mean age of 79 years.

The predominance of males in patients treated by the PCG in the CHSP is a reflection of the PDL of the state of São Paulo, which, in 2017, was composed of 94.5% men and 5.5% women [1]. The lower average age is probably related to the finding, in American prisons, that PDL are weaker than their peers in age and gender, in the community, due to poor health care since childhood, exposure to cigarettes, alcohol and illicit psychoactive substances from a very early age and exposure to unsafe sex [18,19]. It is interesting to note the similarity of the mean age and gender distribution between the population under palliative care at CHSP and the PDL studied by Pazart and collaborators [20] in France, between 2011 and 2013, composed of 94% men, with 54 years mean age. Similar results were found by Rothman and collaborators [21] in California, USA, between 2009 and 2013: 93% of the PDL under palliative care were men and the mean age was 55 years.

The social service was able to contact 34 guardians at the time of hospitalization (87.1%), composed of 33 family members and 1 religious woman who worked with homeless persons; it was not possible to locate five guardians (Table 1). After the 34 initial contacts, we held 23 face-to-face meetings (58.9% of all 39 inpatients).

Table 1. Contact with family members/guardians at the beginning of hospitalization

Contact obtained	n	%
Yes	34	87%
No	5	13%
Total	39	100%

The family reunion process begins when the patient is admitted to the CHSP. The social service contacts all those who are hospitalized and, through the social anamnesis, identifies their family members, the people who are authorized to visit them (list of visits) and the person the inmate deems responsible for maintaining contact with the team about their hospitalization period. When, for some clinical reason, the patient is not able to provide this information, it is searched in the history of previous hospitalizations. In case there is no previous admission to the CHSP, such information is requested from the prison unit of origin. If it is still unavailable, the social service temporarily stops the searches. In situations where the guardians are located, the social service contacts them to inform about the hospitalization. In the most severe cases or when under palliative care, an in-person meeting at the CHSP is requested. The entire process is recorded in the social record.

In these meetings, hospitalized people are listened to regarding their life story and relationships with family members and friends, struggles and conflicts, beliefs and wills manifested. Then, there is explanation of the clinical and emotional situation of the patient, their complexity and the probability of dying due to the current pathology. They try to clarify the doubts arising from the conversation and support family members in their emotions. Then, the care to be provided in the possible scenarios discussed is planned. The literature review of Pazart and collaborators [22] noted the frequency of contact with family members of patients under palliative care, which was around 50%, but it was not reported whether the contacts were in person or not.

Regarding the degree of kinship of the person responsible for the incarcerated person, most were sisters or brothers (12, or 35.2%)

and wives or ex-wives (11, or 32.3%) (Table 2). Their children were those responsible for them in six cases (17.6%), while fathers, stepfathers or mothers were responsible in three cases (8.3%). There was a case of a niece assuming the role of responsible for the hospitalized patient and another case of contact with a religious woman who had worked with the patient when he was homeless.

Table 2. Degree of kinship and gender of family members/guardians

Degree of kinship	n	%
Sister	8	
Wife, mistress or ex-wife	11	
Mother	1	
Daughter	4	
Niece	1	
Religious caregiver of homeless persons	1	
Total responsible women	**26**	**76.5%**
Brother	4	
Father or stepfather	2	
Son	2	
Total responsible men	**8**	**23.5%**
Total responsible men and women	**34**	**100.0%**

According to the study data, most of the time, the role of responsible for the incarcerated person under palliative care at the CHSP was assumed by a female figure (26 women, or 76.5%). Something similar occurs in the non-penitentiary community environment. Melo, Rodrigues and Schmidt [22], from the palliative care team of the Home Care System of Londrina, Paraná, when analyzing the population of caregivers between January and July 2008, found that, of the 35 respondents, 30 were women (85.7%). In another study, carried out in the city of São Paulo in the late 2016, Montenegro [23] found that 20 of the 24 caregivers were women (83.3%). These two studies found the overload of women, who, in general, were aged over 50 years and assumed multiple functions in addition to that of caregiver. Montenegro [23] emphasizes the naturalization of assigning the task of care for a female relative, which seems to result from the culture according to which domestic work is the duty of women. With their participation in the labor market and the consequent accumulation of tasks, women have been subjected to double or triple shifts, when they work in two places and also have to take care of a family member, whether older adults or children. Espíndola and collaborators [24], in a literature review on family relationships in the context of palliative care, assert this situation and its impact on the physical, emotional and financial health of women.

The analysis of medical records enabled observing the reasons for the non-attendance to the family meeting of 11 of the 34 family members contacted when the patient was hospitalized. The reasons alleged by the guardians are described in Table 3, with financial difficulty being the main cause (45.4%). Difficulty in being absent from work without loss of income and/or bearing the costs of transportation to the CHSP were the most mentioned reasons. This result is consistent with the origin of the incarcerated people, from the most deprived strata of the Brazilian population. The 2017 Infopen [1], statistical information system of the Brazilian prison system, shows that 61% of the PDL are either illiterate or functionally literate or with incomplete elementary education, in contrast to Brazil as a whole, since these three profiles represent 40% of the total population.

Table 3. Alleged reasons for not attending the family meeting

Alleged reasons	n	%
Financial difficulty	5	45.4%
Unwillingness	3	27.3%
No explanation	2	18.2%
Impaired health	1	9.1%
Total	**11**	**100%**

The second most alleged reason for not attending the CHSP was unwillingness to do so (27.3%), which explicitly demonstrates the emotional estrangement between family members. A likely explanation for that is the high incidence of psychoactive substance abuse

within this group of patients. According to the CHSP admission anamnesis, of the 39 patients interviewed, 21 reported abuse of alcohol or other illicit substance, while 8 denied it. Other ten patients were either not questioned or unable to provide the information. This means that at least 53.8% of the total patients (21 of the 39) reported a history of abusive use of psychoactive substances, both legal, such as alcohol, and illicit, such as marijuana, cocaine, crack cocaine and others. For comparison with Brazil in general, the *III National Survey on Drug Use by the Brazilian Population* (III LNUD) [25], of 2017, found that 2.2% of the Brazilian population aged over 12 years exhibited chemical dependency criteria for alcohol or other psychoactive substances. This comparison shows the strong relation of PDL with the abusive consumption of these substances.

Nimtz and collaborators [26], in a study based on interviews with drug addicts in a rehabilitation unit in Paraná, in 2012, showed the negative effect of dependency on familial relationships, due to leading to numerous conflicts, material losses, broken bonds of trust, and marital separations. The emotional estrangement is possibly also related to the type of crime committed by the incarcerated person, especially in cases of intrafamily violence; however, this hypothesis was not analyzed in the present study. In two cases, the reasons for not attending the meeting with the PCG were not explained. In one case, a health-related reason was alleged.

Final considerations

Considering the above, it was found that the PDL hospitalized under palliative care in the CHSP between January 2018 and October 2019 are predominantly male and younger than similar populations in a community setting. The characteristics found in the CHSP are similar to those found in other PCGs serving PDL in countries such as France and the USA. It was found that women—as in the community setting in general—are primarily responsible for the care of family members; this situation results from a dogma rooted in Brazilian culture and that needs to be discussed continuously, as the burden on women is unequal. In the case of family members of incarcerated people, the prejudice of this stigma is an additional factor.

It was also observed that the family relationships studied are weakened, as shown by the low rate of family meetings held. The causes seem to be related to multiple factors, including: the origin of this population in very needy communities, which makes visits difficult, and the abuse of psychoactive substances, which can cause emotional estrangement and break ties between relatives. Health problems of family members/guardians also contribute to the estrangement. There are other factors, such as the type of crime related to the imprisonment, which may have been perpetrated against the family members themselves and, thus, may partially justify the estrangement; however, these factors were not analyzed in this study.

Family estrangement and absence hinder the provision of palliative care services, since, in this approach, people close to the patient are fundamental in emotional support and in the provision of information about the patient's life story and desires, as well as about possible advance directives and living wills.

The main limitations of this study are related to the type of data collection from medical records review. Data such as on substance abuse were not obtained upon admission to the CHSP in some cases, which made it difficult to analyze the situation. The causes for family estrangement can be further researched in new prospective studies, due to the limitations of the present method. Moreover, this is an analysis of a small sample of the prison population in the state of São Paulo, which prevents a safe extrapolation of the conclusions to the prison population as a whole.

Still, the study shows the importance of obtaining the patients' complete social history upon admission, in order to find their possible preserved ties and the main support network. The active search and initial approach to people related to the PDL are fundamental starting from the initial incarceration period in order to keep them close to the PDL, as well as to rebuild broken ties with psychological and social support. Keeping the contact phone numbers and addresses of more than one family member or supporter is essential for successful contacts.

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Participation of the authors

Paulo Cintra Antonacio was responsible for the conception and design of the research, data collection and processing, data analysis and interpretation, and preparation of the final text. Vivian Romanholi-Cória was responsible for guiding the study, analyzing and interpreting the data, and preparing and reviewing the final text.

Data availability: All data used or generated in this study are described and presented in full in the body of the article.

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Research