Maternal deaths and deaths of women of childbearing age in the indigenous population, Pernambuco, Brazil, 2006-2012*

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Abstract

Objective: to describe maternal deaths and deaths of women of childbearing age in the indigenous population in the state of Pernambuco, Brazil, from 2006 to 2012. **Method:** this is a descriptive study based on linkage of data from the Mortality Information System (SIM) and its investigation module (SIM-Web); causes of death were considered in accordance with the International Statistical Classification of Diseases and Health Related Problems – 10th Revision (ICD-10). **Results:** linkage provided a database comprised of 115 records, of which only 58.3% were recorded on SIM as indigenous; the main causes of death were diseases of the circulatory system (27.0%), external causes (14.8%), neoplasms (13.0%), and maternal factors (8.7%). **Conclusion:** deaths of indigenous women of childbearing age were underreported; the main cause of these deaths were diseases of the circulatory system, although maternal deaths still represent an important cause of death in the population studied.

Keywords: Maternal Death; Women's Health; Indigenous Population; Information System.

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Introduction

In recent decades, the growth rate of the Brazilian indigenous population has been increasing above the national average. The indigenous population is spread over urban and rural areas, and it has different social-cultural, historical, political and economic characteristics. Its demographic dynamics are gradually becoming known, although available data are still not enough to be able to build an epidemiological profile.[1,2]

> *Information about indigenous mortality is more incomplete when compared to that of the general population, due to low quality information systems, lack of regular surveys and scarce investigations.*

Until the late 1990s, management of indigenous peoples' health was disputed between the National Indigenous Foundation (FUNAI) and the National Health Foundation (FUNASA). But on September 23rd 1999, the Indigenous Health Care Subsystem was instituted through Law No. 9,836 (known as the Arouca Law), with the objective of indigenous healthcare working in articulation with the Brazilian National Health System (SUS). As such, the strategic reference for SUS action, namely being decentralized, tiered and regionalized, should guarantee indigenous peoples' access to health services, while taking into consideration local reality and their cultural specificities. With effect from 1999, the care model for indigenous peoples' health care has been that of local health systems: namely the Special Indigenous Health Districts (DSEI).[3]

There are 34 DSEIs operating in Brazil, strategically located according to the indigenous communities' geographical distribution in the country.[4,5] The Pernambuco DSEI comprises 15 municipalities where the following ethnic groups are found: Atikum, Funil-ô, Kambiwá, Kapinawá, Pankará, Pankararu, Pipipan, Truká, Tuxá e Xukuru.[5]
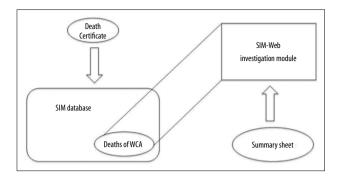
Despite the Ministry of Health's efforts to operationalize the Indigenous Health Care Subsystem, indigenous women's health care faces problems related to the availability of primary care services, such as prenatal care and disease prevention. In addition, epidemiological information to assist evaluation of the health situation of indigenous women and planning health actions for them is precarious.[6]

In 2012, nationwide, 16.0% of female deaths occurred in the 10-49 years age group, these being classified as deaths of women of childbearing age (WCA).[7] When cause of death cause is related to the pregnancy-puerperal period, these deaths – which are preventable in 92.0% of cases – are defined as maternal deaths and characterized as a human rights violation;[8] 99.0% of them occur in poorer regions and/or regions with higher levels of inequality. That is why maternal death indicators are important instruments for evaluating the living and health conditions of a population.[8]

The coverage of the Mortality Information System (SIM) in Brazil is estimated to be 93.0% and this is considered adequate by the Ministry of Health.[9] The standard document used to collect information on mortality for this System is the Death Certificate (DC).[10] Despite SIM's satisfactory coverage, it is estimated that maternal deaths are underreported in a proportion of up to 20%.[11] The surveillance of deaths of WCA and maternal deaths, regulated by Health Ministry Ordinance GM/MS No. 1,119, dated 5 June 2008, establishes compulsory investigation of these events, regardless of the causa mortis. Since then, the monitoring of investigations and discussions on the theme have been done using the SIM investigation module: SIM-Web (Figure 1).[12]

Information about indigenous mortality is more incomplete when compared to that of the general population, due to low quality information systems, lack of regular surveys and scarce investigations.[13] According to FUNASA, there are no reliable global data on the Brazilian indigenous people's health situation. Even though they are incomplete, the numbers show morbimortality coefficients in indigenous people up to four times higher than those identified in the rest of the population. The high frequency of unrecorded deaths or deaths with undefined underlying causes corroborates the low coverage and low resolubility of available services.[1,14]

In relation to information on the indigenous population's health, the Indigenous Health Care Information System (SIASI) was developed jointly with the implementation of the Indigenous Health Care Subsystem. Structured in eight modules (demography, morbidity; immunization; oral health; nutrition; pregnancy monitoring; human

Legend:
SIM: Mortality Information System.
WCA: women of childbearing age.

Figure 1 – Operational diagram of the SIM-Web investigation module

resources; infrastructure; and sanitation), SIASI was simultaneously decentralized to the DSEIs as of the year 2000.[15,16]

Information held on SIASI should help to build indicators that allow analysis of the situation of indigenous people's health. However, difficulties in its operationalization have resulted in the system not providing health teams with consistent information on the necessities and peculiarities of the indigenous population, hindering the construction of reliable health indicators and hindering health manager decision-making.[15,17]

SIASI does not have important variables that enable satisfactory epidemiological analysis to be performed. This compromises the evaluation of this population's health situation. Furthermore, the system works in parallel to the Ministry of Health's official information systems, including SIM. This latter system obtains indigenous death data from the ethnicity/skin color variable informed on the Death Certificate, thus demonstrating the lack of articulation between the two systems.[17]

The ethnicity/skin color variable became part of the mortality statistics with effect from 1996, approximately ten years after SIM's implementation. However, it was only in 2000, when recording quality improved, that the Ministry started to use it to build indicators to analyze risk of death according to ethnicity/race.[18]

The objective of this study was to describe the deaths of women of childbearing age and maternal deaths among indigenous people in the Brazilian state of Pernambuco, in the period 2006-2012.

Methods

This is a descriptive study of WCA deaths and maternal deaths in the indigenous population in the state of Pernambuco, Brazil.

According to the 2010 population census, Pernambuco had a population of 8,796,448 inhabitants and had the fourth largest self-declared indigenous population (53,284 people). Pesqueira was the municipality with the 7th largest indigenous population, while the state capital Recife was the city with the 10th largest indigenous population in an urban area.[19]

The study population, obtained through secondary data, is comprised of WCA deaths occurred between 2006 and 2012, reported on SIM, when field 17 of the DC (ethnicity/skin color variable) was filled in as "indigenous". The deaths of those whose ethnicity/skin color were underreported on SIM were also included, i.e. those which did not have field 17 filled in as "indigenous"; to this end, these deaths were investigated by DSEI investigation and qualified by SIM-Web as deaths of indigenous village women.

DSEI is a decentralized Indigenous Health Care Subsystem management unit. Its mission consists of developing technical, administrative and management activities for the health care of a specific population, with particular ethnic-cultural and geographic characteristics, in a precisely delimited geographic space. DSEI is responsible for the primary health care of the indigenous village population, by means of the Indigenous Health Multidisciplinary Teams (IHMT), composed of doctors, nurses, dentists, nursing auxiliaries, and indigenous health agents (IHA),
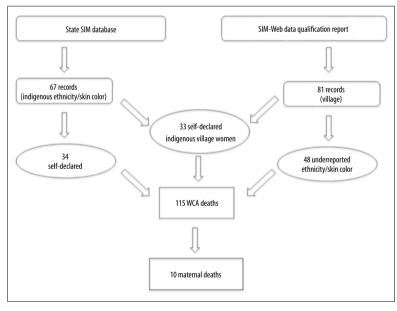
similar to the Family Health Strategy (FHS) team. DSEI operation should be integrated and tiered according to the level of complexity of health care and articulated with SUS.[4,2]

In Pernambuco, DSEI is organized into 12 base-units responsible for administrating a population of 49,454 indigenous village people in 245 villages.[20] DSEI comprises 15 municipalities and has a Indigenous Health Support House (CASAI) located in Camaragibe, besides two advanced units (in Salgueiro and Caruaru). Cases needing more complex care are referred to services in Recife, Petrolina, Serra Talhada, Arcoverde and Vitória de Santo Antão.

Provided by the Ministry of Health and its Special Indigenous Health Secretariat (SESAI), SIM-Web has served the Pernambuco DSEI since 2014; it enables enhancement of information on WCA deaths and maternal deaths in the population whose health is under DSEI's sanitary responsibility. Through SIM-Web it is possible to complement data referring to ethnicity/skin color and add other information not included on the DC. Information added after the investigation and qualification of these data are restricted to SIM-Web and are not transferred to the SIM database, so that this data remains underreported on SIM.

The final study population was obtained through linkage of records notified on SIM and its SIM-Web module. The linkage technique consists of pairing databases, based on a common variable, thus enabling the establishment of a single database.[21] In this study, the common variable used was the DC number. Using this number, the Pernambuco state SIM database containing WCA death records with DC field 17 filled in as "indigenous", was paired with the WCA deaths database qualified on SIM-Web by DSEI. We built a single database containing 115 WCA death records, according to the following stages (Figure 2):

a) On the Pernambuco state SIM database we identified 67 records of WCA deaths with field 17 filled in as "indigenous".

b) In parallel, we obtained 81 records of WCA deaths among indigenous village women from SIM-Web based on data qualified by DSEI,

c) These 81 records contained on the SIM-Web report were also identified on the Pernambuco state SIM database.

d) We identified that 33 records were common to both databases, i.e. with DC field 17 filled in as "indigenous" and qualified on SIM-Web by DSEI. They were self-declared indigenous village women whose health was under DSEI's responsibility.

Legend:
SIM: Mortality Information System.

Figure 2 – Women of childbearing age database development flowchart (WCA)

e) There were 48 records on the SIM-Web report for which the ethnicity/skin color field was underreported on SIM, i.e. DC field 17 was not filled in or it was filled in incorrectly. With regard to the records held on SIM, 34 related to deaths of WCA whose health was not under DSEI's responsibility, although they declared their ethnicity/skin color to be indigenous (non village).

Considering both databases we identified 10 maternal deaths.

We used Microsoft Office Excel 2007 to match the databases.

Causes of death were analyzed using as our reference underlying cause of death as per the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). For explanatory purposes, the group "other causes" referred to ICD-10 chapters III, V, VI, XI, XIII, XIV and XVII , the absolute frequencies of which did not exceed three deaths during the period studied.

The research project was submitted to and approved by the Federal University of Pernambuco Health Science Center Research Ethics Committee, and also by the National Committee for Ethics in Research – Certification of Submission for Ethical Appraisal (CAAE) No. 37649214.0.0000.5208 –, being in accordance with the principles of National Health Council (CNS) Resolution No. 466, dated 12 December 2012. The project was also presented and approved at a meeting of the Pernambuco Indigenous Health District Council (CONDISI).

Results

Among the 115 deaths of WCA of indigenous ethnicity/skin color, 70.4% related to the population of village women. Only 58.3% of these deaths were informed on SIM as being of indigenous people. Linkage of the two information systems provided the study database with a further 41.7% of deaths not initially reported as being of indigenous ethnicity/skin color. In 27.8% of cases, the inconsistency lay in incorrect recording of brown ethnicity/skin color, to the detriment of indigenous ethnicity/skin color (Table 1).

After analyzing death distribution by age group, we observed that 41% of them fell into the 40-49 age range. The intermediate groups, namely 20-29 and 30-39 years, had approximate proportions of 20.0% and 25.2%,

respectively. The youngest group age, 10-19 years, had a smaller proportion of deaths: 13.0% (Table 1).

The low schooling level of the population was evident, with 23.5% of women with no schooling and no records found in the category "more than 12 years of schooling". A slight majority worked in activities related to agriculture (53.1%) and 11.3% were housewives. Regarding marital status, 52% were single and 38.3% were married (Table 1).

Most of the deaths occurred in hospital units (54.8%), followed by 33.9% at home. In 45.2% of cases, people were not in their municipality of residence when they died. Most deaths occurred in Recife (44.2%), followed by Petrolina (11.5%), Salgueiro (9.6%) and Caruaru (7.7%) (Figure 3).

Circulatory system diseases (ICD-10 Chapter IX: codes I00 to I99) were the main underlying cause of death (27.0%). External causes (Chapter XX: V01-Y98) accounted for the second largest proportion of deaths (14.8%). Neoplasms (Chapter II: C00-D48) represented 13.0% of deaths, followed by maternal causes, complications during pregnancy, childbirth and puerperium (Chapter XV: O00-O99), accounting for 8.7% of deaths.

In the group of circulatory system diseases (N=31), the largest number of deaths were caused by ischemic heart diseases (11), particularly due to acute myocardial infarction. Among the cerebrovascular diseases (10), cerebrovascular accident (stroke) was the most frequent cause. There was equal distribution (4) between hypertensive diseases and other heart diseases, specially dilated cardiomyopathy (Table 2).

In the external causes group (N=17), six deaths were caused by assault, five by transport accidents, four by intentional self-harm injuries and two by other accidental injuries with external causes (Table 2).

In the neoplasm group (N=15), malignant neoplasms of the cervix were the main underlying cause of death (5). Malignant neoplasms of the lymphoid, hematopoietic and related tissues (leukemia) and malignant neoplasms of ill-defined sites, secondary and unspecified sites accounted for two deaths each (Table 2).

Maternal causes were responsible for ten deaths, three of which were caused by respiratory system diseases that complicated pregnancy, childbirth and puerperium. Placental abruption and uterine contraction anomalies accounted for maternal deaths from hemorrhaging (2). The other underlying causes were homogenous (1) (Table 2).

Table 1 – Proportional distribution of deaths of indigenous women of childbearing age according to sociodemographic characteristics, Pernambuco, 2006-2012

Variables	N (n=115)	%
Age group (in years)		
10-19	15	13.0
20-29	23	20.0
30-39	29	25.2
40-49	48	41.8
Ethnicity/skin color		
White	5	4.3
Black	8	7.0
Brown	32	27.8
Indigenous	67	58.3
Unkown/not informed	3	2.6
Education level (in years of schooling)		
None	27	23.5
1-3	25	21.7
4-7	24	20.9
8-11	8	7.0
Unknown/not informed	31	26.9
Occupation		
Self-employed worker	1	0.9
Agriculture worker	61	53.1
Student	5	4.3
Housewife	13	11.3
Retired/pensioner	5	4.3
Unknown/not informed	30	26.1
Marital status		
Single	60	52.2
Married	44	38.3
Widowed	2	1.7
Cohabitation	2	1.7
Unknown/not informed	7	6.1

Discussion

The results of this study contribute to knowledge about mortality of indigenous women of childbearing age in the Brazilian state of Pernambuco. This is an unprecedented study. As at the date of the conclusion of this article, there were no studies demonstrating the dynamics of diseases and health conditions in this group, despite the small number of deaths described in the time series.

Most of the deaths studied corresponded to indigenous village women whose ethnicity/skin color was underreported. Regarding deaths of WCA whose health was under DSEI's responsibility, the ethnicity/skin color variable was incorrectly informed for more than half of them. These results reveal the degree of underreporting of this variable in the population that is known to be indigenous. This reaffirms the low quality of information available on this population.
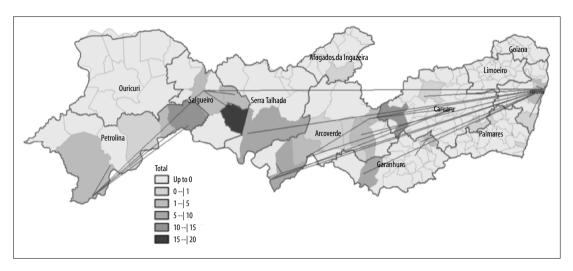
Figure 3 – Flow chart with distribution of deaths of indigenous women of childbearing age, according to municipality of occurrence of death compared to municipality of origin-residence, Pernambuco, 2006-2012

Education level, as in other studies,[7,22] had higher a proportion of data incompleteness, possibly because of the fact that this information is not generally found on hospital medical records, given that most deaths occurred in hospital. Low schooling was evident: only a small part of the population studied had 8 to 11 years of schooling.

In relation to the "occupation" variable, most of the women worked in agriculture. This finding can be associated with cultural issues, or with the form of subsistence proper to this population, which mostly lives in rural areas or urban agglomerations of small municipalities in the inner regions of the state.[23]

In relation to the municipality where death occurred, we observed flows similar to those described by Rohr et al.:[24] indigenous women having to leave their municipality of residence in search of health care when they died. DSEI guarantees Primary Health Care for this population near to their villages, whereas part of the traveling to other locations identified in this study was explained by the need for medium and high complexity health care which is not locally available. The municipalities with more deaths were those that have advanced units and referral services for more complex cases coming from DSEI.

Mortality indicators can express how ethnical and racial differences may lead to inequalities in access to health services. Although it is necessary to aggregate elements of this population's cultural specificity, this study observed that 33.9% of deaths occurred at home. This result may also mean the existence of difficulties in accessing emergency and/or specialized health care.

Analysis of schooling, occupation, location and municipality in which death occurred may reveal similarities between the indigenous and rural populations in Pernambuco. The poor socioeconomic situation and poor working conditions, long distances between home and health services and the precariousness of local services are some factors that can influence these women's vulnerability, thus determining difficulties in accessing health care.[6] Indigenous people in Northeast Brazil live in a manner integrated with the regional environment, where living or even interbreeding with the general population has possibly resulted in partial loss of traditional elements. This is confirmed in part when studying deaths of indigenous WCA and maternal deaths, especially in relation to the female rural population.[25]

When Ferreira et al.[26] compared mortality indicators between the indigenous population and the general population of the Brazilian state of Mato Grosso do Sul, they suggested that these populations were at different stages of epidemiological transition. In Pernambuco, the indigenous WCA population is also seen to be at a different stage in this transition, when compared to the WCA population in the state as a whole.

When we analyzed the main groups of cause of death within circulatory system diseases, ischemic

Table 2 – Proportional distribution of deaths of indigenous women of childbearing age according to main groups of underlying causes of death, as per ICD-10,a Pernambuco, 2006-2012

Underlying cause groups	N	ICD-10[a]
Circulatory system diseases (Chapter IX of ICD-10a) (n=31)		
Chronic rheumatic heart diseases	1	I05-I09
Hypertensive diseases	4	I10-I15
Ischemic heart diseases	11	I20-I25
Other heart diseases	4	I30-I52
Cerebrovascular diseases	10	I60-I69
Arteries, arterioles and capillaries diseases	1	I70-I79
External causes (Chapter XX of ICD-10a) (n=17)		
Traffic accidents	5	V00-V99
Other external causes of accidental	2	W00-X59
Intentional self-harm injuries	4	X60-X84
Assault	6	X85-Y09
Neoplasms (Chapter II of ICD-10a) (n=15)		
Malignant neoplasms of the respiratory and intrathoracic organs	1	C30-C39
Malignant neoplasms of the bones and articular cartilages	1	C40-C41
Melanoma and other malignant neoplasms of the skin	1	C43-C44
Malignant neoplasm of breast	1	C50
Malignant neoplasm of vulva	1	C51
Malignant neoplasm of the uterine cervix	5	C53
Malignant neoplasms of ill-defined sites, secondary and unspecified sites	2	C76-C80
Malignant neoplasms of the lymphoid, hematopoietic and related tissues	2	C81-C96
Benign neoplasms	1	D10-D36
Maternal causes – complications during pregnancy, childbirth and puerperium (Chapter XV of ICD-10a) (n=10)		
Unspecified eclampsia	1	O15
Placental abruption	1	O45
Uterine contraction anomalies	1	O62
Puerperal sepsis	1	O85
Venous complications in the puerperium	1	O87
CSD[b] complicating pregnancy, childbirth and puerperium	1	O99.4
RSD[c] complicating pregnancy, childbirth and puerperium	3	O99.5
DSD[d] complicating pregnancy, childbirth and puerperium	1	O99.6

a) ICD-10: International Statistical Classification of Diseases and Related Health Problems– 10th revision.
b) CSD: circulatory system diseases.
c) RSD: respiratory system diseases.
d) DSD: digestive system diseases.

heart diseases and cerebrovascular diseases (acute myocardial infarction and cerebrovascular accident) stood out: together, these causes accounted for more than half of WCA deaths from circulatory system diseases, similar to the results found by Albuquerque et al.[27] in their study about the city of Recife.

Among the external causes of death, assault and traffic accidents accounted for more than half of the deaths. Although in the 1990s external causes were the third cause of WCA deaths in Recife, 64.1% of these deaths were caused by assault and traffic accidents,[27] similar to the proportion found in this study.

The increase in external causes may be related to the way of life in urban areas. Although the majority of indigenous women in Pernambuco who died in the period studied lived in villages mostly located in rural areas, some of them were directly affected by urban conditions. An example is this is the Fulni-ô ethnic group which forms a neighborhood in the city of Águas Belas.

With effect from the 1990s, neoplasms have been the leading cause of death of WCA.[7,27] However, among the indigenous WCA studied, neoplasms were the third cause of death. Scenarios in which deaths from neoplasms are proportionally lower than deaths from circulatory system diseases and deaths from external causes, common in less developed regions, may reflect different stages of epidemiological transition.[26]

Cervical cancer has been pointed out as a Public Health problem among the North American indigenous population.[28] In our study, deaths caused by malignant neoplasms of the cervix surpassed other primary tumor sites.

Maternal causes, in turn, accounted for 8.7% of the deaths of indigenous WCA. In 2005, 2.5% of WCA deaths were related to the pregnancy-puerperium period in Brazil as a whole; in the state of Pernambuco, between 2004 and 2006, this percentage did not exceed 3.1%.[7,28] Considering these data, the proportion of maternal deaths in the indigenous population is high when compared to general population. This finding corroborates the idea that this group is at a prior stage of epidemiological transition, and that maternal and child health care is still insufficient to respond to its illness pattern.

Sociodemographic issues, associated with the low quality of health services offered to the indigenous population, may hinder access to exams to prevent, diagnose and treat diseases.[6] Sociodemographic characteristics point to the vulnerability of the indigenous population, having a direct influence on self-perception of the need for health care and the consequent seeking of health services. This is identified by the high proportion of deaths at home, these being predictors of deaths with no medical care.

It is also identified by the high proportion of malignant neoplasms of the cervix, as this fact indicates late diagnosis of the disease.

Underreporting of ethnicity/skin color on the specific DC field hampers the construction of a mortality profile and the calculation of health indicators specific to the indigenous population. Efforts by the Ministry of Health and by the Special Indigenous Health Secretariat to add variables to the DC in order to identify the indigenous population on SIM are still incipient. Qualification of the ethnicity/skin color variable on SIM-Web is essential for knowledge about indigenous deaths. However, consideration should be given to the need to include on the SIM database information retrieved following death investigation. Moreover, SIM-Web is available only for deaths of WCA and maternal, child and fetal deaths, so that data on all other indigenous deaths remain unknown.

The importance of this study lies, above all, in the possibility of using SIM-Web, notwithstanding other strategies. Using SIM-Web provides information not originally recorded on SIM, including (indigenous) ethnicity/skin color. Identification of deaths of indigenous women of childbearing age and indigenous maternal deaths underreported on the Mortality Information System is essential for knowing how these women die, as well as for informing specific health public policies adapted to the reality of indigenous peoples.

Authors' contributions

Estima NM participated in the conception and design of the study, data analysis and interpretation, reviewing the literature, discussion of results and writing and revising the manuscript's final version. Alves SV participated in the conception and design of the study, work orientation and critical review of the manuscript's intellectual content and final version. Both authors declare that they are responsible for all aspects of the study, ensuring its accuracy and integrity.

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