# Reflection on moral issues in the relation between indigenous people and health services

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**Abstract**

Medical systems are culturally adapted and may have negative impacts on those that do not share these bases. We discussed the indigenous perspective on moral issues in the relation with health services in the region of Alto Rio Negro/Amazonas/Brazil. It was a qualitative research that used participant observation and interviews in two communities in the region of Alto Rio Negro as techniques. The transfer to health services in urban areas was identified as the main moral issue for the Indians in the region. The diversity of traditions, cultures and values of the indigenous people influence their morality and clinical decisions to be made, what used to be little understood by health professionals. In the relationship between health professionals and indigenous users it was clear the shock between different habits and the configuration of a relation between moral strangers. These facts hinder the dialogue to solve conflicts.

**Key words:** Health of indigenous people. Ethics, clinical. Bioethics. Northwest Amazon.

**Resumo**

**Reflexões sobre questões morais na relação de indígenas com os serviços de saúde**

Os sistemas médicos são culturalmente moldados e podem ter impactos negativos naqueles que não compartilham essas bases. Discutimos a perspectiva indígena de questões morais na relação com os serviços de saúde na região do Alto Rio Negro/Amazonas/Brasil. Trata-se de pesquisa qualitativa que utilizou como técnicas a observação participante e entrevistas em duas comunidades na região do Alto Rio Negro. A transferência para serviços de saúde em área urbana foi identificada como a principal questão moral para os indígenas na região. A diversidade de tradições, culturas e valores dos povos indígenas influenciam na sua moralidade e tomada de decisões clínicas, que eram pouco compreendidas pelos profissionais de saúde. Na relação entre profissionais de saúde e usuários indígenas ficou evidente o choque entre *habitus* distintos e a configuração de uma relação entre estranhos morais. Essas condições dificultam o diálogo para a resolução de conflitos.

**Palavras-chave:** Saúde de populações indígenas. Ética clínica. Bioética. Noroeste amazônico.

**Resumen**

**Reflexiones sobre cuestiones morales en la relación de indígenas con los servicios de salud**

Los sistemas médicos son culturalmente moldeados y pueden tener impactos negativos en los que no comparten estas bases. Se discute la perspectiva indígena de cuestiones morales en la relación con los servicios de salud en la región del Alto Rio Negro/Amazonas/Brasil. Fue un estudio cualitativo que utiliza las técnicas de la observación participante y entrevistas en dos comunidades de la región del Alto Rio Negro. La transferencia para servicios de salud en zona urbana fue identificada como la principal cuestión moral para los indios de la región. La diversidad de tradiciones, culturas y valores de los pueblos indígenas tienen influencia en su moralidad y la toma de decisiones clínicas que eran poco comprendidas por los profesionales de salud. En la relación entre los profesionales de salud y los usuarios indígenas se hizo evidente el choque entre los distintos *habitus* y la configuración de una relación entre extraños morales. Estas condiciones dificultan el diálogo para resolver los conflictos.

**Palabras-clave:** Salud de poblaciones indígenas. Ética clínica. Bioética. Noroeste del Amazonas.

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Research article

The perception, comprehension and resolution of moral problems in health care are strongly influenced by context, rural or urban, which they occur [1,2]. A fundamental characteristic of health services in rural contexts is often the populations have the knowledge, practices and values different from the recognized by health professionals. Variations in comprehending practices and moral values lead to episodes of conflict in health services [3].Turner [4] states that in past decades several studies have shown considerable cultural variation on how families and individuals understand clinical situations such as terminal diagnosis, the definition of death, the use of high technology, among others.

Differences in culture and religious traditions are directly related to this moral diversity in society. Therefore, the relationship between indigenous people and health professionals should take into consideration such differences. Ellerby et al. [3] highlight that ethical decisions of native people differ from the hegemonic values of Western society. Moreover, the historical context of the existing power relations between indigenous people and national societies also influences this relationship. In Brazil, for centuries, colonial agents - such as health institutions - developed the project of "civilizing" the natives, that is, they understood that they should be protected from themselves by adopting the values, customs and *habitus* of Western culture [5]. Thus were not considered as moral subjects, with their own values and knowledge and able to make decisions.

The discussion on moral issues in relation of the indigenous people and health services is fundamental for improving the quality of care provided to this population, once the lack of a culturally sensitive care may be responsible for the non-use of health services and their bad results [6,7]. In several countries it is apparent that the indigenous population presents a lower life expectancy and higher prevalence and incidence of many diseases [7-11]. Medical systems are culturally shaped in Brazil as in other countries in accordance with Western, Christian, liberal values, which may bring negative impacts to those who do not share these bases [2,7].

Turner [4] highlights the importance of studies about the moral point of view of the members of specific communities. Under such approach, it is intended in this study to discuss the indian perspective on moral issues in relation to health services in the upper region of Rio Negro / Amazon / Brazil. Our analysis will start from the recognition that health professionals and indigenous do not share the same *habitus* [12,13] and therefore constitute themselves as moral strangers [14]. In this context, we consider the discourse ethics as a way to resolve these conflicts and how to overcome the coloniser-colonized relationship [15].

## *Habitus*, moral strangers and the discursive ethics

The *habitus*, according to Bourdieu, are durable provisions schemes, acquired in socialization processes, which include two components: the principles and values that regulate everyday behavior (*ethos*) and the attitudes and dispositions of the body (*body hexis*) [13,16]. Therefore, indigenous and non-indigenous, who do not share the same social world, develop different attitudes and ways of acting, perceiving and reflecting.

T*he agents of the same habitus do not need to agree to act in the same manner* [16], as the common coding ensures minimal communication [13]. However, if the objective conditions or context change, a discrepancy between the old *habitus* and the new conditions may occur, what would lead agents to attitudes considered inadequate, triggering conflicts [16].

Engelhardt Jr. [14] called moral strangers who do not share those assumptions, rules or moral authorities, incorporated in *habitus* of individuals and groups. Therefore, the moral friends would be those who share a continuist morality in a group of people. To resolve controverses, moral friends may resort to moral argument or a recognized authority, but not moral strangers: they would have to sort through a mutual agreement because they do not share the same rules, assumptions or moral authorities. The author states that not sharing an essential morality does not mean the impossibility of comprehension of the other's perspective, so that the conflict resolution is proposed through agreements.

We agree with the perspective of discourse ethics, which has been crafted in the context of the relationship between indigenous and non-indigenous in Brazil by Oliveira and Oliveira [15] and Oliveira [17] using as a foundation the concept of communication community and argumentation of Karl-Otto Apel. The communication community is a social space marked by dialogic relations, but to democratically function as argumentation community needs an intersubjective agreement of standards and rules between the interlocutors [15]. However, in the interethnic context of a society ruled by an only-ethical State, it is observed the hierarchization of a culture over another, compromising the conditions of symmetry and

equality, necessary for a truly democratic dialogue. This is the challenge we encountered in the context of relations between health professionals and indigenous people to resolve moral conflicts.

## The subsystem of indigenous health in Brazil

Since 1999, it was implemented a specific health care subsystem for indigenous people integrated to the national health system in Brazil. The National Policy for the Health of Indigenous Peoples (Pnaspi) foresees the implementation of a model of care whose operation is based on 34 Special Indigenous Health Districts (DSEI), responsible for providing access to comprehensive health of indigenous peoples [18]. The districts provide primary health care services performed by multidisciplinary teams of physicians, nurses, dentists, nursing technicians and indigenous health agents (AIS) that must act in indigenous villages. This local network is linked to the rest of the unified health system (SUS) for the provision of medium and high complexity services.

One of the fundamental guidelines of this subsystem is the special attention that advocates the appropriateness of services through the preparation of health professionals to work in an intercultural context, the articulation with traditional health systems and the differentiation of actions and technologies for local contexts. However, this guideline finds many difficulties in its implementation throughout the districts.

Some ethical conflicts that emerged from the intercultural relationship between indigenous people and the national society remain controversial, but the scientific literature on the ethical issues that arise with the implementation of indigenous health subsystem is still incipient. The little available literature addresses the issue of infanticide [5, 19-24] and ethics in research [25].

## Methods

This is a qualitative research, interested in the "point of view of the actor" as a producer of meanings [26,27] and approved by the National Committee for Research Ethics. The techniques used for data collection were the participant observation, as observer [28,29]; the systematic record in field notebook; and international bibliographical review.

The fieldwork was conducted during 40 consecutive days in two communities of the Baixo Rio Içana in Distrito Sanitário Especial Indígenas do Alto Rio Negro (Dseirn), located in the municipality of São Gabriel da Cachoeira. The main informants and translators were four AIS - two women and two men - who worked in these communities. Community and people's names used are fictitious.

Participant observation included the daily monitoring of the collective activities of communities, providing care by the four AIS and therapeutic routes followed by patients attended. Informal conversations with residents about their experiences in health services were held in the cities of São Gabriel da Cachoeira (SGC) and Manaus. The daily records in the field diary were reviewed and categorized in order to identify situations that, from the perspective of the indigenous, represented conflicts in the relationship with health professionals.

The bibliographical review was also made in the PubMed database, in March 2013, which helped to define the categories of analysis and discussion of the empirical data.

## Local context of the study

The Dseirn is located in the northwestern Amazon, region of Alto Rio Negro, in the municipality of São Gabriel da Cachoeira, on the border with Colombia. Currently, in there live 17 languages speaking peoples of three linguistic trunks - Arawak, Tukano and Maku. Our study occurred in Içana river, a tributary of Rio Negro, where members of the ethnic Baniwa [30], target of interest in the research, live.

The study was conducted in the lower course of Içana river in Baniwa villages, fictitiously called Açaí and Buriti. The area of the Baixo Içana comprises a geopolitical region located between the mouth of the Rio Içana and middle reaches of the same river, former site under influence of colonization process; prevailing trade regime established in the extraction of jungle products, economic space whose influence is felt until the mid-twentieth century.

The relative proximity to the municipal headquarters of São Gabriel da Cachoeira favored the intense interethnic contact, continuous action of religious missions and greater contact with the national society agencies, which accentuated the changes in Baniwa way of living [31]. The organization and reproduction Baniwa of social life is strongly supported by a system of knowledge and the mythical form of kinship organization, critical to understanding the origin, maintenance and disease classification in this society [32,33].

## Results and discussion

In the communities studied, families preferentially sought to solve their health problems with local resources, covering: a) domestic / family care, through the use of medicinal plants and / or diets and / or self-medication with drugs industrialized; b) consultation with indigenous traditional healers; c) compliance by AIS; d) less often, the search for assistance with nurses and nursing technicians of the support units named poles base.

In general, the indigenous population used concomitantly different existing health resources in the territory; not for them there were no conflicts or contradictions in the use of biomedical and traditional therapies jointly characterizing a medical pluralism that is, according to Menéndez [34], typical of Latin American societies, in which individuals and social groups consistently perform among the various joints forms of health care.

AIS, as members of multidisciplinary health teams Dseirn, performed the first evaluation and management of indigenous health subsystem users in the villages, as well as deliberated on the first pipeline. If you conclude that the case was serious or that did not have local resources to solve the health problem identified, communicated by radiophone with headquarters Dseirn for guidance on procedures or to request the removal of the patient to the city.

In the city of GSC is located a Indineous Health House (Casai), support unit offering lodging and health care to indigenous referred for care at referral network from the town (hospital and outpatient) managed by state departments and municipal health, respectively. When necessary, patients could be referred to Manaus - in these cases, Casai Manaus housed patients and managed the continuity of care.

During the field work it was identified that the removal to the city generated conflicts among indigenous families and teams Dseirn. According to AIS, people often give up removal or refused to be displaced or to allow the transfer of family to the city. In the literature, this type of situation is also common in other regions. Stamp et al. [35] reported that the transfer to services in urban areas is a daunting experience for indigenous remote areas in Australia, and relates to the environment and fear of unknown people, the difficulties and costs in shifts and accommodation to cultural inadequacies of services and communication difficulties related to bilingualism these people and sometimes the little fluency in the national language.

In the analysis stage of the research records were selected in the field daily situations related to removal, reported by indigenous users or accompanied by the researcher, which served as the empirical material for the discussion about the perspective of indigenous conflict with the services of health.

### *Barriers in services and discrimination in health services*

*"During a visit to the AIS Rodrigo, he says with the three families gathered that I had asked the reasons why people do not like to go to town. The sr. Abreu says the mixture Marry a lot of people, the place is dirty and messy, because employees do not clean the place and say that indigenous is that should clear. After Dona Maria says Marry Manaus is worse than the SGC, that there is no where to put the network, you have to sleep on the floor "* (Excerpt from field diary from acai community).

Many reports made it clear that, for indigenous peoples, the conditions of Kasai were inadequate for hosting patients and families. These negative experiences were reinforced by similar stories from other families in Kasai and other health services - this kind of negative perception of health services has also been identified in Australia by Stamp et al [35] and Aspin [9].

The natives showed distrust in relation to non-indigenous professionals and insecurity when transferred to urban services, because these were uncomfortable, mistreated and subjected to unsuitable conditions. Thus, adherence to guidelines and treatments offered was impaired and removing refused by patients or their relatives, a situation also referred to by other authors [6,7,9,35]. Stamp et al. [35] point out that the lack of information available to the Indians about what to expect from referral hospitals exacerbates this discomfort and consider that this may also be a relevant factor in the Rio Negro region.

This type of situation was classified by Betancourt 6 as structural barriers to accessing services, as it refers to difficulties encountered due to the drawings of the physical structure and management of health services, such as hosting and maintenance of spaces. For the author, this kind of barriers also include the lack of interpreters, delay in care, difficulties in referral to specialist services, lack of culturally sensitive educational materials and other information [6]. These difficulties in access to health

services are also faced by indigenous Brazilian and once again can be understood as a lack of respect for that identifies and characterizes that particular community.

Although Brazilian law [36] determine the humanized, warm and care-free discrimination in services, the operation of health institutions reflects existing conceptions and values in the society. And we realize that stereotypes about the ways of life of indigenous lead to the discrimination of these users in services - which is also observed by other authors [7,9,37]. The record that there are disparities in access and quality of care in health services related to the ethnic profile is reported in several studies [2,6,9], although that would still be little discussed in Brazilian literature.

### *The challenge of diversity and plurality in medical care*

According to Betancourt [6], the recognition of the need to adapt, or of cultural competence of services has become evident in recent years and in the case of health care directed at indigenous peoples is more evident and necessary position shared by several authors [7, 3,2].

For each crop, symptoms, classifications and therapies for health problems vary. For Baniwa, the origin and the classification of diseases are made from a system of mythical knowledge related to wars between families creators heroes [38]. Garnelo and Buchillet [33] establish a taxonomy of diseases rionegrinos indigenous peoples, including the baniwa, whose foundations are diseases related to the offense of beings-spirits; with poisoning, a form of malefaction that plays a central role in cosmology Baniwa; with gender conflicts that recall the ancient wars between men and women; diseases caused by Yoópinai - beings-spirits of the forest; and diseases caused by contact, but part of the traditional cosmology.

Such understanding of the specifics of the health-disease process coexist with the offer of government services based on APS, which are used by the natives in coping with their health problems. However, in the Rio Negro region reports revealed the unpreparedness of indigenous institutions and health professionals to deal with these socio-cultural specificities of the health-disease process:

*"I wonder why people do not like to go to SGC? Denise agent says the problem was that in Marry the food is bad and they mix ethnicities. Denise also talks that there was a man who started with generalized swelling, she asked redemption and family at first agreed, but then gave up. The family thought it was traditional disease (blast) and wanted to treat with traditional medicine*" (Excerpt from field diary from Açaí community).

In this report we identified some barriers classified as clinics for Betancourt [6], related to sociocultural differences in the health-illness-healing and leading to conflicts in services. The misunderstanding of these cultural differences on the part of health professionals and managers, can be expressed, for example, the cultural inadequacy when organizing services in Kasai, such as: a mixture of people of different ethnicities, understood as a situation of health risk; the disregard of traditional diets and dietary restrictions of sick families; and the prohibition of experts, connoisseurs of plants, shamans and healers do their treatments in the areas of public services, in addition to the non-recognition of traditional diseases.

Garnelo and Wright [32] point out that the shift patients to stay in the city and are feared to Casai members of this ethnic group events, for the production of food for people from other groups is identified as a risk for illness, not for biomedical reasons, but for threatening the way of life. In parallel, even among indigenous urbanized there is the fear of not being able to follow the proper diet for each life stage, according to the traditions. The hospital admission or stay in Kasai generates the break, quite restrictive for the sick and their families, some groups maintain dietary rules. In most cases, these rules are not exclusive to the sick individual and extend to the family, which is different from the logic of health services whose focus is solely the sick. In addition, for those companies to family presence serves Support for patients, characteristic found in other contexts [3.35].

For the Indians, there is not conflicting, complementary use of biomedical and traditional resources; but for health professionals is very difficult to accept coexistence. Lorenzo [39] etnocentismo emphasizes the frequent deployment of health, based on a view that *scientific knowledge should clarify and / or validate local knowledge* [39]. Thus, we observe that local practices of healing specialists are tolerated in Indian Country but not in health services.

Currently, most health professionals working in the districts received no preparation for working in an indigenous context. Several Brazilian authors identify the lack of non-indigenous professionals in history, cultures and medical systems of indigenous peoples [39-41], and confirm that health professionals have difficulties in understanding what would be the differentiated attention [41,42]. Health actions im-

plemented in the districts and in Casai are based on national health programs without significant adjustments in technologies, information systems or targets. As a result, the universalist conceptions of health professionals are materialized in a technically standardized patient care without any considerations in relation to their cultural singularities.

### *Different moral values, forms of autonomy and conflict during the decision making*

By the account of indigenous users perceived that the health services they are asked to make decisions based on biomedical values. However, according to Garvey et al [2] in indigenous perspective often the commitment to quality of life is greater than the search for a cure, as well as the desire to receive care provided by indigenous, involving culture, community and spirituality. To Ellerby et al. [3], due to an imposition of Western values health institutions may also be associated with the culture of colonization.

For the Indians, the parameters that guide the decision making in clinical situations do not differ from those applied in other life situations. Indigenous ethical decisions would often situational and highly dependent on values and family and community context [3]. In the rionegrino context, the ethos is strongly guided by the family (kinship) and communal life. To Ellerby and coworkers 3, Indian ethics is best understood as a relational process and, indeed, it was realized that the field work for the Indians was extremely important in decision making, the quality of the relationship with health professionals, especially with regard to trust, friendship and empathy.

We also realize that for indigenous and their families of the Upper Rio Negro risks and benefits for the individual can be made relative to the interests of the family and community, and the presence of the family in clinical decision making is crucial. We agree with authors [2.43] who point out that the dominant emphasis in Western society in respect for autonomy - understood as an individual decision making that prioritizes the individual consent of the patient - should be replaced by collectivist ideas. Instead of assigning a unit of autonomous decision to the individual, this may be the family or the community, as identified by Hanssen [43].

Health professionals should be able to recognize the different modes of decision making, the notion of family and forms of communication of indigenous users [2]. It was observed this difficulty during the fieldwork, when a community member suffered a paralysis. Given the possibility of the individual having suffered a stroke, we tried to convince him to accept the rapid removal via transport Dseirn. But from the first conversation the patient said he wanted to move under its own power, which would take much longer. Only after two days of dialogue was understood and accepted that was sick wanted to manage their care with their own resources, so that he could, on the way, stop at another community to meet with your child, perform traditional treatment, staying at home family in the city and look for hospital autonomously and not by Dseirn.

This initial posture reflects the paternalism that marks the medical practice in Brazil, which emphasizes that the professional should always act to *restore health and extend the the life* of patients, even without your approval and even against his will [44]. This ethos, understood a value which regulates the daily conduct of professionals, is justified by the idea that technical knowledge is the only valid criterion to ensure the best interest of the patient [44]. Menéndez [45] emphasizes that the process of hegemony of biomedicine has built up a position of patient subordinate to the doctor, incorporated into the professional *habitus* posture knowledge.

However, in Brazil, [46] Barroso stated that the Constitution of 1988 is a milestone in the protection of individual rights, adopting the concept of human dignity as the ability to be autonomous. This jurist argues that prevail in the country legally the idea that individuals, based on their values and principles, whether religious or cultural, can decide about their lives and their medical treatments, including being able to forgo a fundamental right, like life .

But it is also at this point we observe that indigenous and non-indigenous are moral strangers. Authors in the field of [47] indigenous health report that the supply of health care is heavily affected by the conflict between the values of equality and individuality of Western society and the organization of the ethnic groups of South American lowlands, characterized as partnerships (and not individuals) and marked by tension between egalitarianism and hierarchy in kinship groups. This is the specific case of ethnic groups in the Upper Rio Negro.

The fundamental notion of individual freedom of choice, which separates the individual's socio-cultural environment, conflicts with the notion of collective construction of these groups [25,43,47,48]. The notion of the individual is something particular and historical and currently is the basis of scientific, political, ethical and health work in Western society theories but designing it to other companies generates misunderstandings and conflicts.

### *Strategies and conflict resolution*

When considering the framework of discourse ethics, the major challenge in the field of Indigenous health is the creation of communities of argumentation [15.17]. Oliveira and Oliveira [15] point three social spaces for democratic dialogue and negotiation: *the "microsphere", referring to the context of family and community; the "mesoesphere" located in relations with the nation states; and "macrosphere" the deliberations and actions of international organizations*.

Internationally, there are legal provisions and milestones that defend indigenous and indigenous discourse. However, under the "microsphere" it was observed that the rules and moral values differed between indigenous and health professionals. Furthermore, little time for dialogue during the sessions, the short period the teams in the communities, the lack of longitudinal follow-up of patients and the high turnover of professional conflict with the importance given by the Indians to the quality of human relations in decision decision and the therapeutic process [3.43] and hinder the formation of communities of argument between professionals and indigenous - a situation found in other districts [49.50].

When disagreement occurred with the indication of transfer to the city, primarily responsible for dialogue and persuasion were the AIS. The Dseirn adopted the strategy to ask who refuse to remove the sick to sign a "*term of responsibility*", whose main objective seems to be exempt Dseirn the consequences of the decision. This strategy is used in other districts and, in our view, hinders democratic dialogue and understanding of the motivations on denials.

Some professionals, with more time and experience, learned to dialogue with leaders and hold community meetings to discuss planning and evaluation of activities or issues. This kind of attitude was welcomed by indigenous and assisted in resolving conflicts. This initiative demonstrates the importance of the health professional to establish dialogue and, through this, seek knowledge about the reality of indigenous peoples, and points to attempts to establish communities of argument between users and professionals.

During the stay in the health services in urban areas, the Indians also reported difficulties in ensuring their rights and wishes with regard to therapeutic approaches. For the care of indigenous experts and use of traditional medication needed to return to communities. Some indigenous therapists interviewed reported strategies and attempts to meet the unnoticed way in services.

Importantly, the regulation of the relationship between health services and indigenous users are under the "mesosphere", the formulation and implementation Pnaspi and their mechanisms of participation and creation of communities of argument. In the current context, we identify different barriers to the creation of democratic spaces for dialogue, as local and district social control agencies have not been effective. Nationally, there is the incorporation of indigenous leaders replacing the construction of spaces of representative dialogue; the last National Conference on Indigenous Health in 2013, managers used different strategies to maintain its hegemony in the conduct of deliberations - and observe different government policies and actions that kick in indigenous rights.

## Final considerations

The refusal of the natives in respect to the transfer to health services in urban areas, identified in Dseirn revealed many conflicting elements of the relationship between indigenous people and health professionals. In our analysis, these reports did not concern the refusal to biomedical care itself, but the cultural barriers inherent in the structure and operational proposal of services, as well as the disregard of the indigenous perspective on the therapeutic process.

It was also possible to verify conflict between social priorities, rituals or family members of groups whose importance was not perceived by health professionals and therefore became competitive with the supply of health care. This situation has led to negative and disrespectful experiences in services, communication failures, dissatisfaction, low adherence to treatment, distrust in the relationship with professionals, among other problems. We highlight some of the problems identified are not specific to this population.

The underlying moral issue is the failure to consider the perspective of Indigenous subject in their way of life and lead to the therapeutic process. Not consider this case means not know or respect and it expresses the persistence of ethnocentric perspective, which advocates that the indigenous still needs to be protected from himself.

In the situations discussed between health professionals with indigenous users were evident clashes between different *habitus* and setting up a relationship between moral strangers. Moreover, it is noticed that the conditions and characteristics

of the encounter between health professionals and indigenous users hinder the formation of communities of argument for resolving disagreements.

We need to pay more attention to the perceptions, expressions and values of each Indigenous user and more flexible practices before each context. Valuing family for the care and decision making, the use of interpreters during the process, recognition and respect for traditional knowledge and practices of health seem fundamental to consolidate the relationship between health professionals and indigenous in health services.

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