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## ***THE SILENCES FRAMEWORK: METHOD FOR RESEARCH OF SENSITIVE THEMES AND MARGINALIZED HEALTH PERSPECTIVES***

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### **ABSTRACT**

**Objective:** To describe the experience of applying of *The Silences Framework* to underpin health research investigating Tuberculosis/HIV/AIDS coinfection .

**Method:** The Silences Framework originally developed following a study exploring the decisions and silences surrounding black Caribbean men living in England, discussing the themes 'sexual health' and 'ethnicity'. Following this study a conceptual a theory for research on sensitive issues and health care of marginalized populations was developed called '*Screaming Silences*' which forms the foundation of The Silences framework. Screaming Silences *The Silences Framework* define research areas and experiences that are poorly studied, little understood or silenced.

**Results:** The Silences Framework supports researchers in revealing "silences" in he subjects they study - as such results may reflect how beliefs, values, and experiences of some groups influence their health. This framework provides the application of four complementary stages: working the silences, hearing silences, voicing silences and working with the silences. The analysis occurs cyclically and can be repeated as long as the silences inherent in a study are not revealed.

**Conclusion:** this article presents The Silences Framework and the application of the notion of "sounds of silence", mapping an antiessentialist theoretical framework for its use in sensitive research in health and nursing areas, being a reference for other researchers in studies involving marginalized populations.

**KEYWORDS:** Inequalities in health. Methods. Nursing. Coinfection. Research. Tuberculosis. Acquired immunodeficiency syndrome.

### **INTRODUCTION**

In the health field, researching sensitive issues and marginalized perspectives requires the development of methodologies that capture a universe of complex and often hidden meanings.<sup>1</sup> This increases the importance of making appropriate methodological choices.

The present article aims to support researchers in health and nursing conducting such research by outlining *The Silences Framework* originally *The Silences Framework* proposed in England and still little known in Brazil. The article illustrates the potential for this conceptual framework to aid in the development of Brazilian studies in these areas. The article presents the framework as used in a research study focusing on the politically sensitive and problematic issues related to why AIDS and tuberculosis (TB) continues to affect so many people in Brazil. *The Silences Framework* facilitated the use of a new methodological approach, exploration of the research problem, data collection processes, analysis and validation of results.

In 2012, there were 1.4 million new TB cases among those infected with HIV worldwide, leading to a mortality rate of 456,000 individuals.<sup>2</sup> In that same year, in Brazil, the coinfection rate for TB and HIV was 9.9% and the mortality rate was 6%, which is three times higher than the mortality rates for other diseases.<sup>3</sup>

Rio Grande do Sul is the Brazilian state with the highest percentage of TB/HIV/AIDS coinfection, with 20.3% of TB cases affecting people with HIV/AIDS. This percentage is almost twice higher than the national average of 10.4%.<sup>4</sup> Porto Alegre is the Brazilian capital with the highest incidence and mortality of TB and HIV/AIDS individually, with the coinfection percentage reaching 28.0% of TB cases, which highlighted it as an example of the challenges associated with combating TB/HIV/AIDS coinfection.<sup>4</sup>

Members of the scientific community, international organizations and leaders in the fight against AIDS and TB agree that combating coinfection from these diseases is a public health issue. As such, it should also incorporate the fight against stigmas and the promotion of human rights, with an emphasis on reducing the vulnerability of marginalized populations.<sup>5</sup>

Historically, TB and HIV/AIDS illness have been marked by stigma and prejudice. Since its inception, AIDS has initiated discourses concerning the behavior of infected individuals, who are often accused of being negligent or irresponsible.<sup>6</sup> Individuals with TB have **also** faced rejection and prejudice, mainly due to concerns about the transmission risk through social interaction. Research focusing on TB/HIV/AIDS coinfection therefore involves more than a disease approach, as it is also dealing with the sensitivities of a social phenomenon. Studying coinfection as a sensitive issue seeks to expand our understanding of TB/HIV/AIDS beyond the biomedical approach, considering the cultural elements that make it a social and personal experience. In this way, it explores the meanings, perceptions, attitudes, beliefs and experiences of the people living with coinfection, dealing with the

disclosure of personal information, sexual and behavioral experiences that have their own meaning specific to each individual.<sup>7</sup>

Brazilian public health policies are perceived as disregarding these issues in dealing with TB and HIV/AIDS coinfection. There is a permanent tension between "expanding the supply of exams and medicines and addressing the stigma and discrimination experienced for vulnerable populations".<sup>8:296</sup> The focus of health policies in compliance with the drug use and more effective treatments has as a result often disregarded the social, cultural and economic factors that influence the failure/success of treatments for HIV/AIDS, TB coinfection .

The research developed in Brazil using *The Silences Framework* method was associated with a series of politically sensitive concerns related to gender, schooling, race/color, territory and sexual behavior, Exploring these issues may help us to understand why TB/HIV/AIDS coinfection still affects so many subjects. This article aims to describe the use of the *The Silences Framework* in health research, concerning TB/HIV/AIDS coinfection

## **METHOD**

*The Silences Framework* was applied in four stages. In the first, a broad literature review was performed using national and international databases with a range of search criteria , review of sources included identifying the nature of researched and possible silencing groups in the studies . This provided the foundations for the development of the project "The Influence of Gender on the Care Pathways of Men and Women Coinfected With Tuberculosis and HIV/AIDS", which was conducted in Porto Alegre, Rio Grande do Sul, Brazil, between 2014 and 2017. This project gave rise to two subprojects: "Epidemiological Study of TB/HIV/AIDS Coinfection and Risk Factors for Hospitalization and Mortality in Porto Alegre, Rio Grande do Sul, Brazil"; and "Influence of Gender and Other Markers on The Care Pathways of Men and Women Coinfected With TB/HIV/AIDS in Porto Alegre, RS, Brazil". The first subproject resulted in a doctoral dissertation<sup>9</sup> that applied the second stage of the method, using a quantitative approach. In this second stage, data from four Brazilian national databases were unified: National Notifiable Diseases Surveillance System (SINAN) for AIDS and TB, Hospital information system (SIH), and the Mortality information system (SIM) of the National Health System of Brazil. The aim was to explore which population groups were missing (silenced) from the profile and the district management records which illustrated where the coinfection cases, deaths and hospitalizations were located. The results

from the first and second stages, enabled the silenced groups to be located and indicated possible other research questions, participants and scenarios that could produce new insights into illness experiences of people coinfecting with TB and HIV/AIDS. The second subproject used a qualitative approach, interviewing men and women currently coinfecting and undergoing treatment at reference centers. The focus here was to explore the experiences of the participants and care management in areas with higher frequency of cases. In the last stage, the integrated data analysis was developed, indicating not only the silences present in the researched area, but also other relevant conclusions relating to the experiences and care of people with coinfection.

A critical perspective guided the creative process of writing, based on the assumption that, considering the multiplicity of conditions in which women live, there is, on one hand, the issue of differences and inequalities among women and, on the other hand, the differences and inequalities among them and men.<sup>10</sup> The criticalist theories that guide *The Silences Framework* provide a basis for methodological strategies guiding the data collection and the concepts and theories that supported the analysis. The argument arising from the analysis was that gender, class and race are daily interrelated and potentiate elements which resulted in inequalities that affected the health experiences and outcomes of the coinfecting men and women who participated in the study.<sup>9</sup>

## **THE THEORY UNDERPINNING *THE SILENCES FRAMEWORK***

The method was developed by the English researcher Laura Serrant-Green and was originally used to study the decisions and silences of black Caribbean men in England in relation to sexual health, considering the importance of gender and ethnic differences in this context. The research resulted in the development of *The Silences Framework* to guide research on sensitive issues and health care of marginalized populations.<sup>10</sup>

Similarly, the research conducted in Brazil set out to study the sensitive issues concerning white and nonwhite men and women residing in different territories who have developed coinfection by TB/HIV/AIDS. The using *The Silences Framework* in this study, aims to challenge the view that people should adopt specific health behaviors regarding the use of protection methods or intake of medicines, without consideration of other social, cultural and economic influences.

The Framework is supported by antiessentialist standpoints, which challenge the idea that the world is constituted in terms of "essences" (absolutes). Essence refers to the

sphere of being, it is the ultimate composition or reality of something, which is unchanging and without it such thing would cease to be what it is.<sup>11</sup>

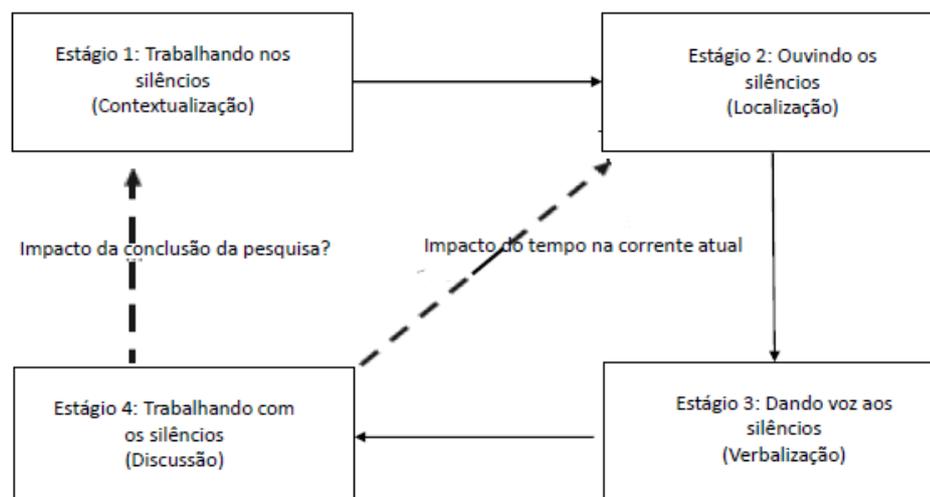
Antiessentialism questions essentialist theories and its conviction in the determination of being, and belief in the biological paradigm as being the determinant of the subject's essence.<sup>11</sup> In this sense, antiessentialism contradicts the existence of binarisms, constituted in superiority terms of the first in relation to the second, e.g., man/woman, heterosexual/homosexual, etc. One of the arguments of the essentialist current is that sex and sexuality rest on a biological conceptual basis, whereas, in the antiessentialist perspective, neither biological sex nor sexuality are conceptually free of social and cultural influences.<sup>12</sup> Although they are biologically based, gender and sexual identity can thus be seen as no more than social interpretations.<sup>13</sup>

The challenging the essentialist view of the world allows exploration of the experiences of people who are rendered invisible and voiceless in society, suggesting that things are not always as they seem to be. This antiessentialist view of the world is evidenced in the way in which people living with HIV/AIDS and TB are seen and treated in Brazil. They live with their illnesses alongside challenges such as deprivation of freedom, living on the street, informal jobs, insecure sexual practice, lower levels of education and living in areas with high levels of violence. These social situations often make the person invisible, with 'silences' around their situation little explored. As a result, care strategies remain focused only on determining the care considered effective for the illness recovery, without considering other aspects that may impact on his or her illness.

## **APPLYING *THE SILENCES FRAMEWORK* TO RESEARCH ON COINFECTION IN BRAZIL**

*The Silences Framework* is proposed as a method for research on subjects that remain under researched, little understood or silenced; reflecting the unspoken or unshared aspects of the ways as beliefs, values and experiences of some groups affect their chances of life and health.<sup>9</sup> By pointing out gaps in the research field, the unsaid aspects of certain realities may contribute to the identification of marginalized discourses in health.<sup>12-13</sup>

The method is divided into four main stages,<sup>10</sup> organized according to Figure 1.



**Figure 1 - Theoretical framework of *The Silences Framework* method (translated)**

The following four stages of the method are described according to its use in a health research study on coinfection in Brazil.

### **Stage 1: Working in 'silences'**

This first stage consists of a contextualized exploration of the literature. It must be situated in the research subject or object and may include exploration of cultural, clinical, psychosocial, or moral context of the proposed research. By doing that, the research project is defined, proposed and located within a certain period and in a specific society. Concluding this stage, the researcher should seek to answer "why research this topic at this particular time?", based on their identification of "what do we not know?" or "what stories are yet to be told?".

In this research, this first step sought to identify in the literature review which groups of people affected by HIV/AIDS and TB coinfection that are missing (silenced). This search was performed in national and international databases, identifying the range and scope of current research. A preliminary analysis showed that studies on coinfection area were mostly quantitative and were dedicated to the identification of risk factors for coinfection and multidrug resistance. They illustrated that there was a higher probability of becoming ill among white men, aged between 29 and 40 years old, with low educational achievement. The evidence indicated that, coinfecting men were the people predominantly included in such research. Thus, it was identified that, among the coinfecting groups of people, there was a greater probability of silenced voices or questions little explored existing among women, as coinfection appears to affect more men.<sup>14-16</sup>

The literature review also showed that there were few qualitative studies exploring the factors impacting on adherence to HIV/AIDS treatment, which have a significant impact on the development of TB and coinfection. Adherence has been a major challenge in combating TB, and treatment is even more difficult to maintain when TB is associated with HIV. This suggests, there is a need to develop psychosocial education strategies, which consider the multidimensionality of adherence to treatment, if we are to reduce dropout rates and break the transmission chain of tuberculosis,<sup>17</sup> and improve the communication between professionals and non-adherent users.<sup>18</sup> Moreover, few studies have addressed the relationship between different cultural or social risk factors that could lead to the development of TB and HIV/AIDS coinfection. Discovering the 'silences' in the research on TB/HIV/AIDS coinfection provided a way by which 'risk chances' could be seen through the intersection of the political, social and personal contexts that affect the health decisions of coinfecting people. Thus, challenging the view of coinfection as a generic subject requiring a singular response.

## **Stage 2: Hearing 'silences'**

The "silences" were defined based on the identification of research areas or experiences poorly investigated, understood, undervalued or silenced in the context of TB/HIV/AIDS coinfection. After Stage 1, a process of silence analysis was started in order to better focus and plan the study itself. Through this process three interconnected aspects are considered: the researcher identity and its relationship with the study, the research theme is, and the participants involved.

### ***Identity of the researcher***

The identity of the researcher influences significantly the delimitation of silences to be heard in the research. They especially influence his or her relationship with the theme and the reasons that led him or her to study these silences. In the specific case of the current survey, the interests originated in the authors' identity as women, nurses and researchers of gender relations in society. As there is already robust scientific evidence of the relationship between gender and HIV/AIDS among women,<sup>16</sup> the researchers were interested in exploring whether such a relationship also existed in the trajectories of those coinfecting with TB and HIV/AIDS, which is still an under-researched area in the literature.

### ***Research topic***

The researcher must identify the specific aspects of the study context that makes it "sensitive", by analyzing the nature of the subject at that specific moment in society. At the beginning of this study, the TB/HIV/AIDS coinfection as identified in Porto Alegre, RS, Brazil, was sensitive due to issues relating to: sexual health, gender, race, schooling, and territory. During the study, this city was the leading Brazilian city in terms of incidence and mortality due to TB, HIV/AIDS coinfection, with high rates of treatment non-adherence and an increasing number of HIV/AIDS cases among women and virus transmission.<sup>4</sup>

In this survey, the second stage of the Framework used a quantitative approach, to produce a comparative profile of HIV/AIDS and TB coinfection, between males and females. In addition, the districts within the city with the highest prevalence of cases by sex and by race/color were identified.

In forming the database, the following associations were included : cases of TB and AIDS from the years 2009 to 2013, reported in SINAN; deaths occurring from 2009 to 2013 recorded in the SIM and hospitalizations from 2009 to 2013, recorded in the SIH. The city of Porto Alegre, RS, Brazil, was divided into eight management districts, following the Municipal Health Plan. The Statistical Package for Social Science (SPSS) (version 19) was used to undertake the analyses and description of average prevalence rates

Data analysis suggested that there are differences between the sexes in the distribution of cases among management district in relation to race/color, age and in TB and HIV/AIDS coinfection cases recorded in SINAN. All these variables showed statistically significant results in comparison between the sexes.

The analysis also showed differences in the prevalence of coinfection cases between the district and local management of the individuals from this study. Only management district A showed a higher coinfection prevalence in women. Management district B showed higher prevalence in males and in the total coinfection cases in Porto Alegre-RS. Finally, management district C had a higher proportion of non-white population. These findings highlighted a need to better understand the coinfection dynamics in the three management districts (A, B and C), due to the average prevalence rates by general population, by gender, and by race/color.

### ***Participants and research subjects***

The participants are all the people who participate in the research and are directly affected by the issues being researched.. Following the analysis performed, the participants

were men residing in management B, women residing in management A, non-white residents from management C, and white residing in management B.

The analysis also enabled identification of the locations in Porto Alegre, RS, Brazil with a higher prevalence of TB/HIV/AIDS coinfection, which showed differences between men and women. This finding changed the focus of the research to study coinfecting men and women as once the characterization of individuals by sex showed differences, it is possible that the care trajectories of men and women were also different.

In short, this phase incorporated more than a descriptive identification of the existing "silences". Through a critical analysis of results from the research's quantitative phase, it was possible to question: "Why do these silences exist?" and "what cultural, clinical, psychosocial or moral aspects influence them?"

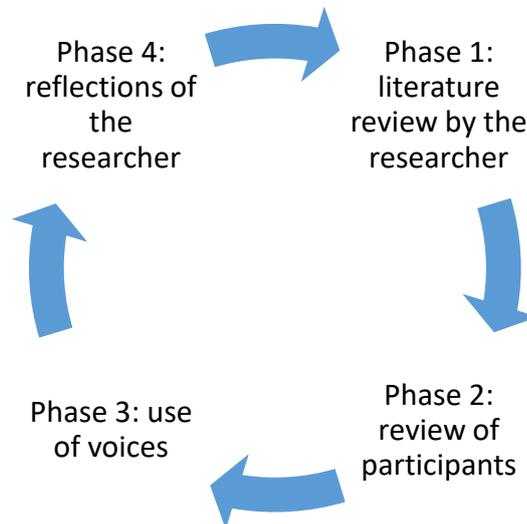
### **Stage 3: Voicing 'silences'**

This stage encompasses the active data collection phase of the research. The exact nature of the participants will depend on the study and may include service users, community groups, individuals and professionals as research subjects. Some studies may also include the perspectives of people in social networks of the research participants. Thus requiring the collection of evidence from those not directly affected by an issue, but whose clinical, political or cultural outcomes and roles influence the participants' experience.

The stage utilized a qualitative approach, incorporating semi-structured interviews that sought to deepen the understanding of the care trajectories of men and women. In this stage, the gender influences and other markers were analyzed in order to reveal the care trajectories followed by men and women in the range of health services. Understanding the impact of experiences in the care trajectory may be fundamental for supporting coinfecting individuals, since TB (coinfection) could be avoided by adherence to HIV treatment.

A total of 22 interviews were conducted in private rooms at reference centers for TB treatment (RCTBs) from the district managements A, B and C of Porto Alegre, RS, Brazil. RCTBs were places where users underwent their treatments. Participants were selected by reviewing medical records to identify TB/HIV/AIDS coinfection, sex, and race/color of the individuals. The interviews were recorded and transcribed for later analysis. The interview had an average duration of 30 min and the data was individually validated with each interviewee at the end of each interview, as predicted by the Framework. All participants gave signed consent. The project was approved by the Ethics Committee of the Federal University of Rio Grande do Sul, the City Hall of Porto Alegre and the Hospital Sanatorium Partenon.

The third stage of the Framework includes the beginning of the data analysis, which is expected to occur cyclically and in four phases. Figure 2 illustrates this process.



**Figure 2 - The cyclical character of *The Silences Framework* method phases<sup>10</sup>**

The analytical process occurs cyclically, with the information collected reviewed by the researcher in stage 1, using the research question and the objectives as a reference, and seeking contextualization of findings in the literature.

In phase 2, the participant review can ratify, refute or contest the study results, leading to identification of issues which may be poorly explored and what else should be followed up from the data collection, Thus providing valuable information on the research impact, importance and results. It is the moment to review what was said in the literature (at Stage 1), the scenario analysis and the subject (at Stage 2), and the information coming from hearing silences (Stage 3). The methods, processes and strategies used to conduct a study will depend on the overall study design. Here is a draft of the results from this study comparing the information gathered from the three stages.

In this study, the first draft of the results suggested that the source of HIV infection differed in men and women, for example whether due to not using condoms or not recognizing infection risks posed by their partner . The development of TB/HIV/AIDS coinfection shows that men and women face barriers to diagnosis and accessing treatment, dependent on the problems in the health services and the professionals who care for them. There are related factors that create a framework of vulnerability: Poor education , employment and income problems, lack of home and food, violation of the human rights of

homeless people or those incarcerated, among other situations. The results showed that gender could influence the illness and the care trajectories, due to its association with these other markers and so creating a programmatic, individual, and social vulnerability framework, including a violation of human rights.<sup>19-20</sup>

In phase 3, 'silenced voices' are included, where the individuals, social networks or cultural groups of the participants that can influence the research question are heard. An additional aspect of exploring the findings may include reflection by the group (family members, professionals, and social movements that advocate for the rights of coinfecting groups) regarding the "silences" that they consider still exist or remain unchanged as a result of the study. In this study, the inclusion of voices occurred through participation in the I Fórum Gaúcho Challenges for Combating TB/HIV/AIDS held at the Hospital Sanatorium Partenon, in Porto Alegre, RS, Brazil. In the event, professionals, users, managers and social organizations participated in discussions about the limits and potential of actions developed in the State. They highlighted the need to treat TB/HIV/AIDS coinfection through intersectoral actions and with the expansion of public policies that guarantee housing, income, food, access to social benefits, exercise of sexuality and fight problems related to alcohol and drug abuse.

In phase 4, the researcher reflects critically on the results of the previous phases of analysis and presents them as the final study results. The action of continually revisiting and reviewing the results of research in development, integrating users and public perspectives, is one of the essential components of this Framework.

**In this stage of the research on Gender crossings in the care trajectories of men and women coinfecting by TB and HIV/AIDS,** it was possible to conclude that gender influences the care trajectories of men and women, but its influence is associated with other markers, such as race/color, income, territory, schooling and the age of affected subjects. The subjects' statements demonstrated that these markers compose their life and care trajectories, composing frameworks of social, individual and programmatic vulnerability.<sup>20</sup>

The researcher can repeat the analysis cycle as long as necessary, following his or her reflection on the data integrity. Stage 4 ends when no new information relevant to the research question is revealed.<sup>10</sup>

#### **Stage 4: Working with 'silences'**

This phase incorporates the final aspects and the elaboration of the study conclusion, besides including a detailed reflection on the theoretical contribution and the pragmatic gains

of the study results. The key question to be answered by the researcher is "What has changed with this study results?".

The care trajectories of men and women are influenced by different markers that make up a framework of individual, social, and programmatic vulnerabilities that have their starting point in situations of basic right violation, such as access to education, housing, income, public transportation, basic sanitation, and health services. The assumption that coinfecting subjects are first diagnosed HIV and that, because they are negligent in their care, end up developing coinfection with other pathologies is not always true. Subjects are often diagnosed with pathologies that subsequently reveal their seropositivity status in a hospital setting. Furthermore, many women receive confirmation of HIV infection during pregnancy or in routine gynecological exams. This reveals that there is a need to change the focus of actions only to the administration of drug therapies, as there are factors related to the living conditions of people that interfere with their illness and care trajectories. In addition, it must be considered that it is necessary to review the participation of the State in guaranteeing the rights of access to health, education, income, and citizenship, which is very precarious in this scenario.

Final considerations may reveal limitations to inform other studies or any other generalization of the completed research. Thus, by accepting that "silences" are an inherent part of all societies, *The Silences Framework* also recognizes that, in conclusion, some "silences" are changed, exposed or even newly created because of the research.

In the research that illustrated here, some challenges had to be faced, such as the difficulty of entering health services due to the social context of the research sites, making it sometimes necessary to return another day. Another difficulty was the inclusion of new participants in the study due to initially foreseen ethical issues, which required in advance description of the nature and number of research subjects. The issue was resolved by providing a list in the research project

## **CONCLUSION**

The development of TB/HIV/AIDS coinfection is strongly influenced by the social, cultural and economic conditions of the people. Inasmuch as we seek to expand our understanding of the wide range of factors affecting their life and health, research possibilities tend to be increasingly directed at exploring sensitive issues experienced by vulnerable communities.

Analytical processes that aim to study health phenomenon are complex. Such complexity is related to the understanding that health goes beyond the absence of disease and the assumption that 'health' is closely related to the multiple relationships established between people and environment in a given geographic space and in a certain historical time. The search for broadening our understanding of health-related issues requires the use of diverse approaches in order to account for the need to grasp the different experiences about what is health and to understand why people become ill.

*The Silences Framework* makes a contribution in this sense, since it uses different research procedures simultaneously: literature review, location of the most silenced groups (quantitative approach), hearing people who have unveiled questions (qualitative approach) and identification of the main study contributions for the researched field. Data analysis integrates all research phases and allows including new participants (people, groups or organizations) that have relationships with the research subjects and that can contribute to the unveiling of silences.

The development of this study was based on assumptions that recognize and seek to voice experiences, themes and issues often hidden, devalued or "silenced". Nursing can benefit from the application of this Framework, expanding its research objects, differentiating itself by the collection and analysis of integrated data, investigating sensitive issues and historically marginalized populations.

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