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Social representation of quality of life among people with HIV residing in small towns

Representação social da qualidade de vida de pessoas com HIV residentes em municípios de pequeno porte

Representación social de la calidad de vida de las personas con VIH residentes en pequeños municípios

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ABSTRACT

Objective: to understand social representations of quality of life among people living with HIV/AIDS living in small towns in Rio de Janeiro State. **Method:** this qualitative, descriptive study of 80 people living with HIV was supported by the structural approach of Social Representations Theory. Data were collected by sociodemographic questionnaire and free word evocation. **Result:** prototype analysis showed that the core contents of the social representation were: good food, health, and psychological state, expressing the body, health-disease, and psychological process dimensions. Similarity analysis showed that the most strongly connected elements were good food, physical activity, and leisure. **Conclusion**: the study made it possible to understand participants' social representations of quality of life and also highlighted the dimensions on which they relied in striving for that quality. It was important in fostering alignment by interdisciplinary support services for this clientele.
Descriptors: Nursing; HIV; Health Knowledge, Attitudes, Practice; Quality of Life; Social Representations.

RESUMO

Objetivo: compreender a representação social da qualidade de vida de pessoas que vivem com HIV/Aids residentes em municípios de pequeno porte do estado do Rio de Janeiro. **Método:** estudo descritivo, qualitativo, apoiado na Teoria das Representações Sociais, em sua abordagem estrutural. Participaram 80 pessoas vivendo com HIV. Os dados foram coletados por questionário e evocação livre de palavras. **Resultado:** a análise prototípica evidenciou que os conteúdos centrais da representação social são: boa alimentação, saúde e estado psicológico, expressando as dimensões corporal, processo saúde-doença e psicológica. A análise de similitude retratou que os elementos com maior conexão são boa alimentação, atividade física e lazer. **Conclusão:** o estudo permitiu compreender a representação social da qualidade de vida e, ainda, colocou em destaque as dimensões nas quais os participantes se apoiam na busca por esta qualidade. É relevante por propiciar a adequação de serviços de apoio interdisciplinares a esta clientela.
Descritores: Enfermagem; HIV; Conhecimentos, Atitudes e Práticas em Saúde; Qualidade de Vida; Representações Sociais.

RESUMEN

Objetivo: comprender la representación social de la calidad de vida de personas que viven con el VIH/SIDA residentes en pequeñas ciudades del estado de Río de Janeiro. **Método**: estudio descriptivo, cualitativo, apoyado en la Teoría de las Representaciones Sociales, en su enfoque estructural. Participaron 80 personas que viven con el VIH. Se recogieron los datos a través de un cuestionario y de técnica de evocación libre de palabras. **Resultado:** el análisis prototípico mostró que los contenidos centrales de la representación social son: buena alimentación, salud y estado psicológico, expresando las dimensiones corporales, salud-enfermedad y psicológica. El análisis de similitud mostró que los elementos con mayor conexión son la buena alimentación, la actividad física y el ocio. **Conclusión:** el estudio permitió comprender la representación social de la calidad de vida y también destacó las dimensiones en las que se basan los participantes al buscar esta calidad. Es relevante para brindar la adecuación de los servicios de apoyo interdisciplinarios a esta clientela.
Descriptores: Enfermería; VIH; Conocimientos, Actitudes y Práctica en Salud; Calidad de Vida; Representaciones sociales.

INTRODUCTION

Over the forty years of the Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) epidemics, several personal, social, political and scientific changes have occurred, as well as in the epidemiological profile and in the representations about the disease and those infected[1,2]. Such aspects influenced the way of living, understanding and facing AIDS, with repercussions in Quality of Life (QoL)[1] among people living with HIV and in the care practices intended for this group[3,4].

Some studies were developed with this population living in medium- and large-sized municipalities in the state of Rio de Janeiro, describing peculiar characteristics of social groups depending on the region where they live and/or undergo monitoring in specialized services[4-7]. By associating with them, the current study sought to expand this investigation, but with residents of small-sized municipalities in the Mid-Paraíba region/RJ.

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QoL is conceptualized as the way in which individuals live, feel and understand their everyday life, including in this context aspects related to health, education, transportation, housing, work and participation in decisions that concern them[8]. Exposure involves multifactorial aspects related to the historical, social, cultural and spiritual contexts experienced by individuals or groups[4,9].

Understanding HIV and QoL implies apprehending the way in which these phenomena are structured in the symbolic and psychosocial dimension of a given social group, as well as the way in which this reconstruction defines practices and shapes attitudes[6].

Given the above, it was considered pertinent to use the Theory of Social Representations (TSR) to conduct the current study, as it allows knowing the symbolic configuration of phenomena and the ways in which this group sees and thinks about QoL.

Thus, the objective was to understand the social representation of the quality of life of people living with HIV/AIDS n small-sized municipalities from the state of Rio de Janeiro.

Its relevance for the health and nursing fields is highlighted, as it enables understanding the biopsychosocial impacts of the syndrome on QoL, as well as it propitiates targeting of health policies and adequacy of interdisciplinary support services to this clientele with a view to assisting them in the search for QoL or its maintenance.

METHOD

A descriptive study of a qualitative nature supported on the structural approach of the Theory of Social Representations.

Social representations constitute a set of concepts, proposals, explanations and attitudes produced in everyday life in the course of interpersonal communications about a given object[10]. In the context of the structural approach, or the Central Nucleus Theory (CNT), the organization of a social representation is configured around a central nucleus formed by one or more elements (words) that give meaning to the representation[11].

The study scenarios were the outpatient services for people living with HIV in the municipal STI/AIDS and viral hepatitis programs in small-sized municipalities from the Mid-Paraíba region in the state of Rio de Janeiro, including: Itatiaia, Piraí, Porto Real and Rio Claro. It is worth noting that these settings include participants living in other municipalities from the region, although not monitored in their municipalities of origin.

The participants met the following inclusion criteria: undergoing outpatient care; being aged at least 18 years old; and living in a small-sized municipality from the region.

Data collection took place from February to March 2020, resorting to a questionnaire prepared by the research team for the collection of socioeconomic and clinical data. In order to obtain the social representation contents, the free word evocation technique was used, requesting five words that came to the participants' mind from the “Quality of Life” inducing term.

The characterization data were organized in a *Microsoft Excel®* spreadsheet and analyzed by means of simple descriptive statistics. The free word evocation contents were organized in a *corpus* subjected to prototypical analysis, or four-quadrant chart technique, and by means of the similarity analysis. For the prototypical analysis, the software used was *Ensemble de programs permettant l'analyse des evocations*, version 2005 (EVOC®), which allows organizing the evocations produced according to their frequencies and evocation order, eventually generating a four quadrant chart[12].

The similarity analysis, which found out the number of connections that a word has with the others evoked by calculating the similarity indices, resulted in a maximum tree, which graphically synthesizes the set of existing connections between the contents of the social representation of the group[13,14].

The similarity analysis makes it possible to give a second indication of centrality[13] which, in association with the prototypical analysis, allows for another approximation on the possible elements that give meaning to the social representation of the group. The participants considered were only those that evoked at least two words, as connectivity relationships can only exist between one term and another[13]. The similarity calculation was performed to obtain the similarity index, dividing the number of co-occurrences between two words by the number of participants, making it possible to prepare the maximum similarity tree

All ethical imperatives established for carrying out research studies involving human beings were considered, observing what is recommended by National Health Council resolutions, and the study was approved by the Research Ethics Committee of the institution involved.

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RESULTS

The study participants were 80 individuals living with HIV: one from Barra do Piraí, 16 from Itatiaia, eight from Pinheiral, 26 from Piraí, eight from Porto Real, eight from Quatis, 12 from Rio Claro and one from Rio das Flores. The characterization data are presented in Table 1.

TABLE 1: Characterization of the people living with HIV/AIDS in small-sized municipalities from the Mid-Paraíba region, state of Rio de Janeiro (n=80). Rio de Janeiro, Brazil, 2021.

	Variable	n	%
Gender	Male	46	57.5
	Female	34	42.5
Age group	18-29	15	18.8
	30-39	30	37.5
	40-49	18	22.5
	50-59	11	13.7
	60-69	6	7.5
Schooling	Complete High School	33	41.3
	Incomplete Elementary School	20	25.0
	Incomplete High School	14	17.5
	Complete Elementary School	7	8.7
	Complete Higher Education	6	7.5
Professional qualification	None	69	86.3
	Higher Education level	6	7.5
	Mid-Technical level	5	6.2
Income	No Income	12	15.0
	Up to R$ 1,044.00 (min. wage)*	6	7.5
	R$ 1,045.00-R$ 2.089.00	39	48.8
	R$ 2,090.00-R$ 3,135.00	19	23.7
	More than R$ 3,136.00	4	5.0
Marital Status	Single/Widowed/No partner/Steady partner	37	46.2
	Married/Lives with steady partner	22	27.5
	Has a steady partner but does not live with him/her	21	26.3
Time knowing the serological condition	1-5 years	30	37.5
	6-10 years	25	31.3
	11-15 years	11	13.7
	16 -20 years	6	7.5
	More than 20 years	5	6.2
	Less than 1 year	3	3.8
ART use	Yes	77	96.2
	No	3	3.8
Stage of the infection	No symptoms	76	95.0
	With symptoms	4	5.0

*The minimum wage in force during the period when the study was conducted was R$ 1,045.00 (One thousand and forty-five reais).

The group under study was comprised by 57.5% of male individuals, of which 56.3% were aged less than 40 years old. They mostly have complete High School and 86.3% have no professional qualifications for the labor market. Regarding income, 48.8% earn up to two minimum wages. In relation to love relationships, 53.8% are in a relationship, with 27.5% and 26.3% living and not living with their partner, respectively.

In relation to the time knowing the diagnosis, 37.5% have known their serological conditions for between one and five years, followed by those with between 6 and 10 years (31.3%). With regard to ART use and the stage of the disease, 96.2% indicate using antiretrovirals and 95% do not have any symptomatological condition associated with the fact of carrying the virus or with drug therapy, respectively.

Analyses of the free word evocations

The *corpus* with all 400 words and expressions evoked was submitted to the EVOC software. For processing the content and its organization, the following parameters were established: minimum frequency of words=7, with 356 being processed; mean evocation frequency=25; mean of average evocation orders=3.0. The contents were arranged in the four-quadrant chart (Figure 1).

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Rank < 3.0				Rank ≥ 3.0		
Central Nucleus				**First Periphery**		
	Content	**Freq.**	**Rank**	**Content**	**Freq.**	**Rank**
Mean Freq. ≥ 25	Good eating habits	67	2.284	Leisure	63	3.175
	Health	36	2.083	Physical activity	51	3.216
	Psychological status	30	2.867	Family	27	3.815
Contrast Zone				**Second Periphery**		
Mean Freq. ≤ 24	Living well	11	2.545	Friendship	17	3.882
	Financial conditions	10	2.700	Treatment	13	3.692
	Housing	7	2.857	Health care	9	3.222
				Solidarity	7	3.714
				Religiousness	7	4.429

FIGURE 1: Four-quadrant chart showing the organization of the constitutive contents of the social representation of the quality of life of the participants from Mid-Paraíba. Rio de Janeiro, RJ, Brazil, 2021.

It is verified that the most frequent and most readily remembered words and expressions present in the central nucleus are the following: good eating habits (67), health (36) and psychological status (30), with health being the most readily evoked word (rank = 2.083).

In the first periphery we find the words leisure (63), physical activity (51) and family (27). Leisure is more frequent in the quadrant, being the second most evoked word by the group (63).

The contrast zone consisted of the following words: living well (11) (most promptly evoked), financial conditions (10) and housing (7). The second periphery includes the following words and expressions: friendship (17), treatment (13), health care (9), solidarity (7) and religiousness (7).

It was verified that 79 participants evoked at least two words in the analysis. After the similarity calculation, it was possible to prepare the maximum similarity tree comprised by the following elements: good eating habits, leisure, physical activity, friendship, treatment, psychological status, family and health (Figure 2).

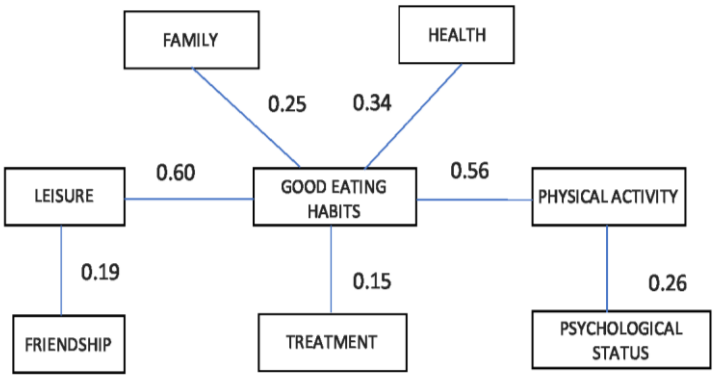

FIGURE 2: Maximum tree corresponding to the similarity analysis of the most frequent terms for the "Quality of Life" topic, evoked by the people living with HIV in the Mid-Paraíba region (n=79). Rio de Janeiro, Brazil, 2021.

"Good eating habits" is the term that establishes most connections with other cognitions, connecting with another five terms and maintaining a high similarity index with leisure (0.60) and physical activity (0.56).

The terms "leisure" and "physical activity" maintained the same number of visible links (two) with other terms, with leisure establishing a connection with good eating habits (0.60) and friendship (0.19); and physical activity with good eating habits (0.56) and psychological status (0.26). These elements are also connected to each other (0.40); therefore, according to the rules to prepare the tree, it was not possible to graphically show such connection.

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DISCUSSION

In the characterization of the group, it is noticed that there is a small difference in relation to the number of participants by gender. In studies carried out in the capital city of the state of Rio de Janeiro, this difference between the genders was more significant, reaching 64.8% for males[15,16]. In another study, closer data are observed, with the difference between the gender reaching 19.6%[17]. Papers with predominance of male individuals show a positive social representation of QoL, unlike those with predominance of the female gender[15].

The age group evidences a young population under 40 years of age, which follows the national trend in the context of the epidemic[18]. A fact that draws the attention is the low schooling level of people with HIV/AIDS in the region. Similar studies carried out in the capital city of the state of Rio de Janeiro describe a very different scenario, with more participants with Higher Education[15,16].

With regard to professional qualification and income, the data are negative, as they place participants at the mercy of underemployment with low wages. A study indicates that, even though they do not experience the stigma of the disease in the work environment, these people already anticipate in their emotions the possibility of undergoing such experiences related to prejudice and discrimination[19].

Almost the entire population under study reports not having any symptoms, either due to the infection and/or in relation to ART use, as well as a short time since diagnosis, and these data are similar to studies carried out with the populations of Rio de Janeiro and Macaé[7,20].

The sociodemographic data, especially the participants' clinical condition, suggests that it influences the positive representation they have of their QoL and, therefore, confirms that QoL can be expressed by multidimensional factors that can be of a personal, social, historical and cultural nature[4,9].

From the analysis of the data of the free evocations, it is observed that the elements that make up the possible central nucleus are seated on three dimensions: body, health-disease process and psychological, which are expressed in the terms good eating habits, health and psychological status, respectively.

The presence of the term “health” in the central nucleus reinforces the importance of this condition as a generator of meaning in the group's thinking. Thus, the group's QoL is anchored in health and well-being, and reinforces that, for individuals to understand that they can lead a life without the discomforts of diseases, they need to be healthy, leading them to reflect on health care habits[21].

The expression “good eating habits” is very recurrent in scientific productions that propose to evaluate QoL[5,7,21], where it makes up the possible central nucleus. This recurrence is grounded on common sense thinking, where individuals associate that eating properly can give them a better QoL by conceiving it as a practice that promotes good health in the context of a chronic disease.

Encouraging the consumption of healthy food products, as well as turning eating into a moment of satisfaction shared with family members and friends, are attitudes incorporated in the ten steps to promote QoL improvements in people living with HIV[22]. For the study participants, eating translates into self-care as a self-protection measure, incorporating new life habits, which also explains the relationship with health[23]. Thus, the group recognizes that good eating habits are fundamental to maintain or promote health, as stated in the Ministry of Health's Clinical Manual of Food and Nutrition in the care of HIV-infected adults[22].

The expression "·psychological status” appears as something innovative as a central element. In a study carried out in the state of Rio de Janeiro, the element appears in the second periphery of the capital city and not in the medium-sized municipalities of Niterói and Macaé[7].

It should be noted that, in this study, psychological status includes terms such as *having a good mind, positive thinking, carefree attitude, good thoughts* and *emotional control*, among others. Thus, psychological status comprises the mental state in which an individual is found, and can also be understood as the balance between the psychological and the emotional spheres[24].

The Mid-Paraíba region/RJ is outside the hustle and bustle of large centers, in a way of life where individuals value peace and the pursuit of activities that provide physical and mental well-being, which may justify the presence of this expression as a possible central element. In a study conducted with 281 people with HIV in large-sized cities from the state of Rio de Janeiro, the authors observed that 78% of the participants indicated a very positive evaluation in relation to how much they enjoyed life, that is, that they took advantage of the opportunities of activities that contribute for the promotion of well-being[25].

Research Article
Artigo de Pesquisa
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Thus, we can assert that psychological status is strongly aligned with health, in relation to the concept of health as physical and mental well-being, as well as with good eating habits, as mental well-being strongly interferes with eating habits.

In the first periphery we find the leisure, physical activity and family elements, with the first two integrating the body dimension and the third, the social dimension. The "leisure" and "physical activity" elements show the knowledge that the group has in relation to the importance of these aspects regarding self-care. In studies conducted in the state and municipality of Rio de Janeiro, elements similar to those found in this paper were also identified in the first periphery[5,7]. The attribution of a positive meaning to the same element with the self-care dimension[5] is described, and that leisure can be related to maintaining a healthy mind and body[7]. The term "family" shows the importance that part of the group attributes to family support for QoL, as it contributes to coping with the disease.

In the contrast zone, we can see the "living well", "financial condition" and "housing" elements, which fit into the psychological dimension and QoL determinants. It is considered that living well is associated with the psychological dimension, as it reflects a new lifestyle as a result of adapting to living with HIV.

The probably precarious economic situation of this group may have activated the expression "financial condition", as it is a situation that must be valued in the search for QoL, given its influence on material support, important for this group with so many demands for disease control. The term "housing" also reveals the thinking of a specific group. Income is the main cause of housing inequalities and, according to the Brazilian Institute of Geography and Statistics, 83% of the people who do not have their own home and live in precarious housing conditions earn incomes of less than three minimum wages[26]. Therefore, it must be considered that part of the group considers that, in order to have QoL, it is also essential to have the guarantee of good housing conditions.

It should be noted that, in the study's contrast zone, the strengthening of the possible central nucleus can be observed, with the expression "living well", which together with "psychological status", makes up the psychological dimension, evidencing the possibility of reinforcing the term "health". On the other hand, we can also observe a record of a specific and particular group, when we cross social data with the terms "financial conditions" and "housing", revealing a thought that differs from the general group of participants by valuing other factors that can influence QoL. According to the CNT assumptions[11], the contrast zone elements can reveal the existence of a subgroup of individuals with a different way of thinking than the general group, as observed in the study.

In the second periphery of the chart we can see the word "friendship", the most evoked in this quadrant, but in penultimate place in the evocation order, which shows recall of few participants in relation to the friendship bonds as a supporting element for QoL.

Also in the same quadrant and in relation to the term "treatment", it is assessed that it is directly related to self-care and that it can be understood as a transforming element, as it enables control of the problem and, consequently, living with the disease. The expression "health care", as well as "treatment", can also be understood as part of self-care and also as a transforming element, as health care is what will guarantee success in controlling the problem and disease, with repercussions on QoL.

Solidarity and religiousness have the same frequency. In the study carried out in the municipality of Rio de Janeiro, the term "solidarity" is also found in the second periphery and, for the author, this element has positive attributions and represents a dimension of caring for the other[5]. Regarding religiousness or spirituality, they can be considered as a source of social support for coping with the disease. The study conducted with people living with HIV in a medium-sized municipality from the state of Rio de Janeiro asserts the positivity of the term "religiousness", or, as stated by the author, spirituality, emphasizing its influencing importance in factors related to QoL[4].

The similarity analysis reveals the possibility of centrality of the term "good eating habits", as well as it evidences the possibility of the terms "leisure" and "physical activity" as candidates for the central nucleus of the representation.

The relationships established in the similarity tree between "good eating habits" and "treatment", health and family are highlighted. The relationship with the family can be associated with material aids that guarantees survival and important social support for QoL. Eating habits also influence the treatment as a whole, especially with drug treatment, as it reduces undesirable effects and assists in absorption, among other benefits.

The expression "good eating habits" also establishes strong connections with "leisure" and "physical activity", showing coherence in this relationship, constituting the body dimension. This triad can be interpreted as a reflection of knowledge and/or body care practices that the group considers important for QoL. Therefore, they are related to health promotion measures that are necessary for maintenance/recovery of health, with positive consequences on QoL.

Research Article
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Artículo de Investigación

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The term “leisure” also has a connection with the term “friendship”, which can be interpreted by the fact that these activities are carried out with friends. It also establishes a connection with the expression “physical activity”, whose relationship is consistent insofar as physical activities can be included in the list of leisure practices and can be developed with friends. These relationships evidence practices to promote health developed by the group and translate into a reflection of the good QoL they claim to have, in addition to revealing the self-care dimension as an important behavior for the concept of QoL[5].

The expression “physical activity” reveals knowledge and/or a form of body care practiced or considered important by the group. It can also be assumed that activation of this term is related to the guidelines provided by health professionals to these people, given the importance of practicing physical exercise in the context of treatment and body care, although it cannot be asserted that it is a usual practice in the group. In the study that relates physical activity and health indicators with 71 people living with HIV in the city of Ourinhos, São Paulo, low levels of physical activity were found in this population, as well as a higher prevalence of physical exercise during leisure time associated with higher social classes[27].

A number of studies point to physical activity for people living with HIV as an important beneficial action, acting on the clinical status and on the various psychological aspects that are altered to the detriment of the infection[28].

In addition to the links already mentioned, the expression “physical activity” also establishes a connection with the expression “psychological status”, reflecting a benefit that physical exercise brings to the improvement of people's mental health.

The *per se* analysis of the similarity tree structure makes it possible to infer that the three core meanings are formed by good eating habits, leisure and physical activity, expressing the group's knowledge about specific good practices for health promotion, or even carried out as a rule that guides them to obtain or maintain the necessary health to safeguard their QoL, thus evidencing a nucleus with a strong practical dimension. Then, it is around these nuclei of meaning orbit that the elements that have a causality, consequence or complementation relationship orbit, but which evidence another facet by showing themselves as more general health promotion actions.

The representational constitution is based on the body, psychological, health-disease processes, social and social determinants dimensions, which translate the group's social thinking, suggesting attention to health protection as a pillar for the pursuit or maintenance of QoL. Similarly to other studies with the same purpose[21,25], the current study contributed important elements that can be observed in the care of this population, as well as it offered useful information to support health policies in different regions of the country.

Study limitations

In view of the conditions imposed by the pandemic caused by the type 2 coronavirus, it was not possible to extend data collection with interviews as planned, configuring a study limitation, as it could confer a broader dimension of the meanings of the words evoked by the participants.

FINAL CONSIDERATIONS

The study made it possible to understand the social representation of QoL among people living with HIV in the Mid-Paraíba region and also to highlight the dimensions or conditions on which they rely in the search for this quality.

It is inferred that the social representation of the QoL of people living with HIV is related to health care and to the pursuit of well-being, important allies for QoL. To this end, the group values self-care, attributing importance to elements such as good eating habits, physical activities and leisure to help promote physical and mental well-being and maintenance of a good psychological status, supporting the search for improved QoL.

Bearing in mind that the social representations show the group's thinking about the representation object, it is considered that the result brings about an auxiliary contribution in the attention and provision of care to people, as well as in the health professionals' awareness for the best possible performance in their professional practices with this population segment.

The current study innovates in carrying out this type of methodology in small-sized municipalities located in the Mid-Paraíba region of the state of Rio de Janeiro. As future developments, it is suggested to conduct studies of the same nature in other municipalities both in this and in other states, with diverse social and cultural contexts, with the possibility of bringing about more contributions on the theme.

Research Article
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