ESCOLA ANNA NERY
REVISTA DE ENFERMAGEM
Anna Nery School
Journal of Nursing
Escuela Anna Nery
Revista de Enfermería

Escola Anna Nery Revista de Enfermagem
ISSN: 1414-8145
annaneryrevista@gmail.com
Universidade Federal do Rio de Janeiro
Brasil

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Escola Anna Nery Revista de Enfermagem, vol. 19, núm. 1, enero-marzo, 2015, pp. 132-139
Universidade Federal do Rio de Janeiro
Rio de Janeiro, Brasil

Esc Anna Nery 2015;19(1):132-139

Health promotion in a northeastern quilombola population - analysis of an educational intervention

Promoção de saúde em população quilombola nordestina - análise de intervenção educativa em anemia falciforme

Promoción de la salud en una población quilombola nordestina - análisis de intervención educativa en anemia falciforme

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Abstract

Objective: The aim was to develop an educational intervention in health for quilombola communities, providing guidance on the genetic risk for having children with sickle cell anemia (SCA), the oral manifestations of the disease, general notions of self-care, and genetic counseling. **Methods:** The pre-intervention sample was 267 individuals, of whom 230 attended the post-intervention phase. A questionnaire was applied pre- and post-intervention and frequency distribution was calculated and analyzed using the Chi-square test, considering a significance level of $p < 0.05$. **Results:** Pre-intervention, 72.3% of respondents did not know about SCA or its trait and 94.8% did not know the form of transmission; post-intervention, the latter index decreased to 32.6%, 60% reported having heard about the theme and 36.1% claimed to know about the subject. **Conclusion:** The intervention was positive and effective, and demonstrated the importance of offering quilombola communities a permanent health education and genetic counseling program.

Keywords: Anemia, Sickle Cell; Genetic counseling; Health education; African Continental Ancestry Group.

Resumo

Objetivo: Objetivou-se desenvolver uma intervenção educativa em saúde para comunidades quilombolas, visando à orientação sobre o risco genético de gerarem filhos com anemia falciforme (AF), as manifestações orais da doença, noções gerais de autocuidado e aconselhamento genético. **Métodos:** A amostra pré-intervenção foi de 267 indivíduos, destes, 230 participaram da etapa pós-intervenção. Aplicou-se um questionário pré e pós-intervenção e a distribuição de frequência foi calculada usando o teste Qui-Quadrado, com nível de significância de $p < 0,05$. **Resultados:** Pré-intervenção, 72,3% dos entrevistados desconheciam sobre traço e AF e 94,8% não sabiam a forma de transmissão; pós-intervenção, este último índice diminuiu para 32,6%, 60% relataram já ter ouvido falar sobre o tema e 36,1% alegaram conhecer o assunto. **Conclusão:** Evidenciou-se a efetividade positiva da intervenção e a importância de um programa permanente de educação em saúde e aconselhamento genético ser oferecido para comunidades quilombolas.

Palavras-chave: Anemia Falciforme; Aconselhamento genético; Educação em saúde; Grupo com ancestrais do continente Africano.

Resumen

Objetivo: Desarrollar una intervención educativa en salud para las comunidades quilombolas, visando la orientación sobre el riesgo genético para generar niños con Anemia de Células Falciformes (ACF), los tipos orales de la enfermedad, las nociones generales de autocuidado y el asesoramiento genético. **Métodos:** La muestra pre-intervención contó con 267 personas, de las cuales 230 asistieron la fase posterior. Se aplicaron cuestionarios pre y pos-intervención y se llevó a cabo la distribución de frecuencia y test Qui-Quadrado, con significado de $p < 0,05$. **Resultados:** Pre-Intervención, 72,3% de los encuestados desconocían el rasgo de células falciformes y ACF, y el 94,8% no conocían la forma de transmisión; después de la intervención, el último índice disminuyó para 32,6%, el 60% ya oyeron hablar sobre el tema, y el 36,1% afirmaron que lo conocían. **Conclusión:** Se demostró efectividad de la intervención y la importancia de un programa permanente de educación en salud para las comunidades quilombolas.

Palabras-clave: Anemia de células falciformes; Asesoramiento Genético; Educación en Salud; Grupo de Ascendencia Continental Africana.

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Submitted on 04/15/2014.
Accepted on 11/26/2014.

DOI: 10.5935/1414-8145.20150018

INTRODUCTION

Currently known as "quilombola communities", these population groups are "remnants of the quilombolas", which were communities set up by escaped African slaves, and are scattered throughout Brazil. The National Coordination for the Articulation of Black Rural Quilombola Communities (CONAQ) has highlighted the existence of more than three thousand communities in the country[1]. In Sergipe there are 25 quilombola communities certified by the Palmares Cultural Foundation[2].

Quilombola communities face many difficulties due to poor living conditions, the lack of effectiveness of public policies for social inclusion and the rediscovery of their history, identity and culture. Among the needs of the quilombola communities is the search for effectiveness of the exercise of the right to health[3].

Among the health problems of black Brazilians the occurrence of inherited diseases such as sickle cell anemia (SCA) can be emphasized. This is characterized by an alteration in the hemoglobin molecule (Hb), in which the exchange of the adenine nitrogenous base for the thymine base, encoding the amino acid valine instead of glutamic acid, resulting in the synthesis of hemoglobin S (HbS), a structural variable, rather than normal hemoglobin named HbA[4].

The self-declared occurrence of the sickle cell trait (Hb heterozygous) in the national black population is higher than in the other racial groups[5] which reflects the heterogeneous miscegenation process in Brazil and leads to the dispersion of the genetic alterations making SCA, for example, a disease present in all ethnic groups.

In a quilombola community, where the population is made up of individuals of African descent who often marry among each other, the chances of the occurrence of SCA remains high, making prevention, health education and genetic counseling strategies necessary.

In recent years the quilombola communities have become a priority target of Brazilian public policy. In this way, genetic counseling and genetic guidance have emerged as one of the options to guide individuals with some type of genetic alteration. However, considering that the quilombola communities have the same right to free and quality public health that the state should offer to all citizens, knowledge gained about the quilombola communities, especially in relation to health is precarious, being almost nonexistent. The invisibility of these subjects is observed within sociedade[3].

In the literature some authors have discussed the issues of justice and equity in relation to access to healthcare for the quilombola populations and, due to their history of socioeconomic vulnerability and social exclusion, they may need to be heard and included in healthcare actions to make the state fully responsibility with regard to ensuring health. These actions should work with empowerment covering cognitive, psychological and social aspects[6,7], promoting an interactive approach inspired by the ideas of Paulo Freire, applied in health education from the beginning of the 1990s[8].

Health promotion is an important tool to reduce inequalities in health and in populations and to enable individuals to fulfill their health potential, being based on the Ottawa Charter which contained its five principles of health promotion, among them the development of personal skills, to promote healthy choices, and the creation of supportive environments[9]. Among the strategies of this ruling that sought to go beyond behaviorist promotion based on changing lifestyles, the development of the capacity of the individual subjects and strengthening of community actions should be highlighted[7].

The Brazilian Ministry of Health recognizes that health promotion is essential for use in primary care from the elaboration of the Education Manual for Health and Self-care in Sickle Cell Anemia[10], which aims to train health professionals of the multidisciplinary team in the context of care for people with sickle cell anemia. Thus, these professionals can encourage and facilitate promotion actions in all healthcare levels.

In order to strengthen the individual capacities of the subjects and the community actions in quilombola communities, a model for coping with diseases that may affect these communities should be considered. The vulnerability of the quilombola population to sickle cell anemia due to genetic reasons raises different implications regarding the performance of health promotion actions. Thus, to facilitate strengthening of individual and community capabilities for coping with this problem, alternatives should be constructed that need to be understood conceptually.

It is recognized that the principles of equality and non-discrimination, which were enacted with the Declaration of Human Rights and confirmed by the III World Conference against Racism and Racial Discrimination, held in Durban in 2001, should be considered. In the report of this conference respect for human rights and fundamental freedoms for all, without distinction regarding race, color, sex, religion, political opinion, national and social origin, property, birth or other status, are encouraged and emphasized[11].

In this context, interventions in healthcare for sickle cell anemia in the quilombola population should be implemented as alternatives. The ethical issues involved, such as social inequity, which often includes the lack of access to services and even information, need to be considered. One of the interesting alternatives is genetic counseling to facilitate the understanding of individuals who need to take reproductive decision regarding genetic alterations and the best way to adapt to them[12]. This involves the performance of professionals, including nurses, trained to interpret the clinical and family histories in order to clarify how heredity contributes to the occurrence of SCA and the likelihood of having sick children, as well as diagnosis, treatment and prevention[13].

Another option would be genetic guidance, which is not synonymous with genetic counseling, as it is carried out with individuals who may be at risk of bearing children with SCA, without the need to make reproductive decision at the moment, for example, depending on the hemoglobinic genotype of a

future partner reproductive. The provision of genetic information is an educational process that aims to supply guidance on some genetic disease (SCA in the case of this study) to an audience not necessarily involved with this disease[14].

Health education is an important tool for nurses to guide the community, and when performing this the cultural representations of the target population need to be considered[15], in addition to seeking to construct knowledge in order to guide the population, in a general way, regarding all the factors that are related and may be the likely cause of the illnesses, aiming to form critical and aware citizens, rather than just transmit information[16].

The need for access to health information on sickle cell anemia and the trait, self-care and genetic counseling in the quilombola communities justified the design of an intervention study aiming to analyze the effectiveness of an educational intervention in sickle cell anemia and genetic counseling to the quilombola community of Patioba - SE.

The level of knowledge of individuals regarding this theme was identified in order to diagnose the information deficiencies, comparing the level of understanding of the population in question before and after the implementation of the intervention.

MATERIAL AND METHODS

This was an intervention study with a longitudinal design performed in the quilombola community of Patioba, Japaratuba, Sergipe, which has a current population of approximately 593 individuals in 160 families, with 323 over 18 years of age.

To compose the study sample the following inclusion criteria were used: to reside in the quilombola community of Patioba - SE, to be over 18 years of age, and to agreed to participate. The exclusion criteria were not being found at home on the days and times of the questionnaire application and failure to comprehend the questions.

At the time of the visit to the community the residents were invited to participate in the study, the purpose of it was explained and they were asked to read and sign the consent form. The study was approved by the research ethics committee of Tiradentes University under authorization Nº. 020512.

Data collection was performed using a semi-structured questionnaire to assess the level of knowledge of the study sample group regarding the trait and SCA, the mode of transmission of the disease, oral manifestations, caries concepts, self-care and genetic counseling, as well as the science of the occurrence in the family of individuals, whether they are carriers of the trait or SCA sufferers, and demographic data such as age, marital status, race/color and number of children of the participants.

This questionnaire underwent face validation by specialists, including three physicians, two with expertise in hemoglobinopathies and one in psychology, and another specialist with a master's in the SCA theme. After the validation, the instrument was subjected to a pre-test, with 10 individuals of the quilombola community of Patioba - SE, aiming to evaluate the suitability of the instrument, the application time and the comprehension difficulties of the respondents. After the validation of the instrument, it was applied in the first phase of the study for three days in January and February, 2013.

After the first application of the questionnaire, a folder was created and provided for individuals in the sample through an educational intervention in health and genetic counseling, considering some concepts, such as: genetic alteration; trait and SCA definition; most common oral manifestations, mode of transmission and diagnosis of SCA; self-care; likelihood that a couple would have a child with SCA, among other aspects.

For the development of the intervention, educational measures were introduced in accordance with the level of understanding of the study sample subject, evaluated through the previously administered questionnaire. The following tools were used: posters demonstrating the oral manifestations of SCA and caries, videos and slides on self-care, exhibition of figures demonstrating the clinical manifestations of SCA and mode of transmission, and the performance of dynamics by responding to questions from individual participants about the theme.

Through easy to understand language, themes were exposed, such as heterozygous, homozygous, blood composition, flow charts with the letters "A" and "S" to explain the concepts of genetic inheritance and the probability of sick children being born, self-care, and an explanation of the folder previously provided.

Considering the most frequent oral manifestations of SCA according to the oral health manual on sickle cell anemia[17], the following aspects were selected to be covered in the health education and counseling: pallor of the oral mucosa; smooth, discolored tongue; delayed teething; higher chance of having caries; periodontitis (inflammation of the gums); and tooth opacity. The characteristics of these manifestations were explained, as well as what prevention measures can be taken and self-care for alleviating the manifestations.

In order to direct the performance of the genetic counseling and genetic guidance, the results of the study of Assis[18] were considered, in which the occurrence of Hb in a sample of 318 individuals of the quilombola community of Patioba - SE was investigated, with it being found that 07 (2.2%) individuals, belonging to two households, carried the sickle cell trait.

The criterion for performing genetic counseling was the selection of heterozygous couples (AS), who were considering the reproductive decision, which in this study was only identified in one couple. Genetic guidance was performed with individuals who may have a genetic risk of bearing children with SCA, however, did not need to make any reproductive decision at the time of the development of this study. It should be noted that the professional who performed the genetic counseling and genetic guidance was a nurse, specializing in hematology and immunohematology.

During the genetic counseling and genetic guidance, questions were asked about the chances of individuals being born with SCA, the importance of early diagnosis, the clinical

manifestations, and the types of treatment for the disease, as well as the transmission mechanisms of the genetic alterations. After the genetic counseling and guidance the basic text of "Sickle cell anemia: know what it is and where to find treatment", of the Ministry of Health[19] was presented to the participants.

The educational intervention in health and genetic counseling was implemented in February and March, 2013. At the end of the implementation of the intervention, a questionnaire was applied, considering only the questions that evaluated the knowledge of individuals regarding the sickle cell trait, SCA and its oral manifestations, genetic counseling and self-care, in order to verify that the educational and counseling measures were absorbed by the population group in question.

According to the information covered in the educational intervention and contained in the folder provided, the appropriate answers to the open questions contained in the data collection instrument were defined as the primary outcome of this study.

Responses considered adequate regarding what SCA and the trait are, the difference between them and the form of transmission of the genetic alteration were: SCA is a genetic alteration that "passes" from parents to children and causes disease. The sickle cell trait is a genetic alteration that "passes" from parents to children and does not cause disease[19].

The adequate response for the definition of genetic counseling was: guidance provided by the health professional regarding the chances for a couple have a sick child[7] (in this case with sickle cell anemia).

In the question addressing the definition of caries, knowing that the Ministry of Health[17] defines caries as a multifactorial disease that causes deterioration of the teeth, an appropriate response was considered when caries was defined as "a disease that deteriorates the tooth or leaves it rotten".

When analyzing the question about the definition of self-care, based on the education manual on health and self-care in SCA[10], the following was considered to be an adequate response: "it is to take care of yourself"[10:25].

The analysis of the descriptive responses was performed through the content analysis technique[20]. From the definition of thematic groups, the data were transformed into quantitative variables. In the cases where it was necessary to transcribe some discourses, the subjects were identified by the letter "S" followed by the study participation number.

Frequency distribution of the variables studied was performed by analyzing the differences between the categories through the Chi-square test, with a significance level of $p < 0.05$.

RESULTS AND DISCUSSION

In the first stage (pre-intervention), the study sample was composed of 267 (82.6%) individuals. Three (0.92%) individuals who refused to participate and 53 (14.6%) who were not found at home on the days and times that the questionnaires were applied were excluded. From this initial sample, 230 (86.1%) participated in the second stage of the study (post-intervention), with 13.9% individuals excluded who did not come on the days of the application of educational interventions in health and genetic counseling, these being 28 men and 9 women.

Of the individuals of the first stage, 70.8% were women, predominantly in the age group 18 to 26 years and 29.2% men, predominantly aged between 18 and 19 years. By analyzing the individuals regarding self-reported color/race, 2.2% of them declared themselves white, 2.6% yellow, 7% Indians, 32.6% mixed, and 61.8% black. The predominance of the black color/race was expected since the quilombola communities are mostly composed of people of African descent.

In evaluating the number of children associated with the marital status, it was observed that 23 (28%) women and 7 (21.2%) men were single and had children (Table 1), demonstrating that these individuals could still constitute a family and have children with people from their own community.

At the end of the questionnaire application, it can be seen that 72.3% (n = 267) of the sample subjects did not posses adequate comprehension of sickle cell anemia and the trait and 95% did not know the mode of transmission of SCA. The familial occurrence and degree of kinship of SCA or the sickle cell trait was unknown for 68.9% of the sample. These data guided the implementation of the educational intervention in the context of sickle cell anemia providing genetic counseling, in order to improve the knowledge deficit of the population in question on the subject of the study.

In this scenario, coping with racial inequities has been given greater attention by the federal government, since the creation of the Special Secretariat for the Promotion of Racial Equality (Seppir), in 2003. Such inequities have been addressed by the implementation of policies for the valorization of black identity and by initiatives to promote equality and equity in the access to public services (health, education, social security, social assistance) and to the labor market[21].

In order to promote equality and equity, this study provided genetic counseling in the quilombola community of Patioba - SE, performing this at the headquarters of the Residents Association of the Quilombola Community of Patioba - SE, with 01 (one) couple who had a child with the sickle cell trait, with the wife having HbS and the man having carried out a laboratory test to check for HbS, totaling two (02) individuals who might have to make a reproductive decision.

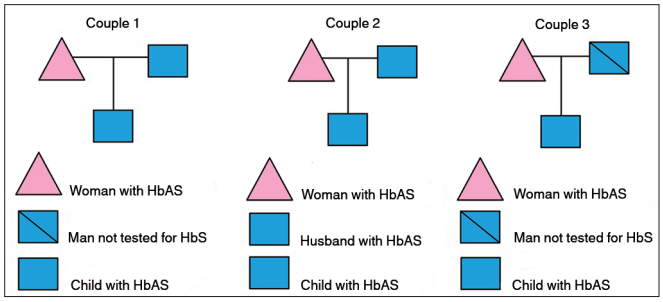
The risk of children with SCA being born was measured by creating a heredogram of the couple (couple 1) who had genetic risk at the time of the intervention (Figure 1), from the genotype presented by parents based on the results of the examination to search for HbS previously performed by Assis[18]. The genetic guidance was performed with one couple (couple 2) in which the woman did not have HbS, however, her husband and son had sickle cell trait and another couple (couple 3) composed of a divorced woman (who presented HbA and had a son with the sickle cell trait) and her current partner who had not been tested in the HbS study (Figure 1).

Table 1. Distribution of individuals according to gender, marital status and number of children - quilombola community of Patioba. Japaratuba, SE, Brazil, 2013

Gender	Marital status	Have children?			
		No		Yes	
		AF* (n)	RF** (%)	AF* (n)	RF** (%)
Female	Married	10	14.3	89	74.8
	Divorced	1	1.4	2	1.7
	Single	59	84.3	23	19.3
	Widowed	0	0	5	4.2
Total		70	100	119	100
Male	Married	6	19	37	80.4
	Divorced	0	0	1	2.2
	Single	26	81	7	15.2
	Widowed	0	0	1	2.2
Total		32	100	46	100

** Relative frequency; * Absolute frequency.

Figure 1. Heredogram of the couple with genetic risk of having children with sickle cell anemia and of the couples involved with the genetic alteration of SCA without the need for reproductive decision - quilombola community of Patioba - SE - 2013.



After conducting the genetic guidance with the couples mentioned, it was also held with another five individuals, as shown in Table 2.

Following the implementation of the educational intervention (n = 230), it was perceived that a significant portion of the population ($p < 0.0001$) of the sample, 60.0%, reported having heard about the trait and SCA, 36.1% claimed to have knowledge on the subject and only 3.9% said they had no knowledge about the trait or SCA. Considering the results of the first stage of the study (pre-intervention) (n = 267), it was noted that 72.3% of the subjects reported having no knowledge about sickle cell anemia and the trait, demonstrating good results for the instituted intervention (Figure 2).

It should be noted that these results are in line with regulation Nº. 1.391/2005, which instituted the National Policy for Integral Care to People with sickle cell disease (SCD) and other hemoglobinopathies, targeting the organization of the service network for sufferers[22]. Through this regulation it became possible to encourage research in order to improve the quality of life of people with SCD and other hemoglobinopathies, and promote access to information and genetic counseling for families and individuals with the trait or sickle cell anemia[23].

Regarding the differences between the trait and SCA, when comparing the results of the stages of the study, it was noted that in the pre-intervention stage 97.4% of the subjects reported not knowing the differences between the trait and SCA, and only 2.6% claimed to have knowledge on the subject ($p < 0.001$). The implemented educational intervention had a positive effect, as after its performance it was found that there was a significantly higher percentage (44.8%) of individuals who had heard about the issue in question, compared with 20.4% who claimed not to have knowledge and 34.8% who claimed to have knowledge ($p < 0.001$).

The results of this study showed that in the pre-intervention stage the significant majority of the individuals (94.8%) said they did not know the mode of transmission of the disease and in the post-intervention stage this percentage decreased to 32.6%. Furthermore, in the pre-intervention stage 5.2% of the individuals claimed to know how transmission occurs and post-intervention this percentage rose significantly to 67.4% ($p < 0.0001$).

In assessing only the post-intervention responses concerning the mode of transmission of SCA, it was seen that the majority of the individuals, 43.1%, answered "from parents to their children", which was considered an adequate response. Another frequent response, 12.4%, was "through the blood", a response that can be considered partially adequate, as it denotes that the individual localized the body portion involved in the pathogenic process, although not the correct transmission mechanism. A total of 27.7% did not know ($p < 0.001$). Responses were observed that differed from those previously presented, which are described below:

The SCA is manifested differently in each individual. (S65).

The blood becomes weak. (S86).

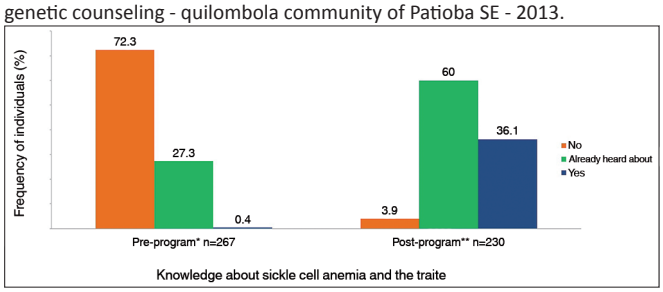
It causes disease. (S164).

Table 2. Implementation of genetic counseling for the individuals involved in the genetic alteration of SCA, without the need to make a reproductive decision - quilombola community of Patioba. Japaratuba, SE, Brazil, 2013

Marital status	Relationship with individual (s) with genetic risk of bearing children with SCA	Has HbAS?*	Has HbA?**
Single	None	Yes	No
Married	Cousin with HbAS	No	Yes
Single	Cousin with HbAS	No	Yes
Married	Niece with HbAS	No	Yes
Divorced	Son and two nephews with HbAS	No	Yes

** Normal hemoglobin A (without sickle cell trait); * Carrier of hemoglobin S - Heterozygous (sickle cell trait).

Figure 2. Distribution of individuals according to claiming to know what anemia and the sickle cell trait are, before and after the health education program and genetic counseling - quilombola community of Patioba SE - 2013.



In a study by Silva[24] in the quilombola community of Caiana dos Crioulos in the state of Paraíba, over 60% of the subjects (22% women and 16% men) said they had heard of sickle cell disease, with only two women 2.3% (mothers of children with SCA) knowing that the disease is hereditary, and 97.7% not knowing the mode of transmission of SCA, a similar profile to the quilombola community of Patioba prior to the program.

The pre-intervention definition of genetic counseling was unknown for 89.9% of the sample, 9% had heard of it and only 1.1% claimed to know what genetic counseling is ($p < 0.0001$). In the post-intervention stage there was a significant predominance (55.2%) of individuals who had heard about the issue and 18.7% said they knew what genetic counseling is ($p < 0.0001$). Probably the change in the knowledge level of the community regarding this concept can facilitate family planning due to seeking genetic counseling in the Primary Health Units (PHUs).

After the intervention, 22.5% did not know what genetic counseling is, 28.5% claimed to have knowledge on the subject, however, could not explain it. The most common definitions were:

> *[...] it is to council, to explain about the disease (S40);*
>
> *[...] the healthcare professional explains to the person whether she could have a sick child (S82);*
>
> *[...] it is something that passes from generation to generation (S101).*

Given the above, it was noted that for the counseling to be better received, the population needs to have knowledge of what genetic counseling is, what the aims are and what benefits can be obtained. The provision of this service currently extends to the public services through the Brazilian National Health System (SUS), private clinics and those attending health insurance patients[25].

The oral health aspects were included as part of the genetic counseling script, as the oral manifestations of SCA may be the first signs of deterioration of the condition. In this scenario, the concept of caries was highlighted, with 36.3% of the sample presenting no knowledge on the subject in the pre-intervention stage, while the majority of the study population, 63.7%, claimed to know what caries is and 56.9% said that they observed their oral cavity. However, it was evident that the oral health care could be improved in the self-care practice, as 59.5% said they did not use dental floss, this being primary care to prevent periodontal disease.

In the analysis of the pre-intervention descriptions of individuals regarding what caries is, only 3.7% described caries adequately. After the educational intervention, there was a significant reduction of 28.5% of those not knowing about cavities, demonstrated by the frequency of 92.2% of individuals who claimed to know what caries is. It was perceived that there was a prevalence of 28.8% of the response "a disease that ruins your teeth", considered appropriate according to the previously established criteria, 21% of the description "it is a bacterium that destroys the tooth", 11.6% cited "bad/rotten teeth" and 10.5% said "a filling which is in the tooth", which suggests that these individuals understood that caries is a disease caused by bacteria.

Epidemiological studies on the occurrence of caries in people with SCA are scarce. Rodrigues, Menezes and Luna[26] reported that these individuals should remain under the permanent control and maintenance of oral health, as dental infections may precipitate the sickle cell crises. It is noteworthy that these individuals are more likely to manifest caries, periodontitis and other oral problems, which, according to Brasil[17] may be aggravated when a person presents a deficit of self-care in relation to oral health.

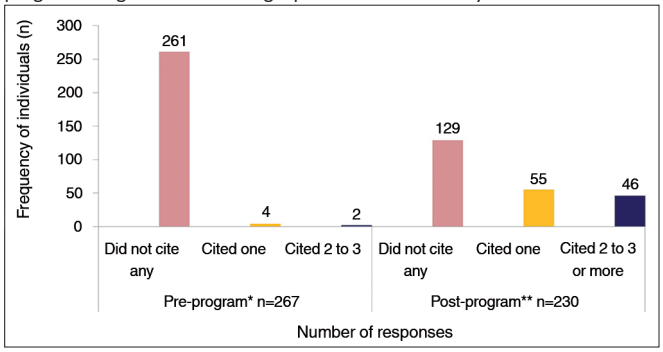
The importance can be noted of guidance for patients with SCA in relation to the oral manifestations of the disease, to identify early any change in clinical status, warning of the severity and

progression of the disease, thus allowing the adoption of measures to remedy or minimize such manifestations. Therefore, the guidelines on oral health for individuals with SCA were introduced into this study as a component of the health education program and genetic counseling.

It is emphasized that in the pre-intervention stage the majority of the population, 97.8% did not have knowledge of the oral manifestations of the SCA, while 73.7% went to a dentist from one to three times annually. Only 1.5% cited an oral manifestation and 0.7% cited two to three manifestations. This reflects the lack of guidance related to oral health in SCA during consultations with the dentist, even being a population with genetic risk, making clear the need for guidance for quilombola individuals.

In the pre-intervention phase, the lack of knowledge of the population regarding the oral manifestations in SCA was significantly reduced, as the index for the knowledge of at least one manifestation rose to 23.9%, 17% cited 2 manifestations and 3% cited 3 or more manifestations, compared to only 0.7% that mentioned from 2 to 3 manifestations prior to the intervention ($p < 0.0001$) (Figure 3).

Figure 3. Distribution of individuals in relation to knowledge of the oral manifestations of sickle cell anemia, before and after the health education program and genetic counseling - quilombola community of Patioba SE - 2013.



The understanding about self-care was another aspect addressed in this study. Prior to the intervention it was observed that 70.8% of the subjects had knowledge about self-care, however, post-intervention 90% of the individuals claimed to understand what self-care is. In the pre-intervention stage 21.7% adequately defined self-care, however, among the other responses, many were incomplete although possessed part of the adequate content:

> *[...] it is brushing your teeth every day (S51, S164, S165, S176);*
>
> *[...] having good personal hygiene (S73, S92, S124);*
>
> *[...] it is to avoid/prevent diseases (S72, S184).*

The program was efficient in the context of self-care, as after the intervention, 65.2% adequately defined self-care. The promotion of self-care should be practiced by nurses based on Orem's self-care theory. This theory has the potential to influence nursing actions in situations where self-care is deficient and, added to health education, may have the ability to provide healthier conditions for the pacient[27].

It was evidenced that the guidance regarding the sickle cell trait, SCA, its oral manifestations, its transmission, genetic counseling and self-care in the quilombola community of Patioba fall within the health needs of the population and could be implemented as part of the Family Health Strategy (ESF), as a premise to reduce the social inequities in health.

The Ottawa Charter also recommended the implementation of a reorientation of health services, which should take place with the expansion of curative and clinical approaches and the strengthening of actions aimed at the promotion and the integral practice of health, including changes in the attitudes of the healthcare professionals. Such changes could occur through educational and entertainment processes, with new organizational formats that include the professionals from the service providing institutions and the community[7].

In this sense, as a secondary outcome of the study, the provision of a permanent program of health education and genetic counseling in SCA was shown to be important. This would be performed in the Family Health Unit (FHU) where the quilombola community of Patioba - SE is registered, and would educate individuals about the probability of having sick children. This would make the reproductive decision concerning the possibility of the occurrence of SCA a conscious issue and help to improve access to health information and self-care in this population.

CONCLUSION

The educational intervention in sickle cell anemia and genetic counseling were positively effective, as there was significant improvement in the knowledge of the study population about SCA and its trait, its oral manifestations, genetic counseling, and health related self-care after its implementation. The importance of educational strategies being part of nursing actions directed toward the construction of knowledge of the clients for the practice of self-care and health maintenance was demonstrated.

This study provided this community with access to information prior to the reproductive decision of individuals with a genetic risk of having children with SCA, considering that the majority, 79% (211), were of reproductive age between 18 and 49 years.

REFERENCES

1. Chasin ACM. Direitos étnicos, conflitos fundiários: a judicialização da disputa pelos territórios quilombolas. Revista Olhares Sociais. 2012; (1):39-60.
2. Ministério da Cultura (BR). Fundação Cultural dos Palmares - FCP. Certidões expedidas às comunidades remanescentes de quilombos (CRQs); 2013; [acessado 2013 nov 14]. Disponível: http://www.palmares.gov.br/wp-content/uploads/2013/06/1-crqs-certificadas-ate-10-06-2013.pdf

3. Alves LPS, Alves DMC. Programa Brasil quilombola e a efetivação do direito à saúde na comunidade quilombola de palmas, PR. Simpósios Nacionais de Tecnologia e Sociedade. IV Simpósio Nacional de Tecnologia e Sociedade, UTFPR Curitiba, Paraná, Brasil; 2011; agosto; 29. Curitiba (PR): UTFRP; 2011. Disponível em: http://ct.utfpr.edu.br/ocs/index.php/tecsoc/2011/paper/view/396.
4. Stypulkowski JB, Manfredini V. Alterações hemostáticas em pacientes com doença falciforme. Rev. bras. hematol. hemoter. 2010;32(1):56-62.
5. Jesus JA. Doença Falciforme no Brasil. Gaz. Med. Bahia. 2010;80(3):8-9.
6. Vieira ABD, Monteiro PS. Comunidade quilombola: análise do problema persistente do acesso à saúde, sob o enfoque da Bioética de Intervenção. Saúde debate. 2013; 37(99):610-8.
7. Carvalho SR. Promoción de la Salud, "empowerment" y educación: una reflexión crítica como contribución a la reforma sanitaria. Salud colectiva. 2008;4(3):335-47.
8. Ciryno AP, Schraiber LB, Teixeira RR. Education for Type 2 Diabetes Mellitus Self-care: from compliance to empowerment. Interface: Comunicacao, Saude, Educacao. 2009;13(30):93-106.
9. World Health Organization - WHO. The Ottawa Charter for Health Promotion. Ottawa (CAN): WHO; 1986.
10. Ministério da Saúde (BR), Secretaria de Atenção à Saúde. Departamento de Atenção Especializada. Manual de Educação em Saúde. Autocuidado na Doença Falciforme. Série A. Normas e Manuais Técnicos. Brasília (DF): Ministério da Saúde; 2008.
11. Organização das Nações Unidas - ONU. Declaração e Programa de Ação da III Conferência Mundial de Combate ao Racismo, a Discriminação Racial, a Xenofobia e as Formas Conexas de Intolerância. Nova Iorque (EUA): ONU; 2002.
12. Robson ME, Storm CD, Weitzel J, Wollins DS, Offi, K. American society of clinical oncology policy statement update: genetic and genomic testing for cancer susceptibility. Journal of Clinical Oncology. 2010;28(5):893-901.
13. Chieng WS, Chan N, Lee SC. Non-directive Genetic Counselling - Respect for Autonomy or Unprofessional Practice? Ann. Acad. Med. Singapore. 2011; 40(1):36-42.
14. Ministério da Saúde (BR). Manual de informação e orientação genética em herança falciforme. Brasília (DF): Ministério da Saúde; 2010.
15. Santos DS, Andrade ALA, Lima BSS, Silva YN. Sala de Espera para Gestantes: uma Estratégia de Educação em Saúde. Rev. bras. educ. med. 2012;36 (Supll.2):62-7.
16. Roecker S, Marcon SS. Educação em saúde na Estratégia Saúde da Família: o significado e a práxis dos enfermeiros. Esc Anna Nery. 2011;15(4):701-9.
17. Ministério da Saúde (BR). Secretaria de atenção à saúde. Departamento de atenção especializada. Manual de Saúde Bucal na Doença Falciforme. Brasília (DF): Ministério da Saúde; 2007.
18. Assis LS. Estudo das síndromes falcêmicas em comunidade quilombola, Sergipe/Brasil [dissertação]. Sergipe: Programa de Pós-Graduação em Saúde e Ambiente, Universidade Tiradentes; 2010.
19. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Departamento de Atenção Especializada. Doença falciforme: saiba o que é e onde encontrar tratamento. Brasília (DF): Ministério da Saúde; 2012.
20. Bardin L. Análise de conteúdo. Lisboa (POR): Edições 70; 2009.
21. Instituto de Pesquisa Econômica Aplicada - IPEA. Boletim - Políticas Sociais: acompanhamento e análise. 2006; [acesso 2013 nov. 23];(12). Disponível em: http://www.ipea.gov.br/082/08201002.jsp?ttCD_CHAVE=2651.
22. Bonini-Domingos CR. Programa de triagem neonatal de hemoglobinopatias - uma reflexão. Rev. bras. hematol. hemoter. 2010; 32(2):99.
23. Portaria GM/MS nº 1.391, de 16 de agosto de 2005. Institui no âmbito do Sistema Único de Saúde, as diretrizes para a Política Nacional de Atenção Integral às Pessoas com Doença Falciforme e outras Hemoglobinopatias. Diário Oficial da União, Brasília (DF), 17 ago 2005: Seção 1: 1.
24. Silva JAN. Condições sanitárias e de saúde em Caiana dos Crioulos, uma comunidade Quilombola do Estado da Paraíba. Saude Soc. 2007;16(2): 111-24.
25. Jorde LB, Carey JC, Bamshad MJ, White RL. Genética Médica. Rio de Janeiro: Editora Elsevier; 2010.
26. Rodrigues MJ, Menezes VA, Luna ACA. Saúde bucal em portadores da anemia falciforme. Rev. gauch. odontol. 2013;61:505-10.
27. Vitor AF, Lopes MVO, Araujo TL. Teoria do déficit de autocuidado: análise da sua importância e aplicabilidade na prática de enfermagem. Esc Anna Nery. 2010 jul/set;14(3):611-6.