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Article

Right to health of the population with albinism: an academic training experience

Direito à saúde da população com albinismo: uma experiência de formação acadêmica

Derecho a la salud de la población con albinismo: una experiencia de formación académica

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Abstract

Objective: to report on the experience of conducting a training workshop on the right to health of persons with albinism. **Methodology:** this is a descriptive study, with a qualitative approach, of the experience report type, about a training workshop aimed at academics and health professionals from the Nursing, Medicine, Psychology and Social Work courses, developed by the Right to Health and the Brazilian Unified Health System Extension Project. **Results:** the workshop was divided into three work stations, which looked at breaking down stigmas related to albinism, the biopsychosocial

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aspects of albinism and health care policies for this population, with an emphasis on the National Policy for Comprehensive Health Care for People with Albinism. The discussion was guided by a self-assessment form on the participants' knowledge and attitudes towards albinism. Thus, through the use of an active teaching methodology and the collaboration of people who are part of the population in question, it is possible to contribute to the training of the professionals/academics involved by making them question the invisibilization of issues related to the individuality of people with albinism as well as their particularities in terms of health demands. **Conclusion:** in view of the lack of a biopsychosocial approach to the health of the population with albinism during undergraduate courses in the health area, the workshop was an important tool for breaking the cycle of invisibilization and denial of the right to health of people with albinism.

Keywords: Albinism; Health of Ethnic Minorities; Right to Health.

Resumo

Objetivo: relatar a experiência de condução de uma oficina de formação acerca do direito à saúde das pessoas com albinismo. **Metodologia:** tratou-se de um estudo descritivo, de abordagem qualitativa, do tipo relato de experiência acerca de uma oficina de formação voltada para acadêmicos e profissionais da saúde dos cursos de Enfermagem, Medicina, Psicologia e Serviço Social, desenvolvida pelo Projeto de Extensão, denominado, Direito à Saúde e ao Sistema Único de Saúde. **Resultados:** a oficina foi dividida em três estações de trabalho que contemplaram as categorias: o rompimento de estigmas relacionadas ao albinismo, os aspectos biopsicossociais do albinismo e a as políticas de atenção à saúde dessa população, com ênfase na Política Nacional de Atenção Integral à Saúde das Pessoas com Albinismo. Como instrumento norteador da discussão, houve a elaboração de um formulário de autoavaliação sobre os conhecimentos e atitudes dos participantes em relação ao albinismo. Assim, a partir do uso de uma metodologia ativa de ensino e da colaboração de pessoas que fazem parte da população em questão, pode-se contribuir com a formação dos profissionais/acadêmicos envolvidos ao fazê-los questionar a invisibilização das questões relacionadas a individualidade do sujeito com albinismo, bem como as suas particularidades no que tange às demandas de saúde. **Conclusão:** tendo em vista a ausência de uma abordagem biopsicossocial no que se refere à saúde da população com albinismo, durante as graduações na área da saúde, a oficina constituiu-se enquanto uma ferramenta importante para o rompimento do ciclo de invisibilização e negação do direito à saúde das pessoas com albinismo.

Palavras-chave: Albinismo; Saúde das Minorias Étnicas; Direito à Saúde.

Resumen

Objetivo: relatar la experiencia de realización de un taller de capacitación sobre el derecho a la salud de las personas con albinismo. **Metodología:** re trata de un estudio descriptivo, con abordaje cualitativo, del tipo informe de experiencia, sobre un taller de capacitación dirigido a académicos y profesionales de salud de los cursos de Enfermería, Medicina, Psicología y Trabajo Social, desarrollado por el Proyecto Derecho a la Salud y Extensión del Sistema Único de Salud de Brasil. **Resultados:** el taller se dividió en tres estaciones de trabajo, que abordaron la ruptura de los estigmas relacionados con el albinismo, los aspectos biopsicosociales del albinismo y las políticas de atención a la salud de esta población, con énfasis en la Política Nacional de Atención Integral a la Salud de las Personas con Albinismo. Como herramienta orientadora de la discusión, se elaboró un formulario de autoevaluación sobre los conocimientos y actitudes de los participantes frente al albinismo. A través del uso de una metodología didáctica activa y de la colaboración de personas que forman parte de la población en cuestión, fue posible contribuir a la formación de los profesionales/académicos involucrados haciéndoles cuestionar la invisibilización de cuestiones relacionadas con la individualidad de las personas con albinismo, así como sus particularidades en términos de demandas de salud. **Conclusión:** dada la falta de abordaje biopsicosocial de la salud de la población con albinismo durante los cursos de pregrado en salud, el taller fue una herramienta importante para romper el ciclo de invisibilización y negación del derecho a la salud de las personas con albinismo.

Palabras clave: Albinismo; Salud de las Minorías Étnicas; Derecho a la Salud.

Introduction

Albinism is a genetic condition in which there are one or more alterations in the genes related to the synthesis of melanin, the biological molecule responsible for coloring the eyes, skin and hair of human beings. Thus, individuals affected by this condition have phenotypic changes marked by a reduction or absence of color in a given affected region or throughout the body, depending on the type of albinism that affects them(1).

According to Silva *et al.*(2)it is possible to classify albinism as "non-syndromic" and "syndromic". Non-syndromic albinism is classified as: 1) ocular albinism, in which the involvement of ocular tissues occurs in a restricted way, with manifestations that affect eye color and visual acuity, and may have repercussions on the appearance of ocular alterations such as congenital nystagmus, for example; 2) partial albinism, which, due to alterations in the formative processes of the human being, still as an embryo, causes an alteration in the distribution of pigmentation in the body of the affected subject, resulting in hypopigmented parts and parts without perceptible alterations; 3) oculocutaneous albinism, characterized as an autosomal recessive syndrome, which affects the eyes, skin and hair, and is related to alterations in the OCA genes (1 - 8), with subtle distinctions between the types of albinism.

In turn, the syndromic variations of the condition are revealed in the presence of albinism and its phenotypic repercussions, added to a set of signs and symptoms, which go beyond the classic ocular and dermatological alterations of the non-syndromic versions(2). The main syndromic variations of albinism are Hermansky-Pudlak Syndrome (HPS) and Chediak-Higashi Syndrome (CHS)(1),but there are also other syndromes that can affect people, such as Cross, Bergsma and Kayser-Kupper, François-de Rouck, Ziprokowski-Margolis, Angelman, Prader-Willi, Waardenburg and Griscelli syndromes(2).

The phenotypic changes produced by albinism contribute to alterations in the health-disease process of those affected. From a biomedical/physiological point of view, the individual with oculocutaneous albinism (OCA), the most common, will be more prone to developing skin lesions caused by solar radiation, as a result of their low protection against ultraviolet rays due to low or no melanin production and ocular alterations. As for the psychological effects, the difficulties are related to the construction of an identity as a subject, given that skin color is socially observed as a mark of difference between subjects in their process of inclusion in social groups. The lack of inclusion of these individuals in social groups makes them victims of *bullying* and/or myths/legends related to their genetic condition, such as the supposed magic inherent in their light skin color(3).

With regard to the epidemiology of albinism, there are few worldwide studies aimed at identifying the incidence of albinism. Magalhães *et al.*(4) compiled worldwide data on its epidemiology and established that there is an average global incidence of 1:20,000 individuals with albinism. Despite this, the distribution of the genetic condition is not homogeneous, with some places having a higher incidence of people with albinism than others, such as the indigenous peoples of the Cuna ethnic group, where the incidence is 6.3 people with albinism for every 1,000 live births.

In Brazil, there are an estimated 21,194 people with albinism, of whom 1,362 were seen by Primary Health Care and were diagnosed albinism there, recorded as part of Metabolic Disorders (ICD-10 E70.3) in their electronic medical records(5). In addition to data from the Primary Health Care Health Information System (Sisab/Saps), there are data from the National Census of Isolated Populations

(Ceniso), which analyzes genetically isolated populations, identifying specific genetic conditions with a higher than expected incidence, called *clusters,* including albinism(5).

In all, Ceniso identified 12 reports of albinism *clusters*, of which one was excluded because it was a duplicate entry, nine are in the process of being investigated and two were located in the Northeast region and confirmed through genetic testing. In the state of Alagoas, where this study was carried out, there are reports of a *cluster of* albinism in the Filús quilombo community, in the municipality of Santana do Mundaú, located in the Zona da Mata region of Alagoas. The phenomenon of albinism in the community has already been investigated from an anthropological perspective(6) but not from the point of view of epidemiology and the conditions of access to health.

Observing the issues related to phenotypic distinctions and the impact of the genetic condition on their health-disease process, the health care provided by professionals is specific, which requires knowledge of the condition and forms of intervention to prevent and treat it, from a perspective that breaks with the purely biomedical model of care. In order for this to be possible, the health of people with albinism needs to be studied from the time health professionals graduate, going beyond genetics classes that deal with albinism as a hereditary and recessive disorder, but understanding the particularities of caring for the affected individual.

Based on the above, and taking into account the particular epidemiological reality of the state of Alagoas, this paper aims to report on a training workshop on the right to health for people with albinism, aimed at academics and health professionals from the Nursing, Medicine, Psychology and Social Work courses, linked to the Federal University of Alagoas, Arapiraca *campus.*

Methodology

This is a descriptive study, with a qualitative approach, of the experience report type. The experience report is a type of scientific production that records and discusses experiences that can come from field research, teaching activities, university extension projects, intervention actions in professional practice, among others. There are no international instruments to guide the systematization of writing an experience report, as there are for other research methods, so this report is based on the study carried out by Mussi, Flores and Almeida(7) who establish, based on world literature, the assumptions for writing an experience report that is relevant to scientific knowledge.

The experience took place in December 2023 and was part of an event entitled "The right to health and the SUS: health policies for vulnerable populations and popular participation in health", which was held at the Medical and Nursing Sciences Complex (CCME), located on the Arapiraca *Campus* of the Federal University of Alagoas, in the municipality of Arapiraca in the state of Alagoas. The event and action were organized by the Right to Health and SUS Extension Project (PROEDSS), which is developed in a multidisciplinary way on *campus*.

Regarding the municipality in which the dynamics took place, about ¼ of its population has already been investigated for the presence of albinism, although the investigation was not intended to produce epidemiological data, it was possible to establish that, within the population studied, there was an incidence of albinism of 1:13,930 people with albinism(1). By comparing this incidence with global estimates, which are approximately 1:20,000(4) we can hypothesize that the municipality has a higher incidence than that established worldwide, which makes it a suitable field for interventions aimed at the health care of people with albinism.

The experience in question is a workshop on the right to health for people with albinism, aimed at academics and professionals from the Nursing, Medicine, Psychology and Social Work courses. It is conducted by Nursing, Psychology and Medicine academics and supervised by a teacher with experience in caring for people with albinism. In addition, representatives of the population with albinism contributed to the development of the action.

As this is an experience report, in which the data presented comes from the perception of the authors and other public materials related to the experience, this work does not require submission to the Research Ethics Committee (CEP) of the Federal University of Alagoas, where it was conducted.

Results and discussion

In order to help explain the results and conduct the discussion in detail, this session will look at how the workshop was carried out according to its stations, correlating the literature on which it was based with the results obtained. In addition, notes will be made on the relevance of the workshop and its replicability for promoting teaching about albinism in an interactive way for academics and health professionals.

The workshop was divided into three stations: Station 1 - Breaking down stigmas related to Albinism; Station 2 - Pathophysiological, epidemiological and diagnostic aspects of Albinism; and Station 3 - National Policy for Comprehensive Health Care for People with Albinism. The division was justified by the need to understand the right to health as something multidimensional, ranging from the experience of individual care of these subjects in public health services to legislation that serves as a framework for public policies.

In all, 45 people took part in the workshop. Of these, 40 were undergraduate students - 23 from the bachelor's degree course in nursing, seven from the bachelor's degree course in psychology, six from the bachelor's degree course in medicine and four from the social work course - and the other five subjects were professionals who had already graduated and were working in the care and/or management of health services, one of whom was a family and community health doctor, two health nurses and two social workers. All the participants were present at the three stations held during the workshop.

The predominance of nursing students is justified by the close link between the extension project, which organized the event, and the course, given that the Complex of Medical and Nursing Sciences (CCME), which hosted the event, is the place of study for these students.

Station 1 - Breaking down stigmas related to Albinism

At first, as a way of starting the workshop and guiding the work stations to be conducted, the participants answered a self-assessment questionnaire about albinism. The questionnaire consisted of 14 multiple-choice questions, focusing on the theme of caring for the person and their personal relationship with albinism, as can be seen in the table below:

Box 1. Questionnaire used in the dynamic

Questions	Alternatives
1. Do you know the cause of Albinism?	( ) Yes; ( ) No
2. Do you think Albinism is inherited?	( ) Yes; ( ) No
3. Do you know what to do to help a person with Albinism?	( ) Yes; ( ) No
4. Do you think Albinism is contagious?	( ) Yes; ( ) No

5. Do you think a person with Albinism will go blind?	( ) Yes; ( ) No
6. Can a person with Albinism have a child with Albinism?	( ) Yes; ( ) No
7. Can people with Albinism learn to read and write?	( ) Yes; ( ) No
8. Do people with Albinism need special food?	( ) Yes; ( ) No
9. Can a person with Albinism go to school?	( ) Yes; ( ) No
10. Can people with Albinism get skin cancer from exposure to the sun?	( ) Yes; ( ) No
11. Is a person with Albinism bewitched?	( ) Yes; ( ) No
12. How would you feel visiting the home of a person with albinism?	( ) I wouldn't have much of a problem ( ) I wouldn't have a problem ( ) I would have a problem ( ) I'd have a big problem
13. How would you feel about a person with albinism in your office?	( ) I wouldn't have much of a problem ( ) I wouldn't have a problem ( ) I would have a problem ( ) I'd have a big problem
14. How would you feel serving a person with albinism?	( ) I wouldn't have much of a problem ( ) I wouldn't have a problem ( ) I would have a problem ( ) I'd have a big problem

Source: Prepared by the authors.

The first station of the workshop was designed to break down the stigmas surrounding albinism. Because it is an unusual and unpredictable condition, which has been around since long before genetics and its particularities were discovered(8) various beliefs, myths and stigmas related to albinism have emerged in an attempt to give meaning to the condition. According to the literature review conducted by Mendes(9) there is a plurality of beliefs and myths about albinism that are still replicated today, divided between positive and negative reports.

While on the positive side, people with albinism can be seen as special, fortunate and/or sacred, depending on the culture, there are also negative beliefs such as that they are people in transition between white and black or between physical and spiritual. All these beliefs contribute to the understanding that they are not ordinary humans, justifying the dehumanization that leads to "stigmatization, discrimination, marginalization and violence exercised by the community" (9) (p. 43).

In this sense, the questions were chosen/prepared based on the identification, through consultation of the literature, of the main challenges, myths, beliefs and stigmas that affect people with albinism in a transversal way, as well as questions that deal with the preparation of professionals involved in the dynamics for caring for people with albinism (from a perspective beyond biomedical care)(3,5,6,8,9). Thus, the issues worked on during the workshop can be classified into themes about stigmas (1, 2, 7, 8 and 11), biological aspects related to the condition (3, 4, 5, 6, 9, 10), and about the subjects' relationship with albinism and persons with albinism (12, 13 and 14).

The lack of knowledge about the genetic and hereditary basis of albinism produces impasses from the moment the subject is born, as it can cause strangeness in the parents who idealized their child with its phenotypical characteristics, but who are faced with a child with no pigmentation in its body.

There are reports that this causes estrangement between the couple, suspicions of infidelity and can also cause the mother-baby bond to take a long time to consolidate(10).

Addressing the possibility of a child being born with albinism should begin during prenatal care, offered in primary health care, as a way of mitigating possible tension within the family, in the same way that parents are advised about other congenital genetic conditions. The family's early understanding of what albinism is contributes to better socialization of the child in the community, since albinism is responsible for affecting the process of building the subject's identity, given that skin color goes beyond a physical characteristic and, in countries like Brazil, represents a relevant trait for the pejorative social reading of the subject(11).

The participants answered the questions described above individually, and then began a dynamic of true or false for the questions whose possible answers were “Yes" or “No”, so that the questions could be debated among the group, with different points of view being explained on the subject in question.

Teaching strategies based on active methodologies have gained relevance in the health area in recent years, with the introduction of *Problem-based learning* (PBL) and *Team-based* learning (TBL) as guiding methods for health training, with studies showing positive results in academic learning through this methodology(12). Therefore, giving participants the chance to contribute their point of view/prior knowledge during the debate was essential for them to remain engaged in the discussion and in the dynamic process of teaching and learning.

The use of active teaching methodologies for workshops follows progressive teaching trends, which break with the perspective of traditional/banking education, which establishes, among other things, a hierarchy and verticalization in the teaching-learning process, with the teacher performing the role of holder of all knowledge and the academics/students empty spaces to be filled by the knowledge of the vertically superior(13). In order to break with this, the progressive tendency proposes a horizontalization of the process, understanding that it must take place considering the individualities of the subjects involved, so as to enable the construction of new knowledge based on that previously established(13).

After the initial discussion, two videos were broadcast featuring members of the Alagoas Albinos Association (ALBINAL) who told their story as people with albinism and answered the questions raised indirectly. Then, at the end of the videos, the participants were invited to answer the questionnaire again, now with the knowledge they had gained from the stories they had watched, and the true or false dynamic was repeated, along with a discussion about what had changed in their perception of albinism after watching people with albinism talk about their experiences. At this point, it was noticeable that there had been a break in the expectations of those present, as some of them didn't see albinism as a condition that had such a drastic effect on the lives of those affected, or even had erroneous notions of what albinism is.

Station 2 - Pathophysiological, epidemiological and diagnostic aspects of albinism

Following on from the workshop, the second station was concerned with providing the necessary theoretical background for the participants, as professionals, to be able to manage albinism and its main repercussions on people's health. In this way, a presentation was given by members of the extension project with academic and/or experiential experience with albinism, covering the epidemiological, pathophysiological and diagnostic aspects of albinism.

In order to get the station started, epidemiology was addressed, starting with global estimates and including national, state and municipal data from the city where the event was held(1,4,14). Although scarce, the available data revealed that the state of Alagoas, where the participants carry out their academic and care practices, is an area with a high incidence of albinism(5) serving as an ideal environment for applying health interventions to the community. At this point, the participants began to dispute the data, as they all knew of one or more people with albinism in their communities, so the incidence should be higher than that presented.

Based on these questions, the approach to the nosological diagnosis of albinism and its inclusion in information systems began, intensifying the discussion on how albinism is presented in the International Classification of Diseases (ICD), which in its version 10 had albinism indexed under the ICD code E70.3, being classified as a metabolic disorder of aromatic amino acids(5). In version 11 of the ICD, albinism is now classified under ICD code EC23.2, which classifies albinism and other genetically determined hypomelanotic disorders, thus appearing in the section on genetic disorders of skin pigmentation(15).

Determining a more specific code contributes to the process of diagnosing the disease, making it possible to record its diagnosis more adequately in databases, but in order to make this diagnosis it is necessary to know the characteristics of albinism. Albinism is not a single condition, there are many phenotypic manifestations that can be observed by the professional who treats this subject and must be taken into account for the clinical diagnosis, so the numerous possible manifestations of albinism were discussed based on photographic records available in the literature(16).

Although the gold standard for diagnosing albinism is genetic testing, this is still rare within the Unified Health System (SUS), requiring medical professionals to perform it clinically. Diagnosis and its recording in electronic medical records enables management to understand the scale of the incidence of albinism and to draw up public policies geared towards the needs of these individuals. The lack of recording of this diagnosis contributes to the invisibilization of individuals with albinism, and the lack of access to adequate health care and attention(17).

After the questions related to diagnosis, the specific care required by people with albinism was addressed. This care ranges from a particular environment for care, in which the lighting of the offices must be observed, given that people with oculocutaneous albinism tend to have photophobia, which makes care in extremely bright rooms uncomfortable, to the investigation of systemic manifestations that may have as their primary cause the genetic alterations that give rise to albinism, as well as other alterations and/or predispositions determined by the genetic condition(1). At this station, the person with albinism present had the opportunity to approach the care required for this condition from a holistic perspective, sharing their experiences and affections as a subject who experiences challenges and limitations in obtaining adequate care. The presence of a person with albinism was essential for the workshop, as all the theoretical background raised during the event could be confronted with reality, contributing to understanding the relevance of the demands of these subjects, as well as breaking down stigmas that vulnerability is linked to incapacity or fatalism. It should be noted that the person with albinism present at the workshop was part of the extension project and a researcher into albinism, not a spectator.

Station 3 - National Policy for Comprehensive Health Care for Persons with Albinism

Given that the aim of the experiment was to address the right to health of the population with albinism, the last station consisted of exploring the theoretical and legislative basis that underpins and guides specific interventions for these individuals. This station was established as the closing station due to the intention of sensitizing the subjects to the health issues of the population with albinism, providing a basis for them to be able to identify the potential and weaknesses of existing rights on their own.

As a way of guiding the moment, the study conducted by Luz(18) which takes a retrospective look at the right to health, with an emphasis on the health of the population with albinism, based on the Federal Constitution and other infra-constitutional legislation, was used as a reference for the discussions that followed. The author developed his study in the period leading up to the promulgation of the National Policy for Comprehensive Health Care for People with Albinism, so the documents and policies cited are non-specific, such as: Articles 196 to 200 of the 1988 Federal Constitution; the Organic Health Law - Law 8.080; Statute of People with Disabilities - Law 13.146; National Policy for Comprehensive Care in Clinical Genetics - Ordinance GM/MS No. 81; and Guidelines for Comprehensive Care for People with Rare Diseases in the Unified Health System - Ordinance GM/MS Nº. 199.

In this context, it is clear that the realization of the right to health, at a national level, was based on parallel legislation, which guaranteed the right universally and/or established guidelines for the care of conditions that people with albinism may present, without taking into account the specific demands of those affected by the genetic condition. However, it was only in November 2023 that the National Policy for Comprehensive Health Care for Persons with Albinism (PNAISPA) was approved, guiding care for persons with albinism throughout the country(19). which is the result of social mobilization.

In order to collaborate with the study of the policy in a dynamic way, the class was asked to divide into smaller groups and work on the main axes of the policy, analyzing whether it managed to get around the problems previously listed and whether it would be enough to eliminate the difficulties of access to health care for people with albinism. After this, the participants presented the policy in detail in a round table discussion between all the groups, broadening the discussion about the construction of the policy.

Contributing to the discussion, the facilitators addressed the local achievements of the movement of persons with albinism, such as State Law Nº. 8.493, of September 2, 2021(20) which provides for priority for people with achromatosis - a term used synonymously with albinism and other hypomelanotic diseases in the body of the law - in scheduling dermatological and ophthalmological appointments in the state of Alagoas; Municipal Law Nº. 6.605, of March 22, 2017(21) which provides for the free distribution of sunscreen by the municipal health network to people with albinism in the municipality of Maceió; and Law No. 3556 of 2022(22) which establishes the free supply of sunscreen and sunblock for people with albinism in the municipality of Arapiraca. Although these achievements seem subtle, they mark the importance of the participation of social movements in guaranteeing the implementation of fundamental rights.

Conclusion

The population with albinism faces a number of issues that require a holistic approach to their health. In this context, actions that increase knowledge about albinism play a significant role in reducing the inequities to which this section of the population is subject.

As such, the workshop made an important contribution to the training process of the future health professionals involved in the action. The contribution of people with albinism, synchronously and/or asynchronously, was fundamental for those present to understand the impacts and effects of albinism on the health of people with the condition, making it possible to contact and understand the issues raised beyond the theoretical aspect and the biomedical model.

At the end of the stations, the participants evaluated the workshop. At this point, it was possible to identify statements that revealed the novelty of the approach to questions about albinism during their training process, making the subjects refer to the moment as a starting point for improving their care/healthcare practices for individuals with albinism.

From this point of view, the absence or scarcity of subjects on the health of the population with albinism in health science courses means that there is a gap in the knowledge of professionals. In this way, actions such as the one reported here are essential for the universalization of care, as they contribute to a broad vision of the health issues of people with albinism.

Conflict of interest

The authors declare that there is no conflict of interest.

Authors contribution

Dantas JEF contributed to the conception/design of the article, data analysis and interpretation, writing of the article, critical revision of its content and approval of the final version. Leite LKT contributed to the conception/design of the article, data analysis and interpretation, writing of the article, critical revision of its content and approval of the final version of the article. Dos Santos Neto D contributed to data analysis and interpretation, drafting the article. Rodrigues LRP contributed to the critical revision of the article's content and approval of the final version. De Oliveira JR contributed to the critical revision of its content and approval of the final version.

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