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People with albinism and skin cancer: a descriptive study

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ABSTRACT

Introduction: Albino people (PA) are more likely to become sunburned, to develop skin lesions and skin cancer than people without this condition. From the Right-to-Health perspective, this study will try to identify PA who has exceeded the skin cancer risk limits.

Aims: To identify PA with skin neoplasms; to describe their main characteristics; to find out about their therapeutic route; and to discuss healthcare from the PA's perspective. **Method:** It is a descriptive study that has been developed in two complementary stages: (i) a sectional study of the PA population who are receiving treatment at the dermatology ambulatory center of the study setting; (ii) this second stage has been carried out using a qualitative approach. The sources of data include medical reports and interviews with the PA participants. The quantitative data will be analyzed through the use of simple statistics. The semi-structured interviews will be transcribed and analyzed using the *Content Analysis method*. This study has been approved under protocol EEAN/HESFA/UFRJ, no 371.467.

Descriptors: Albinism; Right to Health; Skin Neoplasms.

SITUATION PROBLEM AND ITS SIGNIFICANCE

People with albinism (PA) are more likely to get sunburned, to develop skin lesions and skin cancer than those without this condition. So, beyond the congenital recessive condition, this study has tried to identify the PA who has exceeded the skin cancer risk limits as well as their therapeutic routes, based on the Right-to-Health perspective.

The Right to Health, a human right guaranteed by the Brazilian Constitution, is regarded as an essential part of other rights such as the Right to Life. In the broader concept of health, the healthcare provided to PA must be seen as a right to health, regardless of the stage of the disorder. Based on the concepts of visibility, responsibility and public sovereignty over demands and needs, and from a practical point of view, the right to health must cover the triad of integrality, universalism and equity with regard to Unified Health System users⁽¹⁾.

Fair-skinned people such as PA, who get easily sunburned, are particularly prone to develop skin cancer. Excessive sun exposure is the main cause of this type of cancer⁽²⁾.

The government needs to invest more in prevention and control programs instead of focusing solely on social care. It is a paradox that the National Estimates suggests that around 518,510 new cases of cancer will be diagnosed in 2012 and 2013, including in this figure the non-melanoma types, with the possibility of 62,680 new cases for men and 71,490 for women⁽²⁾.

On the one hand, there is a concern about the possible insufficiency of resources to deal with this scenario which includes risk of early death⁽²⁾; on the other hand, an entire group who are genetically vulnerable to the disease have been neglected by the epidemiology specialists, society and the state. This only increases the

inequality of access to public health services, as well as limiting the creation of health programs to address this part of the population. In this context, this study intends to contribute to the scientific research about the cancer care delivered in ambulatory centers⁽³⁾. The intention is not only to promote public awareness of the issue, but also to include PA in the creation of demands that will be discussed and met. Furthermore, this process must take into consideration the relationship between epidemiology, human and biomedical sciences, in order to develop richer concepts and social care strategies that will protect the differences within a public context⁽¹⁾.

OBJECT OF STUDY

To find out about the PA's therapeutic route and to discuss healthcare from their perspective; and to identify the skin cancer risk limits.

GUIDING QUESTIONS

- Who is the PA with skin neoplasms?
- What is the PA's therapeutic route?
- What does healthcare mean for PA?

AIMS

To identify PA with skin neoplasms; to describe their main characteristics; to know about their therapeutic route; and to discuss healthcare from their perspective.

METHOD

It is a descriptive study that has been carried out at Cancer Hospital I, National Cancer

Institute (INCA). It has been developed in two complementary stages: (i) a sectional study of the PA population who are receiving treatment at the dermatology ambulatory centers of the study setting. The sources of data are the patients' medical reports. This data have been analyzed, using simple statistics, between January 2012 and August 2013. (ii) the second stage has been carried out using qualitative approach. The data collection has been undertaken through semi-structured interviews recorded in digital media. The participants have been those PA suffering from skin cancer included in stage 'i', who agreed to participate in the study. The analysis of the interview data was continued until data saturation was achieved. The participants' anonymity has been preserved.

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PROJECT DETAILS

This project has been approved under protocol EEAN/HESFA/UFRJ, no 371.467, and has been carried out at the National Cancer Institute (INCA). It is tied to the project named "People with albinism and the right to health - Phase II". It has also counted with the collaboration of a scholarship holder from FAPERJ/2013.

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