

Albino and albinism

LANGUAGE COLUMN

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Many people with albinism have a negative attitude towards the word *albino*.



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In our society, the word *albino* is used to describe persons with albinism. Many people do not know what *albinism* means. People in general are familiar with the word *albino* from way back, but is it a word that is acceptable? Shouldn't we

be saying *albinism* instead? Or is it appropriate to use these words interchangeably?

Albinism is a diagnosis

Albinism is generally divided into two main types (1). The first is oculocutaneous albinism (OCA), i.e. a lack of pigment in the skin, hair and eyes. The second is ocular albinism, where only the eyes are affected by a lack of pigment. *Albino* is the Latin word for white, and is associated with persons who lack pigment in the skin, hair and eyes (2). Is it correct, therefore, to use the word 'albino' of people with ocular albinism, who have colour in their skin and hair?

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A diagnosis can be defined as the name of diseases or conditions with common features (3). A search on *albino* in the WHO medical coding system ICD-10 does not give any hits. However, a search on *albinism* gives a hit in Chapter E70-E90 on metabolic disorders, where it is categorised as a condition rather than a disease (4). In other words, albinism (Code E70.3) is a diagnosis, but *albino* is not.

Albino in the animal kingdom and in films

In the animal kingdom we hear about animals that lack pigment, such as the white moose Albin (5) and the rare gorilla Snowflake (6). Most people call animals with little or no pigment *albino*. The distinction between animals and humans becomes clearer when we describe animals as *albino* as opposed to people *with albinism*.

In films, *albino* is often associated with villains and homicidal characters. An enormous number of American films and TV series feature such people. Over the years, books have been written in which persons with albinism are portrayed as having supernatural powers, as wicked villains and even as sharpshooters. Portraying someone with an albinism diagnosis as a sharpshooter is highly unrealistic since people with albinism are short-sighted and have nystagmus.

Such portrayals contribute to the alienation of persons with albinism. The production of films featuring positive role characters that have albinism, preferably people who have albinism themselves, would perhaps create balance and promote a more realistic portrayal.

What do people with albinism think?

The Norwegian Association for Albinism represents persons with albinism and their families (7). The Association has approximately 230 members.

In an informal survey on the Association's Facebook page, members were asked whether they preferred *albino* or *albinism*. In total, 14 of the 16 who replied felt that the word *albino* had a negative connotation. For them, the word signals a negative attitude, and can be perceived as a term of abuse in the same way as the N-word. Many find that *albino* is used in an offensive manner like 'ghoul' or 'vampire', and some people even joke that people with albinism have bathed in chlorine. A number pointed out that a person *has* albinism – they *are not* their own diagnosis. The word focuses only on skin colour and not on the person. Many feel that they must refrain from saying *albinism*, because the majority of people do not know what it is, and only understand what is meant when the word *albino* is used.

We should take pains not to use a diagnosis or body part as if it were the person. We should not say 'the stroke', 'the appendix' or 'the hip' when referring to patients in hospital (8). In English scientific literature *person-first language* (or *people-first language*) is preferred. This means saying 'a person with a disability' (or 'a person with a functional impairment'), not a *disabled person* (9). Some people may regard this as splitting hairs, but it is important for those concerned.

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Two of the respondents thought it was acceptable to use *albino*, and did not feel offended if they were referred to in this way. A number of young adults and adults with albinism have readopted the word *albino*. They are tired of political correctness and believe that it is people who do not have albinism who are spearheading the battle against the expression *albino*. Many people use the words interchangeably, provided that *albino* is only used in its correct meaning and not as a term of abuse.

The point of view of the Association

This issue has been discussed by the US National Organization for Albinism and Hypopigmentation (10) and Global Disability Watch (11).

The board of the Norwegian Association for Albinism hopes that society in general and health personnel in particular become more aware of the use of the words *albinism* and *albino*, and we will work to improve people's knowledge of what *albinism* means. So far, we have chosen to use *albinism*, because a

number of our members have a negative attitude towards the word *albino*. We cannot dictate what expression individuals should use, because ultimately it is up to each of us to decide for ourselves.

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