Reviewer’s report

Title: Albinism in Africa as a public health issue

Version: 2 Date: 4 May 2006

Reviewer: Patricia Lund

Reviewer’s report:

General
This paper is clearly written, covering three different aspects of albinism in Africa which I will consider in order:
â€¢ Review of published literature on the frequency of albinism in Africa and medical/social issues
â€¢ A pilot information survey with a questionnaire based design
â€¢ Recommendations for future action eg on health intervention.

The article reviews published population frequency data on albinism in two countries in southern Africa (Zimbabwe and South Africa), one in east Africa (Tanzania) and one in West Africa (Nigeria). The Pub Med search identified all the key published papers in this area but is probably not the best data base to use to source articles with a more sociological focus. The summary table is informative, including estimated number of people with albinism in each country. The analysis of the study design and method of gathering epidemiological data is very useful, as different approaches were adopted in the studies. The date of conducting the study is also important, as well as how the authors estimated or calculated their ‘total’ population. In the Kromberg study in South Africa this was taken from census data from 1970 which is of doubtful accuracy, out of date and should be treated with caution. This study was undertaken in an urban area with a migrant population so the data for the ethnic groups does not necessarily reflect the frequency among that group in the rural areas. The population in Soweto is an unusual one, with many economic migrants. The data from the Venter hospital study is more convincing in that the data are recent and the total population was well defined (total number of neonates). This was done in a rural area among the North Sotho (Pedi) population, so reflects the frequency in this ethnic group only and is comparable to the frequency in the South Sotho found in the Kromberg study. The studies in Zimbabwe give accurate epidemiological data for the school going population- the data from primary schools is particularly convincing as almost all young children in Zimbabwe attend school. It would be useful for the authors to consider census data on school attendance when analysing the school-based studies. It should also be noted that pupils with albinism in Zimbabwe do not attend special schools for the visually impaired. At present they do so in South Africa although there is a push at present for their inclusion in mainstream education. These data from a school going population cannot be extrapolated to the adult population, but is informative from a public health viewpoint, as this is the target population for a health intervention strategy, notably on sun protection.

The data from east and West Africa gives an estimate of the frequency of people with albinism in particular areas- the capital of Tanzania and one state in Nigeria. It is impossible to judge the frequency overall in these large countries. In terms of life expectancy and mortality, the authors correctly assess the situation- there are no reliable data. Anecdotal evidence suggests that life threatening cancers are more prevalent in equatorial parts of Africa than in southern Africa. The mortality data should also be stated in the context of the data for that population so a comparison can be made. In terms of medical issues, I do not know of any published data indicating that people with albinism suffer from malignant melanomas. They appear NOT to; the types of cancer they get are squamous and basal cell carcinomas. The section â€˜as well as malignant melanomasâ€™ should be removed from the text.

Some published studies on social issues have been missed in the Pub Med search- to make this section more comprehensive a further search would identify other refereed studies in the area which could be included.

WHO Albinism Pilot Survey Results

This survey is the novel part of this paper and in my view should be expanded considerably. Although the questionnaire is given the data presented are vague and do not substantiate the comments made. As only 12 countries returned survey responses the data could be presented fully (i.e. the actual responses to the questionnaire), indicating who filled in the survey from each country. I would strongly recommend that the
stated prevalence data for Rwanda, Mali and the Congo reported here be removed from this paper as it is not supported by any detail on how these frequencies were obtained. These data should not be quoted - the authors refer to them as “unrealistic” so clearly do not have much faith in them either. Was any description of the phenotype of albinism given with the survey?

The other comments on health care, lack of trained medical personnel, social discrimination etc ring true but it is not clear what the basis for these comments are. Is it merely anecdotal evidence provided by the respondents to the survey questionnaire or are they based on any studies conducted in these countries?? More detail would be interesting e.g. which countries reported the use of traditional medicines (which “eight”™) and why did they use traditional medicines? Was it to treat skin ailments or to ward off evil? There is quite a lot of evidence in the literature that people with albinism are regarded as being bewitched or cursed. The paragraph on social stigma could also be expanded to give more detail- again, is this anecdotal information or evidence based?

Discussion

This paper highlights the paucity of information on albinism available in Africa, except in southern Africa. In my opinion no sensible comment can be made about the prevalence range for the continent as a whole- for southern Africa the data support a range of frequency between 1 in 1 500 and 1 in 5000. Could the authors justify their statement that albinism qualifies as a “public health issue deserving further attention”™? The point is that albinism can be managed effectively in terms of sun protection etc. Sun avoidance for example is cheap- it just requires education and the political will.

The intervention programmes proposed in South Africa are all multidisciplinary- the literature here could be referenced. Perhaps the authors could state how WHO may be able to facilitate/motivate the studies recommended, perhaps by analysing data reported by African countries? In South Africa albinism is recorded as part of their national Birth Surveillance programme but national statistics are difficult to come by. In a recent study in Venda in northern South Africa we examined hospital records and collated the data (not yet published) on the incidence in this area. The incidence of albinism at birth was recorded, but the data required collating and analysing.

The recommendations are all sound- some of these ideas have been tried in South Africa eg via training workshops on albinism for health care professionals in northern South Africa and integrating albinism into the curriculum for optometry students at the local university. The media is also used as a major means of raising community awareness via “Albinism Days”™ and talks by genetic nurses and others on radio.

“A final comment on the use of the word “albinos”™. In the US and UK this is regarded as a “label”™ ie seeing the person in terms of their condition and its use is discouraged. The use of “people with albinism”™ is favoured instead.

Overall, the methodology is appropriate for a pilot survey, the title of the article is accurate but there is no abstract included. The discussion is interesting and well written.

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Major Compulsory Revisions (that the author must respond to before a decision on publication can be reached)
1. The results of the survey data are not reported in sufficient detail, are not substantiated and need expanding.
2. The prevalence data reported from the WHO pilot survey appears to be anecdotal and is not sound. It should be removed from the text.

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Minor Essential Revisions (such as missing labels on figures, or the wrong use of a term, which the author can be trusted to correct)

A final comment on the use of the word “albinos”™. In the US and UK this is regarded as a “label”™ ie seeing the person in terms of their condition and its use is discouraged. The use of “people with albinism”™ is favoured instead.

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Discretionary Revisions (which the author can choose to ignore)
My other comments in the general section are discretionary.

**What next?:** Unable to decide on acceptance or rejection until the authors have responded to the major compulsory revisions

**Level of interest:** An article whose findings are important to those with closely related research interests

**Quality of written English:** Acceptable

**Statistical review:** No

**Declaration of competing interests:**

I declare that I have no competing financial interests. Some of the data reviewed in part of this paper is my own so I obviously have a personal interest there (although I am happy with the way the published data is presented in this article).