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Families influencing the education of pupils with albinism in Malawi – a prism for educational, social and health practice.

Abstract

Albinism results in lack of pigment in the hair, skin and eyes. The poor vision, extreme sensitivity to the sun and social ostracism associated with this poses a number of challenges for affected pupils, their teachers, families and society in Malawi. These are reflected to a greater or lesser extent in other Sub-Saharan contexts as well. An exploration of the knowledge, beliefs and educational practices associated with the condition allow for an interrogation of a number of issues that challenge the completion of the Millennium Development Goals, in particular achieving universal primary education for all, and perhaps offer insights into ways to promote educational and social inclusion for other marginalised groups. Semi structured interviews with 18 key informants in Malawi provided the evidence base to inform the development of a 30 minute radio drama to educate teachers and the wider community about albinism. The paper briefly reviews current research with regard to the educational experiences of pupils with albinism in Southern Africa, considers the Malawian context in particular and then through the responses to the interviews, examines the manner and extent to which families with experience of albinism in Malawi might shape the attitudes and practices of teachers, to promote the educational inclusion of this group of vulnerable pupils.

Evidence and Knowledge

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1. Albinism in Sub-Saharan Africa

Oculocutaneous albinism is an inherited condition where little or no melanin pigment is produced in the hair, skin and eyes. In Africa this means those affected have sandy coloured hair, blue eyes and pale skin; a very visible difference in appearance in a black population (Lund, 2005). Those with albinism are hypersensitive to the damaging effects of the sun, suffering sunburn, skin thickening and skin lesions (Lund and Taylor, 2008) which can lead to skin cancer at a young age. The lack of pigment also leads to visual impairment, with rapid eye movements, photophobia, poor visual acuity, squinting and refractive errors leading to low vision. Most babies with albinism in Africa are born to parents who are both black; both the mother and father are carriers of the 'albinism' gene and have a one in four (25%) chance of having a baby with albinism. The frequency of albinism in sub-Saharan Africa populations is relatively high, between 1 in 1000 and 1 in 4000 (Lund et al, 1997), with an estimated 5000-7000 people in Malawi affected.

The eye and skin care issues can be managed effectively with appropriate resources (Hong et al,, 2006). More difficult to address are community attitudes leading to social stigma and ostracism that impact negatively on individuals with albinism and their families throughout their lives (Lund and Gaigher, 2002; Braathen and Ingstad, 2006). These are often due to ignorance, fostered due to the mistaken belief that those with albinism have been bewitched, or that the condition is contagious and can be 'caught' (Baker et al., 2010). At the extreme end they have resulted in the abduction, mutilation and death of people with albinism due to the misguided belief that their body parts, used in good-luck charms, have magical power that can bring success and wealth though there are no reported cases of such crimes in Malawi or Zambia. International outrage engendered by these practices has culminated in a UN Resolution in June 2013 recognising the rights of this vulnerable group (OHCHR 2013).

Education strategies for children and young people with albinism in southern Africa vary. During the apartheid era in South Africa they attended and special schools for the blind, supported by teachers trained in visual impairment (Lund, 2001). This is similar to most current provision for them in Zambia. In Zimbabwe they enter mainstream schools, although this proved a challenge to classroom teachers not trained to adapt to their needs, with their low vision sometimes going unrecognised. A similar scenario pertains to Botswana (Dart et al, 2010).

2. Policy and practice in supporting children with Albinism in Malawi

Malawi has taken great strides in terms of increasing the enrolment of children with disabilities in primary schools. Between 2008 and 2010 there was an increase from 43,000 to 83,000 (Ministry of Education, Science and Technology 2010). The Education Sector Plan (2008-17) aims to improve equity in access to education at all levels as well as improve the quality of provision. In the plan Special Needs Education programmes are prominent; for example there are goals to move by 2017 to a ratio of 1 teacher to 5 pupils in Resource Centres, and to raise the profile of special needs education in all teacher training colleges. The Special Needs Education Directorate of the Ministry of Education, Science and Technology (MoEST) supports two approaches to the education children with visual impairment: resource centres and the use of itinerant teachers (ITs). Resource teachers and ITs

are trained at Montfort Special Needs Education College (Lynch and Lund 2011). The ITs move between mainstream schools and communities to offer advice, resources, and support to children with visual impairment, their teachers and parents.

There are residential resource centres for learners with visual impairment attached to 13 primary schools, 15 secondary schools and 7 tertiary institutes. Many centres have excessively high teacher-pupil ratios (e.g. 1:20) and require maintenance and renovation, especially in the primary sector. In 2011 there were 70 children and young people with albinism boarding at resource centres. These students accounted for 75% of those identified as having low vision, indicating that in Malawi albinism is the main cause of visual impairment from birth. Albinism affects both girls and boys equally, however there was a disproportionate number of boys (n=48) enrolled at the resource centres compared to girls (n=22) (Lynch and Lund, ibid).

The challenges that many of these students face are neatly summed up by one of the interviewees in this study:

Elizabeth (adult female, with albinism) *I once left school because of short sight- I was failing to see the chalkboard, failing to read the text book due to the small print and failing to participate because of mocking by my fellow students and some teachers.*

3. The study

This paper analyses the content of 18 interviews conducted in Malawi in early 2013 with a range of participants affected by albinism: adults and children with albinism, and carers of children with albinism. The interviews were conducted with the primary aim of informing the production of a radio drama to be transmitted in Malawi in the second half of 2013. The radio broadcast forms part of a wider project at Coventry University (see Coventry University (no date) for access to other outputs and resources), co-funded by Sightsavers through their strategic partnership with DFID (Department for International Development), UK : *Integrating community and media networks to promote the educational inclusion of children and young people with albinism in Malawi and Zambia* (Sightsavers, no date). Key partners in Malawi are The Albino Association of Malawi – TAAM, and the Malawi Council for the Handicapped – MACOHA and The Story Workshop. The Zambian links are in the early stages of development. Other major strands in the project involve embedding awareness of albinism at teacher training institutions in Malawi and Zambia, and developing a data base of mobile phone numbers of families with albinism and schools educating pupils with albinism, to allow the transmission of SMS alerts and educational material.

The script has been written by a local professional scriptwriter who used the process to mentor a young writer with albinism. The radio drama is targeted mainly at teachers, teacher educators and families living with albinism, but it is anticipated that the wider community will also listen and react to the transmission. Responses to the programme will be captured via short message service (SMS) feedback and phone-in responses. The purpose of this participatory methodology with regards to the development of the drama is to enhance its validity by rooting its context, themes and story line firmly within the milieu of those affected by albinism in the Malawian context. The purposeful use and analysis of radio and SMS offers a relatively cheap, interactive and highly accessible opportunity for the dissemination of information,

guidance and support across much of Sub-Saharan Africa (Aker and Mbiti, 2010), and Malawi is no exception. Although mobile phone ownership rates are not as great in Malawi compared to many other countries in the region (NationMaster; undated) they are rapidly increasing and already provide a successful avenue for projects involved in agriculture (LandO'Lakes; undated), health (Blashke et al 2009, Creel et al 2011), and education (EDC, undated)

The interviews have resulted in the collection of a rich vein of experiences, insights and ideas many of which echo at a micro level some of the discussions that are occurring currently at a macro level with regards to the evolution of the Millennium Development Goals post 2015 such as the need to work in a far more cross-sectoral manner (United Nations 2013) and to include the voices of people with disability (Groce 2011). And so, with the consent of the interviewees, extracts of these interviews are presented and analysed here.

4. Methodology

From its inception, the project aimed to be as participatory as possible and to share the development of skills and knowledge between colleagues in the UK and Malawi. The development of the interview questions was carried out in this spirit as was the writing of this paper as a collegiate project. Ethical approval for conducting the study was obtained from the Research Ethics Committee of Coventry University, with the support of the Department of Education in Malawi. The project can be considered in the light of a framework developed by Stephens (2007; 61) for improving the quality of educational research in developing countries:

1. the identification of a research methodology which is culture- appropriate and suitable for the task;
2. the development of existing methods and techniques which come out of or are sensitive to the cultural arena;
3. a better understating of the role of the researcher – researched relationship in the cultural setting;
4. the generation of practical solutions to a number of subsidiary problems concerned with such things as the training of counterparts, the support of grass roots research organisations and the promotion of indigenous publishing.

These points will be reconsidered in the conclusion.

The aims of the project were explained to each of the respondents and they were offered the choice as to whether they wished to take part in the interview and whether they agreed to allow their responses to be used for a variety of specified purposes. All were offered the choice to remain anonymous or not and all chose not to. First names are used in the course of this discussion.

Interviewees were chosen purposefully to reflect a broad range of experiences and roles, including both rural and urban participants, male and female, primary and secondary schoolchildren, their guardians and teachers, as well as adults with albinism in professional jobs. They were identified from previous related studies and in collaboration with the Albino Association of Malawi (TAAM).

Initially each interviewee was asked to share their experiences of albinism with the interviewer asking for clarification of points if necessary. They were then asked a

series of open ended questions (tailored to suit the background of the interviewee) with a focus on education and seeking their views on what the content of the proposed radio programme should be (see Appendix A for the interview schedule). Sixteen of the interviews were carried out in Chichewa and translated into English by the interviewers. The other two were in English.

The data was analysed independently by Dart and Lund who broadly agreed on the central themes arising. These were then discussed with Massah, the lead interviewer. Table one offers an overview of the characteristics of the participants.

Table one: **The interviewees**

	Female	Male	Total	Notes
With albinism	6	4	10	four at school, one in tertiary education, one teacher, one deputy head, one subsistence farmer, two other professionals
Responsible for relatives with albinism	6	2	8	Mother at work (1 Child with albinism [CWA]), female subsistence farmer (1 CWA), 2 fathers at work (1 CWA each), grandparent (1 CWA), 3 mothers not in formal employment (one with 1 CWA, one with 2 CWA, one with 3 CWA)
Total	12	6	18	

5. Analysis of interview transcripts and discussion

A number of clear themes came out of the open ended discussion that initiated each interview.

5.1 The first was the fact that in many cases there was ***a deep feeling of acceptance*** of the birth of the baby with albinism amongst the immediate family even if the wider family sometimes saw the event as problematic.

Alesi (female with albinism / subsistence farmer) - *In the community they say zungu osauka (poor White man) or napwere but I don't take it seriously. I don't just move in the village but am just here at home with my relatives. So they love me and support me.*

Flora (female, one daughter with albinism / subsistence farmer) - *I gave birth here at home with the help of elder mothers in the village, although we did not understand the baby, but we just accepted as a gift given from God. I have seen people like her before in my village, so I just accepted it as I knew she is a person.*

Suzen (female, mother of 4 year old with albinism) - *The coming of Happy in my family did not change anything; my husband and I accepted that Happy was a gift from God.*

This echoes the findings of Braathen and Ingstad (op cit) who also report that in Malawi there is frequently an acceptance within the immediate family even if the wider family are not always so accommodating and fathers sometimes react negatively to the event.

5.2 The introduction of albinism into lives can cause great ***disruption*** be that familial and social or economic and medical. Malawi is one of the World's poorest peaceful countries, with a Human Development Index for 2012 showing it ranked at 170 out of 186 countries (UNDP, undated) and so many issues faced by those affected by albinism will be similar to those faced by a high proportion of the general population. However the need to access extra resources (even as simple as clothing that is suitably protective) to alleviate the impact of the condition can put an extra burden on already poor families.

Undi (mother of two children [of seven] with albinism) - *Life with my children has not been easy. If you can see them now they have sores and other skin problems because I cannot afford to buy the lotion. At some point a teacher from Machinga would bring me the lotion; this only happened for three months and it stopped. Their skin had started looking and feeling good but now it's hard again.*

Chikayiko (student, 13 years old, with albinism) - ****** and ***** mistreated me especially ***** he always beat me up, so I was fed up and decided to leave my home to town where I stayed for two weeks begging. I was eating and sleeping in town, my wish was just to die so I was sleeping on the road so that a car can run over me just to die but a Good Samaritan a woman with a skin colour like mine (an albino) took me back home.*

Potentially poorer educational and thus economic opportunities further compound the challenges that many families and individuals face. Groce (2011; viii) notes that although links between poverty and disability are "complex and nuanced", it is generally agree that households experiencing disability are frequently "significantly poorer, with fewer resources and more brittle support networks, than non-disabled individuals and households with no disabled members."

5.3 Despite this a striking feature in many of the stories is that of the ***sheer resilience*** of families and individuals in the face of adversity.

Adressi (female (24) with albinism. Attends secondary school. Has two siblings with albinism) - *So things were bad with me and I decided to drop out from school but after I realised that I want to become someone in life then I continue with school because my wish is to pass my form 4 examinations and go to Kamuzu College of Nursing to become a nurse*

Chimwemwe (female, accountant, married, 2 siblings with albinism) - *The first week at this school was hell. I nearly withdrew from this school because of what I experienced within the first week.*

Idrissa (male (20) with albinism, at secondary school) - *For me I could not pay attention to that but just worked hard in school. My mother used to give me at least 2 buckets of groundnuts, and said to me 'My son get these groundnuts for yourself to support you at school.' I used to roast the groundnuts and sell them to get money during my holiday, I recall during that time I was not even bothering my mother. I used to buy soap, exercise books for myself. I could budget my money well. That's why I am here now.*

The UN report on the post 2015 development agenda (UN 2013; unpaginated / executive summary) notes that goals should be designed "… that focus on reaching excluded groups, for example by making sure we track progress at all levels of income, and by providing social protection to help people build resilience to life's

uncertainties." The consensus in the research literature appears to be that resilience is more than just the chance outcome of psychological make-up in an individual (although that can be key) and that factors in the environment can be manipulated to increase the chance of resilient behaviour; "Resilience is not simply an individual trait, but a capacity that arises through interactions between people within organisational contexts" (Day et al 2011; 2).

5.4 Schools have the potential to foster resilience in the student and there were a number of accounts of the **importance of key personnel** in schools supporting individuals with albinism.

Chimwemwe (female, accountant, married, 2 siblings with albinism) - *In standard eight I met a teacher who was assisting very much. He had love for me and my sister (who also has albinism) and he used to give me notes beforehand and I could copy and read before his class... I had also a friend from whom I could copy notes from standard six up to standard eight. She assisted me very much.*

Idrissa (male (20) with albinism, at secondary school) - *But others supported me in class, I could not see in front well so my friends could write notes for me or read on the board for me, others borrowed me their notebooks to copy notes at home. Although I sat in front in class but still I face problems to see well... Teacher support at secondary school is there They help me by telling me to wear a hat and also all the organization for my school fees, the teachers do it so that I get education, so they ask different organizations to support me.*

Tumeriwa (female (17) at University of Malawi, one of 4 siblings out of 7 with albinism) - *About my education, I did my primary school and I didn't face many challenges because my teachers and the director of the school was good; they noticed my challenge of having short sight so they helped me by sitting (me) in front during classes though sometimes it was difficult to access the information on the board. It only needs self-initiative and hard work.*

5.5 Whilst these offer accounts of heartening and exemplary practice an issue that comes quite forcefully out of the interviews is that currently these support systems are ***fragile in their nature***: a key teacher or head only has to leave or the student move school and the scaffold of support crumbles.

Elizabeth (adult female, with albinism) - *The head discussed with the children and the teachers but they refused to assist me; one teacher agreed to give notes in all subjects. The other teachers refused; said there was no provision for them (to do this extra work).*

Challenges at secondary school in form 4: there was a teacher who refused by saying (this was in 2004) 'No, the government does not give me the provision that I should teach specials needs children so I don't want to do this.' I

From there the head passed away. There was no –one to assist me, so I decided to leave school and get married.

Undi (mother of 2 with albinism) - *In primary school the head teacher was very supportive and would empower other learners to take my children like any one of them. The challenge came when that head teacher passed away and then came another head*

teacher who showed no concern at all despite my efforts of trying to push him to address the boys' concerns.

Somehow this exemplary practice has to become standard practice and institutionalised. The project is addressing this by targeting teacher trainers and the teacher training curriculum reflecting the claim by Lewis and Bagree (2013; 4) that,

> *"Inclusive education training and continuous professional development need to be designed and delivered with inputs from diverse stakeholders, in particular community members and professionals with disabilities, to give a stronger sense of reality to teachers' learning experiences."*

Other regional models that seek to reinforce good practice in the support of students with special educational needs include the use of full resource schools and district support teams in South Africa (Department of Education 2001;29), teachers in Botswana with the role of coordinating a School Intervention Teams charged with overseeing the support of students with learning needs (Dart, 2007) and the up skilling of teachers and social welfare officers in Lesotho to help identify, assess and support students with special needs and their teachers (O'Riordan et al 2012; 141).

5.6 The inclusion of students with albinism into school can act as a litmus test for the readiness of the school to engage in inclusive practice. Accounts from the participants show how just ***small changes can go a long way*** to making learning accessible for students with albinism. The interviewees were very clear about how these simple ideas – whether they pertained to the organisation of teaching and learning or more general health and welfare issues - should be made known to all teachers through their training.

Chikayiko (13 year old boy in Std 3) - *In class I sit in front because I am short sighted; the headmaster gave me three text books for Mathematics, Chichewa and Religion for me to access it easily.*

William (male. Deputy Head with albinism) - *In secondary school … my performance at first was poor and teachers were writing bad comments on my paper as if I was lazy in class but after I reported the situation to the head master then the situation changed. I was writing my examination in large print and my fellow students helped me much by giving their notes to copy during night studies.*

Tumeriwa (female (17) at University of Malawi, one of 4 siblings out of 7 with albinism)
- The 1st message: pupils with albinism should not be exposed on sun.
2nd Teachers should know that a person with albinism has short sight.
3rd Teachers should know that a pupil with albinism is a human being like anyone else.
The most important point is point number 3 because the only difference is the skin colour so there is no reason for a pupil to be isolated, or mistreated at school.

Samuel (father of son with albinism) - *For the teachers in terms of children like this one because they are different in appearance and sight, so the teachers need to encourage them and force them to work hard in school. The teachers must know that they are different in the skin and eyes don't see well.*

This is echoed in much of the literature around the development of good inclusive practice in resource-poor contexts. Stubbs (2008: 44) for example notes how many

methods, resources etc. that are deemed to be 'special' "are often no more than good quality, child-focused methods. Every child needs their learning supported in a conducive environment." A criticism of the goal of universal primary education has been that for too long the needs of the teacher were ignored (Moon 2007). The participants in this study were very clear as to the fundamental importance of skilled, quality teachers.

5.7 The feedback from the participants also indicates the need to analyse what such practice might look like in different contexts. Even amongst this interview group there was a ***range of opinion*** as to whether or not students should go to board at resource centres or be educated in the local school (though there was unanimous agreement that the decision should be made by the parents, not the government or education authorities). Each stance was justified by a particular set of circumstances and nuances.

Alesi (female with albinism / subsistence farmer) - *Yes, I think to go there, very far at a boarding is better than the school when they stay home and go to school. You see here their friends will always say bad things, they say the child is weak, so this disturbs the child, then the next time he will not go to school, but in those schools far from here they are all equal and new to each other and used to each other so the child can learn, but not here in the village.*

Mussa (16 year old boy with brown albinism at school in town)*: In the village my school was very difficult, I could not see well and the teachers were writing very fast. The time I finish writing they were rubbing off the board to write more notes, it was hard because I was slow due to my poor sight.*

Diana (working mother of 4 year old daughter with albinism)*: at any school provided it is close and not difficult to reach, like crossing roads. In that case maybe boarding is better because they stay at school*. (Her daughter was almost run over crossing the road – interviewer's comment).

There has been increasing concern that the notion of inclusion that excludes anything other than students being educated in their local community school might not address the needs of all adequately, particularly under the constraints that many resource-poor countries operate under. Calls for a needs based, pragmatic approach are receiving more attention (e.g. Urwick and Elliot (2010) in an analysis of the Lesotho context).

5.8 It is worth noting that when asked the question '**Should name-calling be addressed in the radio programme?'** there was a strong consensus that both the radio programme and teacher training should address the issue. Many names used to describe persons with albinism are highly pejorative within the culture as they diminish the inherent humanity of the person:

Adressi (female (24) with albinism. Attends secondary school. Has two siblings with albinism) - *Yes, name calling like napwere should be included in order to inform the public that those names should not be used.*

Alesi (female with albinism / subsistence farmer) - *It is important to do that because many people will hear it. There are negative attitudes among some community members;*

although some use names that do not fit, I am not worried as I understand myself as a human being.

Elizabeth (adult female, with albinism) - *Yes. When they say napwere it is totally rude; it is some thing (not a person), a thing that is not matured; this name is not good for us. Always we are frustrated with this name. Mazungu dala- just wanting to be like a mazungu but not really. When they say napwere in Chichewa they are saying something left to be matured ... That is what they mean; something that is not yet matured.* (A variety of meanings are ascribed to the word 'napwere' – what they all have in common is a pejorative tone.)

However when asked whether the issue of myths surrounding albinism should be tackled in the radio programme there was no clear consensus;

Undi (Mother of 2 children [of seven] with albinism) - *Yes because that's how people will know and learn like the Azigogo (Old lady) who wanted to kill my child. How do we know maybe there are many of such Azigogos out there who may meet weak parents who can accept the killing of their children? Maybe there are a lot of children who have been killed at birth.*

William (Male. Deputy Head with albinism) - *The radio programme should not include the negative myths/stories because this will be like encouraging the nation/people to continue with their negative mind/attitudes towards albinism. People should know that a person with albinism is like anyone, the programme should inform the nation the positive information only.*

It is interesting that the issue that has dominated the Western press and discourse around albinism in Africa was approached with greater circumspection by the participants who have to live each day in the context.

6. Conclusion

The project so far has also met to some degree or other the criteria set out earlier in the framework by Stephens (ibid - see section 4 above) for genuinely developmental research practice. This interview process has already borne fruit as the material has directly influenced the script for the radio drama. The UK partners have been challenged in their thinking around different perspectives on ethical approaches such as the desire of participants not to remain anonymous but to have their identity attached to their own accounts. Malawian partners have developed their skills as interviewers, editors, networkers and project managers. Indeed as a direct result of the involvement in the project TAAM has greatly raised its profile amongst a variety of stakeholders and been invited by UNICEF Malawi to bid for further funding to support its activities.

With regard to what the experiences of people affected by albinism might have to tell us about the nature of any future developments in the of the post 2015 MDG's this study lends evidence to the claim made by UNESCO (2013; 44) that,

> *'…children and young people with disabilities can enrich policymaking and service provision with their daily experiences and are uniquely qualified to provide information on whether their needs are being met and their contributions utilized across the full spectrum of issues and interventions.'*

Their responses clearly highlight issues around finding ways of integrating sectors (health, social programmes and education being the obvious ones in this case) as well as the need to be sensitive in goal setting to local responses and local needs. The insight and quality of the feedback on issues of social acceptance, the duel challenge of poverty and disability, and on the need for properly trained teachers to become versed in (relatively) simple practices that will support the greater inclusion of students with albinism, is impressive. If it is true that the MDG's lacked the voices of the poor, the marginalised and those with disabilities then it can only be hoped that further developments beyond 2015 will instead tap into such a potentially rich resource.

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Appendix A – Interview schedule

AIMZ: Albinism in Malawi & Zambia

Pre broadcast interview with.

Name: Gender:

Date of interview: Age:

Place:

Cell phone contact number:

Interview conducted by:

Transcript of free, unstructured interview, allowing the participant to speak about their educational experiences; transcript with clarification by the interviewer in brackets.

Where should learners with albinism be educated at primary level?
Who should be involved in making the decision as to where a child with albinism goes to school?
Key messages that should be addressed in the radio programmes for teachers and schools?
Advice to the family of child with albinism going to school for the first time:
What worked best for you (or your child, or the teacher) at school
Ideas on how to portray positive messages about albinism

Should the radio programme include negative myths/stories about albinism?
Should the radio programme address name calling e.g. *napwere*
How can they (the myths) be demystified?
Is there anything about secondary education or college/higher education relating to albinism? Anything else you would like to add?
What is the best time (month, day, time of day?) for the radio broadcasts on albinism? What would suit you best?
What are your hopes for this radio programme?