



Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi



Paul Lynch^{a,*}, Patricia Lund^b, Bonface Massah^c

^a School of Education, University of Birmingham, UK

^b Faculty of Health and Life Sciences, Coventry University, UK

^c The Albino Association of Malawi (TAAM), Malawi

ARTICLE INFO

Article history:

Received 15 September 2013

Received in revised form 4 June 2014

Accepted 1 July 2014

Keywords:

Albinism

Visual impairment

Resource centres

Teacher training

Special educational needs

ABSTRACT

Oculocutaneous albinism is an inherited condition with significant health and social impact on the lives of those affected throughout sub-Saharan, including in Malawi. Myths and superstitions surrounding the condition lead to stigmatisation, rejection and misconceptions. In a participatory study, consultations with educational professionals, children with albinism and their families documented the barriers to full educational access and revealed low-cost strategies that could be implemented in mainstream schools, to minimise the effect of the visual impairment associated with albinism. These were captured in two information booklets in English and vernacular, one for children and the other appropriate for teacher training.

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1. Introduction

I feared his hands; he had sores on them...my belief was that whenever you see an albino you have to spit saliva on your chest (Miles, 2011).

Children in African communities born with the genetically inherited condition oculocutaneous albinism are strikingly different from their peers. Instead of the usual dark pigmentation they lack melanin pigment in their hair, skin and eyes, making their hair sandy coloured, their eyes blue to hazel and their pale skin extremely sensitive to the damaging effects of the sun (Lund, 2005). The high risk of developing skin cancer makes it imperative that all those with albinism adopt sun protection strategies from birth, including wearing protective clothing and avoiding sun exposure as much as possible (Lund and Taylor, 2008). Less obvious are the eye problems associated with albinism: involuntary nystagmus causing their eyes to wobble involuntarily from side to side, photophobia, poor depth perception, strabismus (squint), poor visual acuity, and refractive errors (Yahalom et al., 2012). An optometric study in South Africa found that 85% of the children with albinism had less than 30% vision, even with best optical correction (Raliavhegwa, 2001).

The very visible difference in appearance of those living with albinism can lead to a lack of acceptance and poor social integration. A myriad of myths and superstitions surround the condition (Baker et al., 2010; Braathen and Ingstad, 2006), leading to stigmatisation, rejection and a lack of understanding about albinism. Alex Munyere describing his personal experience of living with albinism in Kenya called it ‘a disability that others do not understand’ (Munyere, 2004). The vulnerability of people with albinism has been dramatically highlighted by reports of dismemberment and killings in Tanzania and other regions of central and east Africa, to obtain their body parts for use as ‘good luck’ charms (reviewed in Cruz-Inigo et al., 2011).

Albinism has been recorded throughout sub-Saharan Africa with estimated frequencies of between 1 in 2000–5000 (Hong et al., 2006); however there are few detailed epidemiological studies that provide evidence of the frequency of the condition in the region. Published data on the prevalence of albinism among schoolchildren in Zimbabwe and South Africa estimate that there are up to 7000 people living with albinism in Malawi, assuming a total population of 14.86 million and a prevalence of 1 in 2000 (Lund, 1996; Lund and Gaigher, 2002).

In order to help address the paucity of data on the lives of people with albinism, a small team of Malawian and UK researchers carried out a study to collect primary data about school children’s experiences living with the condition in different educational settings in Malawi. Seeking to use participatory research techniques (Lynch et al., 2012), the team designed tools that

* Corresponding author.

E-mail address: p.lynych@bham.ac.uk (P. Lynch).

could give equal opportunity and voice to children with albinism, their families as well as teaching professionals who supported these children in mainstream schools and resource centres. It was critical that this study could provide an insight into the educational and social events that impact strongly and negatively on the mental and social well-being of children with albinism.

1.1. Different approaches to educating children and young people with albinism

Children with low vision (including those with albinism) are often educated in specialist schools for the blind, outside the mainstream sector. A recent study carried out in special schools and resource centres in Kenya, Malawi, Tanzania and Uganda revealed that out of 1062 children assessed, 382 children had low vision (visual acuity \geq or = 6/60) and 120 had normal vision (Tumwesigye et al., 2009). Even though a high proportion of children could read print they remained in these educational establishments with blind children and did not have the opportunity to attend their local mainstream school.

Studies (Lund and Gaigher, 2002) at a special school for children with albinism in South Africa give an insight into their education in rural areas of the country. Although the school had access to magnifiers and other low vision devices, the pupils with low vision did not rely on these. They were used only for particular lessons such as map reading. The children with albinism at this school were all taught using print, none were taught Braille although this training was available for the totally blind. The school's aim was to teach the children skills that would enable them to integrate successfully into mainstream school at secondary level.

In nearby African countries, including Zimbabwe and Zambia, children with albinism attend mainstream schools, although inclusion in mainstream schooling can lead to challenges for both the children with albinism and their teachers. In an action research study in Zambia (Miles, 2011), one teacher of a boy with albinism expressed her fears of having 'an albino' in her class 'I was not so free with him, I feared his hands, he had sores on them. . .my belief was that whenever you see an albino you have to spit saliva on your chest'. Fear driven by superstitious beliefs has a negative impact on the way children are treated in education in sub-Saharan countries. Paucity of correct information about the condition at community level inevitably increases the probability of teachers drawing on local superstitions and myths (Baker et al., 2010).

1.2. Disability in Malawi and primary education

Disability issues are often marginalised or excluded from mainstream development strategies. People with disabilities encounter greater poverty than people without disabilities, across a variety of dimensions; including lower educational attainment, less access to employment and greater health related expenditure (Mitra et al., 2013). It is clear that today people with disabilities continue to be marginalised in both local and national development processes, and this marginalisation contributes to the high rates of chronic poverty among people with disabilities (MacLachlan et al., 2014). A recent project on African Policy on Disability and Development (A-PODD) identified negative societal and cultural attitudes as the major obstacle to inclusion, with a perception that people with disabilities are not 'useful citizens' and do not contribute towards the national development agenda (Mannan et al., 2012). Furthermore, there was a lack of empowerment on the part of those who are disabled to challenge and change this perception. The A-PODD study called for more disability-related research and information, including appropriate terminology, which has direct relevance to this study on albinism.

In Malawi, in spite of the signing and implementation of the Disability Act in 2012, there is a disconnect between departments and ministries whose mandates include the health, social welfare and education of people with disabilities (Sightsavers, 2012). The creation of a small Ministry of Disability and Elderly Affairs was considered to be a major breakthrough particularly in making 'disability' more visible in Malawi but the ministry has not been able to play a significant role in the delivery of a national development agenda. This is mainly due to the lack of funding and lack of specialist knowledge by ministerial personnel (Sightsavers, 2012). Significant gaps in knowledge about the main causes of disability and disease, particularly at the health sector level, coupled with inadequate sources of information that can be shared with families affected by disability have led to 'people making up explanations, which could be connected to illness and disease' including those with albinism (Braathen and Kvam, 2008). People with albinism in Malawi are included under the umbrella body of the Federation of Disability Organisations of Malawi (FEDOMA), with their own national association, The Albino Association of Malawi (TAAM) established in 2005. TAAM has a good record in registering individuals with albinism, providing them with counselling on skin protection and fighting for their rights at all levels. The organisation raises community awareness about issues surrounding albinism through the media, talks and participating in research studies, including the one reported here.

The Malawian government, in line with neighbouring states, sets out goals of expanding equitable access, and improving quality, efficiency and governance of the educational process at all levels, from early childhood to tertiary education, in its *Education Sector Plan 2008–2017*. This plan recognises the challenges facing the system, particularly at primary level, due to increasing numbers of school enrolment of all children without adequate funding and management. Specific targets include improving distribution of teachers in rural areas from 1 qualified teacher to 90 pupils to at least 1:70. Special Needs Education programmes feature prominently in this plan, with a stated goal of moving towards a ratio of 1 teacher to 5 pupils in resource centres by 2017, as well as introducing special needs education units in all teacher training colleges. Currently, resource centres which are attached to mainstream schools for children with visual impairment (13 in primary schools, 15 in secondary schools and 7 tertiary colleges) have up to 40 children with only two resource teachers supporting the children in some of the resource centres (Lynch and McCall, 2007). Many resource centres and residing hostels were set up with the financial support of international non-government organisations (INGOs) to educate blind children in specialist curriculum areas such as Braille literacy, Braille maths and daily living skills (Lynch and McCall, 2007), but their intake has expanded to enrolling children with albinism.

A system of delivery was set up in the 1980s to help counter the 'segregationist' approach to educating children with visual impairment at resource centres, through the Malawi Integrated Education Programme (MIEP). This radical approach was set up by the Ministry of Education and Sightsavers, an INGO, to promote the 'integration' of children with visual impairment into mainstream local primary schools. In Malawi, cohorts of itinerant teachers (ITs), specially trained in visual impairment, have been deployed in selected districts across Malawi to conduct community awareness around visual impairment and support the transition of children with visual impairment and those with low vision to their local mainstream schools, rather than to a special school or resource centre extensive distances from their home (Lynch et al., 2011). For example, in 2010 the MIEP supported 90 children with low vision, of whom 66 (73%) children have albinism, indicating that albinism is the major cause of low vision among the group on this programme in central and southern

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