Researchers explore cultural taboos in a bid to raise awareness and save lives.

University of Birmingham researchers are spearheading efforts to combat violence against women, children and other vulnerable people in sub-Saharan Africa, where witchcraft-related killing and deep-rooted prejudice poses a daily threat.

In some areas, lingering superstitions around physical characteristics caused by genetic conditions mean people are regularly victimised, tortured and, in some cases, killed.

Historically, lack of research funding has proved a barrier to international efforts to raise awareness of chilling practices, which, for cultural reasons, remain largely hidden from public view.

Over the last two years Dr Caroline Bradbury-Jones, who heads the University’s Risk, Abuse and Violence research programme, has been collaborating with fellow Birmingham academic Professor Julie Taylor to explore the complex factors which influence and contribute to violence at the intersections between gender, disability and childhood.

Now, thanks to resources from the Global Challenges Research Fund (GCRF) secured by the University’s Institute for Global Innovation (IGI), these researchers are shedding light on gender-based violence in East Africa in an effort to boost international awareness of the problem and support community-based efforts to protect those most at risk.

One strand of their research involves people affected by albinism, which has a higher than usual prevalence in this area of the world, affecting up to one in two thousand people in some regions of Africa. Those born with the condition are frequently stigmatised due to ignorance, superstition and fear. Murder and mutilation is commonplace, often taking place in remote or inaccessible areas far from the eyes of police and the authorities. Girls and young women with albinism are singled out, suffering a disproportionate rate of attack. During an extended trip to the town of Jinja in Uganda earlier this year, one of two fact-finding missions to East Africa funded via the IGI, the researchers worked with a local organisation, going deep into communities to talk to the inhabitants and explore the unique cultural and social factors that contribute to this particular form of violent persecution.

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‘There are many myths surrounding albinism in East Africa which contribute to the violence experienced by all affected people there, but particularly women and children’ explains Dr Bradbury-Jones, a reader in the School of Nursing and a registered nurse, midwife and health visitor. ‘For example, some people believe that having sex with a woman with albinism can cure HIV, which poses significant risk of sexual assault and rape.’

Sadly, atrocities are commonplace. ‘Deep-rooted historic beliefs perpetuate the notion that parts of a person with albinism’s body can be made into powder for medicine or a so-called good luck charm. We heard of people being killed or mutilated specifically for this purpose. There is a lot of mining in this part of East Africa, and we heard stories of miners going to witchdoctors or traditional healers to procure a ‘talisman’ to supposedly bring them wealth and riches in their work.’

Children with albinism are at significant risk of kidnap and consequently are often hidden by their families or sent to live in remote villages in order to protect them, she says. ‘The police just do not have the ability or the resources to reach such areas.’

Despite widespread secrecy and fear among communities, Dr Bradbury-Jones and her colleagues were given a warm reception by the families they met in and around Jinja, facilitated by the Source of the Nile Union of Persons with Albinism (SNUPA).
This trusted local organisation was pivotal in brokering meetings in the villages we visited. We were very careful to be respectful, and as a result we were received incredibly warmly. The people we spoke to offered us whatever they had, even in the poorest families. One woman with albinism who we met ordered a chicken to be killed and she cooked especially for us.

When we visited families we gave them hats, sunglasses and long-sleeved clothes because people with albinism are at particular risk of skin cancer due to their sensitivity to sunlight.

She continues: ‘One mother with albinism was bringing up all of her children, none of whom had the condition. Another mother we spoke to had nine children, five of whom had albinism. We listened to their accounts and felt extremely privileged to be given an insight into their often devastating experiences, but also their determination and resilience.’

One exciting outcome of the team’s research trip is a short promotional documentary film, which came about following what Dr Bradbury-Jones describes as a ‘serendipitous meeting’ with a local driver and film-maker called Timothy Atwine. The film the team produced ‘See My Life’ includes interviews with victims of gender and inequality-based violence and features SNUPA chairperson Peter Ogik, who has albinism. He has taken on the care of a young girl with the condition, who was otherwise living in terrible conditions and had been subjected to kidnapping attempts. ‘Peter makes a huge contribution to advocacy in this field,’ says Dr Bradbury-Jones and we are hoping that he can use the film to influence policy.

She is keen to acknowledge fellow academic Dr Patricia Lund, of the University of Coventry, who as a geneticist, has had a long career studying albinism and has opened many doors to partnerships and collaboration in this area. She led the study that resulted in a recent paper, first-authored by Dr Bradbury-Jones and published in PLoS One: Beliefs about people with albinism in Uganda: A qualitative study using the Common-Sense Model.

So where do they go from here? ‘Our hope is that as well as helping to build networks and highlighting the issues to potential donors, investors and stakeholders, our work will have influence at policy level,’ says Dr Bradbury-Jones. ‘That could be nationally in Africa or through international organisations; working with communities and setting up infrastructure initiatives or, for example, encouraging awareness of albinism in schools to try and tackle discrimination early in children’s lives. Having made ‘See My Life’, we are persuaded of the power of film and would like to produce a version especially for use in schools.

‘We hope this is just the beginning of an awareness-raising programme that will have a transformative impact, and improve the lives of some of East Africa’s most vulnerable people, particularly the women and children.’