

Power of Stigma Against Households' Efforts to Maintain Households' Wellbeing Among Households With Albinos in Tanzania.

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Abstract

This study investigated on outcomes of stigma related to beliefs on albinism and People With Albinism (PWA) on wellbeing of households with PWA. Unstructured interviews on respondents' life history were conducted. Life history method was used for analyzing the impact of the killings on wellbeing. Levels of wellbeing among households with PWA were highly affected. Poverty and lack of education suffered by people with albinism, result from discrimination, social exclusion and stigma, and in some cases human rights abuse due to living with albinism. Attacks on PWA basing on witchcraft beliefs have destabilized peace among households with PWA in rural areas by affecting invariably efforts and sustainability of smooth PWA's households' economical growth. Local governments, Non Government Organizations (NGOs), Faith Based Organizations (FBOs), community members, and households' members should assist people with albinism in various ways to cope with the situation currently facing them.

Key Words: Stigma, Wellbeing, Household With Albinos

1.0 Introduction

Stigma refers to unfavourable attitudes and beliefs directed toward someone (Maduiké, 2010). Link and Phelan (2014) explain that when people have an interest in keeping other people down, in or away, stigma is a resource that allows them to obtain ends they desire. Stigma happens when others devalue a person or a group of people because they are associated with a certain disease, behaviour or practice (International Centre for Research on Women, 2015). Africans with albinism especially in Tanzania suffer alienating social stigma in communities where their neighbours and relatives believe them to be ghosts, cursed, or intellectually incapacitated (Oakford, 2014). According to Werner (2015) stigma has detrimental effects on the rights of stigmatized individuals. Police statistics show that women with albinism are the number one target in which 101 out of 109 (ie. 92.66%) of victims of such attacks have been female (Daily Nations, 2008).

Like with other African countries, in Tanzania there are many superstitions surrounding albinism and the majority in the community fail to realize that, albinism is a genetic disorder (Kiprono *et al.*, 2012). Albinism like other kind of disabilities is associated with a sense of worthlessness or uselessness. Explaining this, Haihambo and Lightfoot (2010) revealed that beliefs and myths regarding the causes of disabilities and community responses and interventions regarding people with disabilities were similar across regions. Underlying versions of the myths and cultural beliefs are the notion that supernatural is the causes of disability.

This study aimed at investigating the outcome of this deadly stigma on wellbeing of households with PWA. It is known that stigma creates physical environment which prevents rather than supporting people with albinism from reaching their potential (Gaigher *et al.*, 2002). Therefore, the study investigated the impact of stigma (which includes discrimination, dehumanization, degrading, discrediting and devaluing of PWA) on PWA and the wellbeing of their households.

2.0 Methodology

2.1 Description of the study area

The study was conducted in Tanzania in Sukuma dominated regions of Mwanza, Geita, Shinyanga and Simiyu. The regions form what used to be known as the Sukumaland, which lies in north-western Tanzania on the southern shores of Lake Victoria. A great proportion of Sukuma are still loyal to their traditional beliefs (Wijsen and Tanner 2000). The practice of Sukuma traditional religion does not take place in a structure like mosques or churches but prayers are said among the family in the compound and are directed to the creator god in hopes of good rainfall and prosperity (Rasmussen, 2009).

Dancing is an important part of Sukuma life. The “*Bagalu*” and “*Bagika*” make two competitive dancing groups in Sukumaland. Both dancing groups use their magical potions to attract spectators to their side of the dance field and to force bad luck on their opponent. Famous people believed to be powerful witches in Sukumaland history like *Ng'wanamalundi*, *Gindunkima* and *Ibambangulu* were leaders in such dancing groups. The societies (*bagalu* and *bagika*) in Sukumaland are still going strong and dancers are affiliated with one of them (Mmasy, 2010).

2.2 Study Population

The study population for this study were members of households with persons with albinism. Heads of households with PWA were key informants.

2.3 Study Design

A cross-sectional research design was used in which data were collected from subsets of the population and from which multiple outcomes had been studied (Mann, 2003).

2.4 Data Collection

Households with albinos and people with albinism were involved in investigation of outcomes of the beliefs on albinos and the wellbeing of albinos and their households. Unstructured interviews on heads of household's life history were conducted. Life history method was used for analyzing the impact of the killings on wellbeing. Life history methods uncovered a number of phenomena that tend to be concealed from other methods (Davis, 2009).

2.5 Data analysis

Life-trajectory patterns developed from life stories were identified, and respondents' stories used to illustrate the impact of discrimination, dehumanization, degrading, discrediting and devaluing of PWA on the well being of respondents or respondents' households. Illustrations were drawn to show various trends and the effect of the crisis episodes on well-being.

3.0 Results and Discussions

This study revealed that people with albinism are victims of discrimination and violence. According to Hong *et al.*, (2006), people with albinism go through emotional stress and difficulties in various ways. While children with albinism face difficulties in completing education due to poor vision and poor educational infrastructure, discrimination and discouragement from families and others lead them to growing up as illiterates and ending up in unskilled jobs. Besides such predicaments, witchdoctors earn from selling fortune charms made from the bones, hair and skin of Albinos.

Families with persons with albinism sometimes are split in to several groups. Persons with albinism are sent away from home to towns or centres for protection while many mothers have been abandoned by their husbands for bringing shame into the family for having children with albinism. Lund and Gaigher (2000) explain this as a result of African traditional explanations which concentrate on the misfortune of illness or deviance rather than on a biomedical explanation of physical causes. In the study area, wellbeing of families with persons with albinism was studied using life histories investigations.

3.1 Wellbeing of families with PWA

Life histories among people from families were used to estimate how beliefs on albinism deprive PWA and their families' wellbeing. A wellbeing classification scheme adopted from Higgins and da Corta (2013) in which the scheme includes six wellbeing classifications ranging from destitute, very poor, poor, vulnerable but not poor, resilient and rich was used for this study.

Ten households gave their life histories precisely. Life histories fell into four categories which are represented by four life histories. In the first category, some people with albinism were able to own businesses or activities which enabled them to live independently in some cases supported their relatives financially. But when the wave of the attacks and killings of people with albinism, they could not go on with their business because the situation was not conducive any more. In another category, some PWA lived life with constant discriminations since their births. Though there were efforts done to set themselves free from discriminations and stigma, the circumstances were not in favour of them. All efforts didn't overcome the force of stigma and negative attitudes towards the condition as a result the level of wellbeing fell gradually in response to lost means of livelihood. There are incidents in which parents were physically injured while protecting their children, but in most incidents families' wellbeing dropped due to lost time and assets. The fourth category was for women with albinism who in most cases had children with albinism too. This is because women with albinism hardly get normal pigmented male partners. This increases the frequencies of the albinism gene in the family. Women with albinism live lonely life with a burden of taking care of their children as single parents.

From life histories it is seen that PWA have been affected greatly by the killings of PWA. Economic hardships and poverty among households with PWA impact the whole family in which

most families with PWA have lost hope for a better future. Hong *et al.* (2006) in a research article “*Albinism in Africa as a public health issue*” describe social discrimination as an obstacle to building relationships and finding or maintaining an occupation among PWA, making most PWA of lower or of the lowest economic status in their society. People with albinism are often stigmatized and discriminated against owing to myths and superstitions held by the public about the condition (Pooe-Monyemore *et al.*, 2012).

3.1.1 Wellbeing in Households headed by PWA

In discussion with a key informant A, who was born in the study area in 1970s, he remembers to spend his early life with his family happily. His family had enough land for family food production. In the 1980s unlike many children with albinism, he was taken to a nearby primary school for his primary school education. He was not lucky to be selected for secondary school education like many children with albinism who faced many challenges at school due to unfavourable learning environment for albinos in most schools. At school, poor vision, skin problems, social adaptation and lack of an appropriate physical environment impede progress of many PWA like A who is among many PWA who struggle to get education in an unfriendly environment ending up with primary education. According to Mesaki (2008), the majority of albinos are semi-literate in which many of them do not reach beyond primary school education. In mid 1990s, A got married to a normal pigmented girl (with no albinism) from whom he got four normal children. He successfully worked as *dagaa* (sardines) trader in which he had to travel all over Sukumaland districts. He could ferry up one hundred bags of *dagaa* at a time. The business enabled him to build a house, to keep him busy as well as enabling him to support his family and relatives.

When the killings of PWA started, one day while he was in one of many Islands in Lake Victoria, accompanied by his friend (fellow PWA) who also had a similar business, he got shocking news. His friend (fellow PWA) was attacked and killed at night. The next morning “*good Samaritans*” warned him that he could be the next prey. He collected some of his belongings handed them to someone who was expecting to travel to the mainland next morning and he secretly left the island at night using a hired small boat to a secret area he considered to be safe. This changed his life a lot since he didn’t get all of his goods from the Island and he could not return back to the island. Most of his goods were lost while escaping.

Economically, A was devastated since he lost his ability to support his family. Economic difficulties led to separation with his wife who left him alone after leaving with the children. Besides facing economic problems, he is also living in constant fear due to the ongoing killings of PWA. He can trust nobody since he knows some persons with albinism were betrayed by their own parents and close relatives. He remembers a community leader who is in detention for using his position to hijack and kill a person with albinism suffering from cancer by deceiving him that he was taking him to a witchdoctor for treatment. According to Schnoebelen (2009), the killings have caused great apprehension and fear among the albino community as they feel very insecure and even afraid of staying, walking or travelling alone because of the potential risks.

Currently, A has no clear source of income. He is living alone since his wife ran away with his children when the business collapsed. He is dependent on casual labour from which he gets his daily requirements. He can no longer support his children in school. He no longer supports his relatives as before, but he still remembers the past days when he was free to travel and do business to support

his family. According to the Albino Foundation (2012), as a result of discrimination, social exclusion and stigma, many people with albinism do not have the full social or economic tools to live productive lives. Lacking the confidence to compete favourably with others in the labour market and therefore unable to reach their full human potential. Both the individuals and the country suffer, as the vast majority of the skills of this group are not being utilized for the greater benefit of society. Staniland (2010) explains that the main barriers disabled people face come from the way in which society is organised, not from their impairment. Gupta and Singhal (2004) further explain that it is the lack of public awareness about the potential of disabled people which often acts as a barrier to their acceptance and participation of the disabled. Fig. 1 illustrates how attacks and killings of PWA affected A and many heads of households like him, who, because of having albinism, were forced to abandon their daily activities in order to save their lives.

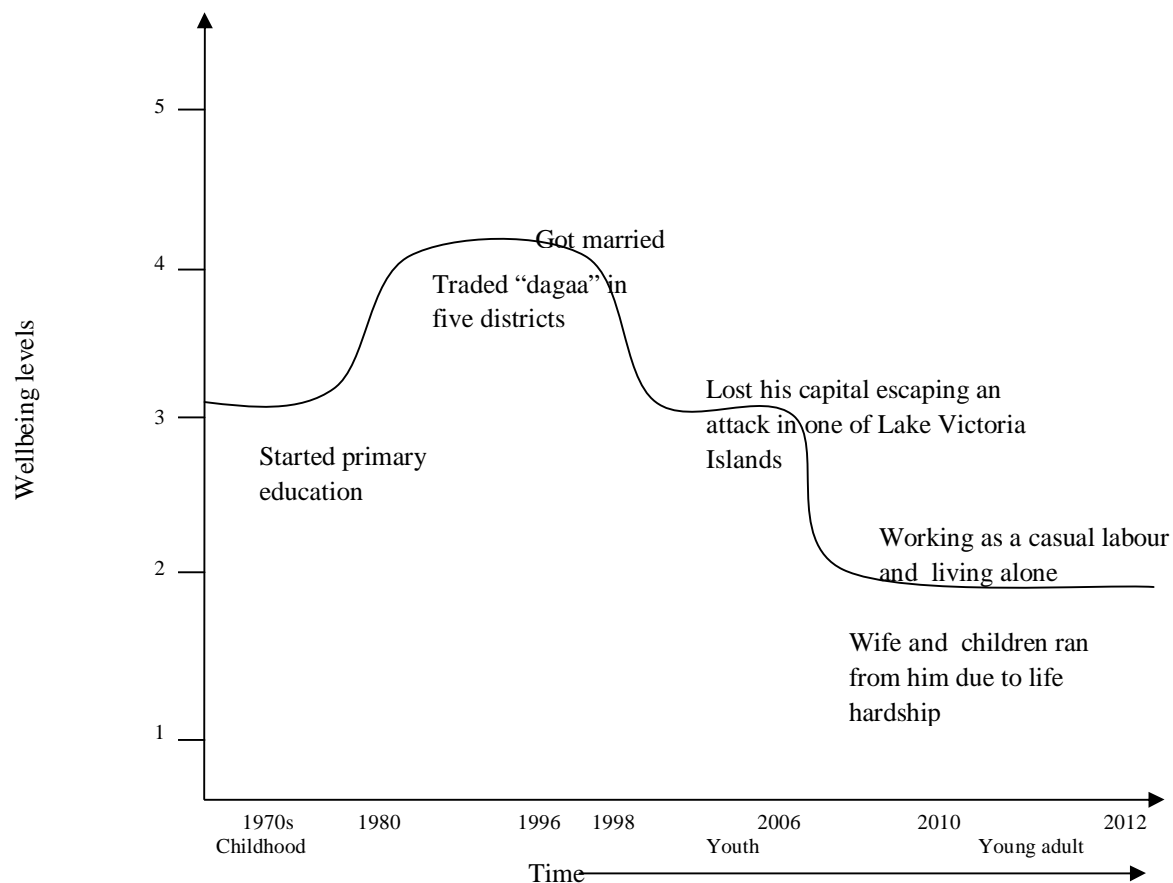


Figure 1: Illustration of life history showing effect of PWA killings on wellbeing of Households headed by PWA

3.1.2 Wellbeing in Households headed by single mothers with albinism

B is a PWA and a mother of three children with albinism. She was born in 1980s. Her parents separated and divorced few months after her birth. Due to family instability and long distance from where she lived to a nearby school, she never went to school. Living with her mother they managed to acquire three acres of land and managed to build a small "tembe" (a mud roofed house) in their village. She got three children with albinism whose fathers are not recognized traditionally because

she then got out of wedlock. This suggests that B got the children from a fellow person with albinism. According to Gaigher *et al.* (2000), the choice of a marriage partner is a serious dilemma for people with albinism. Stigmatized and prejudiced by their condition, their chance of marrying a normally pigmented person is severely reduced. Thus marrying a person with albinism means they end up having off- spring with the same condition thereby worsening their situation.

When the killings of PWA started, the family was forced to flee from the village fearing an attack from people who were looking for body parts from PWA. B lost all means of sustaining her family because they left the land far away and they had no other means of living in town where they took refuge. People could not employ her for any job because they feared in case of an attack on her, they could be the first to be questioned. As a result her children left schools because she could not afford to buy school materials for them as well as provide food. Due to such circumstances, many albinos remain uneducated or drop out of schools.

B is somehow sure that she cannot be attacked in her current home, but she is not sure of her future and her children's future. B's family lacks time and is denied to engage in gainful activities because of their condition, B spends all of her time protecting herself and her albino children. A long history of myths attached to the condition in the study regions, besides attributing supernatural powers or deviant personalities to people with albinism, people with albinism usually look very different from members of their own ethnic group and therefore in most cases feel and are treated like strangers. Such factors contribute to social isolation, poor self-esteem and stress among people with albinism. According to Palmer (2007), their condition is unique and is surrounded by myths and stereotypes, thus albinism has the potential to affect young people both emotionally and psychologically. Concerning the wellbeing of children with albinism, Albino Charity Organization (2013) explains that:

“The albino children of Tanzania face the most challenges compared to any other poor children in Africa. They are limited and cannot function like normal children. Albino children in Tanzania are one of the poorest children in Africa. They live off of less than \$1.00 per day”

Impact of albino killings on households headed by mothers with albinism who mostly lead their lives as single parents is as shown in Figure 2.

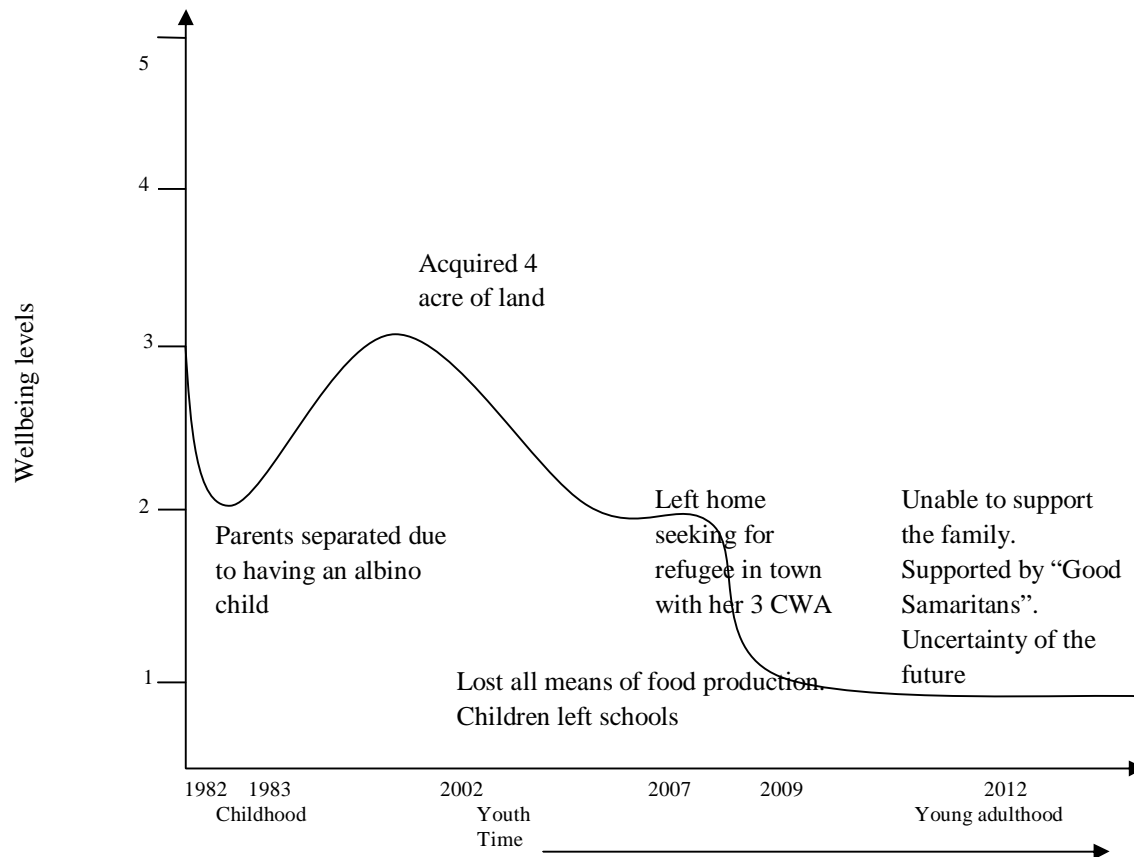


Figure 2: Illustration of life history showing effect of PWA killings on wellbeing of Households headed by single mothers with albinism

3.1.3 Wellbeing in Households of unmarried PWA

In most cases PWA are forced to live lonely life after leaving their households in rural areas taking refuge in towns. In their new homes, they are forced to live singly because according to Gaigher *et al.* (2000), the choice of a marriage partner is a serious dilemma for people with albinism. C is a lonely lady with albinism being born in 1970s in a remote village closer to the famous Gamboshi village (the invisible city believed to be witches' capital city) in Bariadi District. She is the seventh child in a family of eight children. Five of her brothers and sisters died in different years she and her brother are the only survivor from their family which was composed of six children with albinism and two normal pigmented children. C could not go beyond standard three in her primary education due to family disputes, which rose from her birth as a fifth child with albinism in the family. She bitterly remembers her late mother telling her how she fought to save her life because people were convincing her to go and throw her child in a nearby river due to albinism. C reiterated:

“My mother tearfully told me how she was bitterly beaten by my father for having a child with albinism. I was told that my father didn't come to hospital to greet my mother and see me as a newborn because he was informed that I had albinism. If it was not my mother being a committed Roman Catholic Christian she could throw or burry me alive in a nearby river bank.”

Her parents later separated due to birth of the eighth child who had albinism too. She remembers how her father mistreated her mother for having six children with albinism. Upon separation from her parents, she could no longer live with the father who did not need to see a child with albinism in his family. C experienced what Allen (2010) wrote in her work on *“Oppression through omission: The Human Rights Case of Persons with Albinism in Uganda”* when she wrote:

“From the time of birth, most children with albinism, particularly those in impoverished and in rural areas, are immediately exposed to discrimination from within their own families. When discrimination comes from parents or caretakers, a child is constantly exposed to inhumane treatment from an early age, which has lasting effects. It is not unheard of for mothers to throw their own child away, killing or abandoning him/her because of the fear and stigma associated with albinism. Fathers are likely to abandon an albino child, sometimes along with the mother, if not outright kill the child, either from belief in the mother’s unfaithfulness, superstition, or from the stigma associated with having an albino person in one’s family”

C lives alone being economically challenged. Stigmas attached to PWA affected her in several aspects. Having worked as a house maid twice latest being in an educated government staff family, but when the killings of PWA started she was terminated from work because her boss thought he was not safe anymore by staying with a person with albinism. Nobody else could hire her for any activity after that. She was assisted by a *“Good Samaritan”* with money to run a small *“Mamalishe”* (food vending) business but she could hardly get clients. She wondered how people perceive albinism:

“I worked as a “house girl” for several years in which I could cook nice foods, but when I started “mamalishe” business, I never got clients because of albinism! Finally I closed the business”.

She was once again financed to start firewood and charcoal business in which she had to collect firewood and charcoal from villages and sell in town. Respective villages’ authorities stopped her making the business in their villages fearing to be accountable if she would be attacked in their villages. She is currently with nothing in her hands with feeling of being a worthlessness person thus unfit to live in such community. C is currently suffering from skin complications, having undergone surgery twice, she was scheduled to visit her doctor at KCMC (Kilimanjaro Christian Medical Center) hospital for a third surgery for the same problem. C’s life history reveals that, people with albinism’s lives are accompanied with social exclusion and miserable poverty. Fig. 3 illustrates drop in wellbeing level in lives of PWA like C.

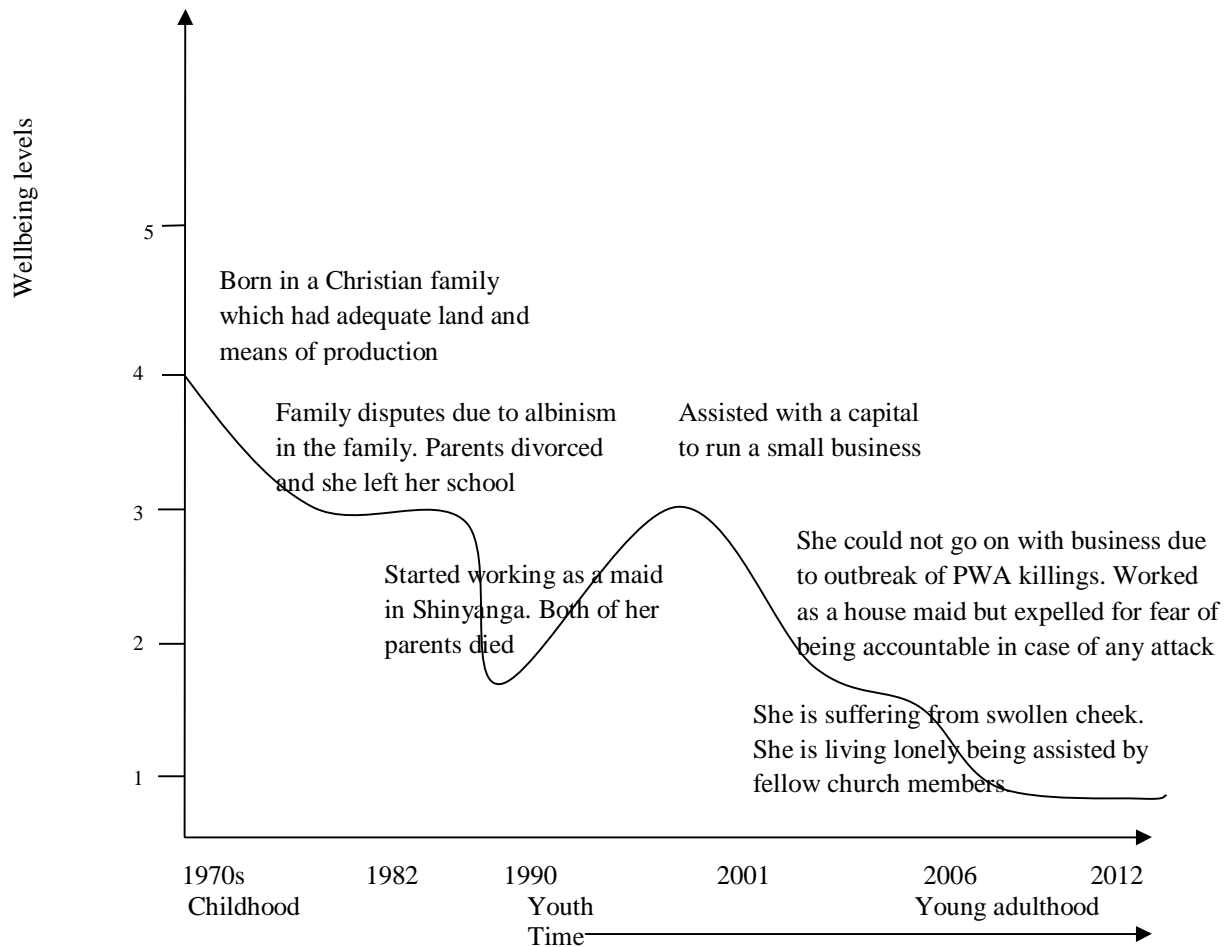


Figure 3: Illustration of life history showing effect of PWA killings on wellbeing of Households of PWA living single (unmarried).

3.1.4 Wellbeing in Households with attacked or killed PWA

All over in the study area, there are families which witnessed one of their family members being mercilessly attacked. Few can dare to tell the whole story while many choose to narrate the story briefly. D is a head of a family of four children. He is a normal pigmented man born in 1930s. He remembers his childhood to be normal being born from married parents. He never went to school because he used most of his time taking care of the family livestock. He got married in his early age because the family instructed him to get married soon. He managed to acquire two oxen ploughs which he uses in his farming activities. He later acquired an oxcart which is used in carrying harvested crops and fetched water. He got four children one of them having albinism. Though the family was shocked by having a unique family member, the family accepted her. All children were taken to school as they reached appropriate age for schooling.

After completion of her primary education, one night she was attacked and lost one her of her hands. The girl is among many PWA attacked by fortune seekers, who believe that a concoction containing some albino body parts could make them rich and powerful. The family was shocked due to the attack resulting into the fall in family well being (Fig. 4). Family assets were sold to take

care of the injured child. Attacked daughter left home for treatment could not return back home for fear of attackers. During data collection, the girl was accommodated in a government Hospital. She sorrowful explained her agony due to the event by saying:

“I don’t think that one day I will go back to my home village. They badly hurt me mercilessly by chopping off my hand! Though I am currently recovering, I face many challenges including adopting to life without my amputated arm”

As a result of the attack, the family used most of the time for taking care of attacked daughter in hospital. The daughter was seriously affected psychologically because she could trust no one anymore. She is learning to write using her left hand since she commonly used her right hand to write. The daughter was learning how to use her left hand in all activities in life. Though D was not physically hurt by the attackers as it happens in many cases when parents try to rescue their children (Thuku, 2011), he remains unstable emotionally.

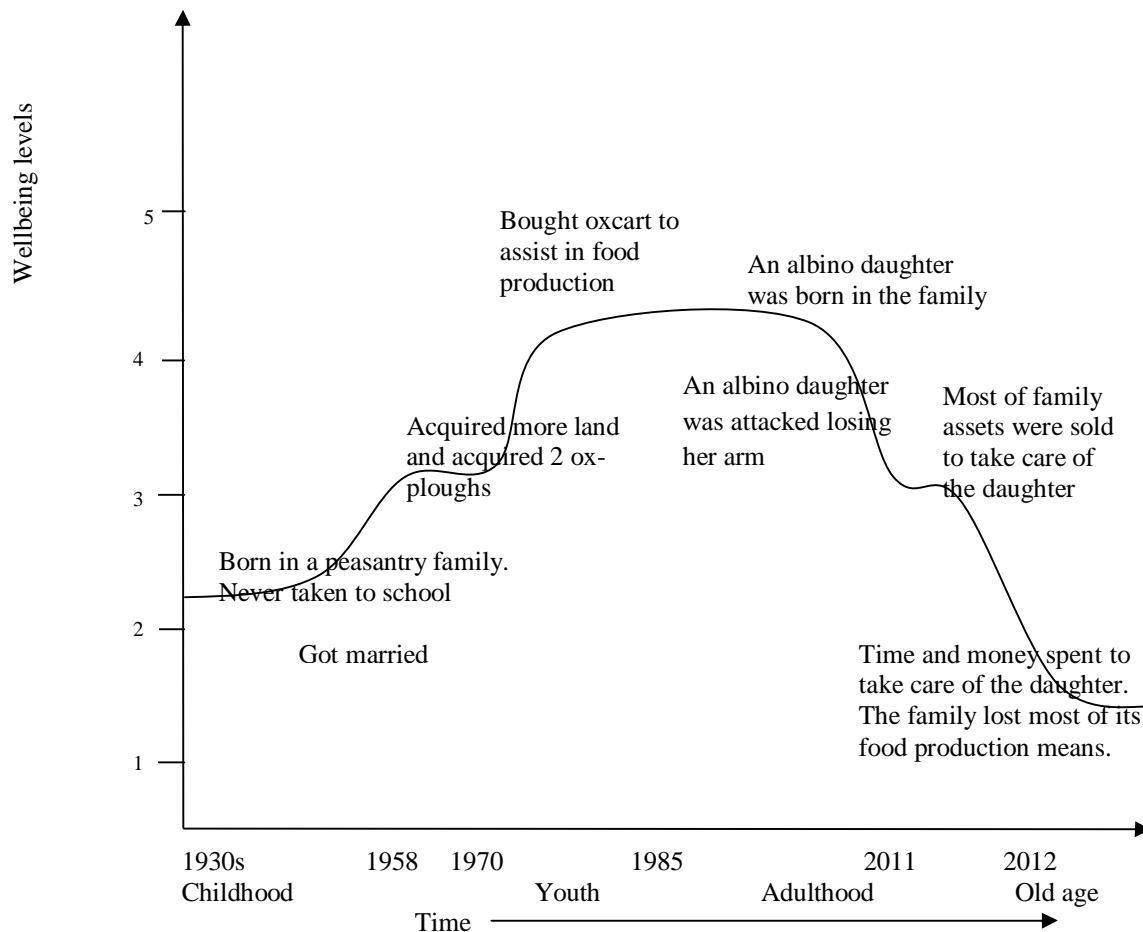


Figure 4: Illustration of life history showing effect of PWA killings on wellbeing of Households with attacked or killed PWA

3.2 Overall Impact of PWA's Killings on Families' Wellbeing

In Tanzania several challenges confront people living with albinism's wellbeing. People with albinism are classified among the vulnerable groups of society, who include people living with various kinds of physical disabilities. In Tanzania PWA don't enjoy significant level of attention, security and support from the government. PWA don't get special requirements for PWA which include special healthcare for PWA, advocacy and social awareness education, social inclusion, academic education, economic empowerment, and socio-political protection from various forms of societal abuse and discrimination which are still experienced among people with albinism. Poverty and lack of education suffered by people with albinism result from discrimination, social exclusion and stigma, and in some cases the human rights abuse due to living with albinism.

From the life history interviews, it is clearly shown that there are adverse effects of the PWA attacks on their families' well-being. Though in some cases there had seen some improvement at certain times, the main causes of these periods of opportunity were like getting capital assistance from good Samaritans, but it seems that the level of discrimination in the community is higher than the efforts to improve their wellbeing failed. For example C's *mamalishe* business could not take off due to lack of customers who could not be attended by a person with albinism. In some cases, the incidence of PWA attacks led to total collapse of businesses. For example the A's *dagaa* business which was the only source of the family earnings collapsed because he could not travel alone as he used before and people feared to associate with him for fear that they would be the first to be questioned in case A would be hurt. As a result of PWA attacks, many people with albinism lost most of their social and economic means to live productive lives.

Like with witch hunting in the study area, which forced mostly old women to flee their homes to urban places, plunging them into becoming beggars and living in poverty, PWA are following the same way. In Shinyanga and Mwanza towns (major towns in the study area), it is common to see women in search of food and other assistance. These are innocent citizens victimized by fellow villagers in rural areas. Attacks on PWA basing on witchcraft beliefs have destabilized peace in rural areas by affecting invariably their efforts and sustainability of smooth economical growth.

4.0 Conclusions and Recommendations

4.1 Conclusions

Due to attacks, killings, stigma and discriminations of persons with albinism, their level of wellbeing were, to a great extent, affected. They lost their ability to produce by being unable to participate freely in their normal and daily activities. They lost their time and means of production when they were bearing costs to treat their family members who lost parts of their bodies. Some left their businesses for fear of being attacked therefore losing means of livelihood for their families. Children with albinism separated from their families to live in boarding schools for their safety. Separation of children from their parents obvious leads to creation of generation gap in which family and community values are never passed on to the concerned children.

4.2 Recommendations

4.2.1 Overall recommendation in dealing with stigma

Proper approach on dealing with discrimination, dehumanization, degrading, discrediting and devaluing of PWA should be considered. Campaigns against stigma should start at household level

with moves to change their attitudes towards albinism and people with albinism. Therefore households' members need to be liberated first from what dominates their understandings on albinism and PWA.

4.2.2 Recommendations to Local Government

Local governments should assist people with albinism to cope with the situation currently facing them. Local governments should assist them through capacitating them with entrepreneurship skills. Being marginalized and denied opportunities for employment, people with albinism have very limited marketable skills and trainings. People exposed to entrepreneurship skills generally have more opportunity to exercise creative freedoms, higher self esteem, and an overall greater sense of control over their own lives. Thus, entrepreneurship skills will provide several alternative ways for them. Entrepreneurship skills will offer increased opportunities to accommodate their challenges and maximize their strengths and skills. Therefore, Women Development Fund (WDF) should consider giving priority to women with albinism in giving soft loans under Community Development Departments in every District Council. Youth capacitated with entrepreneurship skills should be given priority in Youth to Youth Funds to enable them get means of livelihood in safe environments. This is because local governments at village level are responsible with the wellbeing of citizens in their areas including PWAs' wellbeing.

4.2.3 Recommendations to Development Partners

Development partners in the study area should intervene to maintain the wellbeing of families affected due to being affected physically and psychologically by albino murderers. Non-Governmental Organizations (NGOs), Faith Based Organizations, Community societies and other donors should assist affected children to enjoy life at its fullness. They should assist families with means of production so that the families may resume normal livelihood activities.

Development partners should assist in conducting "community conversations" sessions to re-evaluate cultural beliefs which affect people with albinism. This will assist in getting the in-depth views of community members on the beliefs and practices which affect people with albinism. This approach will be helpful in taking proper measures to eradicate unwanted behaviour and practices in the community by the community itself. Being a special behavioural change programme, it should be designed to discourage the practice of using albino parts in preparation of "medicines". The programme should focus on changing the community perceptions, beliefs and attitudes towards PWA among community members, traditional doctors, and traditional leaders.

4.2.4 Recommendations to Parents

Parents are supposed to accept and love their children born with albinism. Non-albino parents of albino children should discuss with their children several times in order to be supportive to their children concerning the condition. They should assure the children that albinism can happen to anybody and to any race. Parents should make sure that the children are taught to accept the condition and learn to cope with challenges accompanied with the condition.

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