

Evaluation of a Lay Health Worker Program to Increase Community Knowledge about Albinism in Same District, Tanzania

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Abstract

Lay health workers have been effectively utilized for a variety of public health interventions. However, such interventions focusing on improvement and retention of community knowledge about albinism have yet to be studied. This article reports results from a program evaluation of a lay health worker intervention in Same District, Tanzania. The program employed 33 lay health workers, who conducted 60-90 minute educational presentations (n=332) about albinism in community locations throughout the district. A 15 item questionnaire that assessed knowledge about albinism was administered to randomly selected community members in each ward during the month before the presentations (n=896), the month after the presentations (n=743), and one year after the presentations (n=1327). Results differed significantly across all three time periods, with significant gains in knowledge about albinism from the baseline to one month following the interventions. No differences were found between the second and third time points, indicating that knowledge gains persisted over a one-year period. Findings suggest that carrying out a targeted education program using lay health workers was associated with a long-term increase in community knowledge about albinism, although overall knowledge levels remained low.

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Keywords

Africa, community health workers, persons with albinism, program evaluation, public health education

Introduction

Public health interventions utilizing lay health workers (LHWs) have gained attention as an effective way to improve access to health services, especially in populations with otherwise limited access to health care (World Health Organization [WHO], 2015). LHWs are individuals who provide health-care services, but have no formal professional education (Lewin et al., 2010). LHWs are often considered to be community health workers (CHWs), which the Centers for Disease Control and Prevention (2014) defines as community members who function as a bridge between health care consumers and providers, often serving demographics with limited access to health care (Arvey, 2012). The movement to increase use of LHWs has gained support from many international institutions, such as the Global Health Workforce Alliance, a collection of organizations hosted by the World Health Organization (WHO, 2012; WHO, 2015).

Several studies have supported the effectiveness of LHW programs in promoting utilization of health care services and improving health outcomes. A systematic review by Lewin et al. (2010) found evidence that LHWs are effective at promoting exclusive breastfeeding, increasing immunization rates in children, as well as some evidence that LHWs can contribute to a reduction in childhood mortality. In a specific example, field workers from the community working in squatter settlements in Karachi, Pakistan who were trained to promote bleach water treatment, soap and hand washing, or flocculent-disinfectant water treatment using slide shows, videotapes, and pamphlets showed a reduction in diarrhea prevalence by 51-64% compared to no intervention (Luby et al., 2006). A systematic review of LHW programs by Viswanathan et al. (2009) in the United States found that they can be an effective means of improving participant knowledge; five studies reported improved knowledge levels of participants for diabetes prevention, condom use, and cancer screening compared to no intervention. However, not all LHW interventions have been shown to be efficacious. There is mixed evidence that suggests that LHWs are no better than alternative interventions for self-management of chronic conditions, blood pressure control, and body mass index (Viswanathan et al., 2009). Direct comparison of interventions is complicated by the wide variety of LHW roles and the diverse nature of the programs they serve (Arvey, 2012).

While LHW interventions have been shown to improve participant knowledge and behavior for specific health-related topics, there is not yet a significant evidence basis for some of the topic areas that LHW programs have been

developed to target (Lewin et al., 2010). More evaluation is needed to determine if LHW programs targeting these topic areas are efficacious. We believe that public health education using LHWs in rural areas of developing countries has the potential to significantly improve health by reducing the disease burden and its demands on an understaffed healthcare system. The use of an educational program that verifiably improves knowledge of both the program attendees and community as a whole is critical to this goal.

Albinism in Tanzania

Oculocutaneous albinism is a collection of genetically-inherited, autosomal recessive disorders that are marked by a deficiency of melanin in the skin, hair, and eyes (Wright, 2015). This melanin deficiency results in pale skin, sand-colored hair, and mild to moderate visual difficulties (Okoro, 1975). The prevalence of albinism in Sub-Saharan Africa varies by region but is relatively high, with an estimated 1/15,000 affected in Nigeria up to 1/1,000 in Zimbabwe; Hong, Zeeb, and Repacholi (2006) provide a low quality estimate for Tanzania at 1/1,400.

Because of their lack of skin pigment, persons with albinism (PWAs) are highly susceptible to sun damage and skin cancer; skin damage is already evident at age one, by age five focal lesions are present, and as early as age nine skin cancer can occur (Luande et al., 1985). Less than 10% of PWAs will survive to their 30's; it has been suggested this is mainly due to mortality attributable to skin cancer, although highly reliable mortality data is not readily available (Greaves, 2014; Hong et al., 2006).

In addition to health challenges, PWAs in Sub-Saharan Africa face extreme hardships due to mythological beliefs and social stigma; from 2001-2011, it is estimated more than 100 murders of PWAs occurred in Tanzania, Burundi, and surrounding areas (Cruz-Inigo et al., 2011). These attacks are believed to stem from widespread and heterogeneous mythological beliefs about albinism (Cruz-Inigo et al., 2011). Longstanding myths include ideas about albinism being a punishment from the gods, the result of conception during menstruation, or from seeing something frightening while pregnant (Okoro, 1975). Other myths, sometimes propagated by witch-doctors, include purported benefits from the possession or use of body parts of PWAs as good luck charms with magical powers, or that sexual intercourse with females with albinism can cure HIV (Cruz-Inigo et al., 2011). These superstitions appear to have fertile ground to flourish in Tanzania, where 80% of the population believes in spells and curses, and 49% believe that "juju, shrines, or other sacred objects can protect you from harm" (Pew Research Center, 2010). In addition to fatal and violent events, some students with albinism reported being bullied, avoided, or mocked and called names by their peers (Lund, 2001; Hong et al., 2006). Many students with albinism had concerns about having fewer friends, and some be-

lieved they were less loved by their parents, and sometimes ill-treated by their families (Lund & Gaigher, 2002; Hong et al., 2006). Misunderstandings about PWAs continue to make integration into society difficult for this population.

Discrimination and violence against PWAs is likely due in part to communities' lack of awareness and education about the etiology of albinism (Hong et al., 2006). Historically, PWAs have often been culturally and physically viewed as completely different than those without albinism (Okoro, 1975). It appears that more education about albinism is needed; in one example from a special school in South Africa, 73% of students with albinism did not know what caused albinism (Lund & Gaigher, 2002). A larger study in Zimbabwe found a similar trend, with 50% of primary and secondary students with albinism not knowing why their skin was pale (Lund, 2001).

In 2013, the United Nations (UN) issued a report documenting the challenges faced by Tanzanians with albinism, and presented recommendations to address them (United Nations [UN], 2013). Among other avenues, this report urged a focus on education to "address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma" (UN, 2013, p.34). The UN recommendations, along with personal experience and conclusions drawn as a result of a review of the literature, inspired Empower Tanzania Inc. (ETI) to develop a LHW program to educate people about albinism using a community-meeting based approach. Previous research by Wall, Peden, and Carithers (2015) reported that these ETI presentations increased knowledge of albinism among program participants. The purpose of the current study was (1) to assess presence of change in knowledge about albinism in communities throughout Same District of Tanzania following the LHW presentations, (2) the degree of knowledge change, and (3) the persistence of change in knowledge over a one-year period.

Method

Organization Background

Empower Tanzania Inc. (ETI) is a non-profit, non-governmental organization that developed a large-scale public health education program designed to encompass the approximately 270,000 inhabitants of Same District, a predominantly rural area in northeastern Tanzania. In 2012, ETI trained 26 women as Community Health Educators (CHEs) to deliver health education presentations throughout Same District as part of ETI's Improving Women's Health Program (IWHP); seven more CHEs were added to the program in 2013 to provide at least one CHE for each of the 31 Wards in Same District. Health education topics covered in the IWHP program have included safe water, hand washing, nutrition, HIV/AIDS, albinism, malaria prevention, family planning and gender-based violence. CHEs functioned as paid employees of ETI, and

received a salary as well as reimbursement for travel expenses.

Initial training of the CHEs in 2012 consisted of a six-day program where they were taught health content, presentation techniques, methods of program monitoring and evaluation, and operation of the audio-visual equipment used in the presentations. Training was provided by a physician and a community development worker. Refresher training was done yearly through a three-day program that included a review of previous topics, and new topics for the coming year. CHE training on albinism was provided during a three-day training session in November 2013. Small-group educational sessions for all CHEs were again held in January 2014, where they were refreshed on the topic of albinism, and taught the presentation format and questionnaire administration procedure.

Albinism Presentation Content

Educational presentations on albinism were delivered by CHEs throughout the 31 wards of Same District during February 2014. Presentations were given by CHEs, who were assisted by two volunteer Health Implementers (HI). Prior to each presentation, CHEs and HIs recruited attendees at a given location with the assistance of village government officials, neighborhood leaders and via announcements at schools, religious functions and medical facilities. Presentations were then given at these locations. A total of 332 presentations were delivered, with 12,000 total recorded attendees. The number of unique attendees was lower, because some participants attended multiple sessions. Attendees were asked to sign in with their name, signature, and phone number. Participants were not required to be residents of Same District, and received no compensation for participation.

Presentations began with a self-introduction of the CHE and her two HIs, followed by an overview of the topic of albinism (included inheritance and social ramifications), a 14-minute informational video in Swahili showing interviews with children who have albinism (<https://www.youtube.com/watch?v=NiJsaiiO7VM>), and a short PowerPoint presentation depicting basic principles of genetic inheritance in albinism and some of the unique risks faced by people with albinism. This was followed by a discussion period during which participants were encouraged to ask questions. Each presentation lasted from 60-90 minutes. Presentations were delivered in Swahili.

Data Collection

Assessment Questionnaire

ETI developed a questionnaire to assess factual knowledge about albinism that was administered to randomly selected individuals from Same District at three distinct times: (1) in the month preceding the presentations, (2) during

the month following the presentations, and (3) one year after the presentations. The questionnaire was drafted in English, translated into Swahili, and then reviewed by a team of bilingual staff to ensure preservation of face validity. Items were constructed to address several topic areas where misconceptions about albinism are common. The questionnaire was pilot tested with a smaller sample of presentation attendees ($n = 426$) prior to administration in local communities. Mean scores differed significantly for all items, with the exception of one that pertained to albinism inheritance (Wall, Peden, & Carithers, 2015). This item was retained in the questionnaire with the hope that a larger sample size would better elucidate any true difference.

The questionnaire included eight items that assessed knowledge of albinism, measured on a five-point Likert-type scale that ranged from 0 (Strongly Disagree) to 4 (Strongly Agree). Three of the items were negatively worded. Respondents were asked to specify their age, gender, religion, and level of education. They were also asked whether they believed in sorcery, whether they had ever seen a person with albinism, and whether they knew someone with albinism. Names and other personal identifiers were not collected to ensure anonymity and protect confidentiality.

Sampling Protocol

Each ward's CHE ($n = 33$) met with their two HIs ($n = 66$) and divided their ward into three non-overlapping areas based on their knowledge of the population distribution. Within their assigned third of the ward, each surveyor (CHE or HI) selected four starting points they thought would provide the most accurate sample of their area. From each starting point, surveyors drew a piece of paper numbered one through six and counted that number of streets in any direction. At the selected street, a new number was drawn and that number house was selected for inclusion in the survey. If no one answered the door, the surveyor proceeded down the street by one house until someone answered. The person with the closest birthday over the age of 13 was invited to participate. If that person declined, the person with the next closest birthday was selected. The selection process continued until someone from the household had completed the questionnaire, or everyone had refused. Surveyors then crossed the street, drew a new number, and repeated the process. Surveyors did not collect more than three surveys from any single street. For areas without streets, the surveyors selected the first house in any direction from the starting location. Subsequent houses were selected by drawing another number and proceeding in a different direction. Each surveyor was asked to collect 12 (pre-intervention and one-month post intervention surveys) to 15 questionnaires (one year-post-intervention survey). Inconsistencies in the initial data collection process interfered with randomization of surveys distributed in the pre-intervention and one-month post-intervention phases. Thus, the samples should not be

considered generalizable to the population of Same District. Response rates were $n=896$ for the pre-intervention (75%) and $n=743$ for the one-month post-intervention (63%) surveys. Subsequent refinement and training on the data collection process resulted in 1,327 one-year post-intervention questionnaires for a response rate of 89%.

Data Analysis

Data were entered into Excel and uploaded into SPSS v23 for analysis. Incomplete responses were minimal and individual item means were used to replace any missing values. Negatively phrased items were recoded and exploratory factor analysis was used to assess dimensionality. Both two and three factor solutions were initially obtained. but there was evidence of cross-loading and one factor in each solution (curse/punishment) did not meet the accepted criterion of four items (Netemeyer, Bearden, and Sharma, 2003). As a result, a mean index score was computed for all eight knowledge questions ($\alpha = .61$). Each item and the mean index were compared across the three administration time points using Analysis of Variance (ANOVA) with Tukey's HSD post-hoc tests. Repeated Measures ANOVA was not used because the respondents only participated in one iteration of the survey.

Results

Descriptive Results

A majority of respondents were female (55%), and the average age was 34. Approximately 67% of respondents had no more than a primary level education. Christianity was the most commonly identified religion (68%), followed by Islam (28%), other religions (2%), and none specified (2%). Over 10% of the sample professed a belief in sorcery. Approximately 90% of respondents indicated that they had seen a person with albinism, and nearly 65% stated that they knew someone with albinism.

Analysis of Variance (ANOVA) and Chi-square tests were used to assess potential sources of bias by comparing demographic characteristics across the three time periods. Age ($F(2, 2916) = 2.158, p = .116$), gender ($X^{(1)} = 4.18, p = .383$), level of education ($X^{(1)} = 12.25, p = .140$), and religion ($X^{(1)} = 1.42, p = .839$) did not differ significantly between time periods. However, those sampled in the first time period (baseline) were more likely to believe in sorcery ($X^{(1)} = 27.26, p = .000$), but less likely to state that they had seen a person with albinism ($X^{(1)} = 29.32, p = .000$) or knew someone with albinism ($X^{(1)} = 17.87, p = .000$).

Significance Tests

Results indicated that all eight items varied significantly ($\alpha \leq .01$) across the three time points (pre-intervention; one-month post-intervention; one-year post-intervention). Mean scores ranged from .86 – 3.08 on the pre-intervention, .64 – 3.32 on the one-month post-intervention, and .61 – 3.34 on the one-year post-intervention (Table 1). Post hoc tests suggested that scores on all three negatively worded statements (Curse, Punishment, and Vision) were greater at Time 1 (pre-intervention) than Time 2 (one-month post-intervention) and Time 3 (one-year post-intervention). These differences remained over a one-year period with no statistically significant variation between Time 2 and Time 3. Similarly, scores on the five positively worded statements increased significantly from Time 1 to Time 2. As with the negatively worded items, there were no differences between Time 2 and Time 3, indicating that knowledge gains persisted over a one-year period. The mean index score also differed significantly across the three time points ($\alpha \leq .01$), and exhibited the same pattern as the individual items (Table 1).

Discussion

The goal of the lay health worker program evaluated was to increase community knowledge about a health-related issue, and promote retention of that knowledge over time. Knowledge change has been used as one component of evaluation of lay health worker program effectiveness (Viswanathan, 2009). Respondents in Same District demonstrated significant improvements in knowledge about albinism in the month after the LHW presentations when compared to the month prior to the presentations. Knowledge levels remained the same one year following the presentations, providing evidence that the effects of the program persisted over a one-year period. This suggests that (1) LHWs can be used to deliver effective community health education, and (2) that even short term interventions have the potential to positively impact knowledge about important public health issues.

While knowledge increased during the study period, both pre and post-intervention levels remained lower than desired. The degree of knowledge change on individual item measures was small, with effect sizes ranging from .011-.045. However, the effect size for the mean index was large (Table 1) (Cohen, 1988). This illustrates the challenge of changing strongly held beliefs about specific aspects of albinism, but suggests that overall knowledge is subject to change.

Although the study design did not include a control group for comparison, the stability of knowledge levels between times 2 and 3 provides evidence that the cause of the demonstrated increase in knowledge occurred in the month following the IWHP presentations. We are not aware of any other widespread

Table 1

Means, standard deviations, and effect sizes for knowledge and beliefs at pre-intervention, one-month post-intervention, and one-year post-intervention time periods.

Variable ¹	Time 1	Time 2	Time 3	n ²
Albinism is caused by genes that are passed down from one's parents.	2.01 (1.22)a	2.65 (1.21)b	2.71 (1.71)b	.045
Albinism is a curse from God. ²	.89 (1.06)a	.64 (.794)b	.62 (.845)b	.018
Albinism is a punishment for the bad behavior of the child's parents. ²	.86 (1.00)a	.65 (.805)b	.61 (.817)b	.015
Albinism is inherited from one's parents.	1.67 (1.22)a	1.93 (1.46)b	2.00 (1.32)b	.011
People with albinism have poor vision.	2.72 (1.04)a	3.14 (.802)b	3.10 (.866)b	.039
People who are albinos have the same level of intelligence as people who are not albinos.	3.03 (.920)a	3.32 (.777)b	3.26 (.849)b	.019
Albinos are the same as everyone else except for the color of their hair and skin and their ability to see.	3.08 (.907)a	3.32 (.795)b	3.34 (.781)b	.020
Albinos have the same visual ability as everyone else. ²	1.41 (1.11)a	1.05 (1.02)b	1.03 (.101)b	.026
Mean Index Score	3.25(.446)a	3.63 (.401)b	3.60 (.398)b	.149

¹ Measured on 5-point scale ranging from 0 (Strongly Disagree) to 4 (Strongly Agree)

² Indicates negatively phrased item

Subscripts indicate significant differences at $\alpha \leq .01$

interventions regarding albinism in Same District during the study period. In addition, much of Same District has limited access to television, radio, and print media. Taking this into account, we believe it is more likely than not that the demonstrated increase in knowledge was due to the IWHP intervention. Thus, we conclude that educational presentations targeted at groups of interested community members by LHWs in Same District, through ETI's IWHP, were associated with a sustained increase in community knowledge about albinism.

Implications and Limitations

The study has a few notable limitations. First, some HIs declined to administer the surveys assigned to them at Time 1 and Time 2, which resulted in a lower response rate for these time points (75% and 63%). Because the wards these HIs were responsible for were thus underrepresented in the samples, our study population was not a true representation of Same District as a whole, and should not be regarded as such. However, statistical tests indicate little variation in demographic characteristics between samples, and serves as a delimitation. Second, the lack of comparable community data regarding knowledge of albinism made it difficult to incorporate a control group. Thus, we cannot be certain that observed changes in knowledge were due to the intervention. Third, because the study population was limited to Same District, our results may have been affected by unique cultural and religious views of the Pare and Maasai people groups who comprised the majority of the study population. Possible heterogeneity of beliefs on a national level is suggested by our finding that while prior data indicated that 80% of Tanzanians believe in spells and curses (Pew Research Center, 2010), only 10% of respondents professed a belief in sorcery. This may be due either to respondents' belief in curses but not sorcery, or represent a true difference in prevalence of belief. However, the religious composition of our sample was similar to Pew Research Center (2010) national approximations.

Despite these limitations, our findings suggest that a targeted education program using lay health workers can be an effective method to produce a long-term increase in community knowledge about albinism. This finding is consistent with other LHW interventions shown to be efficacious for improving knowledge about topics other than albinism (Luby et al., 2006; Viswanathan et al., 2009).

Moving forward, education that addresses the stigma and violence against persons with albinism remains a need beyond Same District (UN, 2015), and even there, additional education is necessary based on the knowledge levels demonstrated here. We suggest that education programs in the surrounding districts be implemented to increase awareness and community knowledge about albinism. This is consistent with the UN (2015) recommendations calling for public education and awareness campaigns to combat prejudice, superstition, misconception and stigma affecting those with albinism. Programs should be tailored to local culture and practices to best address unique local beliefs.

While the overall goal of education about albinism is to decrease violence and social stigma, interventions that increase knowledge may not have an effect on behavior change. Behaviors likely originate not only from attitudes, but also subjective norms and perceived control over the behavior (Ajzen, 1991).

Increased community knowledge through LHW programs could foster changes in both attitudes and subjective norms, but the effect of these changes on behavior is still complex and affected by multiple variables. Further research is needed to determine the relationship between levels of albinism knowledge and behavior. Because violence against people with albinism often originates from superstitions and erroneous beliefs, we hope that knowledge is the first step towards behavior change, but further work is needed to determine whether increased knowledge about albinism leads to a decreased likelihood of discrimination and violence against this population.

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