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Improving Data Collection to Reduce Maternal and Infant Mortality and Morbidity in Malawi: Evaluating Chimwemwe mu'berekhi, a Community Based Intervention

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Improving Data Collection to Reduce Maternal and Infant Mortality and Morbidity in Malawi:

Evaluating Chimwemwe mu'bereki, a Community Based Intervention

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Abstract

Maternal and infant death rates in Malawi are among the highest in the world. Over 17 million people live in this small country in sub-Saharan Africa, where the country's life expectancy is just 60.6 years (World Bank, 2015). These deaths can be attributed to many complex factors, including cultural practices, lack of adequate medical equipment, long travel distances to health facilities, low staffing at hospitals and clinics, extreme poverty, and malnutrition. Without government support and intervention, community groups must fill in the gaps to make needed improvements to maternal and infant health outcomes. African Mothers Health Initiative (AMHI) enrolls high risk mothers and infants in the capital Lilongwe District to provide home-based clinical care in the remote villages of Malawi. During a needs assessment conducted in the summer of 2016, it was determined AMHI currently lacks robust and ample data to ensure the sustainability of this necessary program through grant funding and evaluation. With more efficient collection and comprehensive data, AMHI can better serve program participants and villages, and identify areas to more efficiently and effectively reduce maternal and infant mortality and morbidity in Malawi. The lives of women and their infant children depend on it.

Keywords: Maternal and infant mortality and morbidity, neonatal mortality, Malawi, Sub-Saharan Africa

DATA TO REDUCE MATERNAL INFANT MORTALITY IN MALAWI

Improving Data Collection to Reduce Maternal and Infant Mortality and Morbidity in Malawi:

Evaluating Chimwemwe mu'berekwi, a Community Based Intervention

This paper examines the effect of a community intervention on individual and community empowerment in reducing maternal and infant mortality and morbidity in Malawi through the Social Economic Model. It also evaluates the importance of data collection in the short and long-term sustainability of a program in a developing country.

People are influenced by their environment and the social context where they live. The places around us shapes our experiences every day and either directly or indirectly influence their health and behavior. The social ecological framework considers how social supports, norms, relationships influence behaviors and health towards overcoming individual-level barriers. Incorporating parts of Social Capital Theory, social norms and networks play a key role in either promoting or hindering self-efficacy and health. Studies show that greater social capital is linked to positive outcomes such as reduced mortality, while lack of social capital is related to poorer health outcomes (Roura et al., 2009).

Data provides the opportunity to evaluate a program's effectiveness in improving health outcomes within the Social Ecological Model. It also provides a long-term path to sustainability as programs identify key indicators that identify gaps in outreach, results, and barriers to improving health. Streamlining data collection also helps improve efficiency, allowing data to be entered in real time removes a key barrier to evaluation and a potential time lag in analysis. Giving data collectors the tools to gather comprehensive data on the spot can also empower staff members to take ownership over their responsibility in promoting program longevity and improving health outcomes for participants.

Description of the problem

Healthcare Worker Shortage

Malawi has a large unmet need of healthcare resources, services, and providers. The country has one of the lowest physician densities in the world with only two physicians and 59 nurses per 100,000 people, with 60% of nursing posts vacant (Zimba et. Al, 2012). This is compared to the U.S. which has 245.2 doctors and 981.5 nurses per 100,000 people. (World Bank, 2015).

Medicine is also in short supply and mental health services are nonexistent. The World Health Organization (WHO) finds that the government is not investing enough in the health of the Malawi people, with only \$21 in healthcare invested compared to recommended \$86 (WHO, 2015). The WHO recommends the government provide more funding for infants and new mothers for the 48 hours surrounding a birth. This would be a triple return on investment, saving newborn lives, mothers lives, and reducing stillbirths (WHO, 2015). Health facilities must also be better equipped to serve the number of women and infants in their wards and also the complexity of health problems. Only 47% of facilities offer recommended aspects of compressive obstetric and newborn health services, and 2% health centers had recommended aspects of basic emergency obstetric and newborn health services (WHO, 2015).

Extreme Poverty

One of the poorest countries in the world, 72.2% of the population lives on less than \$1.25/day and desperately lacks quality, personalized healthcare (Zimba et. al, 2012). This is mainly due to the fact that there is no industry in Malawi. The economy is largely agriculturally based, and without diversified farming practices. Making matters worse, climate change has placed an additional strain on the agriculture industry with recent floods and droughts.

Many people in Malawi are not only poor but also malnourished. Anemia is prevalent in 37.5% of pregnant women (Zimba et. al, 2012). Malnourished mothers can lead to low birth weight babies, which can lead to complications during pregnancy and birth (Norton, n.d.). With two major food scarcity crises occurring in the last ten years, researchers note the level of dietary energy supply does not meet demand for dietary energy requirements (The Borgen Project, 2015). Nutrition insecurity is high and the stunting rate for children under five years old is 43%, with 23% of child mortality cases associated with undernutrition (WFP, 2016). There is more need than ever for a maternal and infant health intervention.

High Maternal and Infant Deaths

The country's maternal and child mortality rates rank among the world's highest with each woman facing a one in 34 life-time risk of maternal death (WHO, 2015). Each year there are an estimated 608,000 births, of which the maternal mortality ratio is 675 per 100,000 births (Zimba et. al, 2012). In addition, 82.1% of women experience at least one problem accessing healthcare due to factors such as travel conditions, cultural norms, lack of self-efficacy, and lack of resources (Zimba et. al, 2012).

Most women wait until later in pregnancy, around four or five months, to visit a healthcare facility (48.2%), with 35.6% waiting until six or seven months (Zimba et. al, 2012). A high number of percentage of live births delivered in a health facility (73.2%), however only 43% of women receive a postnatal check-up in the first two days after birth (Zimba et. al, 2012). Postnatal care is not widespread with 47.6% of women not receiving any checkups (National Statistical Office, 2010). Maternal mortality rates leave about 17% of children in Malawi under 18 as orphans (Zimba et. al, 2012). There is also an unmet need for family planning, with 26.1%

married women up to 29 with an unmet need for family planning (WHO, 2015). Malawi's HIV prevalence is also one of the highest in the world, with 11% of the population living with HIV (WFP, 2016).

Infant mortality rates are equally as troubling. One in five babies are born preterm, one in 43 die within the first four weeks of life, and one in 14 die before the age of five (WHO, 2015). The infant mortality rate is 66 per 1,000 live births and neonatal mortality rate is 27 per 1,000 live births, with 18,000 annual newborn deaths (Zimba et. al, 2012). Malawi has the highest rate of premature births in the world: one in three child deaths are newborns due to preterm complications, and there are 14,600 stillbirths a year (WHO, 2015).

Malawi's population is growing and maintaining a high birth fertility rate of five to six children per mother, so the demand for more resources will only continue to grow as increasing neonatal prevention methods remains key and more women need education about current treatment methods and norms (Zimba et al., 2012). Increasing self-efficacy and education through interventions can help improve pre and post-natal healthcare treatment for pregnant mothers, and also help reduce other health disparities across the country.

Socio Ecological Model Application

A 2009 study by Roura et. al is one of the few studies that analyzed the social ecological model application in Africa and has telling implications for improving self-efficacy in Malawi. Researchers examined how behavior influences clinic attendance for antiretroviral therapy in a rural ward in Tanzania and the long-term sustainability of health interventions. Researchers collected data through semi-structured interviews and focus groups with clients and service providers. They used the social ecological framework to guide their data analysis and categorized facilitators and barriers into individual, social, programmatic, and structural level influences, and

explored their interaction and relative significance in shaping patients' behavior. Their findings show how individual level experiences such as personal motivation, perceived health benefits, disease severity, and self-efficacy contribute to program retention. They found these determinants were influenced by the community's opinions and beliefs, and constrained by programmatic and structural barriers.

Roura et. al found patients were most likely to sustain treatment if they had a supportive family and community. They also found that information patients had access to was not always widely available or accurate, and that social networks played a key role in filling this void and correcting misinformation. Environmental factors should also be taken into consideration, as researchers found that factors such as lacking money for transportation and inadequate nutrition were associated with delayed or missed appointments. However, researchers noted that even after these barriers are removed they must be filled with social supports in order to sustain a treatment regime (Roura et al., 2009). This study reinforced other findings that self-efficacy, as sustained treatment was associated with higher levels of drug adherence and decreased likelihood of missing scheduled appointments. They theorized that strengthening interventions at all socio ecological levels would help program retention and treatment, however they found that community-level factors and social networks were some of the greatest influencers and offered the most patient support.

The research can be applied to how programs in Malawi can remove barriers to maternal and infant health. Roura et. al noted how local home-based care providers provide a social support network if patients lack this in their daily lives, and home-based care helped improve patients' self-efficacy. This gives credence to interventions that provide home-based care to be

evaluated for building self-efficacy as they treat patients and educate their community on how to support mothers and their children.

Case Study: African Mothers Health Initiative

African Mothers Health Initiative (AMHI) is a nonprofit in Malawi working to reduce postpartum maternal and infant morbidity and mortality by providing home-based care for women and infants. AMHI also educates village members to help build extended support networks for at-risk families. Women and babies are enrolled in a Mother Care and Baby Care program from the two maternity hospitals in Lilongwe: Bwaila Maternity Clinic and Kamuzu Central Hospital, which together have about 1,000 deliveries each month. Despite being the capital city, Lilongwe suffers some of the country's worst health outcomes (WHO, 2015). To make the greatest impact on improving maternal and child health, AMHI targets those most vulnerable, including orphaned newborns who lost their mothers in childbirth, premature and multiple gestation babies, and mothers with HIV or who had complicated pregnancies and/or births.

AMHI's Mother Care Program provides mothers with skilled care during and after pregnancy. When they are discharged from the hospital, a nurse follows women to their village and provides direct at-home care and health education once a month for approximately six visits or around one year, discharging her only after she has regained her health and her situation has stabilized.

AMHI's Baby Care Program provides home-based care for new infants for up to two years. Neonatal deaths (within the first month of life) constitute a large portion of child deaths. By focusing on caring for the most at-risk newborns, AMHI can significantly impact survival

rates. Many of these babies are premature orphans or twins or triplets. Nurses educate mother or guardian on nursing care and provide porridge and formula to the orphans.

Nurses also educate mothers and village members, recruit and train nurses, educate hospital staff to ensure babies receive needed follow-up, and spread the word about services. Each nurse visit involved an assessment of the woman's health, her home environment, and her ability to care for her newborn. To encourage self-efficacy and the support of the community in reducing maternal and infant deaths, nurses educate the mother, her household, and community members on key health issues such as signs of illness in infants, malaria prevention, hygiene and sanitation, reproductive health/family planning, and nutrition. Nurses educate community members, often women elders, about how to recognize early signs of life threatening postpartum illnesses and to create plans for transportation to health facilities. Nurses also teach and monitor guardians' ability to prepare baby formula safely and to keep clean feeding utensils. For breastfed infants, nurses teach the benefits of exclusive breastfeeding and support mothers' breast milk production by providing supplemental food packages to families with food instability. Nurses help empower Malawian women to take action for their health, providing a support for women who many not have a strong network.

AMHI implements its programs through Joyful Motherhood (JM), a women-led, Malawian organization. JM nurses understand the local language and culture and have become leaders in their communities.

Social Ecological Model for AMHI: Community Based Intervention

To assess the effectiveness of providing care to vulnerable mothers and newborns while supporting the local healthcare workforce in Malawi, the AMHI program can be evaluated using

the Social Ecological Model and particularly the community level intervention. In Malawi, people in the interpersonal web of support could include friends, family, providers, and Joyful Motherhood nurses. The program's success can be evaluated through concepts that promote learning (social learning), social power and someone's ability to influence others, social integration, social networks, social support, social capital and the relationships between community members such as trust, reciprocity, civic engagement, and communication.

AMHI Data Collection

In 2016, a needs assessment was conducted to understand what was working well and to identify areas of improvement. Through observation, research, and potential grant feedback, it became clear that AMHI lacks adequate data to apply for grants or fundraising and evaluate the program. In response, goals and objectives were developed to assess the program and start to implement potential changes in Malawi. The primary goals and objectives were to improve data collection by:

- collecting meaningful data for grant applications and communications (such as stories, photos, and videos)
- testing data collection apps that can be used without Wi-Fi
- compiling qualitative interviews on self-efficacy scale based on the Self Efficacy in Infant Care Scale (Prasopkittikun, Tilokskulchai, Sinsuksai, & Sitthimongkol, 2006).

Collecting New Data

JM nurses know participants by memory, so well in fact that they did not always capture data on paper since it was already stored in their heads. In fact, more data was being naturally

collected by nurses exceed that of the visit forms, including the additional education topics they shared in the villages, including nutrition, income generating opportunities, and referral organizations. There were other pieces of data that were not being collected observationally that when tracked can help provide more comprehensive care, including tracking current family planning, water access in the village, and the level of community support.

Some pieces of data were not being tracked by nurses at all, including exactly where participants are being referred from. To gain a better sense of how participants are coming to the program, the referral section can be built out with options such as which hospital department and staff member referred each participant. This way the program can better evaluate where outreach is strongest and where it is lacking. A photo field was added to the forms to track a participant's growth and evaluate before and after photos to visually track participant progress.

Additional phone numbers and address fields were also proposed to better track emergency contacts, requiring two contacts per person so nurses have a better chance of getting in touch with the guardian in the field. Frequently a woman would be at the market or unable to be found when visited, even though nurses confirmed via phone call one to two days prior. Sometimes the woman's phone would be off or would not accept voice messages, leaving many of these visits up to chance.

Evaluating Current Forms

The current visit and intake forms consist of open ended responses, checkboxes, options, yes or no, and positive or negative. Lack of consistency makes it difficult to easily analyze the data. For improved data assessment consistency, all data can be coded with yes or no responses. Response options should be coded as best possible for easier analysis. For instance, the field

relation to the newborn should be coded with options like mom, grandma, and aunt, etc. instead of left open ended. Other response options were prioritized to help evaluators gain a clearer sense of multiple response options, such as determining the primary reason for enrollment. Women and infants are enrolled for many reasons but it would be interesting to track the primary reason for enrollment. Identifying codes for Mother Care and Baby Care participants (moms coded M01, babies coded B01) should also be used for anonymity and tracking purposes.

Apps and Database Recommendations

To cut down on data entry and ensure all forms are filled out completely, three apps that do not require Wi-Fi were piloted in the villages. The Baby Care Visit form was built out in all three platforms and piloted in the field. The process included a first run pilot by staff to test efficiency and ease of use, followed by the nurses piloting the apps themselves. When nurses piloted the apps they mentioned they were easy to use and easier to carry versus all the paper they were carrying around. Notes were still taken on the current paper forms as backup. Apps were tested back in the office once Wi-Fi was reconnected and uploaded to the app's respective online platform.

Based on use in the field, consultation with nurses, and further research, the app Quick Tap Survey was recommended for the easy interface and immediate integration with Salesforce, a contact management database that will allow us to store data and produce quick reports. The second best option included Device Magic, which was also very easy to use, but it would require a staff member to regularly go into the online app platform and export data to a contact management system like Salesforce.

Database Management Recommendation

The data collection apps tested are not designed to optimize data storage in the long-term. The program currently uses Microsoft Access, an interface that is difficult to update with new questions and export consistent analysis. Quick Tap Survey's integration with Salesforce allows staff to quickly search client names before going out in the field to check recent visit history. It will also allow increase transparency between the AMHI staff in the US and the JM program staff in Malawi, allowing members to pull data from anywhere in the world and login to monitor progress. All data from Microsoft Access could be exported into Salesforce so it can be housed in one database going forward.

Post Program Interviews

To understand what worked best and what could be improved, post program interviews were conducted with a small sample size of 11 women in July 2016. In total, six Baby Care and five Mother Care participants were interviewed with both qualitative and quantitative questions, starting with qualitative to help participants get more comfortable. All interviews were voice recorded in Chichewa and later translated into English, with notes taken in English in real time. Three staff members were trained (not nurses and not biased) who could do interviews and transcriptions. It should be noted that this small sample size limits validity to generalized to the participant pool or Malawian population.

Key Findings

The program was found to be very helpful to women and caregivers: with 100% of respondents agreeing or strongly agreeing on all quantitative questions. Direct service is key, as new mothers in rural areas mentioned they found it difficult to travel the long distances to a local health clinic.

Researchers also found that these environmental factors continue to be a challenge – such as meeting basic needs food, shelter, poverty. These interviews were also a good opportunity to check in to see if the woman was facing any new or reoccurring problems. It also helped staff identify women who are already serving as informal program ambassadors in their village, educating others and carrying out the nurses’ teachings. If the program can expand capacity, this type of Train the Trainer model would be key to help alleviate health problems women face before nurses are called to these villages.

Baby Care Results: 100% Strongly Agree

- As a result of being a patient of Joyful Motherhood, I know a lot more about how to prepare formula safely.
- During the program, I looked forward to Joyful Motherhood nurses’ visits.

Mother Care Results: 100% Strongly Agree

- As a result of being part of Joyful Motherhood, I am better able to care for myself and *[if alive]* my baby.
- As a result of Joyful Motherhood teaching, I now know when to call for help when my baby is sick.
- As a result of being part of Joyful Motherhood, I am better at understanding what the baby needs or wants.

Competing Challenges

Switching the data collection process from paper to cell phones poses some challenges as there are many communication barriers in a developing country. Power is frequently out which

may impact the ability to charge cell phones, necessary to collect data. Back up chargers should be used. Wi-Fi access is also a challenge, a necessary factor to synch cell phones with new data back in the office. Keeping the Wi-Fi loaded with enough funds for use must become part of the current workflow. There is also a chance that cell phones could get stolen. To help protect patient data, all phones will be password protected and locked in case they are misplaced or stolen. New cell phones will also have to be unlocked in the United States (since they do not have that capability in Malawi), which could pose a delay in launching the new program.

Competing Environmental Factors

In order to truly advance maternal and infant health, the root causes of these problems must be taken into consideration. The list can seem unsurmountable, including access to health care education; nutrition; water; sanitation practices; clean air (many people burn trash, some of which is eaten by goats and animals that are then eaten by people); clothing; transportation and planning ahead for the long distances to the local clinic or hospital; recreational activities; farming practices; mosquito nets; power access; and, market access to buy and sell local goods. If any one of these factors could improve, we could see an improvement in the health of the Malawi people. Creating community cohesion and fostering village leadership can also improve health outcomes. The places where many people live are overcrowded, unsafe, and not healthy. Helping villages learn how to build weather resistant homes, promote safe housing practices like not building fires in the home for cooking and light, could improve the health and longevity of Malawians.

Cultural Considerations

Cultural norms and religious practices must also be taken into account as many Malawians in the villages are Christian and very religious. Working with local religious leaders

and educating them about maternal and infant health practices can help spread the word to residents from a trusted leader. Anecdotally, researchers learned that men will leave their wives if they want to stop having children – even after having five or six. They see children as a representation of their wife’s love for their husband. Tragically, many of these same men leave their wives regardless when she becomes pregnant with triplets or twins, which is a growing trend in Malawi. Family planning is still new and is growing in trust over time – but it is hard for many women to gain access to this care and the support from the men in their lives to adhere to it.

Cultural norms must also be recognized for the nurses. During the course of the fieldwork, the importance of data collection was reiterated to the nurses. However, it was only during a final meeting that nurses truly recognized the connection between moving to a data collection tool and fundraising. Although the nurses made it clear they were open to moving to a new process, an explicit line had to be drawn to make the connection between taking on a new tool and improved results and fundraising. This had to be approached from a few different angles, perhaps due to language nuance, but once it was made, it was clear these nurses would become champions for the tool so they could be better champions for the women and infants they serve as well as the program.

Recommendations

The following includes short and long-term objectives that will help the sustainability of this desperately needed intervention in Malawi. By continuing to build self-efficacy within women through education and track outcomes over time, AMHI can help villages create long-term community support networks. Specific recommendations include:

Short-term Recommendations

1. Track self-efficacy and interpersonal level data including qualitative and quantitative pre and posttests to assess progress in improving relationships to improve maternal and infant health. Goal for each month is to conduct 30 interviews for a robust data set.
2. Update data collection forms with more comprehensive data that look at environmental factors and upstream improvements.
3. Select data collection app and a new database that syncs with the app.

Long-term Recommendations

4. Establish partnerships with other organizations to connect women to more services during and after care (malaria nets, water, education) and help meet basic needs.
5. Increase fundraising to expand base and care for clients longer.
6. Conduct focus groups to see what challenges people are facing that we could help support communities.
7. Promote capacity building: The sustainability and empowerment piece is resting within each person and family we help, but can be expanded to the community. There must be a balance between increasing community support to form a strong network that bolsters self-efficacy within women themselves. Once mothers gain self-efficacy this can also help solidify future community support, creating a long-term network for mothers who can continue to pass education onto-others. This all must be done in a way that is culturally relevant to the Malawi people, so they are more likely to accept these changes and continue to progress over the long run. AMHI can implement a train the trainer model so that program participants are better equipped to educate others. Staff can start tracking this capability with the discharge form to gauge interest to be a community ambassador. Meetings can be organized with village chiefs to share information about

our program and educate them. AMHI can also organize larger community meetings in advance or coordinate with churches to give health education talks at certain times so people can plan ahead and attend. By developing champions to carry on program and train others, this would essentially take nurses out of the equation and carry out the program at an even higher level.

Conclusion

There are many limitations to the work AMHI can do in Malawi. Without more government support at the health facility level and upstream challenges caused by poverty and malnutrition, AMHI will only be able to fill in these gaps after the fact at the community level. The sustainability of the program relies on collecting robust and ample data to evaluate the program. This data can also be used to apply for grant funding and help with fundraising. This challenge is achievable since there are immediate changes that can have a large influence on the evaluation and sustainability of the program. By taking steps to update current forms, transition to online data collection, and implement post interviews, AMHI will have a much more comprehensive data set to draw meaningful conclusions that will ensure efficacy of the program for years to come.

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