LIFE *for* MOTHERS

Integrating mHealth Technology and Holistic Health Care Delivery to Reduce Maternal/Neonatal/Child Mortality in Rural Uganda:

Preliminary Findings from Pilot Project (Phase I) Completed May 2012

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Preface

This report summarizes the data collected by Life for Mothers (LfM) baseline study to establish an electronic health database and evaluate gaps in health services from Busujju County in Mityana District. LfM partnered with the Ugandan Ministry of Health, the World Health Organization, the Local Government of Mityana and AIDS Information Centre (AIC) to implement an integrative strategy using mHealth technology and holistic health care delivery to reduce maternal/neonatal/child mortality in rural Uganda (Phase II). LfM evaluated the burden of disease in Mityana District with the intent of formulating interventions that will improve maternal/neonatal/child health (MNCH), as well as strengthen existing health systems (Phase I).

The data was aggregated using mHealth technology by community health workers (CHWs) who were recruited and trained by LfM. The data included inter alia indicators of MNCH, family planning/contraception counseling, HIV/AIDS, STIs, condom usage and male partner involvement. Various social and structural determinants of health were also examined in this study, including but not limited to, education level, village distance to the Health Center (HC) and economic factors.

This strategy minimizes duplicate visits, the need for additional referrals, and increase uptake of family planning options and Preventing Mother-to-Child Transmission of HIV (PMTCT). LfM will also focus efforts to increase primary prevention of HIV and decrease unintended pregnancies in women of reproductive age (14-49) who are HIV+. These interventions should decrease costs and improve efficiency, thus enabling women to access health services. Lastly, LfM will stress the need for male participation and promote gender equality.

Executive Summary

The maternal/neonatal mortality rate is unacceptably high in Uganda, particularly in the rural areas where 90% of the nation's population lives. Low literacy rates for women and men, minimal and/or nonexistent contraception counseling/family planning (CC/FP), and high fertility rates (7 births/woman), distinguish this community. Additionally, poverty and lack of infrastructure make access to health services extremely difficult.

The initial project was undertaken to perform various baseline needs assessments, as a precursor to implementing a holistic strategy for improving MNCH. An electronic health database was created by the CHWs using mHealth technology that ultimately enrolled 5,500 residents, including 1,600 women of reproductive age (WRA) and their households. The use of a cell phone network with mHealth technology enabled the gathering of real-time data by the CHWs, reducing communication gaps with the HC.

To test our initial hypothesis, LfM recruited and trained 50 CHWs from their respective villages from Busujju County in Mityana District. A 10-day intensive workshop was conducted for the CHWs in CC/FP, HIV/AIDS, and MNCH prior to going out into the field. Phase I of the Pilot Project was completed in less than three weeks.

The data revealed huge gaps in health delivery for WRA who had never been pregnant. 70% of the women who were never pregnant did not receive HIV testing and 86% did not receive CC/FP. Of the WRA who had been pregnant, 79% lacked postnatal care and 39% did not use insecticide-treated nets (ITNs). In addition to the 1600 WRA, 700 husbands/partners, 1,100 children < 5, 2,000 children > 5 (women up to age of 14), 40 newborns, and 200 women > 50 were included. 91% of children < 5 were never tested for HIV, 27% were not fully immunized and 46% did not use any ITNs. For husbands/partners, 46% reported no condom usage, 63.7% did not accompany their wives/partners to the HC for ANC/PNC visits, 70% were never counseled on FP, 43% were not tested for HIV, and, lastly, 52% did not use any ITNs.

Our hypothesis is that CHWs using mHealth technology to track patients in real time and subsequently receive regular feedback will improve health outcomes. Additionally, CHWs utilizing mHealth technology can lead to a cost- effective, replicable, sustainable, and holistic model to strengthen health systems.

About Life for Mothers

Life for Mothers (LfM) seeks to identify, address, and prevent complications that can develop during pregnancy, labor, delivery, and most commonly during the first 48 hours after birth. LfM's goal will result in the reduction of maternal, neonatal, and child mortality by empowering women and strengthening health systems.

LfM's holistic strategy addresses the full spectrum of health and social issues which limits women's access to healthcare leading to maternal/neonatal deaths. Non-functioning health systems and the inability to access health centers (traversing great distances and/or difficult terrain) and lack of community awareness regarding these issues contribute to maternal/neonatal morbidity and mortality. LfM intends to create social change by promoting health-seeking behaviors in mothers, children, and men. The CHWs over a 6 month period will establish electronic medical health records (EHRs) for the entire Busujju County and ensure that local residents obtain access to healthcare.

Vertically-oriented approaches, which focus on individual diseases without integration, leave too many gaps in coverage. Therefore, LfM emphasizes providing comprehensive, horizontal preventive and curative health care.

In addition, LfM will assist mothers to detect signs and symptoms of various illnesses including birth asphyxia, diarrhea, and respiratory ailments in neonates. The goal is to increase the number of neonates who survive at least one month and beyond (40% of children < 5 mortality occur during the neonatal period). Educational outreach programs will aid fathers to actively participate in disease screenings, assist mothers in ante/postnatal care, and birth preparedness.

LfM appreciates that community involvement and ownership are essential to achieving long-term success and sustainability. Political will and local government support will enable successful execution of LfM's goals.

Life for Mothers is a registered 501 (c) (3) non-profit organization in the US and is also registered in Uganda and Kenya. LfM was founded and became incorporated in 2008.

Pilot Project: Phase I

Life for Mothers (LfM) will implement a holistic, community and facility based strategy to reduce maternal/neonatal/child morbidity and mortality, as well as strengthen the existing health system in Busujju County, Mityana District.

SELECTED HEALTH INDICATORS

MATERNAL/REPRODUCTIVE HEALTH

Ante/postnatal care increases the odds of safe delivery particularly during the first 48 hours after birth. CHWs will collect health information during the mother's first registration visit. Examples of this information include past pregnancies, if any, menstrual history, and pregnancy test results. By providing early pregnancy identification and screening, the teams will facilitate transport for mothers to receive ante/post-natal care and deliver at the HC. All WRA will be referred for a baseline visit to the HC and women identified as pregnant will be entered into our antenatal care coordination system. At the HC, pregnant women will receive information on nutrition, risk factors and danger signs during pregnancy. The mothers will be incentivized to complete at least four antenatal visits prior to delivery.

LfM targeted Busujju County of Mityana District in rural Uganda (population 82,225), to implement a Pilot Project with the ultimate goal of replicating this model throughout the country. Uganda lags dangerously behind other East African countries in delivering family planning services, which contributes to higher maternal and child mortality rates. Only 24% of Ugandan women of reproductive age use family planning (UBOS, 2007). By contrast, in neighboring Kenya almost 50% of the women utilize family planning options (WHO, 2011). Inadequate funding, negative cultural and religious beliefs, and lack of political support contribute to Uganda's high fertility rates. Furthermore, limited funding, provided by the government, has been directed to urban areas yet 90% of Uganda's population inhabits rural areas.

Uganda is very unlikely to achieve the millennium health goals unless family planning services are enhanced and properly utilized (UNSG, 2011). LfM will encourage Ministry of Health to provide family planning counseling and free contraceptives to all women of reproductive age in Busujju County. Uganda's unmet need for family planning is 40.6%, the highest in the region (WHO, 2011). By targeting family planning options and increasing access to reproductive health services, LfM will reduce fertility rates and maternal/neonatal mortality rates.

In addition, skilled birth attendants (SBAs) consisting of at least two midwives and an additional medical officer will be available at the HC, and an overall manager hired under this program to improve

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maternal health outcomes. These SBAs will also assist with the newborn survival during the critical first 48 hours after birth by treating conditions, such as birth asphyxia, which accounts for over 25% of neonatal deaths. Additionally, we will monitor and treat newborns for respiratory ailments such as pneumonia, and/or aspiration with IV antibiotics, fluids, and resuscitate if needed (ambu bag, suction, and oxygen, etc. at the HC). Midwives will be trained in simple but effective strategies for preventing post-partum hemorrhaging, which mothers are at great risk for developing during the first 48 hours (hemorrhage accounts for over 25% of maternal deaths). The CHWs will educate mothers on self-care techniques at home, including kangaroo mother care (KMC) to decrease the risk of neonatal hypothermia and exclusive breastfeeding to ensure good nutrition. As our program develops, we aim to hire and train additional SBAs to effectively meet the needs of this community.

Since almost all women in Uganda are unable to have Pap smears performed to detect early signs of cervical cancer (due to lack of medical technologists), visual inspection with acetic acid (VIA) will be taught to midwives, nurses, and other personnel so that women can be screened for any pre-cervical lesions. Cervical cancer has an unusually high prevalence rate in sub-Saharan Africa with high mortality rates.

HIV TESTING AND OUTCOMES

CHWs will collect comprehensive health information regarding HIV/AIDS from all residents of Busujju County. Testing rates, antiretroviral drugs (ARVs), and condom usage within all population subsets will be noted in the database. LfM will use this information to develop interventions to tackle related gaps in service delivery.

HUSBANDS/PARTNERS INVOLVEMENT

The sensitization of men to play a primary role of participation in all aspects of their partners' pregnancies is critical to improving PMTCT rates and reducing maternal mortality. The CHWs will assist in educating and providing information to all residents regarding the importance of male partner involvement. LfM will work with the local governments and Ministry of Health to plan awareness strategies utilizing media channels such as newspapers and radio. Efforts to increase awareness will also be emphasized in the schools and faith-based organizations.

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METHODS

(See Timeline Figures 1& 2)

Life for Mothers (LfM) recruited a Program Manager stationed in Kampala. She was able to speak the local language as well as English. In addition, LfM recruited three graduate students, a driver, and a Peace Corps worker, already stationed at the HC, (all of whom spoke the local language) to assist the CHWs in collecting data once they went out into the field. A random clustered sample of 200 CHWs was recruited and then screened to determine their ability to perform a simple application of mHealth technology. From the initial 200 recruits, 50 CHWs (40% male) were chosen, two from each of their respective 25 villages. These teams (25 VHTs) then successfully completed a 10-day workshop conducted by the World Health Organization (WHO) and the AIDS Information Centre (AIC). The training covered the areas of MNCH/Family Planning and HIV/AIDS, which were given by WHO and AIC respectively. In addition, the CHWs were trained to counsel women on the importance of receiving ante-/post-natal care. The teams of CHWs returned to their respective villages in order to complete their fieldwork. Each team administered the questionnaire to each household in their home villages. Upon the start of the fieldwork, three teams of two CHWs were dismissed as a result of being unable to perform the required tasks to collect and input the data.

Templates/questionnaires for basic health information, nutrition, infectious disease, MNCH indicators, and family planning options were developed and downloaded on to the mobile phones. Six questionnaires were developed for the following groups: Newborns, Children < 5, WRA, Children > 5, Husbands/ Partners and Women over 50. OpenXData software was used that enables mobile management and tracking of statistical data. Patient health data was hosted on the OpenXData server allowing for data entry and concurrent validation in the field. The OpenXData application was especially efficient in community settings where access to health services is limited, allowing shared access to patient information by the Project Director (PD) and Project Manager (PM). The CHWs went into the field with the PD, PM and the three students to aid the CHWs in establishing EHRs of WRA and their households from their respective villages. Using the phones with the questionnaires already downloaded, the CHWs were able to collect data on 5500 residents, including 1600 WRA and 1100 children < 5.

The World Health Organization and the Ugandan Ministry of Health endorsed the overall objectives of the pilot project. The Local Government of Mityana District in Uganda along with the AIC signed a Memo of Understanding with LfM. Each patient from every village was asked whether they would consent to being interviewed. Verbal consent was obtained in the presence of various witnesses. If verbal consent was not obtained, then the patient was not interviewed.

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This report includes data analysis for WRA, husbands/partners, and CHWs. A subsequent report will include analysis on children under and over 5, as well as all other cohorts included in the initial data collection.

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TIMELINE

Figure 1. January – March 2011

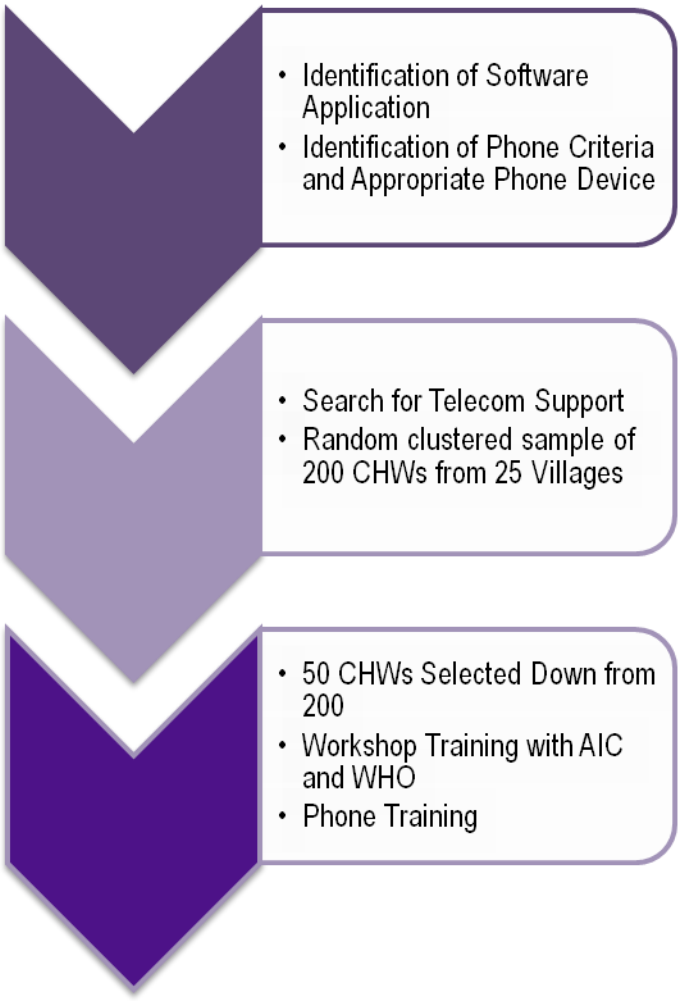
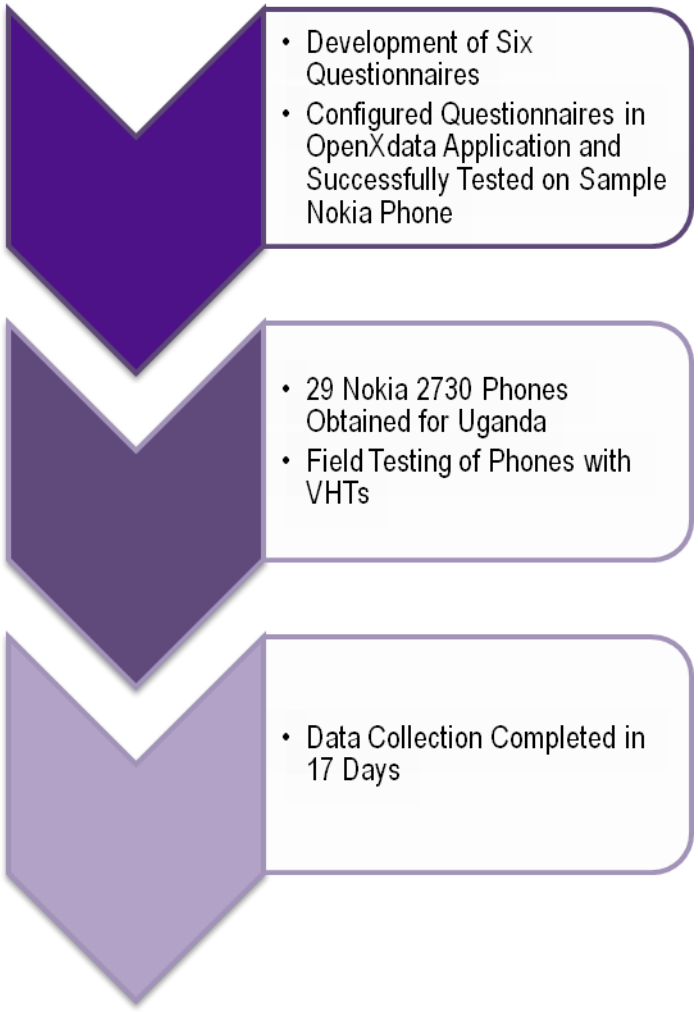


Figure 2. April-June 2011



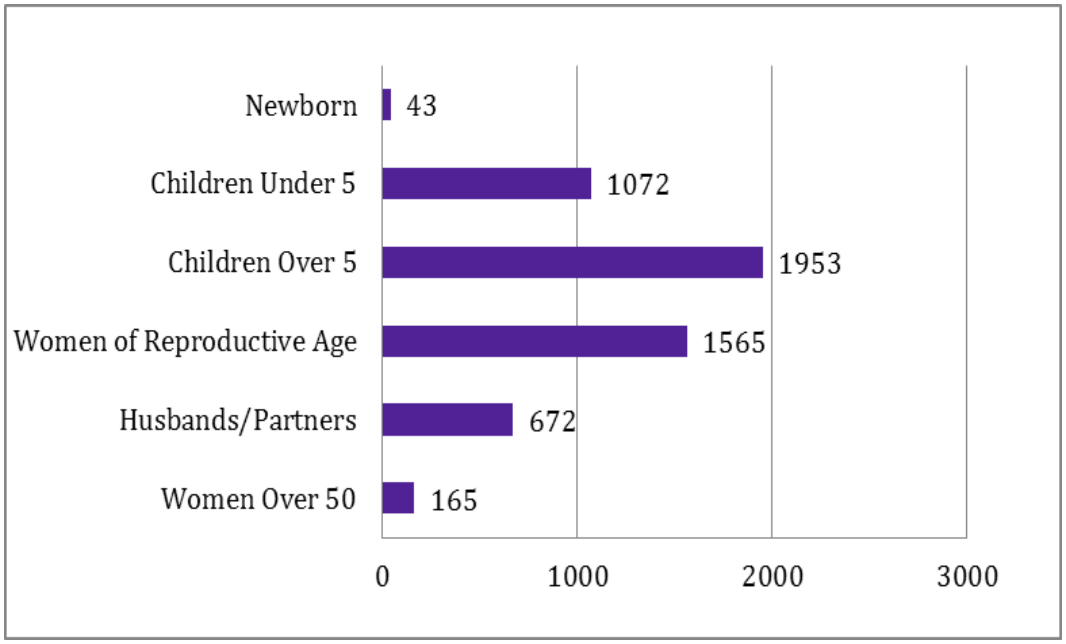
Pilot Project: Phase I

FINDINGS

SAMPLE DEMOGRAPHICS

Figures 3 and 4 describe the characteristics of the 5,470 participants that took part in this study. Specifically, women of reproductive age are thoroughly examined in this document, but husband/partner data is also included to emphasize the urgent need for male partner involvement in Mityana District. The figures following the sample demographics are broken down by maternal health, reproductive health, HIV outcomes, and male partner involvement.

Figure 3. Total Registration by Group (n=5470)



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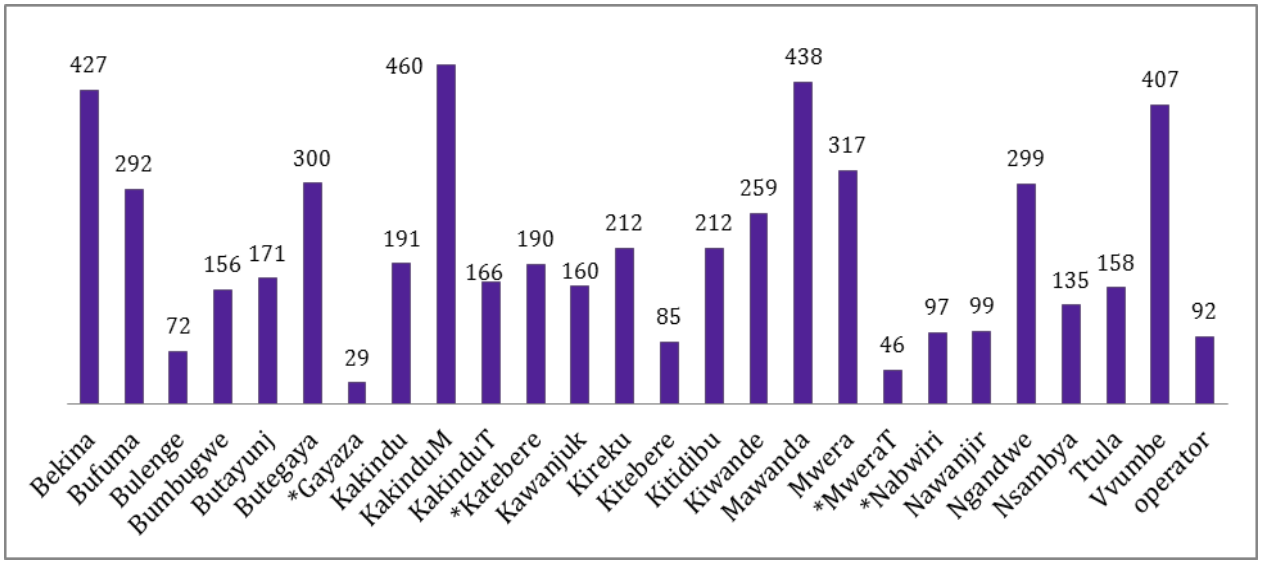
SAMPLE DISTRIBUTION

Figure 4. Registrations by Village Health Team (Village) (n = 5470)

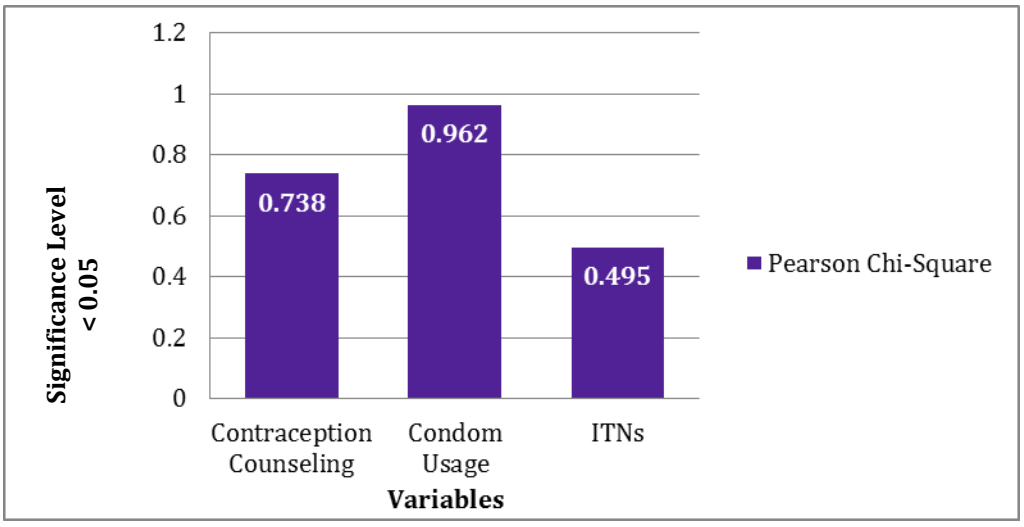


SAMPLE BIAS

Figure 5. Four Highest Number of Resident Villages (n=1723) Compared to the Four Lowest Number (n=232)

Testing for Sampling Bias by Contraception Counseling, Condom Usage, and ITNs

No significant difference of the individual three variables between all villages (no sampling bias).



Pilot Project: Phase I

SELECTED HEALTH INDICATORS

MATERNAL/REPRODUCTIVE HEALTH

Figure 6. Proportion of WRA Received Contraception Counseling and Ever Been Pregnant by Age (n=1441)

WRA who have been pregnant are more likely to have received contraception counseling ($p<0.05$). The inference is that contraception counseling took place after WRA became pregnant when they should be receiving contraception counseling before they become pregnant.

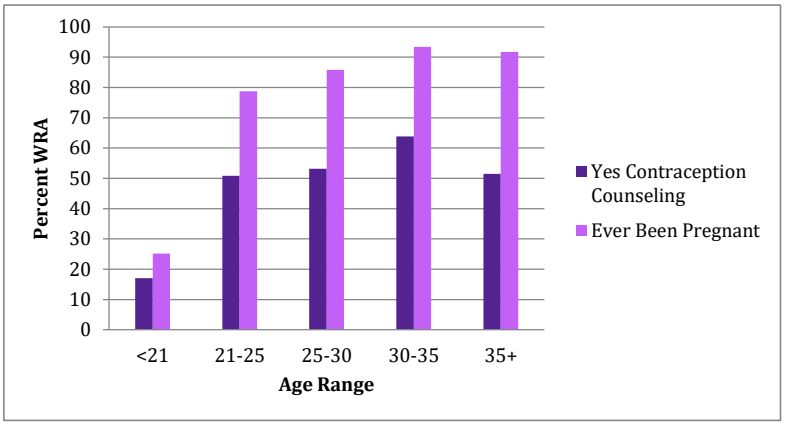


Figure 7. Contraception Counseling, Ever Pregnant, & Use of ANC/PNC and WRA Condom Usage Controlled for Age and Education

WRA were approximately 3x as likely to report condom usage if they received contraception counseling, had ever been pregnant, or attended HC for ANC/PNC.

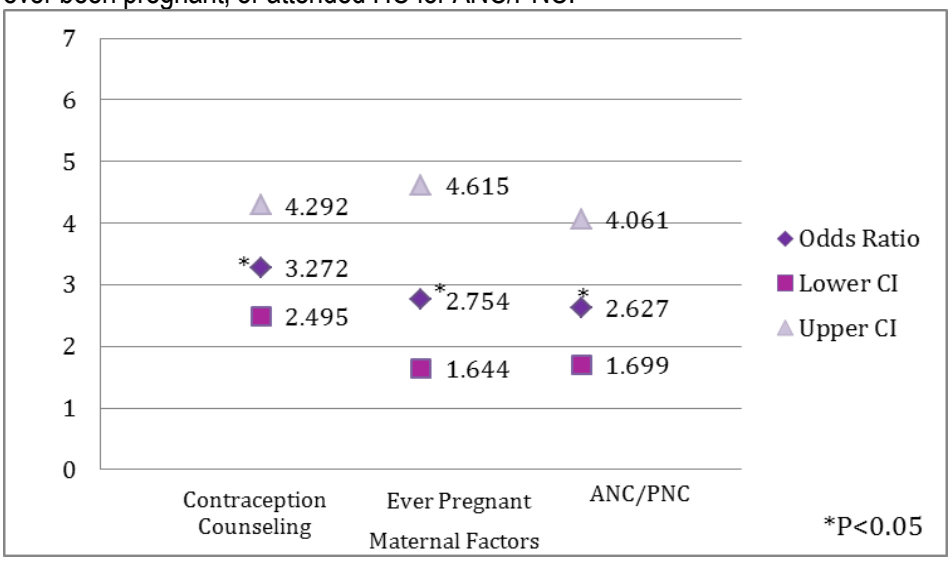


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Figure 8. Proportion of Young WRA Reporting Ever Been Pregnant, Contraception Counseling, and Any Form of Contraception (n=633)

An inflection point is reached for WRA ages 22-24 becoming pregnant without a commensurate rise in contraception counseling.

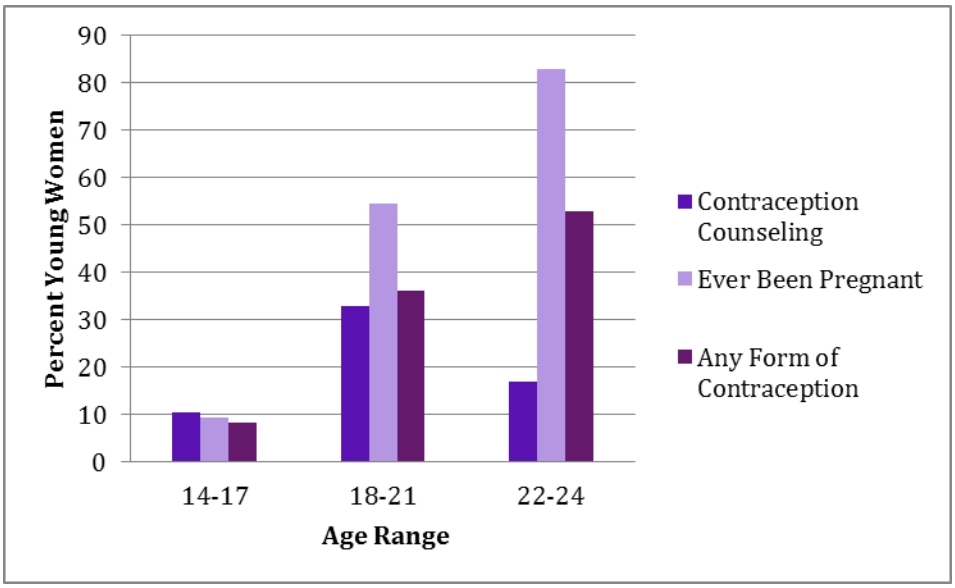

Figure 9. Proportion of WRA with Live Children Reporting Contraception Counseling (n=1014)

Contraception counseling played a role in household size of WRA controlled for age ($p<0.001$).

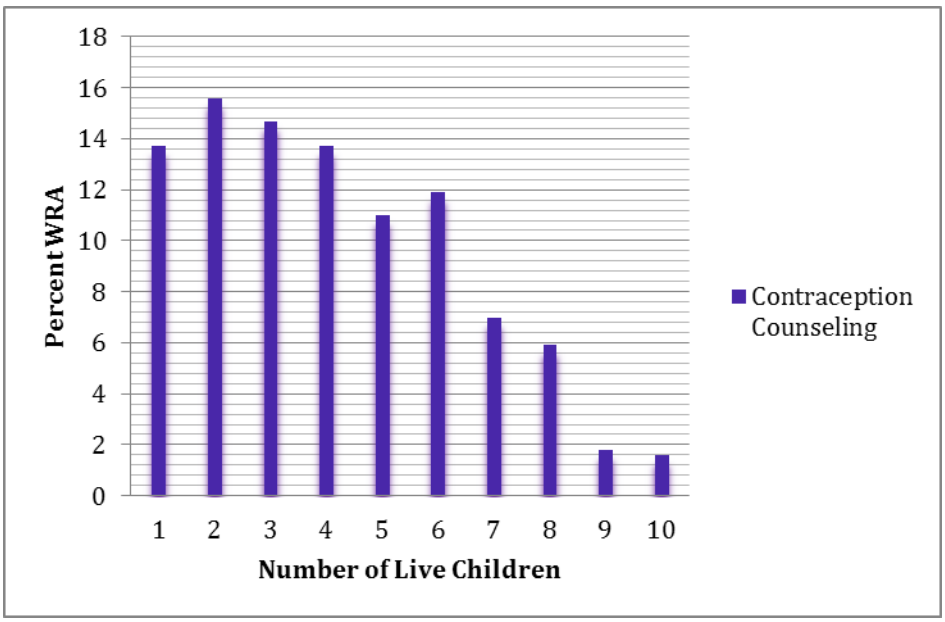

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Figure 10. Proportion of WRA Reporting No Contraception Counseling (n=1521) and No Condom Usage (n=1376)

Married WRA are more likely to report condom usage (P<0.05) and contraception counseling (p<0.01).

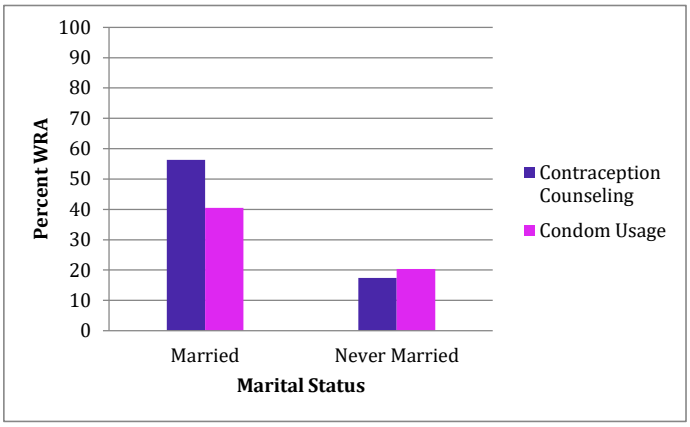

Figure 11. Contraception Counseling, Pregnancy, & Use of ANC/PNC and WRA Tested for HIV Controlled for Age and Education

HIV testing was 4x greater if WRA had ever been pregnant, 3x greater if they had ANC/PNC visits, and only 1.3x greater with contraception counseling.

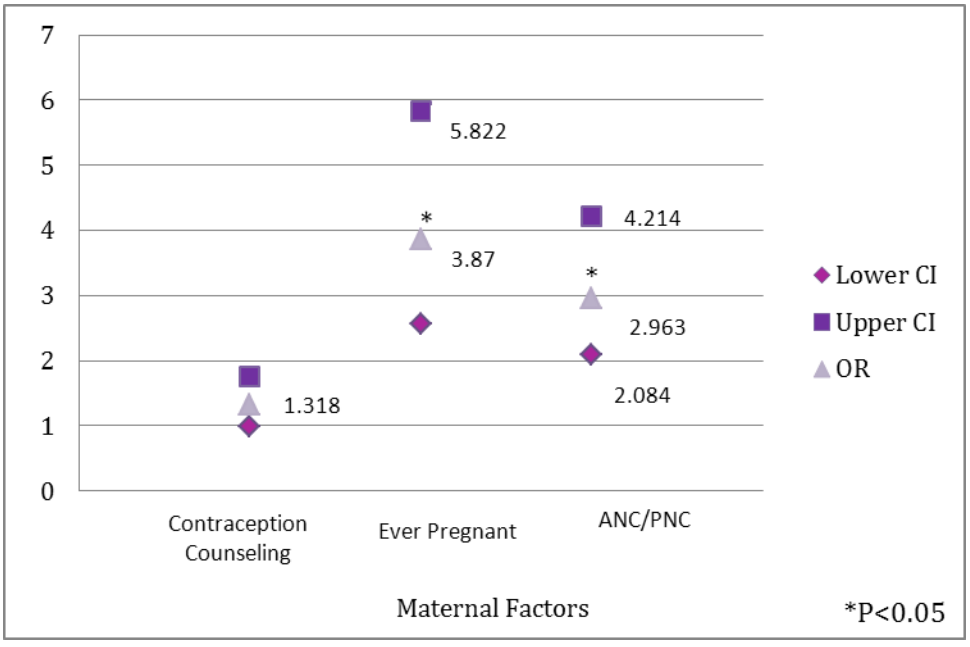

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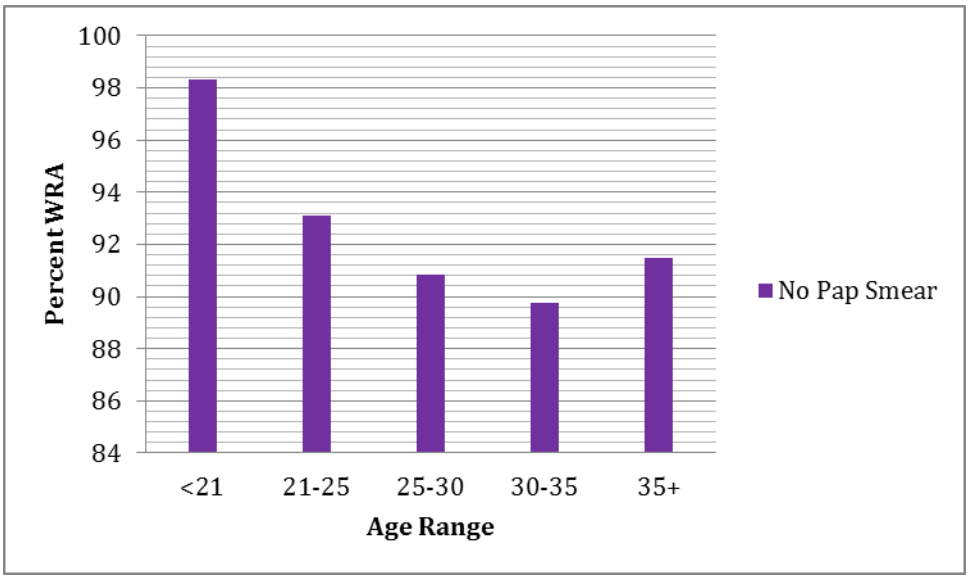
Figure 12. Proportion of WRA that did not receive Pap smear (n=1441)

WRA <21 were less likely to receive a pap smear compared to older WRA (p<0.05)



HIV TESTING AND OUTCOMES

Figure 13. Proportion of WRA Reporting Contraception Counseling (n=1441), Condom Usage (n=1294), and Ever Been Pregnant (n=1441), and HIV Positive by Age

HIV positive WRA were less likely to have received contraception counseling (p<0.01). Condom usage and pregnancy status were not associated with HIV positivity.

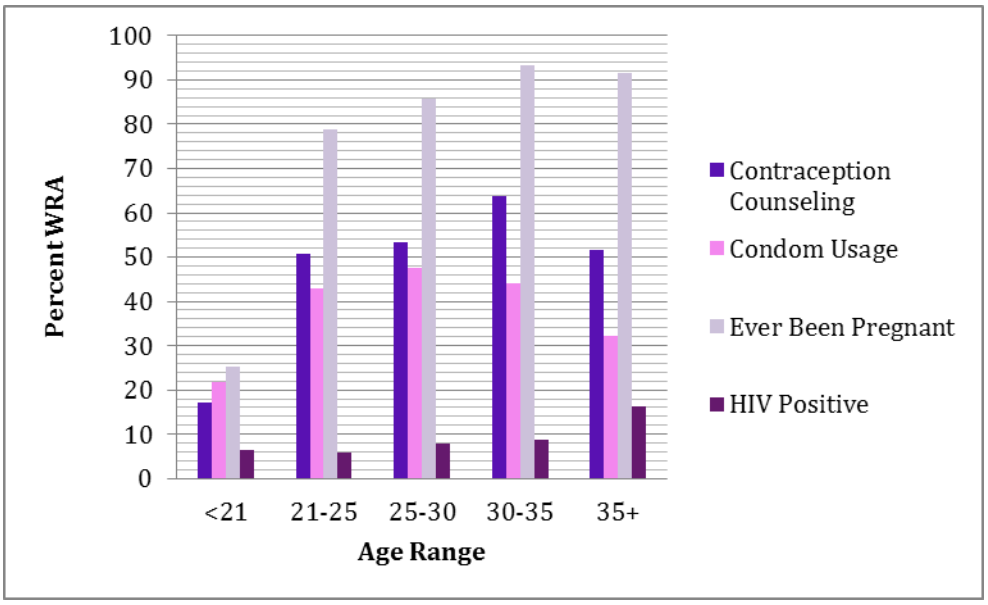


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Figure 14. Proportion of Young WRA Reporting Contraception Counseling and HIV positivity (n=305)

Lack of contraception counseling was associated with HIV positivity in young WRA (p<0.01)

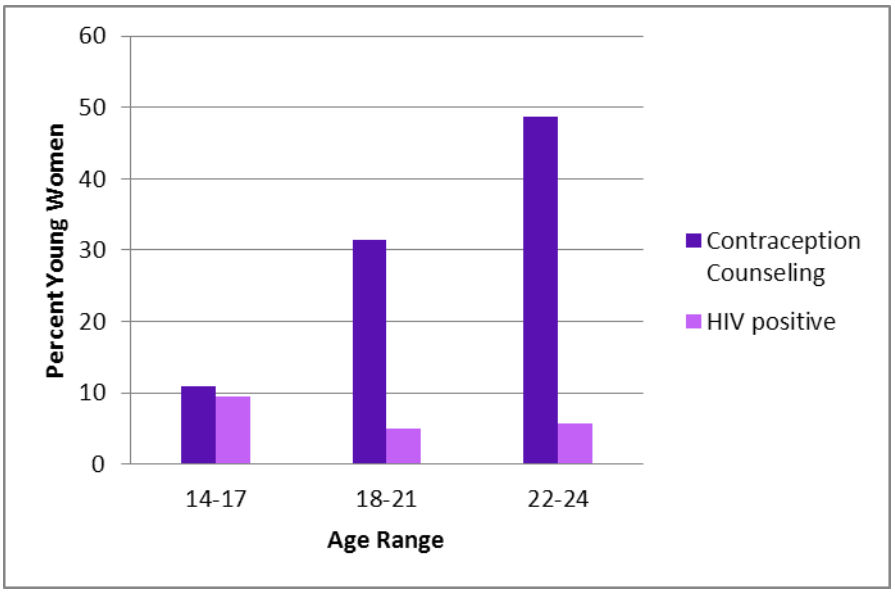

Figure 15. Proportion of Married/Cohabitating WRA Reported Being HIV Positive (n=567) and No Condom Usage (n=678)

HIV positivity was not impacted by marital status. Non-condom usage was associated with HIV positivity (p<0.001)

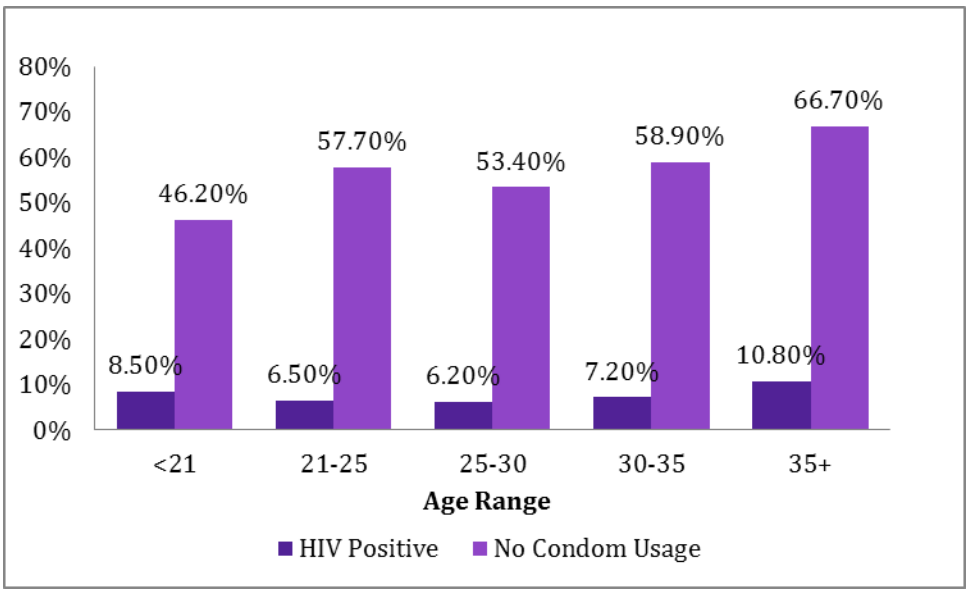

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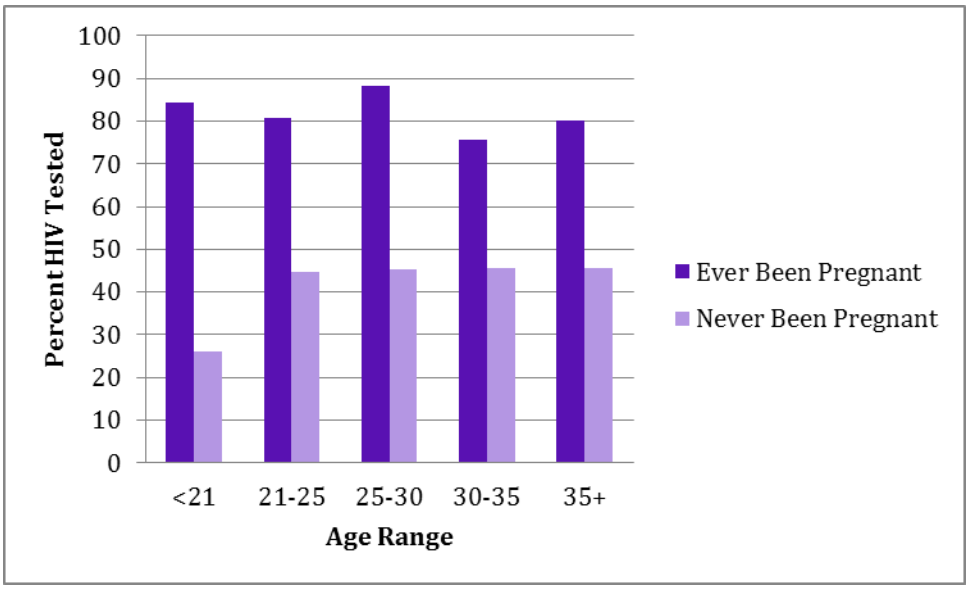
Figure 16. Proportion of Ever Been Pregnant and Never Been Pregnant WRA Reporting HIV Testing

Never been pregnant WRA are less likely to be tested for HIV than ever been pregnant WRA (p<0.05)



HUSBANDS/PARTNER INVOLVMENT

Figure 17. Proportion of Married Husbands/Partners Reporting Condom Usage and Being Tested for HIV (n=574)

Getting tested for HIV was not affected by age. However, young men were more likely to use condoms compared to older men (p<0.001).

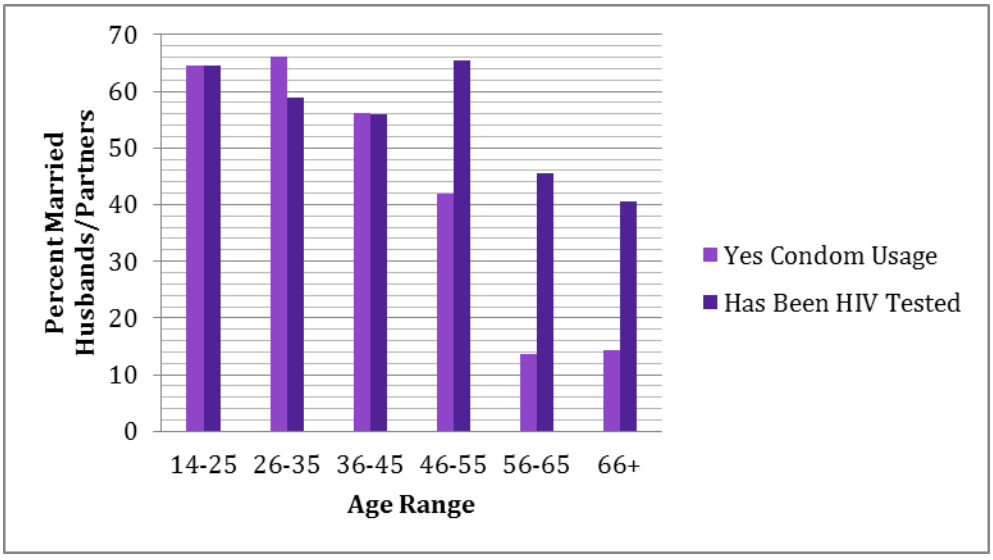


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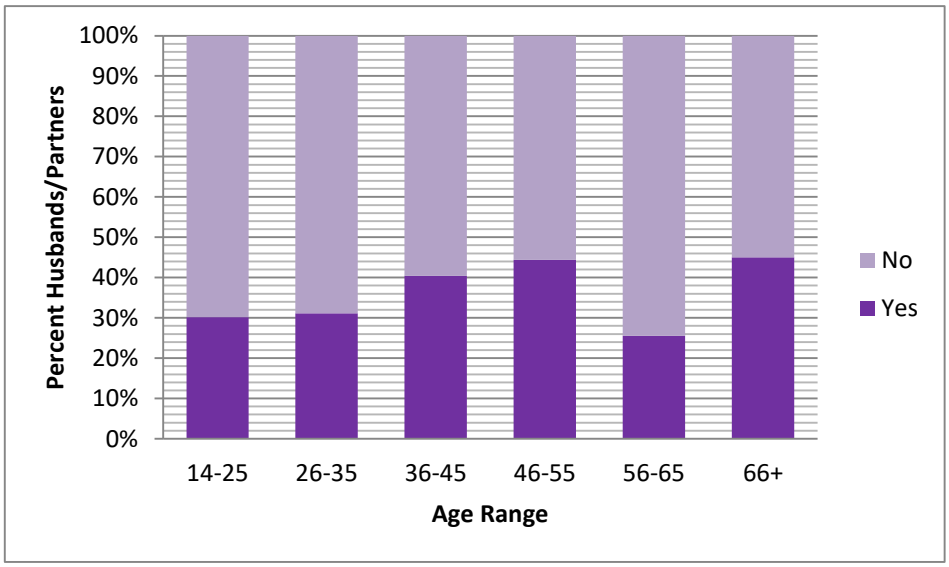
Figure 18. Proportion of Husbands/Partners Going with Wives/Partners for ANC (n=504)

63.7% of all husbands/partners do not accompany their wives to the HC for ANC/PNC visits. No difference between the age groups.



Pilot Project: Phase I

CHALLENGES/LESSONS LEARNED

Some of the challenges encountered during Phase I of the Pilot Project included the following issues:

- Transportation
- Mobile Phones
- Batteries
- Lack of sufficient IT Support
- Weather Conditions
- Selection of CHWs
- Development of Questionnaires
- Training of CHWS
- Supervision and Management

Due to the fact that a random cluster of 25 villages was selected from more than 160 villages, we had to travel as far as 12 to 14 kilometers from the HC. Oftentimes the terrain precluded us even from driving in an SUV and thus we needed to walk door to door to complete our interviews. Obviously, WRA would require transport (feasible only by motorcycle could they get to the HC). The cost for this transportation would have to be incurred by the Pilot Project.

The phones that were chosen required repeated tweaking whenever changes were made to the questionnaire. Lack of continuous IT support prevented the team from including these changes on the phone. This meant that frequently the CHWs and residents were confused regarding the intent of the questions. Additionally, the batteries had a short life and needed to be repeatedly charged and/or changed with new ones. In the future, solar stations operated by the village elders will supply CHWs with recharged batteries on a regular basis.

In addition to the rural and difficult terrain that we had to navigate, we conducted the Pilot Project during the rainy season which limited the time available to conduct the interviews. In the future, we will adjust the timing so that the bulk of the interviews will take place outside of the rainy season.

Selection of the CHWs was hampered by the limited amount of time available to complete the project. In the future, rigorous selection will take place which will include pre-testing and post-testing evaluation on a regular basis. Lengthier training in the areas of HIV/AIDS, reproductive health/ maternal health, and child survival will be done and pre- and post-testing of their knowledge will be evaluated before they go out into the field. The phones will be made more user-friendly and the questionnaires will be developed in tandem with the CHWs and residents in order to create a greater sense of ownership and empowerment. We learned that teams of 2 CHWs were unnecessary and 1 CHW per village was sufficient to complete the interview process. In addition, stringent monitoring of the CHWs' activities will be performed by the management and assessed on a regular basis. Unsatisfactory performance will be assessed and improvement training will be recommended. After a probationary period, if no improvement is appreciated, new CHWs will be selected and trained.

Pilot Project: Phase I

ADDITIONAL FUNDING

Additional funding will be required to implement Phase II of the Pilot Project. Interventions will be undertaken to address gaps identified during Phase I as well as increasing the number of births taking place at the HC in the presence of a SBA (currently 300 deliveries/year scaled up to 600-900 over 18 months). Concurrently with the increased births taking place at the HC, neonatal morbidity and mortality will also be addressed (asphyxia, diarrhea, pneumonia), particularly during the first 48 hours in order to ensure that newborns will survive at least during the first 28 days of life (40% of deaths of children < 5 take place during this period). Due to the expected increase in demand by the mothers and their households LfM will add additional health professionals, particularly, nurses, midwives and medical officers at the HC who will interact directed with the patients as well as the CHWs in the field.

Initially, a ramp-up and preparation period (3-4 months) will be required before interventions can begin. The myriad factors necessary to put these interventions into place include the following: mobilization and extensive training of 160 additional CHWs (including males) over a 6 month period.

CHWs will be equipped with phones, which will enable them to update patient records in real time and manage conditions using health information stored in their phones. All medical professionals working in the HC will also be trained to use mHealth Technology. One CHW will be assigned to their own village (~500 residents). Their responsibilities will include monitoring mothers from pre-pregnancy to delivery by providing nutritional supplements, scheduling and ensuring antenatal visits take place, coordinating Cesarean sections in cases of obstructed labor, and facilitating referrals to the HC and the hospital for severe conditions. Home visits will allow CHWs to distribute supplements such as zinc, folic acid, vitamin A, and co-trimoxazole (pneumonia prophylaxis) to pregnant mothers. A strategy for disease management for fever, diarrhea, malnutrition, and pneumonia will be stored in the CHWs' cell phones. CHWs will assist with transport, a huge barrier for almost all residents, to the HC where women will have access to skilled birth attendants (SBAs) for delivery. Post-natal instructions will be provided by the CHWs who will instruct mothers on self-care techniques at home.

Since human capacity at HC will be increased, as well as the number of CHWs, a management team will need to be in place and operational at the HC in order that communication of information is expedited and made available in real time. Full time IT support will need to be present at the HC so that the collection of health data and the enrollment of new clients runs smoothly. Since the data will be forthcoming almost continuously in real time, statistical analysis will be ongoing and health outcomes will be evaluated and interventions modified as needed. In addition, an epidemiologist will be consulted to assist with the data analysis.

Bottle necks in the field and at the HC will be managed by team leaders and problem solving sessions will be held on a regular basis.

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