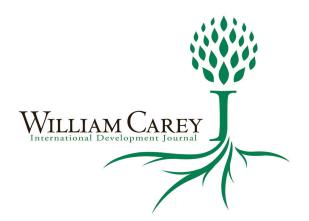
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### GUEST EDITORIAL - Contributions and Correlates from the New

### Christian Journal for Global Health

Daniel O'Neill, MD, and Michael Soderling, MD, MBA

This issue of William Carey International Development Journal includes papers from the Christian Journal for Global Health, an initiative of the <u>Center for Health in Mission</u>. It reflects a broad and expanding collaborative movement involving a large number of individuals and organizations globally. There is a rich history of efforts in health care by people of faith with courage to change with the times. This has inspired the concept of a Christian journal to explore global health issues in a manner that reflects scholarly excellence and scientific credibility.

We seek to capture, catalogue and distribute Christian thinking and practice that has been forged in real-time service among those in need. These experiences, and the motivations underlying them, warrant expression in an **open access** format, available world-wide and without cost. We hope to bring a **scholarly** approach to global health problems, marked by critical analysis and practical application to the world our readers inhabit. This journal will give voice to Christian workers, in every area of the world seeking best practices combined with common values. Few journals have as **integrative** an approach to health and mission, science and faith, policy and practice as we hope for this multidisciplinary resource. Our aim is to maintain a **missional** call to bless the nations and promote the power of the gospel to heal the whole person, community and society. With interdenominational global contribution and distribution, we hope to create new **conversations** using the comments feature and social media platforms. Cooperating with WCIDJ is part of advancing that conversation.

To make this project sustainable and effective, we are <u>calling for papers</u> from around the world with a broad scope including *Public Health, Health Care Service, Organization, Mission and Health,* and *Conditions of Special Interest.* Following the Scriptures which guide our work, we value strength in weakness, humility over bravado, evidence over superstition, honest appraisals over self-serving anecdotes, values over expediency. Recognizing the value of the perspectives of our colleagues of various world views, we hope true wisdom can be applied to express in writing cohesive knowledge for the good of others. As the source of all good gifts, and the reconciler of relationships, God will be glorified, and the Church's role in healing the whole person and all nations will be enhanced.

The tides of change in global health must include people of faith who retain and express the wisdom of God with a relevant Grand Narrative. By letting this light shine, as Jesus taught, it becomes a testimony to the presence and glory of God among the peoples of the world.

Our articles include one that describes a successful contextualized intervention for HIV prevention among the Massai in Tanzania; a report on the challenges facing the Catholic Church in India in the provision of healthcare for the aging population, especially those with neurodegenerative illness; a study of the potential of a Christian mindset to influence community health workers in providing cost-effective maternal health services in rural Kenya; a unique effort to network organizations toward greater synergy for health development in Kenya. A moving final field report gives a window on the West African Ebola outbreak from the standpoint of a Nigerian physician who contracted the virus and her struggle to survive, testifying to the presence of God through suffering.

By promoting intelligent scholarship we aim to see improvements in quality care, revealing God's heart for the healing of the nations, and to articulate theological reflections that inspire a new generation of service in a broken world.

**Dan O'Neill**, MD, is an Assistant Clinical Professor of Family Medicine at the University of Connecticut School of Medicine. He has served as interim physician at Hospital Vozandes Del Oriente in Ecuador, Medical Services Director for Medical Ministry International, and on multiple health and development projects including in West Africa and North India. He is the Managing Editor for the Christian Journal for Global Health.

**Michael Soderling**, MD, MBA, was in private medical practice in WIS before serving 11 years in Guatemala as a development worker. He now serves as Director of the Center for Health in Mission where he facilitates spaces for innovative thinkers to collaborate in order to catalyze movements of health, healing and wholeness among the nations. He is a board governance consultant and a level II Cultural Intelligence consultant.

### Indian Catholic Church's Response to the Elderly with Neurodegenerative and Mental Illnesses

H.E. Msgr. Vincent M. Concessaoa, Rev. Dr. Tomi Thomasb, Anto Maliekalc

- <sup>a</sup> Emeritus Archbishop of Delhi, Bishop Responsible for Pastoral Care in Health, Catholic Bishops Conference of India and Ecclesiastical Adviser, The Catholic Health Association of India
- b Director General, The Catholic Health Association of India
- <sup>c</sup> Programme Manager, The Catholic Health Association of India

### **Abstract**

This article provides an overview of the status of the elderly in India, especially those who suffer from neurodegenerative illnesses. It highlights how the Catholic Church in India responds to the socially and economically marginalized and vulnerable among the elderly, the emerging challenges for the elderly and those involved in geriatric care, and offers recommendations for a way forward for the Church. In spite of the commendable efforts, much needs to be done by the Church for the elderly. The Church must utilize the full potential of health care networks like the Catholic Health Association of India (CHAI) and other Faith-Based-Health-Networks (FBHNs). Inculcating the culture of "involving all" in Christ's healing ministry, the Church in India can facilitate the building of Caring Communities to enable senior citizens to live their twilight years with dignity and peace. The Church can facilitate the democratization and decentralization of medical knowledge through task-shifting. This calls for the empowerment of local communities with information and skills to access health and health care as a fundamental right.

### Introduction

By 2050, in India, due to various factors in health development, the segment of the population aged 60 years and above will surpass the population of children below 14 years (Siva 2006). In absolute terms, according to the data on projected age structure of population by United Nations Department of Economic and Social Affairs (UNDESA 2008), India had more than 91.6 million elderly in 2010 with an annual addition of 2.5 million elderly between 2005 and 2010, which is projected to reach 158.7 million in 2025 (Dey et al. 2012, 371-86). The increasing number of the sick elderly suffering from neurodegenerative illnesses like dementia and mental disorders like depression is an accompanying fact. By 2050, India will have 43 million persons aged 80 or over (United Nations 2009). The situation becomes significantly more challenging with rising health care costs and the facts that 80% of the elderly are in the rural areas and 30% of the elderly live below the poverty line (Times News Network 2012). As per the Global Age Watch Index (GAWI), India ranked very poorly among the 91 countries sampled—73rd in the care of the elderly (Jha 2013).

The message of Pope Francis at the XXI Plenary Assembly of the Pontifical Council for the Family is significant in this context: "Children and the elderly are the two poles of life and also the most vulnerable, often the most for-gotten. A society that abandons children and marginalizes the elderly severs its roots and obscures its future. Whenever a child is abandoned and an old person is marginalized, is not just an act of injustice, but it also demonstrates the failure of that society. Taking care of children and the elderly is the only choice of civilization" (Collins 2013).

This paper gives an overview of the status of the elderly in India, especially those who are affected with neurodegenerative illnesses and mental disorders. It also provides a special emphasis on the socially and economically marginalized/excluded and vulnerable (women) among the elderly; the emerging challenges for the elderly and for those involved in geriatric care; how the Catholic Church (hereafter referred to as "Church") in India responds to the situation; and finally, a way forward for the Church in India.

### **Growth of the Elderly Population**

The National Policy on Older Persons adopted by the Government of India in January 1999 defines "senior citizen" or "elderly" as a person aged 60 years or above. Nearly 7.5% of India's population is currently aged 60 years and above (Times Network 2012). It is projected to rise to 12.4% of the population by the year 2026 (Ministry of Statistics 2011). By 2050, sustaining the existing trend of the longevity of women over men, the

number of elderly women would exceed the number of elderly men by 18.4 million.

### Health and Social Status of the Elderly in Indian Society

Approximately 65% of the aged have to depend on others for their day-to-day main-tenance (Dey et al. 2012, 371-86). Seventy percent of them are women. Nearly 40% of the elderly are still working (60% of men and 19% of women). In urban areas, only 39% of elderly men and approximately 7% of elderly women are economically active. In rural areas, 66% of elderly men and 23% of elderly women are working (Ministry of Statistics 2011).

Based on HelpAge India, 52% of India's Oldest Old (80 +) are in either poor or very poor health, and 80% were without community support. Twelve percent of the Oldest-Old are still working (HelpAge India 2010). Thirty-one percent of older persons reported facing abuse [material exploitation, financial deprivation, property grabbing, abandonment, verbal humiliation, and emotional and psychological torment] (HelpAge India 2012). Most of the cases go unreported in the name of family honor, and victims are afraid of losing even the minimal support they receive.

### **Provisions for the Support of the Elderly**

Article 41 of the Constitution assures public assistance in old age. The enactment of the Maintenance and Welfare of Parents and Senior Citizens Act, 2007 is to ensure need-based maintenance for parents and senior citizens and for their welfare. The government, through the Central Sector Scheme of the Integrated Programme for Older Persons (IPOP), encourages Public-Private Partnership – supporting non-state actors to maintain/organize various facilities for the elderly. The other measures are old age pensions; income tax exemption/ deduction; travel concessions; geriatric departments in medical colleges; and establishing two National Institutes on Aging in Delhi and Chennai.

Many of these measures, however, are not fully implemented. Recently, the National Policy on Senior Citizens 2011, and in line with it, the 12th Five Year Plan and National Mental Health Programme, placed special emphasis on senior citizens suffering from severely disabling diseases. This includes various types of dementias including Alzheimer's, Parkinson's disease, depression, and other psycho-geriatric disorders. On the whole, the country is yet to put in place measures to effectively meet the impending scenario of the growing population of the elderly, especially those suffering from neurodegenerative illnesses and mental disorders.

### Specific Needs Related to Neurodegenerative Disease and Mental Illness

The increased numbers of the sick elderly with neurodegenerative illnesses and various mental disorders will have a marked impact on India's infrastructures and health care systems, which are at present ill-prepared in many regions. Approximately 64 per 1,000 elderly persons in rural areas and 55 per 1,000 in urban areas suffer from one or more disabilities (Ministry of Statistics 2011).

As per the Ministry of Health and Family Welfare, one in every four among India's elderly population is depressed; one in three suffers from arthritis, while one in five cannot hear. While one in three suffers from hypertension in India, almost half have poor vision. Approximately one in ten experiences a fall that results in fracture, while two in five are anemic (Times News Network 2012). As per HelpAge India, 30 million are lonely, and one out of eight elderly feels no one cares that they exist, and 90% have to continue to work if they have to survive (HelpAge India 2013). Eighty-eight percent said loneliness can lead to physical and mental ailments like depression (HelpAge India 2008). Many researchers believe that depression is a risk factor for dementia. There are others who argue that it is an early symptom of the disease (Alzheimer's Society 2014). In 2010, it was estimated that there were 3.7 million affected by dementia (Alzheimer disease [AD] and Vascular dementia [VaD]) in India, and the total societal cost was approximately Rs.1,470 million. People with Dementia (PwD) are expected to double by 2030, increasing the cost by three times (Alzheimer's and Related Disorders 2010).

At present, the elderly with depression and neurodegenerative illnesses are mainly taken care of by their families without much support from the public health care system, even at the primary care level. The joint family system, the traditional support system for the sick and dependent elderly people, is crumbling because of the migration of the younger generation to cities in search of better prospects. The advent of nuclear families also adds to the challenge. Women, who traditionally took on the role of caregivers, are also working and cannot spend as much time caring for the elderly (WHO 2006, 31-110).

A neurodegenerative condition, like dementia, is considered a normal part of aging and is not perceived as requiring medical care. Primary care physicians rarely deal with this condition in their clinical work. Private medical care is thus preferred, and this leads to a higher out-of-pocket expenditure for care. Caregivers experience significant burdens and health strain. More than 80% of

caregivers are females, and approximately 50% are spouses, who are themselves quite old. Most old-age homes do not admit people with dementia. The stigma of aging, arising out of neurodegenerative illnesses like dementia, depression, incontinence, etc., is another social barrier to accessing health care by the elderly. People with dementia and other types of neurodegenerative illnesses and mental disorders are often neglected, ridiculed, and abused (WHO 2006, 41-110).

The key barriers to the access to health for the Indian elderly include social barriers shaped by gender, stigma, and other axes of social inequality (religion, caste, socioeconomic status). The physical barrier of reduced mobility reduces their social engagement and limits the reach of the health system. Health affordability constraints include limitations in income, employment, and assets, and the meager financial protection offered in the Indian health system (Dey et al. 2012, 371-86). Social security coverage, such as employer insurance, pension scheme, etc., covers only a negligible segment of the employed population in organized sectors. The majority of the workforce is engaged either in the unorganized sector or are self-employed. They are not entitled to formal retirement benefits. As a result, a considerable proportion of the elderly is forced to earn their living by engaging in some work to manage their lives.

As 83% of health care expenses are out-of-pocket expenditures (Dey et al. 2012, 371-86), the deprivation is severe and crushing for the elderly whose need for health care increases with age. Even where care is physically accessible, costs of accessing this care become beyond their reach. For the willing caregivers, especially those struggling to make both ends meet, the sick elderly become a severe economic burden. The growing comercialization of health care and the deficiencies in the public health care system also make the situation more complex. Among the elderly, women suffer most, especially widows (due to mobility, employment, property, and financial constraints). The predicament of elderly women is aggravated by a lifetime of genderbased discrimination. Aging women are more likely to get excluded from social security schemes due to lower literacy and awareness levels (Meijer F. 2012).

# The Role of the Catholic Health Association of India in Addressing the Needs of the Elderly

The Catholic Health Association of India (CHAI) is the largest non-government health care network in India with over 3,439 member institutions. Founded in 1943 by Sr. Dr. Mary Glowrey, an Australian nun, CHAI is one of the main arms of the Health Commission under the Bishops' Conference and comprises most of the Catholic

health care facilities: 746 small, medium, and major hospitals, 2,574 health centers, 107 centers for mental health, 61 centers for alternative systems of medicine, 162 non-formal health facilities, 165 leprosy centers and 6 medical colleges, 615 residential health care centers for the aged, 678 training centers and 443 rehabilitation centers involved in the preventive and curative care of people, 123 community care centers for people living with HIV/AIDS including 40 centers for children infected/ affected, 60 counselling centers, 82 centers for tuberculosis and terminally ill (palliative care centers), 120 nursing schools/ colleges) and 600 project-based institutions focused on certain diseases in collaboration with the government, as well as engaged in other social concerns (Moras 2013, 114-19).

CHAI provides critical health care services to the poor and marginalized with a network of over 1,000 nundoctors, 25,000 nun-nurses, 10,000 plus nunparaprofessionals, and 5,000 nun social workers, along with their lay collab-orators (CHAI n.d.). One can safely assume that nearly 130,000 persons (religious, lay workers and volunteers) render services in these institutions collectively.

CHAI's member institutions treat more than 21 million per year. This includes 5,000 HIV patients, approximately 2,000 children affected or infected with HIV in institutional care, 15,000 cared for in community-based care, and 10,000 children with special needs who are provided with annual educational, health, and rehabilitation support. CHAI member institutions and their sister concerns facilitate more than two million Self Help Group members. Over 5,000 students graduate every year from CHAI-member nursing schools (CHAI n.d.).

Throughout India, in all its 615 homes for the aged, CHAI and its member institutions provide free care to nearly 18,500 elderly, who are mostly sick and abandoned by their families. However, most of these homes are located in middle-income level southern states, with nearly 40% located in the State of Kerala and the rest in Karnataka, Maharashtra, Goa, and West Bengal (Catholic Bishops' Conference of India 2013). The Church renders service to more than 60,000 elderly on a daily basis, including approximately 18,500 in its homes for the aged and 1,700 in its palliative care units. This does not include the elderly supported in its project-based institutions/ organizations and those contacted daily during home visits as part of pastoral care. Of late, serious efforts are being made to train nurses and other frontline health workers in geriatric care.

Currently, there are not many government-run geriatric care facilities, especially for the elderly with neurodegenerative illnesses. Some for-profit, private health care providers have recently entered the field, but

are not meant to cater to the needs of the elderly from marginalized sections of the community. Further, none of them are ready to take care of the elderly with neurodegenerative and mental illnesses. It is in this space that the varied services offered by private not-for-profit faith-based-health-networks (FBHNs) like CHAI and other sister concerns in the Church become relevant. These FBHNs can make a major difference in home-based care, palliative care, etc. Recognizing the significance of FBHNs and other not-for-profit organizations, India's 12th Five-Year Plan and the National Health Mission encourage Public Private Partnerships (PPP) to improve health services, including care for the elderly.

The dedicated service of the religious of FBHNs, mostly nuns, along with lay employees and experts, offers affordable quality health care. With their training and inclination for dedicated service, they form a unique cadre of health personnel who can engage in maternal and child health care, as well as the care of the elderly, terminally ill, and mentally-ill persons in a humane and dignified manner. They effectively motivate people, including those outside the faith-community, and inculcate a culture of positive health, encouraging people to adopt healthy lifestyles. The cross-linkages with Catholic Social Service Networks and School Network are also being utilized for public health activities.

### Task-Shifting to Address the Human Resource Gaps in Care for the Elderly with Neurodegenerative and Mental Illnesses

As is the case with any other health service, there is a severe deficiency of trained health professionals, medical practitioners as well as nurses, to take care of the elderly with neurodegenerative and mental illnesses. In this context, the concept of task-shifting is significant. Task shifting involves the rational redistribution of tasks among health workforce teams. Specific tasks are moved, where appropriate, from highly qualified health workers to health workers with lesser training and fewer qualifications, in order to make more efficient use of the available human resources for health (WHO 2008). For example, breakdown of complex health care interventions into simplified, smaller, and locallyrelevant components that can be transferred to and performed by the less-trained, locally available health care workers/volunteers—shifting the specific tasks from physicians to nurse practitioners and from nurses to community health workers (Patel 2012). Task-shifting primarily means the capacity building of caregivers at home and local community volunteers with the basics in geriatric and palliative care, a patient-centred approach, addressing the need to give extra care and happiness for

the elderly to enable them to cope with suffering, to age and die with dignity.

To lead the way in this direction, task shifting would here mean to capacitate, or up-grade the skills, of the nun-nurses, nun-paraprofessionals, lay collaborators of the Church's health care institutions, and the caregivers in providing geriatric and palliative care. Such task-shifting is needed more in medically under-/un-reached areas. As noted earlier, in the midst of rising health care costs, 30% of the elderly live below the poverty line and 80% of them reside in rural areas.

Task-shifting brings down the health care costs by reducing human resource costs, thereby making quality geriatric and palliative care more accessible and affordable, especially in the underserved areas, with special focus on the elderly of the socially excluded and economically marginalized sections of society. Moreover, task-shifting, in fact, is a practical and radical example of the decentralization and democratization of medical knowledge. It empowers caregivers and health workers in the community, with supportive supervision from the professionals, to be more effective in caring for the elderly, especially those with neurodegenerative and mental ill-nesses, and to advocate their rights. Enabling caregivers through task-shifting to take care of the elderly echoes the Church's vision of health-care inspired by His compassionate love, ensuring life in its fullness (Jn.10:10) (CBCI 2005).

In contrast to the growing commercialization of geriatric and palliative care, task-shifting in a Christian context encourages care-givers and local volunteers, especially the young, to be unique, to enable themselves to practice being the 'Good Samaritan' in caring for the elderly, demonstrating the compassionate care of Jesus for the marginalized and vulnerable, irrespective of caste, creed, and sex (Mt. 25:40; Lk. 9:2; Lk. 10:25-37; Acts 10:38). In contrast to the growing culture of consumerism, individualism, and the abandonment of the most vulnerable, task-shifting enables one to experience that "it is more blessed to give than receive" (Acts 20:35) to bear witness that all of life is a gift from God, especially in its final stage.

Task shifting calls Christians as caregivers and young volunteers to invest "hard loving" as Bishop Anthony Fisher puts it, "even with the best of care, pain and death cannot be eliminated from this life. Some problems in this life have no solution. Then comes the really hard loving: the loving of a family surrounding their comatose child, of a husband whose wife's Alzheimer's disease means she no longer recognizes him, of siblings playing patiently with their profoundly disabled brother, of a mother watching and weeping at the foot of the Cross. Sometimes the best we can do is to invest ourselves – our time, companionship, prayer, hope – in the suffering, the

persistently unconscious and the dying. This is a kind of respecting and loving that no one should pretend is easy" (McKenna 2012).

Task-shifting is thus a means to inculcate a culture of empathy among caregivers, and especially the young, local volunteers, to build them into a caring community for "the elderly who are increasingly isolated and abandoned" (Pope Francis 2013). Task-shifting empowers them as Christians to declare, "Old age is not the disappearance of life but its completion . . . Through solidarity between the young and the old, one has a way of understanding how the Church is really a family of all the generations, where each person must truly feel at home, where the logic of profit and possessing does not rule, but the logic of free giving and of love. When during the years of old age life becomes frail, it never loses its value or its dignity: every person is willed, is loved by God; every person is important and necessary" (Zimowski 2013).

### The Way Forward

In spite of all the commendable efforts much needs to be done regarding the care of the elderly in India. The Church, under the aegis of the Catholic Bishops' Conference of India, needs to leverage the full potential of FBHNs like CHAI, and other Christian denominations and Civil Society Organizations.

### The Church also needs to advocate for:

- 1. The recognition of neurodegenerative illnesses like dementia, depression, and other mental disorders, especially affecting the elderly, as treatable under primary health care package systems in the country.
- 2. The availability of essential, affordable drugs for the treatment of the sick elderly with neurodegenerative illnesses and mental disorders.
- 3. The legalization of nurse practitioners as part of task-shifting.

### Other Areas Where the Church Needs to Get Involved

Promoting the significance of task-shifting to make care for the sick elderly and mental health care more accessible and affordable by involving Accredited Social Health Activists (ASHAs), trained birth attendants (Dais), other frontline health workers under the National Health Mission, and successful lay counselors caring for the young at risk in many organizations, etc.

Training and supporting the caregivers/family members to provide maximum home-based care to the elderly, especially those suffering from neurodegenerative illnesses and mental disorders.

Providing refresher trainings to primary care physicians to attend to the sick elderly suffer-ing from

neurodegenerative illnesses, depression, and other mental disorders.

Sensitizing and educating the public against stigma and discrimination of the sick elderly.

Creating awareness among the elderly, caregivers, and youth at the community level on the National Policy on Older Persons, legislations like "The Maintenance and Welfare of Parents and Senior Citizens Act 2007," and various schemes benefitting the elderly.

Promoting the utilization of modern technology, for instance, training frontline health workers in telemedicine, thereby making quality health care for the elderly more accessible and affordable, especially in the rural areas.

Promoting and undertaking research in the field of geriatric care to make it more evidence-based, accessible, and affordable for the marginalized/excluded and vulnerable among the elderly.

#### Conclusion

Compelled by Jesus' love and His preferential stand for the poor and marginalized, Church health institutions fulfil their obligations to continue strengthening their services for the economically underprivileged, socially excluded, and vulnerable, the elderly, children and women, while expanding to more medically underserved areas. The emerging challenges and threats from not-so-friendly external factors, be it technical/ professional, legislative, social, economic, and political, call for serious introspection. The Church has to contend with the lethargic, often corrupt, public health care systems as well as the excessively profit-minded private health care systems.

Inculcating the culture of 'involving all' in Christ's healing ministry, the Church in India has to facilitate the building of local ownership and Caring Communities that support the elderly toward healthy aging with dignity and self-respect. This endeavor has to be shared by the elderly themselves, caregivers, local community/ religious leaders, youth, teachers, professionals, and frontline health workers/volunteers. The Church has to facilitate the democratization and decentralization of medical knowledge through task-shifting. This calls for the empowerment of local communities with information and skills to organize, demand, and access rights and entitlements from the perspective of health as a fundamental right, with a special emphasis on the elderly, children, and women.

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# Field Report Through the Valley of the Shadow of Death—Surviving the Dreaded Ebola Disease

Adaora Chinenye Okoli-Igonoha
a MD, First Consultants Medical Centre, Lagos, Nigeria

On the night of Sunday July 20th, 2014, Patrick Sawyer was wheeled into the Emergency Room at First Consultants Medical Centre, Obalende, Lagos, with complaints of fever and body weakness. The doctor on call admitted him as a case of malaria and took a full history. Knowing that Mr. Sawyer had recently arrived from Liberia, the doctor asked if he had been in contact with an Ebola patient in the last couple of weeks, and Mr. Sawyer denied any such contact. He also denied attending any recent funeral ceremony. Blood samples were taken for full blood count, malaria parasites, liver function test, and other baseline investigations. He was admitted into a private room and started on antimalarial drugs and analgesics. That night, the full blood count result came back as normal and not indicative of infection.

The following day, however, his condition worsened. He barely ate any of his meals. His liver function test result showed his liver enzymes were markedly elevated. We then took samples for HIV and hepatitis screening. At about 5:00 p.m., he requested to see a doctor. I was the doctor on call that night, so I went in to see him. He was lying in bed with his intravenous (I.V.) fluid bag removed from its metal stand and placed beside him. He complained that he had stooled about five times that evening, and he wanted to use the bathroom again. I picked up the I.V. bag from his bed and hung it back on the stand. I told him I would inform a nurse to come and disconnect the I.V. so he could conveniently go to the bathroom. I walked out of his room and went straight to

the nurses' station where I told the nurse on duty to disconnect his I.V. I then informed my Consultant, Dr. Ameyo Adadevoh about the patient's condition, and she asked that he be placed on some medications.

The following day, the results for HIV and hepatitis screening came out negative. As we were preparing for the early morning ward rounds, I was approached by an ECOWAS official who informed me that Patrick Sawyer had to catch an 11 o'clock flight to Calabar for a retreat that morning. He wanted to know if it would be possible to be discharged. I told him it wasn't, as he was acutely ill.

Dr. Adadevoh also told him the patient could certainly not leave the hospital in his condition. She then instructed me to write very boldly on his chart that on no account should Patrick Sawyer be allowed out of the hospital premises without the permission of Dr. Ohiaeri, our Chief Medical Consultant. All nurses and doctors were duly informed.

During our early morning ward round with Dr. Adadevoh, we concluded this was not malaria, and the patient needed to be screened for Ebola Viral Disease. She immediately started calling laboratories to find out where the test could be carried out. She was eventually referred to Professor Omilabu of the LUTH Virology Reference Lab in Idi-Araba whom she called immediately. Prof. Omilabu told her to send blood and urine samples to LUTH straight away. She tried to reach the Lagos State Commissioner for Health but was unable to contact him at the time. She also put calls across to officials of the Federal Ministry of Health and National Centre for Disease Control.

Dr. Adadevoh, at this time, was in a pensive mood. Patrick Sawyer was now a suspected case of Ebola, perhaps the first in the country. He was quarantined, and strict barrier nursing was applied with all the precautionary measures we could muster. Dr. Adadevoh went online, downloaded information on Ebola, and printed copies which were distributed to the nurses, doctors, and ward maids. Blood and urine samples were sent to LUTH that morning. Protective gear, gloves, shoe covers, and facemasks were provided for the staff. A wooden barricade was placed at the entrance of the door to keep visitors and unauthorized personnel away from the patient. Despite the medications prescribed earlier, the vomiting and diarrhea persisted. The fever escalated from 38°C to 40°C.

On the morning of Wednesday 23rd July, the tests carried out in LUTH showed a signal for Ebola. Samples were then sent to Dakar, Senegal for a confirmatory test. Dr. Adadevoh went for several meetings with the Lagos State Ministry of Health. Thereafter, officials from Lagos State came to inspect the hospital and the protective measures we had put in place.

The following day, Thursday 24th July, I was again on call. At about 10:00 p.m., Mr. Sawyer requested to see me. I went into the newly created dressing room, donned my protective gear, and went in to see him. He had not been cooperating with the nurses and had refused any additional treatment. He sounded confused and said he received a call from Liberia asking for a detailed medical report to be sent to them. He also said he had to travel back to Liberia on a 5:00 a.m. flight the following morning, and he didn't want to miss his flight. I told him that I would inform Dr. Adadevoh. As I was leaving the room, I met Dr. Adadevoh dressed in her protective gear along with a nurse and another doctor. They went into his room to have a discussion with him and, as I heard later, to reset his I.V. line which he had deliberately removed after my visit to his room.

At 6:30 a.m., Friday 25th July, I got a call from the nurse that Patrick Sawyer was completely unresponsive. Again, I put on the protective gear and headed to his room. I found him slumped in the bathroom. I examined him and observed that there was no respiratory movement. I felt for his pulse; it was absent. We had lost him. I certified Patrick Sawyer's death. I informed Dr. Adadevoh

immediately, and she instructed that no one was to be allowed to go into his room for any reason at all. Later that day, officials from the Word Health Organization (WHO) came and took his body away. The test in Dakar later came out positive for the Zaire strain of the Ebola virus. We now had the first official case of Ebola virus disease in Nigeria.

It was a sobering day. We all began to go over all that happened in the last few days, wondering just how much physical contact we had individually made with Patrick Sawyer. Every patient on admission was discharged that day and decontamination began in the hospital. We were now managing a crisis situation. The next day, Saturday 26th July, all staff of First Consultants attended a meeting with Prof. Nasidi of the National Centre for Disease Control, Prof Omilabu of LUTH Virology Reference Lab, and some officials of WHO. They congratulated us on the actions we had taken and enlightened us further about the Ebola Virus Disease. They said we were going to be grouped into high risk and low risk categories based on our individual level of exposure to Patrick Sawyer, the "index" case. Each person would receive a temperature chart and a thermometer to record temperatures in the morning and night for the next 21 days. We were all officially under surveillance. We were asked to report to them at the first sign of a fever for further blood tests to be done. We were reassured that we would all be given adequate care. The anxiety in the air was palpable.

The frenetic pace of life in Lagos, coupled with the demanding nature of my job as a doctor, means that I occasionally need a change of environment. As such, one week before Patrick Sawyer died, I had gone to my parents' home for a retreat. I was still staying with them when I received my temperature chart and thermometer on Tuesday 29th of July. I could not contain my anxiety. People were talking Ebola everywhere—on television, online—everywhere. I soon started experiencing joint and muscle aches and a sore throat, which I quickly attributed to stress and anxiety. I decided to take malaria tablets. I also started taking antibiotics for the sore throat. The first couple of temperature readings were normal. Every day I would attempt to recall the period Patrick Sawyer was on admission — just how much direct and indirect contact did I have with him? I reassured

myself that my contact with him was quite minimal. I completed the anti-malarials, but the aches and pains persisted. I had loss of appetite and felt very tired.

On Friday 1st of August, my temperature read a high 38.7°C. As I type this, I recall the anxiety I felt that morning. I could not believe what I saw on the thermometer. I ran to my mother's room and told her. I did not go to work that day. I cautiously started using a separate set of utensils and cups from the ones my family members were using. On Saturday 2nd of August, the fever worsened. It was now at 39°C and would not be reduced by taking paracetamol. This was now my second day of fever. I couldn't eat. The sore throat was getting worse. That was when I called the helpline and an ambulance was sent with WHO doctors who came and took a sample of my blood. Later that day, I started stooling and vomiting. I stayed away from my family. I started washing my plates and spoons myself. My parents, meanwhile, were convinced that I could not have Ebola.

The following day, Sunday 3rd of August, I got a call from one of the doctors who came to take my sample the day before. He told me that the sample they had taken was not confirmatory, and they needed another sample. He did not sound very coherent, and I became worried. They came with the ambulance that afternoon and told me that I had to go with them to Yaba. I was confused. Couldn't the second sample be taken in the ambulance like the previous one? He said a better-qualified person at the Yaba centre would take the sample. I asked if they would bring me back. He said "yes." Even with the symptoms, I did not believe I had Ebola. After all, my contact with Sawyer was minimal. I only touched his I.V. fluid bag just that once without gloves. The only time I actually touched him was when I checked his pulse and confirmed him dead, and I wore double gloves and felt adequately protected.

I told my parents I had to go with the officials to Yaba, and I would be back that evening. I wore a white top and a pair of jeans, and I put my iPad and phones in my bag. A man opened the ambulance door for me and moved away from me rather swiftly. Strange behavior, I thought. They were friendly with me the day before, but that day, not so—no pleasantries, no smiles. I looked up and saw my mother watching through her bedroom window. We soon got to Yaba. I really had no clue where I

was. I knew it was a hospital. I was left alone in the back of the ambulance for over four hours. My mind was in a whirl. I didn't know what to think. I was offered food to eat, but I could barely eat the rice.

The ambulance door opened and a Caucasian gentleman approached me but kept a little distance. He said to me, "I have to inform you that your blood tested positive for Ebola. I am sorry." I had no reaction. I think I must have been in shock. He then told me to open my mouth, and he looked at my tongue. He said it was the typical Ebola tongue. I took out my mirror from my bag and took a look, and I was shocked at what I saw. My whole tongue had a white coating, looked furry, and had a long, deep ridge right in the middle. I then started to look at my whole body, searching for Ebola rashes and other signs as we had been recently instructed. I called my mother immediately and said, "Mummy, they said I have Ebola, but don't worry, I will survive it. Please, go and lock my room now; don't let anyone inside and don't touch anything." She was silent. I cut the line.

I was taken to the female ward. I was shocked at the environment. It looked like an abandoned building. I suspected it had not been in use for quite a while. As I walked in, I immediately recognized one of the ward maids from our hospital. She always had a smile for me but not this time. She was ill, and she looked it. She had been stooling a lot too. I soon settled into my corner and looked around the room. It smelled of faeces and vomit. It also had a characteristic Ebola smell to which I became accustomed. Dinner was served—rice and stew. The pepper stung my mouth and tongue. I dropped the spoon. No dinner that night.

Dr. David, the Caucasian man who had met me at the ambulance on my arrival, came in wearing his full protective 'hazmat' suit and goggles. It was fascinating seeing one live. I had only seen them online. He brought bottles of water and oral rehydration solution (ORS), which he dropped by my bedside. He told me that 90 percent of the treatment depended on me. He said I had to drink at least 4.5 litres of ORS daily to replace fluids lost in stooling and vomiting. I told him I had stooled three times earlier and taken Imodium tablets to stop the stooling. He said it was not advisable, as the virus would replicate the more inside of me. It was better, he said, to let it out. He said good night and left. My parents called. My uncle

called. My husband called, crying. He could not believe the news. My parents had informed him, as I didn't even know how to break the news to him.

As I lay on my bed in that isolation ward, strangely, I did not fear for my life. I was confident that I would leave that ward someday. There was an inner sense of calm. I did not for a second think I would be consumed by the disease. That evening, the symptoms fully kicked in. I was stooling almost every two hours. The toilets did not flush so I had to fetch water in a bucket from the bathroom each time I used the toilet. I then placed another bucket beneath my bed for the vomiting. On occasion, I would run to the toilet with a bottle of ORS, so that as I was stooling, I was drinking.

The next day, Monday 4th of August, I began to notice red rashes on my skin, particularly on my arms. I had developed sores all over my mouth. My head was pounding so badly. The sore throat was so severe I could not eat. I could only drink the ORS. I took paracetamol for the pain. The ward maid across from me wasn't doing so well. She had stopped speaking. I couldn't even brush my teeth; the sores in my mouth were so bad. This was a battle for my life, but I was determined I would not die.

Every morning, I began the day with reading and meditating on Psalm 91. The sanitary condition in the ward left much to be desired. The whole Ebola thing had caught everyone by surprise. The Lagos State Ministry of Health was doing its best to contain the situation, but competent hands were few. The sheets were not changed for days. The floor was stained with greenish vomitus and excrement. Dr. David would come in once or twice a day and help clean up the ward after chatting with us. He was the only doctor who attended to us. There was no one else at that time. The matrons would leave our food outside the door; we had to go get the food ourselves. They hardly entered in the initial days. Everyone was being careful. This was all so new. I could understand. Was this not how we ourselves had contracted the disease? Mosquitoes were our roommates until they brought us mosquito nets.

Later that evening, Dr. David brought another lady into the ward. I recognized her immediately as Justina Ejelonu, a nurse who had started working at First Consultants on the 21st of July, a day after Patrick Saywer was admitted. She was on duty on the day Patrick

reported that he was stooling. While she was attending to him that night, he had yanked off his drip, letting his blood flow almost like a tap onto her hands. Justina was pregnant and was brought into our ward bleeding from a suspected miscarriage. She had been told she was there only on observation. The news that she had contracted Ebola was broken to her the following day after results of her blood test came out positive. Justina was devastated and wept profusely — she had contracted Ebola on her first day at work.

My husband started visiting but was not allowed to come close to me. He could only see me from a window at a distance. He visited so many times. It was he who brought me a change of clothes and toiletries and other things I needed because I had not even packed a bag. I was grateful I was not with him at home when I fell ill, or he would most certainly have contracted the disease. My retreat at my parents' home turned out to be the instrumentality God used to shield and save him.

I drank the ORS fluid like my life depended on it. Then I got a call from my pastor. He had been informed about my predicament. He called me every single day morning and night and would pray with me over the phone. He later sent me a CD player, CDs of messages on faith and healing, and Holy Communion packs through my husband. My pastor, who also happens to be a medical doctor, encouraged me to monitor how many times I had stooled and vomited each day and how many bottles of ORS I had consumed. We would then discuss the disease and pray together. He asked me to do my research on Ebola since I had my iPad with me and told me that he was also doing his study. He wanted us to use all relevant information on Ebola to our advantage. So I researched and found out all I could about the strange disease that has been in existence for 38 years. My research, my faith, my positive view of life, the extended times of prayer, study, and listening to encouraging messages boosted my belief that I would survive the Ebola scourge.

There are five strains of the virus, and the deadliest of them is the Zaire strain, which was what I had. But, that did not matter. I believed I would overcome even the deadliest of strains. Infected patients who succumb to the disease usually die between 6 to 16 days after the onset of the disease from multiple organ failure and shock caused by dehydration. I was counting the days and keeping

myself well hydrated. I didn't intend to die in that ward.

My research gave me ammunition. I read that as soon as the virus gets into the body, it begins to replicate really fast. It enters the blood cells, destroys them, and uses those same blood cells to aggressively invade other organs where they further multiply. Ideally, the body's immune system should immediately mount up a response by producing antibodies to fight the virus. If the person is strong enough, and that strength is sustained long enough for the immune system to kill off the viruses, the patient is likely to survive. If the virus replicates faster than the antibodies can handle, however, further damage is done to the organs. Ebola can be likened to a multi-level, multi-organ attack, but I had no intention of letting the deadly virus destroy my system. I drank more ORS. I remember saying to myself repeatedly, "I am a survivor, I am a survivor."

I also found out that a patient with Ebola cannot be reinfected, and they cannot relapse back into the disease as there is some immunity conferred on survivors. My pastor and I would discuss these findings, interpret them as it related to my situation, and pray together. I looked forward to his calls. They were times of encouragement and strengthening. I continued to meditate on the Word of God. It was my daily bread. Shortly after Justina came into the ward, the ward maid, Mrs Ukoh, passed on. The disease had gotten into her central nervous system. We stared at her lifeless body in shock. It was a whole 12 hours before officials of WHO came and took her body away. The ward had become the house of death. The whole area surrounding her bed was disinfected with bleach. Her mattress was taken and burned.

To contain the frequent diarrhea, I had started wearing adult diapers, as running to the toilet was no longer convenient for me. The indignity was quite overwhelming, but I did not have a choice. My faith was being severely tested. The situation was desperate enough to break anyone psychologically. Dr. Ohiaeri also called us day and night, enquiring about our health and the progress we were making. He sent provisions, extra drugs, vitamins, Lucozade, towels, and tissue paper; everything we needed to be more comfortable in that dark hole we found ourselves. Some of my male colleagues had also been admitted to the male ward two rooms away, but there was no interaction with them.

We were saddened by the news that Jato, the ECOWAS protocol officer to Patrick Sawyer who had also tested positive, had passed on days after he was admitted. Two more females joined us in the ward: a nurse from our hospital and a patient from another hospital. The mood in the ward was solemn. There were times we would be awakened by the sudden, loud cry from one of the women. It was either from fear, pain mixed with the distress, or just the sheer oppression of our isolation.

I kept encouraging myself. This could not be the end for me. Five days after I was admitted, the vomiting stopped. A day after that, the diarrhea ceased. I was overwhelmed with joy. It happened at a time I thought I could no longer stand the ORS. Drinking that fluid had stretched my endurance greatly.

I knew countless numbers of people were praying for me. Prayer meetings were being held on my behalf. My family was praying day and night. Text messages of prayers flooded my phones from family members and friends. I was encouraged to press on. With the encouragement I was receiving, I began to encourage the others in the ward. We decided to speak life and focus on the positive. I then graduated from drinking only the ORS fluid to eating only bananas, to drinking pap, and then bland foods. Just when I thought I had the victory, I suddenly developed a severe fever. The initial fever had subsided four days after I had been admitted, and then, suddenly, it showed up again. I thought it was the Ebola. I enquired from Dr. David who said fever was sometimes the last thing to go, but he expressed surprise that it had stopped only to come back on again. I was perplexed.

I discussed it with my pastor who said it could be a separate pathology and possibly a symptom of malaria. He promised he would research if indeed this was Ebola or something else. That night as I stared at the dirty ceiling, I felt a strong impression that the new fever I had developed was not as a result of Ebola but malaria. I was relieved. The following morning, Dr. Ohiaeri sent me antimalarial medication which I took for three days. Before the end of the treatment, the fever had disappeared.

I began to think about my mother. She was under surveillance along with my other family members. I was worried. She had touched my sweat. I couldn't get the thought off my mind. I prayed for her. Hours later, on

Twitter, I came across a tweet by WHO saying that the sweat of an Ebola patient cannot transmit the virus at the early stage of the infection. The sweat could only transmit it at the late stage. That settled it for me. It calmed the storms that were raging within me concerning my parents. I knew right away it was divine guidance that caused me to see that tweet. I could cope with having Ebola, but I was not prepared to deal with a member of my family contracting it from me.

Soon, volunteer doctors started coming to help Dr. David take care of us. They had learned how to protect themselves. Among the volunteer doctors was Dr. Badmus, my consultant in LUTH during my housemanship days. It was good to see a familiar face among the care-givers. I soon understood the important role these brave volunteers were playing. As they increased in number, so did the number of shifts increase and, subsequently, the number of times the patients could access a doctor in one day. This allowed for more frequent patient monitoring and treatment. It also reduced care-giver fatigue. It was clear that Lagos State was working hard to contain the crisis.

Sadly, Justina succumbed to the disease on the 12th of August. It was a great blow, and my faith was greatly shaken as a result. I commenced daily Bible study with the other two female patients, and we would encourage one another to stay positive in our outlook, though in the natural, it was grim and very depressing. My communion sessions with the other women were very special moments for us all.

On my 10th day in the ward, the doctors, having noted that I had stopped vomiting and stooling and was no longer running a fever, decided it was time to take my blood sample to test if the virus had cleared from my system. They took the sample and told me that I shouldn't be worried if it comes out positive as the virus takes a while before it is cleared completely. I prayed that I didn't want any more samples collected from me. I wanted that to be the first and last sample to be tested for the absence of the virus in my system. I called my pastor. He encouraged me, and we prayed again about the test.

On the evening of the day Justina passed on, we were moved to the new isolation centre. We felt like we were leaving hell and going to heaven. We were conveyed to the new place in an ambulance. It was just behind

the old building. Time would not permit me to recount the drama involved with the dynamics of our relocation. It was like a script from a science fiction movie. The new building was cleaner and much better than the old building. Towels and nightwear were provided on each bed. The environment was serene.

The following night, Dr. Adadevoh was moved to our isolation ward from her private room where she had previously been receiving treatment. She had also tested positive for Ebola and was now in a coma. She was receiving I.V. fluids and oxygen support and was being monitored closely by the WHO doctors. We all hoped and prayed that she would come out of it. It was so difficult seeing her in that state. I could not bear it. She was my consultant, my boss, my teacher, and my mentor. She was the imperial lady of First Consultants, full of passion, energy, and competence. I imagined she would wake up soon and see that she was surrounded by her First Consultants family, but sadly it was not to be.

I continued listening to my healing messages. They gave me life. I literally played them hours on end. Two days later, on Saturday the 16th of August, the WHO doctors came with some papers. I was informed that the result of my blood test was negative for Ebola virus. If I could somersault, I would have, but my joints were still slightly painful. I was free to go home after being in isolation for exactly 14 days. I was so full of thanks and praise to God. I called my mother to get fresh clothes and slippers and come pick me up. My husband couldn't stop shouting when I called him. He was completely overwhelmed with joy. I was told, however, that I could not leave the ward with anything I brought in with me. I glanced one last time at my cd player, my valuable messages, my research assistant (a.k.a., my iPad), my phones, and other items. I remember saying to myself, "I have life; I can always replace these items."

I went for a chlorine bath, which was necessary to disinfect my skin from my head to my toes. It felt like I was being baptized into a new life as Dr. Carolina, a WHO doctor from Argentina poured the bucket of chlorinated water all over me. I wore a new set of clothes, following the strict instructions that no part of the clothes must touch the floor or the walls. Dr. Carolina looked on, making sure I did as instructed.

I was led out of the bathroom and straight to the lawn

to be united with my family, but first I had to cut the red ribbon that served as a barrier. It was a symbolic expression of my freedom. Everyone cheered and clapped. It was a little but very important ceremony for me. I was free from Ebola! I hugged my family as one who had been liberated after many years of incarceration. I was like someone who had fought death face-to-face and had come back to the land of the living.

We had to pass through several stations of disinfection before we reached the car. Bleach and chlorinated water were sprayed on everyone's legs at each station. As we made our way to the car, we walked past the old isolation building. I could hardly recognize it. I could not believe I slept in that building for 10 days. I was free! Free of Ebola. Free to live again. Free to interact with humanity again. Free from the sentence of death.

My parents and two brothers were under surveillance for 21 days, and they completed the surveillance successfully. None of them came down with a fever. The house had been disinfected by Lagos State Ministry of Health soon after I was taken to the isolation centre. I thank God for shielding them from the plague.

My recovery after discharge has been gradual but progressive. I thank God for the support of family and friends. I remember my colleagues who we lost in this battle. Dr. Adadevoh my boss, Nurse Justina Ejelonu, and the ward maid, Mrs. Ukoh were heroines who lost their lives in the cause to protect Nigeria. They will never be forgotten.

I commend the dedication of the WHO doctors, Dr. David from Virginia, USA, who tried several times to convince me to specialize in infectious diseases, Dr. Carolina from Argentina who spoke so calmly and encouragingly, and Mr. Mauricio from Italy who always offered me apples and gave us novels to read. I especially thank the volunteer Nigerian doctors, matrons, and

cleaners who risked their lives to take care of us. I must also commend the Lagos State government and the state and federal ministries of health for their swift efforts to contain the virus. To all those prayed for me, I cannot thank you enough. And to my First Consultants family, I say a heartfelt thank you for your dedication and for your support throughout this very difficult period.

I still believe in miracles. None of us in the isolation ward was given any experimental drugs or so-called immune boosters. I was full of faith yet pragmatic enough to consume as much ORS as I could, even when I wanted to give up and throw the bottles away. I researched on the disease extensively and read accounts of the survivors. I believed that even if the mortality rate was 99%, I would be part of the 1% who survived.

Early detection and reporting to hospital is key to patient survival. Please do not hide yourself if you have been in contact with an Ebola patient and have developed the symptoms. Regardless of any grim stories one may have heard about the treatment of patients in the isolation centre, it is still better to be in the isolation ward with specialist care than at home where you and others will be at risk.

I read that Dr. Kent Brantly, the American doctor who contracted Ebola in Liberia and was flown out to the United States for treatment was being criticized for attributing his healing to God when he was given the experimental drug Zmapp. I don't claim to have all the answers to the nagging questions of life. Why do some die and some survive? Why do bad things happen to good people? Where is God in the midst of pain and suffering? Where does science end and God begin? These are issues we may never fully comprehend on this side of eternity. All I know is that I walked through the valley of the shadow of death and came out unscathed.

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# The Fire is Coming: An HIV Prevention Intervention Contextualized to the Maasai People of Tanzania

Holly Freitas<sup>a</sup> and Marcia A Nayak<sup>b</sup>

- <sup>a</sup> RN, MPH Medical Ambassadors International and Reach Tanzania
- <sup>b</sup> PhD, RN Medical Ambassadors International

### **Abstract**

"The Fire is Coming" film is an innovative HIV-prevention intervention contextualized to the Maasai people of Tanzania through use of a traditional Maasai story. The intervention was developed and implemented in partnership with Maasai Pastoralists for Education and Development (MAPED). Although there have been numerous Knowledge-Attitude-Practice (KAP) surveys conducted among the Maasai, this is the first control-group comparison study designed to measure the effectiveness of an HIVprevention intervention contextualized specifically to the Maasai people of Tanzania. We will first discuss the background and context in which the intervention was developed and methods used to develop the intervention. We will then discuss the evaluation methods, results, and implications of a retrospective Knowledge, Attitudes, Practices (KAP) two-village comparison survey (n=200) for "The Fire is Coming" HIV-prevention intervention among Maasai people. There was a significant effect for HIV-related attitudes, t(16) = 2.77, p < 0.05, regarding willingness to care for an HIV infected person, willingness to be tested for HIV, selfefficacy toward HIV-prevention, married women's ability to use condoms, unmarried girls' ability to refuse high-risk sexual behaviors, married men's ability to use condoms, and married men's ability to limit sex to their spouses. There was a significant effect for HIV-related behavior changes, t(8) = 2.89, p < 0.05, with reported family decisions made, esoto (the ritualized sexual initiation of pre-pubescent girls) stopped, sexual behaviors changed, blade-sharing stopped, and other traditional custom changes reported. Although knowledge rates were often higher in the intervention area than in the comparison area, there was no significant difference in HIV-related knowledge, t(12)=1.85, p >0.05. **Implications:** Belief in one's ability to do something is often the pivotal point for behavior change. The results of the survey denote a highly effective intervention in changing HIV-related attitudes and behaviors. It is promising for replication among other Maasai communities and for adaptation with indigenous people groups in other regions.

### **Background and Context**

HIV infection rates are rapidly rising in Maasai regions (Coast 2007). Although actual HIV rates are difficult to obtain due to governmental restrictions on census and data collection differentiation by tribal identification, sexual traditions and social norms place the Maasai people of Tanzania at high risk for sexually transmitted diseases. Maasai norms and traditions include esoto (coerced sexual initiation of prepubescent girls), encouragement of multiple sexual partners among teenage males, polygamy, marriage of young girls to older men, wife sharing, the obligation for wives to show hospitality by engaging in sexual behaviors with traveling

male visitors, and male circumcision using a common blade (Coast 2001; 2002; 2007; Mbugua 2007). Among the Maasai, the exchange of reproductive fluids is considered essential to both mental and physical health; intentionally high levels of procreation limit the acceptability of condom use for either birth control or prevention of sexually transmitted disease (Coast 2007a; Mbugua 2007).

Significant barriers to health education messages have resulted in limited HIV-related knowledge, misconceptions regarding HIV, and continuance of high-risk, HIV-related behaviors. Language, limited education, and distance from health services make up some of the barriers that keep Tanzania's national efforts to reduce HIV transmission from reaching the

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Maasai people. Approximately 20% of Maasai people speak the national language or have any formal education (May, Ikayo, and Illkarash 2007, 275-98). All public health campaigns in Tanzania, including HIV education, are conducted in Swahili, leaving non-Swahili speakers uninformed (Coast 2002; 2007b). Furthermore, all national HIV surveillance efforts, including KAP studies, have been conducted in Swahili (Tanzania Commission 2008), leaving non-Swahili speakers uncounted, their voices unheard, and their plight unknown to both national and international organizations concerned with HIV and AIDS (United Nations 2013; Peter 2007). Most Maasai people in Tanzania live in rural areas distant from city hubs where HIV prevention, testing, and treatment services can be obtained. Poorly conditioned and infrequently traveled roads limit public transportation. Maasai people generally travel by foot or in the open-bed of delivery trucks on weekly transportation routes from the village areas to the city hub and back.

Additional barriers limit the effectiveness of standard ABC (abstinence, be faithful, and condom) messages (Mbugua 2007; Coast 2002; Kulzer 2002). Many Maasai people believe that they, as a people group, are immune to HIV or that their traditional medicines will cure the disease. The lack of accessibility and acceptability of condoms further complicates the effectiveness of the ABC message (Coast 2002; May 2003). Finally, many of the commonly used HIV education methods, which promote individual behavioral change are rendered ineffective within the traditional Maasai top-down and grouplevel decision making structure (Mbugua 2007; Coast 2002; Coast 2007).

In late 2006, a small Maasai organization, MAPED (Maasai Pastoralists for Education and Development), of the Olbili sub-village in Simanjioro District, Tanzania, became aware of the threat of HIV. Intent on protecting their people, they sought HIV education. In 2007, sixteen of their young Maasai warriors attended an intensive HIV training course which met both international and Tanzanian HIV education standards. The young warriors recognized the dangers of high-risk Maasai traditions and sexual practices and determined to make changes, not only to protect themselves and their families but also to educate other Maasai about HIV to preserve their tribe.

### **Intervention and Methods**

The young warriors, together with MAPED, determined that a public health education intervention was necessary to inform and educate the Maasai people. In response, an educational program was designed to meet three goals: 1) to bring contextualized HIV prevention education to the Maasai, 2) to increase the awareness of vulnerability to HIV infection due to traditional and common HIV-related behaviors, and 3) to facilitate dialog within Maasai communities that would ulti-

mately result in modification, adaptation, or discontinuation of high-risk, HIV-related behaviors.

A participatory process was used to identify the preferred learning medium for HIV prevention education among the Maasai. It was noted that the existing local public-health education was ineffective in Maasai areas for several reasons. First, written health information is inaccessible to a majority of Maasai who are oral learners. Second, health information given via radio is also inaccessible to a majority of Maasai, because all official public-health announcements in Tanzania are made in Swahili—not the Maasai language. Third, Maasai perceive national public-health announcements in Swahili as non-applicable to themselves because of cultural differences. Through discussions and the review of previous HIV-related KAP studies, the Maasai leaders and HIV education team determined that the preferred learning medium for HIV prevention education was audiovisual and chose to create an educational film using Maasai spokespersons, traditions, and storytelling. A private donor provided a sum of money to Medical Ambassadors International for HIV education in Africa. This donation, in turn, was directed toward the proposed intervention.

The next step in the process was to identify traditional Maasai stories that could effectively convey the HIV-prevention message. Maasai stories were collected from every available source. After review of many stories, a widely-known traditional Maasai story was selected which tells about a foolish man who knew that a great fire was coming across the land, posing great risk to his homestead, family, and animals. After many warnings, the man still did nothing to protect himself and was overwhelmed by the fire. The story elicits much laughter among the Maasai people, and they find re-telling of the man's obvious foolishness a source of great humor. The story provided a perfectly contextualized analogy to emphasize the importance of HIV awareness and preventive action among the Maasai.

"The Fire Is Coming" video production began in 2008. Maasai elders, political leaders, warriors, and other tribe members were briefed in the basic story-line and then participated to create the unscripted footage, telling the story in their own words, providing HIV prevention education, advocating for change of high-risk cultural practices, and warning of the dangers of ignoring the issue. Film editing was conducted in cooperation between Media 7, a volunteer HIV educator from Medical Ambassadors International, and MAPED. Field-testing was conducted in 2009, and the film was released for facilitated public viewing in the Maasai community in 2010.

The target level of the intervention was the sub-village level, where general decision-making is done and social and behavioral norms are established. A participatory, adult-learning approach was chosen in conducting the intervention. The approach relied on the intervention's problem-posing

nature and on discussions guided by trained volunteer Maasai facilitators from MAPED following public viewings of "The Fire Is Coming" video to achieve the intervention goals of changing HIV knowledge, attitudes, and behaviors in each village.

### **Evaluation**

In 2011, after one year of active implementation by MAPED in the local Maasai community, an evaluation was scheduled as part of the assessment and quality improvement for the on-going program. The aim of the evaluation was to determine the effectiveness of the intervention in bringing contextualized HIV prevention education and awareness to the Maasai people and to influence change in both attitudes and high-risk behaviors associated with HIV transmission. An additional aim of the evaluation was to determine whether the intervention influenced change in cultural and social norms in the intervention area. A baseline study had not been done prior to the beginning of the intervention; therefore, a two-village comparison survey was designed to obtain HIVrelated knowledge, attitudes, and behaviors among villagers whose community received the intervention and compare them to survey responses from villagers whose community did not receive the intervention. The evaluative nature of an on-going public health education intervention by a Tanzanian registered non-government organization did not require approval by Tanzania's Institutional Review Board.

A Knowledge, Attitudes, Practices (KAP) survey instrument was developed for the evaluation using the following operational definitions as defined by Tanzania Commission for AIDS (TACAIDS).

HIV-related knowledge: TACAIDS defines HIV-related knowledge as knowing that: using condoms and having just one uninfected, faithful partner can reduce the chance of getting HIV; a healthy looking person can have HIV; an infected mother can transmit HIV during childbirth and breastfeeding. Additional HIV-related knowledge included rejecting the two most common myths about HIV transmission: "People get HIV from mosquito bites" and "People can be infected with HIV by sharing food with someone sick with AIDS" (Tanzania Commission 2008; United Nations 2003).

HIV-related attitudes: We adapted questions from the Tanzania HIV/AIDS Indicator survey to measure three areas of attitude regarding HIV/AIDS. 1) accepting attitudes toward those living with HIV/AIDS, 2) attitudes toward negotiating safer-sexual relationships with husband/wife, and 3) attitudes of adults toward educating youth about condoms to prevent HIV.7 Within our definition we also include attitudes toward self-efficacy in reducing HIV risk, vulnerability, or risk in contracting HIV and willingness to be tested for HIV infection.

**HIV-related behaviors:** The concept of HIV risk behaviors includes all HIV-related behaviors that allow for HIV

transmission. These practices include esoto (the ritualized sexual initiation of unwed girls), multiple and concurrent sexual partners of the same or opposite sex, the sharing of blades or sharp instruments that penetrate the skin, and other traditional customs such as sexual hospitality practices (United Nations 2003).

The survey included both closed-ended, sociodemographic questions and open-ended questions modified from international and national KAP studies to capture data relevant to Maasai specific HIV-related knowledge, attitudes, and behaviors. Survey questions also assessed HIV-related knowledge (i.e. condom use) that was not directly addressed in "The Fire Is Coming" video intervention, allowing the evaluators to further ascertain the impact of the intervention. Presumably, there would be little if any difference between the intervention and comparison villages on these items. In order to protect informants, no questions regarding personal sexual activity or sexual practices were included in the survey. Survey questions were originally written in English, translated to KiMaasai, and back-translated to ensure understandability and conceptual translation accuracy. Pilot testing and revision of surveys was done prior to data collection to ensure inter-rater reliability and enhance consistency among data collectors. Survey data was collected using semistructured face-to-face individual interviews conducted in the Maasai language by a trained, bilingual Maasai data collector. Prior to any data collection, MAPED sought and received permission to conduct the survey from village elders and leaders and sub-village leaders. Data collectors received permission from both boma (home cluster) leaders and individuals prior to each interview. Each interview took approximately one hour and occurred over a ten-day period from May 2 to 12, 2011. Intervention and comparison village data were collected simultaneously by four Maasai speaking, trained research assistants, none of whom had visited the villages prior to data-collection.

### Sample

A cluster sampling process was used for the evaluation. Two Maasai villages were selected using purposive sampling to control for location, village size, proximity to the city, and available health services. A distance of approximately 200km between otherwise homogeneous villages controlled for potential intervention crossover effect. Within the villages, a convenience sample of 100 respondents each from subvillages within the intervention and comparison area, respectively (n=200), were surveyed. (Note: All figures represent the number of respondents who directly answered the respective survey questions.) Demographically, there were 54 female and 45 male respondents documented in the intervention area compared with 52 females and 46 males in the comparison area. The age range of study respondents was 13-

70 years-of-age, with an average age of 31 years in intervention area and 37 years in the control area. Adolescents were included in the study based on documented cultural norms of very early sexual debut, especially for girls (Coast 2007). In the intervention area, 73 respondents (11 comparison) reported attendance at an HIV prevention event in their community. Christian religion was claimed by 98 respondents in the intervention area and by 80 respondents in the comparison area.

### **Results**

**HIV-related Knowledge:** Sixty respondents from the intervention area (34 comparison) were able to correctly identify two routes of HIV transmission, with sexual intercourse and sharing of blades being listed most frequently. In the intervention area, 48 respondents (63 comparison) correctly stated that HIV infection cannot be identified by a person's appearance (Figure 1).

Two respondents in the intervention area (23 comparison) were *unable* to identify any HIV transmission routes. Knowledge regarding HIV prevention practices was as fol-

lows: abstinence and/or faithfulness to marital partners (77 intervention, 60 comparison), not sharing blades (52 intervention, 30 comparison), and condom use (19 intervention, 23 comparison). In the intervention area, 74 respondents (38 comparison) reported that women are tested for HIV during pregnancy; 34 respondents (21 comparison) said that HIV transmission from mother to infant can be prevented. Two respondents in the intervention area (4 comparison) listed medication as a possible HIV-prevention strategy for mother to child HIV transmission, and 82 respondents (56 comparison) stated that traditional Maasai medicine does not cure HIV. Knowledge that Maasai are not immune to HIV was high in both intervention (96) and comparison village areas (85). A two-tailed t-test was conducted to compare HIV-related knowledge between the intervention and comparison area respondents regarding condom use, faithfulness to partner, HIV-transmission routes, perceived Maasai immunity to HIV, cure by traditional Maasai medicines, and maternal-child transmission. Although on most survey items knowledge rates were higher in the intervention area, there was no significant HIV-related knowledge difference between intervention and comparison village areas, t(12)=1.85, p >0.05.

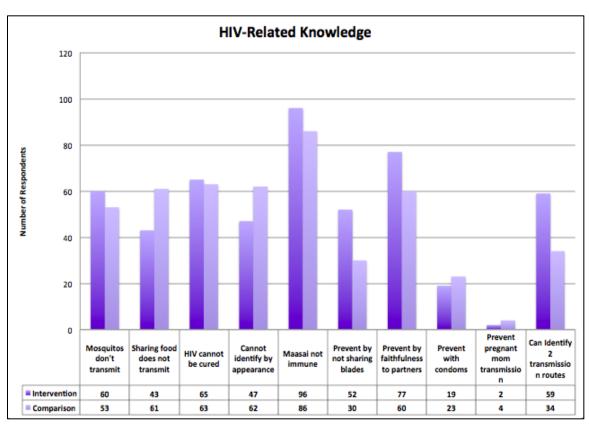


Fig. 1. HIV Related Knowledge (N=100)

**HIV-related Attitudes:** In the intervention area (figure 2), 81 respondents (71 comparison) stated they would care

for an HIV infected person. Willingness to be tested for HIV infection was indicated by 83 intervention area respondents

William Carey International Development Journal Vol 4, Issue 1: Winter 2015 (67 comparison); 84 intervention area respondents (25 comparison) stated that Maasai can do something to reduce the risk of HIV. Conversely, 54 respondents in the comparison area stated the belief that Maasai are unable to reduce the risk of HIV. Levels of concern about HIV in the community were "very concerned" (39 intervention; 81 comparison), "concerned" (52 intervention; 8 comparison), and "unconcerned" (8 comparison).

Few respondents agreed that women can refuse sex with their husbands (10 intervention, 10 comparison); however, 67 respondents in the intervention area (50 comparison) stated that women are able to refuse sex with others and can negotiate use of a condom with their husbands (33 intervention; 20 comparison) and with others (53 intervention; 34 comparison). In the intervention area, 69 respondents (48 comparison) reported that married men are able to limit their sexual activity exclusively to their wives.

In the intervention area, 70 respondents (38 comparison) stated that unwed girls can refuse to have sex or participate in esoto. In the intervention area, 37 respondents (39 comparison) stated that unwed girls can buy and use condoms. A two-tailed t-test analysis was conducted to compare the intervention and comparison area respondents' HIV-related

attitudes regarding willingness to care for an HIV infected person, willingness to be tested for HIV infection, self-efficacy toward HIV-prevention, married women's ability to use condoms, unmarried girls' ability to refuse high-risk sexual behaviors, married men's ability to use condoms, and married men's ability to limit sex to their spouses. There was a significant effect for HIV-related attitudes t(10) = 2.89, p < 0.05.

HIV-related Behaviors: Esoto, the ritualized sexual initiation of unwed girls, was reported stopped by 85 respondents (figure 3) in the intervention area (41 comparison). A family decision to decrease the risk of HIV was reported by 59 intervention area respondents (12 comparison). Participants reported they stopped sharing blades (30 intervention; 9 comparison), changed sexual behaviors (60 intervention; 26 comparison), and changed high-risk traditional customs (87 intervention; 47 comparison). A two-tailed t-test analysis was conducted to compare the intervention and comparison area respondents reported behaviors regarding family decisions made, esoto stopped, sexual behaviors changed, bladesharing stopped, and other traditional custom changes. *There was a significant effect for HIV-related behavior changes, t*(8) = 2.89, p< 0.05.

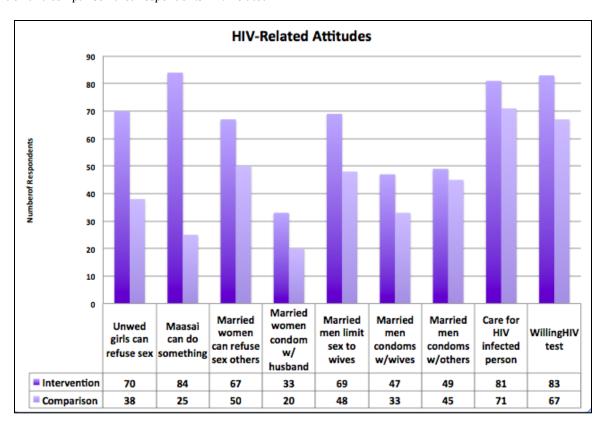


Fig.2. HIV-Related Attitudes (N=100)

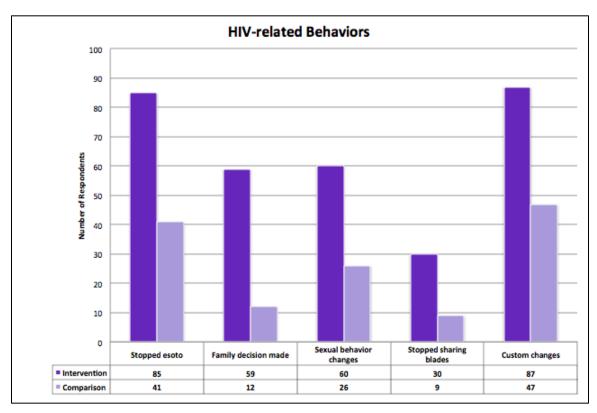


Fig. 3. HIV-Related Behaviors (N=100)

### **Discussion**

The most significant attitude difference between the intervention and comparison villages was that of collective selfefficacy, or the belief that they as Maasai people are able to reduce the risk of HIV in their community. Self-efficacy has been found by researchers to be one of the key factors involved in behavior change. Those who believe that nothing can be done are likely to do nothing, while those who believe they are able to do something are significantly more likely to take preventive action. Self-efficacy, or collective self-efficacy in this case, when combined with risk perception translates into behavior change in ways that knowledge alone does not (United Republic of Tanzania 2009). Maddux (2002) reported data consistent with our findings, that low self-efficacy has been associated with higher levels of anxiety. The high number of comparison area respondents who reported being "very concerned" about HIV is matched with a low number of comparison area respondents who believed that something could be done about HIV. In the comparison area, respondents may have had a perceived helplessness regarding HIV and, therefore, reported the highest levels of concern. Conversely, respondents in the intervention area demonstrated high levels of self-efficacy regarding their ability to reduce the risk of HIV and positive action taken by their community; thus, they reported being "concerned," but not "very concerned."

In our attempts to collect and analyze the data, we have applied national standards of comprehensive HIV knowledge, attitudes, and behaviors. However, we must consider the cultural context in which the intervention took place and the very nature of participatory community based research and development.

The hallmark of community-based participatory interventions is a process wherein awareness of an issue is raised in the community; the community then discusses the issue and arrives at culturally appropriate and, therefore, contextualized solutions to the problem. Among the Maasai communities in this study, a great number of families live in polygynous relationships; early and extramarital sexuality has been sanctioned by the society; and a high birth rate is desirable. Solutions that have come from within the Maasai community focus on the reduction and elimination of extramarital sexual partnerships, elimination of blade sharing practices, and mutual encouragement for HIV testing.

In response to the evaluation results, MAPED continues to work toward their goals of HIV prevention with a focus on increasing HIV-related knowledge and strengthening the positive outcomes in HIV-related attitudes and behaviors among Maasai communities. It is within the context of these community developed solutions that Maasai can be successful in changing both attitudes and behaviors that lead to the reduced risk of HIV in the community.

### **Study Limitations**

Although the results of the program evaluation are indicative of a highly effective intervention, we recognize there are limitations to this evaluation study. Selection of a preexperimental design does not allow us to unequivocally establish a causal relationship between the independent (HIV intervention) and the dependent (HIV-related knowledge, attitude, and practices) variables (Depoy 2005, 241-52.). After controlling for demographics, access to health facilities, distance (to limit cross-contamination), and other variables, we show that there are notable, statistically significant differences between the intervention and comparison Maasai groups.

One possible confounding variable may be present in the selection of communities that were either selected by the program implementers (comparison area) or self-selected (intervention area was in the community where the request originated for an HIV prevention intervention). Either of these two methods of selection may indicate greater interest or awareness of HIV among the intervention communities and, thus, potentially a greater willingness to change HIV-related behaviors prior to the intervention.

Lastly, the highly sensitive nature of the study questions may have inhibited some of the respondents from answering survey questions, thereby limiting or skewing the data and analysis. Although some evidence of behavioral changes can be observed, many reported HIV-related sexual and traditional behavior changes are impossible to validate and, therefore, may not be a true representation of actual behaviors.

Our findings are limited to the study area, and are not directly generalizable to other Maasai or indigenous groups, however the results of the survey denote a highly effective contextualized intervention. It is promising for replication among other Maasai communities and for adaptation with indigenous people groups in other regions.

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### A Study of Volunteer Community Health Workers Promoting Maternal Health Services in Rural Kenya: A Christian Viewpoint

Bradly Alexander Kimbrough<sup>a</sup> and Lisa Baker<sup>b</sup>

- <sup>a</sup> University Scholars Major / Undergraduate Student, Baylor University
- <sup>b</sup> MD, PhD, Clinical Professor in the Honors Program at Baylor University

#### Abstract

**Introduction:** Despite the call for community-based health care interventions in the developing world, there is little research examining the effectiveness of paid versus volunteer community health worker (CHW) programs to increase women's use of maternal health services. From a Christian perspective, the CHW model is, at its root, discipleship: a credible person leads a neighbor to a source of help and health. This effective model can be expanded to address the health of the whole person, both spiritual and physical. This study of a government health center program in rural Kenya addresses these issues.

**Methods:** The current study analyzed the change in maternal health services after a government program, starting with 30 volunteer CHWs, had been in place for nine months. The intervention was designed and carried out by the authors in collaboration with Sigoti District Health Center in the western Kenyan province of Nyanza.

**Results:** The proportion of facility-based deliveries (FBDs) showed a statistically significant increase (p=0.003), from an average of 38 deliveries before the intervention to 60 afterwards. The proportion of health center deliveries of HIV-positive women also significantly increased (p=0.04) from an average of 6.5 to 14 FBDs. Compared to another program in rural Lesotho with paid CHWs, the Sigoti intervention led to a similar increase in FBDs. Despite their successes, the community-based strategies were time-intensive for both programs, with one CHW adding between 1.12 and 1.7 FBDs per year.

**Discussion:** This study demonstrates that a CHW program can be successful, even when using volunteers. Using solely a metric of time and/or money, the CHW model produces value at a high cost. However, the concerns of cost-effectiveness and CHW attrition, as well as the success of the CHW model, can be meaningfully addressed from a Christian perspective. Using the outcome measure of changed lives, volunteer CHWs could be motivated by a Christian call to discipleship. CHWs may be trained and supported to contribute to the health of the whole person. Future research will test these assumptions with a CHW program operating from a Christian health center to be built soon in the study area.

### Introduction

The challenge of disease and death in the developing world has provoked a variety of responses from the international community, including grants of billions of dollars from development agencies, the investment of thousands of overseas micro-loans, and government interventions to build health care infrastructure. All of these approaches have brought some success, and widespread systemic change is essential to address the complex issues of health

today that are inextricably linked with poverty and social injustice.

On the other hand, a response that is deeply personal and local is the popular strategy of using community health workers (CHWs) in their own neighborhoods to encourage individuals to access health care and to teach the means of health promotion. Since the Alma-Ata Declaration in 1978, CHW programs have become a key element in maternal and child health. The CHW model later became an essential strategy in working toward the fifth Millennium Develop-



ment Goal (MDG) of having 80% of births take place with skilled personnel (Bhutta, et al 2008). In another aspect of maternal and child health, CHWs have been utilized to reduce mother-to-child transmission of HIV (Boateng, et al 2013; Kim, et al 2013), which can potentially be decreased to less than 2% with the appropriate use of anti-retroviral therapy (ART) (McIntyre 2005, 981-80).

This approach of affecting one person at a time in the context of a personal relationship is precisely what Jesus modeled throughout his ministry. It is not surprising that CHWs have been well received and are believed to be successful. However, there remains a dearth of evidence to support the claims of success and cost-effectiveness of CHW programs (Walker and Jan 2005, 221-29; Prinja, et al 2013; Prinja, et al 2014; Lewin, et al 2010). Outcome studies that do exist generally focus on CHW programs aimed at health promotion (Wang'ombe 1984, 375-85), tuberculosis care (Floyd, et al 2003; Islam, et al 2002, 445-50; Nganda, et al 2003, S14-20; Okello, et al 2003, S72-79; Sinanovic, et al 2003, S56-62; Wilkinson, et al 1997, 451-55) and immunization services (San Sebastián, et al 2001, 21-24). Consequently, in 2013 the World Health Organization (WHO) called for a comprehensive research effort on the efficacy of CHW programs (Invitation 2013).

The effectiveness of CHWs in reaching pregnant women is still largely unknown. Two major studies have addressed this gap by evaluating CHW programs in Sub-Saharan Africa (Medhanyie, et al 2012; Satti, et al 2012). In an attempt to achieve the MDGs, the country of Ethiopia initiated the Health Extension Program in 2003. With approximately one salaried worker for 2500 residents, there was a documented increase in antenatal care (ANC) and family planning after the program was instituted, but the proportion of women delivering at a health facility did not change. 18 In a more comprehensive effort that employed a much higher concentration of CHWs than in the Ethiopian study, a program was instituted in a highland region of Lesotho where 46 deliveries per year (out of a population of 25,000 in the catchment area) were occurring at a local facility. Traditional birth attendants (TBAs) were retrained as CHWs by the non-profit organization Partners in Health (Satti, et al 2012). The catchment area was served by one hundred CHWs (a ratio of 1 to 250, i.e., ten times more workers per population compared to the Ethiopian intervention) who were paid an incentive-based salary equivalent to approximately \$36 USD per month (extrapolated from original article using the exchange rate at the time of the study) (Satti, et al 2012). Notably, the CHWs were part of a multi-faceted approach to increase utilization that also included the establishment of a maternal "waiting house" where pregnant women could go and receive three meals a day for up to two weeks prior to their due date. The combination of these changes showed an increase from 46 to 178 facility-based deliveries in the first year and 216 in the second year of the program. During the two-year intervention, 55% of the

women who delivered at the facility took advantage of the opportunity to stay in the maternal waiting house. It is unknown how much of the improvement was due to the CHWs versus the benefits of the maternal waiting house.

Broader approaches of examining the cost-effectiveness of CHWs that include relational changes and changes in behavior have generally not been well recognized (Walker 2005, 221-29), though in recent years there has been an increase in this literature (Jan 1998, 1565-72; Jan, et al 2004, 13-21; Jan, et al 2008, 922-32). One such study was of a community-based midwifery program that evaluated whether perinatal outcomes and ANC attendance improved in addition to other factors, such as empowerment and family-centered care (Jan, et al 2004, 13-21). Though the quantitative improvements were negligible in the midwifery study, the qualitative results were quite positive.

The current study took place among a community of Luo people living on the Nyakach Plateau in the Nyanza Province of western Kenya, a destitute area of rocky dirt roads, inadequate subsistence farming, no dependable clean water source, no sanitation services, and little health care. Kenya ranks fourth in the world in the number of people living with HIV/AIDS (World Factbook 2012), and women of the Luo tribe of western Kenya have the highest HIV rate (22.8%) and the highest infant mortality (9.5%) in the country (Kenya 2010). Kenya's maternal mortality has been volatile over the last twenty-five years. In 1990, the maternal mortality rate was 380 per 100,000 births, but in 2005, it increased to 580/100,000 (Chou, et al 2010). As of 2013, the rate decreased again to 360/100,000 (Maternal 2014), a figure that is still alarming and does not meet the fifth Millennium Development Goal (MDG) of reducing maternal mortality by 75%. One issue driving the high maternal mortality is that only one-third of women living in rural Kenya give birth with skilled personnel (Kenya 2010). Some locations in Kenya have a rate as low as 5.4% (Cotter, et al 2005, 467-71), in spite of the fact that skilled birth attendance has been deemed as the most important factor in preventing maternal deaths (Reduction 1999).

On the Nyakach Plateau, the local government district health center (Sigoti Health Center) is staffed by a clinical health officer and two nurses who have had great interest in increasing maternal services. One village in the catchment area is East Koguta (referred to as a "sub-location" in Kenya) with a population of 7360 and an estimated 260 births a year, 59 of them to mothers with HIV.24 Approximately 19% of those births and 15% of the HIV deliveries were occurring at the Sigoti Health Center up to mid-2011. This health center has no resources to pay CHWs. However, the clinic personnel appreciate the value of the CHW model and decided to experiment by training volunteers who wanted to contribute in a meaningful way and invest deeply in their own community. Data suggest that sustainable success depends on salaries and other monetary incentives (Community health workers 2007), yet these leaders believed that

their consistent, supportive relationships with the workers, combined with simple incentives of food and help with travel, would be enough to make a difference. They hoped that financial resources might emerge at some point, but they decided to see if the workers would participate based on the value of the expertise they gained and the satisfaction of doing an important task. Thirty people from East Koguta volunteered to work with their own neighbors to identify needs and serve pregnant women. More than two-thirds of these workers stayed with the program for its first nine months.

### **Methods**

### East Koguta Community Health Worker (EKCHW) Program

Over a two-week period in August of 2011, a public health officer and the head nurse from the Sigoti Health Center trained thirty volunteer CHWs (twenty-nine women and one man) according to the International Center for AIDS Care and Treatment Programs (ICAP) at Columbia University's Mailman School of Public Health. The requirements for becoming part of the EKCHW Program were to have at least a fourth-grade education and to be a respected community member. The CHWs were predominantly Christian and served in a part of Kenya that has been traditionally Christian for many years. However, this government program did not deliberately attempt to recruit Christians or to frame their activities in a Christian context.

The East Koguta CHWs were trained to provide health education for pregnant women, encourage them to go to ANC visits, and urge them to deliver their babies at the health center instead of at home or with a TBA. HIV-positive mothers and other high-risk pregnant women were especially targeted and encouraged to deliver at the health center. The Sigoti Health Center goal was to increase the number of facility-based deliveries from 19% (the rate prior to the program) to 30% of all births occurring within the area.

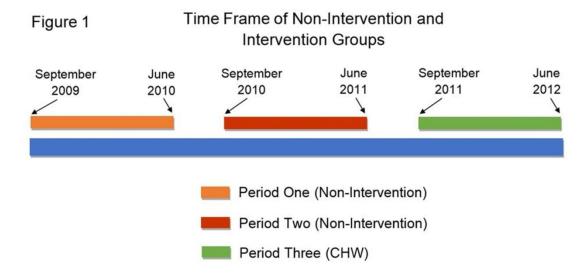
Maternal health services were a primary focus of the CHW program, but the workers were also trained to conduct a variety of other tasks: tracking former patients for check-ups, bringing HIV-positive patients to the health center who had neglected to receive treatment, health education, and identifying and referring community members with suspected illnesses such as malaria, tuberculosis, and HIV-associated illnesses.

During nine months of implementation, eight women discontinued volunteering. According to the head of the EKCHW Program, the main reason for volunteers dropping out was unrealized hopes of future wages, while the main reason for deciding to continue was the CHWs' "heart" for the community. The CHWs met weekly with the public health officer and head nurse. The CHWs were expected to work an average of two to three hours a day beginning in September of 2011. The only compensation for the workers was an occasional free meal or refreshment, use of a communal bicycle, and informal community recognition.

### Analysis of health records

The current study analyzed health center records from the Sigoti District Health Center located in the Nyanza Province of Kenya. The data included information about all women from East Koguta who delivered at the health center from September 2009 through May 2012. The original information was collected and entered by hand into the record by the nurses or the clinical officer at each ANC visit and at the time of delivery. Relevant data were later copied from the medical record by a trained research assistant and were then coded and transferred into an Excel spreadsheet for analysis.

Data from a nine-month period (the first of September to the first of June) for the two years prior to the intervention were compared to the same nine-month period during the intervention year (see Figure 1).



These three time periods are referred to as Period 1, Period 2, and Period 3 (CHW), respectively. The most recent available regional data were used (DHS 2008-2009 for crude birth rate and 2009 Kenya census data for population statistics)<sup>24</sup> to compare the Sigoti Health Center numbers with the number of women who gave birth in the entire area (sub-location of East Koguta) during the timeframe of the study. Given the crude birth rate and the number of people living in East Koguta, the number for a nine-month period was extrapolated to yield 195 deliveries. The number of deliveries was estimated using the following equation: Number of Deliveries = [CBR\*(Pop/1000)]\*0.75. The CBR is the crude birth rate for the area (Kenya DHS 2008-2009), Pop is the population of East Koguta, and the total was multiplied by 0.75 to yield the estimated number of deliveries in nine months.

The number of births from HIV-positive women during a nine-month period was estimated by multiplying 195, the estimated number of deliveries, by the HIV-prevalence among Luo women, 0.228, giving an estimate of 44 HIV-positive women delivering in East Koguta over a ninemonth period (Kenya 2010).

Data from Periods 1 and 2 were combined and compared with Period 3 (CHW) to determine if the intervention significantly increased the number of facility-based deliveries, the number of HIV-positive women who delivered at the facility, and the number of women who received the 4+ ANC visits recommended by the World Health Organization. The mean, standard deviation, and range for continuous variables are reported, and the frequencies, proportions and percentages are reported for categorical variables. The Chisquare and t statistics were used to test differences from before and after the intervention for discrete and continuous variables, respectively. Alpha was set at .05. Statistical analyses were done using the statistical software SAS 9.2 by SAS Institute Inc. (Cary, North Carolina).

Results from the current study were then compared to data from the more comprehensive, salaried CHW program in Lesotho<sup>19</sup> to determine if this volunteer program was as effective in achieving positive results.

### **Ethical considerations**

This study was approved by the Baylor University Institutional Review Board and was exempt from the requirement for informed consent, as it was a study of anonymous subjects with information drawn from previously collected clinical data. During the research process, no patient names were associated with any of the data. The names of individual patients were not recorded in the research database.

### Results

### Sample characteristics

The mean age and parity of women delivering at the health center during Period 3 (CHW) were not significantly different than women in Periods 1 and 2 (see Table 1). During each time period, about a quarter of all deliveries were by first-time mothers. Every woman attended at least one ANC visit.

Table 1. Sample Characteristics Before and After East Koguta CHW Program

Variable	Mean (SD)	t	p	
AGE Periods One		0.17	0.87	
and Two Period	22.66 ± 5.07			
Three (CHW)	22.81 ± 5.78			
PARITY Periods One		0.94	0.35	
and Two	1.70 ± 1.72			
Period	$1.98 \pm 1.74$			

### Results of the intervention

The data for the three outcomes of interest are presented in Table 2.

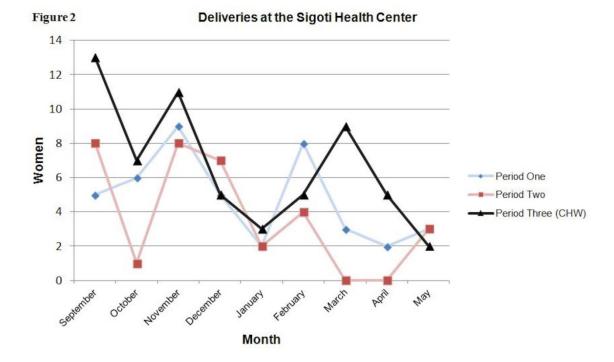
Table 2. Comparison of Three Outcomes Before and After the East Koguta CHW Program

Variable	Proportion	Percentage	Chi-square	р
DELIVERIES			8.65	0.003
Periods One and Two (Combined)	76 / 389.7	19.5		
Periods One and Two (Average)	38 / 194.9	19.5		
Period Three (CHW)	60 / 194.9	30.8		
HIV-POSITIVE			4.23	0.04
Periods One and Two (Combined)	13 / 88.9	14.6		
Periods One and Two (Average)	6.5 / 44.4	14.6		
Period Three (CHW)	14 / 44.4	31.5		
4+ ANC VISITS			3.47	0.06
Periods One and Two (Combined)	19 / 389.7	4.9		
Periods One and Two (Average)	9.5 / 194.9	4.9		
Period Three (CHW)	18 / 194.9	9.2		

There was at least a 50% increase in all three outcomes: number of facility-based deliveries (58% increase), number of HIV-positive deliveries (115% increase), and number of women with 4+ ANC visits (89%). The Sigoti Health Center did, in fact, reach its goal of having 30% of the actual number of catchment area deliveries occurring at the clinic after the intervention began. When comparing the combined number of facility-based deliveries in Periods 1 and 2 (76 out of 390 expected deliveries) to the number in Period 3 (CHW) (60 out of 195 expected deliveries), the change after the intervention was statistically significant (p=0.003). The increase in the proportion of HIV-positive women delivering was also statistically significant (p=0.04). More HIVpositive women delivered during the intervention than in Periods 1 and 2 combined. The number of women receiving 4+ ANC visits during the intervention also increased from

an average of 9.5 women (Periods 1 and 2) to 18 during the intervention. However, even with this substantial increase, the small sample size did not provide enough power to achieve statistical significance, though it was close (p=0.06).

Despite these encouraging results, it is sobering to note that over two-thirds of HIV-positive women in the area did *not* deliver in the health center, and less than 10% of women were receiving the recommended number of ANC visits, even during the intervention. Part of the explanation lies in the difficult geographical environment in which these women live. Health care services are delivered sporadically due to periods of flooding and drought that make travel difficult for patients and for those delivering supplies to the clinic. A pattern of monthly variation exists each year in the number of deliveries, as shown by Figure 2.



Peaks in the number of deliveries occurred in the months September, November, and February while troughs occurred in the months October, January, and May. Dirt roads are rough or nonexistent, almost no one has transportation other than walking, and most women have many children to care for. A trip to the health center for an HIV-positive, pregnant woman with toddlers can be challenging in the best weather. In periods of flooding, during active labor, and perhaps at night in an area with no lights, this journey may be impossible.

# Comparison of East Koguta and Lesotho CHW Programs

A comparison of this study's data with the success of the Lesotho CHW program<sup>19</sup> is shown in Table 3 below. The Lesotho program had a baseline of far fewer facility-based

deliveries (6.8% vs. 19% in East Koguta). With their interventions, however, both programs achieved the same results, i.e., approximately 30% of deliveries occurring at the health facility. East Koguta went from 19.5% to 30.8%. Lesotho increased from 6.8% to 26.3% in year 1 and to 31.9% in year 2, an average of 29.1% facility-based deliveries). The two programs had a comparable ratio of CHWs to the population (one for every 250-283 residents).

It is unknown how much of the improvement in Lesotho was due to the addition of CHWs and how much was a result of the establishment of the maternal waiting house. In the East Koguta region, where people rarely eat more than one meal a day and women must walk an average of 3.8 kilometers to the health center, such an opportunity would be not only an incentive, but sometimes would be lifesaving.

Table 3. Comparison of East Koguta and Lesotho CHW Programs

	Population	CHW Salary	Number of CHWs	CHWs per Population	Additional FBD per CHW per Year	
East Koguta	7360	None	26*	1 / 283	1.12	
Lesotho (yr 1)	25000	About US \$36 per month About US \$36 per	100	1 / 250	1.32	
Lesotho (yr 2)	25000	month	100	1 / 250	1.70	
Non-						
Intervention	Number of FBD		Percentage of FBD per Total Deliveries			
East Koguta	51		19.5%			
Lesotho	46		6.8% ***			
Intervention						
East Koguta	80 **		30.8%			
Lesotho (yr 1)	178		26.3%			
Lesotho (yr 2)	216		31.9%			

Notes. \*The number of EKCHWs (26) is an average based on the 30 original CHWs and the 22 who were still active after nine months. \*\* The table shows the number of facility-based deliveries (FBD) during the EKCHW program extrapolated to one year and the actual numbers for each year from the Lesotho CHW program. \*\*\* To calculate the percentage of deliveries occurring at the Lesotho health facility, the total number of deliveries was estimated to be 677.5 by using the catchment area of the health center and the crude birth rate for rural Lesotho (Ministry 2020).

In East Koguta, one CHW produced an average of 1.12 additional facility-based deliveries per year (extrapolated from nine months). In the Lesotho study, the yield was slightly higher — one CHW (plus the maternal waiting house) produced an average of 1.32 additional deliveries during the first year and 1.70 additional deliveries the second year. This better result was achieved with a slightly more favorable ratio of CHWs to population residents (1:250 in Lesotho vs. 1:283 in East Koguta). With an approximate cost of \$432 (US) per year for a Lesotho CHW, the cost of bringing in one additional woman to deliver in the health center is between \$327 (year 1) and \$254 (year 2). In terms of cost-effectiveness, this strategy is relatively expensive and extremely time-intensive. In contrast, if the CHWs are volunteers and if the health center can absorb the lost workdays of the trainers, then the intervention easily becomes financially cost-effective, though still quite costly in terms of the time invested by the workers.

The Lesotho program, with paid CHWs, did not show vastly different results from the East Koguta volunteer program. However, the Lesotho program also included the excellent resource of the maternal waiting house used by over half of the women in addition to the CHW intervention. The cost of the waiting house is not reported, but it is likely to have substantially increased the cost of the program per woman delivering at the health center.

### **Discussion**

### Success, sustainability, and cost-effectiveness: A Christian viewpoint

This study provides evidence that volunteer CHWs can be effective in increasing the number of facility-based deliveries, especially for HIV-positive women, and the results are encouraging for increasing the number of women with the

recommended 4+ ANC visits. It is striking that this impact was achieved by volunteers in a highly challenging physical environment within only nine months. In fact, the onset of the program's impact was rapid. Within the first few months, there was already a noticeable difference in the number of facility-based deliveries compared to the same months from previous years. It is also promising that this program was just as effective, at least in the short run, as a CHW intervention in a comparable rural African setting that had financial incentives for CHWs and a "waiting house" for pregnant women.

Viewed another way, what is notable about the results from the current study is that so many East Koguta CHWs did continue to volunteer with no financial incentive. The Sigoti Health Center staff believes that success has been due to: close contact between the CHWs and the health center personnel, non-monetary rewards that are meaningful, and early feedback to the CHWs about the apparent success of the program (personal communication, March 2013). Also, the East Koguta intervention was generated and implemented by residents of East Koguta, instead of being imposed by the government or by an outside organization. Another contributing factor was believed to be the important support from the local TBAs, and an increased role for them is possible in the future.

A Christian is not surprised at the success of a CHW model, because the method is the same as that used by Jesus in his work of discipleship. Neither is a Christian discouraged by threats to sustainable motivation for volunteers or by work that is extremely time-intensive in producing results. The approach of Jesus was not to create institutions, but to empower his followers to share the good news with one person at a time. He sent them out with instructions to travel light, meet the needs of the whole person, and spend time with those who have ears to hear and eyes to see. "When you enter a town and are welcomed, eat what is set before you. Heal the sick who are there and tell them, 'The kingdom of God is near you" (Luke 10:8-9, NIV). An effective CHW is one who shares her experience with someone she knows and brings that person along with her to the next level of understanding. An effective follower of Christ does the same.

The positive results from the current study and the Lesotho study are tempered by the questions they raise about sustainability and cost-effectiveness. Having volunteer CHWs may answer the troubling challenge of paying salaries, but it is unknown how much worker attrition over a longer time period would affect success. The positive outcomes achieved in the first nine months of the East Koguta CHW program were accompanied by an average attrition rate of about one CHW per month. It is possible that relying on volunteers is only productive for a short time, regardless of how meaningful the work is. Further research can evaluate this issue. No attrition among the paid CHWs in the Lesotho program is reported, so it is impossible to compare

this aspect of the two programs. The omission in the description of the Lesotho program may indicate no attrition, but it is more likely that the number of CHWs was maintained by replacing any CHWs who left with new paid workers.

To the degree that a volunteer CHW program is framed as meaningful Christian service, it can be maximally sustainable. As this government program did not attempt to frame the work in a Christian context, the attrition of CHWs suggests that altruism alone is not enough to sustain some volunteers. However, it is our belief that volunteers can be uniquely and successfully motivated by a Christian call to the healing of the whole person accompanied by formation and support for that task.

The other concern raised by this analysis is that a program that takes one worker eight to twelve months to yield one facility-based delivery is not likely to be judged as costeffective by most organizations. Still, when unemployment is high and CHW activities can be meaningful, the volunteer CHW strategy remains viable. This is the case when a costbenefit analysis is restricted to an outcome of increased facility-based deliveries. A more convincing case may be made if broader outcomes are considered. It has been said that "examples of wider benefits may result from CHWs that are unlikely to be captured in cost-effectiveness analysis are employment and training opportunities, the value attached by clients to the process of receiving such services, and institutional change," where institutions are described as: "the patterns of behavior that determine how individuals, groups and organizations interact with one another" (Walker and Jan 2005, 221-29).

If the desired outcomes are expanded even further and the health that is sought is spiritual as well as physical, the volunteer CHW model may be the most effective investment of time that can be made to achieve those goals. For a Christian, the "cost" of discipleship is life itself, and the "benefit" is the kingdom of God. This perspective brings a new meaning to concepts of success, volunteerism, and cost-effectiveness. The CHW strategy can be supported—not in spite of, but because of its time-intensive nature—when the task is expanded to address the health of the whole person.

There is a spiritual and material component to every structure, even when it is not created with a spiritual focus in mind. From a Christian perspective, the physical health of the community cannot be the centerpiece of an intervention to the exclusion of the spiritual, nor can the spiritual be the center to the exclusion of the physical. Jesus said about his own purpose, "The Spirit of the Lord is on me, because he has anointed me to preach good news to the poor. He has sent me to proclaim freedom for the prisoners and recovery of sight for the blind, to release the oppressed, to proclaim the year of the Lord's favor" (Luke 4:18-19, NIV).

Community Health Evangelism (CHE), a model for community development and discipleship, is commonly used by Christian development organizations and churches

(Community Health Evangelism n.d.). CHE trainers, generally under the supervision of a local church or mission agency, introduce CHE to their communities and train volunteers to teach lessons on preventive health and Christian discipleship. The East Koguta CHW Program differs from the CHE model primarily in two ways: it was established and supervised by a non-church entity, the local health center, and was created in response to very specific health problems, namely a high HIV prevalence and maternal/infant mortality. The models are similar in that both are formed and operated by community members in order to provide the community with ownership of the program.

Future efforts in the Luo community that is the setting of this study include building a new health center by a Christian non-profit organization (Straw to Bread) that has been working in collaboration with local residents in the area since 2001. This initiative, informed by data from the current study seen through a Christian lens, can move toward building a CHW program that is intentionally Christian in orientation. The volunteer CHW model is a great fit for those who are working to lead people toward spiritual as well as physical wholeness. A CHW who is also a follower of Christ could bring all of who she is to the role.

Following the example of Christ in teaching his followers, a CHW program built on Christian principles would enhance sustainability and the potential for success by placing heavy emphasis on training and encouraging the CHWs. The commitment of the trainers to the CHWs becomes the model for the commitment of the CHWs to the people with whom they work. Trainers for such a program would:

- Take seriously the formation process invest deeply and develop relationships with and among the CHWs.
- 2) Develop a common vision of the health of the whole person.
- 3) Equip CHWs to bring hope, knowledge, and transformation to the whole person.
- 4) Serve, encourage, and learn from the CHWs by listening, adapting, and continually revising plans based on input from those doing the work.
- 5) Trust the CHW to deliver good news out of the strength of her uniqueness.

### Summary

Based on the current study in rural western Kenya, a volunteer CHW program can be an effective means to increase the use of maternal health services. However, the inherent difficulties of sustaining a volunteer model and the cost-effectiveness of the labor-intensive CHW role make its usefulness questionable in the current context. Though the East Koguta CHW program does not have a Christian framework for recruitment, training, or management, we believe that a CHW program in a Christian context could provide the motivation and meaning required for sustaina-

bility and could provide transformational results to communities through relationships formed with a higher purpose. A CHW program within a Christian framework could be successfully carried out by volunteers who see their mission as the supreme joy of sharing good news at every level with all of their heart, soul, mind, and strength. With the mindset of Christian discipleship, CHWs can emulate the two-fold call of Christ to meet both physical and spiritual needs.

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Community Health Global Network: "Clustering" Together to Increase the Impact of Community Led Health and Development

Marianne Safe<sup>a</sup>, Nathan Grills<sup>b</sup>, Elizabeth Wainwright<sup>c</sup>, Ted Lankester<sup>d</sup>

<sup>a</sup> MBBS, Nossal Institute of Global Health, University of Melbourne, Victoria, Australia

<sup>b</sup> MBBS, MPH, DPhil, Nossal Institute of Global Health, University of Melbourne, Victoria, Australia

<sup>c</sup> MSc, NCTA, Managing Director, Community Health Global Network, London, UK

<sup>d</sup> MA, MB, BChir, MRCGP, FFTM, RCPSGlasg, Community Health Global Network, London, UK

**Abstract** 

**Background:** Community Health Global Network (CHGN) is a collaborative network, founded to strengthen collaboration between community-based health programs - many of which are faith based initiatives. It seeks to address this in two ways: through its global network of players in community health and in the formation of "Clusters." CHGN Clusters are networks of community health programmes and individuals in specific geographical locations. This case report outlines the formation of the Kenya Cluster.

**Aims:** To describe the steps in the formation of the Kenya Cluster and to outline the primary outcomes and potential impact of the network. To discuss how learning from the Kenya Cluster may assist other established Clusters and the initiation of new Clusters.

**Method:** Information for this case report was gained from meetings and consultations with various individuals including leaders and members of the Kenya Cluster, other national community health experts, CHGN International staff and advisors to CHGN Uttarakhand Cluster in India. In addition, information was gained from personal observation during in-country field work.

**Results:** The Kenya Cluster is emerging as a platform for community health programs to connect and network. These connections have led to transfer of information through stories, best practice, training, contacts and opportunities amongst Cluster members. The Cluster has also established links with government and multilaterals enabling greater access to support at the community level.

**Conclusions:** There is early indication that the formation of the Kenya Cluster is supportive of the Cluster model as a unique way of strengthening collaboration between community health programs. Clusters have the potential to

improve the link between faith-inspired initiatives and secular and multilateral development organisations. Lessons from the Kenya Cluster can progress the development of other Clusters. Further evaluation will be conducted to assess the impact of the Kenya Cluster and the overall impact of the Cluster approach.

Introduction

One of the key barriers to universal health coverage is multiple actors poorly coordinated (Tulenko, et al 2013). To counteract this weakness in global health, there is growing evidence that networking and intentional collaboration between community health programs can improve service delivery and promote greater impact (Grills and Porter 2013; Grills, et al 2013, 206).

A number of terms are used in the literature to describe the ways community health programs can work together. Agranoff and McGuire define networks as "the process of facilitating and operating in multi-organisational arrangements to solve problems that cannot be solved, or easily solved, by a single organisation" (Agranoff 2003). The terms *consortia* and *collaborative* are typically used to describe similar organizations that benefit more from collective actions than as individual players. The term *coalition* tends to refer to groups of different organizations whose interests converge or overlap but who have separate agendas and interests. Collaboration usually implies a closer working together and is often more intentional (Kegler 2010; Kendall 2012).

Community Health Global Network (CHGN) was founded in 2005 in response to a perceived lack of collaboration between community-based health programs and initiatives. CHGN works in two ways: 1) Through a **global network** of over 700 community health workers (CHWs), programme managers, policy makers, faith-leaders, academics, students and others - using this platform to circulate information, training, stories and expertise through regular bulletins, a website and

social media and 2) through local community-centred movements or "Clusters" of people and programmes involved in the diverse social determinants of community health.

Clusters have been established in India, Bangladesh, Zambia and Kenya and are emerging in other countries including Myanmar (Burma). This article describes the formation of the Kenya Cluster including its outcomes and potential impact, and how experience gained can progress the development of other Clusters.

### The Cluster Model

According to observations by community health expert and CHGN's co-founder, Dr Ted Lankester,

In any given area there were many small, struggling health programmes, mostly funded by outsiders, each doing their own thing . . . they are often not linked with other charities or local government services and usually unaware that 10 miles down the track another group are doing almost exactly the same thing for the population they are serving. In areas of great need there is overlap, competition, and ineffective coordination of NGOs and other healthcare organisations (personal communication, Feb 2013).

Through its global network and local movement through Clusters, CHGN aims to *connect* health initiatives, ensure they are appropriately *informed* and increase their *influence* and impact on a local, national and international scale. CHGN Clus-

ters are groups of community health programmes and individuals in specific geographical locations. Representatives of programmes, as well as community health workers, faith leaders, community leaders and others, seek to collaborate on mutually agreed activities with the vision of improving health and wellbeing in the areas where they live and work.

Figure 1: CJGH focuses on three key themes as a guide for Cluster formation, growth and impact.

Figure 1: CHGN focuses on three key themes which also serves as a guide for Cluster formation, growth and impact: INFORM INFLUENCE CONNECT Stories **Trust-building** Linking with Connections Ideas government **Existing solutions** Friendship Linking with relevant Training Collaboration campaigns and Best practice organisations Encouragement Cluster as platform and This way of working leads to: go-to voice of •Confident communities leading change community health •Impact on local, national, international ways of working Ripple-effect: transfer •Behaviour change of ways of working Health system strengthening •Joined-up responses for holistic community health

CHGN has developed the "Connect, Inform, Influence" concept to facilitate the Cluster development process (Figure 1). The intention is that Cluster members focus on trust-building and connection, resulting in both mutual encouragement and effective collaboration. These connections can lead to transfer of information—through stories, best practice, training, contacts and opportunities amongst Cluster members and beyond. The Cluster has the potential to become the "go-to" source for those involved in community health learning and action in the region where it operates. This enables the government and other actors to engage with one authentic voice from that community. Through this process the Cluster model can begin to influence health policy at a regional level (as seen in the CHGN Uttarakhand Cluster). In turn this contributes to

the strengthening of health systems, a priority in global health. We believe the Cluster model is distinctive from other collaborative initiatives. The collaboration is 'bottom-up' in that the Clusters themselves define their operating principles, membership, agenda and action plans. It allows for highlighting local strengths and resources and helps grass roots responses to issues.

### Rationale for a Kenya Cluster

According to the Kenyan Ministry of Health, "A large proportion of Kenyans continue to carry one of the highest preventable burdens of ill health in the world. Much of this burden can be lifted and prevented with existing knowledge and resources" (Kenya Ministry of Health 2006). Why is this still the

case despite the abundance of development agencies in Kenya? Sylvia Ngatia, a missionary public health officer, believes that local programmes need to be working together effectively to have an impact: "If we truly want to help the community, why don't we hold hands?" (personal communication, April 2013). A leader in an international child health organisation commented similarly: "This is why we need to network. We can be working on the ground in our own corners and we may not realize an expert is close by" (personal communication, Viva International, April 2013). Consequently, there has been a growing desire for a platform to share ideas, resources and training, and to avoid overlap and duplication. With these principles in mind CHGN was invited by leaders of community health programmes to seed a Cluster in order to decrease programme isolation and promote connectedness.

### Formation of the Kenya Cluster

### **Pre-Cluster Launch Visits**

Prior to the Cluster launch CHGN staff and associates visited Kenya and met with key individuals who would act as potential Cluster champions. Two separate nationals had heard of the Cluster concept by word of mouth and the CHGN website and invited CHGN staff to visit their communities. Communication between CHGN and these nationals continued and an initial two week visit was followed up with a two month stay by a CHGN staff member. These visits involved outlining the Cluster vision and potential, identifying participants and exploring the wide variety of benefits. The time taken in developing trust and relationships has proven to be vital to the Cluster model. In the analysis of the Uttarakhand Cluster by Grills et al, the key pioneers are referred to as "brokers" and were found to be "crucial in network formation" (Grills et al 2013). A simi-

lar pattern emerged in Kenya. It was important that CHGN associates stayed within the community and, if invited, lived with the potential members. This often involved travelling to remote areas. When discussing ways to build and sustain the Cluster, one member, speaking to the CHGN staff, said, "we value your opinion on this, you've been here, lived with us and see how we work and now we have built trust" (personal communication, Mathew Owili, Education and Health manager, World Vision Kolowa, Oct 2013).

# Coming alongside Local Change-makers and Champions

Three key champions were identified on the basis of being trusted by their communities and linked to either government or local universities. CHGN staff built relationships with these members, listened to their vision for a Cluster in the region and brought them together. The champions also acted as connectors and networkers. Identifying key champions who were respected and trusted members of their communities encouraged and motivated others to join the emerging Cluster. These champions and CHGN staff met with a large cross-section of people of various programmes to discuss if and how they would benefit from being part of a Cluster and to invite them to the Cluster Seminar.

### Cluster Seminar and Launch

In May 2013, a five-day planning seminar was held and this culminated in the launch of the CHGN Kenya Cluster. Over 30 community health workers, representatives of community programmes, faith leaders, community leaders, local and district government officials and university representatives from the Tropical Institute of Community Health and Development

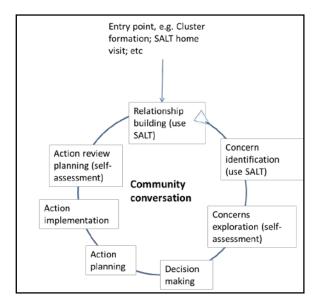
gathered together to share personal experiences and jointly determine priority areas.

The "Connect, Inform, Influence" themes developed by CHGN to facilitate the Cluster process were introduced at the seminar. Members used a self-assessment tool (provided by Affirm Associates) to analyse their current situation within these themes, and to develop their vision for moving forward. They also shared existing concerns and explored appropriate regional solutions. A significant proportion of the seminar was facilitated by the Cluster champions. This increased local ownership and relevance. Towards the end of the launch, a leadership team was elected by the members to progress the vision.

### SALT Methodology

CHGN worked with Affirm Associates to introduce the "SALT" methodology during the seminar. SALT is a widely used way of working based on identifying the strengths and assets of community members. It focusses on encouraging and measuring the way in which individuals and communities respond with hope and enthusiasm to shared challenges. SALT is a mnemonic for Stimulate, Appreciate, Learn and Transfer. It is practised during household or neighbourhood visits, encouraging facilitators to be "learners" rather than "teachers" in order to identify strengths and concerns within a community. By identifying strengths at a household level these solutions can be transferred household to household to create a community movement and a locally relevant shared response to various issues (Figure 2) (Salt Approach 2012).

Figure 2: Use of SALT to stimulate community conversation at local level



During the Cluster seminar, members conducted SALT visits in nearby households. This was a clear way of demonstrating how connections could be made, how neighbourhood strengths and concerns could be recognised and how "community owned" action plans could emerge.

Case study: tackling Female Genital Mutilation

JN is a CHW in East Pokot, North Rift, Kenya from the Pokot tribe. Using the SALT methodology which she learned about through the Cluster, the subject of female genital mutilation (FGM) was raised by the students during a secondary school visit. This was remarkable, in a place where FGM is widely practiced but rarely discussed. JN knows first-hand how the dangerous practice means girls are forced out of school and into early marriage. Around four fifths of girls who undergo FGM are not in school, or drop out of school afterwards. As a result of this encounter, JN has committed to regular visits with the school to encourage the girls to remain in

school and prevent further FGM practices in the current generation. She hopes to continue to talk to the girls about existing solutions, and to support the girls in identifying and achieving their hopes and visions. She will link the concerns there with the work of the CHWs and with other community health initiatives in the region.

### Sub-Clusters

One of the unique features of the Kenya cluster is the existence of sub-Clusters. Kenya Cluster leaders introduced sub-Clusters because members were spread geographically. This is referred to as low *geographical homiphily* in social network theory (Grills et al 2013). The sub-Clusters helped provide geographically relevant connections, a platform for advocacy, mutual encouragement, and local communities of learning. Local sub-Clusters are represented in the larger Kenya Cluster, the platform where their voices could be heard (Figure 3).

### **Ngoron Sub-Cluster**

Members of the Kenya Cluster from the relatively isolated area of Ngoron in East Pokot requested sub-Cluster facilitation in their area. This sub-Cluster facilitation was done by a national facilitator and CHGN international staff. Acknowledging the challenges faced by the community in accessing medical services, the sub-Cluster works together on community health programs based on the Kenyan Government's Community Health Strategy (Kenya Ministry of Health 2006). This Strategy identifies the need for a holistic approach to community health, where physical health is not separated from other facets of wellbeing, such as socioeconomic development, spiritual beliefs and education. Therefore, the sub-Cluster has chosen to include the region's church, agricultural and school leaders to work together with community leaders, NGOs and health workers on the implementation of the community health programmes.

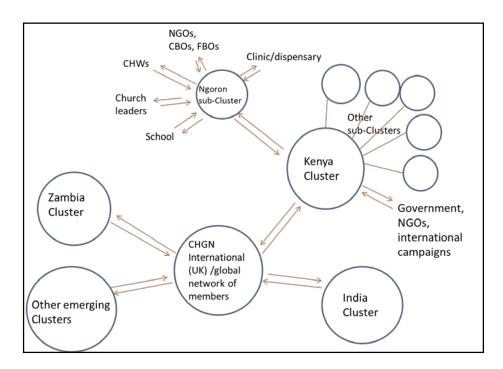


Figure 3: CHGN Clusters. Arrows represent two-way sharing and learning

### **Cluster Follow-up Meeting**

Six months after the launch of the Kenya Cluster, a meeting was held to consolidate and strengthen connections. Stories were shared, and SALT refresher training was given. Kenya Cluster leaders facilitated a discussion to develop draft vision and mission statements:

**Draft vision:** "To see holistically healthy and transformed communities."

**Draft mission:** "To provide a platform to connect, inform and influence for positive change in our communities."

Developing the vision and mission statements provided a foundation and general direction for the Cluster and increased the unity of the group. A list of common concerns was also developed which included sanitation, community health worker provision, malaria, HIV, connectedness and farming/irrigation. These concerns will provide a framework for future training meetings and collaborative Cluster projects.

Cluster members also initiated a communal Cluster fund by each making a small contribution. CHGN contributed hospitality for the initial Cluster seminar and some subsidy for accommodation during the seminar. The Cluster's leadership team directed current Cluster activities and goals. They worked with the CHGN international team who facilitated, supported, signposted, offered solutions and links, and disseminated information or trainings.

### Outcomes

The initial outcomes noted within the Kenya Cluster fit within the concept areas of "Connect, Inform, and Influence."

### Connect

The Kenya Cluster is being used for networking between community-based organisations, pastors, health workers, Non-Governmental Organisations, the University sector and the Government. The Cluster has put together a member directory,

with information about roles and areas of knowledge. As an example, the Kenya Cluster has linked a health worker in East Pokot to the other members in the region. He is now assisting these members by providing immunisations to their community health programs. Other members have plans to assist him with community health worker training.

Connections through the Kenya Cluster are facilitating links between faith based organisations, secular development agencies, and the government. Kenyan community health professor Charles Wafula comments: "Why is it we have good scientific health systems but when it comes to social implementation we fail? What is the missing link? So much has been invested in Africa but the health outcomes are still poor - is the African man trapped? And if so by what?" (Wafula 2013). Among others, he believes one "missing link" is the addressing of African traditional beliefs within communities.

Through the Cluster the Tropical Institute of Community Health, the Africa Gospel Church, the Community Health Empowerment (CHE) program and the Government are planning to work together to implement aspects of the community health strategy. In addition, the various ways through which African traditional beliefs can affect health will be addressed. There are plans for the university to monitor the impact of this unique approach.

In addition, recognition and appreciation from both community and colleagues is cited as a key factor in motivating and retaining health workers, sometimes over financial incentives (Willis-Shattuck, et al 2008). Similarly, many Cluster members explained the benefits of connecting with those doing similar work and having their own work recognised. Those working in remote areas emphasised that this motivated and encouraged them to continue in their workplace despite various hardships.

### Inform

The Cluster model in Kenya is being used to inform its members at various levels:

- Cluster members have been sharing stories, ideas and information with each other.
- CHGN staff have shared stories and learning from the Uttarakhand Cluster in North India, showing the value of global cross-learning.
- The Cluster forum will be used for training on thematic topic areas like irrigation and malaria, but also to share ways of working such as use of the SALT methodology.
- A toolkit of resources (e.g. best practices, fundraising, communication tools) is being compiled by CHGN.
   Members will be able to access the relevant tools both through Cluster meetings and online.

### **Influence**

Existing multilateral organisations in Kenya, such as the World Health Organisation (WHO), have both direct and indirect engagement with community-based health initiatives. Conversely, faith-based, NGO-related and community-based CHW programmes often have their own arrangements for health workers. Therefore, it is not uncommon for there to be barriers to communication between these two sectors (Waage, et al 2010; Grills 2009). With this in mind, the Cluster as a collective provides a representational focus for the government and multilaterals to engage with civil society organisations at local and district levels. For example, the Cluster has established links with the Ministry of Health, the international One Million Community Health Workers Campaign (see below), and with the University sector, enabling greater support to be available at the community level.

A prominent example of the Kenya Cluster's current influence is through their involvement in the One Million Community Health Workers Campaign, an initiative of the United Nations Sustainable Development Solutions Network and the Earth Institute of Colombia University. This campaign seeks to

train and support increased numbers of CHWs across Sub-Saharan Africa (Singh and Sachs 2013; One Million 2014). CHGN is on the steering council for the campaign at an international level, and is linked with the campaign in-country, through the Kenya Cluster. There is much enthusiasm amongst Cluster members as the need for CHWs was identified as a Cluster priority. The Cluster feels their involvement can ensure the campaign reaches areas of need. The link is also meeting the Campaign's intention to build on systems and initiatives which are already established.

### Challenges

The Cluster includes diverse members from diverse organisations and, as expected, there were preconceived ideas about how CHGN would operate. Some prospective members presumed that attending the launch would lead to direct financial benefits to their program. Others presumed that CHGN would be rolling out a program according to its own agenda rather than accompanying and connecting established programs. Time was taken to correct such mis-preconceptions.

Unlike other Clusters, the Kenya Cluster is geographically wide-spread. This presented some logistical challenges regarding travel distances and cost and these issues may alter the frequency of future full Cluster meetings. Prospective members from various remote areas were invited intentionally in order to include those who were relatively isolated. Despite this challenge, it is hoped that specific outcomes will be addressed at sub-Cluster level and the national Cluster will be used as a platform for strategic discussion and amplifying voices for important needs and challenges.

### Lessons and Recommendations

- Trust and relationships were key to the Cluster formation and time should be taken to build these when initiating future Clusters.
- 2. A Cluster model can link primary health care programs working at the community level to larger, more traditional vertical programs e.g. national and international anti-malaria or HIV programs. These smaller community led initiatives can become part of or stimulate a larger community movement, ultimately increasing the impact of the vertical programs.
- of community health. Over time, it can become a platform to address locally relevant social determinants of
  health. The importance of such holistic approaches to
  healthcare has been highlighted in the *Lancet* and London International Development Centre Commission's
  analysis of the Millennium Development Goals. This
  analysis emphasized the need for, "local interventions in
  poverty reduction, health, education, and gender equality
  coming together for the same groups of people," when
  setting goals post 2015 (Waage 2010).
- 4. Only minimal start-up funds were provided in the formation of the Kenya Cluster. This has encouraged the members themselves to contribute financially and in directing the Cluster. Such an approach seems to promote local ownership and contributes to such a network becoming self-sustaining.
- 5. It is reported that 40% of Kenya's health service is provided by affiliates of the Christian Health Association of Kenya (CHAK) and Kenya Episcopal Conference (KEC) (USAID 2007). A Cluster can be used, as is the case in Kenya, to better understand the role of faith-inspired initiatives and improve their linkage with secular

and multilateral development organisations. There is opportunity for both groups to come together to share ways of working and best practices, and CHGN will feed into this dialogue using learning that is coming from local community movements, and from the global network. CHGN is founded on Christian values and beliefs, and on humanitarian principles, and is inclusively open to all those who are committed to making the world a healthier, better and fairer place.

### Conclusion

The recently formed Kenya Cluster of CHGN is emerging as a well-connected and informed platform that can support specific and tangible priorities in different regions through its sub-Clusters. The Cluster will continue to be accompanied and supported and its impact will be monitored. Lessons learnt can be taken from the Kenya Cluster to bring new ideas to other established Clusters and also to inform the initiation of new clusters. In 2015, members from three Clusters will meet for further sharing and analysis of both community response and the overall impact of the Cluster approach.

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