

## Research paper

# Developing low-cost highly sustainable home-based care in rural Kenya

Joy Notter PhD RN RHV CPT HVT PGCEA

Professor of Community Health Care Studies, University of Central England, UK and Lector, Health Care and Social Work, Saxon Hogescholen, Netherlands

Monica Ogutto RN RM HDip Public Health Dip Int Maternal Health

Project Director, Kisumu Medical and Education Trust (KMET), Kisumu, Kenya

Khama Rogo PhD MD

Lead Specialist and Reproductive Health Advisor, Department of Health, Nutrition and Population (HNP), World Bank

Chris Brannigan BSc

Professor of Cognitive Behavioural Therapy, Derby University, UK

John Odera MSc RN

Public Health Officer, Yala Division, Nyanza, Kenya

## ABSTRACT

By the start of the 21st century it was estimated that over two million people in Kenya had been infected with HIV/AIDS. In one small area alone, with a population of 90 000, over 2000 people die every year. Since 1999 the death rate has been approximately seven people per day; this, together with other illnesses and diseases such as TB and cancer, has become an unsupportable burden for all concerned.

There was an urgent need to find a way to help the local communities to cope. The approach selected involved working in partnership with the women elders of the local villages. The women participated in a series of intensive workshops designed to give them the knowledge and skills to provide home-based terminal care for all members of their community regardless of their HIV status. The women were supported and monitored, both individually

and in groups, by the public health officer who had organised the training. This paper presents an account of one strategy used to evaluate the approach. Detailed interviews were undertaken with 17 nurses, nine clinical medical officers and 17 of the women elders. The outcomes showed that both families and healthcare professionals accepted the women's role. There were clear examples of much improved terminal care; AIDS, cancer and TB were the most frequently cited terminal conditions. The women themselves were knowledgeable, committed, enthusiastic and determined to continue their work supporting and educating their communities. In consequence, the programme is now being disseminated in other areas of Kenya.

**Keywords:** empowerment, HIV/AIDS, home-based care, Kenya

## Introduction

It is now generally accepted that HIV/AIDS is a worldwide health disaster, especially in sub-Saharan Africa. Infection rates remain high, and providing care for those in the later stages of the condition places a huge burden on communities with few resources, little

money and limited access to healthcare. In these circumstances, helping communities presents a number of challenges: changes must be low cost, sustainable and culturally appropriate. This paper provides an evaluative account of one approach adopted by a

multidisciplinary team which aimed to improve care for patients who are terminally ill in Kenya. This approach is outlined following an overview of the impact of HIV/AIDS on Kenya and the implications for the health services. The paper then moves on to present the findings of the evaluation and its suitability for other parts of Kenya.

## HIV/AIDS in Kenya

Kenya is a poor country, with the average wage being around \$1 per day, and a gross domestic product (GDP) of around 17.5 billion dollars (see Box 1). By the start of this century almost two million people had been infected with HIV, with the result that today, for every eight adults aged 15–49 years, one is infected. In urban areas the figure rises to one in six and over 100 000 children are HIV positive (Ministry of Health (MOH) Kenya, 2002a). Much of the country remains rural, consisting of villages and small towns, but there is a steady migration into the major cities, especially Nairobi where some 1 200 000 people live in slums with little or no sanitation, and an extremely high incidence of HIV/AIDS. People migrate to seek work, but for many this remains a dream; there is no work and no hope of finding any and so they drift towards the ever-increasing areas of deprivation and misery. There are now generations who are born in the slums

and may well live there until they die. For the people living there, there is nothing, not even anywhere to bury their dead. Those who can afford it pay to bury them in local, government-organised cemeteries; those without any resources have no way of knowing where their loved one is buried. This is a major problem. In Kenya, death is the most important rite of passage, families spend huge amounts on funerals, feeding not only their own families, but also the local community, with funeral services and accompanying ceremonies seen as essential. To allow a relative, or oneself, to be buried in an unmarked grave with little or no ceremony is not just culturally unacceptable, it leaves family members permanently living with guilt, and is a source of perpetual fear for individuals with few or no contacts or support.

Consequently, as their health deteriorates, many of those who left their rural homes with high hopes see a return to their village as their only option. The outcome of this is an ever-increasing burden of care provision for the villagers, not to mention an increased spread of HIV to wives and family members. Once home in the villages, yet another reality of poverty dawns: there is no free care in Kenya; medical treatment and drugs are expensive. Hospital care, assuming it is available, is only ever short term. Individuals are cared for in the community, where, due to increasing numbers and the financial implications of fewer and fewer active workers, both families and communities are losing the ability to cope (MOH Kenya, 2002b; Rogo *et al*, 2006).

### Box 1 Kenya

The Republic of Kenya, situated on the East Coast of Africa, is bordered by Ethiopia, Somalia, Tanzania, Uganda and Sudan. It has a tropical climate, ranging from hot and humid at the coast, through temperate inland areas, to very hot and dry in the north and north east. As with many tropical countries, Kenya is dependent on two rainy seasons: the long rains from April to June and the short rainy season from October to December. The hottest time of year is February to March, and the coldest time July to August. Kenya is not a wealthy country, with the average wage being around \$1 per day, and a GDP of around 17.5 billion dollars.

The population is about 34 000 000, with different tribal groups, the largest of which are Gikūyū (18%), Luhya (15%), Luo (14%), Kalenjin (12%), Kamba (11%), Kisii (7)% and Ameru (6%). There are also several smaller groups including Malakote, Embu, Teso, Gabra, Ndorobo, the Maasai and Samalis. The majority of Kenyans are Christian, with 45% Protestant and 33% Roman Catholic. Of the remainder, 10% are Muslim, and 10% follow traditional religions, with small numbers following Hinduism, Jainism and the Bahá'í Faith.

Kenya received independence from British colonial rule in 1963, and since then has remained politically stable despite recurrent problems in surrounding countries. Administratively Kenya comprises eight *mikowa*, provinces each headed by a presidentially appointed provincial commissioner. These *Mikowa* are divided into 71 *Wilaya'at*, districts, which are in turn further subdivided into 262 *Taarafa*, divisions. Both government and the private sector provide healthcare; currently there are over 3500 healthcare institutions nationwide, with 55% administered by The Ministry of Health and the remainder under private, mission or non-governmental organisation (NGO) ownership. The organisation of services is hierarchical and pyramidal, with the national and teaching hospitals at the apex, and at the base an array of dispensaries and community clinics. Sandwiched between them are the smaller district and provincial hospitals. All services have to be paid for at the point of delivery; private hospitals are often better equipped but may not be affordable to the majority of the population, and there is a distinct bias in the distribution of facilities in favour of urban areas (Rogo *et al*, 1998).

## Healthcare provision and funding

The Kenyan government has traditionally given high priority to improving health; the health sector budget is continually increasing and there has been rapid expansion in public health facilities. However, despite this increase, the picture is actually one of decline, and in real terms, per capita expenditure on health dropped from \$9.5 in 1980–1981 to \$3.5 in 1996, to below \$3 by this century (Brannigan *et al*, 2000). This is, in part, attributable to an increase in the population; thus although the death rate from HIV/AIDS and other diseases is high, the number of people overall is not declining (Jirair, 2006). Notwithstanding this, and a decline in economic performance, by the early 1990s there had been some impressive improvements in basic health indices when compared with those at the time of independence (see Table 1). These gains have been more than negated by the HIV/AIDS epidemic; male life expectancy is now around 39 years, well below the 44 years that existed at the time of independence, and for women there is a similar trend with life expectancy now around 44 years, also much lower than it was (Notter *et al*, 2000; MOH Kenya, 2002a).

To try to address these problems the Kenyan government revised and refined its approach to health through the publication of new policies. The Health Reform Framework (Ministry of Health, 1994) focused on the promotion of good health and community-based healthcare, with a view to slowing down and eventually halting the HIV/AIDS epidemic. Good intentions are compromised by lack of funds. Community services receive about 20% of the recurrent health budget, at present a per capita expenditure of approximately 70 American cents per year, and yet, the Division of Primary Health Care has immense responsibilities for reproductive health, including sexually transmitted infection (STI)/HIV control, family planning, and maternity care, adolescent care, gender and reproductive

health rights. Even in 1994 the services needed to support patients and their families were already overstretched, and the extent and nature of the additional burden that HIV/AIDS placed on families were and are, immense (Jirair, 2006). Further strategic health plans for the years 1999–2004 and 2004–2010 were produced, but the overburdened services have found it difficult to respond to their recommendations (Brannigan *et al*, 2000; Jirair, 2006). None of the measures implemented have mediated against the spread of this disease. Moreover, HIV/AIDS patients need longer and more frequent hospital admissions, thereby inhibiting, and in some instances preventing, the normal functioning of hospitals (Brannigan *et al*, 2000). In an attempt to alleviate their workload, the hospitals are placing increasing pressure on families and communities (Jirair, 2006).

## The project: empowering the community

It is difficult to describe the scale of the HIV/AIDS disaster. In Yala *Taarafa*, in the Nyanza *Mikowa* of western Kenya, the impact of the epidemic is such that the traditional social structures are breaking down. Here, in an area with a population of around 90 000 people, 70% of hospital beds are blocked by HIV/AIDS patients (Clinical Medical Officer, 2001), and over 2000 people die every year. In practical terms this means a death rate of approximately seven per day, a figure that shows no sign of declining (Brannigan *et al*, 2000). The multidisciplinary and multi-international healthcare team convened under the aegis of Kisumu Medical and Education Trust (KMET) and the medical director of Sagam Community Hospital, to work in Yala, had to face up to these statistics and, at the same time, ensure that the mistakes of the past were not repeated. A way had to be found to enable local people to develop techniques, strategies and skills that were consistent with the culture, customs and values of the local people in order to provide ongoing care for individuals who could no longer care for themselves. This way forward would involve caring for people within their own communities, at no extra cost and take account of the critical roles of older women whose traditional responsibilities included care of the sick.

Study of previous research in western Kenya revealed a plethora of projects that have attempted to address the HIV/AIDS situation. These projects were funded by well-meaning western agencies but all have been flawed by short-termism and a lack of sustainability (Rogo *et al*, 1998). Travelling through Kenya, it is not unusual to see graveyards of abandoned four-wheel drive vehicles left behind by one project team or another. All over the country there are locally based ex-project

**Table 1** Changes in health indices

	1963	1993
Perinatal mortality rate (per 1000)	120	67
Crude death rate (per 1000)	20	12
Life expectancy at birth (years)	44	60

Source: Ministry of Health (1994).

workers who have been left without jobs as the short-term initiatives in which they were employed have been completed and the foreign aid has moved on to pastures new, leaving a trail of disruption. Short-term projects have an adverse effect on traditional patterns of care, leaving the communities even worse off than before (Rogo *et al*, 1998; Brannigan *et al*, 2000).

It was crucial to learn from these mistakes and, at the same time, identify successes, one of which was the Bamako initiative (Rogo *et al*, 1998) in which, once a business or community development opportunity has been identified, initial financial support, together with relevant education and training are provided. These schemes, originally funded by the Belgian government, have now been adopted by a range of NGOs. After the initial phase the communities then have to further develop the work themselves with the aim of becoming self-financing. For example, one focused on the education of women, teaching them about malaria and diarrhoeal disease and enabling them to reduce the incidence of these conditions (Rogo *et al*, 1998). The small fees paid to the women, in a rural area where the average wage could be 80 Kenya shillings per day (approximately \$1.4 American dollars), significantly improved the finances of their families. This process of small-scale empowerment fits well within Kenyan culture as it enables women to advance within their own communities. It was therefore decided to use this approach, but instead of focusing only on malaria and general disease prevention, additional areas of expertise could be added. The women would be given the specialist knowledge and skills to support those with HIV/AIDS, within the individual's own family and within the community as a whole.

Following consultations with village elders, it was also agreed that, in addition, the women would also learn how to establish and maintain their own small pharmacies. The law in Kenya permits a restricted number of drugs to be administered by trained healthcare workers, not just doctors and nurses (Ellis, 2004). Thus at the same time as they were taught how to care for HIV/AIDS patients in the community, the women also learned how to care for and support the health of their communities in a range of different ways (Odera, 1999). With support from the village elders, formal approval was then sought from KMET, which is responsible for reviewing and approving local projects; it is the equivalent of a research ethics committee. Once approval had been given, the training was delivered by the public health officer and a senior nursing/midwifery tutor, through short but intense sessions and subsequent follow-up visits by the trainers on an individual and small-group basis. Once trained, the women were supported by the local health clinic.

Informal feedback from the women suggested that they had found both the sessions and the visits beneficial. The women were enthusiastic, committed and extremely knowledgeable regarding the drugs they were able to administer and the care they provided, at minimal cost to the individuals and families. Families and, importantly, the elder men of the villages appeared pleased with the results and wanted the programme to continue.

## Evaluation of the project

The aim of this part of the evaluation was to determine the effectiveness of the training and the project from the perspective of the women, who referred to themselves as community-based distributors (CBDs). Impact evaluation (Patton, 2002) was seen as the most appropriate strategy as it would include the longer-term outcomes as the role of the women developed. The evaluation was also intended to identify any further training needs. It was evident that any methods used had to take account of various levels of literacy, and different languages. In view of these issues, and as postal surveys are very difficult to conduct in Kenya, a face-to-face administered, structured questionnaire seemed most appropriate (Alreck and Settle, 2004). This allowed for some clarification of response, while at the same time providing data that could be coded and collated (Czaja and Blair, 2005). This approach necessitated the recruitment and training of several interviewers. Although it was recognised that reliability and validity could be adversely affected if interviews were conducted by a series of interviewers, careful preparation, and the use of agreed prompts where clarification was needed, ensured consistency in data collection (Babbie, 1998; Bordens and Abbott, 2005). In addition, an audit trail, diaries and reflective debriefing of the research team were used to review the rigour of the data collection process (Maxwell, 2005). Where translation was needed, in order to minimise bias, all translated data were checked by a second independent worker. The proposal for the evaluation project was approved by KMET.

Convenience sampling (Bowling, 1997) was used to target three groups: CBDs, clinical medical officers (CMOs) and nurses. The CMOs and nurses were either members of staff at the Siaya District Hospital which served the *Taarafa* or those small, local dispensaries. Thus the sample covered a large geographical area so that an overall impression of the CBDs' work was possible.

## Findings

In all a total of 43 interviews were completed:

- 17 community-based distributors = CBD
- nine clinical officers/doctors = CMO
- 17 nurses.

It was evident that the CBDs took their role extremely seriously, and were rapidly gaining recognition and acceptance from their communities. They enjoyed their role, seeing it as entirely appropriate that women should provide the care and educate families about health. They saw many advantages to home-based care (see Table 2), but were also aware of the disadvantages of this approach and were careful 'not to take over ... we cannot do it all ... they must care for their own ...'. This recognition of the potential disadvantages is crucial. If families abdicate their role, then the CBDs would be overwhelmed by the sheer volume of work and the depth of need (Jirair 2006).

The CBDs were accepted by the healthcare professionals. Instead of the opposition that might have been expected to new workers with limited training, their role had been recognised and accepted almost with relief. In a relatively short time they had become an accepted part of the community, the link between hospital and home, with healthcare professionals recognising that there was 'no way that we can cope'

and that the CBDs were possibly the only hope the families had of getting any help and support. However, while acknowledging that they 'do a good job', both doctors and nurses were quick to point out that:

'... of course they're not really trained ... but what can we do ... we don't have the staff ... we can't go out into the community [too short staffed] ... somebody needs to sort the families out ... at least it helps to clear the beds ...'

Professionals worked with the CBDs, providing information about needs of individuals both in the hospital and at home. They felt that at least families were given some support and education, even though it was 'a bit limited it is better than nothing ...'. They saw no way in the near future that health services could provide the type of care the women were offering and, as health policy documents (MOH Kenya, 2002a,b) were beginning to indicate, were adamant that community care was 'the only possible road to take' (Rogo *et al*, 2006).

To gain greater understanding of the role of the CBDs and where this dovetailed with existing services, all three groups were asked about terminal care. There was consensus about the key elements that needed to be included in definitions of home-based community care. There were also clear differences in emphasis which appeared to reflect and illustrate the differences in training of the three groups. For example, the CMOs focused on medical aspects of care, with only one mentioning the importance of providing social

**Table 2** CBD perceptions of advantages and disadvantages of home-based care

Advantages of home-based care	%	Disadvantages of home-based care	%
Surrounded by or close to family/ community	78	Emotionally exhausting for family	66
Care needs identified and met	78	Physically exhausting for family	66
Less expensive for family – no hospital bill	72	Emergencies difficult to treat	60
Less transfer of infection	72	Lack of sufficient expertise in community	60
Educates family and community	72	Lack of family understanding of needs	54
Increased psychological support	60	Families not properly taught how to care	54
Personal care (bathing, etc.) better done	60	Family taboos prevent taking precautions	46
Life prolonged by good care	42	Friends and relatives may fear/disown patient	36
Better diet	36	Family needs repeated teaching	36
Frees up beds and staff for treatable conditions	30		

and psychological care; the nurses emphasised physical care, while it was clear that the CBDs had taken on a more holistic approach. These differences were maintained when they were asked how terminal care was actually delivered. The CBDs placed less emphasis on pain relief accepting that, for families with limited means, pain was likely to be ever present. Even where finances permitted, access to morphine was very limited and, with panadol as the most commonly used analgesic, some degree of pain usually remained (Brannigan *et al*, 2000). The CBDs also placed a distinct emphasis on the importance of educating families to provide care, rather than rely on external help. They repeatedly stated the need to increase the confidence of individual carers and to provide ongoing and consistent support. They focused much more clearly than either of the other groups on the need to prevent carers becoming exhausted and/or infected, and were adamant that, provided adequate training and support were given, 'they [families] can care 'til dying'. They argued that without the type of support they provided, families not only became tired and dispirited, but gradually 'slipped back' into previous patterns and practices where care was poorly organised and there was increased risk of transfer of HIV/AIDS.

All three groups were asked what terminal conditions they saw most frequently, and inevitably HIV/AIDS was the most common disease. There were clear differences between the two groups of healthcare professionals and the CBDs (see Table 3). This may be because healthcare professionals tended to see patients either in the initial diagnostic phase or in acute episodes, when pain, the onset of or change in symptoms were seen as major issues secondary to the original diagnosis, rather than primary illnesses in their own right (Bos and Jamison, 2006). In contrast, the CBDs reported the diseases that they perceived, or were told by families, were the causes leading to death. For example, for the healthcare professionals TB was

reported as an 'opportunistic' infection, arising from the loss of immunity associated with HIV/AIDS, and was therefore rarely cited as a cause of death; for the CBDs a patient dying with TB was seen as primarily a TB patient, regardless of whether or not s/he had HIV/AIDS. They were aware that some of the people they cared for exhibited the signs and symptoms of HIV/AIDS, but the families referred only to the TB, and would record the death without using the term HIV/AIDS. This is perhaps not surprising as there is still a stigma associated with dying from HIV/AIDS (Brannigan *et al*, 2000; Fox, 2002; Jirair, 2006). The CBDs recognised this, but, understanding the families' concern that the person should be 'remembered well', saw no way round it. They also raised two other problems with establishing and recording cause of death. They pointed out that the poorest people sometimes died without a formal diagnosis at all. In addition, there was the issue of 'Chira', a local curse. People who believe that they have been cursed see no point in seeking western medicine to resolve what has, in their eyes, a non-organic cause. A number of this group tend to seek alternative medicine through traditional doctors who may be able to 'lift the curse'. However, for this group too, no formal diagnoses are made and thus in reality, the incidence of HIV/AIDS may well be higher than is generally recorded (Ellis, 2004).

The CBDs had accepted that they might never ascertain the real cause of illness and/or death, making it harder to support families, prevent the spread of infection and also, in some cases, to provide adequate care. Where they were unsure of the individual's HIV/AIDS status, the training given had convinced them that they should use all the precautions that they would use when caring for a known HIV/AIDS patient. However, as several pointed out, under these circumstances it was much harder to convince the families of the need to prevent cross-infection.

**Table 3** Commonly seen causes of death cited by participants

Terminal conditions	Doctors (%)	Nurses (%)	CBDs (%)
AIDS	100	100	100
TB	12	18	72
Cancer	72	66	24
Hepatitis	36	30	12
Renal failure	30	30	6
Chronic conditions, e.g. diabetes	36	36	54
Cerebrovascular accident	18	24	36
Malaria	18	18	49

All three groups pointed out that a chronically ill patient was a heavy economic burden on a family; not only was that person unable to contribute to the family economy, but he or she was also a considerable drain on existing resources as the disease progressed. In cases where the family bread winner was ill, all family members, not just the patient, suffered the effects of increasing and extreme poverty. At the same time, and compounding their problems, the lack of any treatment impacted on the rate of disease progression and on the likelihood of secondary infections or complications (Parry *et al*, 2004; Bos and Jamison, 2006). All groups recognised that for the majority of families it would be impossible for them to pay the costs necessary for long-term healthcare, or even to know what they needed. The CBDs saw themselves as providing an essential link, enabling families to receive help and support within the family setting, at an affordable cost.

The CBDs raised another problem not initially mentioned by the professionals: the difference that age and gender made to the care provided. The perceptions of this varied between groups, with the majority of CBDs believing that age, gender and diagnosis all impacted on the care given, a view disputed by the healthcare professionals (see Figure 1). The CBDs were adamant that children tended to be well cared for, usually by their mothers; men were better cared for than women, as wives, sisters and daughters tended to share their care, whereas it was seen as unusual for men to participate in the care of women. For some women, the only hope of care came from the CBDs offering a shoulder for the woman to lean on. They gave examples of women being 'driven out of the village ... back to where they came from' if they needed care and expensive treatment. On marriage, women leave their own villages to live with their husbands. The current crisis means that women who fall ill are pushed into returning to their parental villages. The

CBDs reported mediating between family members, trying to resolve this problem by using members of the extended family, but they were clearly concerned for those women who 'often have nothing', and worked together to maximise the support they could give. The CBDs saw themselves as having to change attitudes so that, whatever the circumstances, all those who were ill would be cared for.

The views of CBDs might differ from those of healthcare professionals who saw only those brought for treatment. CMOs and nurses did admit that more men than women were brought to the hospital. This caused a sense of conflict. They tried to be equitable, treating everyone alike, but it was a difficult situation to resolve. Resources were not unlimited and medical staff had to 'use them where they are more likely to do good'. To those who do not understand the situation this could look like gender bias in decision making (Ellis, 2004).

The CBDs saw themselves as having an assessment role, referring patients back to mainstream services when their circumstances changed. Some even accompanied patients to the hospital to speak with the nurse or doctor to check that appropriate care was ordered and provided. Where patients were admitted and nursing shortages affected the care and personal hygiene of patients, CBDs would travel each day to provide the necessary care, taking the patient home again after discharge. As one of the CBDs pointed out:

'I come each day ... if I didn't they wouldn't wash him ... there are no nurses ... what can they do ... I wash him I speak to the doctor and tomorrow I take him home and teach his family how to care ... I visit often and show them what to do ... how not to catch it [AIDS] to use plastic bags if they have no gloves ... how to feed him ... everything.'

They saw their role as crucial, recognising that hospital staff were very busy and patients were too weak and ill

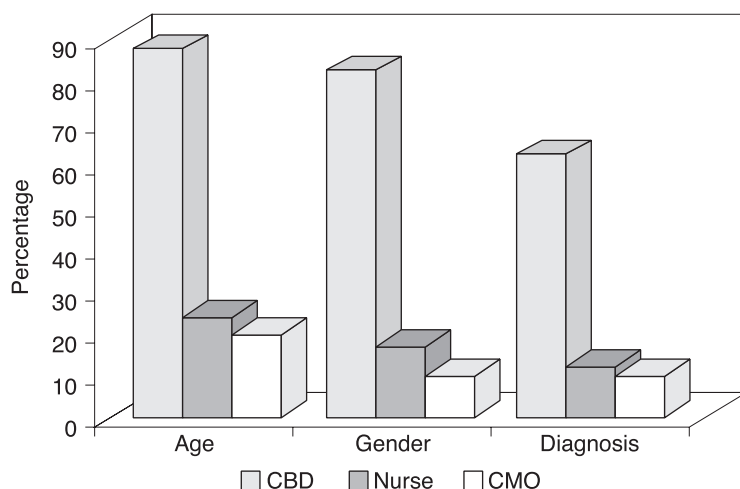


Figure 1 Numbers reporting the impact of gender, age and diagnosis on care

and were unable to speak for themselves. Moreover, as in every country where patients have little or no medical knowledge and have to trust the word of experts and accept treatment with little or no understanding, those (nearly the whole village) who had limited contact with health services were unsure or unaware of what to expect, and were often unable to understand the information they were given without the help of an 'interpreter' (World Health Organization, 1999; Notter *et al*, 2006).

For the majority of CBDs spiritual well-being was part of care and where the family had similar beliefs to the CBDs, praying with the family was seen as an integral element of the support offered. As they explained, the churches in their villages tended to be evangelical and so praying together was a normal activity. They believed that shared prayers 'is good for all ... it helps us cope ... it helps them and gives family comfort'. Thus, whereas the health professionals were focused on physiological and organic factors, the holistic approach taken by the CBDs drew them into the innermost beliefs of their patients.

## Conclusions

It was evident that the CBDs had developed a clear role for themselves and were becoming well established. It is a tribute to their expertise and their communication skills that within a very short space of time they became so well accepted by both health professionals and the communities in which they lived – no mean feat, particularly as they had had no one to prepare the way for them. Their commitment to the communities they served, and their determination to bring about positive change, were impressive. Working for salaries that in western terms would be judged to be very low (a few Kenyan shillings per activity, and 138 Kenyan shillings = £1), they led a new movement, in providing care and support for the sick, and worked to prevent further spread of the disease and remove the stigma associated with HIV/AIDS.

Differences between them and the health professionals showed that the CBDs adopted a more holistic approach. It might have been expected that their views would be nearer to those of the nurses but this was not the case. Possibly the huge demands placed on professionals meant that they could only focus on physical problems and the actual care that they gave, and not the aims underpinning that care and treatment. In contrast the CBDs had approved of and internalised the philosophy underpinning their training, possibly helped by the fact that it fitted well with their own culture and beliefs, and were applying what they had learned.

They worked in difficult circumstances but with an understanding of the problems and the processes that

they needed to use that far outstripped that of the healthcare professionals. Based firmly within the community, they had a 'foot in each camp'. They could consult with healthcare providers but, unlike them, they had authority conferred on them by their communities and therefore were more likely to be attended to. Their ability to interpret information from healthcare professionals not only made them aware of individual needs and constraints, but also enabled them to work with those professionals to devise appropriate strategies for care. They were confident enough to act as advocates for those less vocal than themselves, to ascertain information and advice, but they also knew what they could not do, and when to seek further help. They had taken on an extra role that they had not envisaged with regard to hospital admission, but were comfortable with that and had convinced the healthcare professionals that this additional role was necessary.

They were adamant that their primary roles were teaching and support. They were prepared to take the lead in family settings, and once they had taught the family members what to do, they would then monitor the family's progress, putting in additional expertise when needed. They recognised that to achieve their long-term goals they could not afford to become too committed to any individual family, and that they needed to work together. They appreciated the skills they had been given, and the opportunity to improve lives; they were determined to continue to work to improve and enhance the care of individuals and families. This strong commitment, and their high levels of motivation, were strengthened by their recognition of the problems facing their whole community and the knowledge that their service offered one of the best hopes for the survival.

The support and approval of the village elders were crucial. The project was consistent with their cultural values and beliefs and this enabled all those involved to accept change and move forwards without incurring censure for crossing traditional boundaries or taboos. The project was appropriate and practical, enhancing the role of women. The services provided by the women proved to be sustainable and to have minimal cost. Training, support and supervision entailed some costs at the outset but these were non-recurring. Considering the ongoing care the CBDs provided and the reported difference in quality of life for patients and families, the price seemed well worth paying.

Since the data for this evaluation were collected, interest in the project has grown considerably, with the result that this approach to community care has spread to more villages and communities. Anecdotal feedback from these new areas is positive, and the second phase of the evaluation from the recipients (patients and carers) is now in progress, with initial findings also supporting this model for care.



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## CONFLICTS OF INTEREST

None.

## ADDRESS FOR CORRESPONDENCE:

Professor Joy Notter, Faculty of Health, University of Central England, Franchise Street, Perry Barr B42 2SU, UK. Tel: +44 (0)121 331 5320; email: [joy.notter@uce.ac.uk](mailto:joy.notter@uce.ac.uk)

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