

Seventh Annual Progress Report of the College of Medicine Home Based Care Project – January 2010

Introduction

This is the seventh annual report of the College of Medicine Home Based Care Project written for private donors. It provides details of activities, financial information and outlines future plans. Financial information is also available in the annual report of the “Malawi Home Based Care Charitable Trust”, the UK based charity set up to support the project through which all money is channelled. For a copy of this report please contact kate@malawihbc.org. On behalf of everyone involved in the project, we thank you for your support.

Looking back on 2009

Funding

The National AIDS Commission (NAC), despite earlier advice for us to submit a funding proposal to continue the Bangwe arm of the project, could not bring themselves to fund the nurses on the project. This is a vestigial response based on a historical divide between the Ministry of Health, which are traditionally the nurse employers, and NAC, which funds other things. They said we could resubmit a research proposal excluding the service components of the project. So far we have not done this.

Instead we asked the Diana Princess of Wales Memorial Fund to support the Bangwe as well as Limbe arm of the project, which they agreed to do. To reduce costs, improve integration with mainstream health services we reached agreement with the local District Health Department to take on our nurses, who would be employed and paid by them but still work within the project. This has taken over six months to arrange and only some of the nurses so far have been offered employment. In the meantime the Diana Princess of Wales Memorial Fund has agreed to pay the salaries of the other nurses. This means that the staffing has been at full strength for the whole year, initially supported by you, and in the second half of the year by the Diana Princess of Wales Memorial Fund. We had asked the Trustees to seek funds for Bangwe from other charitable foundations in the UK. This they did with some success, receiving a grant of £7000 from the Trusthouse Charitable Foundation and £2000 from the Strathspey Charitable Trust.



Volunteers at a training session

In the financial year 31st May 2008 to 30th June 2009 the Trust has remitted £26,393 to the Home Based Care account in Malawi. This has paid for salaries of Bangwe staff (identified as College of Medicine Account as the College pays their salaries), fuel for training and transport, incidental running expenses such as phone coupons, orphan and patient support and drama group costs (see table below).

Summary of First Merchant Bank Statement		Debit	Credit	Balance
31/05/2008	Opening balance			£ 2,480.61
26/09/2008	Trust payment		£ 3,400.00	
03/12/2008	Trust payment		£ 4,810.75	
29/01/2009	Trust payment		£ 13,688.81	
20/04/2009	Trust payment		£ 4,493.08	
30/06/2009	Bank interest		£ 12.65	
02/06/2009	Loan		£ 4,373.69	
	College of Medicine Account	£ 15,988.45		
	Training	£ 437.37		
	Transport	£ 763.18		
	Drama group	£ 2,755.42		
	Patient and orphan expenses	£ 9,492.66		
	Bank charges	£ 39.48		
30/06/2009	Closing balance			£ 4,010.86
	Totals	£ 29,476.56	£ 30,778.97	

The original three year Diana Princess of Wales Memorial Fund grant finished in the middle of 2009 and it agreed to give the project a further three year grant, extending it to Bangwe and nurse salaries until they are transferred to the Ministry of Health payroll. This amounts to just under £60,000 a year. We send them an annual report each year which starts and finishes in August and which is available on request.

Achievements in 2009

The two arms of the project are now fully integrated. Together the team comprises five nurses plus Claire, five home based care assistants and a cleaner. They have:-

- Enrolled 246 new patients in the year in the 30 villages identified by our home based care volunteers
- Made 2179 follow up visits in the year, giving them the drugs, support, advice or referral they need.

Looking back over the last 8 years

Looking back over the last 8 years the knowledge and experience we have gained in running an efficient and effective home based care (HBC) service that is appropriate and sensitive to Malawi is an achievement of which we are proud. Without your continued help it would not have been possible. The quality of HBC services and alleviation of suffering for those living with HIV/AIDS in the areas we serve have improved a thousand fold, the standard of staff and volunteer training and commitment has also become more professional and solid. The number of patients seen and villages visited grows every year with potential to expand further.

Having tailor made a model home based care service that can be used throughout Malawi, the lack of support and recognition from Ministry of Health is frustrating. With government hospitals overcrowded and poorly staffed, and over 70% of admissions due to HIV related conditions, care in the community would not only relieve the pressure on hospitals and health centres but also provide a more patient friendly, cost effective and appropriate alternative. The battle to gain national acceptance will continue!



A game of football (support group members)

Our support group for people living with HIV/AIDS remains hugely popular and more or less runs itself without our help. Two more treadle sewing machines will be purchased this year with donor funds to encourage members to keep up their newly acquired tailoring skills and generate some income - school uniforms and alterations are always in demand. And once the rainy season ends in March the hand operated brickette machine, that uses recycled cardboard, paper and wood shavings compressed and dried in the sun, provides an excellent, cheaper and greener alternative cooking fuel to charcoal. Waste cardboard and packaging is collected at the end of each anti-retroviral clinic so running costs are negligible and profit 100%. We also continue to encourage and support weekly adult literacy classes for members of the support group.

Several sponsored orphans have now completed their schooling and are in vocational or further education and one is now a fully fledged mechanic. The drama group has had another busy year performing to huge audiences in all the surrounding villages promoting HIV/AIDS awareness and prevention, family planning and other health related issues. The PA system, purchased with funds from the Just Trust a year ago, has not been quite the money spinner they anticipated but with perseverance and good management we hope that they will become less dependent on our support. We provided a 4 day workshop in Management and Marketing skills for members of both the drama and support group in October 2009.



The drama group rehearsal

Looking forward to the next twelve months

We retired as planned in November and the handover arrangements have taken effect. Norton Gondwe is in charge of the project and we have asked Dr Adamson Muula, a senior lecturer in the department of community health, to take over the director role.

Funding support

The Diana fund will support the home based care work for three years including the nurse salaries except for Norton's and Mishek's which have been approved for transfer to Ministry of Health payroll. Until this actually happens the Trust will be asked to pay for their salaries. None of the CBOs (Civil Based Organisations) which are there to support the volunteers have received funds from the City Assembly despite funds from the National AIDS Commission supposedly been allocated to them for this purpose. Until such time as funds are made available the Trust will be asked to continue to pay for regular refresher training for the volunteers. Without keen fresh volunteers the work is impossible.

Service developments

The need for community home based care continues though the mix of patient needs has changed somewhat. The antiretroviral programme has had some effect. While we see a similar number of patients with terminal disease, we also have those who refuse antiretroviral therapy (ART) for one reason or another who present with full blown AIDS and those who are ill despite their ART either due to treatment failure, serious side effects or poor compliance with the drugs prescribed.

As mentioned last year patients now often suffer severe side effects of ART or default and need to be encouraged to continue treatment. Early mortality on ART is still high – about 20% - and these patients often seek palliative care. Patients well established on ART do get break through opportunistic infections and need prompt treatment. Many know the team well and request help in good time. The clinic held in Bangwe when the support group meets on alternate Thursdays is very busy!



Office and team in Bangwe

Our catchment still covers 170,000 people but there must be 400,000 in Blantyre and Limbe without a similar service. The main effort, therefore, will be to help the Ministry of Health develop home based care services in these areas. We will offer training and support. Indeed we hope that Norton, once directly employed by the local health district, will be given the task of developing and running this district wide health service.

Reflections

What has not changed is the continuing need for home based care, the poverty and high incidence of disease and malnutrition. AIDS is still stripping Malawi of its breadwinners, leaving the very old and the very young.



Rural village scene

The drift from rural to urban areas by the young in search of work increases the risk of HIV and threatens subsistence farming on the land they have left behind. There is little change in behavioural practises which are so ingrained in their culture that westerners find it hard to comprehend. But if AIDS is ever to be reduced on a meaningful scale, it must be through women saying no. AIDS affects more women than men, women have no power to negotiate safe sex, they have few marital rights and seldom a way of escape from the treadmill of poverty and child bearing. It is the women who have to find the money for schooling and food, though most of them are likely to die before their children grow up. Female literacy and adult education not only help to empower women to make more choices but are shown to improve child mortality.

Something that struck me last night when watching the news on BBC1 was of a midwife dashing hysterically down a street in Port au Prince to a breech delivery and complaining about the lack of facilities and equipment. But even in such a devastating crisis they had far more than an average delivery in Malawi where a woman is

required to bring in her own razor blade to cut the cord and her own candle or paraffin to provide light for a night time delivery.

Last year I told you about the boy Chisoma. This year we have been visiting his 28 year old sister, Annie. She had just given birth to a healthy baby boy – her fourth child. She had been admitted to hospital prior to delivery with pneumonia and was discharged with some of the worst pressure sores we have ever seen. She has been paralysed since 1996 from spinal TB and is totally dependent on help for all aspects of hygiene and daily living, including the care of her children. The father of the baby is only 19, out of work and unable to offer any support. She heads an orphan household of 5 sisters, 2 of whom have HIV, none are wage earners, there are several young children and they rely entirely on charity from the church and well wishers. The sisters are weary of the extra burden of care and struggle to look after their own children let alone Annie's. Access to their house is half an hour away by motor bike on a dirt road and the house is squalid and overcrowded. With twice weekly visits the pressure sores are healing slowly, the parents have been counselled and family planning has been strongly recommended. It is rather a no win situation but illustrates the vital need for home based care.



Support group members receiving their certificates in their tailor-made suits

Mostly our patients are not quite so complex though poor nutrition, destitution and late presentation of advanced AIDS always challenge us and our resources. We strive to give holistic care and improve the quality of life however meagre. Lydia Kasakula, one of our nurses, is just about to start a 2 year distance learning diploma in palliative care in Uganda. And Norton attends a palliative care conference in Namibia in October.

Malawi, in spite of such multiple problems, is such a beautiful, peaceful and friendly country and continues to live up to its name as 'the warm heart of Africa'.



Norton Gondwe – Project Manager

We are sad to leave after an amazing eight years and shall always feel indebted for what it has given us in the way of experiences – often frustrating but always challenging, sometimes humbling but always fulfilling. We have learnt to admire the people who cope in the face of such grinding poverty, their resilience and courage in the face of disease and loss. We have learnt to be more cautious of the folly and waste of over consumerism and to be less prejudiced and judgemental. We have left the project in the very capable hands of Norton Gondwe. We shall continue our support of the project and keep in close contact with the staff. Cam has work which will take him back regularly and I shall visit once a year.

Conclusions

The work would have ground to a halt this year without your support. The demand for home based care does not diminish. We hope you feel your support is being well used. The project is becoming self-reliant. The challenge this coming year is for the team to operate and provide quality care without our close support, encouragement and example. Sustainability will occur if the team can be assimilated into the mainstream health service and help to set up similar home based care teams in other areas. This would provide a living example for the rest of the country. So, please continue to donate.

Claire and Cameron Bowie

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