Reviewer’s report

Title: Changing clinical needs of people living with AIDS and receiving home based care in Malawi - the Bangwe Home Based Care Project 2003-2008 - a descriptive study

Version: 1 Date: 27 October 2009

Reviewer: David Lowrance

Reviewer’s report:

Major Essential Revisions:

Title: Conclusion is that clinical needs have not changed much, so the chosen title seems inappropriate.

Abstract: Poorly written, in general.

Results: Need to write out numbers at start of sentences. Provide specific figures, not a “quarter”, “third”, etc. “Early mortality was unchanged” – this is an interpretation; need to provide figures.

Discussion: Mention of “barriers to ART” but these are not described specifically in the Results section. How are patient health-seeking behaviors distinguished from structural service delivery or other access limitations? Conclusions extend beyond the findings presented in the Results section of the abstract.

Introduction:

- Lacking some key information - Home based care eligibility criteria are not defined and described. How is need for HBC determined? How is on-going need determined i.e. are patients graduated from HBC services if they demonstrate clinical improvement?
- How systematically and effectively are the HBC services linked with health facility-based services, including HIV care and treatment, TB, etc. both in the Bangwe program and nationally? (The impression is that there is no formal linkage – if so, why not?)
- There is no mention of key community-based services such as ART retention and adherence promotion.

Methods: Issues raised above may be addressed in either Introduction or the Methods sections however these issues are not addressed in either location.

- Were patients systematically counseled and/or referred for HIV testing?
- ART referral mechanisms are not well defined – are HBC nurses trained in WHO clinical staging in order to refer patients eligible for ART, or are all patients simply “referred” according to the general clinical condition?
- Would provide some detail about the scale-up of ART services in Bangwe. Any
ART coverage data for the catchment area or District/Province?
- What does “positive living advice” consist of?
- Confusing that in first paragraph it is specified that the “project” includes 15 villages but in the section on Study Population it mentions only 9 villages included in the study. Why were the other 6 villages not included? Did they not have routine data collection or was there another reason?
- “Study period and sample” – mentions that patients with a “presumptive” diagnosis were included in the study/project – HIV diagnosis was never confirmed?
- Lost to follow-up outcome is not defined. What about patients who moved/transfered to other locations or discontinued HBC, e.g. if they were initiated on ART and improved clinically?
- The assumption that all patients lost to follow-up are deaths seems unreasonable – given home based services, was it not possible to directly ascertain the true outcome status of most patients from family members?
- The wording in the section “Study period and sample” is confusing.
- Ethical review: the last sentence of the first paragraph in the Introduction mentions that “This research attempted…”. Thus, the manuscript purports to present research findings, i.e. findings which may represent “generalizable knowledge”. Were patients consented at the time of enrollment in the HBC program? To then say in the Methods that this is just an “audit of standard care” seems disingenuous, particularly given the number of publications cited from the “project”.

Results:
- Stage of disease at presentation: the last sentence says ‘However there was no change in the proportion of patients with advanced disease…”. Does this mean at time of enrollment or cumulatively/cross-sectionally including natural disease progression for patients who enrolled at earlier stages and then experienced disease progression? Not clear.
- Longitudinal BMI assessments?
- HIV testing: 17% of patients in HBC services were HIV negative; this should be accounted for in the survival analyses, particularly given strong conclusions regarding lack of ART access. Any data regarding the illnesses of those who were HIV negative?
- Treatment prior to assessment: Not clear what role HBC teams had in TB treatment or follow-up, if any. If median time from TB diagnosis to HBC was 20 weeks, most patients would be close to finishing TB treatment. For patients NOT on TB treatment, was this because they had completed treatment or were non-compliant/adherent? This is hard to interpret. Anything about cotrimoxazole?
- Please provide specific number of patients on ART, not just the %.
- Formatting of Table 1 makes p-values impossible to read.
- Nutritional status: This section is highly problematic and should be reviewed.
First of all, analyses should be stratified by HIV and ART status, at a minimum. Second, the statement “There was no change in nutritional status…” is confusing – is this a reference to the trend in nutritional status of patients enrolling in HBC services or longitudinal analyses of patient-level weight measures?

- Activities of daily living: Were the 32% who reported that they were “able to continue normal activities” discharged from the program? If not, what HBC services were they receiving?

  - What explains the trend in “less dependency? Positive living advice? Self-care skills? This is not well described in the Methods, if so.

- Functional status is mentioned indirectly – is this measured routinely at follow-up? If so, using what scale?

- “Fewer patients were bed-bound” – should provide p-values with comparison statements suggesting significance (general comment throughout the Results).

- Diagnoses: Poorly written and generally hard to interpret.

- Antiretroviral treatment: the barriers described should be cited in the Abstract Results to substantiate the Conclusions.

- ART eligibility criteria are not described so it is hard to know whether, for example, Stage II patients are eligible for ART.

- Survival: need to have stratified analyses by HIV and ART status.

- Nothing about cotrimoxazole prophylaxis? Shown to reduce morbidity, mortality, and CD4 progression in pre-ART patients...

- Figures 2 and 3, and references in text, are confusing and hard to interpret.

- Home based care team workload: HBC referrals decreased but visits increased, with no data presented to explain why.

Discussion:

- The main conclusions in the first paragraph are not fully supported by the findings presented. There is no doubt that there will continue to be a role for HBC services in countries like Malawi with massive generalized epidemics that are still in the process of rapidly scaling up ART and pre-ART services. However, it would seem to be much more relevant and inspiring to have the Discussion focus on how the findings from this study highlight how home based care and other community-based services may more effectively address barriers to HIV testing – why such high testing refusal rates? Mobile VCT? Task shifting?; facilitate evidence-based non-ART interventions such as cotrimoxazole and TB screening (not reported on); and facilitate ART screening (transport?), provision, and adherence, rather than suggesting that the fact that “patients were too sick” or “refused to be tested” is an acceptable status quo. Of course, until HIV testing and ART coverage are further expanded there will continue to be patients who are unable to access services in time, however rather than present this as a justification for continuing current HBC services it should be seen as an urgent appeal to develop stronger community-facility linkages, more effective testing messages and strategies, and enhanced roles in pre-ART counseling, i.e. if a
patient is deemed eligible and refused, what is the role of HBC workers at continuing to inform, educate, and advocate for this life-saving treatment? Also, there is no mention of “enhanced” community-based services that are not seen as separate from facility-based ART services but interconnected, with key roles such as in promoting retention and adherence.

- Generally the Discussion is not well written or constructed.

Minor Essential Revisions

Results:
- Treatment prior to assessment: median is misspelled.

Abstract:
- In Background - Use of term “comprehensive” HBC not defined or distinguished from general term “home based care. Use of questions confusing – need to clearly define the primary research question for the study. No description of rapid national scale-up of ART in Malawi, which has been well-documented. In 2nd to last sentence, data collection period should be included in methods. Service delivery period should be cited in the Background.
- Methods: Would specify “routine” programmatic data collection, i.e. this was not a research/prospective cohort context.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Not suitable for publication unless extensively edited

Statistical review: Yes, but I do not feel adequately qualified to assess the statistics.

Declaration of competing interests:

I declare that I have no competing interests.