AFRICAN PALLIATIVE CARE ASSOCIATION
HOME-BASED CARE REVIEW

Appendix 1

PRELIMINARY REPORT ON THREE COUNTRIES

(Zambia, Kenya, Tanzania)

INTRODUCTION

Background

- APCA, in collaboration with the Elton John AIDS Foundation, set out to undertake a review of home-based care services.
- The aim was to make clear and practical recommendations for the integration of all aspects of palliative care within existing home-based care (HBC) services.
- Mukooza and Biraro Consult (M&BC) was assigned to undertake the 2nd phase of the review which explored the general picture of existing home based care models in the project countries. The four countries included Kenya, Zambia, Tanzania and Malawi

Problem statement

- Home-based care was assumed to be one of the appropriate models for delivering services for PLWHA, including palliative care.
- There was a general out-cry among supporters and promoters of palliative care globally for countries to integrate palliative care into existing services for PLWHA including home-based care
- There was also no knowledge as to which were the best practice home based care models in African countries, and in addition there were no recommendations and guidelines for the integration of all aspects of palliative care into existing home-based care models.

General objective of the review

To explore the existing home-based care models for PLWHA within project countries and to make clear and practical recommendations for integration of all aspects of palliative care.

Specific objectives

1. To examine home based care services for PLWHA and thus determine their models.

2. To examine the home based care models for PLWHA thus identified and understand their strengths and gaps for palliative care provision.

3. To discover if there were any “best practice models for HBC for PLWHA” that can be promoted by APCA for adaptation by countries across Africa.

4. To determine any practical recommendations that could be made for the integration of all aspects of palliative into existing home-based care services for PLWHA.

METHODOLOGY

Design of the review

- This was a cross-sectional review

- It was mostly qualitative

Area and population under review

- The review is being done in four countries: Zambia, Kenya and Tanzania and Malawi.
- So far data has been collected from three countries: Zambia, Kenya & Tanzania.
- The review population constituted those working with home-based care services within the project countries, both at service operational level and managerial level.
- The population also included policy makers and beneficiaries of HBC services.

Sample size

1. Four project countries were selected by APCA

2. In each project country, four services (adding up to 16) were selected purposively by APCA contact persons using certain inclusion criteria

Respondents

1. A policy maker from each project country
2. A person in managerial position in each HBC service selected
3. Five formal care givers from each HBC service
4. Four volunteers from each HBC service
5. Four PLAWAs and four home care givers

Sample selection criteria

Sampling was purposive in each country:

- A service offering home based care with or without palliative care.
- Two services that were urban and two that were either rural or peri-urban.
- Two services that were private and two that were public
- At least one hospital /health centre based home care service.

Data collection

In-depth interviews, focus group discussions and observations

including document review were the main methods of data collection.

Limitations

- Tools were developed without reference to the literature review which came later.
- There was no inventory of HBC services which could have been used as a sampling frame.
- The sample was ‘small’ and therefore only qualitative inferences can be made from it.
- Ethical approvals took long to be obtained and as of now, Malawi approval is not yet available.

RESULTS

Introduction to results

Themes of data analysis

Theme I

Examining the home based care services for PLWHA and thus determining their models.

Theme II

Examining the home based care models for PLWHA and understanding their strengths and gaps for palliative care provision.

Theme III

Discovering if there are any "best practice models for HBC for PLWHA" that can be promoted by APCA for adaptation by countries across Africa.

Theme IV

Determining practical recommendations that can be made for the integration of all aspects of palliative into existing home-based care services for PLWHA

Theme I
Examining the home based care services for PLWHA and thus determining their models.

[Based on HBC types in APCA draft literature review document:
"Home-Based Care for People Living with HIV/AIDS in Resource-Constrained Settings" **(APCA, 2007).**

ID	Model Name	Description	Examples
1	Community home-based care (CHBC) (Type/ Who)	"Community home-based care (CHBC) has been broadly defined as care provided to the ill in their homes or more generally, in their natural environments, by families and available community resources."	-KICOSHEP (K) -CHISILANO (Z) -ST FRANSIS (Z) -BWAFWANO(Z) -PASADA (Tz) -WAMATA (Tz) - HOLY CROSS (K)

Theme 1 contd

ID	Model Name	Description	Examples
2	Integrated community-based home care (ICHC) (Type)	ICHCs meet the needs of PLWHA leaning on “the inter-connectedness of several stakeholders in providing a continuum of care. Collaboration and networking are essential among ICHC partners and other community resources which can be brought into the ICHC model in a given community.” Palliative care is an integral part of ICHC.	-SIAYA (K) -MALINDI (K) -KIWAKKUKI (Tz

Theme 1 contd

ID	Model Name	Description	Examples
3	Hospice care with HBC services	-Institutions (IP and/or OP) -Give care according to the needs of the patient/s and their family -In the context of HIV they have started to give HBC -May or may not function as part of ICHC	Not Met

Theme 1 contd

ID	Model Name	Description	Examples
4	Hospital-supported HBC services	-HBC services are directly connected to and administered by hospitals. -HBC may following up patients with palliative care.	Not met

Theme 1 contd

ID	Model Name	Description	Examples
5	Government district-level HBC services	-HBC administered by the district in collaboration with multi-sectoral stakeholders. -Palliative care may be provided by teams linked with the government's district health services.	KINONDONI

Theme 1 contd

ID	Model Name	Description	Examples
6	Home visiting	-Volunteers provide home-based support to patients. -Services are not as comprehensive as CHBC or ICHC. -Volunteers may assist with transporting patients to clinical facilities -Volunteers may arrange for material support to be provided to homes. -Helping with household tasks such as cooking, cleaning, and tending to errands.	FOCA

Theme 1 contd

ID	Model Name	Description	Examples
7	Outreach services which include HBC	Outreach teams provide services in areas away from the main base of services (e.g. Kyt, Ktv). -Patients may walk-in to the outreach clinics, but home care may be taken to patients who are unable to attend the clinic.	Not met

COMPONENTS OF HBC IN CHBC MODELS IN KENYA

Component	KICOSHEP	HOLYCROSS
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +	+ +
- Facilitation of IGAs - Orphan support	+ +	+ +
- Referral -Training/capacity building	+ +	+ +
-Provision of food supplements - ART (referral)	+ +	+ +
-Access to simple pain killers only -Direct access to ART	+ +	+ +
-Access to strong pain killer with the prescription of a doctor -Home visiting	+ +	+ +

COMPONENTS OF HBC IN CHBC MODELS IN ZAMBIA

Component	CHISHILANO	ST FRANCIS	BWAFWANO
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +	+ +	+ +
- Facilitation of IGAs - Orphan support	+ +	+ +	+ +
- Referral -Training/capacity building	+ +	+ +	+ +
-Provision of food supplements - ART (referral)	+ +	+ +	+ +
-Access to simple pain killers only -Direct access to ART	+ +	+ +	+ +
-Access to strong pain killer with the prescription of a doctor -Home visiting	+ +	+ +	+ +

COMPONENTS OF HBC IN CHBC MODELS IN TANZANIA

COMPONENT	PASADA	WAMATA
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +	+ +
- Facilitation of IGAs - OVC support - PMTCT	+ + +	? ? ?
- Referral -Training/capacity building	+ +	+ +
-Provision of food supplements - ART (referral)	+ ?	+ ?
-Access to simple pain killers only -Direct access to ART	+ +	+ ?
-Access to strong pain killer with the prescription of a doctor -Home visiting	+ +	? +

Components of HBC in models classified as ICHC in Kenya

Component	SIAYA	MALINDI
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +	+ +
- Facilitation of IGAs - Orphan support	+ +	+ +
- Referral -Training/capacity building	+ +	+ +
-Provision of food supplements - ART (referral)	+ +	+ +
-Access to simple pain killers only -Direct access to ART	+ +	+ +
-Access to strong pain killer with the prescription of a doctor -Home visiting	+ +	+ +

Components of HBC in model classified as ICHC in Tanzania

Components	KIWAKKUKI
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +
- Facilitation of IGAs - Orphan support	+ ?
- Referral -Training/capacity building	+ +
-Provision food supplements - ART (referral)	+ +
-Access to counseling and simple pain killers only -Direct access to ART	+ +
-Access to strong pain killer with the prescription of a doctor -Home visits	+ +

Components of HBC in model classified as Home Visiting in Zambia

Components	FOCA
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ ?
- Facilitation of IGAs - Orphan support	+ ?
- Referral -Training/capacity building	+ +
-Provision of food supplements - *ART (referral)*	+ +
-Access to simple pain killers only -Direct access to ART	+ ?
-Access to strong pain killer with the prescription of a doctor -Home visits	? +

Components of HBC in the model classified as government district level HBC in Tanzania

Component	KINONDONI
-Counseling/Psychosocial support -Nursing care & Treatment of opportunistic infections	+ +
- Facilitation of IGAs - Orphan support	? ?
- Referral -Training/capacity building	+ +
-Provision of food supplements	+
-Access to simple pain killers only -Direct access to ART	+ +
-Access to strong pain killer with the prescription of a doctor -Home visits	? +

Comments on the models

1. Seven out of twelve services reviewed, were CHBC models. There is a strong community involvement in these models. The community involvement is congruent with the African culture of collectivism.

2. Of the models reviewed, ICHC offered more comprehensive services.

3. ICHC had characteristics that favored sustainability whereas CHBC had characteristics that made it more efficient in team work at the community level

Theme II

Examining the home based care models for PLWHA and understanding their strengths and gaps for palliative care provision.

Strengths of ICHC and CHBC models

Model	Common strengths	Unique strengths
ICHC	1. Teamwork 2. Guidance and policies available 3. Political good-will 4. Community involvement 5. Volunteers 6. Strong support from CBOs NGOs, FBOs and donors 7. IGAs 8. Support of founders 9. Networking 10. Training programs *The effectiveness of HBC is attributed to these common strengths.*	1. Strong govt. structures and systems 2. Technical staff 3. Two way flow of referrals via CCC desk 4. Capacity building of both staff and community 5. Stronger networking *Sustainability of ICHC is attributed to these unique strengths*
CHBC		1. Strong community involvement 2. Dedicated volunteers 3. Strong boards *The appreciation of CHBC model by communities, is attributed to these unique Strengths.*

Gaps found in ICHC and CHBC models

<table>
<tr><th>Model</th><th>Common gaps</th><th>Unique gaps</th></tr>
<tr><td>ICHC</td><td rowspan="2">1. Inadequate capacity to mobilize resources
2. Donor dependence
3. Inadequate knowledge of HBC by providers
4. Failure to implement government policies</td><td>1. Understaffing
2. Transfer of MOH staff after training</td></tr>
<tr><td>CBHC</td><td>1. Inactive volunteers
2. Lack of several components of HBC (strong pain killers, skills for PC, ARVs, skilled staff)
3. Minimal male involvement</td></tr>
</table>

Challenges to HBC

Model	Common challenges	Unique challenges
ICHC	1. Financial resource constraints 2. Brain drain 3. The priority needs of PLWAs are changing to economic empowerment 4. Shift in donor interests 5. Lack of comprehensive Palliative Care 6. High expectations from clients 7. Increasing defaulter rate	1. Motivation of technical staff
CBHC		1. Stress of volunteers due to nature of work 2. Rising number of orphans

Strengths, gaps and challenges found in Home visiting and Government District Level HBC

- So far, only one model classified as home visiting and another as government district level had been reviewed.
- Generalization about these two models was not appropriate.
- There were no strategies to ensure operational research including M&E in the area of HBC/PC services
- There were no reference inventories of HBC/PC service providers in the project countries.

Issues of integration of Palliative Care in HBC

- All services provided some components of PC such as SPS, spiritual support and treatment of opportunistic infections
- There was no service with a comprehensive package of HBC including holistic PC
- Government policies were restrictive regarding access to strong painkillers in HBC
- Knowledge and skills regarding administration of holistic palliative care were generally inadequate

Theme III
Discovering if there were any "best practice models for HBC for PLWHA" that could be promoted by APCA for adaptation by countries across Africa.

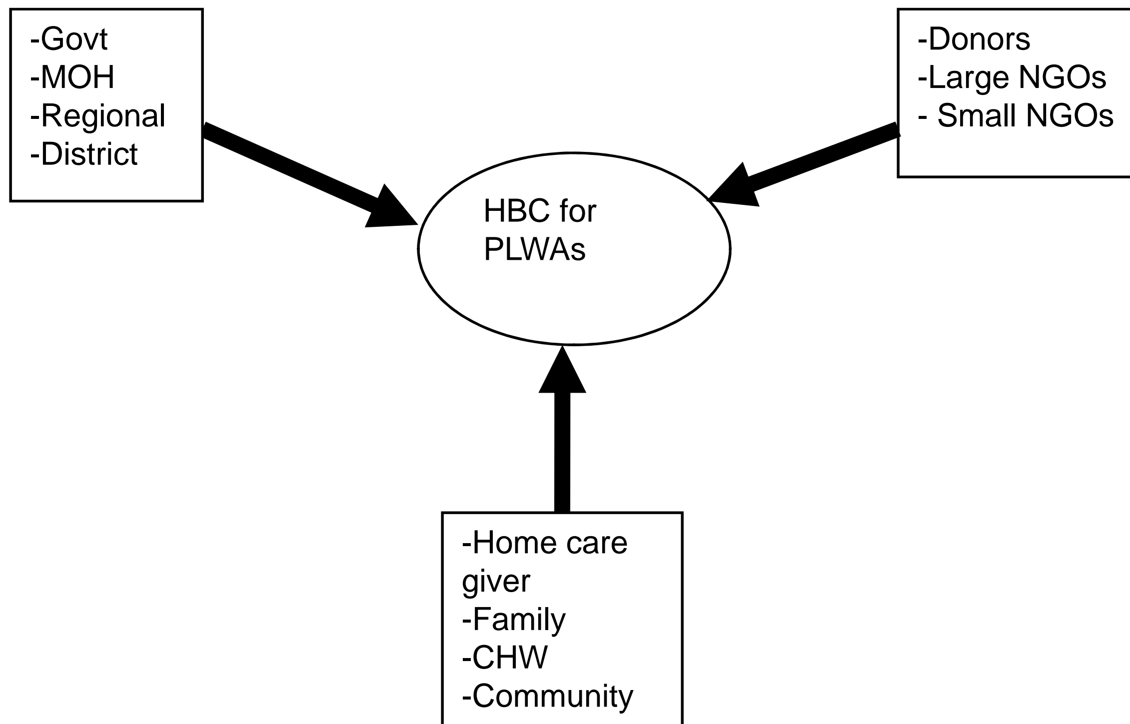
Criteria for determining best practice model

In this review, it was observed that the HBC for PLWAs and their families was influenced and supported by at least three pillars:

1. Community participation – responsible for actual provision of HBC to PLWAs
2. Government - responsible for creating an enabling environment for HBC (policy, administration and support supervision)
3. Donors and NGOs – responsible for capacity building of all stakeholders

See conceptual framework in the next slide

Conceptual framework



Best practice model

- The better model was that which :

a) Had a more comprehensive list of HBC components

b) Utilized larger sections of each of the three pillars
i.e. it called into play a wider list of stakeholders and therefore was more sustainable (refer to conceptual framework in [previous slide)

- According to the above criteria, the best practice model was ICHC followed by CHBC and Home visiting

Theme IV
Determining practical recommendations that can be made for the integration of all aspects of palliative into existing home-based care services for PLWHA

Recommendations

1. Advocate for promotion of ICHC model which lends itself easier to integration of PC into HBC
2. Advocate for governments to adjust policies to enable access to strong pain killers
3. Advocate for easy access to ARVs in HBC
4. Advocate for capacity building in HBC (financial resources, skills & knowledge regarding PC, ARVs and human resources development)
5. Design strategies that address economic empowerment of communities/PLWAs
6. Strengthen operational research including M&E in the area of HBC/PC
7. APCA to promote establishment of an inventory of HBC and PC services in Africa.