

So what and where to from here?

Background reading about the STEP-UP programme for the November 2014 exchange visit

Introduction

The Palliative Care Association of Malawi's (PACAM) STEP-UP programme aims to ensure the provision of sustainable, accessible palliative care services for adults, children and their families through district health delivery system in the 13 districts of southern Malawi. The programme is currently in phase two, earmarked for two years with financial support from True Colours Trust. The table below gives a summary of what we want to achieve, how we will achieve it and how successful implementation will be measured.

Table 1: Key activities in the STEP-UP programme, 2013-2015

What do we want to achieve?	How will we do this?	How will we know we have succeeded?	What tools will we use to measure success?
Objective 1: increase knowledge, skills and awareness of palliative care among staff in the 13 district hospitals	<ul style="list-style-type: none"> provide training in palliative care for seven hospitals train 21 people in paediatric palliative care provide leadership training for 13 palliative care co-ordinators provide mentorship and supervision to 13 hospitals provide clinical placements develop two District Hospitals into clinical placement sites provide opportunities for leaders and health professionals to get together to share successes and lessons (including an exchange visit for two hospitals) 	<ul style="list-style-type: none"> there will be an improvement in reported palliative care knowledge and skills among those trained (50% will report improvement at follow-up) two hospitals will fulfil all the criteria to become clinical placement sites all 13 districts will include palliative care in their district implementation plans 	<ul style="list-style-type: none"> activity log of training, events, mentoring and placements completed and number of participants survey before and after training and at annual meetings follow up interviews with staff and stakeholders towards the end of each year
Objective 2: improve the quality of palliative care provided in the 13 district hospitals (such as better pain relief)	<ul style="list-style-type: none"> provide equipment and resources to help refurbish rooms in seven hospitals ensure continuous supply and accessibility of morphine by April 2015 by providing training and annual follow up visits to 13 district pharmacy sites by the Drug Access and Availability Officer 	<ul style="list-style-type: none"> all 13 hospitals will have a room used as a palliative care clinic and staff trained to provide palliative care between October 2014 and March 2015 all 13 district hospitals will have access to a supply of morphine at least 75% of the time 	<ul style="list-style-type: none"> activity log of equipment provided, training and follow-up visits and participants records of the number of patients supported and drugs supplied at hospitals (using official Ministry of Health supervision form) pharmacy supervision checklist photographs
Objective 3: improve the quality of palliative care provided outside hospitals by increasing knowledge and skills among home-based care providers and other community stakeholders in the 13 districts	<ul style="list-style-type: none"> train home-based care providers in seven districts conduct a one day orientation workshop for health surveillance assistants, social workers, religious leaders, traditional healers in each of the 13 districts run one orientation session for IEC professionals from all 13 districts provide palliative care branded golf-shirts to health professionals and t-shirts to home-based care providers to raise awareness 	<ul style="list-style-type: none"> there will be an improvement in reported palliative care knowledge and skills among home-based care staff, social workers and other community stakeholders (50% will report improvement at follow-up) all 13 districts will have trained home-based care staff 	<ul style="list-style-type: none"> activity log of training, workshops and t-shirts disseminated home visit quality checklist completed during supervision visits survey before and after training and at the end of short events interviews towards the end of each year with stakeholders

Planned activities

In the period between June 2014 and November 2014 STEP-UP planned to undertake the following activities from the master plan above selected from the three objectives:

- Finalisation of new clinical placement sites
- To provide clinical support to the two sites earmarked for clinical placement
- Conduct HBC Volunteers PC Training – Phalombe, Neno and Chikwawa districts
- Continuation of Room refurbishment
- Facilitate Clinical placement at Queen Elizabeth Central Hospital for the district PC providers
- Organise Educational visit for the two districts in preparation for the clinical placement - Mulanje to Queen Elizabeth Central Hospital
- Organise Educational visit - Mangochi to Queen Elizabeth Central Hospital
- Finish a session of Providers Training that was a back log from year one of phase two
- Organise Opiates Training.
- Conduct Coordinators meeting.
- Clinical placement at Mulanje district hospital
- DHMT Meetings to Phalombe, Chiradzulu, Chikhwawa and Blantyre
- Mentorship and supervision to all the 13 districts
- HSA/ social worker/ religious leader's orientation for Neno
- Clinical Placement at Queens- Chiradzulu and Machinga
- Exchange Visit to Kenya

What has STEP-UP done? (Progress made so far)

As we are reporting on the progress made so far in this phase showing progress on the planned activities against the overall objective of STEP-UP, this report will create a forum for discussion on the 'so what?' to reflect the impact of the activities for our patients, families, staff, organisations and health delivery service as a whole. This will help us understand where we are making real difference and where we have more work to do. It will also demonstrate which of our activities are having the biggest impact and explain the reason why.

Since we are going deep into the second year of this phase of the project the report shall serve as a midterm review that will take us to the next steps to enable us plan for continuation while putting up measures to help us sustain palliative care service delivery without solely depending on the donors.

On capacity building to ensure that palliative care is available at hospital level, STEP-UP has now managed to train all the providers planned for this project and we are continuing offering scholarships for clinical placement. The number of people earmarked to undergo clinical placement do not match with the capacity of the clinical placement centre currently Queen Elizabeth Central hospital. This is because the uptake is low and the time needed for clinical placement is long. Usually we send two that are expected to complete two weeks of clinical placement.

Two districts earmarked to become clinical placement centres are almost set and very soon placement of providers will commence. Mangochi clinic needed partitioning to improve patient's privacy and this is done. Examination kits comprising of weighing scale, thermometers, Blood Pressure machine and stethoscope was procured and delivered. Representatives made an education visit to QECH Umodzi and Tiyanjane to appreciate clinical placement.

The same supplies were procured for Mulanje and the team is yet to come to QECH on an educational tour.

Clinical placement timetable for the two sites were brainstormed during Fred's clinical placement and clinical support to the two districts. Everything seems feasible. The gaps identified and communicated to management for consideration.

Room refurbishment has progressed well with six out of seven budgeted districts have their funding disbursed and work is almost through.

So far during this period 8 providers have undergone clinical placement out of planned 44.

We are now through with PC training and so far a total of 71 Providers have been trained by STEP-UP against the planned 70.

All sessions planned for opioids prescribing were done and in this phase STEP-UP has trained 60 Prescriber out of planned 60.

Due to management change-over the team planned to organise management briefing and sensitisation on the concept of palliative care and STEP-UP project. During this period we have managed to conduct two meetings with Phalombe and Chiradzulu district.

Mentorship and supervision is on track and during this period the team managed to supervise 12 districts out of the planned 13. The remaining district is Blantyre. Blantyre is still lagging behind and it is left for special arrangement. Management is aware of the coordination challenges and promised to look into that.

The progress made so far was equally shared with the districts and each district through the coordinators meeting was able to give highlight on the status of palliative care in their districts focusing on their strength weaknesses opportunities and threats.

During the coordinators meeting which was held in Zomba the team used a different approach to capture the above information while promoting learning among the coordinators. Through group work each district shared statistics on the following indicators as contained on their routine quarterly report form:

1. Number of trained palliative care service provider.
2. Workload; Number of patients on program.
3. Drug availability
4. List of stake holders assisting the implementation of palliative care service at institution level and the form of support.
5. General successes/strength in the implementation of palliative care.
6. General challenges encountered in the implementation of palliative care.
7. General comments on the possible solutions.

In addition there was enough time for each district to share own evaluation using SWOT analysis. Below is the summary of what came out from the districts.

Strength:

Generally the districts highlighted that they feel there are a number of strengths which include the increased number of patients being enrolled for palliative care, having a specific room to provide the service, Improved availability of drugs, having the supportive management and increased number of palliative care providers.

Weakness/challenges:

Poor coordination, Lack of transport for patient follow up, only few community home based care volunteers are trained in palliative care, few trained providers have undergone clinical placement and increase staff turnover.

Opportunities:

Management is more willing to support the program, availability of stakeholders such as PACAM and STEP-UP project, increased demand for palliative care service, Availability of community home based care volunteers, availability of trained providers and improved availability of drugs through government funding.

Threats:

Unstable economic environment for the country, ever changing political environment and donor dependency

HAS, Social worker, religious leaders and traditional healers orientation:

Mentorship and supervision for Neno was combined with a session of HAS, Social workers, religious leaders and traditional healers' orientation. The session went well and was well represented.

The other three remaining activities on the work plan will go as planned; the exchange visit to Kenya is on and by the end of November the HBC training planned for Chikwawa will take place along with another round of clinical placement.

Table 2 summarises our progress.

Table 2: Progress as of October 2014

Activities planned to achieve objectives	Progress towards activities	Measures of success / targets	Impacts to date (as of October 2014)
Objective 1: increase knowledge, skills and awareness of palliative care in the 13 district hospitals			
Provide training for 26 new Palliative Care providers.	26 providers trained (100% complete)	50% will report improved knowledge and skills	More than 95% reported improved knowledge
To train 26 members of the management team in PC providers training to become palliative care ambassadors. (5 days)	Scheduled for later in the year two	50% will report improved knowledge and skills	Scheduled for later in the year
To Provide clinical placements for 44 trained Palliative Care providers	8 providers have so far undergone clinical placement	50% will report improved knowledge and skills	100% reported improved knowledge
To provide District clinical support by STEP-UP Clinician and Nurse to the two clinical placement sites	So far a clinician has managed to spend two weeks to each of the clinical placement site	Systems to support clinical placement in place ie draft rota, essential equipment procured.	Sites now recommended for placement uptake.
To provide starter pack of basic tools e.g. office improvement and provision of reference books, checklist	Basic tool such as clinical examination kit procured and distributed.	Two Palliative care clinic provided with basic tools	100% reported having received the basic tools.
To conduct mentorship/supervision visits twice a year to the 13 district sites	12 out of 13 districts visited for mentorship and supervision	Districts will report improved knowledge and skills	Qualitative feedback suggests improved knowledge
To conduct regional coordinators meetings twice a year	One out of two meetings conducted 50%	90% of the coordinators will attend the meeting	95% attended the first meeting.
To organize District Health Management Teams for 6 of the 13 Districts for PC sensitization:	Two out of six meetings conducted 33.3%	50% management members report improved knowledge and awareness of PC	95% management members report improved knowledge of PC and STEP-UP
Objective 2: improve the quality of palliative care provided in the 13 district hospitals			
Provide resources to help refurbish rooms in seven hospitals	Funds provided to seven districts	7 additional districts hospitals will have a room used as a palliative care clinic and staff trained to provide palliative care	6 rooms refurbished with PC services running.
Train 20 prescribers about opiates	20 trained (100% complete)	50% will report improved knowledge and skills	More than 95% reported improved knowledge
Printing of Palliative Care Clinic registers	Scheduled for later in the year to be coordinated by PACAM secretariat and MOH.	90% of the palliative care clinic using standard palliative care registers	
To review National Palliative Care Training materials for purposes of standardization.	Scheduled for later in the year to be coordinated by PACAM secretariat / MOH.	100% of certified palliative care training to be based on standard presentations.	
Objective 3: improve the quality of palliative care provided outside hospitals by increasing knowledge and skills			
Train 100 home-based care providers in five districts	40 trained (45%)	All 13 districts will have trained volunteers 50% will report improved knowledge	100% of trained volunteers reported improvement knowledge and skills
Run one-day workshop for HSAs, social workers, religious leaders, traditional healers in each district (260)	One session of 20 done	50% will report improved knowledge and skills	100% reported improved knowledge and skills
Run one orientation session for IEC professionals	Scheduled	50% will report improved knowledge and skills	Scheduled for later in year two
Exchange visit to Kenya to learn from KEHPCA for best practice sharing	Kenyan team came to Malawi.	Both teams will participate in the exchange visit	
Project Monitoring and Evaluation by PACAM and MOH	Scheduled for later in the year to be done by PACAM secretariat and MOH.		

What impact has STEP-UP had?

Increasing knowledge and confidence about palliative care in district hospitals

STEP-UP is achieving its objective to increase knowledge and confidence about palliative care within the 13 district hospitals. This is evidenced by more than 95% of palliative care co-ordinators and providers taking part in training and clinical placements reporting to having improved knowledge and skills based on pre and post-test measures.

With the increased number of palliative care providers in the districts, palliative care services are widely covered in the hospital. Almost all the sections of the hospital have nurses and clinical officers trained in palliative care. With some district allocating full time personnel to manage palliative care clinics.

Before STEP-UP project, line managers were reluctant to release staff to cover palliative care clinics. During the recent round of supervision, we have learnt that each clinic is maintaining a clinic staff rotation that is working well as opposed to the past where the clinic was only left to few individual providers mainly coordinators.

The management support is attributed to the high level of awareness achieved by STEP-UP to persistent engagement with District Health Management team and the level of confidence achieved by the trained providers to engage with the same management. There is recognition of palliative care service even in the district pharmacy.

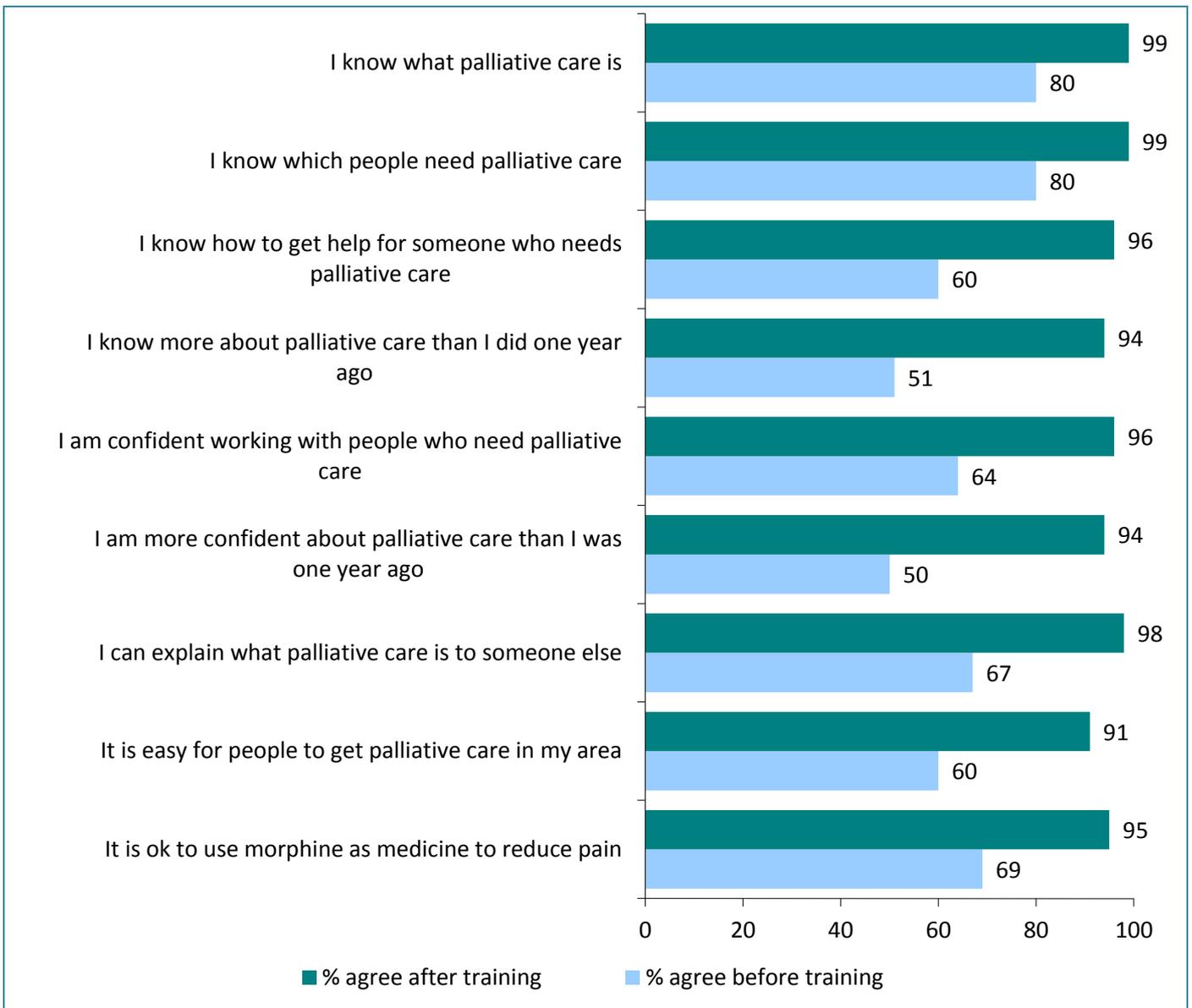
One nurse had this to say *“Our clinic rota is now integrated into the main hospital rota and the clinic is always covered without problem.”*

And the patient collaborated to say; *“nowadays this clinic is always open and covered with a provider. In the past you could travel on your appointed day only to hear that the nurse is not available the clinic is closed come next time. This had a negative effect on us since we struggle to find money used for transport to get here.”*

Nowadays I feel more confident and I can respond to any call to attend to a palliative care patient because I know the approach. Palliative care training has helped me to become more competent. I feel my attitude has changed.....even by behaviour is not the same. I encourage my fellow clinician who have difficulty personalities to join palliative care for them to change. Kumanda PC Coordinator for Mwanza district.

We conduct surveys before and after each training activity to assess changes in self-reported knowledge and confidence. Our survey data suggest that the training is having an impact on increasing knowledge and confidence. We have 369 before and after assessment forms from our training in introduction to palliative care, leadership training, children’s palliative care, pain management and community leaders training. Taking all of the courses together, Figure 1 shows that there is a clear improvement in self-reported knowledge and confidence after taking part. These improvements are equally likely whether the person attending training is a volunteer, provider, palliative care co-ordinator or community or religious leader.

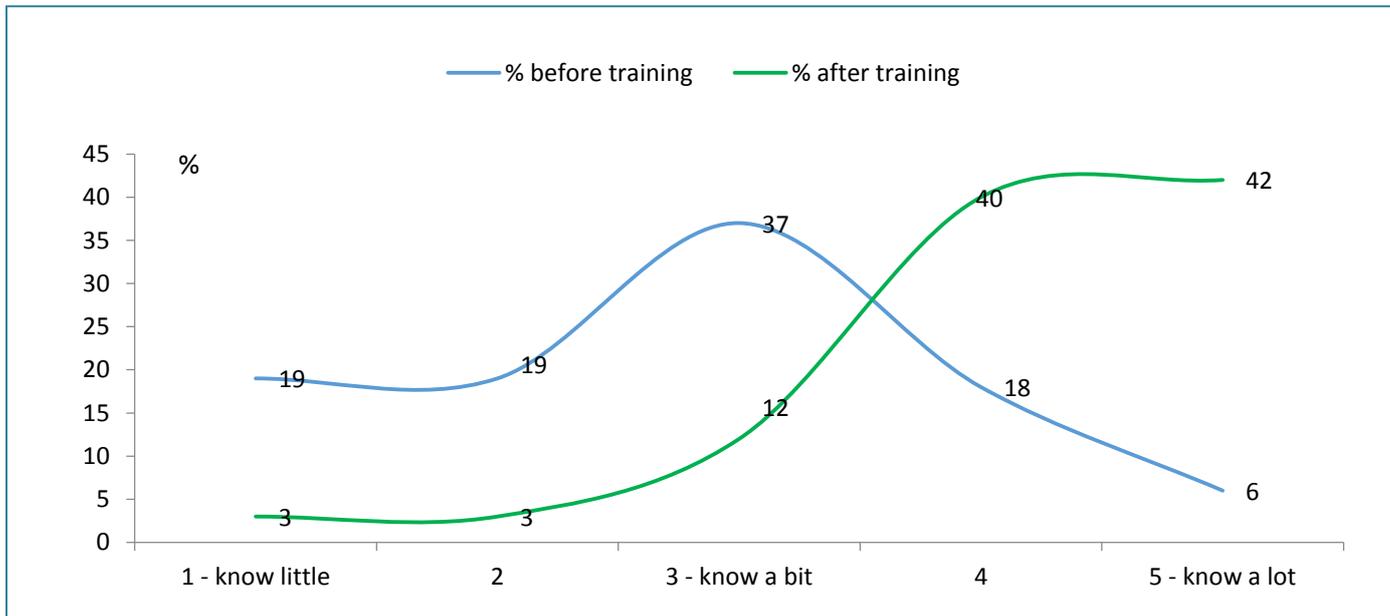
Figure 1: Changes in self-reported knowledge and attitudes before and after training



Note: based on 369 forms.

We also asked 'On a scale of 1 to 5, where 5 is the highest, how much do you know about palliative care?' Before training, the average score was 2.7 out of 5. After training this had risen to 4.2 out of 5. Before training, 24% said they knew a lot (4 or 5 out of 5). After training, this had increased to 82% (see Figure 2).

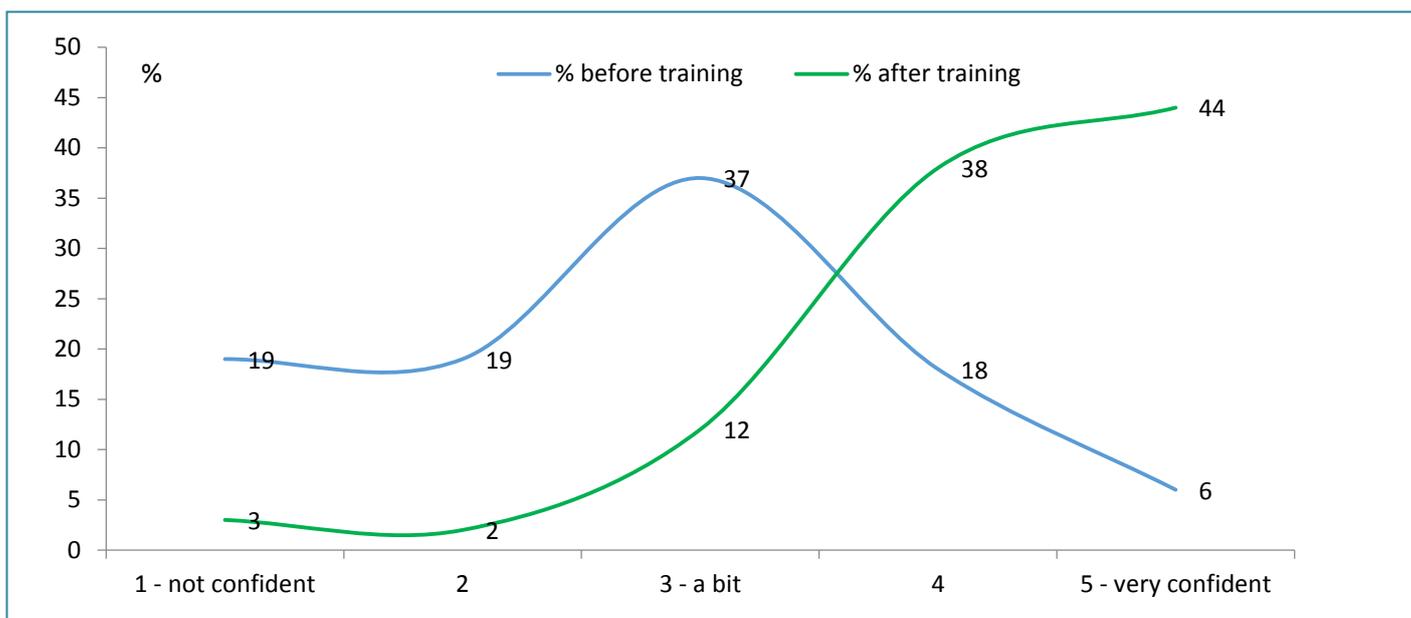
Figure 2: Changes in self-assessed knowledge before and after training



Note: based on 369 forms.

In answer to the question 'On a scale of 1 to 5, where 5 is the highest, how confident are you about palliative care?' Before training the average score was 2.7 out of 5. After training this had risen to 4.2 out of 5. Before training, 24% of people said they were very confident (4 or 5 out of 5). After training, this increased to 82% (see Figure 3).

Figure 3: Changes in self-assessed confidence before and after training



Note: based on 369 forms.

Increasing palliative care in hospital

STEP-UP is achieving its objective to increase the quality of palliative care in the 13 district hospitals. This is evidenced by 85% of hospitals having access to morphine at least 75% of the time over the past six months. Hospitals making progress to refurbish their palliative care rooms to make palliative care service more visible as you can see in the picture below.



Mwanza district hospital palliative care room

In addition to the above management is now able to supervise coverage of palliative care clinics. The hospital matron in Chikwawa said,

“We are assured of coverage because the nurse is specifically allocated to palliative care and we let others support him.”

Long queues of patients continue to be noticed in clinics such as Mangoch, Mulanje, Balaka, Chiradzulu, and Thyolo. These queue are a clear testimony that patients have developed trust in the service and one patient had this to say:

“Through palliative care clinic, I have a better understanding of my condition. This is very different from the approach used in the general clinic where drugs were administered to us without any explanation. We couldn’t understand the importance of adhering to pain medication.”



Table 3: Data from monitoring forms completed by hospitals

	Balaka	Chikwawa	Chiradzulu	Machinga	Mangochi	Mulanje	Mwanza	Neno	Nsanje	Phalombe	Thyolo	Zomba
Latest reporting	Q2, 2014	Q2, 2014	Q2, 2014	Q2, 2014	Q2, 2014	Q2, 2014	Q3, 2014	Q2, 2014	Q2, 2014	Q2, 2014	Q2, 2014	Q4, 2013
Total NEW adults (latest quarter)	9	55	7	7	31	40	58	16	15		15	No data yet
Total NEW child (latest quarter)	0		0	0	3	2	11	0	8		34	
Level 1 drug availability in last 365 days	90	365	365	365	365	90	365	90	365	365		
Level 2 drug availability in last 365 days	0	0	0	0	0	0	0	90	90	0		
Level 3 drug availability in last 365 days	90	365	198	195	90	250	365	60	60	365		
Pain relief adults (latest quarter)	159				591	675	58	5	10		275	
Pain relief children (latest quarter)	4				3	6	11	0	0		46	
Oral morphine adults (latest quarter)	40				43	79	36	10	8	57		
Oral morphine children (latest quarter)	0				3	1	11	0	0	6		
MST adults	0				27	0	17	7	2	0		
MST children	0				0	0	0	0	0	0		
Total trainers (all figures cumulative from this point on)	2	2	0	2	4	2	4	1	1	3	2	
Total trained doctors	0	0	0	0	0	0	0	2	0	0	0	
Total trained clinical officers	5	2	3	5	12	30	5	7	6	3	6	
Total trained D/tech	0	0	0	1	0	2	1	0	1	0	0	
Total trained P/tech	0	2	1	1	2	2	2	2	1	1	1	
Total trained nurses	7	11	4	7	18	106	4	10	8	8	21	
Total trained HSA	0	0	0	2	0	30	0	0	0	0	6	
Total trained others	1	0	0	0	0	0	0	0	0	0	4	
Total trained volunteers	19	0	0	0	29	284	20	20	20	20	21	
Total trained paediatric orientated	3	3	1	4	3	5	5	4	2	3	2	
Total	1	0	0	111	0	616	20	5	2	20	5	

Increasing palliative care outside hospital

STEP-UP is achieving its objective to increase knowledge and confidence in palliative care outside hospitals. This is evidenced by increased number of home-based care volunteers being trained and 100% of these volunteers saying they had increased knowledge and skills after training. It is only STEP-UP so far that is moving on with this initiative. Much as other organisation would want to undertake this initiatives it seems they lack capacity in terms of skills and resources to do that. Districts are very appreciative of this gesture.

There have been many successes in year one. In year two the focus is on;

- (a) Increasing knowledge about palliative care in home-based care teams and amongst the wider community through training and awareness raising events. By the end of year two each district will have at least 20 community home based care volunteers trained in Palliative care. So far we have done these training in 10 districts and the total number of volunteers trained are 100.
- (b) Strengthening the quality of our mentoring visits so that we can facilitate improvements in the overall quality of care. Now our approach to mentorship has changed from hands on palliative care service delivery by members of the STEP-UP team (mentors) to more observation on how the trained providers are offering the service. We thereafter have time to discuss patients on case by case basis.
- (c) Working more closely with senior managers in hospitals and in PACAM. The relationship between STEP-UP team and senior managers in the district is working well from strength to strength with most districts highly regarding the STEP-UP as partners in development. They are more supportive and free to share with the team the contents of the district implementation plan.



Participants to a Home based care volunteers PC training in Neno



Home visit in Nsanje



Home visit in Mwaza

Our hope was that district providers will be in a position to start patient follow up at community level but up to now this is not happening and the main reason cited is lack of transport. STEP-UP vehicle in this regard is playing an important role to make sure that each district in the southern region have a feel of a home visit. This has led to number of patients seen at home to be on the lower side although the service is appreciated.

The general challenge is the economic situation Malawi is going through and the budgetary allocations this year is not sufficient enough to include new activities. As STEP-UP we are happy to note that there is strong will and commitment on part of the management as opposed to the begging of the project.

What is working well?

PACAM remains committed to supporting the project staff with more understanding and dedication now than before. The environment still remains favourable for STEP-UP to achieve its objectives. The districts continue to be open and positive about the initiative with seemingly increased expectations.

District management teams are more supportive than previously. This is evidenced by willingness to release palliative care trained providers to cover palliative care clinics. The staff rotation for the clinic is now widely accepted by the hospital management. When there is shortage of staff to cover the clinic management is now able to hire staff on temporary ground to cover palliative care clinic.

Essential palliative care drugs continue to be available in almost all the districts which is a sign of recognition of palliative care services although this has been observed from the district hospitals alone. The situation in the health centres remain unsatisfactory. Patients have to still travel long distances in order to get treatment. Most palliative care patient are bed ridden in their homes. There is a challenge for these patients to travel. It would be better for them if home based care is strengthened as a Malawian model of delivering palliative care.

Everything we see in the districts was not there as we were starting the project in September 2011. Palliative care services have been widely accepted by District Health Management Teams and we can challenge an independent evaluation that can see its way to the districts to seek views/opinion of management member without necessarily going through us.

The big question remain on what is the quality of palliative care service being provided and how are we going to sustain these gains? STEP-UP acknowledge the gap that is still there at community level. There is a big challenge to ensure continuation of care and support once the patient is discharged home. The number of volunteers trained do not match with the demand. Currently STEP-UP is only training 20 volunteers per district but ideally there was supposed to be 10 volunteers per village.

The STEP-UP team is particularly proud of having organized a sensitization workshop in Neno for HSAs, Traditional leaders, Tradition healer and social workers. This was a very good multidisciplinary team that is based at community level and this is a significant milestone. We envisage that there will be improved understanding of palliative care at community level following these sessions. The outcome of this session has encouraged us to move on with this activity to all the 13 districts in the southern region of Malawi where about 260 participants are targeted.

The current set up enables the project team to be in constant communication with the district as a result the fire is always burning. The team has established a helping relationship with the district palliative care providers and we regard each other as partners in developing palliative care because of the hands on involvement. STEP-UP does not just give instructions for district to follow. Our visits to the districts are treated as supportive because of the contribution the team make on various aspects of service delivery including mentorship which provide immediate relief when providers are faced with difficulty palliative care cases.

Management involvement has transformed the entire set up because they are now approachable. Providers needed recognition which has been achieved through management understanding of the concept of palliative care.

A small financial contribution made by STEP-UP towards room refurbishment has proven that it was a very good idea and has provided an incentive to encourage each hospital to set aside a room for palliative care service making the service more visible, accessible while promoting privacy and cut on patients time to queue along with the general patients.

Capacity building through training and clinical placement has increased knowledge, skills and confidence among palliative care providers. More people are now practicing palliative care with those who had a chance for clinical placement leading the way because of increased confidence to manage challenging cases.

Knowledge on how to prescribe and handle drugs has consequently led to sustained availability of palliative care essential drugs. This was not the case before. People had tried to advocate for availability of drugs without necessary emphasising on the use of various essential palliative care drugs.

The regular team visits to the districts is working well and providers have a lot of expectation on the mentorship and supervision visits. During these visits the team find chance to discuss complicated palliative care cases.

Challenges

During the period under this report, STEP-UP has experienced a stable environment without many challenges affecting operations. However, it has not been easy on our part due to extensive travel to the district. The workload was just too much and the team had to work long hours in the district. The weather was too hot and there are poor accommodation and food in most of the districts.

An observation on the quality of service being provided in the district is that although we are celebrating improved availability of pain control medication such as morphine, the prescribing practices remain poor. This makes patients think morphine is not effective. The main factor is that patients are left with the starting dose without titration due to lack of patient follow up. Transport is not readily available in the districts. We are encouraging hospitals to adopt pain management protocols and we are working with PACAM to provide special training in pain management using opioids. There is also a need to scale up palliative care training targeting more health centre staff.

Through our mentoring visits we continue to educate teams about drugs. There is improved knowledge and skills. Practice will enhance change of attitude. This is the main reason we recommend that mentorship and supervision should remain an ongoing program probably integrated into the ministry of health activities as done by the national ART program. Clinical placement should be extended to as many providers as possible because we see significant differences between providers who have undergone clinical placement and those that have not.

Providers are encouraged to continue with team meetings which most districts are unable to conduct routinely in order to discuss operational challenges and plan together.

In some districts patients are still experiencing double queuing as the palliative care clinics are not supplied with all the drugs. When a patient is seen in the clinic, a prescription is made for him/her to go and get the medication from the hospital pharmacy along with the general patients.

It is observed that majority of the enrolled palliative care patients are diagnosed with Kaposi's Sarcoma. This is the most common cancer in Malawi and is associated with HIV/AIDS. This is a fast growing cancer that can rapidly spread to all parts of the body. A drug known as vincristine is used as monotherapy in Malawi to slow the progression of the disease. There is evidence that this works well when combined with ART that helps to build the patient's immunity. However, little can be achieved when the drug is introduced when the patient has an advanced disease and unfortunately most palliative care patients are in their terminal stages of their illness. Due to lack of knowledge about how these drugs work, we have discovered that patients are still asked to travel long distances to receive this chemotherapy without proper counselling about the expected outcome. The administration of this drug is raising unnecessary hope to these patients and their family members. From our previous supervision it was disappointing to note that providers were not clear on the goal of care for these patients. Mentorship visits have provided an opportunity for case management discussions, emphasising pain and symptom control. The issue of wound care is currently among the topics that are handled with emphasis during case management meetings because advanced Kaposi's Sarcoma can produce a nasty smell that no one can cope with, including the patient. This can lead to isolation and lack of interest in food so people's quality of life becomes severely compromised.

Through our mentorship visits we have shown providers how to improve their wound care skills and use crushed metronidazole to reduce the bad smell. We were also able to discourage providers from continuing these patients on chemotherapy even when there is no progress. This is one example of how the STEP-UP team is needing to provide practical advice and support to upskill providers on an ongoing basis.



Patient with advanced KS in the guardian shelter at Chikhwawa District



A patient found in Thyolo recently with advanced and disseminated Kaposi Sarcoma.

We continue to experience slow response from the district and lack of pro activeness. This has led to the project missing out on deadlines for some activities especially those that were dependent on the availability of the entire management team. STEP-UP failed to conduct the planned DHMT meetings because of this reason. The project appreciate that there are many other important priorities too. This means that STEP-UP needs to be in constant communication with the district authorities to advocate for palliative care.

Hospitals are plagued by constant staff turnover of management and providers. This has created a need for sensitisation to be considered as an ongoing activity in order to capture new team members joining the district. Despite all these challenges, STEP-UP is currently impressed with the response at district level and we now believe that the general objective of integrating palliative care into the district health delivery system has been achieved.

Next steps: where to from here?

We feel the project has generally met the overall objective and our recommendation is that it can now be subjected to independent evaluation in order to see how the findings will collaborated with our impression. The project used an element of advocacy which is supposed to be an ongoing activity. Deliberated effort need to be set aside to ensure that the gains are sustained in the long term. Activities such as regional review meetings with the coordinators, mentorship and supervision as well as support for clinical placement need to be maintained.

Future mentorship and supervision can be conducted under the leadership of the ministry of health headquarters which can coordinate a team of supervisors selected from palliative care implementing sites such as PCST, College of Medicine, Ndimoyo Palliative care centre, representatives from the health zones and PACAM.

At the same time, STEP-UP would like to respond to the demand for same project to be rolled out to other regions. The approach will not be that of one size fits all the districts. The region will benefit from a specially designed project that will be developed basing on the findings of the comprehensive base line survey to identify specific gaps and challenges within these region bearing in mind that there are pocket of palliative care programs already underway in the regions. As STEP-UP was busy in the southern region PACAM through local funding from the National AIDS Commission was doing some activities which need to be considered.

The baseline is planned to be carried out within the first half of 2015 so that the report is ready in May the same year. STEP-UP is also appealing for serious involvement of all the concerned parties such as PACAM, Ministry of Healthy, True Colours Trust, the Evidence Centre and other palliative care implementing sites within the regions to avoid duplication of efforts. There shall be a relocation of STEP-UP Blantyre office to be strategically placed in Lilongwe for easy coordination.

Key lessons and advice

During the course of project implementation, STEP-UP has identified the following lessons:

- Palliative care service delivery remains a team effort and requires ongoing support. One-off interventions will not work to sustain the service on the ground, so ongoing follow-up is needed.
- Training alone is not enough. Prior to STEP-UP, some providers in the districts had been trained by the Ministry of Health but there was no follow-up support and management often did not know that they had trained providers within their districts. It was hard to make use of them. Having a co-ordinated approach that informs management and fuels a constant supply of trained providers is necessary for sustainability.
- Getting senior management involved and make them understand earlier on is crucial for success as these people control budgets, room allocations and staff time.
- Small incentives, such as funds towards room refurbishment, can encourage Districts to set aside a room for palliative care.
- Combining a bottom up (staff-focused) and top down (management-focused) approach may have the greatest impact.
- Regular contact with the district through forums such as coordinators meetings and mentorship visits is key to sustaining gains.
- Training community workers may improve the referral system and improve the quality of palliative care provided at home.