5 YEAR STRATEGIC PLAN FOR PALLIATIVE CARE SERVICES

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Introduction to Palliative Care

Palliative care supports the person with a life-limiting illness and their family to offer quality care and to make dying easier (Clark 2007). It is a concept that not only addresses pain and symptom control but also considers the psychosocial and emotional suffering of the seriously ill person, and supports the family as they care for their loved one (WHO 2014).

The latest definition of palliative care as used by the World Health Organisation is:

> 'an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.' WHO (2002)

Palliative care for children as defined by the World Health Organisation is:

> 'The active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease'. WHO (1998)

The roots of the modern palliative care movement started in the United Kingdom in the 1950s and 1960s (Wright *et al.* 2006). Now, palliative care is an important part of the world health agenda; on May 22nd 2014 the World Health Assembly passed resolution EB134.R7, which requires that member states address palliative care within the continuum of care. The resolution states unequivocally that relief from pain, whether physical, psychosocial or spiritual is the ethical responsibility of health care professionals and the governmental institutions that support health care provision. Therefore governments are required to include palliative care in the planning and implementation of health care services. This includes having appropriate palliative care policies at the local and national levels, providing budgetary support, ensuring appropriate access to needed medications and supporting training and ongoing education on palliative care (WHO 2014).

This plan discusses the continuing scale up of palliative care services in Ethiopia. To unpack this important issue, four pertinent questions will be addressed.

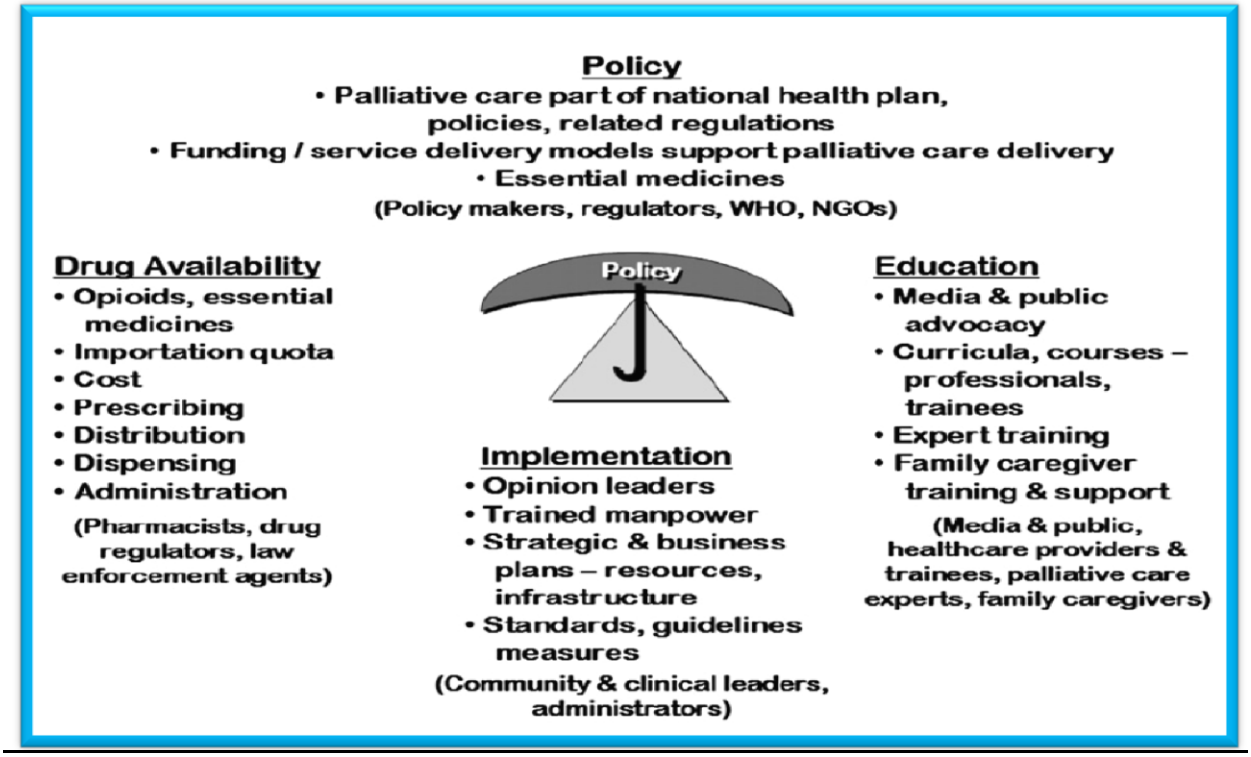
- What is the situation in Ethiopia at present?

- What are our goals for the next five years?
- How do we realistically implement these goals?
- How do we monitor and evaluate services?

What is the situation in Ethiopia at present?

The Federal Ministry of Health (FMOH) recognises the importance of palliative care as part of the country's health strategy and has been working over the last four years to improve services. Palliative care has been a part of the Medical Services and subsequently Clinical Services Directorate plan and by using the World Health Organisation blue print (see diagram below) the following has been achieved:

WHO Public Health System Approach to Palliative Care (Stjernswärd *et al.*2007)



Policy

National Palliative Care Guidelines were published in June 2017 and have been distributed to hospitals and health centres and given to participants on all palliative care courses. Palliative Care was also included for the first time in the Ethiopian Hospital Services Transformation Guidelines, September 2016 (Volume 2 Chapter 12) and hospitals have subsequently been assessed using the chapter during supportive supervision. Furthermore,

Palliative Care has been included in the Ethiopian Primary Healthcare Clinical Guidelines, 2017(Pages 120-121). It also has become part of the Essential Healthcare Package and is the fifth pillar in Ethiopian's Health Policy.

Education

At this present time, FMOH is involved in an important project known as 'Pain Free Hospital Initiative' (PFHI) that aims to provide teaching on pain control to doctors, nurses and pharmacists throughout the country; along with the provision of oral morphine solution. As part of the course, an introduction to palliative care is given to the health professionals to create awareness.

More extensive training has been given to hospital health care professionals (doctors, nurses, pharmacists and social workers) over 5 days. After the training a palliative care hospital hub team has been formed and a clinical service has been commenced. At this current time 12 hospitals in Addis have been trained and 10 regional hospitals.

A 3 day social worker training has also been performed for social workers in Addis Ababa. Furthermore, emergency health care professionals and anaesthesiologists have been trained in Addis Ababa.

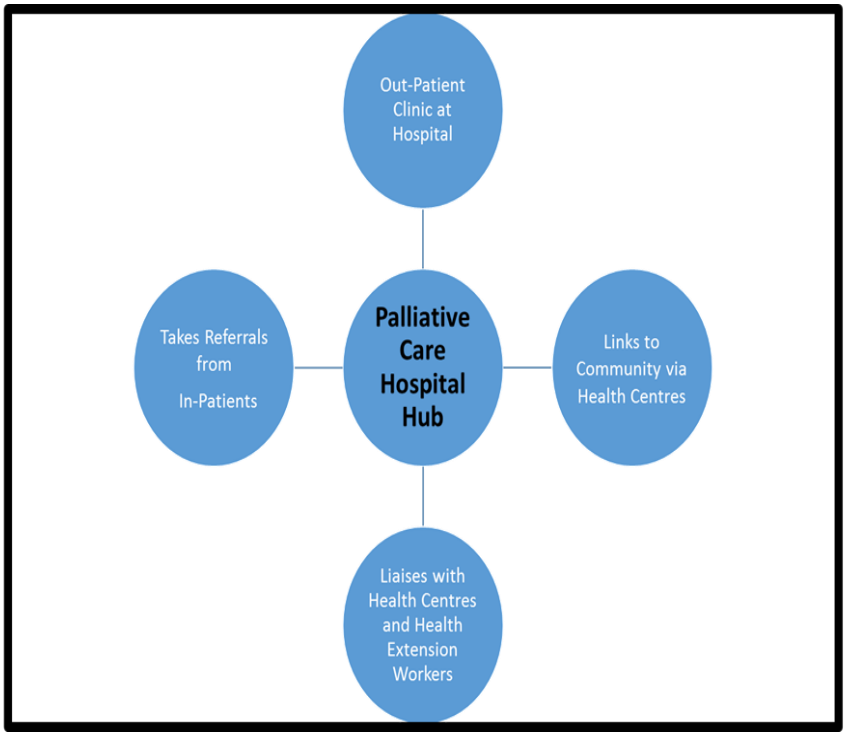
24 health centres have also received a 3 day training in order to provide care in the community and the health centres are able to link into the hospitals, so that their patients can receive morphine if required.

Palliative care is part of the student nurse curriculum and some medical colleges. (see Educational Needs Assessment Document for further details).

Implementation

People requiring palliative care services are predominantly those with advanced cancer, end- stage Acquired Immune Deficiency Syndrome (AIDS) or other life-threatening illnesses. The services for people living with Human Immunodeficiency Virus (HIV) and AIDS are more developed than the cancer services, and, with the introduction of Anti-Retroviral Therapy (ART), people are living longer (Balcha et al. 2011). However, with patients diagnosed with cancer, due to late presentation and the lack of resources, palliative care, for the majority of the population, palliative care appears to be the main option.

There are multiple models for setting up palliative care services, however after consultation the most appropriate model found was the hub and spoke approach (see diagram).



Hub and Spoke Approach Model for Palliative Care Set Up in Ethiopia

The backbone of the service is the palliative care hospital hub that takes referrals for in-patients and provides an out-patient clinic. Each hospital department has a palliative care focal person that can refer to the team if required. Health centres can refer to the hospital hub and vice versa and both hospital and health centres can link to NGOs such as Hospice Ethiopia and Strong Hearts (these services are in Addis Ababa only).

As previously mentioned 12 hospitals in Addis Ababa and 10 regional hospitals, 24 health centres in Addis Ababa have all had training and are in various stages of implementation.

Drug Availability

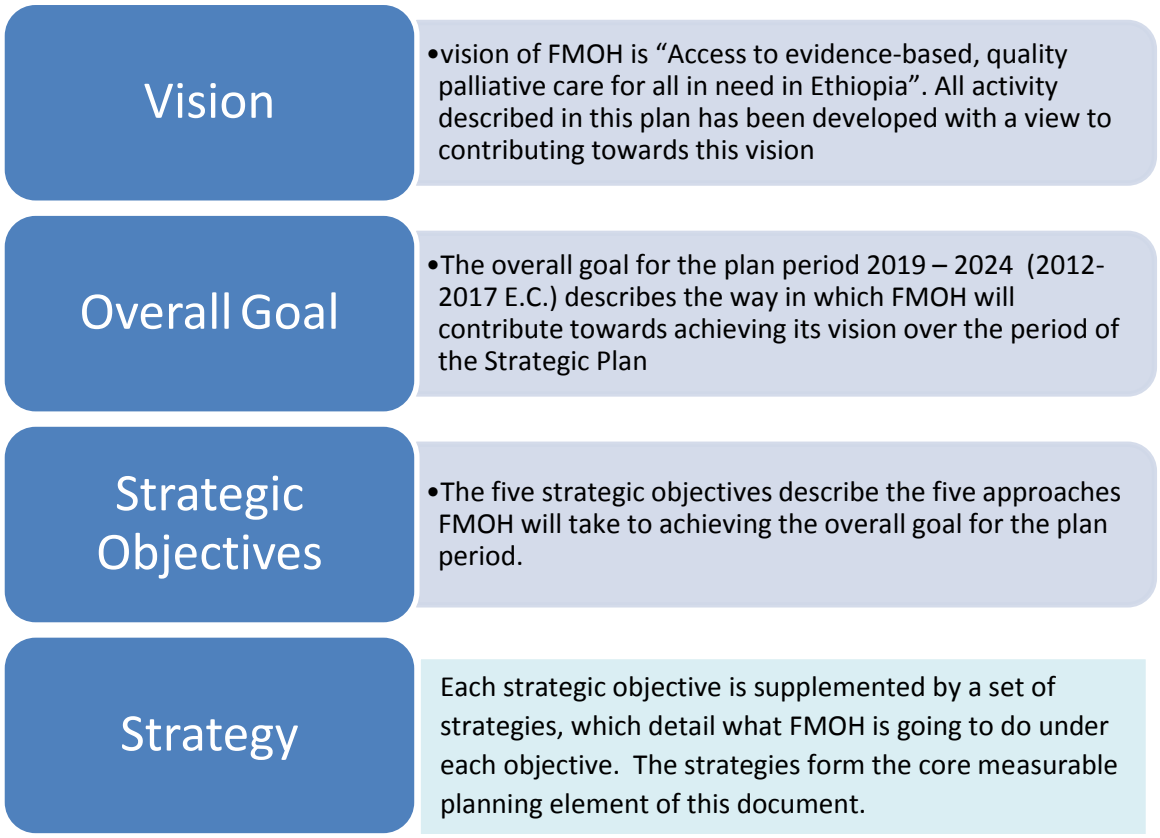
At this present time, morphine is available at government hospitals only. The number of hospitals that have morphine have greatly increased due to the FMOH's Pain Free Hospital Initiative. The Clinical Services Directorate has been working towards providing a stable source of morphine that is manufactured in-country.

After considering the current palliative care situation in Ethiopia we now ask the following question:

What are our goals for the next five years?

A Five Year Plan

Below describes a strategic five year plan for the scale up of palliative care services in Ethiopia.



Overall Goal for 2019-2024 (2012-2017 E.C.)

To continue to scale-up and implement a sustainable, Ethiopian-led model Palliative Care Services in collaboration with our partners, which delivers and demonstrates a quality evidence-based service and carries out training, capacity building and research.

Strategic Objectives

Objective 1: Clinical Service Provision
To provide and scale-up an integrated clinical service to patients and families across the country.

Objective 2: Education and Training
To provide education, training and capacity building for healthcare workers at all levels.
Objective 3: Awareness Creation
To enhance and promote clinical credibility for palliative care
Objective 4: Research
To expand the evidence-base for palliative care by encouraging a research culture, and supporting and initiating research into palliative care in Africa.
Objective 5: Sustainability
To develop a well-resourced service, with the capacity and infrastructure capable of supporting a sustainable Ethiopian palliative care team.

How do we realistically implement these goals?

Management Structure

To fulfil the objectives as described below a Palliative Care Working Group has been established under the Speciality Case Team Clinical Services Directorate. The rationale for this is discussed in objective 5. This core team will support the clinical, educational and research needs for palliative care in Ethiopia. For the goals to be implemented it is also essential that there is a palliative care group in the Speciality Case Team with employed Palliative Care Officers to work with the TWG and other implementing health care professionals.

Strategic Objective 1- Clinical Service Provision

To provide and scale-up an integrated clinical service to patients and families across the country.

As already mentioned in this plan, a core objective of this strategic plan is to ensure government-led integrated palliative care services.

The model of care that is most suitable for Ethiopia is a community-based programme due its large population and geography and the fact that the majority of people live in a rural setting (WHO 2009). However, a community-based approach would require a centre or 'hub' such as a local hospital to support the provision of morphine and provide specialised services and training and this is why the hub and spoke model has begun to be implemented. From these hospital hubs, palliative care clinics will be provided and health centres and community-based home care teams will provide a service to the community.

The backbone of this service will be trained nurses to support clinical delivery. Nursing, due to its holistic focus on the psychological, social, spiritual and physical wellbeing of the patient puts them in the best position to deliver palliative care (Downing 2007). The nurses will be supported by medical staff at the hospital hub. At each hub there will be one specialist nurse to work in the hospital, he/she will train link nurses on each ward who will refer patients with complex palliative care needs.

With regards to the community, the health centres will work with and mentor the health extension workers. The health extension workers (who need training) will provide basic palliative care and will refer more complex cases to the health centres and if necessary the hospitals.

Children's palliative care needs to be set-up during this five year period. A Needs Assessment has been carried out and training and clinical services need to be set up in hospitals that already have adult palliative care services.

All clinical services will be overseen by the Speciality Case Team of the Clinical Services Directorate and the Technical Working Group.

Capacity will also be expanded through development of a volunteer network. Furthermore, throughout this period good communication strategies will be developed between different health-care providers and clinical pathways.

Strategies for delivering the Clinical Objective:

- Strengthen palliative care working group to assist Speciality Case team by having bi-monthly meetings to discuss strategy and progress.
- Supportive supervision for the palliative care hubs that are functioning and discuss with hospital teams that require further support.
- Develop a children's palliative care on-going training programme for palliative care teams. This can be a combination of original Ethiopian palliative care professionals (Trained Hub staff who have TOT, FMOH staff, Hospice Ethiopia staff) developing training resources and providing trainings.
- Establish hospital based palliative care teams at all Regional Hospitals and District Hospitals
- Establishing community-based home care teams, with health centres providing a service and health extension workers in rural areas.
- Commence delivering clinical service in the community.
- Develop communication strategies between health providers and instigate referral system between health-care providers and clinical pathways and from hospital to community level.

Strategic Objective 2- Education and Training

To provide education, training and capacity building for health care workers at all levels.

The World Health Organisation recommends that education should be included in the curricula for health care workers at every level (WHO 2014). However, in many parts of Africa this is not the case, so with regards to a strategy this is a key issue.

As there are relatively a small amount of health care professionals in the country who have a detailed understanding of palliative care, education and clinical service provision need to go hand in hand as services are scaled up.

As already mentioned FMOH is at present mobilising the Pain Free Hospital Initiative where one unit of this course includes an introduction to palliative care and extensive training is provided for hospital staff to set up hubs and a 3 day course for health centre staff.

For palliative care to become an integrated part of health care workers educational programme; it needs to be a part of the medical students' curriculum. It is also necessary as part of continuing education for qualified health care professionals and in Higher Education so that post graduate palliative care training can be provided in-country as going to other countries is very expensive and may not be culturally relevant.

Strategies for delivering the Educational Objective:

- Establish palliative care education team as part of working group from palliative care specialists in country
- Develop educational programme strategy to incorporate medical students, social worker students, pharmacy students, health officer students.
- Provide a comprehensive in-service programme
- Plan and develop a Pain and Palliative Care Fellowship Package for the doctors and a Masters in Palliative Care Training Package for health officers, nurses, social workers and pharmacists and other qualified allied health care professionals.
- Complete and print and distribute training manual for participants and trainers for hospital hub staff and health centres
- Develop on-going training programme for palliative care team in hospital hubs and health centres(see clinical objective)
- Develop a training package for health extension workers.
- Work with other partners to assist with capacity building for training health care personnel.

Strategic Objective 3- Awareness Creation

To enhance and promote clinical credibility for palliative care

Awareness Creation or Advocacy is a broad concept and is defined by the Worldwide Palliative Care Alliance as, 'seeking to influence policy makers to design, adopt, implement or change policies and practices' (WPCA 2005:4). FMOH has been involved in promoting palliative care through the production of morphine and the Pain Free Hospital Initiative and Palliative Care Imitative.

As palliative care is a relatively new concept in Ethiopia, awareness creation plays a key part in promoting the service. This needs to occur amongst various groups, these include the General Public, the media, health care facility management, health care training establishments, professional organisations and health care professionals.

Strategies for delivering the Awareness Creation Objective:

- Working group to spearhead awareness creation initiatives
- Group to establish a plan with communications and media department at FMOH to create palliative care awareness among the General Public, using TV, radio, internet and newspapers.
- Consider using a Public figure in Ethiopia to become an ambassador for Palliative Care, e.g. Haile Gebrselaisse or First Lady or other.
- Palliative care advocacy group to create links and awareness with teaching facilities and university hospitals.
- Create a Palliative Care Association
- Palliative care link doctors and nurses to promote palliative care awareness in their own hospitals, by face to face meetings and hospital media.
- Working group members, Palliative care nurses and doctors in hospital hubs to visit other health care facilities and professional organisations to create palliative care awareness.
- Palliative care awareness group to work with community based organisations to form a plan to create widespread community awareness.
- Working group to work with African Palliative Care Association to promote further links with other countries in Africa.

Strategic Objective 4- Research

To expand the evidence-base for palliative care by encouraging a research culture, and supporting and initiating research into palliative care in Africa.

Palliative care is based on evidence-based practice. To ensure best practice, Ethiopian palliative care professionals need access to current research findings. However, there is a dearth of palliative care research in Africa, which is mainly due to financial constraints (Powell et al. 2014). To expand the evidence-base in Ethiopia, a Palliative Care Research group needs to be established to promote a research agenda for the next five years. Furthermore, the research that has been carried out needs to be disseminated more effectively to health care professionals.

Strategies for delivering the Research Objective:

- Develop a research agenda and plan for 2020 and update annually thereafter. Develop and document research policies, procedures to include ethics and governance
- Establish an Ethiopian-based research network consisting of internal, national and international stakeholders and researchers, and hold a meeting by 2020 and annually thereafter.
- Hold 2 capacity building workshops per annum for 20 people each time and develop resource materials for delivering these workshops on an ongoing basis. Facilitate a minimum of 10 undergraduate/postgraduate students per year to undertake research in palliative care.
- Develop a national database of palliative care research.
- Palliative care research group is to develop relationships with grant donors and other appropriate organisations to assist with financing research
- Palliative care research group is to be involved in disseminating current research so that is available for health care professionals by using hospital links, hospital and mass media.

How do we monitor and evaluate services?

Strategic Objective 5- Sustainability

> To develop a well-resourced service, with the capacity and infrastructure capable of supporting a sustainable Ethiopian palliative care service.

One of the criticisms of palliative care is that apart from morphine availability, most palliative care services are donor-funded and have been resourced outside of government systems, thus leading to 'islands of excellence' but not widespread national coverage. For Ethiopia to have a well-resourced service the management of the service needs to be considered and scaled up. A strong core palliative care group in the Speciality Case Team, Clinical Services Directorate needs to be established at the FMOH, so that it is able to manage palliative care among HIV/AIDS patients, cancer patients and patients with other non-communicable diseases such as diabetes and heart disease.

To counteract the donor-funded services in other African countries, the strategy in this plan is to establish operations within the national system by the use of link doctors and nurses in the government hospitals and in the community. There is a need for sustainable capacity building within the government system while accessing external funding to develop the programme in other areas, particularly education and research. The aim of FMOH is the development of a core team that works with the government system, but also works with other suitable partners.

Strategies for delivering the Sustainability Objective:

- Development of a palliative care core group within the Clinical Services Directorate of the FMOH to implement, manage and develop the service.
- Develop Monitoring and Evaluation package for palliative care services including educational services using Palliative Care Indicators (e.g. for hospitals use those described in EHSTG).
- Develop indicators for community services.
- Seek sustainable funding for the development of palliative care

- Palliative care working group to liaise with EPharm to continue morphine availability and extend manufacturing to different dosages and forms
- Working group to be involved in reporting and liaising with partners to ensure sustainability of the service
- Working group to plan for the next five years to continue to expand the service.

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