

ANNUAL REPORT

January-December 2020



Palliative care aims to improve the quality of life for patients with life limiting illnesses and to provide caring support to their families while they are going through difficult times.

Hospice Ethiopia provides care thru home care and out-patient care settings.

January - December 2020
www.hospiceethiopia.com



TABLE OF CONTENTS

LIST OF ACRNOYMS	iii
EXECUTIVE SUMMARY	1
1. INTRODUCTION	2
2. MAJOR OBJECTIVES	3
3. PROGRAM ACTIVITIES.....	3
4. MAJOR ACHIEVEMENTS	3
A) Home Based Care (HBC) and Out-Patient Care (OPC).....	3
B) Day Care (DC)	4
C) Comfort Fund (CF)	4
D) Provision of Supplies	4
E) Expansion of Services	5
F) Bereavement Support	6
G) Training.....	6
H) Expanding Awareness.....	7
I) Other	9
5. HUMAN CAPITAL.....	11
6. MAJOR CHALLENGES AND CONSTRAINTS	12
7. CASE STORY.....	12

LIST OF ACRNOYMS

CF	-	Comfort Fund
COVID-19	-	An infectious disease caused by a newly discovered corona virus
DC	-	Day Care
HBC	-	Home Based Care
HCWs	-	Health Care Workers
HE	-	Hospice Ethiopia
IAHPC	-	International Association for Hospice and Palliative Care
MNCH	-	Mother and Neo-natal care Health
MOH	-	Ministry of Health
PC	-	Palliative Care
PPE	-	Personal Protective Equipment
WHPCD	-	World Hospice and Palliative Care Day

ANNUAL ACTIVITY REPORT JANUARY TO DECEMBER 2020

EXECUTIVE SUMMARY

Hospice Ethiopia (HE) is an indigenous secular non-governmental organization that works closely with local and international governmental and non-governmental stakeholders to build a sustainable, culturally appropriate palliative and hospice care model for people living with advanced progressive life-limiting illness in Ethiopia. HE is the only charity that provides a holistic home based, out-patient and day care palliative care services in the country. Ethiopians living with chronic illness and suffering from cancer, HIV/AIDs and other life-limiting diseases have palliative care (PC) needs that are mostly unmet. Hospice Ethiopia has been providing palliative and hospice program by trained healthcare professionals in Ethiopia since 2003. The major program areas are comprehensive home-based care (HBC) and out-patient care (OPC) which entails physical, psychosocial and spiritual support, day care (DC), comfort fund (CF), and provision of supplies. Hospice Ethiopia assisted the federal government palliative care efforts through active collaboration with Ministry of Health (MOH).



As a result of HE's support; during the past one year 262 patients received PC services (115 HBC services, 98 patients received OPC and 25 patients attended the DC). Thirty-nine patients were referred to the program by health facilities and care givers. 9 patients left the program due to improvement of their health. Additionally, 25 people were provided additional support thru our Comfort Fund (CF) and 185 patients were provided with various supplies including food, medicine and medical supplies, sanitary materials and personal protective equipment (PPE). During the reporting period, 37 patients died and 5 families received bereavement support. On April 12th, 2020 we had to temporarily discontinued the DC program due to the COVID-19 pandemic. However, the program provided care to 25 patients until it closed.

Hospice Ethiopia had a vision to expand the care services outside of Addis Ababa. During the past year we launched a branched of HE services in Bahir Dar at the Tibebe Ghion hospital. The program was again replicated in another location at Hawassa referral hospital. Basic training on palliative care was given for nurses and physicians. Following the training, the hospitals assigned a focal palliative nurse in collaboration with HE as well as a room to provide PC services to patients in need. We have also begun receiving request outside Ethiopia from countries that are caring for patients who wish to return to Ethiopia to receive car in their final days. During the past year we received 5 inquiries and facilitated the transfer of 3 patients to return to Ethiopia.

1. INTRODUCTION

VISION

To be a centre of excellence in the provision of quality hospice and palliative care services to all people living with life threatening illness in Ethiopia.

MISSION

To provide compassionate, affordable, accessible and culturally appropriate palliative care to those in need throughout Addis Ababa and the rest of Ethiopia through trained health care professionals.

GEOGRAPHIC LOCATIONS

HE's main office is located in Ethiopia, Addis Ababa and provided its assistance to patients with life-threatening illness that reside in Addis Ababa. Understanding the high demand of the holistic care, HE has recently expanded its program to Bahir Dar, Tibebe Ghion Hospital and Hawassa Referral Hospital.



2. MAJOR OBJECTIVES

1. To improve the quality of life of patients with incurable diseases particularly cancer, HIV/AIDS, diabetics and hypertension and their families through provision of palliative care and support services.
2. To provide compassionate, affordable and culturally appropriate palliative care services to those in need by trained health care professionals.

3. PROGRAM ACTIVITIES

MAJOR PROGRAM ACTIVITIES

- a) **Home Based Care (HBC):** Delivered physical, psychological, and spiritual services to housebound patients
- b) **Out-Patient Care (OPC):** Provision of pain relief and psychosocial support to patients who are able to come to HE's office.
- c) **Day Care (DC):** A weekly program that provides psychosocial support in a group setting at HE office.
- d) **Bereavement Support:** Provision of support for families who have lost their loved ones.
- e) **Training:** Working to expand hospice and palliative care services by providing training to health care professionals.
- f) **Expanding Awareness:** Provision of workshops and use of mass media to explain the benefits of Hospice and PC services.
- g) **Comfort Fund (CF):** Contribution of limited financial support to destitute patients for basic food supply, utility and house rent.
- h) **Supplies:** Provision of food for needy patients with low income as well provision of medicine and medical supplies.
- i) **Expansion of Services:** Replicate similar services in other hospitals out-side of Addis Ababa.

4. MAJOR ACHIEVEMENTS

A) Home Based Care (HBC) and Out-Patient Care (OPC)

The physical, psychosocial and spiritual support is the care and support areas that strives to provide for patients experiencing serious illness. This holistic support is provided by trained healthcare workers and volunteers/caregivers while patients are in their home. Providing these services was challenged due to



the global pandemic and implemented restrictions. We were very fortunate that services during this difficult time were not stopped. However, we adjusted by prioritizing patients based on need and we reduced the frequency of home visits. where possible, to minimize the risk of corona virus transmission. Some of the patients were advised and followed by regular phone calls. During this reporting period comprehensive services were provided to 115 patients through home-based care. Due to fear of the COVID virus, many patients that could walk into our office did not come for care. However, of the total 262 patients seen, we saw 98 patients this year in the OPC program.

B) Day Care (DC)

Hospice Ethiopia (HE) has provided a psychosocial support for 25 beneficiaries via day care services. The day care program is appreciated by the patients as they go out from their houses



for a meaningful gathering and group support. This program is organized every Thursday at the center in Addis Ababa. Those patients attend the lunch, the traditional coffee ceremony and music entertainment organized for them by HE in the hospice premises. This program gives patients a forum to share their experiences, social issues and emotionally support each other. Due to the COVID-19 pandemic, we had

to temporarily discontinue this program. However, HE is working to develop COVID standard procedures to restart this program in 2021.

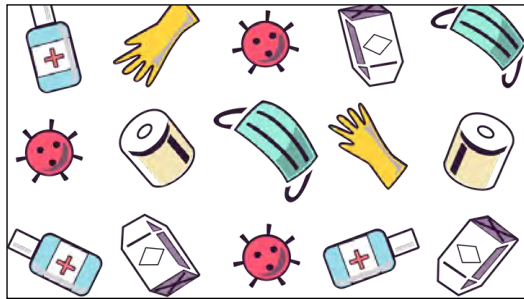
C) Comfort Fund (CF)

Most of the patients supported by hospice Ethiopia are economically disadvantaged and do not have jobs or have the ability to earn an income. Therefore, they struggle to survive as they do not have enough money to cover their house rent or purchase basic household supplies such as food and medication. Understanding this situation, HE provides financial support to the most destitute patients. During this reporting period 25 patients benefited from the CF service.

D) Provision of Supplies

Another category of HE's support is the provision of various types of supplies. Through this support we provided basic medicines for patients based on their needs for their pain and symptom management. During the past year, these supplies supported 179 patients.

This has been an unprecedented year for many. While providing for home-based (HBC) and out-patient palliative care visit, HE nurses have observed how COVID-19 pandemic affected



elderly patients. Since most of the elderly are out of work, their income is greatly compromised, and it becomes difficult to pay their house rent and purchase essential food items. Thus, HE as part of the provision of holistic palliative care services, provided food items and sanitary materials to ease their burden. During the reporting period, 205 patients

were provided with food items and sanitary materials (soap, cleaning detergent, hand sanitizer and face masks). During this reporting period supplies were distributed to 185 patients to mitigate the impact of the corona virus.

E) Expansion of Services

Launching outreach programs to other regional hospitals was found to be a sustainable approach to expand PC services and address more patients with limited expenses. Therefore, HE established partnerships with Tibebe Ghion and Hawassa Referral hospitals to expand palliative and hospice care support. HE provided the necessary training to HCWs and created awareness among the hospital administrators. Following this, the initiative has been implementing by the hospitals in collaboration with HE and they have begun providing palliative care services. A palliative care focal person is assigned at both hospitals following the training and established partnership. Further, a PC room is designated by the hospital which will facilitate patients to be seen as out-patient. During the reporting period, 31 out-patients and 8 patients were addressed through the home-based care program. Additionally, 20 family members were supported. Moreover, various health facilities referred 49 patients to the hospital in order for them to receive PC services. These patients joined the program since they now know about the availability of the services in the hospital. One patient died at the extended facility during this period and bereavement service was given for one family.

However, due to frequent management turnover at the Tibebe Ghion Hospital and resignation of the nurse that was hired by HE to serve as a focal person, the services were not delivered as planned.

F) Bereavement Support

The aim of the bereavement support is to assist patients' next of kin who lost their loved ones due to illnesses with their grief. This support was given to 5 patients' families.

G) Training

I. **Palliative Care Training for HCWs Working in COVID-19 Treatment Centers:**

The Ethiopian government, following the increase of the number of patients tested positive for COVID-19, temporarily converted hospitals and other big halls to serve as COVID-19 treatment centers. Following this, HE provided a training for front line HCWs treating patients tested positive for corona virus. This training aimed to enable HCWs to support patients and family members in management of distressing symptoms, patients and families cope with their distress, psychological and medical needs as well as to be able to provide end of life care. Moreover, the provision of this



type of training will support the national level COVID-19 health responses through palliative care. After the training a brief assessment was conducted in one of the hospitals. The review stated how the training helped HCWs in providing PC to COVID-19 patients. As COVID-19 is a new global phenomenon, HCWs face many challenges in terms of handling especially patients' pain and symptoms, psycho-social issues as both the patients and their families have little or no information to cope during this critical time. HCWs stated on the training enlightened them on how corona patient would benefit from palliative care and end of life care.

II. **Refresher Training for HE HCWs and staff:**

To keep HCWs updated with the always changing medical world and enhance their counseling skills, and knowledge on palliative and hospice care, a two-day refresher training was given to HE's nurses. The training mainly focused on role of communication in PC service delivery, its quality improvement, cancer disease, staging and treatment protocol and staging of cancer. Three health care professionals and one program staff attended the interactive training.

Communication Training: A-half day training was given to all staff aiming to enhance the communication skills of the staff working at various levels. Interactive sessions were

used during the training which helped in identifying common and strong areas and weaknesses and gaps existed in the organization both at the management and staff level. Outcomes of the sessions will help the management as well as the staff to work on the gaps identified and more strengthen the team work .

III. Training for volunteer care givers:

HE provided an essential patient caring techniques training, for 20 volunteer care givers.

Main objective of the training was to capacitate trainees to be able to give basic care

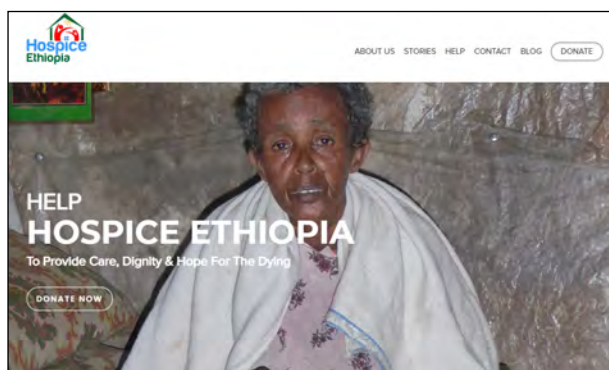
services to patients. Additionally, they are trained on key business and entrepreneurial skills with the intension of enabling them to start their own small-scale businesses in order to maintain the volunteer work and relieve their family from financial burdens. Hospice provides the home care kit and necessary personal protective equipment such as gloves, apron, and face masks for them to be able to give safe care to those that they are caring for.



IV. Basic PC Training for HCWs in Bahirdar and Hawassa Referral Hospitals:

A training was conducted for 23 nurses and 2 physicians at Tibebe Ghion hospital and for 24 nurses and 3 physicians at Hawassa referral hospital. The PC focal person at the MOH was trained as well. The trainees were provided with National PC guidelines, poster and other supportive documents. The training supported them to start PC and home based care services in their hospital.

H) Expanding Awareness



HE used mass medias such as FM radio and TV stations to promote HE and increase awareness on the benefits of palliative and hospice care and the rights of patients to receive PC services. We shared that PC need as part of the universal health coverage and as the sustainable development goals and advocated on the necessity of the

government's engagement to support and allocate funds for PC services in the country. The messages were transmitted through interviews with HE's Executive Director and a PC beneficiary "stakeholder" who advocated necessities and benefits of PC services from her personal experiences. Additionally, during the reporting period, COVID-19 prevention messages were transmitted on a radio station. Moreover, stakeholders' testimonies, after getting their consent, were also utilized on social media and HE's website to increase knowledge and demand among the community on PC.



The staff, along with board members planted trees in response to the national call for the green legacy initiative. The plantation took place in a neighboring area where by 160 trees were planted. During the time, staff and board members promoted HE by wearing HE t-shirts and caps.

World Hospice and Palliative Care Day (WHPCD)

HE in collaboration with MOH commemorated World Hospice and Palliative Care Day on November 14, 2020 with the theme "My Care My Comfort". Forty-six participants comprised of staff at the MOH, HE's board members and staff, beneficiaries, care givers, and other invited guests attended the event. Various papers focused on the needs, importance and gaps in



hospice and PC were presented and a panel discussion was held on the presented papers.

A patient with cancer and HIV/AIDS shared her experience before and after the holistic support provided to her by HE.

Moreover, a short documentary film prepared by HE and the MOH

depicting the need and benefits of PC was screened. It was fortunate that the documentary film featured the vice minister from the MOH, Dr. Dereje Duguma. Dr. Duguma mentioned in the film,

“ We need to disclose we would appreciate partners support and many people are in need of this service (palliative care). We need to mobilize resources as the service demands it.” “In the 2nd transformation plan we put PC as one of the focus areas. Not only the MOH, but other partners and stakeholders including the community should also take parts and involved”. “When we say health for all, it involves especially those in bed, seriously illness no one should be left behind, they are part of this campaign. Those people are part of the universal health care coverage”. Opening remarks and way forward was delivered by Director of Clinical Service Directorate of MOH.

Additionally, a poster (both in English and Amharic), sanitizer, mask, flier and key holder were prepared and distributed to participants.



I) Other

International Association for Hospice and Palliative Care (IAHPC) Meeting

Mr. Ephrem Abathun, Executive Director of HE, attended a meeting which was organized by IAHPC (International Association for Hospice and Palliative Care) together with participants from Hospice Africa Uganda and other international organizations. The current WHO Director, Dr Tewodros Adhanom, made a remark on the various issues related to the need for support access and availability of palliative/hospice care in the world and Africa. He made a commitment to communicate with ministers in order to advocate the importance of PC as a universal health care coverage.

Strategies and Guidelines Launching Meeting

A two-day meeting was organized and conducted by MOH on December 31st, 2020 and January 1st, 2021 at Ethiopian Public Health Association. The main objective of the meeting was to launch the various strategy and guideline documents developed by the Ministry in collaboration with other stakeholders including HE. The documents prepared and presented included: 1) National Rehabilitation and Assisted Technology (AT) Service Provision Guideline;

2) National Priority AT List; 3) National Healthy Ageing Strategic Document; 4) National Palliative Care Strategic Document; 5) National Psycho-Social Service Guideline; 6) IPC (Infection Prevention and Control) Strategy and Policy; 7) Governing Board Manual; 8) Nutrition Directive Document; and 9) Patient Advisory Protocol.

MOH acknowledged HE for its strong engagement in the development of the above mentioned documents especially taking full responsibility for the preparation and printing of the National PC Strategic Document.

It was recognized during the Ministry's presentation that PC services in Ethiopia did not find the necessary attention in the past although the care aims to support patients and their families who are living with life-limiting illnesses by improving their quality of life through provision of physical, psychological, spiritual and social care. HE's long years of service in relation to the delivery of the above-mentioned services was greatly appreciated by the representative of MOH.

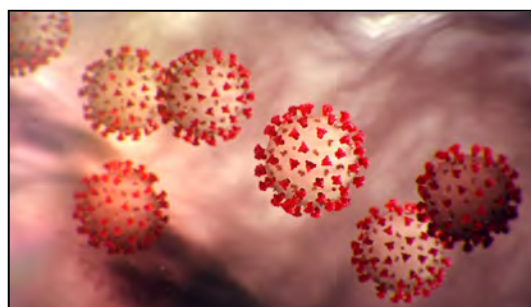


The Ministry, by recognizing the gap and the need of the service, has developed a five-year (2021-2025) National Palliative Care Strategic document with the support of the technical working group which involved the Ministry, HE and other stakeholders. The document entails clear definition of PC, rationale, vision, goal, and the seven strategic pillars with detail objectives, interventions and strategic results. The document, through the sponsorship of HE, was distributed to participants by hard and soft copies. Discussions were held on the presented papers.

This initiative taken by MOH will greatly support HE's mission which aims to provide compassionate, affordable, accessible, and culturally appropriate palliative care to those in need throughout the country.

COVID-19 Response

Following the government's request for citizens to stay at home and protect themselves from COVID-19 and as well as the announcement of a state of emergency, necessary orientation on COVID-19 prevention as well as supplies such as masks, hand



sanitizers, and soaps were available to all staff; and out-patients who visit the office for medical consultations. The management ensured that these office rules were properly maintained. One of our nurses was confirmed positive for COVID-19 and the management facilitated for her and the staff to be tested. The nurse was also re-tested and became test negative.

With the objective of creating awareness among the patients and the community on COVID-19 as well as to increase their preparedness for the prevention and impact, HE conducted the following activities.

- Provided awareness sessions to the HE staff on general COVID-19 prevention, transmission virus, use of PPEs, and related issues. Additionally, they were given information on how to take care of family members if they are infected with the virus. The staff were provided with PPE.
- Hand sanitizers, soaps, and hand gloves were supplied to 70 patients and community care givers. The PC team created awareness of patients, their family members and the community care givers on corona virus. 300 informative fliers on COVID-19 were distributed to HE patients.
- HE supported 105 poor patients and community members selected by their constituents, and 80 beneficiaries from partner organizations named Care Epilepsy and Nehemiah Autistic Center by providing food oil, flour and pasta.
- 1000 face masks for Black Lion Referral Hospital and 900 face masks to Zewditu Memorial Hospital.

5. HUMAN CAPITAL



Currently, 13 staff are working at HE (9 are administrative staff and 4 are clinical staff).

New Additions: At the end of 2020 we added 2 new staff members. Azeb Teferi started on July 7, 2020 as our Senior Office Manager, he has a BA degree in Communications and Business Administration with an experience in program and administrative management. Eyob Solomon started on September 20, 2020 to work as a driver in the organization.

6. MAJOR CHALLENGES AND CONSTRAINTS

- Following COVID-19 pandemic throughout the world, movements from place to place was halted and forced citizens to stay at home, and due to this our patient referral was greatly affected. HE's healthcare providers were unable to reach out as planned as possible to patients. Additionally, the day care program was temporarily discontinued. Some of the patients also had a fear to go out of their houses so there was a decrease in the out-patient flow and in admitting new patients as planned.
- One of our senior nurses was confirmed positive for COVID-19. HE's management advised those who had contacts with her in the office shall isolate themselves until they give a test and confirm their status. Following her test result, the management closed the office for fourteen days and facilitated for the staff to get tested for COVID-19. Fortunately results of those tested for the virus became negative thus the office re-opened and the staff resumed work.
- Resignation of the nurse that was hired for Tibebe Ghion Hospital. Turnover of medical directors in the hospital was also another challenge faced in the expansion program implementation.
- There was a car accident which HE lost a car. However, the insurance has reimbursed for the total loss of the vehicle.

7. CASE STORY

Seni Bekele (not her real name) was a 30 year old married woman who lived with her husband and four children in Addis Ababa. Seni was diagnosed with cancer on her left jaw and she had gone through surgery. Unfortunately, after the surgery her wound had returned and had a very offensive smell. The mass was exceptionally large, and it affected the symmetry of her jaw and disfigured her face. Additionally, it had a pus discharge with an unpleasant smell. Moreover, she was struggling with taking food by mouth due to the wound. Seni took



chemotherapy at Black Lion Referral Hospital but it did not help.

Following her illness, she had severe pain on the wound, and headaches. As a result of the continuous and unrelieved agony pain, Seni and her husband spent several sleepless days and nights. She also felt sad, hopeless, and unworthy and blamed herself for putting her family members in a difficult situation. Her depression level and hopelessness incurred due to the unmanaged pain and increased bad odor. She believed her disease is a curse and lost hope, and even wished for God to take her life. She continued to struggle on a day-to-day basis.

As Seni was desperate by her situation, Black Lion Referral Hospital referred her to Hospice Ethiopia (HE) for palliative care. HE nurses and care givers started to visit Seni at her home on a regular basis. Her physical pain was controlled and managed with medications. Further, wound care was done Seni and her family were relieved from the bad odor that emerged from the wound.

The nurses also gave her emotional and psychological support and consultation. They educated Seni and her husband on basic wound care and gave her relevant information about cancer since she had no understanding about her illness.

When she started to receive support from HE nurses and care givers, the positive changes became noticeable. She started to cope with her challenging conditions. Her coping capacity and mechanism to handle her situations were greatly enhanced from time to time. Her emotional and psychological symptoms; depression and hopelessness also showed improvement. The health care professionals supported her with her spiritual guilt and information on cancer.

Even though she was not cured from her illness and the cancer progressed, her living conditions were greatly improved as a result of the overall support of HE. Her emotional and psychological issues had improved. Seni and her husband started to sleep better which they did not do for a long time. They were both grateful for all the treatment, support, and consultation that Seni got from Hospice Ethiopia because how their lives improved.

Seni recently died due to the cancer, but she did so with dignity, peacefully, and without suffering.



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