

Hospice Nepal



Annual Report 2018-2019

(BS 2075-2076)

Prepared by Rajesh N Gongal

Introduction

In the year 1999, four friends came together to unite for a cause – the initiation of palliative care in the country. It was a humble beginning- four beds in a private hospital providing free palliative care service for the patients sponsored by four persons with big hearts. Working as doctors in a busy hospitals, we realized that there were many patients who presented with advanced cancer whose only option was palliative care but were having to suffer in silence as there was no such service in the country.

Soon we realized that we had to move out of a hospital to a more homely environment. So we leased a land near Patan Hospital and built a 8- bedded independent unit. The building was built for us by CE Construction and Comfort Housing, companies which were led by one of the four founding members , Mr Om Rajbhandary. This was completed in year 2000 where we moved as 'Hospice Nepal' , a Non-profit Non -Government Organization duly registered with the Government.

We felt that there were many patients who prefer to be cared at home or patients who come to Hospice and return home after improvement in their symptoms who would like to stay at home as far as possible. So in 2005 we started home care services with the help of a van donated by INCTR.

In 2003, Prof. Max Watson, a palliative care specialist who had worked as a General Practitioner in Tansen Hospital in Nepal, visited us. Soon we became very good friends. He ran the Princess Alice Palliative Care Course at Patan Hospital. We modified this course to suit the context of Nepal and started running this course on a regular basis. Since 2005, we have trained more than 1200 health professionals.

80% of the population live in rural areas of Nepal and by logic, 80% of palliative care need is in rural Nepal. Therefore, it becomes imperative for us to develop palliative care in rural areas of the country. To this end, we have been working in rural area of Makwanpur, a hilly district 5 hours drive from Kathmandu since 2014. We are working to develop a rural model of palliative care. Two local health care workers have been trained and are now providing community based palliative care services in Makwanpur.

Inpatient service

This year we admitted 160 patients in the inpatient Unit. **This service is provided at nominal charge and free for poor patients**

Diagnosis

Disease	No of patients
Carcinoma Lungs	28
Carcinoma Stomach	4
Carcinoma Gall bladder	23
Carcinoma Cervix	23
Carcinoma Pancrease	9
Carcinoma colon	6
Carcinoma Breast	4
Other tumors	55
Non-malignant disease	8

Age Factor

Age group	No of patients
1- 10	1
11-30	1
21 -40	13
41-60	55
61-80	79
81 and above	11

Community service in Kathmandu Valley

This year we cared for 104 patients in the community. These patients were scattered across Kathmandu Valley and included patients from Kathmandu, Lalitpur and Bhaktapur. **This service is provided free for patients**

Diagnosis

Disease	No of patients
Carcinoma Lungs	24
Carcinoma Stomach	5
Carcinoma Gall bladder	10
Carcinoma Cervix	5
Carcinoma Pancrease	6
Carcinoma colon	3
Carcinoma Breast	2
Other tumors	49
Non-malignant disease	0

Rural community service (Makwanpur)



Since 2014, we have been trying to develop a rural palliative care model based on the model of ‘**For the locals , by the locals**’. Apart from providing clinical care of the patients in the community, we have also been running orientation program for local public, local leaders and develop a cadre of local volunteers. We have

been advocating with the local elected leadership for taking ownership of the program. **This service is provided free for patients**

Clinical care of patients

Patients are usually identified by Female Community Health Volunteers (FCHVs) and referred to our palliative care health professionals who visit patients at home and provide continuing care.

This year we have made another leap. In the past, we had focused only on cancer patients. Realizing that there were many patients with non-malignant conditions requiring palliative care, we conducted a study on the need of palliative care in a rural community as a whole, looking at both the malignant and non-malignant disease.

This study showed that there was a need to look after patients with non-malignant conditions as well. So we extended our service accordingly.

Cancer patients

We have cared for 66 cancer patients in the community since we started our program. Total number of home visits made were 305. The number of home visits ranged from one to 23 depending on the requirement of the patients.

Age group	No of patients
1-20	5
21-40	15
41-60	27
61-80	17
Above 80	2

Non- cancer patients

This year we provided service to 147 patients in the community. We made total of 423 visits for these patients, number of visits depending on the need of patients ranging from 4 to 17.

Condition requiring palliative care:

condition
COPD
Hemiplegia
Blindness with old age
Parkinson in elderly
severe arthritis in elderly
cardiac failure
Paraplegia
frailty due to old age
Others
Total

Some patients served in the community



Mr China Lama and Ms Kiweta Bista, Community palliative care health professionals with an elderly lady.

She lives with her elderly husband in the village. Their children are outside the country. She had been having severe abdominal pain for last three months. They have not visited the health centres. The local FCHV informed Mr China. We visited her in one of our visit to Makwanpur. She was started on strong pain killers which relieved her of her pain. The pain killer now has been weaned off and she is able to do simple house chores.



Elderly lady with Chronic obstructive airway disease (COAD) who would never visit a health facility because of difficulty taking her to the centre.



91 year blind lady previously relatively independent; developed tremor and required help for ADLs (activities for daily living); treated her at home with anti-parkinsons drugs. Became independent again!

13 year old girl with mental illness tied by rope at home by the family; appealed for help.

Help was forthcoming from the community. She was treated at Hetuuda hospital and has returned home. She is now free!!



13 year old mentally ill tied by rope at home by the family; appealed for help by the health worker.





92 year old lady who had given up on life and had remained in the shed for four months without coming out. Encouraged and coaxed, she saw sunlight after a long time!

Public awareness programs



Orientation program for community leaders

Orientation program for mothers group



Orientation program for school teachers

Orientation program for school children





Orientation in the community

Training programs

This year we conducted four two days training programs, one of which was in Pokhara and three in Kathmandu. One of the course was conducted at National Health Training Centre. This year the NHTC has recognized this course as an important course and will be conducted in future under Government regulations.



Course in Pokhara at Green Pasture Hospital

The Handbook



Research

Two important research papers in relation to rural palliative care in Makawanpur was published this year.

Providing Palliative Care in Rural Nepal: Perceptions of

Mid-Level Health Workers Rajesh N Gongal, Shambhu Kumar Upadhyay, Kedar Prasad Baral, Max Watson, George W Kernohan



A qualitative descriptive design, using focus group discussions, was used to collect data from a rural district of Makwanpur. Twenty-eight MHWs participated in four focus group discussions. The data were analyzed using content analysis.

Result: Four themes emerged from the discussion: (i) suffering of patients and families inflicted by life-threatening illness, (ii) helplessness and frustration felt when caring for such patients, (iii) socio-cultural issues at the end of life, and (iv) improving care for patients with palliative care needs.

Conclusion: MHWs practicing in rural areas reported the suffering of patients inflicted with life-limiting illness and their

family due to poverty, poor access, lack of resources, social discrimination, and lack of knowledge and skills of the health workers. While there are clear frustrations with the limited resources, there is a willingness to learn among the health workers and provide care in the community.

Population based need assessment of palliative care in rural

Nepal Paras Kumar Acharya, Kedar Baral, Dan Munday, Rajesh N Gongal



This was a cross-sectional population based study in Thaha Municipality using a 30-cluster sampling method and employing the Supportive and Palliative Care Indicators Tool (SPICT) to identify patients with palliative care need. Assessment of symptom burden was done for patients identified to have palliative care need.

Results: Out of 330 households with a population of 2168, we found 139(6.4%) suffering from chronic non-communicable diseases and 66 (3.04%) met the SPICT criteria for palliative care need and 60% were elderly above the age of 60. The disease of respiratory system followed by frailty and dementia were common condition requiring palliative care.

Conclusions: This study showed a high level of need for palliative care in a rural population in Nepal. This needs to be considered in further planning of health services in the country.

In Appreciation.....

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TRUST NEPAL
OVERSEAS PVT LTD

Trust Overseas Nepal Pvt Ltd for helping us to improve the facility in the Inpatient Unit.



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*Sharmila Gongal
Endowment Fund*

Sharmila Gongal Endowment Fund was created by the Sisters of Late Sharmila Gongal in her memory. The fund has been steadily increasing. The interest accrued from the fund is used for poor patients.

Prof Max Watson(UK) and Ms Jenika Graze(Australia) for providing us with much needed syringe drivers.

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To all our friends and supporters who have been with us all along

& above all to our patients and their families whose courage in facing the challenges of extremely difficult part of journey of life with grace continue to inspire us.

At the end, if I may, I would like to end with a story of a patient who has been an inspiration to us all.

He was a 54 year old gentleman from Thimi who had cancer of lungs which had spread to other parts of body. He was in pain but suffered in silence. A quiet man, his wife told us their story. They had sold a small plot of land they had to pay for chemotherapy. They now had nothing. We provided him with free service and medications.

He died quietly but left behind a beautiful gift, a gift of vision. He donated his eyes.

