Hospice Nepal

Annual Report

2017-2018

(BS 2074-2075)

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 Practioner 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 133 patients in the inpatient Unit.

Diagnosis

Disease	No of patients
Carcinoma Lungs	31
Carcinoma Stomach	17
Carcinoma Gall bladder	17
Carcinoma Cervix	5
Carcinoma Pancrease	4
Carcinoma colon	3
Carcinoma Breast	2
Other tumors	50
Non-malignant disease	4

Age Factor

Age group	No of patients
1- 10	0
11-30	1
21 -40	11
41-60	20
61-80	88
81 and above	14

Hospice Stay in days

days	**No of patients**
1-7	90
8-14	20
15-21	4
22-28	8
More than 28	13

Community service in Kathmandu Valley

This year we cared for 105 patients in the community. These patients were scattered across Kathmandu Valley and included patients from Kathmandu, Lalitpur and Bhaktapur.

Diagnosis

Disease	No of patients
Carcinoma Lungs	10
Carcinoma Stomach	16
Carcinoma Gall bladder	11
Carcinoma Cervix	6
Carcinoma Pancrease	4
Carcinoma colon	2
Carcinoma Breast	2
Other tumors	54
Non-malignant disease	0

Age Factor

Age group	No of patients
1- 10	0
11-30	0
21 -40	8
41-60	34
61-80	56
81 and above	7

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.

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, 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 60 cancer patients in the community since we started our program. Total number of home visits made were 246. 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	21
61-80	17
Above 80	2

Non- cancer patients

This year we provided service to 51 patients in the community. We made total of 468 visits for these patients, number of visits depending on the need of patients ranging from 4 to 17.

Condition requiring palliative care:

condition	nos.
COPD	24
Hemiplegia	8
Blindness with old age	2
Parkinson in elderly	1
severe arthritis in elderly	2
cardiac failure	1
Paraplegia	1
frailty due to old age	7
Others	5
Total	51

Age of patients:

Age group	No. of patients
40-50	3
50-60	2
60-70	9
70-80	14
80-90	17
90-100	6

Some patients served in the community

Mr Chinya 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 Chinya. 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 Hetuada 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 yr old lady who had given up on life an dhd remained in the shed for four months wihtout coming out. Encouraged and coaxed , she saw sunlight after long time

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

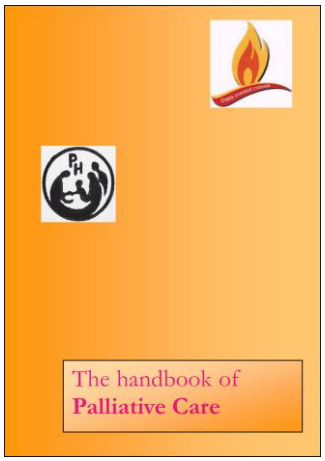
Orientation program for school children

Orientation in the community

Training programs

This year we conducted four two days training programs, one of which was in Pokhra 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 Pokhra at Green Pasture Hospital



The Handbook

Course at National Health Training Centre , Kathmandu

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.

Future Plan

Evaluation of the Rural Palliative Care Project in Makwanpur

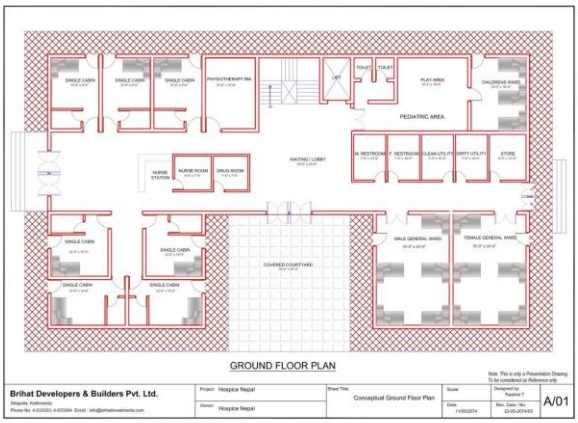
It has now been four years since the rural project was launched. The model of community based care seems to be working in Makwanpur with the local bodies taking ownership, This year we plan to evaluate the impact of this project. This will help us in taking this model to other areas of Nepal.

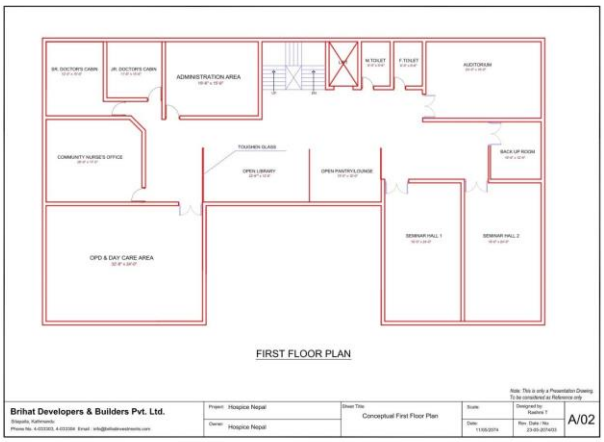
New Building plan

The inpatient unit in Lagankhel at present is in a land that has been leased. It is now important for us to build a unit in our own land which will serve as a model of excellence in palliative care for other care providers to emulate and set a national standard. Besides, it will serve as a national training centre for health professional of all cadres – doctors, nurses and rural health professionals working in collaboration with academic organization like Patan Academy of Health Sciences (with which it is already collaborating) to develop fellowships in palliative care.

Besides, it will serve as a research centre to develop clinical care in local context. Advocacy with the Government and public will be an important agenda.

Concept Design of the proposed building





Building Cost

No	Particulars	Area in sq. ft	Rate	amount	Remarks
1	Structure Cost	14000	1800	25,200,000	
2	Civil Finishing cost	14000	900	12,600,000	
3	Interior finishing	14000	1200	16,800,000	
4	Electrical and sanitary	14000	800	11,200,000	
5	Service lift			2,500,000	tentative
	Total			**68,300,000**	

No	Particulars	Area in sq. ft	Rate	amount	Remarks
1	Interplot and External development which includes	27380	500	13,690,000	
	a. Boundary Walls				
	b. Water tank				
	c. Septic Tank				
	d. Road & Ramps				
	e. Greenery				
	f. Pavement Tiling for Courtyards				
2	Guard House & Kitchen/Dining	1500	2000	3,000,000	
	Total			**16,690,000**	

Total estimated cost for the building project

Particular	NRS	US$
Total Estimated amount for building	**84,990,000**	**785,307**
Estimated amount for land	**75,600,000**	**700,000**
Grand Total	**160,590,000**	**1,485,307**

National Fund Raising Strategy:

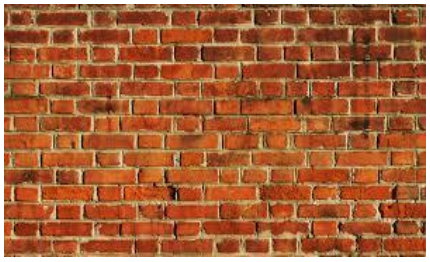
A. Dedication of Rooms and wards.

You can dedicate a room or a ward in your name of a name of your loved ones:

Single rooms	1500000 (15 lakhs)
General ward	3000000 (30 lakhs) (or 1 bed for 6 lakhs)
Pediatric ward	2000000 (20lakhs)
Courtyard	1500000 (15 lakhs)

B. Stars in "Wall of Love"

You can have your name or name of your loves ones in the star for Rs 100000(1 Lakh).



C. Buy a Brick

You can buy a brick for Hospice for Rs 5000 (5 thousand) per piece. Your name will be kept on a website.

D. Donate any amount you wish.

International Fund Raising Strategy

We are grateful to our friends in UK, New Zealand, Canada, USA and other countries for their support for the New Building Project of Hospice Nepal. A meeting was held in Kathmandu with participation from these countries and strategies for fund raising was discussed.

Meeting with International Partners in Kathmandu, February 2018

Appeal.....

Towards a compassionate community, a compassionate society and a compassionate nation....

How compassionate a community is, is seen in how the community looks after its dyings, elderly and disabled. Hospice Nepal has been working for 18 years to improve the quality of life of people approaching end of their journey.

It will not be an exaggeration to say that a foundation in palliative care has been laid. To take this care to a greater height at a national level, a model palliative care centre providing excellence in care, training to health professional of all level and facility to conduct research is paramount.

To this end, we appeal to all our friends and supporters to help in fund raising to achieve our goal to construct a new 20 bedded palliative care centre.

In Appreciation.....

Hospice Nepal is grateful to....

Nick Simons Foundation, New York , USA (www.nicksimonsfoundation.org) for their continued support for running Hospice.

Two Worlds Cancer Collaboration Foundation , Canada (www.twoworldscancer.ca) for their support in rural palliative care program in Makwanpur.

TRUST NEPAL
OVERSEAS PVT LTD

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

Brihat Investment for it support in improving the facility at Hospice Nepal and creating the concept design of new facility.

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.*

& *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.