Home hospice care in Nepal: a low-cost service in a low-income country through collaboration between non-profit organizations

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Founder and President, Binaytara Foundation
• Nepal is a low-income country in south Asia with a population of more than 27 million people.

• Because of late diagnosis and poor access to care, almost 90% of approximately 60,000 people diagnosed with cancer in Nepal annually will die within 1 year of diagnosis.

• Here, we describe our experience in successfully establishing a home hospice program in Kathmandu, Nepal.
Methods

• Collaboration between the Binaytara Foundation and Cancer Care Nepal in 2015
BTF was established in 2007 to promote health and education in resource poor communities. We

• Innovate
• Educate and
• Advocate to improve healthcare
**Binaytara Foundation Supports First Blood and Marrow Transplant Center in a Government Hospital in Nepal**

BELLINGHAM, Wash., Sept. 06, 2016 /PRNewswire/ -- Through the support of the Binaytara Foundation (BTF), the first bone marrow transplant in a government hospital in Nepal was performed on August 14, 2016 at the Civil Service Hospital located in Kathmandu. The blood and marrow transplant center in Nepal will serve not only the population of Nepal but also patients from neighboring countries.

BMT is a standard procedure for the treatment of blood cancers, genetic blood disorders such as sickle cell anemia or thalassemia, and diseases causing bone marrow failure such aplastic anemia. The procedure involves a multidisciplinary approach with the expertise and efforts of well trained physicians, nurses and allied healthcare professionals.
Need assessment

• Experts
• Interviews with patients and their families (150 interviews conducted)
• Project leader identification
• Storytelling method to gather information about what patients and their families wanted from a potential home hospice program
• Questionnaire was developed in collaboration with GlobalGiving, a charity fundraising website
• We asked 150 patients and their families open ended questions
The Binaytara Foundation is establishing home hospice services in Nepal. We would like to learn about your experience with end of life care in Nepal.

Talk about a time when someone you know was dying. Who cared for them? How could they have been helped?
• Helplessness
• Financial burden
• Care provided by family members
• Frequent hospitalizations
• Problems with transportation
Local project leader

Dr. Madan Piya, oncologist, Nepal
Tricia Raynolds, a hospice NP from Boise, Idaho
• “These visits have been much appreciated, at least by the families. For one family we encouraged them to have the patient take his pain medicine at bedtime, so he would sleep better, as the patient denied pain but was up all night, which was tiring everyone out. We also encouraged allowing the patient to eat for pleasure, rather than having it as a source of conflict in the home.

• For another we facilitated discussion about stopping the oral chemo, which the patient wanted due to side effects, but some of the family was reluctant.
• For the third family, we simply advised to put the lactulose in juice to prevent constipation.

• These may seem like little things, but these little things can make a big difference for patients and families coping with incurable diseases. And the nurses come into the homes with respect, knowing that we are there to prepare, support, and teach. The goal is quality of life and comfort for the patient.”

Tricia Raynolds, a hospice NP from Boise, Idaho
Binaytara Home Hospice Program, Nepal formally launched in January, 2016
Binaytara Foundation Starts Free Home Hospice Services in Nepal

In collaboration with Cancer Care Nepal, the Binaytara Foundation (BTF) has established a home hospice program in Patan, Nepal.

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Hospice care for terminally ill patients in Nepal
Binaytara Home Hospice Program, Nepal

- A total of >80 patients have been enrolled
- The service is provided free of cost to the patients and their families
- Average cost of care is 17 USD/day
- BTF provides salary, staff training, EMR, and other monthly expenses
- CCN provides office space
BTF Home Hospice program

- Identification and agreement with partner organization (October, 2015)
- Need assessment (Nov- Dec, 2015)

Training

Training and EMR

- Training of Healthcare providers (December, 2015)
- Opensource EMR customization (December, 2015)
- Program start date (January, 2016)
- Through CAPC training modules
- Purchased motorbike

Continued education/EMR support
• Clearly, home hospice program is very important in low income countries like Nepal where most patients with cancer are diagnosed at late stages, and many do not have access to cancer centers.
  • Dignified death—basic human right

• To make a home hospice project successful, several factors such as the selection of appropriate local partner, training, and financial support are necessary and the project needs to be tailored to the local cultural context.
“Countries have man-made boundaries, humanity does not” – Dr. Binay Shah

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