



InTouch

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Palliative Care Department
Emmanuel Hospital Association

Striving to Serve – Stretching to Love



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Chronic Illnesses Require Palliative Care

An evaluation of the palliative care service at HBM Hospital, Lalitpur was undertaken in November 2011, 18 months after the service started. One recommendation was to include patients with chronic life-limiting diseases such as those with heart, lung and kidney failure. Up to that point we had been caring for cancer and HIV positive patients alone. Acting on this guideline, the service now looks after 2 patients with heart failure, 3 with chronic lung disease and 2 with kidney failure.



Laxmi (30 years) has chronic kidney failure and was admitted in the palliative care ward of HBMH in a serious condition. Her family is from Andhra Pradesh but moved to Lalitpur when her parents and brothers started working in the stone mines. Her husband also joined the same trade, helping to build a dam, and working for daily wages. In 2006 when Laxmi was expecting her first child, it was discovered that she had shrunken kidneys and high blood pressure. The baby was born premature and died 3 hours after birth. The couple was devastated by the loss. In 2008 Laxmi conceived again. Although the course of her pregnancy was complicated she delivered a healthy baby boy who is now 4 years old. No treatment was sought for Laxmi's kidney problems because of financial restraints.

In early 2012 Laxmi had swelling of her feet and fluid accumulation in her lungs and abdomen. She was treated in a local hospital resulting in a debt of Rs.35,000 from medical costs and loss of wages for her husband, her main caregiver. The family was very encouraged by visits from Pastor Rajesh, Calvary Church, Lalitpur who also informed the palliative care staff about her condition. Admitted in the PC ward for 10 days, she was given medication, a special low protein diet provided by HBMH staff, and daily prayer. Laxmi's condition improved and she is now able to do housework. Her husband said, "We felt so relaxed when my wife was being treated at HBMH. The staff was very kind and supportive. My wife has a good appetite now, her swelling is much less and she enjoys caring for our family again. We are very thankful. Please continue to pray for us."

Neurological Deficits



During a home visit to Talbehat, a town about 50 kilometres from HBM Hospital, Lalitpur, the PC team discovered a young man in a terrible state. Paralyzed from the waist down from tuberculosis of the spine, Nanhe Das had isolated himself in a small room, refused to bathe and eat, and lay in his own excrement for 2 months. He was covered with pressure sores and flies. He reminisced about happier days when he was a prosperous army cook. His life changed when his wife left him to re-marry, leaving him with 3 sons and a daughter. Unable to work, he spent his time alone in the room, shouting at whoever passed by. His parents and children were in total despair.

Admitted in the PC Ward at HBM hospital he received loving medical, emotional and spiritual support. After a good bath he made a round of the little garden in a wheelchair and had dinner with our volunteers. Following a restful night Nanhe expressed his gratitude and new found hope that there really are people who care and who will walk alongside him. His elderly mother wept at his transformation. The road to recovery is long but he was no longer alone. He was given a hand controlled wheelchair by the Government that brought him great joy.

We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop.
Mother Teresa

Training

Cairdeas International Palliative Care Trust, Scotland and EHA collaborated to run a Training and Leadership workshop from June 11-15 at Landour Community Hospital. Beautiful setting, great weather, wonderful hospitality, and a welcome learning experience! Apart from 5 participants from EHA we also had Osama and Jomana, both nurses from Khartoum, Sudan; Dr. Mohan from CanSupport, Delhi; and Dr. Sanjay Dhiraaj from SGPGI, Lucknow.



Drs. Mhoira Leng, Chitra Venkatesh and Grahame Tosh ably led the workshop that started with exploring self-awareness tools and implications for leadership, training and team functioning. This was followed by an outline of theories of learning, how to utilize good presentation skills, and a demonstration of use of teaching methods. We also explored principles of leadership, strategic planning, change and conflict management. The sessions were extremely interactive and we came away inspired and refreshed.

Building Awareness in Schools



During the past 2 months there has been a big thrust towards building awareness among school children about risky behaviours, causes of cancer and palliative care. Leela met the Superintendent of Schools and also several principals who were eager to invite the team to their schools. So far 466 children and 7 teachers have heard presentations about cancer and its prevention and watched dramas about palliative care. There was a time for questions and the children were rewarded with sweets and pens. HBMH PC department now has an agreement with World Vision, Lalitpur to conduct one school awareness programme per week in partnership in their target area.

Cervical Cancer

Cervical cancer is the number one cancer killer of Indian women. In India, every 7 minutes, 1 woman dies due to complications of cervical cancer. Pap smear is one of the best known diagnostic tests to detect cervical cancer. Barely 5-6% of women in India undergo the test. In slums, the figure is much lower.

Cervical cancer is linked to infection with the human papilloma virus. A trial of **HPV vaccines** in India, run by *PATH*, involved more than 23,000 girls from Gujarat and Andhra Pradesh. The trial (now halted & under investigation), examined the safety & feasibility of routinely offering the vaccine. A committee of Indian Govt. scientists found the study involved a number of ethical violations. Cancer surveillance, registration & monitoring in India are incomplete, making it impossible to predict the success of disease prevention. Hence there is no justification for the general rollout of an HPV vaccination programme in India. It is among the most expensive vaccines in the market.

Bereavement Support is a Critical Part of Palliative Care

Research shows that the distress created by bereavement is among the worst of life's experiences. As medical personnel it is easy to trivialise the stress of bereavement. Grief can potentially lead to mental or physical illness with a greater risk of self-harm. Majority of bereaved people experience normal grief but it is important to recognise those in whom the adjustment is complicated and provide appropriate help.

Normal Grief

80%-90% bereaved persons suffer normal grief, slowly accepting the reality, and moving on with life. The stages of normal grief are described as:

- Disbelief or shock
- Separation distress or yearning
- Ultimate acceptance of or recovery from the loss
- Angry protest
- Depressed mood or despair

Complicated Grief

Criteria based on the addition for DSM-V, Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. The symptoms cause dysfunction socially, in work and other areas, and last at least 6 months.

- Distracting and troublesome yearning at least once a day for the past month
- 4 of the following 8 symptoms:
 - Trouble accepting death
 - Inability to trust others
 - Excessive anger or bitterness
 - Feeling the future holds no interest
 - Feeling emotionally numb/detached
 - Difficulty in moving on with life/building relationships
 - Feeling that life is meaningless
 - Agitation or restlessness

Physical and Psychosocial Outcomes in Normal Grief: Acceptance of the loss occurs after about 6 months into bereavement. There is a desire for future meaningful relationships. There is recognition that abilities, skills and self-worth are unchanged, leading to finding purpose in life, engaging in fruitful work, experiencing enjoyment and taking interest in physical appearance.

Physical and Psychosocial Outcomes in Complicated Grief: Feelings of excessive loneliness or emptiness. Becoming reclusive and avoiding places/activities that bring back memories. Unusual levels of sleep interference, loss of interest in work, social interactions, self-care, or leisure activities. There is an increased risk of cancer, hypertension, cardiac events, and suicidal thoughts as well as increased alcohol use, smoking, medication or hospitalization

Possible interventions

- I. **Universal** interventions: offering help to all bereaved persons such as through phone calls or visits, which are most beneficial if the family seeks this. Self-help or informal group therapy where there is remembering and information sharing.
- II. **Selective** interventions: targeting those with complicated grief or the high-risk group done by trained psychotherapists employing techniques such as dialogue and behaviour change.
- III. **Indicated** interventions: for those manifesting problems such as depression or anxiety, mostly beneficial in depression or improving sleep quality. This persists for the duration of drug therapy (tricyclic antidepressants, selective serotonin reuptake inhibitors, bupropion, benzodiazepines)