

Kavaratty and Amini, Lakshadweep, November 2016 (third visit)

Lakshadweep islands are a group of coral islands in the Arabian Sea. Inhabitants live on fishing and coconut farming. Many inhabitants suffer from chronic diseases, rising incidences of CVA and access to medical care is limited and in case of medical emergencies the only option is to take the patient to main land which takes 4-5 hours in chopper. Previously chopper service was available from Agatti to Kavaratti, but now it is being limited to patients only. This chopper is an Air Ambulance which is used to carry sick and very ill patients or emergency patients to hospitals in Cochin. All islanders belong to Islam and they consider it as their religious obligation to help others. This became the root cause of volunteering. But we could see that these trends are changing as the culture is changing slowly.

Site

Thanal Charitable Society

The center has wonderfully developed a community model of palliative care. In 2013, it was just a budding center limited to one island- Kavaratti. When we made our last visit in 2016 – they have expanded and now they have their presence in 6 islands.

Patients are cared for at their homes and most home care patients visited are bedridden living with chronic illness, subarachnoid or CVA- induced hemiplegia, bronchiectasis, encephalopathy with spasticity.

Participants from APLI

- Dr. Sophia Lam, Registrar of Palliative Care Unit, Monash Medical Centre, Victoria, Australia
- Ms. Sara Rose, Palliative Care Nurse Specialist, Melbourne City Mission

Participants from Thanal Charitable Society

- Abdul Hameed Moulana – Chairman
- Dr. Ali Azher, Palliative Care Doctor

Participants from Pallium India

- Dr. Abu Laize C.B. deputy project manager

Past visits were made to the below mentioned islands

- **Kavaratti – 2013**

Site visited: Lakshadweep Institute of Palliative Care

Summary:

- The center had inaugurated only 8 months previously and was driven by the vision and passion of a local teacher and unofficial community leader, Moulana.
- The service is a community-based palliative care and is staffed entirely by volunteers—actively seeing patients either as regular visits or via a 24 hour on-call service.
- The team included one ‘fulltime’ doctor and nurse (Dr Ali and Brother Khafee) both undergone a 6 week training course at the Trivandrum-based Pallium India Institute and 6 other nurses and 13 ‘volunteers’ who had the rather nebulous role of identifying suitable patients and supporting families.
- The center is a registered morphine prescribing service with medications, equipment and staff time all provided free of charge to patients and referrals were taken from all sources
- The APLI team saw patients in home care and at the Indira Gandhi hospital with very basic wound care needs to others with more complex psycho-social issues.
- The APLI team delivered a grand rounds presentation at the hospital in addition to some formal education sessions.
- Due to the need of a political and administrative will to fund ongoing services, the APLI team met numerous officials and administrators to raise awareness about palliative care and raise funds.

- **Kavaratti and Agatti – 2014**

Site visited: Lakshadweep Institute of Palliative Care

Summary:

- The service has gone from strength to strength and among many successes, have been able to care for 27 patients at the end of life at home.
- They have maintained a continuous supply of morphine over the last year.
- The teams visited the neighbour island of Agatti where they plan to expand the service.
- One of the services biggest successes was that, a year on, the same staff and volunteers remained, a testament to the support and leadership provided by their leader Moulana.

- Most services are home care services and the team dress pressure ulcers, check blood pressures, urinary catheters, Ryles's tubes, tracheostomy tubes, contractures , hygiene and diet. They encourage and support the carers, who are mostly women, who are providing most of the hands-on care
- The teams visited homes of patients together and again lobbied hospital directors of government figures to provide greater support to the service.
- Tthe nursing education of families had improved significantly with each family we visited knowing how to care for their loved one at home.
- The APLI team conducted formal and informal sessions about reflective practise, communication, teamwork and self care.

2016 visit:

Objectives of visit

- Train the volunteers

Summary

- We met the chairman, who briefed us of the activities for the coming few days.
- We attended a public function in the evening, during which the center thanks everyone for the help provided and presents awards to the best nurse and center.
- The team went on home visits at Amini so at to provide on-the-job training for the volunteers and team at thanal. Training was given on wound care, bed sore, catheter, constipation and general patient care. The team also met several officials in the evening public function and requested their support for the cause.
- Training was also provided for doctors, nurses, volunteers and the care givers of the patients at the Community Health Center Hall. Topics were based on the cases seen in home care and as per the request from the unit members. Topics ranged from What is palliative care? The role of each member in palliative care team, Patients' care taker – a part of palliative care team, Bed sore prevention and its management with role play, Constipation, Communication skills and Counseling and self-care
- Volunteers expressed complete satisfaction and feel empowered to care for patients
- The chairman of the Amini unit expressed training needs to be the biggest need that the unit is faced with currently.

- The APLI and the Thanal team met Mr. Farooq Khan, the Administrative head of Lakshadweep islands. Mr Khan expressed concern about the increasing number of cancer cases in Androth and Minicoy which are far off islands from Kavaratty and promised support.
 - The team shared their dream to start a hospice facility / In-patient unit in Kavaratti to provide care for the sick patients which could be used as a training center also. A proposal was asked to be put forward for the same, which Mr Khan said he would try to forward to concerned authorities for action.
 - Developing a person as a trainer was also discussed, in which we suggested Ahmed Khaafi, the senior most and very experienced nurse who is now the Nursing Super intendent of Thanal.
 - The team requested to have a nurse posted in each of the islands.
- The ALPI and the thanal team also met the Health Secretary and other officials and requested their support for Thanal. We shared our concerns in the increasing cases of CVA in the islands and requested the health secretary to have a research study on this.
- Thanal's activities are restricted due to lack of sufficient funds and since they are isolated from the mainland where people are unaware of the needs of the island inhabitants.
- Thanal received some funds from the Lakshadweep health services and from some CSR initiatives and some from the volunteers. Funding from the volunteers being unstable, a sustainable model for funding needs to be identified.
- Future plans include extending services to far off islands and to start an in-patient facility at Kavaratty. Development of existing centers, training of volunteers are the immediate plans and are getting delayed due to lack of funds.