

Project Hamrahi visit to Mizoram

Background

Ed Gaudoin and Anil Tandon travelled to Aizawl, Mizoram from Sunday 24 March to Sunday 31 March 2019. We were accompanied by Shalini Arora Joseph, Project Officer with Pallium India, and Santanu Chakraborty, Director of Ruma Abedona Hospice (RAH) in Kolkata.

This was Shalini's fifth visit to Aizawl, the most recent one being in February 2019 with Mhoira Leng. Mhoira's visit built on previous visits by her to Aizawl (commencing in 2008) and this most recent visit had the objectives of meeting with key health and community leaders and delivering a ten-day foundation course in palliative care for doctors and nurses from the state's various district hospitals.

Santanu is a long-term friend and colleague of Anil's and was invited to observe the Project Hamrahi model in action and to conduct detailed discussions with Shalini about a proposed foundation course to be conducted as a joint initiative between RAH and Pallium India in Kolkata. As the week unfolded, Santanu was also able to observe various models of palliative care provision as provided in Mizoram, share his learnings from having developed a grass-roots non-government charitable community palliative care service more than 15 years ago, and benchmark the care being provided at RAH with other Indian services.

General information

Mizoram is a unique part of India. Located in the remote north-east, the state is mountainous, culturally homogeneous, with an almost universally Christian population and a road network outside of the capital of Aizawl which is basic, although this is determined mainly by geography.

Administratively, Mizoram is divided into eight districts: Aizawl, Kolasib, Saiha, Champhai, Lawngtlai, Lunglei, Serchhip and Mamit. Only Aizawl has established palliative care services (in the government run Civil Hospital which houses the Regional Cancer Centre and Synod Hospital, managed by the Presbyterian Church).

In Mizoram the prevalence of HIV / AIDS is high, as is substance abuse (both alcohol and injectable use of heroin). Of note, the state government of Mizoram re-introduced the prohibition of the sale and consumption of alcohol from 31 March 2019. Synod Hospital operates the free-standing Grace House for patients with HIV / AIDS as well as K Ward for patients with substance abuse patients (K being the abbreviation for Khawngaihna, meaning 'Grace' in the Mizo language).

Grace House was opened in 2004 and over time has become increasingly important as other centres which previously had provided HIV treatment ceased operation in 2013 due to lack of support at a national level. Patients are provided with free bed and free food but only some treatments are provided free of charge.

Palliative care at Synod Hospital

Grace House

- Opened 2004 for the treatment of patients with HIV / AIDS
- Located on the campus of Synod Hospital but physically separate from the main hospital buildings
- Commenced palliative care 2016
- 20-30 beds capacity
- Free bed, free food but only certain treatments provided free of charge

- Other centres in Mizoram ceased providing HIV treatment in 2013 due to lack of support at national level
- Six nurses have now completed training in palliative care: Arinie, Tetei, Zoremi, Maduhi, Dami and Rosalind
- Although there is a room for the palliative care outpatient clinic in the outpatient building of Synod Hospital, outpatients are more often seen in Grace House or K ward (the inpatient ward for substance abuse patients)

Palliative Care team members / staff

Dr Sanghluna Renthlei

- Joined Synod Hospital 1992
- Completed Hyderabad six-week course in 2016
- Has conducted sensitisation workshops several times since 2017

Dr Ralte Lalchhanhima

- Graduated 2005, joined Synod Hospital 2007
- Completed TIPS six-week course in 2017
- Completed training in Dignity Therapy

Sena Renthlei

- Project manager for the HIV community care centre
- No medical background
- Completed TIPS two-week course in 2017
- Since then has been the social worker for the Synod Hospital palliative care service

Dr Evelyn Pachuau, Civil Hospital, trained February 2019 but is currently pregnant and appeared more interested in research

Dr V Dochai, Seaha District Hospital, trained February 2019

Dr HD Lallawmkima and Sister Amteii Vamlalhnaai, Kolasib District Hospital, trained February 2019

Meetings were held with the following Executive staff:

- Dr Eric Zomawia, State Director of the National Health Mission
- Dr Lalhmuchhuaka, Medical Superintendent of Civil Hospital
- Dr James Mawia, Medical Superintendent of Kolasib District Hospital
- Sister Lalfamkimi, Principal for the Department of Nursing, Regional Institute of Paramedical and Nursing Sciences (RIPANS)
- Dr LH Thanga Singson, Director of Synod Hospital
- Dr Vanlalsiama Chhangte, Director of Ebenezer Hospital

Presentations were delivered to:

- Third year nursing students at RIPANS (30 students)
- Synod Hospital nursing staff (30 nurses)
- Synod Hospital medical staff (26 doctors)
- Civil Hospital medical staff (60 doctors)
- Ebenezer Hospital doctors and nurses (40 staff in total)

Regional Institute of Paramedical and Nursing Sciences (RIPANS)

- Four-year nursing degree, intake of 35 students per year
- MOU between Pallium India and Synod is to provide a two-hour session annually
- During our visit to RIPANS, an education session on palliative care was given by Ed Gaudoin which therefore satisfied the requirement for 2019
- The Oncology component of the nursing curriculum has a 10-hour allocation
- The two-hour education session on Palliative Care is included within this 10-hours
- Encouragement given to leadership team for RIPANS to 1) organise nursing student placements at Synod Hospital for exposure to palliative care and 2) send a tutor for the six-week training course in palliative care

Kolasib District Palliative Care Service

- A day trip was conducted to Kolasib to support and provide supplementary training to the recently trained doctor and nurse there, as well as to meet with the Medical Superintendent of the Kolasib District Hospital
- Doctor and nurse trained in February 2019 and so palliative care service only just commenced
- The hospital, with 60 beds and 13 doctors, has been granted RMI (Recognised Medical Institution) status and so can stock and dispense essential narcotic drugs
- Despite the above, morphine has not yet been obtained and the plan is for morphine to be provided by the Civil Hospital in Aizawl
- The palliative care service currently has four community patients and the outpatient clinic has not yet commenced
- The current expectation from the Medical Superintendent is for the doctor and nurse to provide palliative care outside of their rostered hours, ie. in their own time

Strengths

- The depth and breadth of Dr Sanghluna Renthlei's clinical experience and standing in the community
- English speaking community thus gives ease of translation of teaching to caring
- The genuine care for and commitment that the Synod Hospital palliative care team have to the people of Mizoram
- Dr Sanghluna Renthlei's foresight to incorporate the philosophy of palliative care into the care provided for HIV and substance abuse patients. These patients are not 'traditional' palliative care patients but the care provided to them – and their very real needs – align very closely with the recently developed definition of palliative care proposed by the International Association of Hospice and Palliative Care: 'the active holistic care of individuals across all ages with serious health-related suffering due to severe illness'.
- The strong medical and nursing team at Grace House, Synod Hospital
- A ten-day palliative care foundation course was conducted in Feb 2019 for all district hospitals of Mizoram under the National Program for Palliative Care (NPPC) in collaboration with Pallium India and the National Health Mission (NHM) Mizoram. Nurses from all districts came but three districts could not send their doctors – Mamit, Serchhip, Lunglei.
- The philosophy of palliative care is easily incorporated into Grace House
- Philanthropic support provided to patients / family by various contacts and supporters

Threats

- The absence of Dr Ralte Lalchhanhima while he is working in the USA in 2019 / 2020
- Maternity leave cover for Dr Evelyn Pachuau at Civil Hospital
- For sustainability Dr Sanghluna Renthlei needs to be given the opportunity to further enhance his knowledge and skills – this is difficult given his heavy clinical commitments
- Very long travel time to outlying districts
- Lack of occupational therapy / activities / diversions for the K ward inpatients
- Lack of pharmacological options (methadone or buprenorphine) for the management of opioid addiction

Questions

- Where does the responsibility lie for providing education, training and mentoring to the outlying districts? Is this with the government palliative care service or with the Synod Hospital palliative care service?
- How will education be provided to the districts who were not able to attend the February 2019 foundation training course?
- Has the action plan for the Mizoram Institute of Medical Education and Research (MIMER) been progressed: workshop for staff / faculty, incorporating palliative care into curriculum

Recommendations

- Further development of Mr Sena Renthlei's role given his compassion, thoughtfulness and clear leadership potential
- Provision of palliative care – both OPD and home visiting service - to be incorporated into the office-hours duties of doctors and nurses, and not relegated to a service provided out-of-hours. This is particularly important in the district hospitals outside of Aizawl.
- Repeat visit by Ed Gaudoin and Anil Tandon – together with Shalini AJ / Pallium India project officer to maintain relationships with and between APLI and Mizoram state – in 2020.
- Remaining districts (Lunglei, Serchhip, Mamit) to each have a doctor trained in palliative care. As noted above, one nurse from each of these hospitals has already attended the foundation course conducted in Feb 2019.
- For a productive garden or similar constructive activity to be developed and coordinated (perhaps by a volunteer organisation such as the Young Mizo Association) for the K ward inpatients who are clearly struggling with boredom.

Summary of clinical work

Ward round at Grace House

- HIV patient lost to follow up
- Dr Sanga's relaxed, informal bedside manner
- HIV viral load counts not available in Aizawl
- Co-existent HCV, TB, alcohol abuse, IV drug use
- Patients need to take responsibility for six-monthly checks of CD4 count
- Anti-tuberculous and anti-retroviral therapies provided free of charge
- Ganciclovir not available
- No access to Infectious Diseases specialist
- Cylinder oxygen only
- Ex-prisoner with HIV admitted in respiratory failure secondary to empyema, had been diagnosed with HIV whilst in prison last year but was not on ART, had presented to Civil Hospital the day prior but was sent home without a CXR having been performed, deceased less than 48 hours after admission

Ward round at Synod Hospital

- Female with myeloma, on regular morphine for pain but did not appear to be available prn
- Adjustable bed headrest
- Female with ovarian cancer and pleural effusion on noradrenaline infusion plus IV meropenem, appears very unwell, patient wants to go home as she feels she is a burden to her family
- Wall oxygen available
- Male with gastric cancer, reviewed on Monday, deceased on Friday

Ward round on K ward (for substance abuse patients)

- Leg wounds managed with skin grafting performed by Dr Sanga
- A dermatome donated by a German team has broken so a knife is now used
- Significant problem with recidivism: long-term success rate of only 5% to successfully rehabilitate patients
- How to improve: more activities, more psychological support
- Patients appeared generally bored, seemed to have good insight into the emptiness of their lives and were well aware of the high risk of relapse into drug abuse
- Table tennis provided but only one bat was available with no balls
- Guitar provided but one string broken
- Patients were keen to discuss the pros and cons of buprenorphine and methadone as pharmacologic treatments for addiction
- Patient with scalp vein

Home visits, Aizawl District

- Home visits by the Synod Hospital palliative care service are generally conducted every Wednesday and on other days if required
- Young female with CML on chemotherapy at a cost of RS 7,000 per month, four children, associate of Dr Sanghluna is paying their school fees
- Middle-aged male with HIV, receiving food kit from Synod Hospital (daal, flour, oil etc. to the value of Rs1,000 every six-months)
- Elderly female with past history breast cancer and no evidence of disease recurrence, she is now a local advocate for cancer and palliative care in her community
- Bereavement visit to the family of a middle-aged male who died four months earlier, his grandson is an ex-IVDU known to K Ward
- Young male with C6 quadriplegia following a road traffic accident six years earlier, bed-bound but lying on air mattress and free of pressure sores, his wish is to be able to walk and consideration was being given to organising an inpatient admission for rehabilitation (to be paid for by an associate of Dr Sanghluna) but he is currently unable to leave his bedroom and be with family in the communal living room because of poor sitting balance and inadequate support in wheelchair but when attempt made to sit him up he fainted.
- Middle-aged female with cervical cancer prescribed morphine 20mg 4-hourly but it was very unclear to all present how much she is actually taking (perhaps only 30-50mg per day) because of confusion between the three colour-coded formulations of oral morphine: 10mg, 20mg and 30mg.

Kolasib District patients

- Elderly patient with gastric cancer with secondary gastrointestinal bleeding and high transfusion requirements, teaching discussion held about the potential role for tranexamic acid and the concept of Ask-Tell-Ask in communication
- Middle-aged male with carcinoma of the piriform sinus with lymphoedema of the arm, teaching discussion held about massage / positioning of the arm and opioid conversion to morphine
- Middle-aged female with carcinoma of the cervix, currently appears well
- Elderly lady with tonsillar cancer, not interested in knowing her prognosis and at peace with her mortality but daughter not accepting of poor prognosis
- Middle-aged male with gastric cancer and a foregut malignant bowel obstruction from severe omental caking, teaching discussion held about the role of dexamethasone
- Middle-aged male with lung cancer who is currently asymptomatic following radical chemoradiotherapy for locally advanced disease, teaching discussion about him not having any palliative care needs

Ebenezer Hospital

- Elderly female with end stage chronic lung disease, deteriorating performance status prior to admission, now an inpatient in the intensive care unit for non-invasive ventilation. Prolonged family meeting to discuss withdrawal of non-invasive ventilation (as per the patient's request). Of note, the patient was the grandmother of Dr Evelyn Pachuau at Civil Hospital