

Strengthening Forward Backward Linkages between Palliative Care Centre and Other Tertiary Care Centers for Effective Management of Episodes of Acute Illness among People Living with HIV

Paramesh Gorkhal, K Sulekha, Divya Sarma, Annarao Anehosur, Shafiulla H Billali, Sharada Yecharappa and Kamalakshi Kammar

Background

HIV is now considered a chronic manageable condition, but there are still phases of acute illness during the course of life with HIV, either due to opportunistic infections, other HIV related conditions or severe side effects of ART medicines. Palliative care centres need to establish effective linkages with tertiary care centre, so that there are smooth transitions in care and these phases of acute illness can be managed.

Samraksha is running Asha Jyoti, a HIV Palliative Care Centre in Koppal Karnataka. Over the years, the centre has established good connections with some important tertiary care centres and refers patients to these services based on their needs.

Methods

A case file review was undertaken for all the patients who were referred to tertiary care services over the last two years, in order to understand the reasons for the referral, the processes through which Samraksha facilitated the referral and the outcomes of these referrals.

Tertiary Care Centres Where Referrals were Made

1. District Teaching Hospital in Koppal, Hubli and Bellary
2. Oncology centre: Kidwai Institute in Bangalore
3. NIMHANS in Bangalore
4. Ophthalmology Department of Vital Malya Hospital, a private hospital in Bangalore
5. MS Ramiah Memorial Hospital, a private teaching hospital in Bangalore
6. CHK Hospital, a private hospital

There were 31 accompanied referrals. 23 patients were admitted back in Asha Jyoti after seeking treatment from the tertiary care centres for pain management. For four patients, support was mobilized in the form of community volunteers who accompanied the patients and also supported them at home, post discharge.

Referrals were made to manage different health conditions, opportunistic infections as well as for procedures or specialized services.

Health Conditions for which Referrals were necessary

Opportunistic Infections

- MDR TB
- CMV
- Herpes Zoster in Eye

Cancer

- Cervical Cancer
- Oral Cancer
- Leukemia

Other Health Conditions

- Pleural Effusion and Breathlessness
- Low Platelet Count
- Dengue
- Pericardial Effusion
- Granuloma
- Gastritis
- Fistula
- Hernia
- Haemorrhoids
- Pancreatitis
- Obstruction in Urinary Passage

Psychiatric Conditions

- Severe Depression

Need for Special Procedures or Surgeries

- Hysterectomy
- Endoscopy
- Intensive Care Unit Services

Practices adopted by Asha Jyoti to Facilitate Smooth Transitions between the Different Service Delivery Points

1. Discussion with Family Prior to the Referral

Prior to making the referral, the counselors have a discussion with the family members or the patient in which the health condition of the patient and the need for referring to another tertiary centre for treatment is completely explained to them. Clear information is given to them regarding the treatment which they can expect at the proposed treatment, and the prognosis. If there are different options for the tertiary care centre where they can seek treatment, this is explained to them, and they are allowed to choose where they can take the treatment. If the patient or family members share impediment to seeking services at the tertiary care centre, then this is addressed. Community care volunteers and other resources within the community is used to address some of these impediments.

2. Assessment of Family's Capacity to Support Treatment Costs at the Tertiary Centre

The potential costs of the treatment is also explained to them. The staff make an assessment of whether the family can bear the cost of the treatment, and if they are unable to bear it, then the centre helps the family to mobilize some resources for this.

3. Accompanied Referral or Discussion with the Service Providers at the Tertiary Care Centre

Wherever possible an accompanied referral to ensure that the admission process is smooth. If an accompanied referral cannot be made, there are telephonic discussions with the service provider at the tertiary care centre, to explain the patient's issues to them.

4. Backward Linkages to the Palliative Care Centre whenever Necessary

Frequently, after managing the crises in health or performing the procedure, patients continue to need some regular care and monitoring. Asha Jyoti centre staff therefore follow up with the progress of every patient after the referral has been made and if their condition needs it, they are admitted back to the care centre after discharge from

5. Arranging for Community Based Support Systems Post Discharge

If the patient continues to need some basic care after discharge, then with their consent, they are linked to community care volunteers. These volunteers visit the patient and their family to check on their progress and see if they are facing any problems.

Accompanied Referral and Mobilizing Different Resources to Support the Patient during the Referral

Shivamma, a widowed lady with one young daughter had to be referred for hysterectomy because she had cervical cancer. Shivamma was very reluctant to go to the hospital for surgery. She had no family to support her and she felt that no one could help her at the hospital during the surgery and there was no one to care for her daughter either. The cost of travelling to the hospital and other expenses there could also not be borne by her.

Asha Jyoti explained the importance of immediate surgery to her and how this could improve her health. Resources to help her seek the treatment were mobilized from different places. Local volunteers contributed some money to provide for her food and other expenses at the Hubli District Hospital. Her travel was supported by Samraksha. At first, the district hospital in Hubli could not immediately admit her due to heavy case load, and she was asked to come later. The second time, one of the centre staff accompanied her to Hubli and ensured that the admission went on smoothly. A care volunteer also accompanied her and stayed with her during the surgery and post operative care phase. Her daughter was enrolled in a student hostel run by a local religious charitable group, so that she could continue with her school during this period.

After discharge, she was admitted back to Asha Jyoti for pain management and control and eventually discharged after a month.



Discussion with patients and family members regarding the need for referral and what can be expected from the Tertiary Care Centre

Motivating Patients and Family Members to See Services at the Tertiary Care Centre

Lakshnavva and her two daughters had been living with her parents since her husband's death. She was a daily wage laborer and was from a poor family.

Lakshnavva was diagnosed with cervical cancer and was advised to go to Kidwai Oncology Centre in Bangalore for surgery and further treatment.

At first her family was a bit reluctant to take her there. Lakshnavva herself did not want to go there, because she felt that she was already being a burden on her family and this would bother them further. When she heard that the surgery would remove her uterus, she also expressed fears about this process and did not agree to it. She was also worried about the costs of the treatment.

The counselor explained the need for the surgery to her and helped her understand how this intervention could substantially improve her health. Other positive women who had undergone the surgery came to share their experiences and how their health had improved after the surgery.

The importance of the surgery was also explained to her family and they agreed to it. Resources were mobilized to support their travel to Bangalore. One of the center staff accompanied them and ensured smooth admission and also briefed the doctors on her health condition. They also linked her with the Vajpayee Health Assurance Scheme to cover treatment costs. Staff from Cancer India also supported her and ensured that the costs of treatment were reduced.

This case highlights multiple economic and psychological impediments to access treatment from a tertiary care centre. Through a strategy of testimonial sharing, accompanied referral and linkages with welfare schemes, the patient was eventually motivated to seek the service and this ensured better health outcomes for her.

Samraksha Registered Office
No. 17, 1 Cross, 3 Main, SBM Colony,
Anand Nagar,
Bangalore 560024.
Ph 080 23534563
Website : www.samraksha.org
E Mail : samraksha@samraksha.org

Samraksha
Asha Jyoti Palliative Care Centre
Old District Hospital
Koppal 583231

Conclusion:

Palliative Care Centres and Tertiary Care Centres complement each other and help in recovery of people living with HIV from acute illness. It is critical for palliative care centres to establish a good referral system and support the patient and family member as they transition between different service delivery systems.