

The Need for Integrated Care to address Medical and Psychosocial Concerns among Long Stay Patients at a HIV Palliative Care Centre
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Background:

The advent of ART medicines has meant that for most part HIV is now a chronic manageable condition. The intensity of care required therefore varies across time. Intense levels of care is needed when patients is acutely ill or in terminal condition. Both physical and psychosocial care is essential in these stages as they face multiple issues.

However, the current care and support initiatives for HIV affected people does not acknowledge this need. There are not many services which offer intensive and integrated care.

Methods:

Samraksha is a developmental organization which runs Asha Jyoti, a HIV palliative care centre, in Koppal, North Karnataka.

A case-review of all long stay patients at the centre over the last two years was done. All the patients who had been admitted for 60 days or more in this period were identified and a desk file review was undertaken, to list their physical and psychosocial issues.

Results:

A total of 32 patients had been admitted to the centre for 60 days or more in this period.



Multiple Issues Reported by Long Stay Patients at the Palliative Care Centre

Major issues regarding physical health for each patient ranged between 3 to 7, and on an average, patients had about 5 major physical health issues.

Pain scores at the time of admission ranged between 6 to 10, and most patients had a pain score of 8 at the time of admission

There were often multiple sites of pain, from 2 to even 6

26 patients were completely bed ridden. 2 patients were semi-conscious and 1 patient was unconscious

Number of psychosocial issues reported by each patient ranged from 2 to 7 and on an average, patients had about 4 major psychosocial issues.

9 patients had no carers who could stay with/support them



Long Term Patients at the Asha Jyoti Palliative Care Centre

Profile:

- 22 women, 9 men and 1 transgender
- Age ranging from 14 to 50
- 30 patients on ART and 2 patients in the pre ART phase
- 26 patients were discharged after their health improved. 6 patients were in the terminal stages and passed away

Major Medical and Nursing Interventions

Interventions	Long stay patients needing intervention(%)
Regular Pain Assessment	100.00
Monitoring impact of pain medications and shifting from opioid to non-opioid based treatment	65.63
Blood Transfusion	56.25
Oxygen Support	75.00
Back Support	78.13
Monitoring reaction to ATT medicines	56.25
Special Liquid diet	81.25

All Figures in Percentages
Total number of Patients: 32

Conclusion:

Despite ART having done much to improve the health of people living with HIV, there are still phases of acute illness, where patients are acutely symptomatic and in high levels of pain. Very often, they may be completely bed-ridden. and need intensive, round the clock care.

A significant number of these patients may also lack support systems within the family which can provide a certain level of care, either because of stigma or estrangement from the family or because the family is not even aware of the condition.

Hence there is a need for an integrated service, which can regularly assess their issues and respond to them. Such services can lead to favorable outcomes, allowing patients to recover from the acute illness and resume their lives, or ensure minimum pain and suffering in terminal stages.

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Most Common Psychosocial Issues Among Long Stay Patients

Issue	% Reporting the Issue
Loss of Hope	56.25
Anxiety and Fear about HIV	28.13
Depression	21.90
Suicidal Ideas	12.50
Guilt	18.75
Loss of Motivation for ART Adherence	37.50
Lack of Support from Family	34.38
Discrimination in Family	50.00
Issues in Disclosing status to families	15.60

All Figures in Percentages
Total number of Patients: 32



Most Common Physical Issues among Long Stay Patients

Issue	Long Stay Patients Reporting the Issue(%)
Anaemia	71.88
Dyspnoea	62.50
Fever for more than a month	56.25
Tuberculosis	68.75
Candida	90.63
Herpes Zoster	25.00

Major Psychosocial Interventions among Long Stay Patients

Intervention	Interventions done with Long Stay patients (%)
1 Daily Psychosocial assessment and counseling	100.00
2 Emotional Support	100.00
3 Counseling to resolve psychosocial issues	96.88
4 Family Counseling	62.50
5 Counseling for Positive Living	37.50
6 Referral for socioeconomic support	18.75
7 Psychiatric Referral	6.25
8 End of life counseling	25.00
9 Bereavement Counseling	18.75