Conflict of Interest

The author has declared no conflict of interest.

Lived experiences and perceptions of palliative care among advanced HIV patients: qualitative study, Bihar, India

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Introduction

- Adult prevalence of HIV in India is estimated at ~0.22% (95% CI 0.16-0.30)
- In Bihar, MSF provides in-patient care to acutely unwell people living with HIV/AIDS (PLHA)
- Defined by World Health Organization (WHO) as CD4 cell count <200 cells/mm3 or a clinical stage 3 or 4 event
- High mortality rate of up to 40%
- Very few research studies of palliative care in the Indian literature

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Study objectives

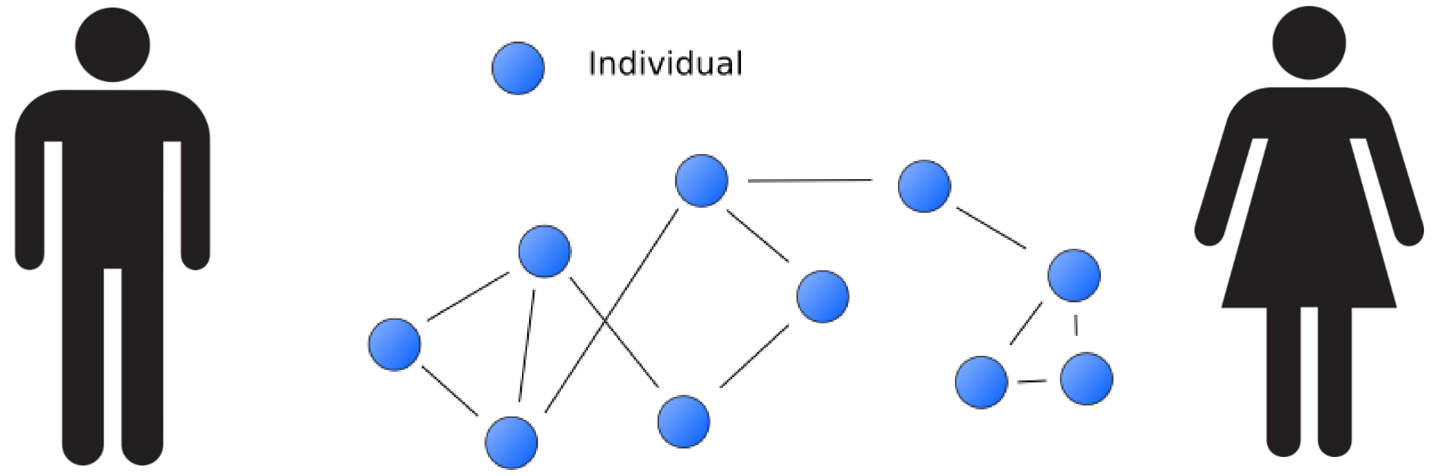
The objectives of this study:

- To understand how PLHA and caregivers of hospitalized patients view palliative care and end-of-life care, and uncover their expectations of healthcare providers
- To uncover how the dying process is experienced by other patients and relatives of deceased patients

This study was approved by the MSF Ethical Review Board and the Ethics Committee of the All India Institute of Medical Sciences, Bihar, India.

Methods

- Exploratory, qualitative study design with semi-structured in-depth interviews and one focus group discussion (FGD)
- Purposively selected **29 participants**
- Ten critically unwell PLHA, five caregivers, seven relatives of deceased patients, seven key informants from community-based organizations (CBOs)
- Face-to-face interviews with audio recording
- Verbatim transcription and translation from local languages
- Thematic analysis of data using NVIVO 11
- All participants provided written informed consent



12 men

17 women

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Results (1):

Fear of dying and the need for a separate ward for dying patients

"*With this disease, some are coming for the first time…and some of them are coming for the last time [stage of disease]. So if you keep all the people [together], they will become really worried and anxious and think I will also become [dead] like that one day*" [male, aged 36, relative of deceased patient].

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Results (2):

Transparency regarding a poor prognosis

"The only thing that makes me sad is that I was not informed beforehand of my mother's condition. If I knew ahead of time that she was going to die, I could have let my sister talk to my mother on her deathbed" [male, aged 17, relative of deceased patient].

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Results (3):

Critically ill PLHA lacked awareness of palliative care

"I am illiterate and haven't studied anything…so what will I understand?" [female, aged 35, caregiver].

"Most important of all, the patient should get the medicines timely, the treatment should be done well, the lodging and food…all these facilities should be good" [male, aged 25, patient].

Results (4):

Experiences of patient deaths and discharge procedures

"Like when he died, then and there within a few seconds, they called an ambulance and sent him onward to his home…they were only concerned with whatever paperwork was required to be done, they only hired and paid the ambulance and turned them [deceased patient and relatives] away from there" [male, aged 18, relative of deceased patient].

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Results (5):

Hospital-based palliative care patients require social support

"We do nothing all day. When my husband comes and visits, I smile and laugh with him, but when he returns home, I feel all alone…my father is there, and I can't speak that much with him. I don't know. Everything is good, but I get a little bored here" [female, aged 21, patient].

Results (6):

Preference for home-based palliative care and other services

“*If the doctor knows they will no longer be able to save the patient, they should send him home. So, the patient can meet the rest of his family, talk to everyone, and die peacefully at home*” [female, aged 40, caregiver].

Discussion

- PLHA have complex care needs beyond pain management
- Advanced care planning and psychosocial support are critical components
- Western bioethics values full disclosure between doctor and patient, but our findings indicate some cultures may not be as welcome to this kind of transparency
- Palliative care should be introduced and discussed early in the care process
- The grieving process should allow patients to spend time with the deceased in a private room
- Home-based palliative care services should be expanded in Bihar, especially for this vulnerable cohort of PLHA

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Limitations

- Recall bias for relatives of deceased patients
- We achieved saturation in the study, but not in each analytical sub-group of participants
- Geographic coverage and sample size was limited in the study

Conclusion

- A pressing need to improve palliative care provision in Bihar, particularly for PLHA
- Patients in end-of-life care may benefit from a separate dedicated ward with adequate psychosocial counseling and recreational activities to prevent social isolation
- Crucial to understand how patients want information to be delivered and whether they want to delegate decision-making to family members

Acknowledgements

Chhavi Kumar, Rohit Kumar, Shweta Singh, and the Medecins Sans Frontieres field and capital coordination teams. We are grateful to Ria Roy, Pallavi Lohani, Anuradha Ratan, Apurv Agrawal, and all medical interns and residents at the All India Institute of Medical Sciences (Patna) for their support in the study.

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