

# Family based Interventions to Improve the Quality of life of People living with HIV

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## Background

HIV related issues can cause many stressors in the family, which affects a patients' relationship with significant others. All this affects a patients' ability to have a good quality of life with HIV and leads to pain and distress – both physical and emotional. A through assessment of family stressors and support to resolve them has to be a critical part of HIV related palliative care.

## Objectives

1. To understand the impact of familial stress on people living with HIV and the different strategies used in palliative care to address this.
2. To assess how these interventions contributed to reducing pain and distress of patients and family members.

## Methodology

Case discussion with the counselors at Asha Jyoti, a palliative care centre which is being run since 2001 by Samraksha in Koppal, Karnataka and addressing the palliative care needs of people living with HIV and their families. Based on this discussion, 10 cases were identified, in which there was in depth family intervention.

A detailed file review was done of these 10 patients in order to understand how family issues were contributing to pain and distress for the patient. The strategies used to address these issues and the outcomes for patients and family members were also reviewed.



## Family Interventions Used

A patient centered strengths based approach to counseling was used in the family interventions. This included :

Systematic assessment of all patient concerns including concerning relating to family issues using a checklist

Creating a safe non-judgmental space for patient and family members to express emotions, vent feelings of anger or resentment through open ended questioning, and a stages of change approach

Helping rebuild relationships after the crises of HIV by identifying strengths in the self and positive aspects of the relationship

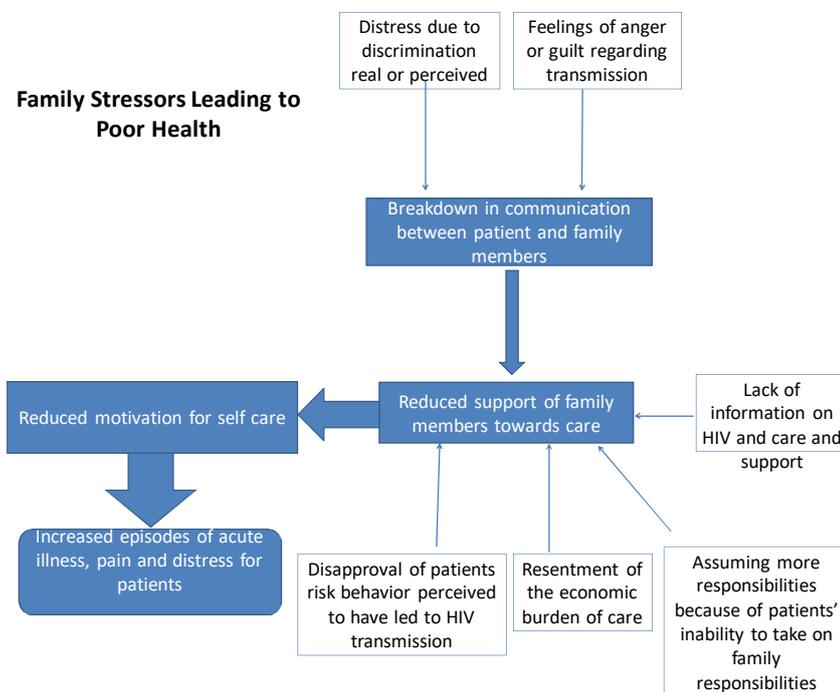
Clarification of roles and expectations between patient and family members, helping in addressing and reframing unrealistic expectations using techniques like active listening, focusing, reflection of feelings and clarifications

Family psychoeducation to give correct information on the patient's condition and its implications

Highlighting the importance of family role in care through sharing of examples and testimonials

Acknowledgement and acceptance of carer stress and appreciation of family efforts in care. Helping identify options for respite care to relieve care giver stress.

## Family Stressors Leading to Poor Health



## Impact of the Interventions

### Reported Impact

75% of the patients reported significantly fewer concerns relating to family at the time of discharge, as against the time of admission.

### Observed Impact

Improved communication between patients and family members

Shared decision making on care decisions

Improved self worth of the patients leading to increased motivation to adhere to positive living practices

Greater involvement of family members in care. Increased willingness to manage basic care at home and reduced time of admission

Reconciliation on issues which lead to estrangement. Family members being with the patient in terminal phases

## Conclusion

Family support plays a crucial role in ensuring that people with life limiting conditions can have a good quality of life. An illness like HIV can cause certain issues in the family which compromise the support to the patient from different family members, thereby affecting the quality of life of patients.

In depth family interventions are therefore a crucial part of palliative care. These interventions have to focus on strengthening relationships, resolving conflict and increasing the involvement of family members in care. This helps in improving patients' motivation and capacity to live well and improves their quality of life.

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