

HIV Specific Issues to be Addressed in Post Bereavement Support Visit to Family Members

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Background

Post bereavement support visits to the family are a critical part of palliative care. It helps to assess the extent of coping with grief by family members and provides an opportunity for providing support.

In the context of HIV related palliative care, post bereavement support is very important because family members face certain psychosocial issues like stigma which are specific to HIV.

Additionally, families affected by HIV usually have multiple people living with the illness, and death of a family member leads in addition to issues like anticipatory anxiety about one's own health. Family members are, therefore, not just grieving for the loss of their loved ones, but sometimes, for the loss of their own health and dealing with fears about their future.

Methods

Samraksha runs a palliative care centre for people affected by HIV in Koppal, North Karnataka. The practice of post-bereavement support visits was initiated by the centre 24 months ago. Consent was taken from the family members prior to them leaving the centre, and the visit was done a fortnight after the death of the patient. The extent of disclosure of HIV status in the family was also ascertained prior to the visit, so that the counselor would maintain the required level of confidentiality.

There were 74 deaths among patients at the centre over the last 24 months. Home visits were made to 66 families after taking consent. In the case of the remaining 8 patients who passed away, the family was from another district and lived very far from the centre. Hence home visits could not be undertaken. Follow up was, therefore, done over telephone. The home visit as well as the telephonic follow up was made by the counselors.

Findings

Among the 74 families, 26 families also had other members living with HIV. In some families, there were multiple members living with HIV.

Among the major issues reported, at least 50% of the issues were specific to HIV.

Interventions

On an average, each of the families reported at least 3 or four of the major issues listed. Intensive counseling support was needed to handle the issue and an average of 3 to four sessions was required with each family.

An Accompaniment Model of Support

The counselors built on the existing relationship with the family members, which had been developed during the period when they were caring for the patient at the centre. They adopted an accompaniment model of supporting the bereaved family members. This gave the family members a space to express different emotions with regard to the death of a loved one – grief, anger, guilt, anxiety and fear.

Expressing and dealing with these emotions helped them in the process of reconciliation. Through this process, some family members have become motivated enough to serve as community care volunteers. They help other families in the community which are affected by HIV. They also share their own experiences of caring for family members during group meetings with other patients and family members.

Supporting Family Members to Deal with Issues during Post Bereavement Support : Some Illustrations

Support in Dealing with Strained Relationships in Family

Parvati had cared for her husband Raju in his terminal stages. The couple were estranged from Raju's family. Raju had been married earlier but was separated from his wife. His marriage to Parvati was not accepted by his family. After his death Parvati was very worried about whether his family would accept her. She had never even been acknowledged by his family and she wondered whether they would even accord her the status of his wife. These fears deepened her grief process.

During the bereavement support visits, the counselor was able to give Parvati emotional support and reassurance about her role and her rights as Raju's wife. At the same time, the counselor also supported Raju's family, highlighting the way Parvati cared for her husband in the terminal stages. This encouraged the family members to accept Parvati in their lives.



Counselor engaging with Family Members for Bereavement Support

Support for Coping with Loss

Gangamma's family, specially her two daughters were unable to accept the idea of her death. They were growing up with her mother and sister. They had not been in regular touch with her for many years, and had only got back in touch in the terminal stages. They had cherished a hope that she would also recover now just like she had recovered from other acute episodes in the past.

The daughters expressed their feelings to the counselor – guilt because they felt they had not been able to support her adequately in the final stages, sadness that they had not been able to share enough about their lives with her as well as anxiety about their own future now. The counselor empathetically listened to these feelings and also validated them. Expressing these feelings helped them to cope better with the process of grieving.

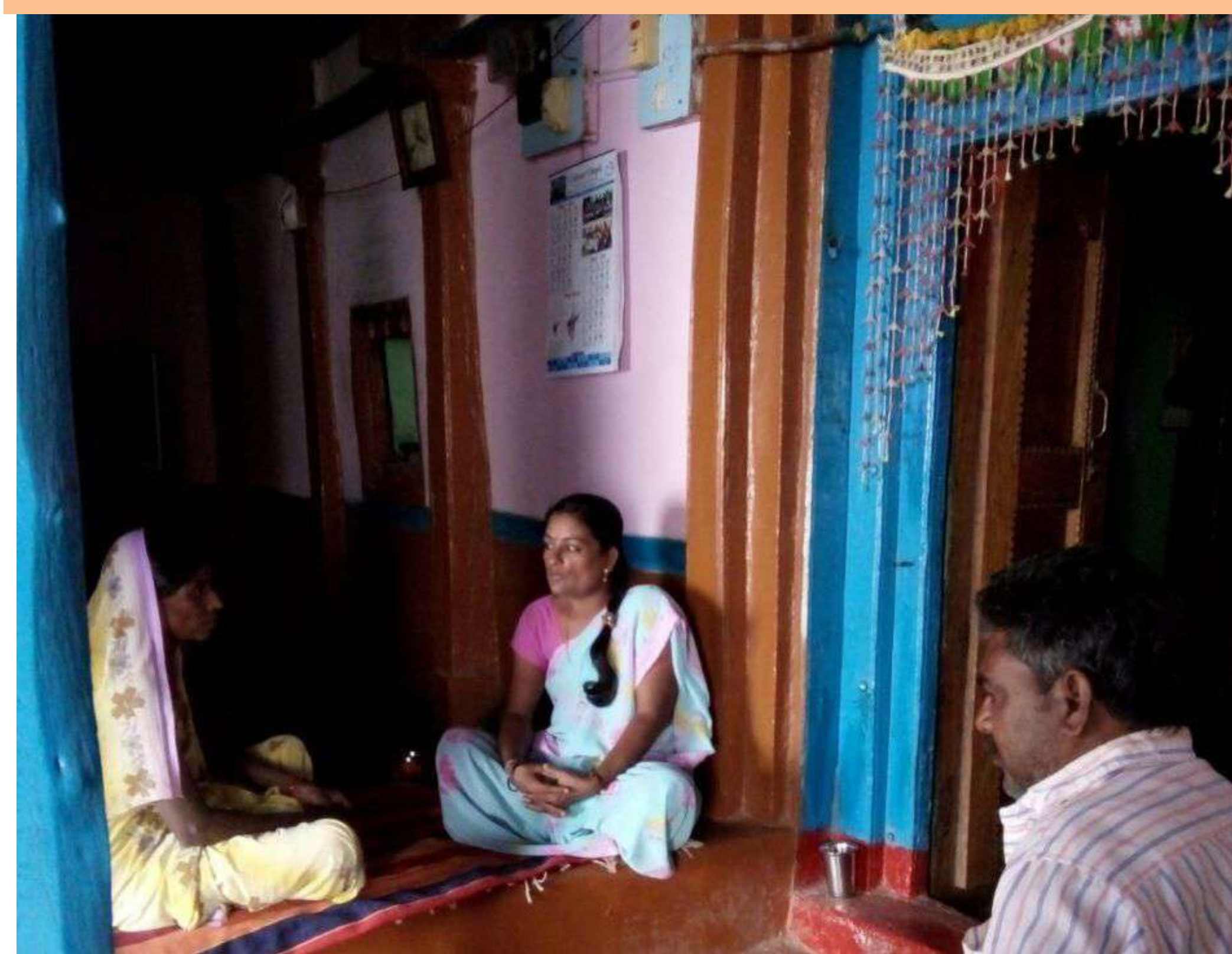
Support to survivors for disclosing their own HIV status to family members

Paddamma had tested positive many years ago but had never shared her status with her family or even gone for subsequent tests or medication. She had only focused on her youngest son who was also positive.

Paddamma was the carer for her son in his terminal stages. She had to deal with many issues after her son's death. She was anxious about her own health, but at the same time felt that nothing could be done for her, because her son had died despite all his medicines. The counselor helped her deal with these emotions.

During the bereavement support visits, in addition to accompanying her on grief journey, the counselor also discussed disclosing her own status to her family - her surviving son and daughter as well as her siblings. The counselor encouraged her to consider disclosure so that she could now focus on her health and also draw support from her family.

Paddamma made the disclosure and her family assured her of their support. They helped her take some positive steps for her own health – start on ART medicines and also undergo hysterectomy, since she had been diagnosed with early stage cervical cancer.



Motivation for HIV Testing while in the process of grief

When Lakshamma passed away, she left behind two daughters who were being cared for by her mother and younger sister. Lakshamma had only been in intermittent touch with her family, including her daughters for many years.

During the support visit, the counselor realized that only the younger daughter had tested for HIV and the older daughter had not gone for testing. The family was still grappling with the issue of loss and it was challenging to introduce the issue of testing to them. The counselor allowed the family members to first express their emotions and then gradually brought up the issue of testing to the older daughter and her aunt. Both of them realized the need for testing, particularly since the daughter was now approaching marriageable age and this would have implications for her future. They agreed to go for HIV testing.

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Conclusion:

An accompaniment model or providing support is effective in supporting bereaved family members during follow up visits. In the context of HIV Palliative care, there are many HIV specific psychosocial issues which need to be addressed during follow up visits. Care providers need to be sensitive to identify these issues, assess them and support family members in handling these issues.

Difficult Situations following the Death of a loved one due to HIV		
1	Grief over the Loss	100.00
2	Difficulty in accepting the loss	32.43
3	Dealing with strained relationships in families following death or disclosure of HIV status	27.02
4	Dealing with Stigma and Discrimination due to HIV	18.90
5	Loss of interest in adhering to ART among surviving HIV Positive family member	22.70

Support Needed		
1	For HIV Testing	21.62
2	For Disclosure of HIV Status to family members	21.62
3	Linkages for Child Support Support for Employment	43.24
4	Legal support for claiming Property	2.70
5	Emotional support to cope with the impact of the loss.	10.81