

# **Tailoring social support to the needs of individuals who test for HIV:**

## **Action Research on Disclosure of HIV status in Uganda**

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## **Background**

- Disclosure of HIV results is crucial for Voluntary Counselling and Testing (VCT) to enhance prevention, care and support.
- In 2005 a study on the process of disclosing HIV results was conducted in two districts of Uganda by the JSI-Uganda Program for Humana and Holistic Development (UPHOLD) project with technical assistance from MACRO International to: (1) understand the importance of the clients' social context in accessing HIV testing and sharing of test results with others (2) identify the type of social support needed by VCT clients to reduce exposure to HIV infection.

## **Methods**

105 in-depth interviews were conducted with VCT clients to explore their social relations, how they came to get tested, and their discussion of the test results with others. The clients were selected with assistance of the counsellors at the VCT sites. The word processed scripts were analysed for content and recurrent themes.

## **Results**

It was noted that:

- VCT clients needs and worries after knowing their status had not been well addressed by the counsellors
- Clients' needs for social support varied tremendously in form and in scope
- VCT clients needed contact with someone to help them negotiate the effect of the knowledge of their HIV status with family and friends
- Respondents approached disclosure of HIV test results in a variety of ways depending on their situations
  - ▶ Men who were not overtly ill-looking chose not to share their test results with their wives to avoid rumours, blame and disruptions in family relationships
  - ▶ Critically ill men chose to disclose their results to their wives whose care and support they needed
  - ▶ Critically ill women feared their husbands might blame them for unilaterally taking the test thus implying they were guilty of 'misbehaviour'
  - ▶ Women who had lost trust in their husbands also saw no value in sharing their status with their husbands.

## **Conclusions**

- Disclosure is a diverse and evolutionary process that is shaped by the social situation of the client and changes over time
- The current method and context of HIV related counselling does not contain the flexibility necessary to provide a range of advise and counsel to fit individual situations
- According to our observations, VCT has become an end in itself and as a result, the purpose of using VCT as a stepping stone to strengthening HIV prevention is not achieved. There are two critical limitations worth mentioning:
  - ▶ Lack of follow up to help the clients to negotiate their new status
  - ▶ Failure of counsellors to address individual specific needs

## **Programmatic Considerations**

- Counsellors need assistance to better listen to clients concerns and to fit advice to specific needs of family groups
- Disclosure should be viewed as a process that occurs over time involving negotiation of social relations in light of the (newly discovered) HIV status needs. Hence VCT providers should ensure continuity with their clients to negotiate the disclosure
- There is need to link with the clients to the community based support services such as TASO, post-test clubs and other community based CSOs to facilitate process of negotiating social relations and disclosure of the new post-test identity

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### **For further information**

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