Structural, social and personal barriers to linkage and retention in HIV care
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Despite well-established clinical benefits of HIV antiretroviral therapy (ART), millions of individuals do not present for care or do not stay in care for a multitude of reasons. Challenges arise at every step of the path from HIV testing to collecting test results, determining CD4 count, initiating ART when appropriate, and adhering to ART. One recent study estimates that less than one-third of adult patients in sub-Saharan Africa who tested positive for HIV, but were not eligible to receive ART when diagnosed, were retained in pre-ART care (Rosen et al 2011). In the US, those numbers are much higher, with 72% of HIV-diagnosed persons entering into care within 4 months of diagnosis. (Marks et al 2011)

Members discuss structural, social and personal barriers to HIV care, as well as high and low tech solutions currently being tested to increase linkage and retention to HIV care in low resource settings.

Key Points:

- Barriers to care include: lack of support, mental health or substance abuse, feeling healthy, poor information or understanding of treatment, internalized and external stigma, low income or resources (no health insurance, housing, employment, food, funds for transportation), long distances to travel for care, low quality treatment centers, poor experiences in post-test counseling or at treatment centers, and difficulty navigating the healthcare system.
- Care in the pre-ART period has been characterized as the "broken link" between the successful scale-up of HIV testing and ART initiation efforts. When HIV testing and the ART clinics are geographically separated, this creates a logistical barrier.
- Normalization of HIV care is vital to linking the patient with care. This includes decreasing the stigma associated with HIV on both societal and structural levels, through public advocacy and awareness campaigns, for example combining HIV-treatment centers within existing health centers.
- It is important to map out HIV care from the viewpoint of the patient. This helps identify obstacles and attrition points, but also steps that can be taken to improve the care process at the clinic level with, for example, CD4 machines to identify at-risk patients or a system to track medication refills or clinic visits. Mobile health clinics/programs have also been shown to help.
- Information technology approaches that show promise include providing cell phones with minutes to support patients during the months following diagnosis or sending weekly Short Messaging Service to ART patients.
- Many programs are also looking at the role improved care services, patient-centered or comprehensive care programs, aggressive outreach, and the use of peer navigators, accompagnateurs, case managers, counselors, mentors and community health workers.
- Future research needs include finding techniques for engaging patients in pre-ART therapies and better understanding of why patients refuse HIV care.

Key References

Enrich the GHDonline Knowledge Base:

Please consider replying to this discussion with:

- Suggestions for additional ways to decrease stigma and normalize HIV care
- Strategies for linkage or retention in care that you have tried, or would like to evaluate
- Research findings or ideas that you would like to share with practitioners