I-TECH PROJECT PROFILE

Case Management: Managing Adherence and Preventing Loss to Follow-up in Antiretroviral Therapy Clients

The case-management process proactively identifies clients who are not likely to adhere to complex treatment requirements such as antiretroviral therapy (ART)—clients who are at risk of being lost to follow-up. "Lost to follow-up" refers to clients who have dropped out of their treatment regimens and are unfindable. Case management is about preventing clients from dropping out of treatment by proactively managing and meeting their specific, individualized needs. Case management also involves shifting tasks from overburdened clinical staff to a trained case manager.

The best way to prevent lost-to-follow-up clients is to proactively identify those who may not be likely to adhere to treatment requirements. In the case-management process, when ART is initiated, clients are assessed on an "acuity scale" to determine whether they are at risk to become lost to follow-up or to not comply with the treatment requirements that help people living with HIV/AIDS (PLWHIV) maintain a better quality of life. The acuity scale provides the case manager with an indication of the level, intensity, and frequency of support services that may be required by those clients who are at risk to help ensure their treatment adherence. Once identified, clients are provided with timely and sustained support.

Health care providers who administer ART refer patients to case managers based on need and risk status for compliance to adherence, such as food insecurity, lack of transportation, substance dependency, non-disclosure of HIV status, shelter instability, pregnancy, or disease severity/complexity. The case manager develops a comprehensive care plan after performing a holistic assessment of the client's needs. The case manager is a vital member of the ART client treatment team.

Case management is not a new phenomenon. Many countries have implemented case management as a mode of services delivery for chronic illnesses, where customized and sustained care is required.

SMART Case Management

The identification of at-risk clients enables the planning and execution of a "**SMART**" case management approach. The acronym **SMART** delineates the elements of an appropriate, customized follow-up for at-risk clients. Utilizing such human resources as peer supports, health extension workers, and significant others (family members), case managers develop a plan that has:

- **S** = Specific and customized support tailored to each at-risk client.
- **M** = Measurable interventions to ensure the level and intensity of services for each client.
- **A** = Achievable support to ensure success in adherence outcomes.
- **R** = Realistic support to ensure the use of personal, community, and clinical resources.
- **T** = Timely support to ensure responsiveness to the client's felt, real, and perceived needs.

SMART case management is also economical and enables organizations to target scarce resources at clients who are truly in need of support—where impact is high and positive outcomes are assured.

To this end, case managers proactively plan and support clients by:

- Conducting adherence counseling to the client and their significant others.
- Organizing the work of the adherence support team, such as peer counselors or outreach workers.
- Conducting planned outreach activities and offering onsite community support.
- Linking with and teaching clients how to access and use internal health care facility and external community resources for continuity of care.
- Engaging significant others to actively support the client.

Development of a Case Management Model in Ethiopia

With the number of clients on ART that are lost to follow-up reaching 25% in Ethiopia, the Ministry of Health requested that I-TECH Ethiopia (referred to subsequently as "I-TECH") develop a National Case Management Model that shifts some vital tasks from over-burdened health care providers administering ART to case managers. To begin, I-TECH defined the need and role for case management in late 2005. In October 2006, discussions with leaders of the President's Emergency Plan for AIDS Relief (PEPFAR) such as the United States Agency for International Development (USAID) and the Centers for Disease Control and Prevention (CDC) helped I-TECH to develop the conceptual framework for case management and define its role in the context of treatment. Additional discussions with stakeholders led to an expanded and refined conceptual framework, which is described below.

Development of the Case Management Model

With support from Visions for Development, Inc., I-TECH developed a sustainable, pragmatic, and culturally competent model for follow-up and the provision of support and care for clients on ART. Moreover, a phase-based development process to further refine the case management model was initiated in 2006:

Phase 1

In an assessment designed to better understand social supports given to clients on ART, stakeholders—which included a group of policy makers and health care practitioners—were interviewed. The data gathered was analyzed, and a conceptual model of case management was developed accordingly. This model was presented to stakeholders; based on their feedback, it was then validated with ART-related service providers across Ethiopia.

Phase 2

The flow of ART clients through the health care system was studied to learn about how clients are managed and how different care providers interact with them to provide a continuum of care. This study of the process flow provided the details necessary to validate the case management model with various service providers, as well as clarified a definition of case management and a detailed position description for a "specialist case manager." Again, the results were presented to stakeholders for approval.

Pilot Testing of Case Management Model

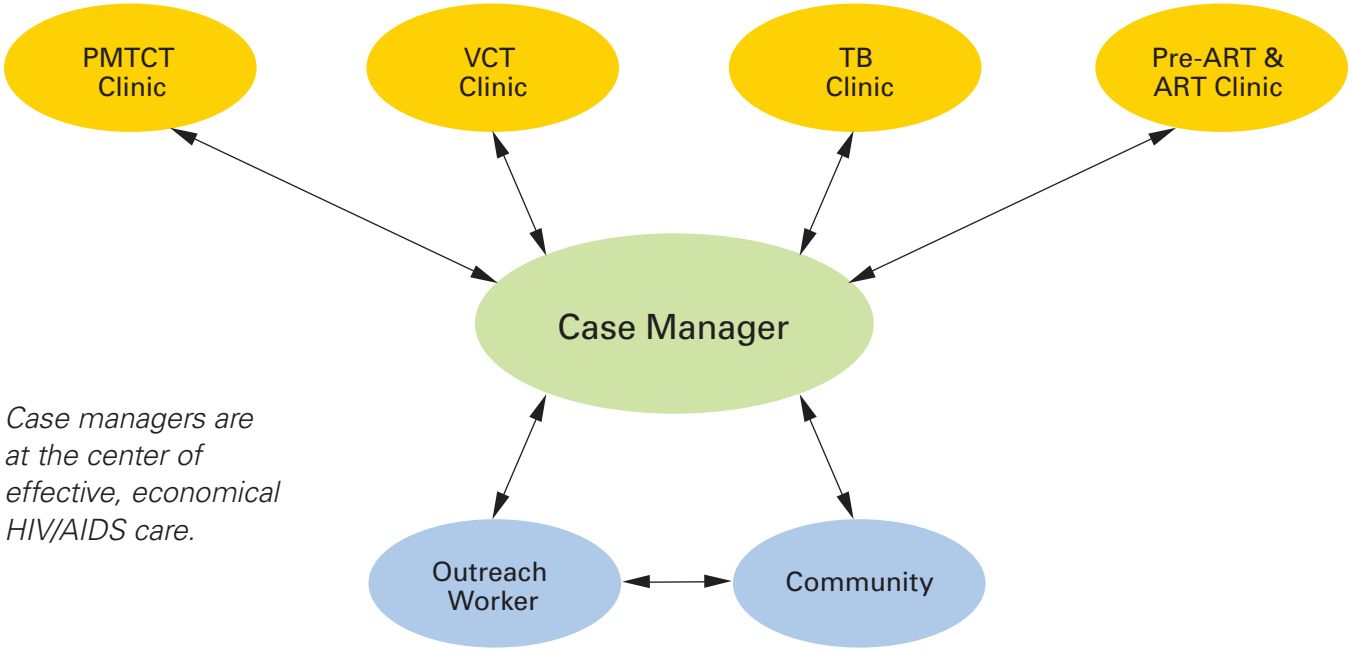
Phase 3

Pilot testing was conducted in six sites around Ethiopia. To support the trial, I-TECH developed a comprehensive training and induction program for the new case managers who were hired in July 2007. The pilot test was evaluated after 3, 6, and 9 months to assess the effectiveness of case management in practice and to glean whether there were strategies that could be used to improve the model.

Based on the successful findings of the evaluation, I-TECH expanded case management services to 10 additional hospitals and added two additional case managers at the busiest hospitals.

Case managers, some of whom are PLWHIV, were hired and trained to:

- Monitor adherence of at-risk ART and pre-ART clients.
- Promote clients' ART adherence through education and adherence counseling at hospitals and community settings in order to prevent them from being lost to follow-up.
- Link clients to community resources to ensure a continuum of care.



Case managers are at the center of effective, economical HIV/AIDS care.

Outcomes from 6 Months of Pilot Tests

- A total of 639 clients at-risk for ART adherence entered the program for regular and intensive case management follow-up.
- Of these, 260 clients qualified for exiting the program with improved adherence and with problems solved.
- Case managers referred 331 clients at-risk for adherence to community resources: 36% of those referred were provided with services, with the remainder referred but waiting for services.
- In the absence of community-based services, case managers mobilized the community to help meet clients' needs, including assistance with clothing, rent, and food.
- Case managers provided adherence counseling and mass health education in hospitals and community settings.
- Case managers traced 1162 clients who had been lost to follow-up and found that:
  - 613 died.
  - 99 self-transferred care to other facilities.
  - 450 discontinued for various reasons. Of the 450 individuals lost to follow-up, 56% were counseled, restarted their treatment, and were enrolled in intensive case management follow-up.

A Client's Case: A True Story

One client had lost all hope when he was presented with an HIV-positive test result. His wife also tested positive. He could not find work. He started avoiding others and was not adhering to his ART regimen. Eventually, he became blind and lost hearing in one ear. He says that, "I lost all of my strength, and was counting the days until I died."

A year and a half after receiving his diagnosis, the client was introduced to a case manager at Mekele Hospital. "My hope was rekindled," he says. The case manager informed him about the importance of adhering to his antiretroviral medications (ARVs), and he now takes them regularly. Currently, rather than hiding from people that might recognize him, this client is publicly educating others about HIV and AIDS. "I am a full member of the Adherence Support Group organized by my case manager. I regularly attend the meetings and have assumed the task of counseling fellow clients who are about to quit taking the medications. My wife also works like me."

He adds, "Even though I am visually impaired, I found out that I can work and learn. My case manager referred and linked me to different care and support organizations. I received a rope weaving training for 4 months at the Association for Disabled People. I received my certificate and some money as an initial investment. Now I am making preparations to start working at home to sell the items. I had quit my education after passing the 8th grade. But now my case manager is helping me to [continue] my education at a school for the blind."

Conclusion

The case management approach is not a new approach, but rather a strategic response that is integrated into existing health care system infrastructure. A case manager does not work with all clients—only those most at risk for not adhering to ART. The case manager takes a proactive approach to the complex treatment of HIV/AIDS. Proactive and SMART case management works because it is cost effective, anticipatory, and planned. The best way to address adherence is to identify those at risk and manage their needs.

Strategic implementation of the case management model helps shift tasks from over-burdened health care providers to specialist case managers. The case management model maximizes the use of scarce human and physical resources to address the intricacies of a complex treatment regimen. Case managers have proven to be an effective strategy to mitigate the numbers of clients being lost to follow-up in the Ethiopian health care environment.

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