HIVOutcomes
BEYOND VIRAL SUPPRESSION

CASE STUDY ON USER DRIVEN CARE FOR PLWHIV

Context

Kristiansand, a town in the county of Vest-Agder in southern Norway, has a user-driven outpatient clinic for People Living With HIV (PLWHIV) at its hospital. This is the only hospital overseeing HIV patients in the counties of Aust and Vest Agder. The outpatient clinic has responsibility of following up with approximately 150 patients.

Introduction

The follow up of HIV patients at the outpatient clinic in Kristiansand had customarily focused mainly on HIV treatment and on biomedical markers. There was little attention paid to the physical, mental, social and spiritual needs of service users. In 2012, Dr Ole Rysstad, Head of the Infectious Diseases Unit and responsible for the HIV Kristiansand outpatient clinic, saw the need to initiate a user-led initiative. He invited ten PLWHIV to brainstorm the question of "*How do you want us to run this clinic?*" This led to the formation of a seven-person user board.

During their early meetings, user board members reflected on, and talked about, their experiences with healthcare services. They unanimously agreed that the current treatment model can contribute to dangerous and unwanted medical situations, perpetuates stigma, prevents openness among PLWHIV, thus contributing to increased number of people being infected with the disease. Service users concluded that better, more holistic care, together with good information would lead to greater transparency, less stigma, a lower threshold for self-testing and ultimately fewer new infections. As a result, the user board drafted and submitted a document to the hospital management, which outlined the needs of the entire patient group.

This document, referred to as the "patient order" outlined the components needed to allow the hospital to provide better, comprehensive care. The patient order was well received by the clinic management and now forms a treatment and follow-up model for all patients receiving services at the clinic.

Aims

The project was initiated to ensure there was comprehensive and integrated patient care and to ensure and improve interaction between service users, the specialist health care service and other parts of the health and social care services. With an aim of '*Promoting optimal health through holistic care and empowering each individual patient'*, the project seeks to provide optimal health, holistic care and the active involvement of service users in designing and implementing services at the decision-making level. The basic idea is that the patient/user is best placed to know what works and what doesn't.

Method

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Dr Rysstad invited service users to provide input to services provided. Service users appointed user board members and a board leader. The user board then conducted a survey on the needs of the entire user group. Based on these results, the user group drafted a patient order to the hospital, in the form of a project description with proposed action. This set out the required components for better care as defined by the patients

These included:

- Establishing a full-time 'HIV coordinator' position to oversee all aspects of care and to act as the link between the patient, specialist health services, the GP and other health and social care services;
- Establishing micro-teams around each patient and initiating interdisciplinary team meetings with the HIV clinician, primary physician, nurse and patient to discuss distribution of responsibility;
- Active use of individual patient plans;
- Developing comprehensive checklists to ensure that all aspects of the user's care are addressed and monitored;
- Developing and implementing learning and mastering courses for all service users to provide them the knowledge and skills to be active in their own care;
- Systematic use of peer support in treatment;
- Establishing a standardised system for secure, effective communications between all parties involved in HIV care;
- Providing clear and consistent information to patients regarding all matters related to living with HIV;
- Standardising routines for STD/SOI screening;
- Integrating psychosocial measures into services;
- Evaluating the services provided.

All the care components requested in the patient order were implemented. User board members and health professionals formed internal working groups to meet each of the requests. In addition, service users have had regular contact with health professionals to report progress and to evaluate the services.

Currently, the user board consists of 18 members, of which approximately eight are active members, meeting four times a year to discuss progress and work with new issues.

Results

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The initiative started as a pilot project. It has since been successfully applied to approximately 150 patients. Since 2012, user involvement in care has increased significantly at the clinic, with users and service providers now actively engaged. In addition, there are:

- Increasing levels of collaborative care, partnership and support planning.
- A more holistic approach to care of PLWHIV; the individual patient is now seen as a whole and is treated with dignity and respect.
- Coordinating services to respond to the needs of service users
- Personalising services tailored to the needs of individual users.
- Improving the patient experience, quality of care, quality of life and health outcomes.
- Supporting for service users in developing the knowledge, skills and confidence to manage and make informed decisions about their health.
- Bringing benefits to both PLWHIV and the community in general by offering low-threshold testing services at the clinic.

The clinic is keen on implementing changes that will improve long-term health outcomes and quality of life for people living with HIV. For example, the clinic is working on combatting stigma/discrimination within health systems, has arranged a course for GPs who wish to follow up HIV patients and is working on providing courses for peer support workers.

- Multi-level prevention: Prevention of the spread of HIV virus, prevention of spread of STD's, prevention of serious health problems through early intervention.

Recommendations

- Seek innovative ways to integrate comorbidities into long-term care.
- Raise funds to employ a peer worker at the clinic.

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