

Equality in accessing HIV care – the community HIV nurses role

June 2017

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Introduction

This poster considers the role of the community HIV nurse specialist (CNS) in managing patients who find it difficult to access HIV care. The CNS caseload consists of patients with complex HIV needs living in the London boroughs of Lambeth, Southwark and Lewisham (LSL). Many of the referrals we receive are patients who are not attending their specialist clinic and we have found that there are many contributing factors to this.

It is widely documented that consistent attendance at medical appointments plays a central role in both prolonging life and enhancing quality of life in people living with HIV and non-attendance is closely linked with medication non-adherence. (Mitchell and Jelms 2007)

In this poster presentation we aim to cover how a community CNS team can work closely with a patient and hospital clinic to ensure the patient has access to specialist care. Depending on the patient's problems there may be a simple answer such as providing transport but in many cases there are a number of reasons why patients cannot or do not attend clinic appointments. As community nurses we have the opportunity to work with the patient to overcome these problems and either engage them back into the clinic or manage the role of the clinic in a community setting.

The aim of the study is to identify the reasons why patients do not attend their HIV clinic appointments and the activities the CNS carry out to ensure equality of access to care.

Background Information

The community CNS team works across LSL. Lambeth has the highest prevalence of HIV in the UK at 14.6 per 1000 population. Southwark ranks second with an incidence of 12.71 per 1000 and the incidence in Lewisham is 8.26 per 1000. The London average is 5.4 per 1000 in comparison to the UK's average of 1.6 per 1000.

Method

- To identify patients in the HIV CNS caseload, whose reason for referral was non-engagement with their HIV clinic within the last 18 months.
- To identify patients who have difficulty in engaging with a HIV specialist clinic without CNS input within 18 months.
- To identify the reasons why, this cohort struggle to attend clinic appointments.
- To analyse what the CNS provides in order for this cohort to gain equality in access to HIV care.

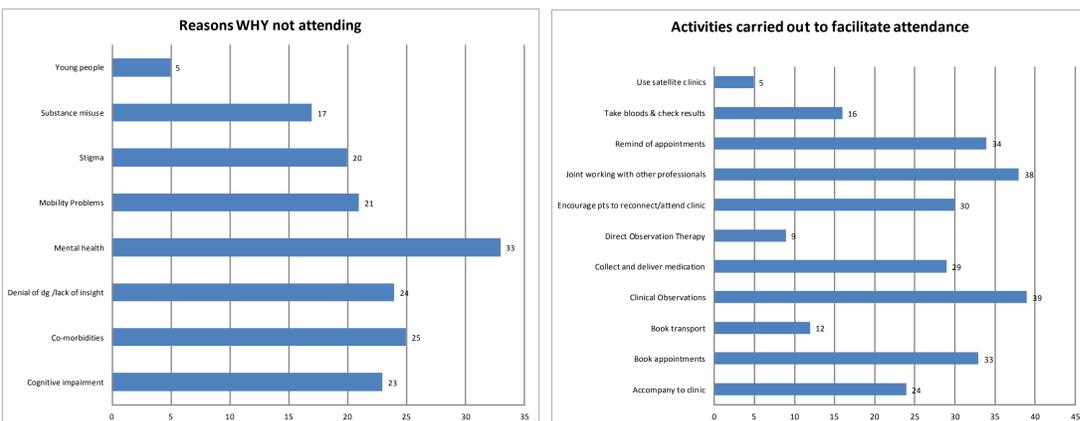
Case study

Background

Grace was referred to the CNS team by her HIV consultant. Grace was diagnosed with HIV in 1998. She had not been properly engaging with the hospital for a prolonged period of time and had been taking medication erratically. Her CD4 was 24, her VL 25000. She was recently diagnosed with TB and PML. She had been treated for KS and lymphoma in the past.

Grace was 48, she had a 17 year old son at home and an elder son who was in prison. Neither of them were aware of her diagnosis. Her younger brother was the only family member that was aware and tried to encourage her to get to hospital appointments. Grace understood how sick she was but still denied that it was due to her not taking her medication. For many years she had denied her HIV status. She wanted to at least live until her son was 18 and "an adult".

Data



CNS Assessment

Grace was weak and bedbound on initial assessment. She was in extreme pain which stopped her leaving her flat. She was taking some medication, including a variety of analgesics. She was non-adherent to her ARTs and TB treatment. This was a complicated regime with over 20 tablets daily. She had not had bloods taken for a period of time as she could not physically access the hospital. She was now keen to take her medication but due to the complicated regime she was finding this difficult.

Grace was cared for at home for over a year avoiding unwanted hospital visits. Sadly her pain became more acute and she chose to be admitted to hospital for investigations. Her lymphoma had returned and she was deemed too unwell for further treatment and rapidly deteriorated and passed away. She had however managed to remain comfortably at home for over 18 months from the initial referral.

Data Analysis

The data collected indicates that there are multi-factorial reasons why patients have difficulty in engaging with their HIV care.

In our cohort we have found that mental health, cognitive impairment, substance misuse, denial of HIV diagnosis or lack of insight into their ill-health played a major role in the non-attendance.

The data also shows that the CNS carries out many activities to encourage the patient to attend clinic or manage the role of the clinic in a community setting.

What the data fails to capture is the complexity and time needed to engage effectively with this cohort. Successful results are often due to a good relationship with a patient and a holistic and flexible approach by the CNS.

Summary

To engage this cohort with their HIV care is a complex process which requires building a good interpersonal relationship in order to gain their trust and confidence. This requires a flexible approach, patient centred care, understanding of patient's needs, skilful communication and a non-judgmental attitude.

Our data also shows the many reasons why patients do not engage and often there is no simple solution for this. However the community CNS can play a major role in supporting patients to attend their specialist clinic or where necessary, manage care in the community setting, therefore providing equality of access to care.

Care Plan

