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**A service evaluation of the care
young HIV-positive women
experience in a rural Ugandan
clinic.**

Dissertation submitted for Master of Nursing
Science, School of Nursing, Faculty of Medicine,
University of Nottingham

I declare that this dissertation is my own work.

Signed..... Date.....

Rebecca Dickens (ID number 17209)

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Word Count: 15,995

Acronyms

AIDS – Acquired Immune Deficiency Syndrome

ART – Antiretroviral therapy

ARVs – Antiretroviral drugs

CLV – Community Liaison Volunteer

CME – Continuing Medical Education

HIV – Human Immunodeficiency Virus

JCRC – Joint Clinical Research Centre

MOH – Ministry of Health

PMTCT – Prevention of mother-to-child transmission

STIs – Sexually Transmitted Infections

TB – Tuberculosis

TREAT – The Regional Expansion of Antiretroviral Therapy

USAID – United States Agency for International Development

VCT – Voluntary Counselling and Testing

WHO – World Health Organisation

Abstract

Background: HIV is a global pandemic, affecting the lives of millions, hitting sub-Saharan Africa the worst. Young women in sub-Saharan Africa are particularly vulnerable to HIV, frequently experiencing lack of power in relationships and engaging in transactional sex. Good HIV services are essential to test, treat, care and support HIV+ clients.

Aim: To evaluate the care young HIV+ women experience in a rural Ugandan HIV clinic.

Methods: A qualitative approach was selected and in-depth semi-structured interviews were conducted with ten HIV+ women aged 18-24. Observations of the clinic and informal discussions with staff were also used.

Findings: The majority of young women are satisfied with the service and care they receive from the clinic. Specifically, the testing process is reported to be of high-quality with rapid testing and in-depth counselling. The clinic was found to be in an ideal location for maximum access. Young women seemed to manage their treatments well, with the support and encouragement of staff and regular health talks, although frequent drug shortages hindered their efforts. Staff were found to have positive attitudes with the occasional exception. The women suffered from stigma but often found support within their families and the clinic staff. Home visits and the drama group were found to be useful to those who came into contact with them.

Conclusion: Findings have suggested that care given by the clinic is very good on the whole, especially the VCT process and the support and counselling provided by nurses, doctors and counsellors. Recommendations include ensuring staff attitudes are always positive, and expanding existing services, through malnutrition care, home visits, support groups, and drama groups. However, it is recognised that the capacity of the clinic to respond to most of the recommendations will be limited by financial constraints.

Chapter 1 – Introduction

Introduction to Evaluation

This report evaluates the care young HIV-positive women experience in a rural Ugandan HIV clinic. The literature surrounding this topic is discussed and used to compare findings from this evaluation with findings from a wide range of research in order to evaluate the care provided by the clinic in question and provide recommendations for future practice.

Rationale for Evaluation

HIV is a global pandemic, affecting the lives of millions in every country across the world. Sub-Saharan Africa has been the worst hit region, with 22 million people living with HIV/AIDS, two-thirds of the global total (UNAIDS, 2008a). The East African country Uganda documented some of the earliest cases of AIDS in Africa back in the early 1980's (Mugenyi, 2008) but has frequently been commended for its achievement in reducing HIV prevalence from 33% in the early 1990's to 5.4% in 2007 (AVERT, 2009).

Northern Uganda has been subjected to over two decades of a brutal conflict between an insurgent group called the Lord's Resistance Army and the Ugandan government army (Westerhaus, et al., 2007). The war was characterised by child abductions, frequent rapes and attacks on civilians resulting in 90% of the region's population living in Internally Displaced Peoples camps (Patrick, 2005). In 2005 HIV/AIDS was the second most frequently reported cause of death in the region (Chamla, et al., 2007) with reports that infection rates were reaching almost 12%, approximately double the national rate (Badenoch, 2006). "People living within these often transient and volatile settings are vulnerable to violence, poverty, and natural disaster, all of which make consistent management of HIV a challenge"

(Jacob and Abongomera, 2009). Young women are especially vulnerable to HIV, particularly in areas of conflict where they may be forced into transactional sex for survival (Cottingham, Garcia-Moreno and Reis, 2007).

HIV testing is particularly important where HIV rates are high and where 90% of the population do not know their status, as in sub-Saharan Africa (WHO/UNAIDS, 2007). Good HIV services are essential to test, treat, care and support HIV-positive clients. Through counselling and supportive attitudes, clients can be assisted in living positively and healthily.

According to Kelly (2006), it is important to find out how and why services work or do not work in order to improve existing and future services. Regular evaluation of services and patient satisfaction can help improve the effectiveness, acceptability and quality of HIV services (WHO/UNAIDS, 2007). Indeed, some analysts have expressed the concern that "the 'patient's view' is likely to be downplayed in favour of scientifically and statistically orientated 'evidence'" (Gilbert and Walker, 2009).

My interest in this area stemmed from having lived and worked in Uganda for a year and then returning on several occasions to work voluntarily in the clinic in question. With the help of the Clinic Director in Gulu, my supervisor here in the UK and careful review of the literature, the evaluation question was generated. The findings and recommendations of the report will be presented to the clinic in order to further improve practice and motivate staff.

Evaluation Process

In order to fulfil the aims and objectives of this evaluation, a qualitative approach was employed conducting interviews with ten HIV-positive young women attending the clinic for care and treatment. The data were then discussed in the context of the wider literature in order to draw conclusions for recommendations and find areas of high-quality practice.

Chapter 2 – Literature Review

Introduction

This chapter will explore the background literature surrounding the evaluation subject. The HIV pandemic will be described in terms of sub-Saharan Africa, Uganda and Northern Uganda. The factors affecting youth services and young women will be explored before investigating what makes an HIV service effective and successful, how stigma affects the lives of HIV-positive people and the uptake of services. Finally the research is brought together to assess why this evaluation is useful.

Literature Review Method

In order to review a wide range of literature, searches were conducted using databases such as Pubmed, Medline and CINAHL and websites including AIDSmap, AVERT, UNAIDS, WHO and Google. Search words included combinations of HIV, AIDS, VCT, testing, counselling, nursing, young women, Africa (sub-Saharan and East), Uganda, stigma, disclosure, medications, treatment, prevention and care.

Background

In 2007, an estimated 1.9 million people were newly infected with HIV in sub-Saharan Africa bringing the total to 22 million people living with HIV in the region (UNAIDS, 2008a), two thirds of the global total of 32.9 million. Three quarters of all AIDS deaths in 2007 occurred in this region, despite having only just over 10% of the world's population (World Bank, 2009). Heterosexual intercourse remains the driving force of sub-Saharan Africa's HIV crisis, with women disproportionately affected in comparison with men. The gender difference in HIV infection is especially stark among young people.

Uganda

In 2001, only 49% of households in Uganda had access to healthcare facilities, mainly due to the poor infrastructure, especially in rural areas where the majority of the population live (WHO, 2001a). The average life expectancy was 48 (although some suggest the current life expectancy to be 42 due to the HIV pandemic) (WHO, 2001b). 46% of the Ugandan population (61% in Northern regions) live below the absolute poverty line, earning less than \$1 per day (WHO, 2001b).

In 2007, there were an estimated 940,000 people living with HIV in Uganda with an estimated infection rate of 5.4% in adults (UNAIDS, 2008b). This compares with 5.0% in sub-Saharan Africa as a whole, and 0.8% globally. Young people (15-24 year olds unless otherwise stated) are particularly at risk of HIV and, in 2007, accounted for 45% of all new infections in adults worldwide. Furthermore, young women are at much greater risk of contracting HIV than their male counterparts with a prevalence rate in Uganda of 3.9% in young women compared to 1.3% in young men (UNAIDS, 2008b).

Northern Uganda

Gulu is one of the main towns in Northern Uganda and is therefore central for healthcare facilities and services (see map in Appendix 1). The people of the town and surrounding areas have been subjected to 21 years of violence. An estimated 1.5 million people were displaced, and are only now starting to attempt to put their lives back together (Patrick, 2005). As previously stated, the HIV prevalence rate in the region is around double the national rate, which Westerhaus and colleagues (2007) attribute predominantly to poverty, political instability and gender inequality. A study from Côte d'Ivoire which distributed questionnaires across 24 urban settings, found a 90% decrease in the number of healthcare workers along with collapse of the health system and other public infrastructures, interruption of condom distribution and lack of antiretroviral drugs (ARVs) during conflict times,

demonstrating the magnification of barriers to care during complex human emergencies (Betsi, et al., 2006).

Uganda's Success

Uganda has frequently been commended for its achievement in reducing HIV prevalence from 33% in the early 1990's to 5.4% in 2007. However, this success has proved difficult to sustain and praise for Uganda's prevention efforts has waned in recent years with indications that infection rates may be on the rise again (AVERT, 2009). Research in Uganda has shown that the proportion of people who report having sex outside long-term relationships has risen since 1995, from 12% to 16% in women and from 29% to 36% in men (UNAIDS, 2008a). One key to Uganda's earlier success was through implementation of the ABC strategy; Abstinence; Be faithful; and Condom use (Eboko, 2005). However, as the incidence of sexual risk-taking increases, particular criticism has been aimed at US-backed "abstinence only" campaigns (Global Health Watch, 2008) whilst others suggest a general complacency or "AIDS fatigue". The arrival of ARVs may also have changed the perception of AIDS from "death sentence" to "treatable, manageable disease" (AVERT, 2009), a suggestion corroborated by findings from an urban South African HIV clinic (Gilbert and Walker, 2009).

Youth Services

According to UNAIDS (2008b), young people are grossly under-educated about the facts of HIV and lack accurate information on how to avoid exposure to the virus. Research from the Uganda AIDS commissions (2007) suggests they are more likely to make uninformed decisions, often based on inaccurate peer advice, instead of reliable information from parents and schools. Young people are often greatly under-represented among those accessing VCT (Voluntary Counselling and Testing)

services despite research demonstrating that many young people want to be tested (Horizons, 2006). A recent survey by the Ugandan MOH (2008) assessed HIV services throughout the country finding that only 22% were “youth-friendly”; most of these were in hospitals or in the capital, Kampala. Among these, only 13% had specific guidelines for young people, although 77% employed a specially trained youth advisor. WHO wrote a framework for Youth-Friendly Services stipulating that organisations should have policies and guidelines within youth-friendly health facilities with specifically trained health care providers (Ross, Dick and Ferguson 2006). Many young people do not have the basic knowledge and skills to prevent themselves from becoming infected with HIV. WHO suggests that young people continue to have insufficient access to information, counselling, testing, condoms, harm-reduction strategies and treatment and care for STIs and state that in most countries, young people’s access to effective health services is lower than older people’s (Ross, et al., 2006).

A recent large, mixed-method study conducted over four districts across Uganda found that many HIV-positive adolescents were already or wished to become sexually active but engage in poor preventive practices. 37% reported using condoms at first sex, mainly for pregnancy prevention, and of those, less than half used them consistently (Birungi, et al., 2009). Researchers found that counselling programmes for HIV-positive adolescents tended to encourage abstinence from sex and relationships, and failed to address their needs for sexual and reproductive health information and services. Although this study only included adolescents acquiring HIV via vertical transmission, (that is, from their mother at birth) it is nevertheless useful and relevant in relation to all HIV-positive adolescents. Data collection methods for this study included questionnaires, focus group discussions and in-depth interviews showing triangulation, which helps to validate findings and suggests a well-founded piece of research (Green and Thorogood, 2004).

Young Women

Women are particularly affected by the HIV epidemic in Uganda, representing 59% of those infected (AVERT, 2009). In most countries, males are significantly more likely to be sexually active by the age 15. However, in sub-Saharan Africa, girls are almost 50% more likely to be sexually active (UNAIDS, 2008b).

In Uganda, women tend to be married at a far younger age, to men who are older, more sexually experienced and thus more likely to be HIV-positive (UNAIDS, 2008b). Research by the Uganda AIDS Commission (2007) suggests that in Uganda 57% of girls are married by age 19 compared to just 7% of boys; only 30% of sexually active young people use a condom during first intercourse; and overall only 47% of females and 61% of males have ever used a condom. A study in Eastern Uganda, in which 457 women were interviewed and 96 people participated in focus group discussions, found that 35% of women reported their husbands having another sexual partner, including those in polygamous marriages, a figure comparable to the rest of the country (Karamagi, et al., 2006).

A large study in rural Malawi, an environment similar to rural Uganda, showed that young women are more likely to engage in transactional sex (Poulin, 2007). Studies in Uganda also suggest that 75% of young women have received money or gifts in exchange for sex, whilst nearly one in five adolescents reported force or coercion involved in their first sexual experience (UNAIDS, 2008b). In the aforementioned Eastern Ugandan study, researchers found that men often react violently when women go for VCT, disclose HIV results or request condoms (Karamagi, et al., 2006).

These findings are accentuated in conflict areas such as Northern Uganda where women are vulnerable to rape and may be forced to exchange sex for money or basic resources as a survival strategy (Cottingham, et al., 2007). All these factors

create conditions in which women's vulnerability to HIV is disproportionately increased (WHO, 2004)

HIV Services

A successful HIV service is essential to educate clients about HIV, including topics such as transmission methods, condom use, adherence and treatment as well as providing them with support and encouragement to live positively. A large study conducted across Uganda and Kenya found that adolescents valued good counselling during VCT (Horizons, 2001). This study is of particular value because it incorporates the views of both HIV-positive and HIV-negative youths, parents, community leaders and service providers. Staff attitudes, particularly confidentiality and friendliness, were other factors defining successful services, as found in a large qualitative South African study investigating young people's views on HIV services (MacPhail et al., 2008). Although these studies were conducted in urban regions or in other sub-Saharan countries, the basics of HIV services, counselling sessions and the needs of HIV-positive clients should be consistent across sub-Saharan Africa, in urban and rural regions alike. Indeed, WHO/UNAIDS guidelines (2007) highlight the importance of effective counselling and give guidance on the inclusion of topics such as disclosure and HIV transmission during counselling. A positive experience during the initial HIV test will encourage people to come back for further support and also encourage others to come forward to find out their HIV status. Knowing their status allows people to protect others and themselves from infection, to access appropriate care, treatment and support, and to plan for the future (Bell, et al., 2007). Unfortunately, as Bell and her colleagues go on to state, people are often not tested until they show symptoms associated with AIDS and are very ill and thus HIV testing has been associated with dying.

Birungi and colleagues (2009) concluded at the end of their Ugandan study that there is a “need to provide preventive sexual and reproductive health information and services to HIV-positive adolescents in order to prevent further HIV transmission and unwanted pregnancies” thus empowering them with the skills to negotiate disclosure and condom use. They found that most treatment, care and support programmes for HIV are organised around either adult or paediatric care, neglecting the needs of those in the transition stage between childhood and adulthood. WHO’s framework for youth-friendly services suggests small-group cognitive behavioural interventions, educational interventions and face-to-face counselling and skill-building programmes work best in reducing sexual risk. Such teaching should include proper condom use, negotiation and refusal skills, (Ross, et al., 2006).

Stigma

People with HIV are stigmatised worldwide, often causing reluctance to attend testing, treatment, care and counselling for fear of being judged. Stigma and discrimination is widespread throughout all levels of society, from family members to health care providers and even governments. In Uganda, President Museveni supported the policy of dismissing HIV-positive members from armed forces (AVERT, 2009). According to this report, in 2001 he claimed a rival presidential candidate was HIV-positive and therefore unsuitable for office. Such attitudes are a significant hurdle in prevention and treatment efforts.

A study investigating men’s views towards VCT in Uganda showed that fear of stigma was a major hindering factor, along with fear of inaccurate results, separation from partner and lack of confidentiality (Bwambale, et al., 2008). These men also felt the community would view them differently, denying them certain

rights such as political positions. The study only investigated men's views. Though as it was conducted in another rural area of Uganda, some comparisons can be made between these men, and the women in rural Northern Uganda.

In a review of 21 worldwide research papers on stigma, Brown, Trujillo and Macintyre (2001) found that HIV-related stigma impacts negatively on factors such as condom use, VCT and the perception and treatment of people living with HIV. The authors conclude that, given the impact of stigma, it is critical that interventions which effectively reduce HIV-related stigma be identified and implemented. For some individuals in the research papers studied, not knowing their HIV status was far preferable to being tested. Therefore, for effective VCT, it is imperative that stigma issues within the community are tackled.

Why is this service evaluation useful?

The literature has shown a gap in research aimed specifically at young women between adolescence and womanhood. As discussed, young women are particularly vulnerable to HIV and represent a large proportion of HIV service users. Although there is research covering a wide range of sub-Saharan African countries, research into HIV services set in post-conflict areas is lacking. Furthermore, according to WHO/UNAIDS guidelines (2007) regular evaluation of services and patient satisfaction can help improve the effectiveness, acceptability and quality of HIV services. Studies such as Gilbert and Walker's (2009), which explores the social complexity of antiretroviral therapy (ART) in one South African clinic using interview methods to explore patients' views, are few and far between. These authors also highlight the lack of studies investigating the views of the service users. It is clear that Uganda needs to continue to work hard in order to maintain its success with HIV and, due to the high infection rate among young people and the vulnerability of young women, work needs to be especially focused here.

Summary

This chapter has discussed relevant literature surrounding HIV and young women in sub-Saharan Africa, highlighting the need for successful HIV services. The next chapter will look at the clinic context.

Chapter 3 – Clinic Context

Introduction

This chapter will put the clinic into context by describing its background, structure, staff roles and departments and the environment, resources and services available.

JCRC, Gulu

The Joint Clinical Research Centre (JCRC) was founded in 1991 by the Ministry of Health (MOH), the Ministry of Defence and Makerere University (Mugenyi, 2008). JCRC has since expanded and is currently the largest ART provider in the country with over fifty treatment sites (JCRC, 2008). It is also involved in current research including, most recently, pioneering the first HIV vaccine.

The JCRC clinic in Gulu was established in 2004 and serves a population of 141,500 in Gulu town, although people travel from far afield to receive treatment (City Population, 2009). The clinic is funded partly by the Ugandan MOH and partly by The Regional Expansion of Antiretroviral Therapy (TREAT), a project funded by the US Agency for International Development (USAID), the US Government's main aid organisation.

Clients at the clinic are divided between those funded by MOH and those funded by JCRC/TREAT. Poor adults, children, orphans and pregnant women are placed under TREAT and all others under MOH. Likewise the staff is divided, resulting in different contracts, pay, hours and obligations although everyone works together, and clients currently all get the same treatment for free, despite their different sources of funding.

However, USAID only agreed to a five-year contract, which was due to end in September 2009. Funding is slowly being withdrawn though there is an agreement it will continue in Gulu for one more year. This clearly has an implication on enrolling new clients, the future care of existing clients under TREAT, and staff employed by JCRC/TREAT.

By July 2009, the clinic had a total of 6497 clients enrolled in HIV care, 4020 of whom were TREAT funded and 2470 MOH (JCRC, 2009). During July 2009, 773 people attended the clinic for VCT, 128 of whom tested positive. 99 people were enrolled in HIV care. Excluding those attending for VCT, the clinic on average will attend to 100-150 clients daily for treatment, counselling and the prescription and supply of medications.

Departments and Staffing

The clinic has approximately 30 staff and volunteers, including many part-time:

Department		JCRC staff	MOH staff	Volunteer
Clinical	Doctors	2	1	0
	Clinical Officers	1	1	0
Nurses		2	5	0
Adherence (total 9)		2	0	7
Laboratory		0	1	0
Pharmacy		0	1	0
Data/Records		2	1	1
Support Staff		0	2	0
Transport		1	0	0

Table 1

Clinical officers and doctors work side-by-side, attending to the more acute patients. Doctors have slightly more influence due to their level of expertise.

Nurses have to be multi-skilled since they work in all departments, wherever the need is greatest that day. The majority of their day is spent seeing clients who do not have any complaints or complications and are only attending for a repeat prescription. Other duties may include registering clients as they arrive, keeping records of clinic activities, taking blood for CD4 counts and VCT, and preparing for the fortnightly outreach clinics. They are also responsible for managing clients who require post-exposure prophylaxis, such as after rape or contraception failure, and for detecting severely malnourished clients. Malnourished clients are started on a high nutritional and calorific peanut-based paste called Plumpy'nut® (Clayton, 2005). Nurses work closely with the adherence department, giving regular health talks, helping with VCT, counselling before and after tests and helping register new clients if test results are positive. The nurse's job is client-orientated and allows them more time than other staff to work alongside clients to identify any problems, give further advice and refer them to other departments as necessary.

The adherence department is run mostly by volunteers. They are involved in counselling for VCT, health needs and adherence to medications. Clients are referred to the department before they start any new medications, whether it be Septrin or ARVs, and also if the clinician has any concerns over their adherence. Staff teach clients how and why they need to take their medications correctly. CLVs (Community Liaison Volunteers) are part of the adherence team but work out in the community.

The laboratory and pharmacy are both run by single members of staff. The pharmacist is not qualified although he knows everything about HIV medications. The data department does the filing and electronic record keeping. Support staff keep the clinic clean and tidy and prepare tea for staff but may assist in other understaffed areas. They prepare and serve porridge on Children's day. The driver

collects supplies, takes staff to outreach clinics and transports particularly weak clients for further treatment.

Structure of the Day

Clients usually come to the clinic once a month. Those who live particularly far (often 50-100km if not further), may be given two months supply of drugs. However, this is rare and often shortages of drugs prevent staff from giving out such large quantities. The clinic is open Monday-Friday, 8am-5pm although clients tend to arrive early. The final few quieter hours of the day allow staff time to organise the clinic and manage paperwork, whilst being available in case of emergency.

When clients arrive for their appointment, there is often a health talk by one of the nurses or counsellors. This is an opportunity for staff to educate clients on topics such as nutrition and eating healthily; sickness and what to do; stigma; or the importance of adhering to medication and ideas on how to do this.

Nurses or volunteers triage clients. This consists of weighing, measuring heights and assessing for signs of malnutrition by measuring mid-upper arm circumferences. If clients have no problems and have just come for a repeat prescription, they will then see the nurse. If they have any health problems they are advised to see the doctor. Clients then continue to wait in the waiting area until their clinician is ready. A sample form kept in clients' files and filled in by the clinician is shown in Appendix 2. The clinician also writes in the clients' Treatment book for their reference at home and gives them another appointment in one month's time. The clinician may refer the client to another department if, for example, it becomes apparent they are having problems with adherence or are starting new medications. Clients' final visit for the day is to the pharmacy. The

pharmacist uses this opportunity to explain how to take the drugs, important because frequent changes in branding means instructions differ from month to month. Many people cannot read so a standard format is used. For example “2 x 1” means take two tablets once a day. A client would normally spend 3-4 hours at the clinic, although this is constantly improving and depends greatly on staffing levels.

The clinic roughly structures its week as follows, although nobody is turned away in an emergency:

Day	Clinic Timetable
Monday	VCT
Tuesday	Children and caregivers day
Wednesday	Adults
Thursday	Adults
Friday	CME (Continuing Medical Education), filing and general organisation
Weekend	Closed for treatment. Sometimes open for workshops and other events.

Table 2

Resources

The clinic building itself is based in the grounds of a hospital situated within Gulu town. It is fenced in and all rooms and gates can be locked to help prevent burglaries. The building is open plan with a waiting area in the middle with benches and mats. Rooms are small, especially for the storage of necessary equipment and drugs, but fit a desk, chairs and sometimes an examination table. All rooms have curtains for privacy. There is running water outside the long-drop style toilets and an old wheelchair and stretcher for transferring weak clients. Soon the clinic hopes to move to a new building slightly outside town, which is brand-new and purpose built as an HIV clinic. It is much more spacious giving clients more privacy in their treatment.

Resources in the clinic are limited. However, there are posters on the walls and the adherence department has access to many teaching tools. For example, for younger clients at weekend workshops there is a comic-strip style magazine and accompanying CD, which deals with common problems encountered by young people living with HIV.

Services

The clinic provides basic services such as VCT, medications, counselling and blood tests. A drama group works in the community to help reduce stigma and provide HIV education. CLVs provide extra support to vulnerable or struggling clients through home visits and advise on cleaning, cooking, childcare, medications and other aspects important to good health. Unfortunately, there are too many clients requiring additional support, so CLVs struggle to see everyone.

The laboratory within the clinic performs HIV testing and takes blood for CD4 counts (measured every six months), viral load tests and other tests as necessary. However MOH samples go to the MOH hospital laboratory, which has basic equipment and tests CD4 counts by hand. Only ten MOH clients a day can have their CD4 counts taken, leaving some having to return another day. TREAT samples are tested in the JCRC laboratory, which contains high-technology equipment and therefore has no limit on the number of tests performed each day. The JCRC laboratory also does testing for clinics over the whole Northern region of Uganda.

Voluntary Counselling and Testing

Clients arriving for VCT first receive pre-test counselling in small groups, individually or as a couple. Counsellors clarify what HIV is and how it is transmitted. The testing process is explained including the difference between a positive and

negative result. There are many myths surrounding HIV so it is important to set the facts straight before testing.

Clients are then referred to the laboratory for testing. Rapid testing equipment is used which produce results within 15 minutes and only requires a finger-prick.

When results are ready, clients are called into the counselling room, usually individually. If negative, people are taught about healthy living, encouraged to return every three months for regular testing as good practice, informed about the benefits of condom use and advised to bring their partner. If results are positive, counselling differs from client to client. As one counsellor told me "people might be ready for their results. But others, especially the youths, cannot accept and they can cry". Counsellors try to encourage positivity and talk through treatment plans with clients. They will open a new file for the client for treatment and may discuss disclosure to partners or a close, trusted friend. Finally, they are referred to the doctor or given a date on which to return to start treatment.

Summary

This chapter has described the workings of the clinic in detail to put the clinic into context for this evaluation. The next chapter will describe the evaluation design, including data collection and analysis methods.

Chapter 4 – Methodology

Introduction

This chapter will describe the evaluation design, sample group and how the data were collected and analysed.

Evaluation Aims

To evaluate the care young HIV-positive women experience in a rural Ugandan HIV clinic.

Evaluation Objectives

- To explore young women's experiences of HIV testing; their reasons for seeking initial testing; and whether the testing process helped them to access follow up care and support.
- To explore young women's experiences of living with HIV including the social context particularly in relation to support, stigma and disclosure to family, friends, sexual partners and the community.
- To explore young women's management of physical symptoms and medication and how their behaviour or ability to practise safer sex has changed.
- To explore young women's understanding and use of HIV care including their views of the different services offered, the nursing care provided and how these could be improved.

Evaluation Design

Evaluation is defined by WHO (1998, p3) as "the systematic examination and assessment of the features of an initiative and its effects, in order to produce

information that can be used by those who have an interest in its improvement or effectiveness”.

Service evaluations, namely process evaluations, define and aim to enhance current care through greater understanding of the service (WHO, 2000). Qualitative methods are ideal for evaluations since they “describe and interpret complex phenomena that involve individuals’ views, beliefs, preferences, and subjective responses to places and people” (Rusinová, et al., 2009). The method is concerned with how people behave and how social systems operate (Smith, et al., 2005). Data is commonly collected through interview, allowing participants to interpret their experiences in their own words and focus on issues significant to them (Green and South, 2006). Thus it allows findings to focus on the individuals involved rather than on diseases or clinical outcomes.

Barbour (2008) suggests that in-depth semi-structured interviews give the interviewee time to develop their own thoughts and describe what is most important to them, whilst still guiding them towards the topics and agenda set by the interviewer. This enables the evaluator to set the themes but the interviewee’s responses determine the kinds of information produced about these topics and the relative importance of each of them (Green and Thorogood, 2004). Since this evaluation was based on a sensitive subject, individual interviews were conducted, allowing people to talk more freely than in group sessions.

A frequently cited limitation of interviews is that they only offer access to what people say and may not necessarily portray an accurate representation of the experience in question (Green and Thorogood, 2004). To help overcome this problem, and to broaden the scope of the evaluation, I conducted informal interviews and discussions with a varied selection of staff. Furthermore, working as a nurse within the clinic for a total of nearly three months gave me ample

opportunity for observation. I worked in all departments to give as complete a picture as possible, and to provide an overall picture of the running of the clinic and the services it provides. According to Øvretveit (1998, p201), observation allows the evaluator to study what people do in a natural setting whilst “‘participant observation’ reduces the influence of the observer on people’s behaviour”. “A description of occurrences in a natural setting tells a more convincing story” (Smith, et al., 2005, p166) and can illuminate discrepancies between intent and outcome. This data will not be formally presented in the findings but instead used to discuss and reflect upon data obtained from the interviews with young women, helping to contextualise the findings.

Sample Group

The sample group for the evaluation was HIV-positive young unmarried women aged 18-24 who sought VCT because they considered themselves to be at risk of HIV. When “young people” are discussed in most HIV related literature, they usually include those aged 15-24. However, using children under the age of 18 for any piece of research has considerable ethical implications especially in terms of gaining consent (Green and Thorogood, 2004). Therefore for this evaluation, only women over 18 were interviewed. Before starting the study I had specified that the sample group be unmarried women. However after discussion with my translator it became apparent that the vast majority of women in rural Uganda are married by 18 (UNAIDS, 2008b). Therefore, I decided that in order to provide a more accurate representation of women aged 18-24, relationship status should not be specified.

Since this evaluation was conducted as part of a Masters dissertation, ten interviews were thought ample to fulfil the required criteria in the time available and more than enough to fulfil the recommended sample size for a homogenous sample group in a qualitative study. Kuzel (1999, p42) states that “five to eight

data sources or sampling units will often suffice for a homogenous sample”.

Endacott (2007) concurs in a series of papers advising investigators on clinical research. Ten participants represented a reasonable and feasible percentage of the sample group in question.

All the women were receiving HIV treatment and care from the JCRC HIV clinic in Gulu, a rural town in Northern Uganda. Interviewees ranged from those recently diagnosed to those who had attended the clinic for many years.

Interview number	Age	Marital Status	Length of time attending clinic	Commenced on ARVs?
1	24	Married	9 years	Yes
2	21	Widow	1 year	No
3	19	Widow	1 month	No
4	18	Single	2 years	Yes
5	22	Separated	6 years	Yes
6	19	Separated	6 months	Yes
7	23	Widow	1 year	Yes
8	20	Single	6 months	Yes
9	24	Married	2 years	No
10	22	Widow	5 years	Yes

Table 3

Access

When clients first arrive for their appointment, they are seen at the triage desk to be weighed and assessed. It was during this time that the service evaluation was mentioned and discussed by staff on the triage desk with those fitting the correct selection criteria. Women who were interested then had several hours to think, discuss, read an information letter and ask questions while they attended their appointments throughout the day. The information letter was available in both English and Luo for those who could read and triage staff or the study's interpreter were available to read it to women who could not. The information letter can be seen in Appendix 3. Participants were then accepted on a first-come, first-served

basis. Before the interviews began, women were assured that everything would be confidential and a consent form was signed or a thumbprint given.

Since clients usually only attend the clinic once a month and only stay for the day, it was not feasible to give people more time to consider participation. However, recognising that it was imperative that participants feel completely at ease with taking part and should not feel coerced, women were approached appropriately and were given sufficient information and as much time as possible for consideration (Green and Thorogood, 2004).

Data Collection Methods

An outline structure for the interviews was designed after I had worked in the clinic for two months. I tried to ensure that open rather than leading questions were asked, and that they were not influenced by my own preconceptions.

During this time, informal discussions with patients and staff provided an insight into the services, and the issues that might arise in interviews. For example, I knew that drug shortages had previously been a problem in the clinic. I was therefore careful not to mention the topic unless the participant raised it. Observations and informal discussions were not used as formal data but to contextualise and understand the young women's experiences in greater depth. The interview structure was tested on a member of staff to ensure it made sense and was culturally sensitive (Tillman, 2002). A semi-structured interview design worked well, permitting participants to focus on topics important to them while allowing me to guide them towards themes relevant to the evaluation (Barbour, 2008). A copy of the interview schedule can be found in Appendix 4.

As the majority of clients spoke Luo as their first language, it was necessary to have an interpreter present at all times to help translate and transcribe. On advice from the Clinic Director, a Community Liaison Volunteer (CLV) was used. CLVs visit clients in the community and are consequently bound by the same confidentiality regulations as other clinic staff. However, they do not work within the clinic building itself so were unfamiliar to most participants. This helped participants to dissociate the translator from the clinic staff, and to feel at ease discussing their care, whilst still ensuring their confidentiality. Not working directly alongside clinic staff also gave the translator a useful measure of independence and objectivity in their own view of clinic provision. Before interviews commenced, the aim of the evaluation was explained to the interpreter, emphasising the importance of unbiased questioning and translation to further ensure accurate findings. The presence of a local interpreter also helped interviewees to relax and speak freely to me, who, being a white European, was a stranger from a culture very obviously different from their own.

Interviews were held in a quiet room at the back of the clinic, enabling participants to talk freely without feeling under threat and without interruptions (Byrne, 2001). The interviews were recorded and transcribed later although brief notes were made during and immediately after each interview, which helped to place the data in context and were invaluable in ensuring accurate analysis later on.

Combining my observations of the general, everyday running of the clinic, the insight gained from working alongside other nurses, and the interviews with the young women, I grasped a good overview of practice within the clinic. Triangulation has been used to add to the validity of the evaluation (Green and Thorogood, 2004).

Data Analysis

Interviews were transcribed as soon as possible after they were conducted. They were then analysed manually by thematic content analysis, aiming to present the key elements of respondents' accounts (Green and Thorogood, 2004). According to Webb (1999) manual rather than computer analysis is more appropriate for inexperienced evaluators conducting small-scale service evaluations. Thematic content analysis identifies common key themes within the data and is useful for deriving underlying issues and views from a sample group (Flick, 1998).

Analysis began with coding every section of each transcript. Coding is an essential part of qualitative data analysis, the object being to ensure that all the data relevant to each category can be identified and examined (Smith, et al., 2005). Coding took place in a series of stages as explained by Barbour (2008).

Stage One: All interviews were read through and notes were made about interesting points and main areas of discussion.

Stage Two: Transcripts were read again and each recurrent point was given a code or sometimes several codes. For example, when a participant discussed a lack of drugs, this was coded with the letter "c". When a participant mentioned counselling, it was coded with letter "k". A list of these codes and their meanings were kept in a codebook for reference purposes.

Stage Three: Examining the codes, it was possible to group the points raised into sub-themes. A word processor was used to change the colour of each interview in order to distinguish between quotes and a new document was opened for each sub-theme as described by Green and Thorogood (2004). The use of a word processor was useful since it meant quotes could be moved easily if necessary. Sections of transcripts were then cut and pasted into each sub-theme as relevant.

Stage Four: These sub-themes were examined carefully and were eventually divided into three main themes: testing; health aspects of living with HIV; and social aspects of living with HIV. I liaised closely with my supervisor, who also read over interviews, in order to agree the key themes and sub-themes. Use of more than one data analyser adds to the validity of the study (Lacey and Luff, 2001).

Stage Five: The themes and sub-themes were visualised by creating a mind map (figure 1).

Stage Six: The data were then analysed using these themes and sub-themes.

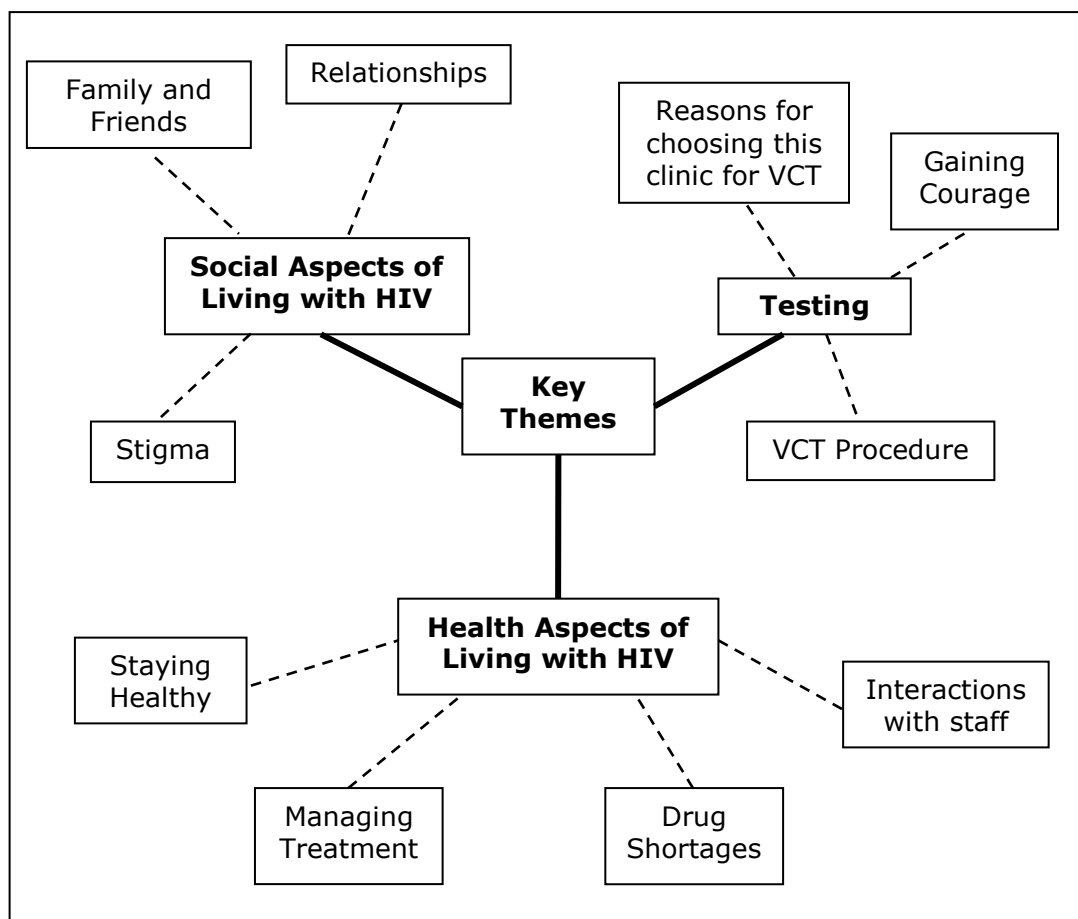


Figure 1: Mind map of key themes from data

As discussed by Maykut and Morehouse (1994) care was taken that the whole interview was also taken into account to ensure the context of the discussion was not lost. Within-case analysis, which looks at interviews individually, alerts the investigator to the presence of key elements and enables the evaluator to understand the full sense of each individual account (Ayres, Kavanaugh and Knafli, 2003). When using coding as a data analysis method, data are decontextualised as they are separated from the original interview (Miller and Glassner, 2004). Coding is thought to be a crucial part of qualitative data analysis as it captures commonalities of experience across cases although it can lose the individual uniqueness within cases (Ayres, et al., 2003). During data analysis for this evaluation, interviews were read numerous times in order to understand each individual woman's experiences and life, minimising the loss of context after coding.

Ethical Considerations

Since this was a service evaluation and not a piece of research, formal ethical approval was not necessary (Green and South, 2006, p105). However, ethical implications have been considered in detail, and the usual standards of professional and ethical conduct adhered to in order to protect participants (Barbour, 2008). The clinic gave its support for the evaluations to be conducted. The Clinic Director is a doctor specialising in HIV. He provided guidance on the choice of a feasible topic, which would also serve a useful purpose within the clinic, and acted as my on-site supervisor for the whole project. His letter of formal written consent can be seen at Appendix 5.

Confidentiality and anonymity are essential. In order to ensure that they were maintained at all times, only staff bound by confidentiality rules were used, and participants' names were not recorded (Sánchez-Jankowski, 2002). However, if during the course of an interview, it became apparent the participant was in need

of further help or guidance, it was possible to offer them a referral to the appropriate health care provider. For example, one participant expressed the need for further support at home so she was referred to a CLV for further follow-up. This was discussed with participants before they consented to ensure they were fully comfortable with participating (Green and Thorogood, 2004).

Rigour and Reflexivity

In order for an evaluation to be successful and useful, it is important for the evaluator to rigorously test the validity of the information gathered, especially in terms of the reliability of the methods employed (Lacey and Luff, 2001). In this evaluation, several steps have been taken to ensure this:

- All methods for data collection and data analysis have been justified here in the methodology in relation to how they are appropriate for this evaluation.
- During data analysis, a clear process for generating key themes and theories has been documented.
- Findings have been discussed in relation to external evidence to back up the validity of this evaluation.
- Data analysis has been undertaken by more than one evaluator to ensure consistency in results.
- A variety of original data is used in the analysis stage demonstrating how interpretations relate to the data gathered.
- By using a varied range of data collection methods, a fuller perspective and greater insight into the care and practice within the clinic can be gauged. This is an example of triangulation, which demonstrates rigour in the evaluation technique and adds to the validity of findings (Green and Thorogood, 2004).

- Respondent validation is a means of feeding back findings to participants to check for accuracy and ask for comments. It is increasingly being seen as a method for demonstrating rigour (Lacey and Luff, 2001). However due to time constraints, it was not possible to perform respondent validation for this service evaluation although it would be recommended for future evaluations.

Reflexivity has been defined as the “open acknowledgement of the complex influences among the researchers, the research topic and subjects on the research results” (Kitto, Chesters and Grbich, 2008). The majority of qualitative evaluators now consider reflexivity a vital part of critical practice (Adkins, 2002). By recognising the consequences of their own actions and decisions, and being aware of their socio-cultural position, evaluators add to the credibility of their work (McBrien, 2008).

In the case of this evaluation, there were many aspects to consider to ensure validity of data. One of the main considerations was that I was a visitor to the community and therefore did not fully understand the local culture, beliefs or language. This may have affected findings in two ways. Firstly, participants may have altered their revelations according to what they thought appropriate to discuss with me. Secondly, my own cultural background may influence my interpretations of data. This factor is mitigated slightly by the fact that I lived and worked in Uganda for a year from 2004-2005 wholly integrated into the local community. I also worked in this particular clinic for two months, meeting the staff and learning about their work, culture and some of the language. The use of interpreters aimed to overcome some of these barriers, especially by making participants feel more at ease although, as previously discussed, it was important to ensure the interpreters were aware of their own preconceptions.

My previous experience working in the clinic and my own cultural background may have given me preconceived ideas about the outcomes of the investigation. In the interviews, I tried to ensure that questions were open, not leading, and that I left it to participants to raise issues and describe problems. Furthermore, I tried to minimise preconceptions by postponing the full literature review until after data had been collected and analysed.

As a nurse, I also need to be aware of my own westernised medical background and endeavour to understand the participants' perspectives during analysis. My own understanding of HIV may influence my interpretations since I am still learning about this complex disease.

These matters will all contribute to preconceived ideas about what is expected from the evaluation. However, by incorporating reflexivity into the study, and by being aware of and addressing such matters before the evaluation begins, bias and predispositions will be minimal (McBrien, 2008).

Summary

This chapter has described and justified the evaluation design, sample group and data collection and analysis methods. In doing so, a transparent and rigorous account of evaluation design and procedures has been provided. The next chapter will present the findings of the interview data.

Chapter 5 – Findings

Introduction

This chapter will present the findings taken from the interviews, supported by evidence from observations taken whilst working in the clinic and discussions with staff.

Three main themes have emerged from data analysis: testing; health aspects of living with HIV; and social aspects of living with HIV. Each of these themes has several sub-themes, which will be discussed individually.

Testing

All participants had, at some point, been tested at this clinic, although some had been tested before JCRC became involved in the running of it. Participants' experiences of VCT were investigated at the start of the interview to ascertain how they decided where to test, what the actual testing procedure was like (including support from clinic staff) and how they felt on learning their status. Three sub-themes emerged: reasons for choosing this clinic for VCT; gaining courage; and the VCT procedure.

Reasons for choosing this clinic for VCT

The clinic is a popular place for VCT since it is one of the few clinics within the town to offer both care and treatment after a positive diagnosis. During July 2009, 773 people attended for VCT (JCRC, 2009).

Many women cited the location of the clinic as a reason for their choice:

"This one is a bit nearer to the town...it is easy for me to come this side."

(YW8)

The clinic's reputation was also a reason as one lady stated:

"We had a friend who told us we should come here because it is good."

(YW9)

The clinic is well known in town being located in the hospital grounds. Many people considering testing will have seen it and know about its work.

Gaining Courage

HIV is hugely stigmatised in Uganda and the decision to come for testing is not easy. One woman discussed her fear before testing:

"I was really scared because I thought 'how am I going to cope? How are people going to look at me now?'" (YW2)

But the clinic provided the support she needed to overcome her fears, and gave her the courage to continue attending:

"I have seen many people here who are infected and they are even looking good so I got more courage. That's why I decided to keep getting drugs from here." (YW2)

The positive attitude of staff also encouraged clients to return for treatment as they provide help, advice and support. When asked about her first VCT session, one woman described:

"At first when I came I was really scared how they were going to speak to me, maybe they would blame me for something, but then they gave me more courage...The people were showing me the love and support I really needed at that time. I was so scared but then I really felt at home." (YW10)

Clients receive counselling both before and after testing, regardless of results.

Through this, clients are taught about HIV, consider life as an HIV-positive person, and are encouraged to believe the disease is manageable. The participants felt that it provided sufficient support and reassurance to ensure they returned for further

treatment. Seeing other people looking healthy gives them encouragement and a positive outlook.

VCT Procedure

The clinic provides rapid on-site testing, giving clients results within 15 minutes, meaning they can receive results and post-test counselling immediately.

"It was good because my results were there for me that same morning...maybe if I was asked to come back then I would have avoided because I was scared." (YW6)

Good counselling is as important as the test itself. It ensures clients understand their disease, its implications for themselves and others and encourages them to return for treatment. One woman described her experience:

"I didn't really know what HIV was. I thought it meant I would die. But then when I came for testing, they explained to me everything and told me I could be healthy again." (YW8)

Another said of finding her status:

"I was a bit disturbed and actually I didn't know that many people who were infected, you may think you're the only one. But when I came here I found very many people and I did relax." (YW9)

One member of staff described the counselling they give after someone tests positive saying it was important to "encourage positivity" especially in younger people who often find it harder to accept their results. Counsellors talk through treatment plans, healthy living and disclosure to partners or a good friend for support. They are then referred to the doctor for examination and to start treatment.

Overall, the VCT procedure was held in high esteem by all the women. They spoke of the support and encouragement, which helps them deal with the disease. Since

the clinic is open-plan with the waiting area in the middle, clients meet all members of staff. Thus all staff are responsible for helping clients to feel welcome and giving them confidence in their status.

Usually the adherence department deals with VCT. However when staffing is low, nurses take on all roles. They will often be found working in counselling rooms, greeting people arriving for VCT, directing clients, or taking blood samples from anxious clients. Therefore it is essential that nurses in particular are trained in providing advice and support.

Although the women were unquestionably worried about coming for VCT, they were glad they had been. As one woman said of her testing experience:

"It was good actually because I know my status now." (YW9)

Health Aspects of Living with HIV

All the women discussed the health implications of living with HIV, how they cope with such implications, and how the clinic affects them. In particular they focused on staying healthy, endeavouring to maintain a positive outlook even when feeling ill; managing their treatment; coping with drug shortages; and their interactions with staff.

Staying Healthy

Most women were worried about their health, particularly because they had families to care. Many have seen loved ones die of the disease.

"Sometimes they [other young women] are actually not feeling well and are talking that they may easily die." (YW9)

The clinic staff try to reassure patients and provide treatment for opportunistic infections. Healthy living talks are regularly given by nurses and counsellors to

advise people on topics such as the importance of adherence, eating healthily, contraception, and good hygiene, both personally and around the house. There are also posters for people to read.

One woman said she was disappointed that food was not provided in addition to the other services:

"If they could provide milk for the young kids...because some women cannot afford...you can see some of the children here, they are really very weak."

(YW9)

The clinic provides a fortified peanut paste for severely malnourished clients, particularly children, but supply is limited. However, the staff provide information, care and support to help people feel confident in their health and treatment regimes, and the women agree the care is good. Many of them were sick before and now feel healthy again with the clinic's help.

"The care was so good. They taught me everything I needed to know. I eat healthily, I sleep healthily and I take my drugs. This way I can be strong."

(YW5)

Although the women have concerns about their health, many have very positive outlooks on their lives, and appreciate the support the clinic provides. One woman described:

"Every person normally has very many problems and when I get difficulty I can always come back." (YW7)

This woman knew she could always come to the clinic for help and treatment. People who are not diagnosed with HIV often have no one to turn to for help.

Another woman explained what she tells other people when they try to sympathise with her:

"Now it is God's plan. If you are sick, you just take your medicine, you will feel better...I say "for me I am now taking medicine and I am fine, I am better than you". Because if you have known your status you can feel free and you can be easy." (YW9)

From my observations of the counselling, advice and information given by all members of staff, I believe the clinic is the main educator in bestowing this mindset.

Managing Treatment

Most women reported no problems adhering to their medications and some discussed tricks to help them remember:

"I have a watch and I listen to the radio. And it's already in me that at 8 in the morning, I have to take it." (YW2)

"When I get up in the morning, I know I have to take them. And even my husband, if he is forgetting the time, I have to remind him." (YW9)

However, the youngest of the participants discussed the problems she experienced before she left school.

"I would get my drugs from the tin and pour it in a paper. I didn't want my friends to see me take it because one of my friends told me, 'they were talking about you and saying you were taking ARVs'. I was feeling bad...I used to sometimes miss a week." (YW4)

The clinic has a specific adherence department, and much advice on the importance of maintaining good adherence is provided through counselling and health talks. Before JCRC arrived, clients were given one single adherence session before starting ARVs. Clients now receive one session before starting any new long-term medication, at least three sessions before commencing ARVs and also receive additional adherence sessions if they experience any problems. They are

encouraged to bring a family member or friend to adherence sessions to provide support and help with compliance.

"For some people who are not so clever, they were confused. They needed more time and more help to make sure they know how to take these drugs. Now it is so good for them." (YW5)

ARVs are powerful drugs with many side effects, some worse than others. Clearly side effects will have an impact on clients' health and adherence (Pratt, 2003) and were a topic brought up as a problem when living with HIV:

"The care is good but the drugs that they have given me are giving me problems with my eyes and messing with the right side of my body." (YW1)

This lady had been on ARVs for nearly a decade and was suffering a great deal due to being prescribed new ARVs.

Drug shortages

During the time of interviews, the clinic had run out of its supply of Septrin (co-trimoxazole), the antibiotic of choice to reduce the chance of opportunistic infections developing (aidsmap, 2009). All the women discussed the frequent drug shortages in their interviews. Poverty is rife. Few people have spare money. Affording drugs is a real problem.

"Like this week there is no Septrin but...it finds us when we don't have any money to go and buy... you cannot go and beg...It started long time ago and sometimes it can take even three months without coming so you find someone who has no money having to buy Septrin and these days are days of anger in our region." (YW7)

When asked if and how they will manage to get hold of Septrin, women replied:

"Sometimes you may not afford and then you have to go without." (YW9)

"Normally when people first get money they first think of food, and also to buy drugs...the expense is even more." (YW7)

Septrin is not the only drug in short supply. So far the clinic has managed to keep the supply of ARVs flowing but even these can run low sometimes, meaning people can only receive two weeks' supply instead of a month's and have to return to clinic more often.

"A major problem is about the drugs for opportunistic infections...Like the antimalarials, like Coartem, sometimes it can take like three months without coming so when a child or adult is sick they should go and look for another treatment from other places." (YW7)

Interactions with Staff

In general, the care provided by staff was deemed to be good by the young women, though two mentioned rudeness and unfriendliness by certain staff members.

"That lady she likes to shout. She is rude...that is why I don't like her. Otherwise everyone is ok with me." (YW4)

"...you may come when you are absent minded. They call your name and you might not even hear...they shout on you and make you feel bad and you may be affected." (YW9)

This is a serious issue as just a few bad-tempered members of staff can undo all the good work achieved in helping clients gain confidence. However, some described the opposite:

"At first when I came I was really scared how they were going to speak to me, maybe they would blame me for something, but then they gave me more courage." (YW10)

From my observations, I noted a few members of staff acting brusquely with clients although inappropriate behaviour was rarer in the clinic than for instance in the

adjoining hospital. If staff are seen to be rude or unprofessional, the clinic director issues reprimands.

Social Aspects of Living with HIV

The social aspect of living with HIV is a huge issue. The women all discussed how HIV had changed their lives. This theme is divided into the sub-themes of relationships; friends and family; and stigma.

Relationships

HIV undoubtedly affects every woman's relationship with her husband or partner. Many of the women first thought of testing after their husbands became sick or died.

"My husband fell sick but he didn't tell me what he was suffering from. He would always come here to get drugs but I was not sure what he was coming here to do. So one day I followed him...when the counsellors heard I was the wife they told me that I should also test since the husband is already sick." (YW10)

This story is all too common and highlights the lack of power many women experience in their lives and relationships. One described how her child was always sick so she wanted to test herself and her child. But her husband refused to let her and said he would leave her if she did.

"It caused many arguments...he used to beat me. I was so scared so I couldn't test." (YW5)

It was not until her husband fell sick and was admitted to hospital for five months that she was able to get tested.

From my observations, young women frequently turned to the nurses for help and advice. Clients usually meet a nurse at some point during the day, simply due to

the number of roles nurses cover within the clinic. Therefore many of the young women get to know certain nurses well and form a relationship with them. In this way nurses are best positioned to provide support and encouragement to give young women the confidence they need to cope.

"The counsellors are very good here and the nurses are so supportive. We come with our problems and they can listen until you feel better." (YW9)

When asked about current or future partners, many women said they would only choose another HIV-positive person.

"You may get a man who does not understand your situation, you may be infected while he is not infected. And that one may bring quarrels inside your family...they end up even chasing you saying 'you are the one who brought this in, go away'...They are experiencing that their husbands disturb them, sometimes they quarrel and they get drunk and they shout on them...That is the problem we are facing as young women." (YW9)

"He is also HIV-positive. It is much better like this. He understands me and when I am sick, he can help me. I don't think an HIV-negative partner would understand." (YW6)

Other women said they felt they could not have another relationship.

"I know my status so I am thinking that in order for me to live longer I should stay alone without getting married to any other man...because the man has left me with three children." (YW7)

Most of the women discussed their children and the impact being HIV-positive has had on them. Some had had their children tested already, many of whom were positive. Others said they were planning to bring their children for testing, an issue encouraged by clinic staff. Knowing their HIV-status undoubtedly impacts heavily on the women's lives, especially after the loss of, or separation from, their

husbands and partners. One woman discussed how alone and scared she felt, but with the encouragement and support of the staff she has managed to turn her life around and find courage:

"I decided to change the way I live and am now more focused on taking care of my children." (YW7)

Counselling is offered during every contact with clinic staff, not only with counsellors. Nurses in particular have the time to give extra support in a confidential and private setting. Many of the women discuss this support and report that it has given them the strength to continue to look after themselves and their family properly. The form filled in by the clinician at each appointment asks about family planning methods, offering the opportunity to advise people on the benefits of family planning and condoms. Health talks also feature family planning and safe sex.

"I always disclose my status to partners as I don't want to infect anyone...One man refused to believe me because I look so healthy...I showed him my tablets. He still refused to believe so I brought him here and the nurse confirmed it. But then he no longer wanted to be with me...Now I always use condoms...but I am also on injectable contraceptives because I don't want any more children, it would be too much for my body and will make me sick." (YW6)

The women who admitted to being sexually active stated they used or wanted to use condoms, suggesting that the clinic staff's advice is being heeded. The clinic has an erratic supply of condoms, which nurses give out during appointments, or women must find another means of obtaining them if they want to use them.

Family and Friends

The war in Northern Uganda has caused many family separations and many deaths. Therefore some people rely heavily on friends and neighbours for support, rather than family. The clinic encourages clients to bring someone to adherence sessions for support. These people can help clients disclose their status to other family members, friends, partners and the community and support the clients when they are sick.

Some of the women found their family to be of great support after disclosure to them.

"I have disclosed to my mother, a brother who normally takes care of me when I am sick, and my close friends...the guy is so supportive." (YW7)

"With our family members, they took it as something which is now very common. They see us in the normal way." (YW9)

Others however, found that although they were supportive initially, it did not always last. One woman talked about her relationship with her brother who she moved in with when she found her status and left her husband.

"He told me I would soon die and leave my child with him so I should start paying him money for the child and for my burial. It was very upsetting because I felt so healthy and this was my brother...My mother was very angry and made him see his errors so he apologised. But I had to move out on my own." (YW5)

Other women have no family to turn to. One young woman felt so alone since the death of her husband that she was planning to move back to Sudan to find her family for support, and then return to the clinic every month for drugs.

The clinic aims to give clients confidence, support and courage by showing them they can lead healthy, normal lives. Many of the volunteers are HIV-positive themselves and openly disclose their status to prove that "HIV does not have to kill and ARVs really work well", as one volunteer told me. Many of the women discussed how the clinic and its staff had given them the confidence to accept their status.

"I can share the idea with someone that I am now free. I am going to get my medicines." (YW9)

"I am not ashamed since I know this was not my fault, I had no choice. So I feel I can openly disclose my status to anyone." (YW8)

CLVs visit clients at home to provide extra support and advice. However they are limited in numbers so can only cater for clients deemed to be truly vulnerable, such as young single mothers. CLVs advise on subjects such as cooking, cleaning, child care and medications to ensure both the client's and their children's health is well looked after. The women who receive this support seem to value it, but as ever, resources are limited. One woman felt she was struggling after the death of her husband:

"I would love them to follow me up because sometimes maybe I will feel down and no-one will know." (YW2)

Another woman suggested setting up support groups:

"I think that those who are infected should be put in groups for therapy, so that we discuss matters that affect us and our family members." (YW9)

Stigma

Stigma is hugely associated with HIV and experienced by everyone affected by the disease. The interviews involved questions on women's experiences of living with HIV, which inevitably led to discussions on stigma and the community. In some

areas, the stigma is so great that people have to move away, while others have to reassess friendships:

"My neighbours don't want to move with me, thinking I'll infect them...They really talk a lot. I left that home and am now staying with another relative."
(YW10)

"The ones who are like me are ok with it. But then these other ones who do not have the virus are the ones who talk about me...I left those friends and now have friends who are like me." (YW4)

Others want to live an open life and disclose their status to all but they then have to live with issues associated with stigma.

"Some people they may talk on you...they may think you are the one who looked for that sickness actually. Our neighbours they may say "oh she is now sick, she is what"...But I just take it easy because I know at any time, they may get sick." (YW9)

"In some areas like mine, it is worse, they can talk on you seriously. But other people can sympathise. They may say "sorry"..."they didn't want it to be like that"...others may not know their status but they can point fingers."
(YW8)

However, other women felt that the stigma was starting to reduce in their area:

"One of my neighbours has a big child who is also infected and so I am close to her and she comforts me. But then there is this other neighbour who does not like my child because my child has these rashes...so she stops her other children from playing with my children...The stigma is reducing because now even that neighbour who didn't like me, my other neighbour spoke to her and explained to her that playing with children doesn't infect them and she really taught her a lot about the disease that this doesn't need all this

stigmatisation. So she has really changed and has stopped her behaviour towards me and my family.” (YW2)

Volunteers and CLVs from the clinic run a drama group aiming to tackle stigma and discrimination. The group goes out into the community and performs a musical play to educate people about HIV and how to live with it.

“The drama group started in communities to tackle stigma and disclosure and discrimination issues...so they have started learning how to treat people in the community to reduce stigma.” (YW7)

Initiatives such as these seem to be a good way to help reduce stigma, encourage people to come for testing and help people to live freely, no matter what their status.

Summary

This chapter has presented the findings from the analysed interview transcripts using information taken from observations and informal interviews with staff. Three main themes emerged: testing; health aspects of living with HIV; and social aspects of living with HIV. These themes were used to analyse the care the clinic and its staff provides for young women. The next chapter will discuss these findings in relation to the wider literature.

Chapter 6 – Discussion

Introduction

This chapter will discuss the data collected from the interviews in greater depth, drawing on relevant literature in order to analyse the findings and draw conclusions. It will focus on key findings from the data and compare these to findings in the literature.

Testing

Reasons for choosing this clinic for VCT

The location of the clinic proved to be a factor for women when deciding where to go for testing citing its convenient site in town. This was interesting in that it appears contrary to many studies across sub-Saharan Africa. These suggest that patients often travel far in order to avoid stigmatisation and maintain anonymity (Gilbert and Walker, 2009; van Dyk and van Dyk, 2003). One such study investigating men's views on VCT in rural Western Uganda found that men wanted to test in areas where counsellors did not know them, fearing "they would easily be identified and labelled as HIV victims" (Bwambale, et al., 2008). However, while 56% of men said they chose the site for confidentiality reasons, a sizable 38% reported choosing the site for its proximity, concurring with the results of this service evaluation. None of the women mentioned fear of confidentiality as a worry when testing, suggesting they felt comfortable with the services.

Reasons why women preferred the close proximity to town could include the time away from work or childcare, and lack of funds for transport (Karamagi, et al., 2006). Indeed Bwambale, et al. (2008) found that 70% of men in their study walked to VCT sites.

As previously mentioned, the clinic was one of the only VCT services that also offered care and treatment after diagnosis, which would further encourage attendance. It also offered free testing which is essential for many women who live in poverty (Bartlett, et al., 2009). One study investigating young people aged 14-21 in urban areas of Uganda and Kenya found that costs deterred them from seeking testing, (Horizons, 2001), a finding supported by Bwambale and colleagues (2008).

Chamla and colleagues (2007) investigated VCT and PMTCT specifically in Northern Uganda finding that most health facilities in rural areas lack appropriate health personnel and medicines, suggesting that health facilities in towns, such as this clinic in Gulu, provide fuller and better-equipped services, a conclusion supported by my observations of the clinic.

VCT Counselling

The data suggested that the clinic's counselling service was extremely beneficial to the women and provided a strong source of support and courage, especially during VCT. In Horizons' 2001 study based in Uganda and Kenya, young people declared counselling to be the most important component of their testing experience. In that study, one Kenyan woman even discussed how counsellors gave her courage, which strongly relates to findings from this service evaluation. Attitudes of staff greatly affect uptake of VCT and the experiences of those undertaking VCT. A recent large South African study investigating young people's attitudes to VCT found that they were worried about nursing care during VCT. In particular, a lack of confidentiality, fear of being shouted at, and the ability of nurses to provide adequate counselling were mentioned (MacPhail, et al., 2008). Painter and colleagues (2004) discovered that women from Côte d'Ivoire cited staff behaviour and stigma to be the main factors affecting their decision not to return for treatment after testing. However,

findings from this evaluation suggest otherwise. Although some women attending the clinic felt worried, they were quickly reassured, resulting in a positive VCT experience.

According to guidance by WHO/UNAIDS (2007), post-test counselling is an integral component of VCT, for both positive and negative clients. They stipulate that issues which need to be addressed during counselling include: advising on methods to prevent HIV transmission; providing condoms; supporting the patient as they cope with emotions arising from results; assisting the patient to find someone to disclose to for support; and describing follow-up services and treatment plans. The women in this evaluation all stated they had sufficient information and support at time of diagnosis, and many discussed how staff had helped them gain courage. Women discussed how seeing others looking healthy gives them encouragement, a finding corroborated by Gilbert and Walker (2009). I observed counselling and advice being given in accordance with these guidelines during VCT within the clinic. "A positive diagnosis can damage young people's self-esteem and their ability to learn how to negotiate life needs" (Bell, et al., 2007). According to Evans and Ndirangu (2009), for many people, contact with their VCT service is their only source of psychological support. Thus, effective counselling is the cornerstone of the testing experience.

Counselling in this clinic was mentioned as a main source of support by all the women, and perceived to be of very high quality. A number of staff, in particular CLVs, are HIV-positive themselves and openly disclose their status. According to Bell, et al. (2007) patients may prefer HIV-positive counsellors because they are less likely to have judgemental attitudes, providing an important role in encouraging and educating others. One CLV told me she loves her job, despite the low or non-existent pay, because the clinic gave her support when she found out her status, and she wanted to do the same for other women. She has now left her husband and has dedicated her life to helping other young women live positively.

From my observations, attitudes such as these are commonplace throughout the clinic, and I believe this to be one of the main reasons why the counselling is of such high quality.

Rapid Testing

The clinic performs rapid testing during VCT. Some of the women appreciated the ability to get their results immediately. A study investigating the use of rapid testing in a Ghanaian clinic found that patients were more likely to receive their results since they did not have to return another day, and were also more likely to return for HIV specialist care, thus improving their health and reducing transmission (Appiah, et al., 2009). According to Kalichman and Simbayi (2003), it is common for people to not return for their test results when they have to wait days for them finding that a third of their large South African study did not return for test results. Hutchinson and Mahlalela (2006) also conducted a study based in South Africa and found that the availability of rapid testing doubled the likelihood that men would be tested from 11.4% to 22.2% although it barely affected women's uptake.

WHO/UNAIDS (2007) guidelines discuss the rapid testing as being "highly sensitive, specific, simple-to-use, rapid antibody tests that do not require sophisticated laboratory services, running water or electricity". This is ideal for use in the clinic where a simple-to-use test enables many people to be trained, overcoming the problem of staff shortages. Furthermore, the clinic's frequent water shortages and power cuts are not a problem.

Health Aspects of Living with HIV

Staying Healthy

Health concerns were a significant feature in the interviews and again, the clinic seemed to be a strong source of support with this, not only through the provision of medications but also through counselling and health advice. Pratt (2003) advocates the benefits of providing in-depth education about adherence and healthy living, suggesting that well-informed people are more likely to feel in control of their illness. Gilbert and Walker (2009) discuss the benefits of the care provided in an urban South African clinic. Their care is similar to the clinic in this evaluation whereby clients are counselled in adherence and healthy living aspects and receive regular health talks in addition to their private consultations. This leads to better understanding of their disease thereby giving the young women control to improve their health.

One woman suggested the clinic should provide food for children since many young women cannot afford to feed them properly, a finding Westerhaus and colleagues (2007) concur with. Good nutrition is essential to help prevent malnutrition, strengthen the immune system and thus delay the progression of HIV (Uganda MOH, 2006). Malnutrition is a common characteristic of HIV and can lead to the development of opportunistic infections and poor health (Pratt, 2003, p320). Indeed, when HIV first emerged in Uganda, locals dubbed it "slim" (Mugenyi, 2008). However, to provide a successful nutrition regime would cost a vast amount of money. According to an extensive literature review conducted for WHO, the total cost of imported RUTF (ready-to-use therapeutic food) exceeds the health budget per person in most sub-Saharan African countries (Ashworth, 2005). The clinic provides a fortified peanut paste for severely malnourished clients but does not have a constant supply. The Ugandan MOH has published "Improving the quality of life through nutrition", a booklet for healthcare providers to use as a tool for

advising clients on nutrition. The clinic aims to improve the nutrition and health of clients through use of such books and through healthy living talks and counselling but in terms of providing food, it is evidently bound by significant financial constraints.

Managing Treatments

Most of the women stated they had no problems adhering to medication regimes, corresponding to findings that adherence rates are unexpectedly high across resource-limited countries (Gilbert and Walker, 2009). Kiboneka and colleagues (2009) recently conducted a large study of HIV drug adherence within Gulu district over a period of 30 months finding that over 90% of patients adhered to ART more than 95% of the time.

Gilbert and Walker (2009) mention how in 2001, the director of USAID suggested "AIDS drugs' wouldn't work in Africa because many Africans don't use clocks and 'don't know what western time is'". However, women in this evaluation discuss using mobile phones, watches and radios in order to remember their medications. Pratt (2003) discusses the nurse's role in adherence, suggesting that nurses are ideally placed to support patients, especially in terms of helping them identify how best to integrate taking medication into daily routines. He suggests patients develop "cues" to remind them to take their medications, which staff members have evidently discussed with these women.

Women also discussed working with partners or family members to manage their medications, a finding supported by recent research (Medley, et al., 2009). As Pratt (2003, p384) states, "the presence of stable relationships and access to social and emotional support are important factors in maintaining adherence". Clients receive a great deal of adherence advice and are encouraged to bring someone to adherence sessions to provide support, aid disclosure to others and assist with

compliance. In this way, the clinic can ensure that clients have adequate support outside the clinic and can provide extra support, such as CLV home visits, if deemed necessary.

Drug Shortages

At the time of interviewing, the clinic had run out of Septrin, meaning that all clients had to purchase it elsewhere. All the women discussed drug shortages as a significant problem involving all drugs, including ARVs and TB medications. According to IRIN (2009), Northern Uganda is particularly affected by drug shortages. Ugandan government ministers blame drug shortages on the global financial crisis, a successful testing regime and policy changes increasing the numbers qualifying for treatments (Wasswa, 2009). A leading Ugandan newspaper however suggests "donors have over the years been getting despondent over the high infection rates, which seem to be showing no signs of abating, coupled with embezzlement of HIV/AIDS funds" (Saturday Monitor, 2009).

An annual supply of Septrin costs around £6 per person and should be a basic component of HIV care (Mermin, et al., 2004). However poverty in this region is such that many clients are forced to choose between food and drugs (Bartlett, et al., 2009). Interruption of HIV or TB treatments can lead to resistant strains developing. It is imperative therefore that supplies be reliable (IRIN, 2009).

The impact of drug shortages on all clients is clear, especially on these young women who have families to provide for and may not have access to money. However, as the literature demonstrates, this is a nationwide problem and is therefore very difficult to resolve.

Interactions with Staff

Staff attitudes are one of the most important aspects of good HIV care in order to help clients feel welcome, gain courage and seek help and advice. Negative staff attitudes is a recurrent theme in several studies across sub-Saharan Africa (Evans and Ndirangu, 2009), but only two of the ten participants in this study discussed it.

Studies from South Africa show that young people are worried about being shouted at by staff while ignorance causes nurses to have negative attitudes towards HIV-positive patients (MacPhail, et al., 2008; Deetlefs, Greeff and Koen, 2003).

In contrast to much of the literature, the majority of participants in this evaluation were very pleased with the care from staff concurring with findings from Gilbert and Walker's 2009 study where respondents relied heavily on the clinic and its staff to make them feel welcome and uninhibited. Many of the women discussed the support and courage counsellors and nurses gave them. From my observations, nurses seemed to be chief confidant for many women. During a discussion with one MOH nurse, I asked about her job satisfaction. She explained how she had not been paid in over six months but continued to work to "support and care for her fellow people". As previously discussed, this optimistic attitude was observed in many members of staff leading to a positive atmosphere which appeared to permeate the clinic environment and provide encouragement for clients. Further research needs to be conducted to comprehend how and why this unique positive atmosphere and attitudes are maintained.

Social Aspects of Living with HIV

Relationships

From listening to the young women's stories and viewing the interviews as a whole, it is obvious that many women have very little power in their relationships. This is well documented throughout sub-Saharan African literature. Women are financially and socially dependent on men, limiting their power to make independent decisions (Bell, et al., 2007; Medley et al., 2009). Lack of power also makes it difficult for women to request their partners to wear condoms and, according to Hendriksen and colleagues (2007), "young women in particular may fear that their request for condom use will be interpreted as an admission of infidelity or will trigger violence".

In contrast to the literature, the women in this service evaluation stated they used condoms when possible, which the clinic provides, although supply is erratic. Family planning advice is given during every appointment and is often a topic for health talks. Joint appointments for couples are advocated in the clinic where possible. Uganda's HIV policy uses the ABC approach (Abstinence, Be faithful, Condom use) and is advertised everywhere (AVERT, 2009) therefore awareness of the message is high.

The clinic aims to provide holistic care to all clients. Helping them to manage their social situation is hugely important. Counsellors are available every day to discuss problems with clients and discuss issues such as disclosure and stigma with clients.

Nurses have frequently been documented as patient confidants (Ford, 1996) and nurses' uniforms give people greater confidence in them, suggesting they can be trusted (Staines, 2009). This concurs with my observations. All the clinic nurses are female and are the only members of staff to wear a uniform. Many members of the adherence department and doctors are male. Nurses are frequently the person

young women confide in for personal issues such as safe sex, marital problems and rape.

All the women interviewed stated they either did not want a partner or would only choose an HIV-positive partner, for fear of transmitting the virus and because of the support and understanding an HIV-positive partner provides, a finding supported by a range of literature (MacPhail, et al., 2008; Golub, Tomassilli and Parsons, 2008). This is not something that is either encouraged or discouraged in the clinic, although the importance of condom use is emphasised. However one Ugandan study suggests that HIV discordance is common with over 30% of married HIV-positive people living with HIV-negative spouses (Bunnell, et al., 2005). Nevertheless, they found many of these couples tended to feel isolated and have worries about the future, trust and sexual intimacy.

Disclosure

The majority of young women had disclosed their status to their family and friends who were mostly supportive. This concurs with findings from Gilbert and Walker's 2009 study of HIV-positive patients' experiences and with findings from Medley and colleagues' (2009) literature review. However, the decision to disclose is generally a difficult and complex process and requires a great deal of support. Fear is often the main factor behind a deep reluctance to disclose results (Gilbert and Walker, 2009). Youths indicated a fear of disgracing their family in a recent study in South Africa (MacPhail, et al., 2008). The clinic staff support clients a great deal in disclosure and discuss it from the beginning. Disclosure is hugely important for adherence to medications but, as the women described, it can also generate support for when they are feeling low or are sick.

There was only one woman who had not disclosed her status to anyone. This woman was recently diagnosed and had no family around her since her husband

had recently died. According to Medley, et al. (2009), nondisclosure can isolate women and can lead to negative psychological and health outcomes whilst Pratt (2003, p384) states that people with poor social networks are more likely to have problems with adherence. CLVs provide home visits for such isolated women, especially young single mothers. It was evident in the interviews that the women who receive these visits really appreciated them. This extra support is vital for many to continue living positively although it was also apparent that the service needs expanded as many more women would benefit it.

Another young woman suggested setting up support groups, which are currently only provided for adolescents. In Medley and colleagues' 2009 study, support groups across central Uganda aided women with coping mechanisms and disclosure advice. Support groups can help people realise they are not alone, allowing people to share experiences (Dlamini, et al., 2009). However, support groups require longer hours or extra staff and staff within the clinic are currently working at maximum capacity.

Stigma

The data exhibits forms of stigma affecting all the women's lives, causing some to move to a different community and others to re-evaluate friendships, all concurring with other research from Uganda (Medley, et al., 2009). MacPhail and colleagues (2008) found that gossip resulting from disclosure to friends might be more harmful than the potential emotional support. Stigma has been identified as one reason for missing medication doses (Dlamini, et al., 2009). The clinic suggests clients use codes such as "airtime" meaning "ARVs" to help young people remind each other to take their medications.

Despite high levels of stigma surrounding HIV, some women from this evaluation stated they thought stigma was reducing as people become more educated about

the disease. Again this concurs with findings from women in central Uganda who depicted a more supportive environment surrounding HIV over the previous decade (Medley, et al., 2009). One of the reasons for the reduction in this region may be the introduction of a drama group set up by the clinic. The group aims to educate the community about HIV and how to live with it. A local Ugandan newspaper reported on recent puppet theatre productions around the country "using entertainment to fight HIV/AIDS is a strong weapon of communication" (Basudde, 2009). Drama groups set up in Zambia have succeeded in increasing the number of people openly talking about HIV/AIDS, reducing new infection rates among youth aged 15-25, educating thousands on stigma and HIV (Musonda, 2004). Initiatives such as these seem to be effective in reducing stigma, encouraging people to come for testing and helping people to live freely, no matter what their status.

Summary

This chapter has discussed the findings from the interviews in depth, focussing on key aspects from the data and drawing on relevant literature and my observations to analyse findings in order to demonstrate the positive and negative workings of the clinic.

Chapter 7 – Conclusion

Introduction

This chapter will draw conclusions from the findings of the evaluation and discuss recommendations for future practice. It will also consider the limitations of the evaluation and my own personal learning.

Conclusion from Evaluation

The data and discussion both suggest that the majority of young women are satisfied with the service and care they receive from the clinic.

Specifically, the testing process is reported to be of high quality with rapid testing and in-depth counselling before and after testing in accordance with WHO/UNAIDS guidelines (2007) being a particular strength. The clinic is in an ideal location to provide services to a maximum number of people who may not have time or money to travel far.

Young women seemed to manage their treatments well, with the support and encouragement of clinic staff and regular health talks. However, drug shortages frequently hinder treatments and cause many women to miss important doses when they cannot afford to buy their own medications. Staff were found to be supportive and encouraging with the occasional exception.

The women suffered from stigma but frequently found support within their families and the clinic staff. Home visits were crucial for many women although many more would benefit if this service grew. Drama groups seemed to be an effective method of educating the community and reducing the level of stigma.

Recommendations

The evaluation indicates that the clinic seems to be effective in providing a comprehensive service, with consistent support to young women. However, it suggested that some areas could be developed or improved upon:

- Drug shortages are a nationwide problem and dependent on donor money, therefore difficult to change.
- Staff attitudes were generally encouraging although staff could be congratulated on having supportive, positive attitudes and reprimanded more readily if otherwise.
- The suggestion of provision of food for children would be an excellent method to overcome malnutrition in children, but again comes down to the provision of funding.
- If the budget allows, employing more CLVs, would allow more home visits to vulnerable clients, in particular young single mothers. They could also set up support groups for young women and other client groups in order to provide isolated women an opportunity to meet other people in their situation and share advice and support.
- The drama group could be expanded in order to educate people about HIV across the region, thereby reducing stigma.
- A service user advisory group could be set up in order to receive regular feedback from clients.

These recommendations aim to improve care for all clients, not only young women. Unfortunately many rely on an increase, or even simply consistent, funding which is not easy in today's financial situation, especially in the clinic where donors are withdrawing. Bartlett and colleagues (2009) conclude "extreme poverty and insufficient resources remain a key issue in resource-limited regions" while WHO (2006) reports that sub-Saharan Africa has 24% of the global burden of disease but

only 3% of the world's health workers commanding less than 1% of world health expenditure.

The findings, conclusions and recommendations from this evaluation will be communicated to the clinic through means of a summary report and discussions with the clinic director when I return to the clinic in a few months. This will help to ensure that morale is upheld and staff are motivated and encouraged by knowing how critical their role is to many clients. One study from Zambia suggested high levels of nurse burnout and discouragement (Kruse, et al., 2009) and it is therefore imperative to report feedback to staff.

Limitations

The evaluation had several limitations:

- Due to time constraints, it was not possible to obtain respondent feedback to check that participants agreed with findings and interpretations.
- Interviews were conducted during a time when the clinic had run out of drugs. Drug shortages might not be such a significant topic for discussion if the evaluation were conducted at another time.
- For ethical reasons, women were given time to think about participating. Thus interviews were more often conducted towards the end of the day when women may have wanted to get back to their families, rather than staying to talk.
- The sampling method may mean that only women who were satisfied with the service took part; they may not be a true representation of all young women. Although 10 interviews were deemed adequate to provide a reasonable selection of the sample population, it was still a relatively small sample size. Further research including the use of questionnaires would be

able to reach a much larger sample size and would gain a more accurate insight into young women's views.

Summary

This service evaluation has explored the views of young HIV-positive women receiving care in a rural HIV Ugandan clinic. Findings have suggested that care given by the clinic is very good on the whole, especially the VCT process and the support and counselling provided by nurses, doctors and counsellors. The capacity of the clinic to respond to the recommendations will be limited by financial constraints, although staff attitudes can be improved upon on some occasions.

I have learnt a great deal from conducting this service evaluation, both in terms of nursing and caring for the HIV-positive patient and in broadening my understanding of living with HIV. I feel the staff in the clinic can be used as a role model to other healthcare staff and they have motivated me to provide my best care, no matter what the situation. The staff are paid minimal, if any, wages and still manage to maintain an optimistic view on life and HIV care. I hope to develop my nursing skills and knowledge surrounding HIV so that in the future I may provide optimum care for such patients in both resource-limited settings and developed environments.

As one lady concluded her interview "*but I am glad of this place*" (YW9).

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Appendix 1 – Map of Uganda



Map of Uganda (Maps of the World, 2006)

Appendix 2 – Treatment Form

Appendix 3 – Information Letter

**University of Nottingham, School of Nursing
B Floor (South Block Link)
Queen's Medical Centre
Nottingham
NG7 2HA**



**The University of
Nottingham**

An investigation into the experience of HIV care for young women in a rural Ugandan clinic

Name of Investigator:

Rebecca Dickens

Dr. Catrin Evans (academic supervisor)

Research Information Sheet

Invitation to the research

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet. Thank you for reading this.

Background

My name is Rebecca Dickens and I am a nursing student from Nottingham University in England. I am conducting a study to investigate young women's experiences of HIV testing and HIV care in rural Uganda. The study is being done as part of my degree programme. It will focus on your experiences of HIV testing, your experiences of living with HIV and your views of the HIV care that you have received.

What does the study involve?

If you agree to take part, the study will involve an interview with myself and a translator. The interview will last between 30-60 minutes. The interview will be tape-recorded in order to translate it into English. The interview will be done in a private room within the clinic. A translator who is bound by confidentiality regulations will be present. No-one else will know what you have said to us. All information that you provide will be kept completely confidential and anonymous. We hope that the findings of the study will be used to help improve HIV services for young women like you.

Why have you been chosen?

You have been asked to take part because you are a young woman living with HIV who attends this clinic. Your views and suggestions would be greatly appreciated.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Your participation in this study will not have any impact on the care that you receive.

What if something goes wrong?/Who can I complain to.

In case you have a complaint about this study, you can initially approach the lead investigator, my academic supervisor in the UK. If this achieves no satisfactory outcome, you should then contact the Ethics Committee Secretary, Mrs Louise Sabir, Division of Therapeutics and Molecular Medicine, D Floor, South Block, Queen's Medical Centre, Nottingham, NG7 2UH. E-mail louise.sabir@nottingham.ac.uk

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept on a password protected database and is strictly confidential.

What will happen to the results of the research study?

We hope the research will help develop HIV services particularly in terms of the care provided for young people and young women. Results of the research will be available in the University of Nottingham library sometime after February 2010. Young women's views and suggestions will also be shared with the clinic. However, it will not be possible to identify you personally in the report.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

Contact for Further Information

For further information, please contact Rebecca Dickens on +256773493842.

Thank you so much for taking the time to take part in this study.

Appendix 4 – Interview Schedule

Interview Schedule

Greetings and introduction to the study.

1. [To explore YUW’s experiences of HIV testing including reasons for seeking initial testing and how the testing process helped them to access follow up care and support].

- *Can you tell me how you found out that you had HIV?*
 - *Why did you seek out HIV testing? How did you decide where to go for testing? Did you take anyone with you?*
- *What was the HIV testing experience like?*
 - *What suggestions would you make for providing a good service to young women like yourself?*
- *Were you provided with information or follow-up care and support?*
 - *What sort of care and support were you given?*

2. [To explore YUW’s experiences of living with HIV].

- *What was it like for you to find out that you were HIV positive?*
- *What has your life been like since your diagnosis? How would you describe your experiences of living with HIV on a daily basis? Has your life changed? In what ways?*
- *Have you disclosed your status to family and friends, sexual partners or the community? Why/why not? What has their reaction been like?*
- *In what ways do you look after health? Do you have any health problems? How do you manage your ARV treatment?*
- *Do you have a boyfriend or any sexual relationships? Do you practise safe sex now that you know your diagnosis?*

3. [To explore YUW’s understanding and use of HIV care including their views of the different services offered, the nursing care provided and how these could be improved].

- *What are your views on the care and support that you have received so far? Who/what has been most helpful? Can you remember any incident where you felt particularly well looked after? Or any incident where you felt the care was not so good?*
- *Is the support offered to you adequate for your needs?*
- *How could the services and support offered to you be improved?*

Thanks and goodbye

Appendix 5 – Consent Letter from Clinic Director

Joint Clinical Research Centre

GULU REGIONAL CENTRE OF EXCELLENCE

For Quality Medical Research and Health Care



Plot 14/15 Peter Paul Opok Road-Gulu
P.O.Box 160, GULU- Uganda
Fax: 04714 32-407

Telephone contact:
Office: 04714-32407

1st July 2009

To Whom It May Concern,

RE: MISS REBECCA DICKENS

This is to confirm that the above-mentioned nursing student has been authorised to conduct research with JCRC Gulu Regional Centre of Excellence. She will be involved in interviewing clients at the JCRC HIV clinic, under my supervision.

Yours Sincerely,

**Dr. George Abongomera,
JCRC Regional Co-ordinator (Northern Uganda)**