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'Then her neighbour will not know her status': how health providers advocate antiretroviral therapy under universal test and treat

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Introduction: Universal test and treat (UTT)—antiretroviral therapy (ART) for all HIV-positive individuals regardless of CD4 count—is the WHO's recommended treatment guideline. UTT has implications for health providers' workload in areas of high HIV prevalence and for understandings of ART and HIV. This article explores health providers' experiences of implementing UTT in Hhohho Region, Eswatini.

Methods: Between March 2015 and October 2016, in-depth interviews were conducted with health providers implementing UTT. Interviews were transcribed verbatim and translated into English for qualitative content analysis.

Results: Twenty-five providers from eight facilities were interviewed. Respondents encouraged early ART by promoting its overall health benefits, and the possibility of avoiding disclosure and HIV-related stigma in the community. Some health providers downplayed UTT's preventive benefits to avoid discouraging condom use. Respondents suggested that initiating ART immediately after testing could improve linkage-to-care, but recognized that overly hasty initiation might affect adherence. Viral load testing was seen as a potentially useful tool to monitor clients' response to ART.

Conclusions: Health providers appropriated stigma to encourage early ART. This suggests an attentiveness to the social burden of HIV/AIDS, but potentially exacerbates discrimination and conflicts with efforts to reduce HIV-related stigma.

Keywords: ART, Health providers, HIV, Universal test and treat, Eswatini

Introduction

Universal test and treat (UTT)—antiretroviral therapy (ART) for all HIV-positive individuals regardless of CD4 count or disease stage—recently became a WHO guideline.¹ This policy has clear implications for health systems in areas of high HIV prevalence, which are often under-resourced; under UTT, the number of potential ART clients would increase by an estimated 18 million across sub-Saharan Africa.²

Responding to questions about the feasibility and effectiveness of UTT, several large-scale clinical trials and implementation studies are under way in sub-Saharan Africa,³ including one in Hhohho Region, Eswatini.⁴ UTT also has consequences for the

understandings of ART and HIV,⁵ particularly because clients initiate ART when asymptomatic. Alongside the ongoing clinical trials and implementation studies, scholars have therefore explored the social and behavioural consequences of extending the availability of ART under UTT, with a view to informing the design and roll-out of this policy.⁶

Health providers play a crucial role in implementing UTT, particularly in terms of communicating a policy change that entails visibly healthy individuals beginning a life-long course of treatment.⁷ Through their messages in clinical encounters, they mediate between clients' understandings of HIV and ART, and UTT's public health aims. This article explores the experiences of health providers who implemented UTT as part of an

implementation study in Swaziland. The article examines how health providers explained this policy and describes how—from the perspective of health providers—UTT influences the process of HIV testing, counselling and disclosure, and ART initiation.

Materials and methods

Setting

In light of its HIV prevalence—at 27.2% in 2016, the world's highest among 15- to 49-y-olds⁸—Swaziland was selected as the site for a large-scale UTT implementation study, 'Maximizing ART for better health and zero new HIV infections' (MaxART).

Between 2014 and 2017, in Hhohho Region, in northern Eswatini, MaxART used a randomized stepped-wedge design, with a control, transition and intervention phase, to implement UTT in an incremental fashion across 14 facilities. During the control phase, HIV clients were initiated on ART following the standard Swaziland care model (CD4 count of <350 cells/mm³/ <500 cells/mm³ (from 2015), or WHO disease stage 3 or 4).⁹ During transition and intervention, ART was offered regardless of CD4 count or disease stage. During the 4-mo transition period, study personnel mentored health providers to implement the new care protocol. Clients gave verbal informed consent to participate in MaxART.⁴

Data collection

The findings presented here are based on interviews with health facility providers at eight (of the 14) UTT facilities. Trained social scientists undertook interviews using a pretested guide between March 2015 and October 2016. An exhaustive diversity sampling approach was taken at the eight health facilities (seven rural clinics and one regional hospital). Depending on the facility size, either all available health providers involved in HIV testing and counselling and ART provision or at least one provider per cadre (expert clients, senior nurses, nurses) were interviewed. The interview guide included questions on their experience of the UTT study, in terms of its impact on HIV testing and counselling, ART initiation and ART. Respondents were asked about their knowledge of the study, how they explained it and its benefits to prospective participants. Interviews lasted between 25 min and 1 h. Interviews were conducted in siSwati, transcribed verbatim and translated into English for analysis.

Data analysis

Qualitative content analysis was conducted using NVivo 11 Pro (QSR International, Doncaster, VC, Australia). An inductive and deductive approach was taken to the development of a codebook—preliminary codes were based on initial research questions, then, during reading and coding, substantive topics that emerged were subsequently added. The first author (CP) conducted line-by-line coding, consulting throughout with EV and RR. The resultant codes were used to formulate the themes described in the results, which were also discussed with the Amsterdam- and Swaziland-based social scientists.

Results

A total of 25 health providers were interviewed. The respondents included four senior nurses, 10 nurses, seven expert clients, one volunteer and three providers whose position was not recorded. Between one and five respondents were recruited from each of the eight facilities. Most of the respondents (20) were female.

The following section outlines the key themes that emerged during the analysis of the interview transcripts with regard to how health providers presented UTT to clients and the process of ART initiation. Another prominent element of the interviews was how health providers also described the implications of UTT for ART initiation and adherence.

Messages about the benefits of early ART

Health providers' messages about the benefits of MaxART varied, with no discernible pattern across facilities or cadres. Explanations often focused on clients' overall health, particularly ART, helping them to avoid becoming 'bed ridden'.

The benefit [of starting treatment early] is that you live long. Also you're not vulnerable to diseases when you are on ART. Plus, the virus doesn't multiply in the body when you've started ART early. Instead, it decreases so you don't reach a stage where you are sick. [Interview with a female senior nurse, facility #1.]

Respondents outlined how these health benefits had social and economic consequences. Clients could continue paid employment, maintain caring activities and reduce the risk of a costly hospital admission. Avoiding visibly apparent illness was explained to be particularly advantageous: clients could evade disclosing their HIV status to friends and neighbours. Early ART was thus a way of preventing 'gossip' caused by visible symptoms, such as weight loss. Health providers therefore adapted messages about UTT enrolment to attitudes to disclosure to the wider community.

I explain that [initiating ART early] will be helpful to her when ... what can I say ... if she does not intend her neighbour to know that she is HIV positive. If she starts taking care of herself early, then her neighbour will not know her status. [Female expert client, facility #2.]

Interviewer: What is it that makes people wish to start on the pills ... those that maybe are at [disease stage] stage 1 or 2?

Respondent: It's still that they fear getting sick ... people fear being noticed ... [Female nurse, facility #3.]

Health providers carefully explained the benefits of ART in terms of HIV prevention, seeking to avoid reductions in condom usage. They made reference to the possibility of reinfection and used the concept of viral load (VL) to emphasize that the virus would still be present and there would still be some risk of transmission. Good ART adherence was also mentioned as a prerequisite for any protective effect. Some respondents described how the

preventive benefit of early initiation was an important point to communicate and was a potentially motivating factor for clients to adhere to ART.

Interviewer: How do you explain [that starting treatment early reduces the chance of infecting a client's partner]?

Respondent: I tell them that when you have started treatment, treatment reduces the viral load in the body. If the viral load in the blood has been reduced, the chances that you can transmit [HIV] to your partner are reduced. It is not to say that you will not infect them, because they then misinterpret [the message]. It is not that you will not infect them; you can infect them, but the chances of doing so are reduced. [Female general nurse, facility #3.]

Initiating ART (on the day of diagnosis)

Disclosure to one's partner(s) and/or close friends or relatives—difficult to avoid when initiating ART—also impacted upon enrolment. Respondents suggested that, particularly for female clients, decisions about ART initiation were sometimes influenced by their male partner(s).

Disclosure to one's partners was, however, also seen as an indication of having accepted one's status and being prepared for ART.

If a woman comes to the facility and tests positive, and agrees to start treatment, when she returns to her partner, the man throws the pills away. We try to talk to them: what do they think would help them? ... They say they want to start treatment and they can hide it from their partners; they are ready to start [ART] and they do not want to [die]. [Male expert client, facility #3.]

Sometimes the reasons for non-initiation were unknown to health providers—potential clients simply stated that they wished to discuss it at home or think it over.

As part of MaxART, clients were able to initiate ART the day of HIV diagnosis. Respondents recognized that initiating ART was a difficult decision with critical implications for clients' future health. For a person who was not emotionally prepared, hasty ART initiation could have implications for adherence. However, a client who did not initiate and returned home—often with the stated intention of discussing with her or his partner—might not return. Although opinions varied about how to identify whether a client was prepared to initiate ART, health providers usually described that the client had the final word on initiation.

... It seems difficult that you test today [and] then you start on the treatment ... Let's say you did not know your HIV status and you must leave the clinic with the ART pills ... you still have to go and disclose ... at times that seems like a huge burden ... If that person did agree to take the pills and when he welcomes his status it's fine [Female expert client, facility #1.]

Health providers also suspected that some clients were already aware of their status, having previously tested positive, yet not

been retained in care. Delaying initiation had given them time to come to terms with their diagnosis. Others, respondents suggested, were prompted to initiate on the same day by their partner's HIV status.

OK, a lot of people most of the time, those are willing [to initiate] quickly are people that have tested before somewhere but ran away and then come back because maybe they fear something or they have counselled themselves and accepted [their status]. [Female general nurse, facility #4.]

Viral load testing

During the control and intervention phase of the implementation study, the addition of VL testing was a notable difference between the UTT and standard care package. Tests occurred on enrolment, at initiation and after 6 mo.

Health providers described VL testing in terms of monitoring the quantity of virus in the body, and explained this as a benefit of enrolment, particularly during the control phase. They saw VL testing as a more accurate method of checking the effectiveness of ART than testing the CD4 count, which they viewed as more dependent on the individual's constitution or immune system. According to respondents, clients saw VL testing as a benefit of enrolment and, for some, it had become a way of monitoring the progress of their illness. Respondents also made references to VL testing as a tool to monitor adherence, but identified no specific cases when this had happened.

I usually explain to them that [VL testing] will help us see if this regimen is good for you or this regimen is not good for you. [Female general nurse, facility #4.]

So [the CD4 count is] not a true reflection of what is happening in your system, but the viral load gives us a true clear picture of what we are doing and how we are doing. And also the viral load shows us clearly your adherence: if you are taking the pills honestly or not. [Female general nurse, facility #5.]

The blood that was sampled from UTT clients also underwent HIV-resistance testing during enrolment. When asked about their explanations regarding this test, health providers often reported not remember talking to clients about it.

Adhering to ART when healthy

Initiating ART with a high CD4 count, when in good health, could have implications for adherence—clients might not see the benefits of sustained ART adherence if they have not yet experienced any deleterious HIV-related health effects. Health providers recognized this possibility, but were generally confident that initiating ART as part of MaxART—instead of at a more advanced disease stage—would not reduce adherence. The respondents rather viewed clients' disclosure to their partner, as relevant to whether they were likely to adhere to ART.

What I see as bad [about initiating ART on the same day as testing] is that the person may not have accepted her status, because you may find that she is overwhelmed ... Then she will not take [the ART] even at home. [*Female senior nurse, facility #2.*]

Interviewer: Has [UTT] made [clients] honest when drinking the pills?

Respondent: Yes ... it has changed it very much because we tell them that after six months the blood results will tell us whether they are taking the pills honestly ... [*Male volunteer, facility #1.*]

Respondents identified two additional factors that encouraged ART adherence, particularly as part of *MaxART*. First, they explained that the VL testing could be used to identify non-adherence and suggested that this would discourage non-adherence. Secondly, the fear of becoming sick (and physical indications of ill health leading to inadvertent disclosure and stigma) prompted adherence.

Practicalities of UTT in health facilities

The practicalities of UTT had implications for the duration of health providers' interactions with clients or potential clients. This was caused by the extra time investment needed upfront with patients to explain the rationale for early ART and VL tests. These changes also led to additional questions to which health providers had to respond. Respondents also mentioned an increased bureaucratic burden of 'paperwork and stickers', placing additional demands on their time. Increased time spent on initiation had implications for the time spent on other tasks, such as ART refills for returning clients (which often involved questions, as well as collecting and checking medication).

You discover that we have booked many people to come for refill and the time for that person who is refilling is short [ART] and she will only do her refill without being asked if there are problems with the pills ... [*Female expert client, facility #2.*]

There were reports that the study design, using an initial control and transition period in which study staff members were present to assist with enrolments, was helpful in terms of managing the extra burden of work. For some respondents, the initial introduction of UTT was particularly challenging but, with time, they became accustomed to the new protocols.

Discussion

For health providers, explaining the changes to the HIV care package and its benefits was the most notable additional task of UTT as part of *MaxART* in Hhohho Region. The following section reviews the most prominent influences on these messages:

- local attitudes to HIV disclosure and visible signs of illness;
- providers' concerns about reducing condom usage.

How health providers viewed HIV care and ART adherence under UTT will also be discussed.

Appropriating stigma to encourage ART initiation

Since the 1980s, HIV/AIDS-related stigma has been recognized as a barrier to reducing incidence and providing appropriate care.¹⁰ Research on HIV prevention and care has often highlighted stigma's pernicious impact,^{11–13} with a 2013 systematic review identifying stigma as a barrier to HIV testing and ART adherence in low- and high-income countries.¹⁴ Efforts to address HIV-related stigma have therefore often been incorporated into intervention packages.¹⁵ In Swaziland, HIV-related stigma—largely experienced as disapproval from the wider community—is ubiquitous and pronounced for women.^{16,17} This was reflected in the responses of health providers—clients were reportedly reluctant to disclose their status to the wider community and feared inadvertent disclosure.

When describing the benefits of enrolling in *MaxART* and initiating ART early, health providers appropriated HIV-related stigma to encourage participation; they appealed to clients' unwillingness to disclose their HIV status to the wider community and their desire to hide the visible signs of illness.

Such an approach may exacerbate HIV-related stigma; health providers are often respected and yield authority that extends beyond the health facility.¹⁸ This approach has potential implications for the wider efforts to reduce HIV-related stigma in Eswatini and sub-Saharan Africa,^{19,20} but health providers did not reflect on the contradiction between seeking to reduce HIV-related stigma to encourage testing and making use of it to encourage ART initiation. Nor did they consider the possibility that they might be compounding HIV-related stigma.

Adapting their messages about UTT in this way, health providers drew on their familiarity with the local social implications of HIV. This highlights how health providers are intertwined with the context in which they work (and how their biomedical personae cannot be extricated from their social personae). Ultimately, by promoting ART initiation in a way that ignored the common 'confessional imperative'²¹ of HIV intervention programmes, health providers were attentive to clients' social well-being. Indeed, social scientists have—through detailed ethnographic analysis—highlighted how secrecy and limited disclosure can help people living with HIV navigate the social realities they face.²¹

Downplaying the preventive benefits of early ART initiation

When first proposed as an approach to HIV care, reducing population incidence was envisaged as an important benefit of early ART.³ The *MaxART* study was conceived with this aim in mind. However, during the process of design and implementation, particularly because of concerns about the possible impact of messages around ART's preventive value on condom usage, prevention became ancillary to the goal of increasing 'access' to ART.²² This ambiguity towards the preventive benefits of early ART (at a study and international policy level) was reflected in health providers' explanations during enrolment.

Recent research in Eswatini highlights how the determinants of condom usage while on ART are complex, embedded in the local context and informed by concerns about resistance.²² It is perhaps, therefore, overly simplistic to assume that communicating the preventive value of ART will reduce condom usage. Nonetheless, given the complex circumstances that surround one's infectiousness when on ART—and how this is poorly understood in low- and high-income contexts^{23,24}—empirical research must directly address its impact.

HIV care and ART adherence under UTT

In Eswatini, stigma and discrimination compounds the logistical demands—the number and frequency of appointments—of ART initiation.²⁵ Offering ART on the day of diagnosis—as the health providers recognized—has the potential to link more clients into HIV care. This is particularly relevant to the UNAIDS target to achieve 90% ART coverage amongst HIV-positive individuals.²⁶ However, for providers, the difficult nature of this decision meant that hasty initiation could have implications for ART adherence.

Initiating ART without HIV-related symptoms could reduce ART adherence.⁷ In the absence of symptoms, clients might not be motivated to adhere to the treatment. As recently reported in southern Eswatini,²⁷ for the interviewed health providers, whether a client had *accepted* her/his diagnosis—inferred from partner disclosure or his/her reaction to the diagnosis—was more important than disease stage on initiation. Interviews with clients who had delayed ART initiation under *MaxART* also indicated that expedited ART initiation does not necessarily accommodate some clients' need for time to come to terms with the diagnosis and the prospect of lifelong treatment.²⁸

In terms of the UTT care package, for clients, VL testing was a notable addition. Little research has addressed how the availability and utilization of VL testing influences client-provider interactions for those on ART. Some health providers described how VL testing enabled the monitoring of clients' health and their response to ART. Such an approach illustrates the potential value of VL testing to improve HIV care. Clients' understanding of VL testing also requires analysis.

Conclusions

In Hhohho Region, Swaziland, when implementing UTT, health providers appropriated stigma to encourage early ART. Their acquiescence with discrimination is at odds with wider efforts to reduce HIV-related stigma. However, it suggests an attentiveness to the social realities of people living with HIV/AIDS. Any impact of such messages on stigma and HIV testing requires attention. Explaining the preventive benefits of early ART provoked reflection among health providers and such concerns highlight the need to evaluate the influence of such messages (and early ART) on condom usage. Viral load testing was well received by health providers, but further research is needed on clients' understanding of this technology.

Authors' contributions: RR, EV and EM conceived the study; RR and EV designed the study protocol; ND conducted the interviews under the

supervision of EV; CP conducted data analysis in consultation with RR and EV; CP drafted the manuscript; RR, EM and EV critically revised the manuscript for intellectual content. All authors read and approved the final manuscript. CP is guarantor of the paper.

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