

PEOPLE LIVING WITH HIV: SOURCES OF INFORMATION ON ANTIRETROVIRAL TREATMENT AND PREFERENCES FOR INVOLVEMENT IN TREATMENT DECISION-MAKING

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Abstract

Objectives: This study reports on the sources of anti-retroviral treatment information that are important to people living with HIV (PLWH) in treatment decision-making and their preferred role in treatment decision-making.

Design: Cross-sectional qualitative and quantitative study.

Method: PLWH in Florida (n = 79) with a CD4-nadir below 350 cells/ μ l were interviewed about the sources of information they used in decision-making about antiretrovirals and their knowledge of resistance. Their desired involvement in the treatment decision was assessed using the Control Preferences Scale.

Results: The ten most frequently cited sources of information included the primary HIV-physician, magazines written for PLWH, drug advertisements, Internet, HIV-positive friends, seminars/conferences/symposia, expert literature, other physicians, peer educators, and naturopaths/nutritionists. The HIV-physician was the most important source of information, followed by publications. PLWH declining antiretrovirals placed significantly less importance on information from their HIV-physician than those accepting antiretrovirals. Poor and less well-educated participants (in particular African-American women) had less knowledge of resistance. Most, but not all PLWH preferred to be actively involved in decision-making. The greater the desire for involvement, the more sources of information were used in decision-making. Knowledge of resistance was not significantly associated with the preference for involvement in decision-making.

Conclusions: Physicians and publications, particularly those targeting PLWH, play a key role in informed decision-making. Physicians need to ensure that PLWH are informed and understand resistance as a consequence of non-adherence. Patients' needs for information are different from their desires to participate in decision-making. Regardless of their treatment knowledge, most PLWH want to be involved in the decision-making process.

Key words: HIV/AIDS, antiretroviral therapy, sources of information, decision-making, patient knowledge, patient involvement

INTRODUCTION

Over the last few decades, there has been a call for health care to enhance informed shared decision-making, shifting the patient-physician relationship from a paternalistic model to a model that creates a partnership between patient and physician. Towle and Godolphine defined informed shared decision making as "decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient specific characteristics and values." [1] A successful partnership involves working together to achieve common goals, sharing decision-making and responsibility. The key to successful physician-patient partnerships is for physicians to recognize that patients are also experts [2]. Patients are more satisfied with physicians who are in favor of shared decision-making, even when the patient is less positive to shared decision-making [3]. In addition, some studies indicate that informed shared decision-making is associated with better health outcomes in chronic diseases [4-6].

Interviews with people living with HIV (PLWH) [7] also suggest that patient involvement in treatment decisions is related to better health outcomes, including quality of life. Informed decision-making is important for PLWH since it is related to adherence to antiretroviral treatment (ART) [8], which is one of the key factors of treatment success [9]. Insufficient adherence leads to resistance mutation jeopardizing future treatment options [10, 11]. A patient's adequate knowledge about the consequences of non-adherence is a vital factor in treatment success [12]. It is important to recognize that taking medication correctly can ultimately be achieved by patients themselves, and that making the commitment to adhere to a treatment is most likely when patients are informed, active participants in the treatment decision [13]. Informed shared decision-making programs [14] are not simply about educating or instructing patients about their condition and then measuring success on the basis of patients' adherence. These programs have been designed to empower patients to take effective control over life with a chronic illness [14]. The concept of informed shared decision-making combines two distinct dimensions: informed decision-making and shared decision-making [1].

Few studies assess how PLWH gather information for decision-making about ART. Little is known about the desire of PLWH to participate in medical decision-making or the role that they would like physicians to play [9, 15]. For this reason this study assesses three questions:

1. What sources of antiretroviral treatment information are important to PLWH in decision-making about treatment?
2. Do PLWH know how drug resistance develops?
3. Which role do PLWH prefer in decision-making about treatment and how does this relate to their preferences for information and their needs for information?

METHOD

STUDY POPULATION AND SAMPLING

The study was conducted as a substudy. The longitudinal parent study on Psychology of Health and Long Survival with HIV/AIDS [16] started in March 1997 and recruited a diverse paid volunteer sample ($N = 177$) from AIDS-organizations, doctors' offices and community-events. Between February and September 2003, this substudy investigated 79 PLWH, in which antiretroviral treatment (ART) was recommended according to the US treatment guidelines [17]: (1) PLWH with symptoms ascribed to HIV-infection, (2) asymptomatic PLWH with CD4-cells $< 350/\text{mm}^3$ or plasma HIV RNA levels $> 55,000$ copies/ml (by RT-PCR or bDNA). All participants of the parent study in which ART was not yet indicated according to the US guidelines [17] were excluded from the substudy. Physicians had offered ART to all participants of this substudy. The sample was representative of PLWH in Florida with respect to gender and ethnic groups (Table 1).

PROCEDURES

The local Institutional Review Board approved this study, and all participants gave written informed consent. For the visit at the study center participants were reimbursed \$50. Participants completed their medical and demographic information (Table 1) with the researcher. Blood was drawn to assess CD4 cell counts using CD4-Flow cytometry (Coulter XL-MCL) and HIV-1 viral load using RT/PCR (Roche Amplicor HIV-1 MONITOR[®] Test, measuring viral loads at levels as low as 400 HIV-1 RNA copies/ml). The participants then underwent the interview on sources of information and their knowledge of resistance and were given the Control Preferences Scale (CPS; [18]).

SOURCES OF INFORMATION AND KNOWLEDGE OF RESISTANCE

The participants were asked to list what sources of information they used in the decision-making process. Based on each individual's responses, the interviewer divided these into four categories: HIV-physician, publications, other PLWH, and other people not living with HIV. For each of the four categories of the

sources of information listed, the participants rated the importance in decision-making about ART on a 5 point Likert-type scale ranging from 1 = very little to 5 = very much. If the participant did not list any sources of information for a given category, this category was rated as zero (= not at all important in the decision).

Subsequently, participants were probed regarding whether they had ever heard of drug resistance. If so, they were asked to explain what drug resistance is and what may cause it (e.g., "What is drug resistance? Where does it come from?"). Three raters rated consensually [19] whether the participants had knowledge of resistance or not, based on transcripts of the responses. Having knowledge of resistance was defined as being informed that HIV has the potential to mutate so that it is no longer sensitive to certain antiretroviral medications. Those who were able to define drug resistance, were further classified according to the strength of their belief that non-adherence is linked to drug-resistance.

CONTROL PREFERENCES SCALE

Degner et al. [18] developed the Control Preferences Scale (CPS) as a useful tool to assess the role that patients want to play and perceive to play in treatment decision-making. The CPS measures a construct that emerged from grounded theory about how treatment decisions are made among people with life-threatening diseases [20]. The control preference construct is defined as "the degree of control an individual wants to assume when decisions are being made about medical treatment" [18]. CPS consists of five cards (A-E), each of which has a picture portraying a different model of medical decision-making. The cards range from an active/semi active role (cards A/B: patient deciding without/with considering physicians opinion) through a collaborative role (card C: shared responsibility in decision-making) to a semi passive/passive role (cards D/E: physician deciding with/without considering patients opinion). The cards were placed in a fixed order, ranging from most to least control. Then the participants were asked to select the one that best represented their preferred role in the decision they have actually made about ART over the past year. To ensure the validity, they were asked to explain their selections and to discuss any difficulties they had in choosing a card [21]. Administered in this way, the CPS has been tested in a variety of populations of several hundreds of people with different disease background, and has proven to be a clinically relevant, reliable and valid instrument to measure decisional control preferences [18, 22-24].

STATISTICAL ANALYSIS

For the sources of information used: the importance of the sources, knowledge of resistance, and the preferred level of decisional control, basic descriptive statistics were calculated and their association with demographic and medical characteristics was examined. Furthermore, the association between knowledge of resistance and the preferred role in decision-making

was determined. Chi-square tests and Fischer's exact tests (indicated as *pf*) were calculated for associations between dichotomous variables. Mann Whitney U tests were used between dichotomous and ordinal variables. For variables on an interval scale, mean differences between two groups were tested using Student's *t* tests. For associations between continuous variables, Pearson's correlations were calculated. SPSS version 12 statistical software (SPSS Inc., Chicago, Illinois, USA) was used for statistical evaluation.

RESULTS

DEMOGRAPHIC AND MEDICAL CHARACTERISTICS

Table 1 summarizes the demographic and medical characteristics of all 79 participants of this study. The sample was diverse with respect to gender, sexual orientation, ethnicity, and socioeconomic status (education, employment, and income).

Overall 58 (73%) of the participants were taking ART [55 (69%) highly active ART, 3 (4%) combination therapy] and 21 (27%) were not taking ART. Only

Table 1. Demographic and medical characteristics (N = 79).

Characteristics	n	(%)
Gender (% female)	28	(35%)
Sexual orientation (% heterosexual)	42	(53%)
Ethnicity (%)		
African American	33	(42%)
Latino	22	(28%)
White	19	(24%)
Other	5	(6%)
Income level (%)		
less than \$ 10,000/year	43	(54%)
\$10,001-\$30,000/year	23	(29%)
more than \$30,000/year	13	(17%)
Education level (%)		
High School or less	29	(37%)
Trade School/some College	27	(34%)
College Graduate/+	23	(29%)
Employment status (% employed)	29	(37%)
Partnership (% having a partner)	24	(30%)
Insurance coverage (% insurance/program)	73	(92%)
Antiretroviral treatment (% taking)	58	(73%)
Use of complementary/alternative medicine	40	(51%)
Symptoms of AIDS (% CDC Category C)	11	(14%)
	M	(SD)
Viral load copies/ml	37,858	(83,125)
CD4 cells/ μ l at interview	347.00	(227.65)
CD4 cell/ μ l nadir	149.95	(93.99)
Years since HIV diagnosis	11.14	(4.15)
Age	42.03	(7.88)

five of the participants not taking ART were still treatment-naïve, the others had decided to discontinue an existing treatment. The participants were diagnosed with HIV on average 11 years ago (ranging from 3 to 20 years), and the majority (74%) had CD4 cells below 200/ mm^3 at some point in time, but only a few (14%) had a physician-verified AIDS defining symptom in the past. According to patients' reports, 20% experienced HIV-related symptoms over the past 6 months. At the interview, CD4 ranged between 8-921 cells/ mm^3 , and the maximal viral load detected was 611,682 copies/ml.

SOURCES OF INFORMATION USED IN THE DECISION ABOUT ART

The most frequent and important source of information for the decision about ART was the HIV-physician. The ten most frequently cited sources of information (Fig. 1) (multiple responses allowed) were the primary HIV-physician, magazines written for PLWH (e.g., POZ magazine), drug advertising, the Internet, HIV-positive friends, seminars/conferences/symposia, expert literature (e.g., CDC newsletter, medical journals), other medical experts (e.g., seeking another physician's opinion), peer educators, and naturopaths/nutritionists. Less frequently used sources of information were other HIV-patients (18%), HIV-negative friends (14%), HIV-positive partners (13%), HIV-negative family members (8%), case managers (1%), and spiritual literature (1%).

Sources of information and demographic characteristics

Participants with a higher education were more likely to read magazines written for PLWH ($U = 452.00$, $Z = 2.157$, $p = .031$). Participants relying on drug advertising as a source of information were significantly less likely to make use of complementary/alternative medicine ($\chi^2(1) = 4.60$, $p_f = .043$). Internet use was significantly positively associated with higher education ($U = 424.00$, $Z = 3.581$, $p < .001$), higher income ($U = 454.00$, $Z = 3.228$, $p = .001$), use of complementary/alternative medicine ($\chi^2(1) = 6.80$, $p_f = .013$), and use of multivitamins ($\chi^2(1) = 5.97$, $p_f = .013$). Internet use was less common in African Americans, compared to participants of Latino, Causasian, or other ethnic origin ($\chi^2(1) = 7.65$, $p_f = .007$). Exchanging information with HIV-positive friends was significantly less common in African American ($\chi^2(1) = 6.66$, $p_f = .012$), heterosexual PLWH ($\chi^2(1) = 6.48$, $p_f = .013$), and women ($\chi^2(1) = 22.73$, $p_f < .001$), as compared with gay men of white, Latino, or other ethnic origin. Only 24% (5/21) of women and 33% (4/12) of men of African American origin used information of HIV-positive friends, compared to 43% (3/7) of women and 59% (23/39) of men of white, Latino or other origin.

PLWH attending seminars, conferences or symposia were significantly more likely to take multivitamins ($\chi^2(1) = 10.36$, $p_f = .002$), and to have a higher education ($U = 593.50$, $Z = 1.813$, $p = .070$). Participants reading expert literature were significantly more likely to use complementary/alternative medicine ($\chi^2(1) = 3.93$, $p_f = .039$). Those consulting peer educators were less likely to be African American ($\chi^2(1) =$

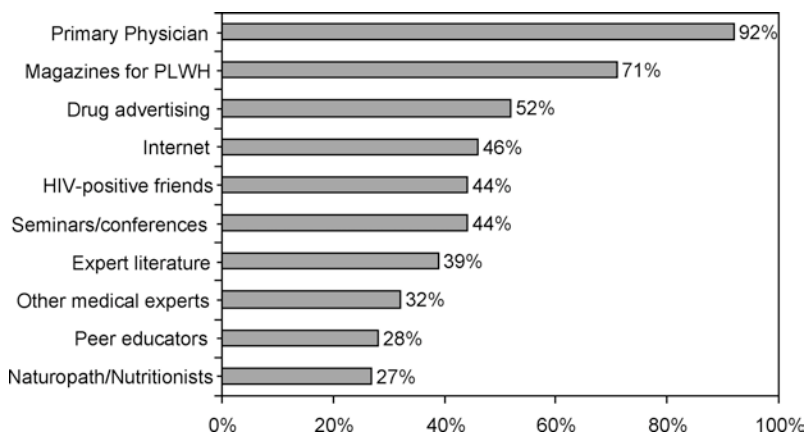


Fig. 1. Top ten sources of information in decision-making about ART (multiple responses allowed).

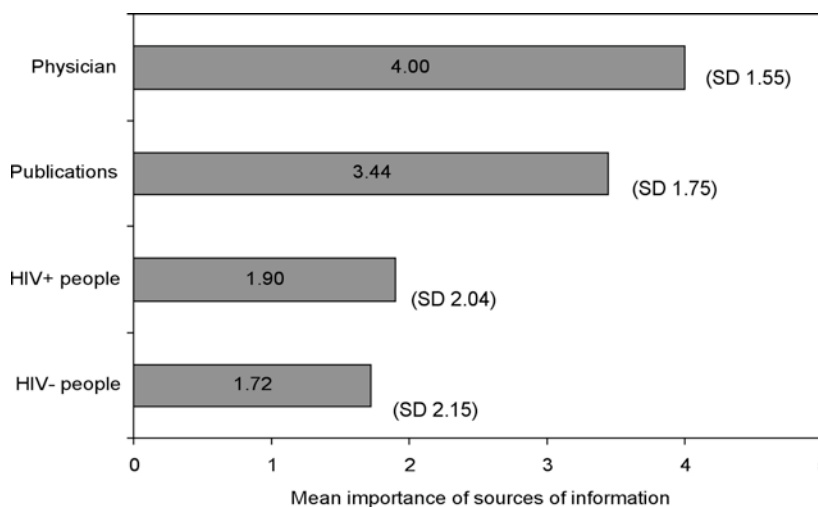


Fig. 2. The importance of the four categories of sources of information. Means (SD) on a scale from 0 = not at all to 5 = very important.

4.55, $p_f = .043$). Seeking information from the primary HIV-physician, other medical experts, or naturopaths/nutritionists was not significantly associated with demographic characteristics.

Sources of information and medical characteristics

Participants citing their HIV-physician as a source of information in decision-making about ART were more likely to take ART than participants not citing their HIV-physician as a source of information ($\chi^2(1) = 17.93$, $p_f < .001$). All participants taking ART considered information from their HIV-physician, compared to 80% of the participants not taking ART. The mean time since HIV diagnosis was longer in participants using information both other HIV-patients ($t(77) = 3.49$, $p = .001$) and drug advertising ($t(77) = 2.06$, $p = .042$) than in participants not reporting those sources of information. Seeking information from the Internet, seminars/conferences/symposia, expert literature, other medical experts and naturopaths/nutritionists was not significantly associated with medical characteristics.

THE IMPORTANCE OF THE INFORMATION SOURCES USED IN THE DECISION ABOUT ART

As Figure 2 indicates, the HIV-physician and publications were rated as the most important sources of in-

formation, whereas the information of other people living or not living with HIV was less important in decision-making about ART. Participants taking ART rated the information from the HIV-physician as more important ($M = 4.55$, $SD = 0.73$) than participants not taking ART ($M = 2.48$, $SD = 2.14$; $t(77) = 6.49$, $p < .001$). The greater the importance the participants placed on information from the HIV-physician, the lower viral load log ($r = -.26$, $p = .023$). Furthermore, participants using complementary/alternative medicine considered publications as more important than those who did not ($t(77) = 2.41$, $p = .018$).

The importance of information from other PLWH was significantly different between African Americans and other ethnic groups ($t(77) = -2.87$, $p = .005$), women and men ($t(77) = -2.23$, $p = .028$), and people with different sexual orientations ($t(77) = -2.13$, $p = .036$). Women ($M = 1.10$, $SD = 1.95$) and men ($M = 1.33$, $SD = 1.67$) of African American origin rated the information from other PLWH as less important compared to women ($M = 1.71$, $SD = 1.98$) and men ($M = 2.59$, $SD = 2.04$) of white, Latino or other ethnic origin.

KNOWLEDGE OF DRUG RESISTANCE

Overall, 71% of the participants had knowledge of drug resistance (e.g., "Drug resistance is when your

medication stops working because the virus mutates"). This included 51% who firmly believed that non-adherence to ART leads to drug resistance (e.g., "Being non-adherent is like playing with fire."), with 15% considering non-adherence as one of several possible cause of drug resistance (e.g. "Resistance is partly from not adhering to the regimen enough. I think it's more just the virus itself that mutates."), and 5% believing that non-adherence may lead to drug resistance in other PLWH but not in themselves, or thinking that development of drug resistance develops over time independent of adherence. In contrast, 29% explained that they had never heard of drug resistance and did not know what it was (e.g., "Resistance? What is that? Can I take it?"). Having knowledge of resistance was significantly associated with education ($U = 593.50$, $Z = 3.33$, $p = .001$), income ($U = 373.00$, $Z = 3.00$, $p = .003$), ethnicity ($\chi^2(1) = 10.30$, $p_f = .002$), and gender ($\chi^2(1) = 9.17$, $p_f = .004$).

Only 43% (9/21) of women and 67% (8/12) of men of African American origin (who usually had a lower education and income) had knowledge of resistance, compared to 71% (5/7) of women and 87% (34/39) of men of white, Latino or other origin. Knowledge of resistance was not significantly associated with other demographic or medical variables.

In addition, knowledge of resistance was higher in participants using the Internet ($\chi^2(1) = 13.81$, $p_f < .001$), seminars, conferences or symposia ($\chi^2(1) = 9.52$, $p_f = .003$), expert literature ($\chi^2(1) = 9.34$, $p_f = .002$), HIV-patients ($\chi^2(1) = 6.99$, $p_f = .008$), peer educators ($\chi^2(1) = 5.92$, $p_f = .015$), positive magazines ($\chi^2(1) = 5.51$, $p_f = .029$), and other medical experts ($\chi^2(1) = 5.19$, $p_f = .033$) as sources of information. No significant association was found between knowledge of resistance and using friends/partners/family members living or not living with HIV, naturopaths/nutritionists, and drug advertising as sources of information. There was also no significant association between using the HIV-physician as a source of information and having knowledge of resistance ($\chi^2(1) = 1.37$, $p_f = .350$). However, this interpretation is limited, because 92% of the participants used the HIV-

physician as a source of information; therefore, there was no variability.

PREFERENCES FOR INVOLVEMENT IN DECISION MAKING ABOUT ART

The majority of PLWH preferred shared responsibility in decision making about ART, which was followed by wanting to make the decision on their own. Whereas only a few indicated the HIV-physician making the decision about ART for them as an ideal (Fig. 3). Role preferences were not significantly associated with demographic and medical characteristics. Participants using expert literature ($t(77) = 2.65$, $p = .010$), seminars, conferences, or symposia groups ($t(77) = 2.64$, $p = .010$), naturopaths or nutritionists groups ($t(77) = 2.33$, $p = .001$), the Internet groups ($t(77) = 2.27$, $p = .026$) and positive magazine groups ($t(77) = 2.09$, $p = .040$) wanted to be more involved in decision-making about ART, than those who did not use these sources of information.

In contrast, decisional role preferences were not significantly associated with other sources of information, such as the HIV-physician, other medical experts, drug advertising, peer educators, or other PLWH. Further, decisional role preferences were not significantly associated with the importance of the sources of information and knowledge of resistance.

DISCUSSION

The main contributions of this study are (1) the identification of the key roles of publications in addition to physicians in providing information relevant for treatment decision-making about HIV, (2) the lack of knowledge of PLWH about resistance and the connection between resistance and non-adherence, (3) what can be done to enhance patient's knowledge depending on the individual's socio-cultural background, and (4) how involved PLWH want to be in decision-making about their treatment, and (5) the dilemma of PLWH with a lack of treatment knowledge and the desire to be involved in the decision.

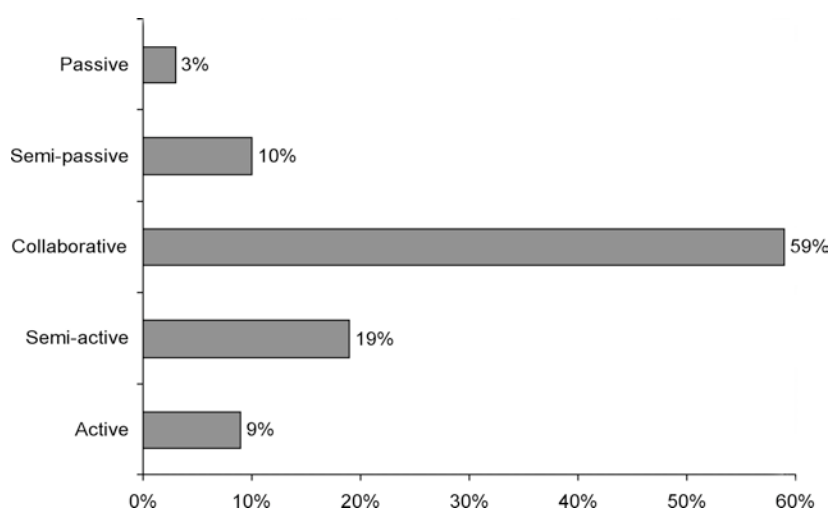


Fig. 3. Decisional role preferences as indicated on the Control Preferences Scale.

PHYSICIANS AND PUBLICATIONS, THE KEYS TO INFORMED PATIENTS

The HIV-physician is the most important and most frequently used source of information in PLWH. This study, as well as other studies [25, 26], indicated that PLWH who decided to take ART rely heavily on their physicians' advice, in particular if they have a low literacy level [27]. However, PLWH often do not have a good understanding of information relevant to decision making, such as the consequences of non-adherence, as this and other studies indicate [12, 26, 27].

A new important finding of this study is that PLWH who decide not to take ART consider the information from their HIV-physician as significantly less important than participants that decide to take ART. This suggests that HIV-physicians should non-judgmentally ask their patients if they are not taking ART and to then find out why they made this decision [28]. Furthermore, caution should be taken by physicians to meet the information needs of PLWH who forgo a recommended treatment and to ensure that those patients are adequately informed about the consequences of their decision. The goal of evidence based medicine is for physicians to discuss the risks and benefits of all available options (including no treatment) with a patient, as well as to recognize patients' treatment goals and risk tolerance.

Another notable finding of this study is that PLWH place almost as much importance on positive magazines (particularly the POZ magazine) as they place on information from their HIV-physician. This validates the utility of these magazines. PLWH may differ from people living with other chronic diseases, because women with breast cancer preferred personal sources of information (physician, nurse, friend, or relative) over written sources, although publications were more relevant to women with higher levels of education [29].

GATEWAYS TO KNOWLEDGE ABOUT RESISTANCE AND THE CONSEQUENCES OF NON-ADHERENCE

While other studies examined the use of particular sources to improve patient knowledge, our study additionally examined which sources PLWH place importance on, and how the use of these sources is related to their knowledge gained. Knowledge of resistance was significantly positively associated with using the Internet, attending seminars, conferences or symposia, consulting other HIV-patients and peer educators, reading of positive magazines and consulting additional medical experts for information. Other studies confirmed that using the Internet [30, 31], attending patient seminars [32] and interacting with peer-educators may provide PLWH with information and offer a forum to express their fears and reluctance regarding ART [33].

In this study, it appeared that unmet information needs were most common in African Americans, in particular in women. They were least aware of resistance as a consequence of non-adherence and placed the least importance on information from peer educators and other HIV patients. As adequate patient

knowledge about resistance is key to treatment success [12], physicians and educators should place more emphasis on providing better treatment information to these patient groups. This may be achieved by using a simple and non-technical language, taking into account the educational level, cultural background, and language spoken by their patients [34].

Many participants of this study reported obtaining information relevant to decision making from drug advertising and expert literature. However, in this study obtaining information from drug advertising and expert literature was not associated with having better knowledge of resistance. Expert literature could be an important contribution to patient's knowledge about HIV/AIDS if written in a language that patients are able to understand and published in magazines written for PLWH. Participants using the Internet or expert literature, but not drug advertising as sources of information, were better able to access more comprehensive treatment options such as complementary/alternative medicine. The most effective method of providing information to patients will likely vary depending on the individual, and it is unlikely to be a "one size fits all" approach.

INVOLVEMENT IN DECISION-MAKING ABOUT ART

Our study indicates that most of the participants preferred to be involved in treatment decision making. Interestingly, not having a partner was associated with a higher desire to make the treatment decision for oneself. Another study in PLWH [26] found a higher desire for active engagement in decision-making in English speaking individuals, compared to Spanish speaking. Thus, a patient's socio-cultural background may affect preference for involvement in decision-making about ART.

Compared to patients with other diseases, PLWH want to be more involved in the decision about their treatment. For example, 18%-78% of people with cancer [23, 35-39], 40% in people adults with asthma [40], and 47% in people with hypertension [41] preferred to leave treatment decisions to their doctors. In other diseases, predictors of a preference for a passive decision-making role were the severity of the patients' conditions, older age, less education, and being male [42]. However, demographic and situational characteristics explained only 20% or less of the variability in preferences [42]. Thus, it is important to identify a patient's role preference. Studies in people with hypertension [41] and advanced cancer [43] showed that the accuracy of the physicians estimate of a patient's preference for involvement in decision-making does not exceed chance. The best way a physician can gain insight into an individual patient's desire to participate in decision making is through direct inquiry [44].

TREATMENT KNOWLEDGE AND DECISION-MAKING PREFERENCES

This study confirms the results of a qualitative study in PLWH [15] that the desire for active participation in decision-making was associated with considering more sources of information. On the other hand, the ability

to understand treatment information (i.e., having knowledge about resistance) had little to do with the preferences of PLWH for participation in decision-making. Some PLWH were not very knowledgeable about HIV treatment, despite considering multiple information sources apart from their physician, but still preferred to make the final decision about the treatment.

The role patients wish to play in treatment decision-making and the amount of information they have are at times inconsistent. Because of this, studies need to differentiate between the two distinct dimensions of the decision-making process: information exchange and sharing decision-making [45]. The desire for information is quite separate from the desire to assume responsibility for treatment decisions [18].

Information exchange requires a certain ability to understand health information. In a study at a US HIV clinic, 48% of patients were reading below a 9th grade level, and 75% of those with a low reading level did not know the meaning of a CD4 count or viral load [27]. Furthermore, patients' medical decision-making depends on how the information is framed and their choices are often irrational [46]. Understanding the different success rates between the treatment options requires numeric skills people often do not have [47, 48].

Several studies in other diseases also found that the preference for information is distinct from the preference for participation in decision-making [49-54]. For example, older men with prostate cancer did want to be informed but wished to delegate decision-making to a physician [36]. However, providing information has shown to enable men with prostate cancer to assume a more active role in decision-making [55].

In our study, we found a different scenario: PLWH often lacked relevant treatment information (i.e., knowledge of drug resistance, and its relationship to non-adherence), but still wanted to be actively involved in the treatment decision. This may cause a dilemma, as patients may embark on the decision not to adhere to a prescribed treatment without knowing that this may cause irreversible drug-resistance and jeopardize their future treatment options. There is a clear need for physicians to make sure that PLWH have adequate knowledge about treatment to prevent that PLWH make autonomous uninformed choices, which they may later regret.

LIMITATIONS OF THIS STUDY

The main limitation of this study is the small sample size. Despite the significant associations we found between sociocultural factors, knowledge of resistance, and sources of information, conclusions based on this small group have to be treated with caution. In particular, the results cannot be generalized to different sociocultural environments. This data may even not be representative of PLWH in the US and there may be several biases. The participants were diagnosed with HIV for at least 3 years (an average of 11 years), so that PLWH who are newly diagnosed with HIV were not included. Further, all participants who

were not physically well enough to visit the location of our research centre were excluded from this study. PLWH who are newly diagnosed with HIV, or who are bedridden might differ in their sources of information or treatment knowledge from the participants in this study. Because this was an observational study, the associations that were found between variables, have to be considered as correlations and may not be causal.

IMPLICATIONS FOR CLINICAL PRACTICE

The results of this study propose some practical suggestions for physicians to facilitate access to information for PLWH in their office and to meet PLWH preferences for involvement in decision-making about ART:

- Explain risks and benefits of all treatment options (including no treatment) and take into account what is important from the patient's individual view
- Ask patients how much they want to be involved in decision-making about ART and encourage their active participation for patients that are so inclined.
- Make sure that all patients understand resistance and understand the connection between resistance and non-adherence.
- Facilitate contact with peer educators and HIV positive support groups for those who seek information from peers.
- Provide access to information (e.g., positive magazines, other patient-oriented written information, and guidance where to find useful information, such as the Internet).

CONCLUSIONS

In summary, we have identified that many PLWH lack knowledge of drug resistance. About one third of the participants were not aware that adherence to ART is important in preventing drug resistance. There is no panacea for enhancing patients' knowledge about the goals of ART and the importance of adherence to ART, but HIV-physicians play a key role in assessing and responding to the information needs of PLWH. This is particularly important for African American women, who not only are more likely to lack knowledge of resistance than other groups, but also rely more heavily on their physician than on other sources of information.

In addition, publications such as literature written for PLWH, as well as literature written for medical experts, drug-advertising, the Internet (for those who have access), and seminars can be used efficiently to disseminate information for PLWH. These sources are both frequently used and considered important by PLWH. Most, but not all PLWH prefer to be actively involved in decision-making about ART. However, sometimes PLWH want to make their own choices without understanding the consequences of their decision. In health care for PLWH, it is important to meet patient's needs for information first. To optimize treatment choices, shared decision-making needs to be accompanied by patient knowledge.

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REFERENCES

1. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ*. 1999 Sep 18; 319(7212):766-71.
2. Coulter A. Paternalism or partnership? Patients have grown up-and there's no going back. *BMJ*. 1999 Sep 18; 319(7212):719-20.
3. Carlsen B, Aakvik A. Patient involvement in clinical decision making: the effect of GP attitude on patient satisfaction. *Health Expect*. 2006 Jun; 9(2):148-57.
4. Greenfield S, Kaplan S, Ware JE, Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med*. 1985 Apr; 102(4):520-8.
5. Greenfield S, Kaplan SH, Ware JE, Jr, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med*. 1988 Sep-Oct; 3(5):448-57.
6. Rost KM, Flavin KS, Cole K, McGill JB. Change in metabolic control and functional status after hospitalization. Impact of patient activation intervention in diabetic patients. *Diabetes Care*. 1991 Oct; 14(10):881-9.
7. Gerbert B, Love C, Caspers N, Linkins K, Burack JH. "Making all the difference in the world": how physicians can help HIV-seropositive patients become more involved in their healthcare. *AIDS Patient Care STDS*. 1999 Jan; 13(1):29-39.
8. Gellaity G, Cooper V, Davis C, Fisher M, Date HL, Horne R. Patients' perception of information about HAART: impact on treatment decisions. *AIDS Care*. 2005 Apr; 17(3):367-76.
9. Golin CE, Smith SR, Reif S. Adherence counseling practices of generalist and specialist physicians caring for people living with HIV/AIDS in North Carolina. *J Gen Intern Med*. 2004 Jan; 19(1):16-27.
10. Arnsten JH, Demas PA, Farzadegan H, Grant RW, Gourevitch MN, Chang CJ, et al. Antiretroviral therapy adherence and viral suppression in HIV-infected drug users: comparison of self-report and electronic monitoring. *Clin Infect Dis*. 2001 Oct 15; 33(8):1417-23.
11. Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, et al. Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. *Ann Intern Med*. 2000 Jul 4; 133(1):21-30.
12. McPherson-Baker S, Jones D, Duran RE, Klimas N, Schneiderman N. Development and implementation of a medication adherence training instrument for persons living with HIV: the MATI. *Behav Modif*. 2005 Mar; 29(2):286-317.
13. Guarinieri M, ICoNA Community Advisory Board. Highly active antiretroviral therapy adherence: the patient's point of view. *J Acquir Immune Defic Syndr*. 2002 Dec 15; 31 Suppl 3:S167-9.
14. Department of Health. *The Expert Patient: A New Approach to Chronic Disease. Management for the 21st Century*. London: Department of Health; 2001.
15. Marelich WD, Johnston Roberts K, Murphy DA, Callari T. HIV/AIDS patient involvement in antiretroviral treatment decisions. *AIDS Care*. 2002 Feb; 14(1):17-26.
16. Ironson G, Balbin E, Stuetzle R, Fletcher MA, O'Cleirigh C, Laurenceau JP, Schneiderman N, Solomon G. Dispositional optimism and the mechanisms by which it predicts slower disease progression in HIV: Proactive behavior, avoidant coping, and depression. *Int J Behav Med*. 2005. 12: 86-97.
17. Department of Health and Human Services (DHHS) (US). Guidelines for the use of antiretroviral Agents in HIV-Infected Adults and Adolescents. April 7, 2005; Available from: URL: <http://www.aidsinfo.nih.gov/guidelines>.
18. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res*. 1997 Fall; 29(3):21-43.
19. Mruck K, Mey G. Qualitative Research in Germany [54 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research [on-Line Journal] [serial online]* 01/2000; Available from: URL: <http://www.qualitative-research.net/fqs-texte/1-00/1-00mrucl-e.htm>.
20. Degner LF, Beaton JI. *Life-death decisions in health care*. Washington: Hemisphere Pub. Corp.; 1987.
21. Davey HM, Lim J, Butow PN, Barratt AL, Redman S. Women's preferences for and views on decision-making for diagnostic tests. *Soc Sci Med*. 2004 May; 58(9):1699-707.
22. Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nurs*. 1996 Feb; 19(1):8-19.
23. Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carrieri KC, O'Neil J, et al. Information needs and decisional preferences in women with breast cancer. *JAMA*. 1997 May 14; 277(18):1485-92.
24. Chapple H, Shah S, Caress AL, Kay EJ. Exploring dental patients' preferred roles in treatment decision-making - a novel approach. *Br Dent J*. 2003 Mar 22; 194(6):321,7; discussion 317.
25. Cunningham WE, Markson LE, Andersen RM, Crystal SH, Fleishman JA, Golin C, et al. Prevalence and predictors of highly active antiretroviral therapy use in patients with HIV infection in the united states. *HCSUS Consortium. HIV Cost and Services Utilization. J Acquir Immune Defic Syndr*. 2000 Oct 1; 25(2):115-23.
26. Laws MB, Wilson IB, Bowser DM, Kerr SE. Taking antiretroviral therapy for HIV infection: learning from patients' stories. *J Gen Intern Med*. 2000 Dec; 15(12):848-58.
27. Wolf MS, Davis TC, Cross JT, Marin E, Green K, Bennett CL. Health literacy and patient knowledge in a Southern US HIV clinic. *Int J STD AIDS*. 2004 Nov; 15(11):747-52.
28. Kremer H, Ironson G, Schneiderman N, Hautzinger M. To take or not to take: decision-taking about antiretroviral treatment in people living with HIV/AIDS. *AIDS Patient Care and STDs*. 2006 May; 20(5):335-349.
29. Bilodeau BA, Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. *Oncol Nurs Forum*. 1996 May; 23(4):691-6.
30. Draper LA, Marks EB. Reducing barriers to accessing HIV/AIDS information for urban communities through collaboration; 1998 June 28-July 3, Geneva, Abstract 34111: Program and abstracts of the 12th World AIDS Conference.
31. Kalichman SC, Cain D, Cherry C, Pope H, Eaton L, Kalichman MO. Internet Use Among People Living with HIV/AIDS: Coping and Health-Related Correlates. *AIDS Patient Care STDS*. 2005 Jul; 19(7):439-48.
32. Igboko E, Hardy WD, Rice MML, Kogut SJH. THE (Tools for Health and Empowerment) course: a unique disease management program. 1998 June 28-July 3, Geneva, Abstract 34236: Program and abstracts of the 12th World AIDS Conference.

33. Jones J, Ranta V, Corbett D. Peer Health Educators: Improving Adherence in HIV Positive Women. New York City, NY: Center for Health Care Strategies Inc. Ressource paper. MetroPlus Health Plan; 2003.
34. Stricker JD, Oieribone D, Scheuer J. Providing HIV/AIDS treatment education to an ethnically diverse population in a large urban setting. 1998 June 28-July 3, Geneva, Abstract 42229: Program and abstracts of the 12th World AIDS Conference.
35. Beaver K, Bogg J, Luker KA. Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. *Health Expect*. 1999 Dec; 2(4):266-76.
36. Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. *Oncol Nurs Forum*. 1995 Oct;22(9):1401-8.
37. Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs*. 1997 Jun; 20(3):187-96.
38. Rothenbacher D, Lutz MP, Porzsolt F. Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *Eur J Cancer*. 1997 Jul;33(8):1184-9.
39. Stewart DE, Wong F, Cheung AM, Dancey J, Meana M, Cameron JI, et al. Information needs and decisional preferences among women with ovarian cancer. *Gynecol Oncol*. 2000 Jun;77(3):357-61.
40. Caress AL, Beaver K, Luker K, Campbell M, Woodcock A. Involvement in treatment decisions: what do adults with asthma want and what do they get? Results of a cross sectional survey. *Thorax*. 2005 Mar;60(3):199-205.
41. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making?. *JAMA*. 1984 Dec 7;252(21):2990-4.
42. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. *Behav Med*. 1998 Summer;24(2):81-8.
43. Rothenbacher D, Lutz MP, Porzsolt F. Treatment decisions in palliative cancer care: patients' preferences for involvement and doctors' knowledge about it. *Eur J Cancer*. 1997 Jul;33(8):1184-9.
44. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. *Behav Med*. 1998 Summer;24(2):81-8.
45. Deber RB, Baumann AO. Clinical Reasoning in Medicine and Nursing: Decision Making versus Problem solving. *Teaching and Learning in Medicine*. 1992; 4:140,140-146.
46. Tversky A, Kahneman D. The framing of decisions and the psychology of choice. *Science*. 1981; Jan 30;211(4481):453-8.
47. Schwartz LM, Woloshin S, Welch HG. Can patients interpret health information? An assessment of the medical data interpretation test. *Med Decis Making*. 2005 May-Jun;25(3):290-300.
48. Malenka DJ, Baron JA, Johansen S, Wahrenberger JW, Ross JM. The framing effect of relative and absolute risk. *J Gen Intern Med*. 1993 Oct;8(10):543-8.
49. Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nurs*. 2002 Feb;25(1):42-9.
50. Flynn KE, Smith MA, Vanness D. A typology of preferences for participation in healthcare decision making. *Soc Sci Med*. 2006 May 10;.
51. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Soc Sci Med*. 1994 Jul;39(2):279-89.
52. Hashimoto H, Fukuhara S. The influence of locus of control on preferences for information and decision making. *Patient Educ Couns*. 2004 Nov;55(2):236-40.
53. Krantz DS, Baum A, Wideman M. Assessment of Preferences for self-treatment and information in health care. *J Pers Soc Psychol*. 1980 Nov;39(5):977-90.
54. Wallberg B, Michelson H, Nystedt M, Bolund C, Degner LF, Wilking N. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol*. 2000; 39(4):467-76.
55. Davison BJ, Kirk P, Degner LF, Hassard TH. Information and patient participation in screening for prostate cancer. *Patient Educ Couns*. 1999 Jul; 37(3):255-63.

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