

THE DECISION TO FORGO ANTIRETROVIRAL THERAPY IN PEOPLE LIVING WITH HIV – COMPLIANCE AS PATERNALISM OR PARTNERSHIP?

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Abstract

Objective: The purpose of this study was to examine the self-reported reasons that people living with HIV (PLWH) provide to support their autonomous (i.e., against medical advice) decisions not to take, or to stop taking, highly active antiretroviral therapy (HAART). A further purpose of this study was to examine physicians’ reactions to their patients’ autonomous decisions and to examine physicians’ conceptualization of compliance.

Design/Methods: Semi structured interviews were conducted with 11 PLWH (5 male, 6 female) and their 8 HIV-care providers (4 male, 4 female). Interviews were analysed qualitatively using thematic coding. Patients also completed sociodemographic and medical information questionnaires. Interrater reliability was also calculated on patients’ reasons supporting their decisions with coefficients ranging from .84 to 1.00 (all $ps < .01$).

Results: For all 11 patients, preservation of quality of life and critical attitudes toward allopathic medicine were identified as reasons supporting autonomous decisions to refuse HAART. In addition, 10 patients cited the prior experience of, or the anticipated fear of, side-effects as central to their decision. Nine patients articulated their preference for alternative medicine and five patients expressed moral objections as significant reasons underlying their decisions.

Gender differences emerged in care providers’ conceptualization of compliance. Female care providers tended to view compliance as a collaboration between patient and care provider whereas male physicians tended to view compliance more as the patients’ capacity to adhere to the prescribed HAART-regimen.

Physician response strategies to patients’ autonomous decision to refuse HAART were characterized as coercive or not. Neither the physicians’ conceptualization of compliance nor their response strategies were consistent with the patients’ perspective. In contrast, the central component of the patients’ decision making was the patients’ subjective view of the benefit they would derive from HAART.

Conclusions: The results of this study provide some initial evidence that health care providers in-

tegrate recommendations for HAART with patients concerns for their own quality of life and make these recommendations within the context of the patients’ worldview. In addition, these results suggest that traditional views of compliance, that emphasize obedience to physician prescriptions, may be inadequate in this regard. Rather, these results suggest that a theory of compliance that is based upon collaboration between physician and patient will allow for a consideration of patients’ subjective views, their worldview, and their health care beliefs.

Key words: antiretroviral therapy; compliance; medical decision making; quality of life; doctor-patient relationship

INTRODUCTION

In the era of highly active antiretroviral therapy (HAART) the issue of compliance has received renewed interest because of the complexity of the medication regimen and the high level of adherence required to achieve HIV viral suppression [1]. There is substantial research examining the factors that can influence patient compliance [2]. Much of this work has focused on traditional concepts of compliance such as that listed in the Index Medicus, which defines compliance as “the extent to which a persons behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice” [3].

This conceptualization of compliance has been characterized as a relict of an outdated paternalistic medical model and has been criticized for requiring patients’ unquestioning submission to expert medical opinion and for requiring patients to blindly obey doctors’ orders [2]. As treatment guidelines change frequently this view of compliance remains questionable. In addition, this conceptualization of compliance can be misused to characterize treatment failure as the patient’s failure [4]. Although there has been considerable advances in HIV-research this paternalistic conceptualization of compliance prevails [1].

It may be naive to prescribe medication regimens that are still largely experimental without regard for the patient's lifestyle or quality of life, particularly if these medication regimens are endorsed only by the authority of the physician [2]. In the Random House Dictionary "complying" is defined as: "to act or be in accordance with wishes, requests, demands, requirements and conditions." In addition, adherence is defined as "the extent to which a patient's behaviour coincides with the prescribed treatment regimen determined through a shared decision making process between the patient and the doctor" [5]. It has been demonstrated, that adherence greatly influences the success of HAART [6, 7]. For some treatment regimens at least 95% adherence to anti-HIV medications is required to suppress viral replication [6, 7]. However, several studies have shown that 40-60% of patients achieve less than 90% adherence [7]. Less than perfect adherence is the rule rather than the exception [8]. Moreover taking medications correctly can only be achieved by patients themselves, and making the commitment to do so is most likely when patients can be active participants in the treatment decisions [9].

The British Royal Pharmaceutical Society adopted in 1997 the position that the term concordance should be used instead of compliance as it more accurately reflects the sense of partnership and collaboration between patient and doctor [10]. According to the contemporary and developing conceptualization, concordance is viewed as an agreement that has been reached after negotiations between the patient and doctor that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken [11]. However, the patient must be free to choose, we must not be repressive or practice "coercive health" [11].

In Germany, where the English term compliance is still in use, there has been a shift from the paternalistic concept of compliance based solely upon medical authority to an emphasis on partnership between doctor and patient and shared decision making [2, 12]. In this more contemporary view, compliance is defined as the process of finding a consensus between doctors and patients [2]. Although this developing view of compliance or concordance is reciprocal, it recognizes the primacy of the patient's decision about taking the recommended medications, and may lead to optimal medicine taking [11]. A recent study revealed, that "critical compliance", based on an autonomous and reflected decision made by PLWH to take HAART, showed most solid adherence. In PLWH who faithfully agreed with their doctors' prescription, without reflecting their decision, adherence was often unstable during times of stressful life events [13].

The contemporary view of compliance emphasizes the patient's ethical rights (e.g. autonomy, self-determination), and may endorse the patient's right to refuse treatment [14]. There has been little medical research, to date, investigating PLWHs

informed choices to forgo HAART. There is no research of which we are aware, examining doctors' reaction to this decision. The purpose of this study is to examine these issues of compliance from the perspective of the patient and the physician. In this regard, patients, who had made an informed choice to refuse HAART against medical advice, were interviewed to ascertain their reasons supporting their decisions. Patients also reported their perceptions of their doctor's reactions to the decision and their overall satisfaction with the decision making process. Physicians were interviewed to ascertain both their response to patients' refusal and their conceptualization of compliance.

METHOD

PARTICIPANTS

Eleven HIV-seropositive patients (5 male and 6 female) who had decided within the last year, against medical advice, to refuse HAART participated in this study. The men and women were equivalent on estimated times since infection and time since HIV-diagnosis. Men and women were equivalent on CD4 cell number or HIV-1 viral load.

ASSESSMENTS

Patient sociodemographic and medical information were assessed through self-report questionnaire. Each patient gave their consent for their physician to be interviewed. Quality of life and physical well-being were assessed by self-report on a 7-point Likert scale. Participants underwent a semi-structured interview in which they were questioned as to the reasons relevant to their decision whether or not to take HAART. In addition, patients were asked open ended questions that focussed on their attitude to HIV, their fears about the disease, their coping strategies, and their views of medication therapy. The patients' physicians were interviewed with respect to their conceptualization of compliance and their responses to patient's refusal of HAART. Patients were asked about their perception of their doctors' response to their decision to forgo HAART and about their satisfaction with the decision making process.

THEMATIC CODING

All patient and physician interviews were taped, transcribed and analysed using thematic coding procedures developed by Flick [15]. Thematic coding originates from grounded theory [16], which is one of the primary methods of qualitative analysis. Thematic coding allows for the analysis of responses from predefined groups and was considered the most appropriate method for examining the responses from the patients and physicians in this study. Thematic coding is comprised of four steps, which include summary char-

acteristics, open coding, selective coding, and thematic coding with case comparison. These steps are described below.

1) *Summary Characteristics*

Initially a brief summary of each interview was developed that was most representative of the content of the interview, addressing the key-issues and central motivations, giving preference to the individual's original wording. This initial analysis also included a brief overview of the sociodemographic data and the patients' medical situation, as well as the physicians experience in HIV-treatment.

2) *Open Coding*

The entire interview was analysed line by line to identify all the possible codes that may be relevant for answering the research questions. A code is an abbreviated label representing a concept, that may be the individual's own words or it may be assigned by the rater. This procedure was adapted from grounded theory [16] in which participants' responses that concerned antecedents, interactions, coping strategies and consequences were identified. Thus as part of the detailed analysis of the single case the decision making process of the individual was examined in context. Similarly, for physicians their responses to their patient's refusal were also examined in contextual detail.

3) *Selective Coding*

Beginning with the interview that appeared to be most representative of the group the codes that were previously identified were recoded. Codes that shared similar themes were grouped together and arranged into hierarchical categories (thematic fields). This is a procedure oscillating between inductive category acquisition and deductive category application. Thematic fields were derived from both the interview material and from pre-existing theories that apply to the text (which were used to summarize codes hierarchically). In this way the thematic structure of the interview emerged. Also during this process constant comparisons were made between the interviews to determine if the thematic structure derived from one interview applied to the next. If the thematic structure could not accommodate subsequent interviews the thematic structure was modified. In addition, any information in the interview that contradicted the thematic structure required the structure to be modified. The thematic structure of the participants' responses was then constructed by organising the hierarchies and their categories and providing definitions of each category.

4) *Thematic Coding with Case Comparison*

Finally, using the thematic structure developed above, the thematic coding proceeded by identifying specific examples, from the text of the interview, for each person in each thematic field. This allowed frequencies to be generated for each individual and across groups (gender, CD4-cells below

or above 200 cells/ml). Similarities or differences between individuals were identified.

MULTIPLE TRIANGULATION

In order to establish the reliability of the measurement system, to guard against experimenter bias and to help establish the validity of the thematic fields, multiple triangulation was employed. Triangulation of the data was already part of the thematic coding process because categories developed during the analysis were assessed for their generalizability across participants. Categories that failed to generalize across subjects or that were refuted in the transcript of the interviews were modified. Triangulation of theories is part of the selective coding, whereby the results of previous research are used to assist in the generation of thematic fields. Triangulation of investigators was utilized to obtain interrater reliability of participants' assignment within each of the categories. Three raters independently assigned participants responses within the autonomous decision making category, from which Fleiss Kappa-coefficients for multiple raters were calculated. For the remaining categories two independent raters assigned participants responses. Reliability estimates were generated for the categorical variables using Cohen's Kappa-coefficients and using Kendall's Tau-b for the ordinal variables (e.g., social influence, locus of control).

RESULTS

DEMOGRAPHICS

The average age of the PLWH in this study was 42.6 years. This was a highly educated sample with all PLWHs having educational experiences beyond secondary school. Only four PLWH were employed and five were on disability. All men in the study were homosexual and five of the six women identified themselves as heterosexual. Six were involved in committed relationships and all but two of the PLWHs were German nationals. The demographic characteristics of the study participants are summarized in Table 1.

The eight physicians (4 male, 4 female) had an average age of 51.9 years (SD = 4.7). Three physicians were very experienced, seeing 300 PLWHs per quarter and treating HIV for more than 15 years, four were experienced treating 12 to 180 PLWHs between 9 and 14 years and one female physician was inexperienced, having only one HIV-patient for two years.

MEDICAL CHARACTERISTICS

The average length of time since receiving an HIV-positive diagnosis was 10.3 years. The average length of time between estimated date of infection and diagnosis was 4.9 years. The mean CD4 cell number, at study entry, was 255 and the mean HIV-1 viral load was 117,759 copies /ml. Five pa-

Table 1. Demographic characteristics for male and female study participants.

Demographics	Women (n = 6)	Men (n = 5)	Total (n = 11)
Mean age, years	43.0 (11.9)	42.0 (8.1)	42.6 (9.9)
Education			
Less than High-School	4	3	7
High-/Trade-School	2	2	4
Some College	2	1	3
College Graduate	2	2	4
Employment			
Fulltime	1	1	2
Parttime	2	0	2
Unemployed	1	1	2
Disability	2	3	5
Sexual Orientation			
Heterosexual	5	0	5
Homosexual	1	5	6
Relationship Status			
Single	3	3	6
Committed	3	2	5
Immigration Status			
German National	5	4	9
Immigrant	1	1	2

Table 2. Physician experience treating PLW.

Physicians (n = 8)	Male (n = 4)				Female (n = 4)				Mean (SD)
HIV-patients/quarter	12	180	300	300	1	12	60	300	145.6 (139.7)
Years HIV-treating	14	11	15	16	2	11	9	16	11.8 (4.7)

Table 3. HIV disease characteristics for male and female PLWH.

	Women (n = 6)	Men (n = 5)	Total (n = 11)
Diagnosis in years, mean (SD)	10.0 (5.2)	10.6 (3.1)	10.3 (4.2)
Latency in years, mean (SD)	5,0 (2.1) (n = 5)	4.8 (4.4) (n = 4)	4.9 (3.1) (n = 9)
Route of Infection Heterosexual Sex	2	0	2
Homosexual Sex	0	5	5
I.V. Drug Use	2	0	2
Other	2	0	2
CD4-cells > 200/ μ l	3	2	5
CD4-cells < 200/ μ l	3	3	6
CD4-cells/ μ l, mean (SD)	226 (171)	263 (179)	255 (167)
HIV1 Viral Load c/ml mean (SD)	29,558 (65,828)	223,600 (436,514)	117,759 (296,818)

tients had CD4 cell numbers below 200. Seven PLWHs reported contracting HIV through sexual contact and two through intravenous drug use. Two women were unsure as to the specific route of infection. These characteristics are summarized in Table 3.

Antiretroviral Therapy

All participants in the study had decided to forgo or discontinue HAART within the past year. One man and one woman had no prior experience with HAART and one man and one woman had substantial experience with HAART with multiple

treatment interruptions. With these exceptions men and women differed in their experience with HAART. None of the women but three men initiated HAART within the last year. None of the men but four of the women discontinued HAART on average one year ago (SD 0.8), which they had taken for an average of 3 years (SD 1.0). In addition, none of the men but four of the women had experience with AZT monotherapy in the pre-HAART era.

RESULTS OF THEMATIC CODING

1) *Summary Characteristics*

An example of the summary characteristics is presented in Table 4 for one patient-doctor dyad.

2) *Thematic Structure*

The results of the thematic coding are presented in the Meta-Matrix in Table 5. The thematic fields that were identified were decision making autonomy, quality of life, disease concepts and treatment concepts. These are the central content areas relevant to PLWHs decision to forgo HAART. Within the decision making autonomy category PLWHs differed with respect to how they asserted their autonomy. Some patients made autonomous decisions that they shared with their doctor (disclosed), others did not disclose the decision (undisclosed) whereas others asserted their decision in direct opposition to their doctors advice (defiant).

Quality of life was categorized into its physical, psychological and social components reflecting patients' multidimensional cost-benefit appraisals in each of these categories in addition to social comparison in the physical category. The appraisals of physical quality of life were based upon a cost benefit analysis weighing the anticipated and actual side effects of the medications against the actual symptoms of HIV infection. In addition, physical quality of life was evaluated through social comparison: patients compared themselves to other PLWH who had died or become very ill despite treatment. Social quality of life was estimated based upon the patients' considerations of the impact of their decision on their partners, family, and friends, their ability to work, and their eligibility for disability benefits.

Psychological quality of life was judged balancing the fear of HAART against the fear of HIV related symptoms and death. The cost benefit analysis in this regard focussed upon being tied to a strict medication regimen, being dependent on the medications, and a fear of medication side effects (i.e., "I am no longer myself") on the one hand and controlling HIV related symptoms and hoping to prolong life on the other hand.

Disease concepts were categorised by locus of control, ars moriendi, attribution of cause of disease and prognosis expectancy. Locus of control reflected the degree to which the PLWH felt he/she could influence the course of the disease. Ars Moriendi is an ethical position that questions

Table 4. Summary characteristics of one doctors-patients dyad.

Patient	Physician
<p>"I have a positive attitude. The virus can not harm me."</p> <p>41 years, female, single, retired account-clerk, 1987 HIV/HCV-diagnosis, Infection1981-1983 via i.v. drug-use Physical well-being 3, QoL 3, 1992 AZT mono-therapy for 6 months 1997-2000 HAART CD4-cells 189/μl, VL 50 copies/ml.</p>	<p>If someone absolutely does not want HIV-therapy - I will try to induce him to take it.</p> <p>47 years, male HIV-care-provider since 1986, 300-patients/quarter year.</p>
<p>I do not have any trust in people doing research. Too much is in the dark, I am trying to shine a light on it. Long-term damage, cellular toxicity, irreversible deformations of my body. My physician was not honest, did not provide comprehensive information because he wanted to make me take medications. He does not know yet, that I have stopped. I need a doctor who supports me in my decision. If you do not try to stop HAART you cannot find out if it is good for you. I do not like to take pills. My liver can't cope with it. It is only you who can take the responsibility for your life and yourself. The doctor should not act as a general ordering patients to take pills. Those who do not obey are lost. They have nothing to say. Physically I cannot perform great actions. But I do not believe, that the virus can harm me. A positive attitude can do a lot. I intend to make it until I am sixty years old.</p>	<p>Compliance means getting along with each other, struggling through an effective therapy, helping the patient stay the course with all the ins and outs of medical therapy Adherence is the most important part. Non-compliance is not accurately defined as patients taking their medication inadequately - it must be the result of a disturbance in the doctor-patient relationship. Sometimes I need blood levels as well as contact, information and dialogue [with the patient]. But, so far, I have not used blood levels of medication very often [to assess adherence]. If you check this, you are no longer on the level of trust. If someone absolutely does not want therapy; I try to make him take it when I am convinced, that he needs it. Almost without exception over time they all strived to take medication</p>

Table 5. Meta Matrix of the coding agenda.

Thematic Field	Categories	Definition	Examples
Decision Making Autonomy	<ul style="list-style-type: none"> • Undisclosed • Disclosed • Defiant 	<ul style="list-style-type: none"> -Made own decision, did not tell the doctor -Made own decision, and told the doctor -Made own decision, had to defend autonomy in opposition to doctor 	<ul style="list-style-type: none"> -I decided against [HAART], my doctor does not know -[The doctors] accepted it, this is my way -You put yourself in opposition to the Healer's self-image, the fight for this position was hard
Quality of Life	Physical: <ul style="list-style-type: none"> • Social comparison • Cost-benefit ratio 	<ul style="list-style-type: none"> -Well-being without HAART vs. others on HAART -HIV-symptoms vs. experienced or potential side effects 	<ul style="list-style-type: none"> -If I compare myself to others on HIV-therapy, their condition is as bad as mine, if not worse. -I felt it in my body, that the medications would kill me, rather than the disease
	Psychological: <ul style="list-style-type: none"> • Cost-benefit ratio 	<ul style="list-style-type: none"> -Well-being without HAART (i.e. no dependency on medication) vs. fear of AIDS/death 	<ul style="list-style-type: none"> -It was liberating, no longer dependant on mountains of pills. I'm afraid of getting HIV symptoms. It's a dilemma and I prefer to be on the other side.
	Social: <ul style="list-style-type: none"> • Cost-benefit-ratio 	<ul style="list-style-type: none"> -Positive vs. negative social effects (i.e. reaction of the social environment, ability to work) 	<ul style="list-style-type: none"> -The pressure from my friends and family [to take HAART] is getting stronger and stronger. -Under HAART I was maximal six hours awake.
Disease concepts	<ul style="list-style-type: none"> • Locus of Control 	<ul style="list-style-type: none"> -Degree PLWH perception of internal control 	<ul style="list-style-type: none"> -I think, my psychological balance and stability has a stronger effect than any medication
	<ul style="list-style-type: none"> • Ars Moriendi 	<ul style="list-style-type: none"> -To live a fulfilled life in readiness for the natural end, and to die peacefully. 	<ul style="list-style-type: none"> -Is it okay for me to prolong my life artificially? I do not want to live until the bitter end with the power of chemicals.
	<ul style="list-style-type: none"> • Attribution of cause of disease 	<ul style="list-style-type: none"> -Belief in Duesberg hypothesis: "HIV does not cause AIDS" 	<ul style="list-style-type: none"> -I believe, that I have a serious illness in me, but I do not believe that this HIV
	<ul style="list-style-type: none"> • Prognosis-expectancy 	<ul style="list-style-type: none"> -Expectancy of long life with HIV 	<ul style="list-style-type: none"> -I said already in 1985, that I am not going to die of AIDS and I will not.
Treatment concepts	<ul style="list-style-type: none"> • Critical view of medicine 	<ul style="list-style-type: none"> -Critical vs. accepting view of HIV-therapy 	<ul style="list-style-type: none"> -They [doctors] just measure their success statistically and never look at the other aspects (e.g. lifestyle).
	<ul style="list-style-type: none"> • Preference for alternative medicine 	<ul style="list-style-type: none"> -Preference for alternative medicine over HAART 	<ul style="list-style-type: none"> -I always preferred alternative medicine
	<ul style="list-style-type: none"> • Social influence 	<ul style="list-style-type: none"> -Degree of influence of other PLWH on the treatment decision 	<ul style="list-style-type: none"> -My friend took only vitamins and lived a healthy life and he did well.
Physician concept of compliance	<ul style="list-style-type: none"> • Traditional • Contemporary • Mixed 	<ul style="list-style-type: none"> -Patients adherence to therapy -Doctor-patient collaboration -Combination of both 	<ul style="list-style-type: none"> -Compliance is the capacity of the patient to take the pills as I taught him. -Compliance is collaboration, to work together on treatment-concepts
Doctor-Patient Interaction	<ul style="list-style-type: none"> • Coercive doctors • PLWH view of physician as coercive • PLWH satisfaction with decision making process 	<ul style="list-style-type: none"> -Whether or not doctor tries to force PLWH to take HAART -PLWH perceived that the doctor was coercive -Degree of satisfaction of PLWH with decision process 	<ul style="list-style-type: none"> -First is, that the patient has the freedom of choice, which means not to pressuring him, "You have to take it!" -He wanted to make me take medications. -He gave me a lot of confidence in my own decision

Table 6. Frequencies of categorical assignment, and interrater reliability.

Thematic Fields Categories	Category Assignment/ Likert Score (1 _{low} -5 _{high})	Kappa (κ)/ Kendalls Tau b (τ _b)	Concordance Measures
Decision Making Autonomy Undisclosed Disclosed Defiant	3 6 2	κ 1*	11/11
Quality of Life Physical Psychological Social	Neg. Neutral Pos. - - 11 - - 11 2 4 5	κ 1 1 .59	11/11 11/11 7/11
Disease Concepts Ars Moriendi Belief in Duesberg Hypothesis Likert Scale Internal Locus of Control Expected prognosis	Present Absent 6 10 1 2 3 4 5 1 1 - 4 5 1 1 5 1 3	κ. .84 1 τ _b .84 1	7/11 11/11 9/11 11/11
Treatment Concepts Critical View of Medicine Prefer Alternative Medicine Likert Scale Social Influence	Yes No 11 - 10 1 1 2 3 4 5 2 8 - - 1	κ .81 1 τ _b .84	10/11 11/11 10/11
Physician (n = 8) Concept of Compliance Traditional Contemporary Mixed	3 3 2	κ 1	8/8
Doctor Patient Interaction Coercive Doctors PLWH Perceive Coercion Likert Scale PLWH Satisfaction with Decision	Yes No 3 6 1 2 3 4 5 1 4 0 2 4	κ 1 1 τ _b .84	8/8 8/8 9/11

¹ When Kappa or Kendalls-Tau is zero, agreement is what might be expected by chance. Agreement of at least .70 is generally used as a cut-off.

the morality of artificially prolonging life. Under the attribution of cause of disease category patients were rated as to whether they considered that HIV was the cause of AIDS.

The final disease concept category relevant for PLWH was prognosis expectancy. In this category patients were rated on a five point scale as how long they expected to survive. Treatment concepts were comprised of critical view of medicine (reflecting patients' attitudes towards traditional anti-HIV therapy), preference for alternative medicine (reflecting the patients' attitudes towards complimentary treatments) and social influence. Social influence was rated on a five point Likert Scale and reflected the saliency of significant others' opinion of treatment.

Physician conceptualizations of compliance were identified as traditional (reflecting paternalistic conceptualizations of compliance), contemporary (reflecting doctor-patient collaboration) and mixed (reflecting a combination of traditional and

contemporary conceptualizations of compliance). The doctor interaction with the patient was dichotomised according to the presence or absence of coercive strategies as reported by the doctor and also as perceived by the patient. Finally, patient satisfaction with the decision making process was rated on a 5 point Likert scale from very low (= 1) to very high (= 5).

3) *Frequencies of Categorical Assignment and Interrater Reliability*

The frequency of assignment of patient responses within the thematic fields and the categories is summarized in Table 6. In addition, interrater reliability estimates and concordance measures are also presented.

RESULTS OF INTERVIEWS WITH PLWH

For all eleven PLWH in this study the decision to forgo HAART was predicated on considerations

of decision making autonomy, the physical and psychological aspects of quality of life, and a critical view of traditional medicine (including HAART). Ten of the 11 PLWHs articulated a clear preference for alternative medicine as important in their decision. For 9 PLWHs who scored high on internal locus of control their perceived ability to influence the course of their disease was relevant to their decision to forgo HAART. For 5 PLWHs the philosophy of *ars moriendi* influenced their decision. Four of the PLWHs reported that their expectation of a good or very good prognosis supported their decision to forgo HAART. The belief in the Duesberg Hypothesis and Social Influence were each relevant for only 1 PLWH. PLWHs responses to social quality of life were not reliably assigned to categories and, as such, cannot be interpreted.

RESULTS OF INTERVIEWS WITH PHYSICIANS

Physicians were interviewed as to their concept of compliance and their responses were categorized as traditional, contemporary or mixed. The traditional conceptualization of compliance emphasizes the physician as expert and decision maker, and the patient as unquestioningly following the doctors' prescriptions. The contemporary view of compliance supports the view of consensus between patient and physician and recognizes the primacy of the patient in the decision making process. Of the 8 physicians interviewed 3 were subsequently categorized as having a traditional view of compliance, 3 as having a contemporary view and 2 as having a mixed conceptualization of compliance (a combination of traditional and contemporary views).

RESULTS OF PATIENT-PHYSICIAN DYAD INTERACTIONS

Five physicians (who treated 8 patients) reported using coercive strategies in response to their patients' refusal of HAART, and 3 physicians (who treated 3 patients) refrained from using coercive strategies. Of the 8 patients who were treated by the physicians who reported using coercive strategies only 5 patients actually perceived the coercion and 3 patients did not. The 3 patients who were treated by doctors who reported not using coercive strategies perceived the interaction as non-coercive. Five of the PLWH reported being either dissatisfied or very dissatisfied with the interaction with their doctor in the process of deciding to accept or forgo HAART. Six of the PLWH reported being either satisfied or very satisfied with the decision making process with their doctor.

RESULTS OF THEMATIC CODING WITH GROUP COMPARISON

Gender Differences: All of the patients who made undisclosed decisions ($n = 3$) were women who perceived their doctors as being coercive.

Stage of CD4 Cell Depletion: All of the patients with CD4 cells above 200 ($n = 5$) could not say whether or not they expected a good prognosis. Whereas 4 of the 6 patients with CD4 cells below 200 expected a good or very good prognosis.

Coercion: Contrary to expectations, 2 of the 5 doctors who used coercive strategies endorsed a contemporary definition of compliance. Whereas, 2 of the 3 doctors who disavowed the use of coercion endorsed a traditional or mixed view of compliance.

Patient Satisfaction: All of the patients who perceived their doctors as coercive ($n = 5$) reported being dissatisfied or very dissatisfied with the decision making interaction process. Conversely, all of the patients who perceived their doctors as non-coercive ($n = 6$) reported being very satisfied with the decision making strategy.

DISCUSSION

The results of this study have identified several issues that are of central importance to the patients' decisions to forgo HAART. In particular, for all patients in this study, autonomous decision-making, quality of life issues, and critical attitudes toward traditional medicine were all reliably identified as factors supporting our patients' decision to refuse HAART. For all but one of the participants a preference for alternative medicine and perceptions of internal control were also germane to their decision. Clearly, for these patients the decision process to accept or refuse HAART is a complex one. These results suggest that prescribing physicians could involve their patients more fully in the decision making process by soliciting information in each of these areas. Particularly, considerations of quality of life, which were paramount for all of our patients, may contribute positively to the decision making process. It is possible that such an inclusive process may assist the patient in making the best decision and may promote his or her optimal adherence. These conclusions are supported in the literature [2, 13].

Although physician conceptualizations of compliance were reliably coded as modern, traditional or a combination of both they were not consistently related to patient satisfaction with the decision making process. Rather the results of this study suggest that patient satisfaction with the decision making process was related to whether or not physicians attempted to coerce their patients to alter their decision and whether or not the patient perceived their physician as coercive.

Five patients reported having to defend their decisions and being accused of attempting to commit suicide by their physicians. In addition, the three women in our study who felt coerced to take HAART, discontinued HAART without informing their physicians. Further, the results of interview analysis revealed that four of the female patients reversed earlier decisions to accept HAART that they felt had been based solely on

doctor recommendations. These results suggest that the use of coercive persuasion by physicians in response to patient refusal of HAART may be counterproductive, particularly for female patients. In addition, the use of coercive strategies, if perceived by the patient, may well undermine the doctor-patient relationship. Elsewhere the quality of the doctor-patient relationship has been directly related to medication adherence [17, 18].

The results of this study suggest that physicians recommendations for HAART may need to be made within the context of the patients' decision making style [13, 19, 20], the patients' concern for their quality of life [2, 8, 13], and the patients' attitude toward treatment [2, 21]. It may well be prudent to incorporate into HIV treatment guidelines specific considerations of the patients' quality of life. A consideration of these issues when prescribing treatment may support a more collaborative relation between the patient and the physician which other researchers have related to improved adherence to HAART among PLWH [13, 21, 22]. It is also compatible with the move of the international medical community in the direction of what has been described here as the contemporary view of compliance [2, 8, 10, 12, 13].

It was not possible, within the limitations of the study design, to specifically relate physician conceptualizations of compliance to either patient decisions to forgo HAART or patient satisfaction with the decision making process. However, physician behaviour and patient perceptions of physician behaviour appear from our data to be more relevant to the patient when assessing their satisfaction with their physician. These findings are consistent with other studies [17, 18, 20, 23].

LIMITATIONS OF THE STUDY

Although this study utilized physician/patient dyads and presented a systematic methodology for examining patient and physician responses that incorporated acceptable reliability and methodological protections against threats to internal validity of the study, the design of this study is not without limitations. The sample size was small and the sample was not randomly selected which restricts our ability to generalize the findings. In fact the patient sample in this study may represent a special group of PLWH. Although convincing reliability data are presented for the majority of patient and physician responses two categories of patient responses were not measured reliably. Further, the data presented here are based upon self-report and are vulnerable to the biases associated with that methodology. In addition, patients were selected who had at any time in the past year refused HAART against medical advice. For some patients answering the questions involved recollecting reasons for their decisions over a long period of time and for three patients their recollections may have been further overshadowed by their subsequent decision to start HAART.

IMPLICATIONS FOR RESEARCH

Further research should address the preferred and perceived decision-making process about HAART and its impact on adherence, quality of life, attitude towards medication and health, as well as the doctor-patient relationship and satisfaction with the decision-making process. With respect to the dynamics of these factors longitudinal research is required in order to understand the long-term effects and to develop interventions to improve the quality of decision making and the quality of life in people living with HIV.

CONCLUSIONS

In summary, the results of this study suggest that among PLWH who, against medical advice, refuse HAART, autonomy of decision, quality of life considerations, and beliefs concerning illness and treatment are central to their decision. Also, it appears that patient satisfaction with their physician is related to both physician behaviour (coercive persuasion) and patient perception of physician behaviour as accepting or coercive, respectively.

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