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Doctor-Patient Relationship: Active Patient Involvement (DPR:API) is related to long survival status and predicts adherence change in HIV

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Abstract

Background: Active patient involvement is one of the aims of patient-centered care. Little is known regarding the unique impact of patients' active participation in their care on health outcomes, and scales are needed to measure this construct. The aim of the present study was to examine the application of the Doctor-Patient Relationship: Active Patient Involvement (DPR:API) scale, a 5-item scale, in predicting relevant health outcomes among HIV positive patients.

Methods: In Study 1 we compared active patient involvement between long survivors (those who survived more than twice as long as expected after getting an AIDS defining symptom; *n*=176) and normal course controls (HIV positive patients; *n*=79). Study 2 was a longitudinal study following the normal course controls to determine whether active patient involvement at baseline would predict adherence to combination antiretroviral therapy (ART; percentage of missed doses) using the AIDS Clinical Trials Group scale (ACTG) at one-year follow-up.

Results: In Study 1, long survivors were significantly higher on active patient involvement than the normal course HIV controls. In Study 2, hierarchical multiple regression models showed that patients' involvement in their care at baseline significantly predicted change in percentage of missed doses one year later, such that patients who were more involved early in treatment became more adherent to ART after one year.

Conclusion: Findings highlight the relevance of patient involvement in their care to important health outcomes. Interventions designed to help patients become more active in their care throughout the illness trajectory might positively affect medication-taking behaviors and survival. The DRP:API offers an easy and quickly-administered tool to assess patient involvement within the context of both research and practice.

Keywords: Doctor-patient relationship; Patient involvement; Medication adherence; Survival; HIV; Patient-centered care

Introduction

In the last decade, healthcare delivery has gone through many transformations to address medical patients' needs in a more comprehensive manner, emphasizing the whole person as the unit of care rather than focusing on a specific disease. Person-centered care has emerged as a new organizing framework for medical practice, and the quality of the doctor-patient relationship represents an important driving force in that new comprehensive approach to care [1,2]. As the significance of the doctor-patient relationship is reiterated and recommendations are formally integrated into medical guidelines for healthcare professionals, there is an increasing need to carefully assess the quality of that relationship and further examine its impact on patient- and health-related outcomes [2].

The choice of an assessment tool should be carefully informed by the conceptualization of the construct [3] or by its proposed relevance to outcomes of interest and the settings in which the assessment is conducted –whether in the context of clinical practice or research. Many measurement instruments have emerged to quantify the doctor-patient relationship, thus echoing the multidimensionality of this construct, as emphasized in a recent review by Eveleigh et al. [3]. Considering the range of assessment measures and conceptual models developed to date, no single measure of doctor-patient concordance is likely to reflect all relevant components of the relationship.

In an era of patient-centered care, examining patients' involvement in their own care is key. In fact, it is thought to be at the core of the doctor-patient relationship and a critical component of modern quality care [1,4]. This relationship is also thought to be associated with important health-related outcomes. For instance, a collaborative doctor-patient relationship has previously been emphasized as critical to adherence in medical patients [5]. Yet, the unique role of patients' active participation in their care has received scant attention to date. Furthermore, short and psychometrically sound instruments to measure patients' active involvement in their care are not currently available. Thus, the questionnaire examined in the present study first aims at providing an efficient instrument that can be used among patients with a chronic illness, whereby medication adherence is paramount to treatment success and survival. HIV is one such illness.

To date, mounting evidence has established a positive association between different components of the doctor-patient relationship and adherence behaviors among HIV-infected patients receiving antiretroviral therapy [6-15]. In a recent study of highly adherent HIV-infected patients (at least 90% adherent), the doctor-patient relationship was identified as a key factor in the successful management of their disease and medication regimen [16]. Overall, trust has consistently emerged as the most common correlate of adherence [6,7,12,13] along

with communication with the doctor [17] and accessibility [9,16]. Studies conducted among other medical populations have emphasized this relationship as well [18,19], consequently giving this observation more credence.

Most of the evidence accumulated to date has relied on cross-sectional studies, thus leaving a void for prospective studies to elucidate the proposed causal links. In addition, the range of health outcomes examined in relation to the doctor-patient relationship should be expanded beyond adherence, as suggested by a recent meta-analysis that highlighted the impact of the doctor-patient relationship on both subjective and objective health outcomes across diverse medical conditions [20]. Within the context of HIV, one study has identified a link between a good doctor-patient relationship and having undetectable serum HIV RNA [21].

In sum, the present study examines the application of a new instrument that aims to assess patients' active involvement in their own care, addressing a critical, yet understudied, construct of the patient-centered approach. In addition, this study aimed at examining the prospective relationship between patients' active involvement and adherence, as well as examining its association with long-term survival in HIV-infected patients.

Methods

Overview

Two studies were conducted as part of this investigation. Participants were paid volunteers recruited from physician offices, community organizations, local advertisements, and organizations that provide services to people living with HIV in the Miami/Ft. Lauderdale and Los Angeles areas. Participants were included if they were HIV positive. Exclusion criteria included being under 18, being diagnosed with another life threatening illness, taking medications affecting stress hormones (e.g., steroids), street drug use in the past month, active psychotic or suicidal ideations, and current drug or alcohol dependence. All participants provided written informed consent prior to entering the study. Studies procedures were approved by the Institutional Review Board.

Design

Study 1: The first study was a cross sectional study comparing a group of long survivors to normal course controls on psychosocial and biological variables, and medical outcomes for a study on stress and coping with HIV [22]. The long survivors of AIDS were defined by the Centers for Disease Control as those who had survived more than twice as long as expected after getting an AIDS defining symptom (e.g., Karposi sarcoma, PCP pneumonia), which, prior to the advent of protease inhibitors, was 18 months x 2 or 3 years (to be conservative our criteria was 4 years). The normal course controls were HIV positive participants in the mid-range of illness (CD4 cell count between 150 and 500, never had an AIDS-defining symptom). When followed

longitudinally, normal course controls may become long survivors, this group thus represents a conservative control group. Participants completed questionnaires (including the DPR:API), a clinical interview, and provided a sample of blood for CD4 and Viral Load (VL) assay.

Study 2: Study 2 was a sub-study of Study 1 that prospectively followed the normal course controls mentioned above for a year. For this sub-study, all materials, including psychosocial questionnaires, clinical interview, and blood sample, were collected at the entry of the study and at a 1-year follow up.

Measures

The Doctor-Patient Relationship: Active Patient Involvement Scale (DPR:API) is given in Table 1. The five items measure an aspect of the doctor patient relationship, namely the extent to which patients are actively involved in their treatment including their communication with the doctor, with higher scores indicating greater patient involvement. The scale was developed by the PI and Co-PI on this study, Gail Ironson, and George Solomon. Items were generated noting behaviors from clinical interactions with people living with HIV. The main purpose of this scale was to capture behaviors indicating patients' active involvement in their care with a focus on behaviors related to treatment decisions. The alpha for this scale is 0.80. Since we could not find other doctor-patient relationship scales that measure active patient involvement, it was not possible to correlate it with other measures of the same construct. Rather, validity was established by exploration of relationships with survival and adherence as reflected in the rest of the paper.

Adherence to combination antiretroviral therapy (ART) was measured by the AIDS Clinical Trials Group (ACTG) [23]. The measure of adherence that was used was the proportion of missed doses.

CD4 lymphocyte count (CD3+CD4+) was assessed by whole-blood 4-color direct immunofluorescence using a XL-MCL flow cytometer (Beckman/Coulter, Miami, FL). The total lymphocyte count was determined using a MaxM electronic hematology analyzer (Beckman/Coulter, Miami, FL) in order to convert the percentage of total lymphocyte values generated by the flow cytometer to absolute count for each subset.

Demographics

Age, gender, education, ethnicity, and income were self-reported at study entry by all participants.

Results

Study 1

Demographics of the groups (long survivors and normal course controls) for the cross sectional study are given in Ironson et al. [22]. The demographics of the longitudinal sample are in Table 2. In Study 1, the cross-sectional comparison between long survivors of HIV and the

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The questions on this questionnaire ask you about the relationship between you and your doctor. All should be rated on the following scale:

0=Never   1=Rarely   2=Sometimes   3=Usually   4=Always

1. I complain to my doctor if I notice side-effects of a medication.
2. I read up on my own about new medications and treatment.
3. I ask my doctor questions about new treatments and new research.
4. I suggest possible useful treatments to my doctor.
5. I tell my doctor about any "alternative" treatments I am using (such as meditation, herbs, acupuncture, etc.).

Table 1: Items from the Doctor-Patient Relationship: Active Patient Involvement Scale.

Characteristics	n=102
Age (years)	38.6 ± 8.6
Gender (male)	71.6%
Ethnicity	
African American	31.4%
Non-Hispanic White	28.4%
Hispanic	34.3%
Other	5.9%
Education	
Did not graduate high school	16.7%
High school graduate or equivalent	12.7%
Trade school or some college	38.2%
College graduate or grad degree	32.4%
Income	
Less than $10,000	56.4%
$10,001 - $20,000	22.8%
$20,001 - $30,000	8.9%
Greater than $30,000	11.9%
CD4 cell count	311.9 ± 125.9
Viral load $\log_{10}$	3.2 ± 1.0
Medication adherence at baseline	92.32%
Baseline proportion of missed doses	7.68%
Medication adherence at one year f/up	93.51%
One year f/up proportion of missed doses	6.49%
Active patient involvement	14.28 ± 4.6

Table 2: Demographics.

Model	R	R^2	ΔR^2	ΔF	df	β
Step 1: Immune status	0.01	<0.01	<0.01	0.16	1,99	
CD4 cell count						-0.13
Step 2: Disease status	0.03	<0.01	<0.01	0.10	2,98	
CD4 cell count						-0.02
Viral load						-0.03
Step 3: Demographic	0.22	0.05	0.05	1.12	5,94	
CD4 cell count						-0.05
Viral load						-0.06
Age						-0.07
Gender						0.19
Race (Black)						-0.06
Race (White)						-0.08
Step 4: Baseline Adherence	0.62	0.38	0.34	50.31	7,93	
CD4 cell count						-0.05
Viral load						0.03
Age						-0.06
Gender						0.08
Race (Black)						0.11
Race (White)						-0.03
Medication adherence at baseline						-0.60***
Step 5: Active patient involvement	0.65	0.42	0.04	5.65	8,92	
CD4 cell count						-0.08
Viral load						0.05
Age						-0.03
Gender						0.07
Race (Black)						0.11
Race (White)						-0.01
Medication adherence at baseline						-0.62***
Active patient involvement						0.20*

Table 3: Hierarchical Linear Regression with 1 Year Change in Adherence as Dependent Variable.

normal course controls showed that the long survivors had significantly higher scores (t(253)=2.44, p=.015) on the DPR:API (mean=15.50, SD=3.83, n=79) than the controls (mean=13.91, SD=4.98, n=176). In other words, patients' active participation in their care was greater in participants who had survived more than twice as long as expected after getting an AIDS symptom than in normal course controls.

Study 2

Table 3 provides results for a simple hierarchical multiple regression conducted to determine whether change in combination anti-retroviral therapy adherence over 12 months could be predicted by the DPR:API Scale after controlling for HIV disease management and demographic variables in Study 2. The null hypothesis tested was that addition of the DPR:API would result in a regression coefficient equal to zero and non-significant change to the model. The data was screened for normality and there was no missing data.

The results of the regression suggest that the reported change in non-adherence to ART over 12 months was predicted significantly by the level of patient involvement at baseline (Entered in Step 5) after controlling for immune (CD4 cell count; Entered in step 1 of the model) and disease status (Entered in step 2), demographic variables (Entered in step 3) as well as non-adherence at baseline (Entered in step 4). The overall model predicting change in non-adherence to ART over 12 months was significant (F(8,92)=8.23, p=0.02). The DPR:API explained an additional 3.6% of the variance in 12-month adherence increase to ART over and above the other predictors (ΔR^2=0.04 in Table 3 due to rounding). Note that there was a 15.5% increase in adherence over one year (from 7.68% missed doses to 6.49% missed doses as showed in Table 2). Holding other variables constant, the significant beta coefficient for DPR:API on one year change in medication adherence was significant (t=2.38, df=8, p<0.001) beta=0.20. A one standard deviation increase in active patient involvement predicted a 0.20 standard deviation

decrease in missed dosages over 12 months. In other words, on a 20 point scale for every 1 point increase in ratings of participation in their care the patient becomes adherent to an additional 1% of their total dosages. When considering the ≥95% adherence needed for efficacy of antiretroviral therapy, this effect for active patient involvement bears clinical significance for viral suppression in HIV.

Discussion

This study discusses the application of the DPR:API Scale, a new assessment tool that assesses patients' involvement in their care, which we examined in the context of different health outcomes in the present studies. First, findings from study 1 revealed that patients who have survived more than four years after getting an AIDS defining symptom were more involved in their care than those from a normal course control group. This result is in line with a previous study showing that patient-centered care was associated with better survival rates in patients hospitalized for acute myocardial infarction [24]. Active participation during medical visits has also been associated with positive health

outcomes in patients diagnosed with lupus [25]. Altogether, these results bring our attention to the fact that patients' involvement in their care might impact important objective health outcomes.

Second, our results from Study 2 indicated that HIV patients who actively participated in their care –by asking questions of their providers about treatment or reporting side effects for instance - exhibited an increase in adherence to ART over one year. Our findings are consistent with previous results showing that patients' perception of engagement with their providers was related to adherence in a cross sectional study conducted with HIV patients [26]. Participatory-decision making also showed a trend toward statistical significance in relation to HIV medication adherence in a different cross-sectional study [13]. The relationship between a collaborative doctor-patient relationship and better adherence has also been found in other populations of medical patients [5].

Overall, our results are consistent with previous research showing the importance of the doctor-patient relationship and extend this to patients' involvement. In addition, our findings offer new insight into the prospective relationship between patients' participation in their healthcare and medication-taking behaviors among HIV positive individuals. Thus, the present study differs from past research in that it focuses more directly on the patient's active role within the relationship. As the importance of patients' participation in their own care has resurfaced in recent years through the patient-centered care approach [1,4,27], it is critical that we become better able to measure and gauge its impact.

Implications for clinical practice and research

Our findings have important clinical implications in light of the fact that patients' involvement is one determinant of adherence that is likely amenable to intervention. In light of the importance of adherence to antiretroviral medication for HIV survival [28], improving patients' participation in their own care and refining its assessment throughout the illness trajectory could thus yield beneficial health outcomes. It has become a necessity to monitor the extent to which patients actively participate in their care, in accordance with the guiding principles of patient-centered care. The DPR:API offers the advantage of being quickly administered and can therefore serve such a purpose. In addition, within the context of clinical practice, it could allow healthcare providers to initiate a discussion about treatment decisions with their patients.

Interventions can also be designed to facilitate patients' involvement throughout the illness trajectory and increase subsequent adherence to recommended care practices [27]. Bergeson and Dean [4] suggested for instance that patients could receive assistance in formulating their health concerns and setting an agenda prior to their medical appointment, so as to empower patients to express health-related concerns and be more engaged during the visit. The use of technology also offers a new avenue to increase participation among patients diagnosed with a chronic illness such as HIV [29]. Offering communication skills training for physicians has also been shown to improve adherence across a range of illnesses [30] and it has been identified as an important factor in the treatment of HIV [17]. It is possible that interventions aiming at providing tools for physicians to elicit or maintain patients' engagement in their care might further yield positive results.

Limitations and directions for future studies

Some limitations should be noted in these findings. There is no question that medication adherence plays an important role in influencing CD4 cell count, HIV viral load and ultimately HIV disease severity [31]. Despite the potential introduction of memory bias and the lack of precision inherent to self-report, the ACTG is the most commonly used measure of HIV medication adherence in the HIV/AIDS literature [23]. Although electronic measures of medication usage may be superior [32], our findings suggest that active patient's involvement may be added to a gamut of psychosocial and behavioral response mechanisms implicated in medication adherence for persons living with HIV/AIDS [33,34].

Another issue pertaining to including the ACTG measure as a covariate in our model is that 16% of the cohort were not prescribed or taking anti-HIV medications. This proportion of non-medicated patients is not unusual in HIV spectrum disease research; previous medical history (CD4 count nadir, viral load), medication adherence, housing status, substance abuse/dependence history, and psychiatric state may play a role in physician decisions to prescribe ART [32,35]. A second limitation of this study lies in the fact that we did not correlate or validate the DPR:API against other measures of the doctor-patient relationship because we do not know of any other measure that focuses primarily on patients' involvement. Finally, future studies should establish the prospective association between patients' active involvement in their care and survival, and examine whether adherence might act as a possible mediator in that relationship. Different components of the doctor-patient relationship should also be examined concurrently to determine the relative importance of each of them to health outcomes in HIV patients.

Conclusions

While patient-centered care has previously been associated with self-reported health in medical patients [36], our findings further document its relevance to other important health-related outcomes, namely adherence and HIV survival. Specifically, as a core component of patient-centered care, patients' involvement in their care should be examined more systematically and the DPR:API offers an easily-administered assessment tool to that effect.

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