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Coercion or Caring: The Fundamental Paradox for Adherence Interventions for HIV+ People with Mental Illness

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Abstract

Objective—To determine if an escalating HIV treatment adherence intervention would be considered by participants from a caring or coercive perspective.

Methods—Perceived coercion was examined in 238 community-based dually diagnosed individuals (HIV+ and a serious mental illness) randomized to a treatment-as-usual Control group or PATH+ Intervention (Preventing AIDS Through Health for HIV+ Persons) that increased intervention intensity when adherence fell below 80%.

Results—Minor differences were observed in perceived coercion between the PATH+ Intervention and Control groups with perceived coercion marginally higher in the PATH+ group. Latent growth curve analyses indicate that perceived coercion was not related to duration of the intervention for either the PATH+ or Control group.

Conclusions—The experience of coercion by HIV+ individuals receiving community-based mental health services was not related to the intensity or duration of delivered services.

Keywords

HIV+; serious mental illness; perceived coercion; treatment adherence; intervention cascade

INTRODUCTION

Persons with a serious mental illness are at increased risk to contract and transmit human immunodeficiency virus (HIV) (1) with prevalence estimates ranging from 4 to 23%, as compared to .4% to .6% in the general population. To reduce HIV incidence within

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Compliance With Ethical Standards:

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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community-based networks of vulnerable populations, adherence to care is of particular importance (2–3). Yet numerous structural barriers to mental health and HIV treatment exist including financial concerns (4), inadequate transportation to treatment centers, and inconveniently timed office based treatment (5). Attitudinal barriers include poor coping skills, the perceived stigmatization of mental illness, HIV status, and suspicion of health care and social service providers (6).

The context of treatment for individuals with a severe mental illness has a long and complicated history (7) with Phillippe Pinel promoting humane mental health treatment as far back as the 1700s (8). Advances in psychotropic pharmaceuticals in the 1950s in conjunction with a well-organized advocacy effort in the 1960's provided the impetus for the historical shift to deinstitutionalization during the 1970s (9–11). It has been argued that deinstitutionalization led to the advent of compulsory community-based treatment (12–13) which engendered its own negative history as rights of people with severe mental illness conflicted with concern for their mental health and wellbeing (14). This clash between a public health mandate and individual rights to self-determination has produced a nuanced literature (15) concerning perceptions of involuntary commitment with research on ways in which those perceptions affect mental health outcomes and treatment adherence.

Relationship between commitment status and treatment adherence

The MacArthur Network on Mental Health and the Law (e.g., 2001) reviewed the relationship between perceived coercion and treatment adherence/outcomes for psychiatric inpatients and those in mandatory community treatment programs. Legal commitment *per se* was identified as a poor predictor of treatment outcomes (16–19). Rather, the treatment experience itself appeared to be mediated by the decision-making process associated with fairness, benevolence, and justice, collectively referred to as the domain of 'procedural justice' (20–22). When psychiatric inpatients perceived their inpatient experience to be typified by procedural justice, they experienced low perceived coercion whether the treatment was mandated or not (18, 20, 22–25).

These formative studies of voluntary and involuntary psychiatric inpatient experience initiated a series of randomized clinical trials of 'outpatient commitment' or 'mandatory outpatient commitment' (26–29). Numerous studies found that mandatory commitment was associated with reductions in length of hospital stays but concurrently, inpatients reported elevated levels of perceived coercion associated with these treatment episodes (30–33). This mixed finding prompted later research to focus on the relationship between perceived coercion and treatment adherence. For example, Swartz and colleagues (27) found elevated levels of perceived coercion reported by individuals living in urban areas, African Americans, substance abusers, those with more psychiatric symptoms, more days of commitment, poorer treatment adherence, and repeated reminders of the consequences of non-adherence by case managers. A study of Medicaid claims data (29) also found reductions in hospitalizations, increased medication and treatment adherence in a group of individuals assigned to involuntary community commitment, compared with individuals who received treatment-as-usual. In contrast, Steadman and associates (26) conducted a study of 142 inpatient psychiatric patients randomized either to court-ordered treatment or no

mandated treatment groups and found elevated levels of perceived coercion among Caucasian women with more education who were treatment adherent at the one-month follow-up. Importantly, the relationship between perceived coercion and adherence disappeared in later follow-up assessments (34).

These inconsistent findings may indicate the dependence of perceived coercion upon contextual cues related to fairness, benevolence, and justice (17, 29, 35). Given the continued stigma associated with HIV (36–40) and mental illness (41–44) there are clear challenges with treatment adherence for those who have these co-morbid conditions. The current study examined perceived coercion in dually diagnosed individuals (HIV+ persons with a serious mental illness) who were randomized to receive either treatment-as-usual or Preventing AIDS through Health for HIV+ persons (PATH+), a program of assertive community treatment that implemented a treatment increasing in intensity when adherence goals of 80% were not met.

The PATH+ Intervention

PATH+ was an HIV regimen management study involving advanced practice nurses (APNs) utilizing an adaptive treatment design (45) or “intervention cascade” to manipulate intervention intensity (and its corresponding expense) based on treatment adherence (46; refer to Blank & Eisenberg, 2013 for a more complete discussion of the PATH+ intervention). The basic intervention was supplemented with escalating intensity if adherence fell below 80% that included activation of social networks, then the use of reminder beepers and cell phones to encourage participants to follow their regimen, with the highest intensity level involving the direct observation of medication administration. If adherence fell below 80%, the next level of intensity was implemented until 80% adherence was achieved and maintained for three weeks.

The PATH+ intervention is based on reasoned action theory, which assumes that health care behavior is determined by intention to perform a behavior. Intention is determined by attitudes regarding the outcome expectancies of the behavior, perceived normative pressure relative to the behavior, and self-efficacy regarding one’s autonomy to perform the behavior and ability to carry out the behavior when confronted with barriers to doing so (47). The PATH+ intervention used individualized treatment plans that adapt to real-time shifts in treatment adherence, making this an in-vivo test of the intrusiveness of an assertive community treatment intervention by virtue of the involvement of a multidisciplinary team located in the community and tasked to decrease inpatient hospitalizations, reduce contact with the criminal justice system, improve housing, and encourage employment and general health promotion activities (48).

The cascade design provided an a priori naturally occurring opportunity to examine gradations of the intervention’s perceived coercion as monitoring by the advanced practice nurse increased and personal autonomy was reduced. We posed the following research question: “Would escalating efforts at treatment adherence be considered within a perceived caring or coercive framework?”

METHODS AND MEASURES

Design & Settings

The parent study was a longitudinal randomized clinical trial (baseline, 3, 6 and 12 month interviews followed by a 24-month follow-up interview to monitor decay or persistence of effects after the intervention period) with randomized assignment to either the PATH+ intervention where Advanced Practice Nurses provided community-based care management at a minimum of one visit per week and coordinated clients' medical and mental health care for one year or to a Control group where treatment as usual was provided. Viral load and CD4 cell count were evaluated at baseline, 12, and 24 months. All other data was gathered at baseline, 3, 6, 12, and 24 months.

Eligible participants were age 18 or older, English speaking, with a diagnosed mental illness, competent to provide informed consent in accord with the Declaration of Helsinki provisions, receiving case management for a serious mental illness, and self-identified as HIV seropositive. A diagnosis of mental illness and HIV status were confirmed via HIV testing and contact with mental health service providers although PATH+ participation did not require current psychotropic or ART medication.

Recruitment was conducted at HIV treatment sites throughout the City of Philadelphia. Participants who were not receiving care for HIV were referred to the outpatient clinic at the Hospital of the University of Pennsylvania. All participants received \$40 per interview. An incentive payment of \$100 was provided to all participants who completed the full complement of five study interviews. The study took place from September 2004 to April 2008. Oversight for the trial was provided by the University of Pennsylvania Institutional Review Board as well by the Philadelphia Department of Public Health Institutional Review Board.

Participant Characteristics

Three-hundred and thirty individuals were screened with 92 individuals ineligible due to an inability to consent or exclusion based on other inclusion criteria. Of the remaining 238 HIV-positive participants with a serious mental illness, 128 were enrolled and randomized to the PATH+ intervention group while 110 were assigned to the Control group. Eleven Experimental Group participants did not complete the study (3 due to death, 4 due to incarceration, 4 requested a formal study withdrawal). Five Control Group participants died before completion of the study protocol (see Figure 1). Fifty-four percent were male, 81% were African American with an average age of 43 (Experimental group: 42.8 ± 6.70 ; Controls: 42.1 ± 7.82 ; range: 18 to 63) (Table I).

Measure of Perceived Coercion

Our perceived coercion measure was modified from the MacArthur Admission Experience Survey (18) in three ways. First, wording in the modified measure refers to 'mental health treatment' rather than 'mental hospital admission' as in the original (20). Second, in order to increase variance, an ordinal scale coded from "strongly disagree" (1) to "strongly agree" (7) was used rather than the dichotomous 'Yes/No' coding of the original instrument. Third,

only items from the Perceived Coercion subscale were administered (Procedural Justice and Voice subscales were omitted in the interest of brevity). The five Perceived Coercion items were (1) I felt free to do what I wanted about getting mental health treatment; (2) I choose to get mental health treatment; (3) It is my idea to get mental health treatment; (4) I have a lot of control over whether I get mental health treatment; and (5) I have more influence than anyone else on whether I get mental health treatment.

Statistical Analyses

To test the adequacy of the perceived coercion measure we used the polychoric alpha as an equivalent measure to the Pearson's R because it is commonly used for ordered-category data and served as an estimate of what the correlation between variables would be if variables were made on a continuous scale (49), Cronbach's alpha (50–51), and confirmatory factor analysis (52) using the baseline data (e.g., pre-intervention) pooling the PATH+ and Control groups. In the regression analysis that does not impose a functional form of change over time, we used seemingly unrelated regression to identify differences in perceived coercion scores by assigned group at each wave.

Our longitudinal analysis plan was guided by structural characteristics of participant contact. Self-report data was collected at baseline and 6, 12, and 24 months, but biomarkers were collected only at baseline, 12, and 24 months. Latent growth curve analysis (53–54) was chosen because it allows estimation of growth curves over the same 24 month time period with differing number of measurement intervals. Here, it was used to determine if perceived coercion was temporally related to length of intervention exposure. Missing data was the proxy for missed appointments or for data from participants enrolled in the study who were lost to follow-up. Because this is an intent-to-treat study, follow-up data for these participants was included in all analyses.

Because our item measures were ordinal, we used Mplus (55) to perform the baseline confirmatory factor analysis on the perceived coercion items. When Mplus encounters ordinal indicators it implements a weighted mean and variance estimator that has been shown to have excellent statistical qualities even with small samples (56). Mplus also has the advantage of using a maximum likelihood estimation method that eliminates list-wise deletion bias of observations when missing values are present (57). All other analysis used STATA, Version 13 (58).

Measurement of the Nursing Dose

During the 12 months of the project, the APNs recorded the activity, person focus, place of intervention activity, mode of communication, and time of each service provided, yielding 20,419 intervention events for participants in the treatment group. Case management was the most common activity (38%) followed by documenting the client (17%) and teaching, guidance, or counseling (15%). The Nursing Dose was calculated as a function of intensity, the time, and duration of the activity. The *intensity* of the activity was a function of the person focus of the activity, the location where it took place, and mode of communication. The person focus was classified as client (88% of the events), medical service provider, or other (e.g., family member, pharmacist). These three foci were coded as reflecting an

intensity score of 5, 3, and 1 respectively. The place of intervention was grouped into client's home (32%), provider's point of service (67%), or other. The intensity score of each was also coded as 5, 3, and 1. The mode of communication was classified as face-to-face (37%), telephone (39%), and other and the intensity codes were identical to the above. The *time* of each activity was measured in minutes (travel time to and from the location of service was entered separately). The *duration* of each activity was the total number of weeks client received services during the intervention year. The *Nursing Dose* was defined as $(A * B) / C$ where A = total number of weeks the client actually received services. B = the intensity score (e.g., the sum of the integers assigned to person, place, and mode of communication) and C = the total time per week of an intervention activity (including all services) summed over each participant and activity for each three-month period of the intervention year (e.g., quarter 1 through 4, M: 1.15 SD: 1.48 at quarter 1; M: .8 SD: 1.25 at quarter 2; M: .6 SD: 1.07 at quarter 3; M: .62 SD: 1.07 at quarter 4).

*Stata code: gen t1dose = (intensity * time_tot)/t1time if t==1*

Coercion and Nursing Dose

To relate Nursing Dose and the coercion index we plot their relationship at three time periods: the first, second, and last quarter of the intervention year (i.e., because there was no survey data on perceived coercion collected at month 9 – quarter 3 – we cannot use the third quarter dose measure). Unfortunately, the Nursing Dose could not be calculated for some treatment group participants, due to missing data, but for the purpose of the coercion analysis, we are concerned with measuring the association between Nursing Dose and the coercion index and not using the dose information to model treatment effects (e.g., interactions between treatment effect size and intervention dosage).

RESULTS

Table I shows the characteristics of the patients and outcome measures by experimental status at baseline. There were no statistically significant differences at baseline between the intervention and control group on any of these demographic characteristics. At baseline, the polychoric alpha of the five coercion items was .83. There was not a significant difference in coercion scores between the experimental and the control groups.

Figure 2 shows the plots of Nursing Dose and coercion for the three time periods. We include a regression (dotted line) as well as a smoothed fit function (dashed line, Cleveland, 1979) to graphically display the association between the two variables. For the first and last quarter of the intervention, there is no association between coercion and dose. For the second quarter, there is a significant positive slope of .35 ($t = 2.74$) relating dose to coercion. However, this is due to a small number of respondents (7) whose coercion values are greater than four. It is, after all, exactly these kinds of outliers that regression weights more heavily in the calculation of the slope measure (Berk, Hennessy, & McCleary, 1976). The figures for the first and third quarters clearly show no association between levels of coercion and Nursing Dose. A significant positive slope was observed during the second quarter. This could be an intervention effect, however, given the small number of participants with the

highest coercion scores ($n=7$ participants recorded a coercion score greater than 4), it is more likely that these are outliers that are spuriously impacting on the regression weight.

The measurement model for the perceived coercion items at baseline using standardized coefficients (Figure 3) shows two correlated error terms (59–60) accounting for residual covariances between Items 2 and 3 (both having to do with *autonomy* to make the mental health treatment decision) and Items 4 and 5 (both having to do with the *self-efficacy* to make the mental health treatment decision). Goodness of fit measures demonstrate excellent model fit (61).

Two approaches were used to look at change over time in the Perceived Coercion scale. First, we use seemingly unrelated regression (SUR) to estimate differences between the PATH+ and Control groups in perceived coercion at each time period under the assumption that the multiple regression equations could be independent. Because the SUR approach estimates all the differences at each wave simultaneously, it does not maximize Type I error in a manner similar to step-wise regression (62). In Table II, very minor differences in the Perceived Coercion scale are shown between groups. Indeed, if anything, perceived coercion appears to be marginally higher for the PATH+ group than Controls (i.e., all PATH+-Control differences are positive) although none of the differences between groups are significant.

We also estimated latent growth models of perceived coercion over time. For a linear model applied to all respondents, the initial (intercept) value at baseline was 1.91 ($p < .05$), but the slope of change over time was $-.001$ ($p = .74$). When we predicted the slope from the experimental status (the intercept at baseline was assumed to be the same for each group given randomization), the Control group slope was $-.003$ ($p = .59$) and the PATH+ group slope was $.001$ ($p = .58$). Therefore, although the slopes of the two groups were of different signs, the change over time was not significant. We also estimated data derived non-linear models (63). For the non-linear time model, both the PATH+ and Control slopes were negative, although the change for PATH+ was less negative than Controls. In any event, both of the slope estimates were non-significant. We conclude from these latent growth curve analyses that perceived coercion was unrelated to duration for either the PATH+ or Control group.

DISCUSSION

Coercion is characterized by compelling the actions of another by force of authority (64). In the case of non-adherence to treatment for individuals who are HIV+ and have a serious mental illness, the essential characteristics of non-adherence are failure to reliably take medications, missed treatment appointments, and engagement in high-risk sex and substance abuse behaviors. As such, these behaviors could be considered to reflect a generalized resistance to engage in the treatment process as demonstrated by a concerted effort to avoid contact with treatment professionals. In this study, we experimentally manipulated coercion up to and including directly observed therapy both for psychiatric and HIV medications; i.e. the APN or network members watched experimental participants actually swallow their medications. In this way, the PATH+ intervention increased engagement at the precise point in time when participants made a resolute effort to disengage. This intervention design

element could have been perceived as coercive, paternalistic, or infantilizing by virtue of the inverse relationship between treatment adherence and intensity of professional involvement, yet our findings indicate that, at least for PATH+ participants, the potential for increased perceived coercion was not experienced.

Research over the past three decades shows that potentially coercive mandates during the earliest stages of mental health treatment are associated with later treatment benefits (48). Consistent with prior findings regarding the valence of treatment outcomes versus procedures that could be considered coercive (65), we found no differences in perceived coercion between Control and PATH+ group participants. Indeed, our findings confirm the potency of intensive community-based services to support and enhance adaptation and recovery (66–67). We need to consider the intersection between the ethics of an effective treatment intervention that embeds coercion as a deliberate but subliminal design feature with long-standing arguments against such a design (14, 68–69). The public health model posits that the presumed benefits of treatment override temporary abridgments of civil liberties (70–72), although we contend that our findings support employment of abridgements only when delivered with the highest of ethical concern for the individual.

A particularly useful paradigm is one that has been developed by the National Association of Prevention Professionals and Advocates (73) who offer five principles for intervention science and treatment delivery (non-discrimination, delivery of services at the highest level of competence, professional integrity, respectful and non-exploitive services, and confidentiality). For the first four principles, the PATH+ intervention has been sensitive and fully accountable. It is only the fifth and final principle, confidentiality, which could potentially be jeopardized within the PATH+ intervention cascade, due to the inclusion of social network members as supportive elements intrinsic to the escalating nature of the intervention itself. However, issues of confidentiality can be ameliorated via the consenting process, which includes full disclosure of the possibility that the social network might be engaged in the interests of treatment adherence.

Much of the coercion literature has been devoted to overt legal elements associated with an involuntary commitment yet legal status appears to be a poor predictor of perceived coercion (8, 22). Bonnie & Monahan (74) have suggested that actions traditionally labeled as ‘coercive’ be re-framed within the dichotomy of ‘threat’ versus ‘offer’ put forward by Wertheimer (75) which proposes an evaluative or decision-making process engaged in by the individual before legal commitment procedures are finalized. This paradigm confirms the relevance of structuring overt coercive processes within a commitment experience characterized by the three classic principles of decision-making: fairness, beneficence, and justice (76).

Study Limitations

Some limitations may have affected obtained results. First, in order to limit the burden on participants, only the Perceived Coercion subscale was administered to participants, resulting in the omission of the Procedural Justice and Voice subscales (18). While reliability testing on the modified measure indicated high internal consistency, without validation testing it is possible that the single subscale may not have been sensitive enough to capture

more subtle aspects of treatment coercion. Second, questions were modified from the original measure restricted to only 'mental health' treatment, excluding consideration of perceptions regarding HIV treatment. Future studies should include the full complement of subscales from the MacArthur Admission Experience Survey within both mental health and HIV treatment domains, which may reveal more nuanced dimensions of perceived coercion between PATH+ and Control group participants. Third, group assignment, while initially blinded to research assistants, may have been disclosed by a few participants during data collection, effectively unblinding group assignment for those participants. Fourth, while prior history of incarceration or involuntary inpatient psychiatric experience would be important to know within the context of coercive community treatment, this information was not collected for this study. Fifth, outside of reliance on the Perceived Coercion subscale of the MacArthur Admission Experience Survey, there is no examination of factors that might influence perceived coercion in the participants, for example, a consideration of severity and duration of psychiatric symptoms at the time of the trial, the quality and extent of case management services, level of education and employment status at the time of the study. Sixth, endorsement frequencies from our measure of perceived coercion were limited to the lower range of coercion responses, which restricted our ability to conduct analyses between low and high perceived coercion groups. Finally, Hoge et al (20) suggest that the subjective quality of coercion underscores the value of multiple respondents who could provide a more complete picture of subject experience. Unfortunately, we collected only egocentric data here.

CONCLUSION

Although the elements of procedural justice are often represented as being of equal import, in practice equivalence between the principles is difficult to achieve with patient advocates and civil libertarians highlighting the importance of autonomy versus the social paternalism often associated with involuntary commitment (77–78). We contend that this ethical dichotomy need not be characterized by competing and non-overlapping positions. A balance between respect for personal autonomy and public health is realized when interventions such as PATH+ are designed to be culturally competent and delivered with integrity, respect and confidentiality by public health professionals.

In our study, in the presence of a measure of perceived coercion that is psychometrically sound, we observed no differences between intervention and control groups over time. Our negative results confirm that we cannot assume that each and every mental health consumer will experience coercion, even when structurally coercive elements are in place if those elements are delivered with fairness, benevolence, and justice. Given the highly sensitive statistical analyses presented, we think it provides compelling evidence that increased coercion was not present even in the group that had the highest Nurse Doses of PATH+. We believe that the unexpected observation of increased coercion within the second quarter is the result of a small number of outliers disproportionately affected the findings, however, it is possible that a larger sample of high perceived coercion respondents might reveal additional insight into this observed non-linear relationship between perceived coercion and treatment adherence over time. Specifically, in a future investigation we would like to test for the presence of a learning curve, where coercive elements might require time for the

participant to perceive them, and then once perceived, the participant might require an adjustment period to consider their coercion experience within a procedural justice framework. From the present study we conclude that it is possible for individual treatment ends to justify the public health means if the intervention is designed and delivered with principals of procedural justice as a foundation.

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Figure 1.
Recruitment and Retention of PATH+ Participants

Figure 2.
Intervention Dose and Coercion at Three Periods During the Intervention Year

Figure 3.
Baseline Measurement Model of Perceived Coercion Items (N = 238)
Notes: $\chi^2 = .75$, $df = 2$, $p = .69$, RMSEA = 0, CFI = 1.0

Table I

Characteristics of PATH+ Participants at Baseline

	PATH+ (n =128)		Control (n = 110)	
	n	%	n	%
Male	67	52%	58	53%
African American	104	81%	87	79%
Mean Age & Standard Deviation	43±6.70		42±7.82	
Mean Perceived Coercion Score & Standard Deviation	1.97±1.22		1.88±1.11	

No respondent characteristics or outcomes measures are significantly different by experimental status.

Perceived Coercion CI: PATH+ (1.76 2.09); Controls (1.67 2.09).

Table II

PATH+ versus Control Differences in Perceived Coercion by Data Collection Period (N = 238)

Data Collection Period	Perceived Coercion Score Average Differences (PATH+ vs Control)
Baseline	.088
Month 3	.135
Month 6	.178
Month 12	.084
Month 24	.221

Notes: None of these differences are significant at the .05 level or less (two tailed tests). The Breusch-Pagan test of independence of residuals is significant:

$\chi^2 = 302.588$, $df = 10$, $p < .05$, so as anticipated, the errors across waves are not independent.