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The impact of representative payee services on medication adherence among unstably housed people living with HIV/AIDS

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ABSTRACT
Rates of viral suppression among people living with HIV/AIDS remain low, especially within marginalized populations such as people who are unstably housed. Representative payee is a service in which the US Social Security Administration appoints an individual or an organization to provide financial management for vulnerable individuals who are unable to manage their finances including housing payments. Little or no published research examines the association between financial management services such as representative payee and HIV clinical adherence. We conducted a pilot study with 18 unstably housed participants living with HIV/AIDS to examine the impact of representative payee services on viral suppression. Of the 11 participants who were not virally suppressed at baseline, 9 (81.8%) of them had achieved viral suppression at six-month follow-up ($p = .004$). Our findings suggest that providing unstably housed people living with HIV/AIDS with representative payee services may help them to improve their housing stability and clinical adherence. Additional research is needed to fully explore correlations between representative payee services and viral suppression.

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HIV; adherence; unstably housed; representative payee; financial managment

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Background

Advances in the treatment of HIV infection have transformed the disease into one that is often manageable and chronic in nature as compared to its early days, when it was fatal for nearly everyone who was infected (Volberding & Deeks, 2010). Unfortunately, retention in care and adherence remain significant challenges for marginalized and vulnerable populations, as indicated by viral suppression rates as low as 13% among individuals who have mental health diagnoses, have substance use disorders, and are unstably housed (Bangsberg et al., 2000; Baum et al., 2009; Friedman et al., 2009; Knowlton et al., 2006; Mann et al., 2012; Milloy, Marshall, Montaner, & Wood, 2012; Mills & Cooper, 2007). Poorer socioeconomic status is also associated with negative clinical outcomes including virological non-suppression (Burch et al., 2014). Viral suppression is an indication of very low viral presence, and is a widely accepted measure of medication adherence. Finding ways to help vulnerable individuals maintain medication adherence is literally a matter of life or death, since viral suppression radically improves one's clinical prognosis (Gardner, McLees, Steiner, Del Rio, & Burman, 2011) and also reduces likelihood of secondary transmission (Bhunu & Loxton, 2015; Cohen et al., 2011).

Representative payee is a financial management service in which the US Social Security Administration appoints an individual or an organization to provide financial management for vulnerable individuals who are unable to manage their financial entitlements, including Social Security Disability Income and Supplemental Security Income payments. While family members or friends may serve as representative payees, in many situations human service organization or for-profit agencies provide this service. The official appointment of representative payees is made at the directive of the Social Security Administration when it is apparent that an individual is unable to manage his/her own funds ("When People Need Help Managing their Money"). In many cases, representative payees are assigned to individuals with depressive symptoms (Weiser et al., 2006), to those with severe mental illness, or to people with histories of homelessness and/or history of substance abuse, especially when there is a demonstrated lack of financial skills (Dixon, Turner, Krauss, Scott, & McNary, 1999; Evans, Wright, Svanum, & Bond, 2004; Luchins, Roberts, & Hanrahan, 2003).

Representative payee services have been examined for their impact on a number of potential client outcomes. The service is often implemented with the aim of

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ensuring the availability of housing and other basic needs, or to limit the purchase of drugs and alcohol (Luchins et al., 1998; Luchins et al., 2003; Rosen & Rosenheck, 1999). A recent randomized controlled trial assessed the impact of representative payee services on housing, quality of life, substance use, and depressive symptoms. This study demonstrated positive trends in the reduction of homelessness, as well as statistically significant decreases in money mismanagement and increases in quality of life (Conrad et al., 2006). However, results are mixed with regard to the impact of these services on substance use. Although it has been demonstrated that monetary reinforcement and representative payee may reduce substance use among some patients with mental illness (Conrad et al., 2006; Shaner et al., 1997), other studies have demonstrated no such effect (Frisman & Rosenheck, 1997; Rosen, McMahon, & Rosenheck, 2007; Rosenheck, 1997; Swartz, Hsieh, & Baumohl, 2003).

Representative payee has also been investigated for its impact on improving mental health clinical outcomes. In some therapeutic settings, representative payee is assigned specifically for this purpose, with the thought that if clients must visit the clinical setting to access funds, they will also access clinical care (Angell, Martinez, Mahoney, & Corrigan, 2007). However, this practice can be associated with feelings of coercion and reduced client autonomy (Appelbaum & Redlich, 2006). When representative payee is used as coercion to promote adherence, this approach can lead to conflict and interruptions within the therapeutic relationship (Angell et al., 2007).

It is likely that the perceived value of representative payee and the experience of coercion by the client are predicated upon the intent of the service as well as subsequent positive outcomes. Not surprisingly, consumers do not find representative payee services to be useful or desirable when access to financial benefits is conditioned upon adherence to mental health regimens (Elbogen, Soriano, Van Dorn, Swartz, & Swanson, 2005). Clients who continue to struggle with mental health adherence, both in terms of attending appointments and taking medications as prescribed, are more likely than those who are adherent to perceive representative payee services as being coercive (Elbogen, Swanson, & Swartz, 2003). Individuals who experience representative payee services as being coercive are more likely to report coercion in other areas, such as in housing services, criminal sanctions, or outpatient commitments (Appelbaum & Redlich, 2006), suggesting that resources and services are all too often provided with conditional expectations. It seems contradictory that although many recovery models regarding substance use prioritize personal responsibility, money management for using substances has historically been linked with limiting client choice in an effort to control client behaviors, thus reinforcing client powerlessness (Torrey & Wyzik, 2000). Representative payee would likely demonstrate the most positive outcomes if these services incorporated client-identified outcomes as a means to improve personal responsibility (Rowe, Serowik, Ablondi, Wilber, & Rosen, 2013).

The associations between representative payee services and adherence to HIV clinical regimens have not yet been documented. This is a significant research gap given that HIV medication adherence rates remain low, especially among the same marginalized populations that often receive representative payee services (Bangsberg et al., 2000; Baum et al., 2009; Friedman et al., 2009; Knowlton et al., 2006; Mann et al., 2012; Milloy et al., 2012; Mills & Cooper, 2007). This paper describes one setting in which representative payee was implemented using a client-centered approach to ensure clients' basic needs would be met, and reports results of a study that was completed to explore correlations between representative payee services and viral load status. The ultimate goal of representative payee in this setting is to improve HIV clinical adherence among homeless or unstably housed individuals.

Methods

The Open Door, Inc. is a 15-unit supportive housing program that has been shown to improve clinical outcomes for chronically homeless individuals living with HIV/AIDS (Hawk & Davis, 2012). Results from a 2012 qualitative research study with residents indicated that the provision of representative payee services was a critical step in the path to adherence (Davis, Hawk, Marx, & Hunsaker, 2014). In response to these findings, the program expanded its services beyond the provision of supportive housing for homeless individuals to include representative payee services for those who are unstably housed but not living in the program. Representative payee clients of this program include those who are homeless from the street, live in transitional or bridge housing, temporarily live in the homes of friends or families, or live in their own apartments with eviction notices or with histories of inability to pay rent or otherwise maintain stable housing.

As compared to traditional representative payee situations, including those in which the Social Security Administration mandates representative payee assignment, clients in this program voluntarily enroll and are able to terminate the representative payee service at any time by notifying Social Security. However, clients

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are referred to the service by clinical and supportive service providers primarily because they repeatedly experience financial chaos, housing instability and homelessness, and the inability to maintain medication adherence. The Open Door reports that while many clients are initially reluctant to have someone else manage their funds, they agree to accept the referral to the representative payee program when they recognize that they are caught in repeated cycles of instability.

The current study used pre- and post-intervention comparison to assess the degree to which representative payee services were associated with decreases in viral suppression, which is widely used as a measure of antiretroviral adherence. Viral load < 200 copies/ml was used as the cut point for viral suppression in keeping with the practices of local HIV clinics where participants received care. The study included client viral load data collected from December 2012 to January 2014. During this period, the program enrolled 40 new representative payee clients. Since the study collected only de-identified viral load and engaged no human subjects, it received exempt approval from the University of Pittsburgh Institutional Review Board.

Because the purpose of this study was to assess for changes in viral load status correlated with representative payee services and not housing, clients who received housing services in addition to representative payee services were excluded from this study. Therefore, inclusion criteria for this study were individuals who were prescribed antiretroviral regimens and who received representative payee services from The Open Door during the study period but did not reside at the program. Twenty-five participants met these inclusion criteria; however, pre- and post-intervention viral load data were only available for 18 of them, primarily because clients were out of care prior to representative payee enrollment.

Client viral load data were collected by staff of The Open Door from medical providers at baseline and six months after the initiation of representative payee services for each client. All of the clients remained in services at the six-month follow-up point. The study hypothesis was that six months after assignment to representative payee, a greater proportion of clients would demonstrate improved rates of viral suppression. Using 200 copies/ml as the cut point for viral suppression, a McNemar's test was conducted to assess paired samples data, examining the number of study participants who were not virally suppressed at baseline but were virally suppressed at follow-up. SPSS 22 was used for all analyses. Using a Fisher's exact test, we also examined correlations between viral suppression and mental health diagnoses as well as between viral suppression and substance use disorders.

Table 1. Participant demographics, $N = 18$.

Age	
Range	39–63
Mean (SD)	51.0 (6.4)
Race	
African-American	14 (78%)
Caucasian	4 (22%)
Gender	
Male	14 (78%)
Female	4 (22%)
Substance use disorder	
Yes	15 (78%)
No	3 (22%)
Mental health diagnosis	
Yes	17 (94.4%)
No	1 (5.6%)

Results

Of the 18 study participants, 14 were African-American and 4 were Caucasian, while 14 were male and 4 were female (Table 1). Only clients for whom viral load data were available prior to initiation of representative payee services were included in this study, and the average number of days between the date of last viral load test and initiation of services was 69. Baseline viral load data for residents ranged from undetectable to 48,850 copies/ml with a mean of 11,512 (SD = 17,457.7). Follow-up viral load counts were measured at six months after initiation of services and ranged from undetectable to 2700 copies/ml, with a mean of 257 (SD = 686.3). As given in Table 2, a total of 7 (38.9%) of the participants had undetectable viral loads at baseline and 16 (88.9%) of them had undetectable viral loads at follow-up. Of the 11 participants who were not virally suppressed at baseline, 9 (81.8%) of them had achieved viral suppression at six-month follow-up ($p = .004$). Only two individuals (11.1%) were not virally suppressed at baseline or at follow-up.

Results of the Fisher's exact test examining correlations between viral suppression and mental health diagnoses as well as between viral suppression and substance use disorders are demonstrated in Table 3. Of the 15 people who had diagnoses of substance use disorders, 13 were virally suppressed at follow-up and 2

Table 2. Viral suppression: Viral load < 200 copies/ml.

	Viral suppression at follow-up			*p*-Value
Viral suppression at baseline	No	Yes	Total	
No	2	9	11	*.004*
Yes	0	7	7	
Total	2	16	18	

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Table 3. Substance use disorders and viral suppression at follow-up.

	Viral suppression at follow-up			*p*-Value
Substance use disorder	No	Yes	Total	
No	0	3	3	*.686*
Yes	2	13	15	
Total	2	16	18	

Table 4. Mental health diagnosis and viral suppression at follow-up.

	Viral suppression at follow-up			*p*-Value
Mental health diagnosis	No	Yes	Total	
No	1	0	1	*.111*
Yes	1	16	17	
Total	2	16	18	

were not ($p = .686$). Of the 17 people who had mental health diagnoses, 16 of them were virally suppressed at follow-up and 1 was not ($p = .111$) (Table 4). The most prevalent mental health diagnoses included depression (10), anxiety (5), bipolar disorder (4), and schizophrenia (3), with most clients having more than one diagnosis.

Discussion

Our findings suggest that providing marginalized and unstably housed people living with HIV/AIDS with financial management services may help them to decrease their viral loads. The results are promising given that 89% of participants were virally suppressed at follow-up, which compares to only 28% of all people living with HIV in the USA who are virally suppressed (Gardner et al., 2011). The number of participants who had detectable viral load counts at baseline but were undetectable at six-month follow-up may be even greater than reported here, given that data were unavailable for seven participants. Because these individuals were largely out of clinical care at initiation of representative payee services, it is likely that some or all of them would have demonstrated marked improvements in viral load status at follow-up.

Interpretation of findings is limited given the small sample size, and causal links cannot be inferred given that confounders were not assessed, such as the degree to which participants engaged in outside services during the study period. In addition, participants were not randomized to the intervention but agreed to participate after being referred by providers, primarily because the clients had experienced repeated episodes of homelessness, financial chaos, and inability to adhere to treatment regimens. In spite of the limitations that are inherent to non-randomized trials, this study may represent a realistic picture of what typical representative payee clients may experience.

It is encouraging there were no significant differences in viral suppression at follow-up for individuals with or without mental health diagnoses and substance use disorders, as this suggests that representative payee services may be effective for the most marginalized populations. In fact, when examining people with mental health diagnoses and substance use disorders, a greater proportion of people in each category achieved viral suppression than did not. This finding suggests that the intervention may be effective for a range of individuals, including those with substance use disorders and mental health diagnoses. The approach is also consistent with harm reduction methods that have shown to be effective in improving outcomes for substance users (Bamberger et al., 2000; Douaihy, Stowell, Bui, Daley, & Salloum, 2005), since this model of representative payee service prioritizes client-centered outcomes.

All of the clients enrolled in this study agreed to participate in this intervention without coercion and with no other incentive other than the goal of improved financial and housing stability. However, most clients were generally reluctant to have someone else manage their money and agreed to this arrangement with the full recognition that it was a salvage attempt to reduce the chaos in their lives, given that they had historically been unable to achieve treatment adherence and viral suppression. Though not reported here, client satisfaction with representative payee services at six-month follow-up was high, suggesting improved levels of acceptance over time. Additional follow-up is needed to assess persistence of viral suppression. However, these initial findings are promising and suggest that this approach to care may present an opportunity to improve HIV clinical adherence in unstably housed individuals.

As noted previously, representative payee has often been assigned as a mandate of the Social Security Administration or as a coercive measure to push clients toward prescribed treatment outcomes, especially when mental health diagnoses or substance use disorders are present. These traditional representative payee models may serve to further marginalize already vulnerable individuals. The Open Door uses a client-centered approach in which the client self-enrolls in the service, decides how his/her funds will be disbursed, and has the ability to terminate the service at any time. The program also uses peer staff members as the main point of contact for representative payee services, and these staff members are able to quickly build trust and rapport with clients. The peer staff members operate from a harm reduction perspective, which prioritizes the client's self-determined

goals and focuses on helping the client move to the next lowest acceptable level of risk on the path toward optimal health. As such, they are able to help clients understand the self-determination they have in voluntarily signing up for services that support their personal health goals. This client-centered representative payee framework is likely to improve the client experience, and, in turn, maximize its impact on client outcomes.

Additional research is needed to fully explore correlations between financial management services and viral suppression, as well as to establish mechanisms for change. Anecdotal feedback from participants suggests that by decreasing financial and housing chaos, individuals are able to spend more physical and emotional energy on their health and on engaging in care. It may also be the case that engaging in representative payee services exposes clients to additional providers who support their positive health outcomes. If financial management services such as representative payee are found to be replicable and cost-effective in improving stability and medication adherence, the approach may be translated for use with other vulnerable populations in helping them engage and retain in care. For example, this service may provide an avenue to help people who are HIV-negative but at high risk for infection successfully access and maintain compliance with Pre-exposure Prophylaxis regimens.

It is clear that despite the availability of effective clinical regimens, large numbers of people living with HIV/AIDS are not able to retain in care and maintain antiretroviral adherence. Multi-faceted structural barriers exist that continue to keep people from retaining in care. We must explore avenues to reduce these barriers and provide services that are relevant to clients' housing and other challenges. Our findings suggest that representative payee services may be one key to unlocking care for marginalized populations.

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Disclosure statement

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