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Adherence among chaos: Exploring how control and relationships influence adherence to HIV medication

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Abstract: While many HIV-positive individuals with "chaotic" lives (e.g. unstable housing, substance use, etc.) have difficulty adhering to their antiretroviral therapy (ART), others have achieved successful adherence. We used focused ethnography to interview 14 HIV-positive individuals to learn why, despite their chaotic lives, they were able to achieve consistent ART adherence. Data revealed that participants felt that while they had little or no control over their life circumstances they recognized that, by taking their ART, they could have control over their HIV. Social services and health care providers must incorporate support for this sense of control in efforts to improve adherence

Subjects: Ethnography & Methodology; Research methods; Sociology of Health and Illness; HIV/AIDs; Quality of Life; AIDS & HIV Infection

Keywords: HIV/AIDS; medication adherence; control; relationships; health care; focused ethnography

1. Introduction

HIV/AIDS impacts millions of people worldwide. At the end of 2016, an estimated 36.7 million people were living with HIV/AIDS (UNAIDS, 2018). Successful treatment of HIV/AIDS demands strict adherence to antiretroviral therapy (ART) over the course of life-long treatment (Department of Health &

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ABOUT THE AUTHORS

We are a team of researchers from University of Alberta who worked with staff at the Northern Alberta HIV Program (NAP) and HIV-positive individuals who attend the NAP to find out reasons for HIV medication success. Throughout our research we discussed how to effectively share our findings and decided to create a video, "Living with HIV and it's OK". Our video features HIV-positive participants, HIV physicians, and pharmacists talking about reasons for HIV medication success. We shared our research by hosting pizza parties at a local HIV organization where our participants talked about their experience in the research, shared our video and hosted a chat. Clients of the organization told us "it was cool to hear from the celebrities themselves". To us, this meant, our participants and research inspired community members to the gain confidence to make positive changes in their lives.

PUBLIC INTEREST STATEMENT

Worldwide, 36.7 million people live with HIV, and of these, 20.9 million take HIV medication. But not everyone takes their HIV medication all the time. We wanted to learn why HIV-positive individuals with "chaotic" lives (e.g. homelessness, substance use, sex trade involvement, incarceration) were able to take their HIV medication all the time, despite living in "chaos". We know a lot about why people don't take their HIV medication, however, we don't know a lot about reasons for success. We wanted to learn from the experts and worked alongside HIV-positive individuals who always take their HIV medication and HIV clinicians at a Canadian HIV clinic. We identified "control" was the cornerstone for consistently taking medication. Participants felt while they had little control over their life circumstances. They recognized, however, by taking their HIV medication they could have control over their HIV, which enabled them to make additional positive life changes.

Human Services, 2014). Individuals need to achieve and maintain high adherence levels to suppress the HIV-1 viral load (VL), prevent drug resistance and disease progression, and minimize the risk of ongoing transmission (Bangsberg, 2008; Cohen et al., 2011). Development of drug resistance mutations in non-adherent individuals can make current treatment ineffective and lead to virologic and immunologic failure (Liao et al., 2013). From a community health perspective this is significant because a drug-resistant strain of HIV caused by non-adherence can be transmitted to uninfected persons, leaving newly infected and previously treatment naïve individuals with reduced treatment options (Taniguchi et al., 2012).

It is unclear from the literature what individual, social, and systemic factors are associated with not achieving and maintaining good adherence. Further, reviews on ART adherence barriers have revealed inconsistent findings (Atkinson & Petrozzino, 2009; Mills et al., 2006; Malta, Strathdee, Magnanini, & Bastos, 2008). Atkinson and Petrozzino (2009) identified a number of barriers, including therapy-related (e.g. type of regimen prescribed), condition-related (e.g. number of HIV-related adverse events) and patient-related factors (e.g. hopelessness, depression) associated with poor adherence from 22 studies worldwide. However, using data from quantitative and qualitative studies, Mills et al. (2006) suggested that the region where the study was conducted, adherence cut-off points, and study quality can explain differences in barriers to achieving good adherence. Conversely, a systematic review by Malta et al. (2008) stated that active substance abuse, depression, and low social support are barriers to adherence.

While ART adherence barriers have been well documented, little attention has been given to facilitators of ART adherence, exploring *success* rather than failure. In a review of qualitative adherence literature, Vervoort, Borleffs, Hoepelman, and Grypdonck (2007) highlighted processes associated with ART adherence. They suggested individuals should adapt their ART regimen to their lifestyle rather than their lifestyle to their ART regimen. A multi-centre US study conducted from 2000–2005 identified baseline factors which differentiated injection drug users' (IDU) ART treatment success versus failure. Findings indicated those having informal care, such as emotional or peer support, were more likely to be successful. These authors suggested their findings underscore the importance of social factors for successful ART outcomes among IDUs (Knowlton et al., 2007).

Although some research has attempted to clarify determinants of ART adherence, findings are inconsistent, focus primarily on therapy-related barriers, and are confined within a ten-year time period (1996–2006). Staff at the Northern Alberta HIV Program (NAP) in Canada have commented on how some HIV-positive individuals with chaotic lives (e.g. unstable housing, substance use, involvement in the sex trade, and/or incarceration) have maintained consistent ART adherence over prolonged periods of time. Because understanding consistent adherence to ART is such a community practice priority, our objective in this research was to describe why some HIV-positive individuals with chaotic lives attending the NAP were able to consistently adhere to their ART.

2. Methods

Our study was guided by principles of community-based participatory research and focused ethnography (Mayan, 2009). Rigor was ensured according to Morse, Barrett, Mayan, Olsen, and Spiers (2002).

2.1. Setting

Our study involved HIV-positive individuals attending the NAP. The NAP provides care by an interdisciplinary healthcare team (i.e. infectious disease physicians, nurses, pharmacists, social workers, psychologists, dietitians) to all HIV-positive individuals in northern Alberta. HIV-positive individuals are seen four weeks after initiating ART and then every three to four months; additional support may be provided by team members between physician visits. Antiretroviral prescribing is limited to infectious disease physicians and ART is dispensed from outpatient pharmacies. ART and associated testing (i.e. CD4 cell counts, VL measurements, genotypic ART sensitivity testing) is provided at no cost to the individual through a provincial government program. Viral load is typically monitored either prior to, or at each visit, as part of routine care.

The NAP currently cares for roughly 2,000 individuals with approximately 100 new HIV-positive individuals per year. The population of HIV-positive individuals in northern Alberta is heterogeneous; 50% of individuals are Canadian-born, non-Aboriginal; one third of individuals identify as Canadian-born Aboriginal or Métis; and 20% are foreign-born. Similarly, there is a variety of HIV transmission risk groups, including heterosexual transmission, men who have sex with men, and IDU. A substantial proportion of individuals have mental health and socio-economic obstacles to adherence such as unstable housing, substance use, mental illness, involvement in the sex trade, and / or incarceration, comprising a broad spectrum of threats to adherence. The program focuses on enhancing access to care among such individuals through the activities of program staff and connections with community organizations (e.g. collaborating with inner-city community-based organizations to address adherence barriers).

2.2. Sample

Study participants included 14 HIV-positive individuals who experienced chaotic lives, but were able to maintain consistent ART adherence ≥ one year. Our inclusion criteria were individuals who: (1) experienced chaotic lives; (2) were prescribed ART for ≥ 12 months; (3) maintained consistent ART adherence (i.e. HIV treatment success) for ≥12 consecutive months; and (4) were ≥15 years of age when starting ART. We defined ART as a combination of at least three antiretrovirals, other than ritonavir, recorded as prescribed on the same date. We defined the start of ART as the first date that an ART prescription was recorded in the NAP database and we assumed participants remained on ART. We defined consistent ART adherence as those individuals who maintained virologic suppression (VL ≤50 copies/mL) for the previous ≥12 consecutive months. Virologic suppression is objective and the biologically/clinically relevant indicator of treatment success (Hoffmann & Mulcahy, 2007). Therefore, since NAP staff collect HIV-related information and laboratory results are reviewed at each individual's clinic visit, clinicians could determine if an individual had maintained consistent ART adherence. We excluded participants if they: (1) were missing VL data for ≥6 consecutive months; (2) were prescribed directly observed ART; or (3) started ART ≤26 weeks before delivering a baby.

From this potential pool of participants, we used purposeful sampling whereby key informants from the NAP identified individuals who would be able to articulate their experiences and approached them following their routine clinic visits. Staff described our research and if the participant agreed to participate, staff reviewed the information letter with the participant, obtained written informed consent, and scheduled an interview. We offered participants a $25 honorarium. The participants' (11 men and three women) ages varied from 37 to 57 years. The participants had been aware of their HIV status for between two and 26 years and the duration of ART treatment varied between two and 16 years.

2.3. Data collection and analysis

We collected data using unstructured one-on-one interviews. The main question asked was, "why are you able to take your HIV medication all the time?". Additional questions included the experience of taking ART (e.g. "how are you doing on your HIV medication?"), general ART adherence questions (e.g. "why do you think people take their HIV medication?") and questions about daily life. We conducted all interviews in a clinical examination room at the HIV clinic; interviews were audio-recorded and lasted approximately one hour.

Using qualitative content analysis, our goal was to describe facilitators of adherence by systematically identifying, coding, and categorizing patterns (Mayan, 2009; Hsiu-Fang & Shannon, 2005). Data collection and analysis were iterative wherein evolving categories were alternately compared to new data and modified when necessary. The evolving analysis was brought to the co-investigators, the NAP staff, and the participants themselves for further analysis and interpretation. These three groups confirmed the final analysis and interpretation independently.

3. Findings

Participants spoke about their HIV medication regimen, their daily adherence to HIV medication, and their daily life in substantial detail. The following categories and overall theme of control capture why participants consistently adhere to their ART.

3.1. To be with my family

Every participant spoke about how their family connection, support, love, and involvement motivated them to continually take their ART despite their chaotic lives. Family was broadly defined: Immediate family; step-family; friends; and the NAP staff. Although participants were not thinking of family at the moment they took their pills, they understood that taking their ART afforded them the ability to be part of their family. A woman described her initial reluctance to take her medication, and on account of her family, she changed,

> I didn't want to be here anymore, the depression caught up with me, I started drinking and it took me two years to realize that my kids love me…and my boyfriend telling me that you need to take your medication. I didn't take it right away but eventually when I did decided to take it, that's what kept me taking it. So my motivation for my kids and my boyfriend. They gave me back that hope that I lost two years ago.

The effect that family had on these participants was underscored when a participant explained that he took his medication to be able to see his son. When asked what advice this participant would offer to an HIV-positive individual struggling with consistent adherence, he said, "You want to live don't you? And I'd tell them, don't you have kids? You want to see them grow up." These participants clearly illustrated that 'family' provided meaning to their lives and was a powerful motivator for lifelong adherence.

3.2. Because I am grateful

Participants appreciated what and who they have in their lives. Although these participants faced extremely tough situations, they focused on the positive and were grateful for the ability to "participate" in life. As such, a participant offered,

> I owe a lot to a couple of family members who stood by me, and I don't know if you can apply this to anyone else and use it as a trick, but it's my story. My mom took care of me for a lot of years and watched me decline and enabled my drug use to a large extent, um I'm honored to start looking after my mom. You know, her and I are friends today. Our relationship was pretty toxic, as you can imagine. Today we laugh and we enjoy each other's company, to an extent!

One man talked about being grateful for having a home and being fortunate enough to have his family in his home,

> They [participant's children] were on the street, in foster care, my wife was in jail and we all finally, we're all living together, and my kids are safe, one's working, one's just at home, my wife's at home, we got a dog. And we have a home. But you know, something as simple as that, everybody could be all broken up or in jail or on the street.

Another participant reflected on how he "got on board" and began taking his medication properly because he recognized that he "was being given an opportunity to sort of re-do my life". He realized he had "been given another chance" and later stated "it's an honor for me to be able to participate [in life]." Lastly, participants often used the word "grateful" not only for what, who, and where they were, but also for their ART being covered by the provincial government, "I don't feel sorry for myself, you know, I guess I'm just a pretty grateful guy. Shit, the pills are covered [by provincial government], you know."

3.3. Because I am important

Many participants described how today, amongst their chaotic lives, they took responsibility for their actions and had confidence in themselves to cope with challenging circumstances including taking their medications consistently. Participants were able to face life's adversities, to understand and solve problems, acknowledge their right to achieve happiness and be given respect. One participant, because of the encouragement he received from a health care professional, had a "big epiphany",

> I've probably went to 15–18 treatment centres over a 26-year cocaine addiction. Yeah, most people don't live that long, you know and my psychologist looked at me once, five years ago, probably the most meaningful thing she ever said, was 'you are incredibly intact for what you've been through.' You know, I was all beat up at the time, I don't mean physically beaten by someone, but beaten by myself and I hung on to that [what she said], and, I am *not* a complete waste of skin.

This sense of self-worth was shared by other participants when they spoke about having satisfaction from taking care of themselves, "not just thinking good things about themselves, but actually taking action". Another participant remarked,

> You find out what you want from yourself, 'cause if you want to die, it's easy to die, but if you want to live, just that one pill, and watch your life start to become better. It can't get any worse, because that's where you are right now. You're dead zone. But if you start to take the moves you were scared to take when you were sick, now you're beaming with all these things to do, to keep you wanting to live, to progress, to go on, and to care, to love, to share, to be part of the world.

3.4. Clinic staff and community support workers care about me

According to participants, the NAP staff and community workers treated them with respect and sincerely cared for their well-being. These participants trusted the staff; as one participant commented, "they are all here to help me, so I just know that they want the best for me and they would never steer me wrong." To most participants, the NAP staff were like "the family we never had because they [NAP staff] focus on the positive, whereas our family focuses on the negative". As a result, participants were motivated, confident, and determined to be as healthy as possible by consistently taking their ART. A participant explained how seeing his doctor smile, because of something *he* did, motivated him to stay on his HIV medication,

> He goes 'check this; this is what I want to show you.' He showed me my blood, my counts, and my CD counts and everything, and he says 'right here.' You know it's going to be up and down cause of the medication. But as of now, you can't detect any HIV in my body. And the face, and the smile on him, it was just elating me. It was like, wow, look at this guy, he was just happy, you know, over me.

Participants noted that the care at the NAP was not only from their physician, but from the *team*, including nurses, psychologists, pharmacists, dietitians, social workers, and administrative assistants. A participant said "I met all these magnificent people up here, you know, and they've just been wonderful." Another woman remarked,

> [Participant's doctor] is one of the best to talk to. I like coming here, since I've known him he's been great to me so, keeps you more confident because he has a whole team of people that help you out, it's not just one person, you have a dietitian you have a social worker you have these ladies if you need them.

3.5. Participants can have control: An overarching theme

Why do participants adhere to their HIV medication? The theme of control, which is woven throughout the above categories, answers this question. The nature of participants' "chaotic" lives did not allow for a lot of control over their lives (e.g. "I'm a slave to drugs", "I wasn't raised right as a baby"). But participants saw their "chaos" and their HIV separately. Participants recognized that by taking

their ART they could have control over their HIV, which enabled them to become stronger. As such, participants understood that they *were* in control of doing something positive for themselves and had the ability to express gratitude for and appreciate meaning in their life, largely involving family. Further, participant constructive behaviour was positively reinforced by workers within the community and the NAP.

4. Discussion

Our findings raise important considerations for healthcare professionals and community services workers about participants' reasoning behind ART adherence; consistent ART adherence provided these participants with the ability to have "control" over one important part of their lives, despite living in "chaos". According to conventional ART adherence literature, determinants of adherence correspond to five factors defined by the World Health Organization (2003): therapy-related (e.g. regimen complexity, side-effect severity and previous treatment failures), condition-related (e.g. rate of disease progression and disease severity), patient-related (e.g. substance abuse, depression, age, and attitude and beliefs towards treatment), health system (e.g. the patient-provider relationship, lack of health services, and poor medication distribution systems), and social/economic factors (e.g. poverty, low education, unemployment, lack of social support and unstable living conditions). Our research, however, provides insight beyond this traditional view and explains adherence from the psychological perspective of internal locus of control which addresses the question: Do you believe you are in control of your life, or that your life is controlled by powers outside of your control? (Rotter, 1966).

Few studies have investigated the concept of control and ART *adherence*, and the findings are mixed. Lynam et al. (2009) suggested there was no relationship between internal locus of control and ART adherence. Whereas Evans, Ferrando, Rabkin, and Fishman (2000) explored the multiple dimensions within locus of control (i.e. the self, powerful others, and chance) to determine the best predictor of ART success. Evans et al.'s findings suggest a significant relationship between believing in powerful others, such as physicians and other healthcare professionals, and ART adherence.

Our data also suggest a large motivation for participant medication success was their meaning in life, largely involving family (broadly defined). Interestingly, when we worked alongside the NAP staff to analyze the data, some clinicians were unaware of the importance of "family" on ART adherence; these clinicians routinely failed to ask participants about their family within the context of ART adherence. This finding underscores the value of adopting a broad view of health and ART adherence and including this in clinical practice with this population.

There are limitations to our findings. Canadian society is highly heterogeneous, and although we gathered data in an urban setting in Canada, we did not interview HIV-positive immigrants or refugees. Reasons for ART adherence should be explored in other vulnerable populations, such as "chaotic" HIV-positive recent refugee individuals. Future qualitative inquiry is also needed to understand the perspectives of those who care for and influence HIV-positive individuals, including HIV-related healthcare professionals and community service workers within local HIV community organizations.

5. Conclusion

We worked with local HIV clinicians and asked the most valuable source of ART-related experience information, the HIV-positive individuals, why they were able to maintain consistent ART adherence. We identified "control" as a cornerstone for these individuals to maintain adherence; a determinant not usually considered within traditional views of ART adherence. Meaning to one's life, relating to family (broadly defined), positive interactions with and support from community organizations, and local HIV programs may provide the necessary self-worth to overcome life- and illness-related difficulties. Lastly, the impact of a person's worldview cannot be ignored; clinicians must be aware of the extent to which a person believes he/she can control their HIV which, subsequently, may impact his/her ability to adhere to ART. Clinicians and community services workers should be mindful of the influence psychosocial factors, such as control, have on consistent ART adherence and adopt a broad perspective of determinants of adherence when addressing adherence-related concerns.

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Competing interests
The authors declare no competing interest.

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