Published in final edited form as:

AIDS Care. 2018 November ; 30(11): 1400–1405. doi:10.1080/09540121.2018.1492699.

Exploring the dynamics of ART adherence in the context of a mindfulness instruction intervention among youth living with HIV in Baltimore, Maryland

Deanna Kerrigan¹, Suzanne M. Grieb², Jonathan Ellen³, Erica Sibinga²

¹Department of Health, Behavior & Society, Johns Hopkins Bloomberg School of Public Health

²Department of Pediatrics, Johns Hopkins School of Medicine

³Johns Hopkins All Children's Hospital

Abstract

Youth living with HIV have sub-optimal rates of adherence to antiretroviral therapy (ART). Mindfulness instruction interventions have shown promise for improving medication adherence, but the effects and mechanisms of these interventions are still being explored among people living with HIV, including youth. In the context of a randomized controlled trial of the efficacy of a Mindfulness-Based Stress Reduction (MBSR) program on ART adherence and viral suppression among youth living with HIV, we conducted 44 iterative, semi-structured, in-depth interviews with 20 study participants (13–24 years) recruited from clinics at two academic centers in Baltimore, Maryland. Interviews explored the social context and psychosocial dynamics of ART adherence in the context of the MBSR intervention, compared with those in a control arm. We employed thematic content analysis to systematically code and synthesize textual interview data. Participants' challenges with ART adherence were often situated within an ongoing process of working to manage HIV as a stigmatized, chronic condition in addition to other intersecting social stigmas, inequalities, and stressors. Participation in the MBSR program and related group support allowed participants to non-judgmentally observe and accept difficult thoughts, feelings, and experiences associated with living with HIV and taking ART, which facilitated greater reported adherence. Mindfulness training may stimulate new perspectives and understanding, including greater self- and illness-acceptance among youth living with HIV, leading to improved HIV outcomes.

Introduction

There are an estimated 2.1 million adolescents (10–19 years of age) living with HIV worldwide (UNICEF, 2017). Over the last two decades important advances have occurred in the global response to HIV, with significant reductions (48%) in AIDS mortality, as a result of growing access to antiretroviral therapy (ART) (UNAIDS, 2017). AIDS deaths have

Corresponding author: Deanna Kerrigan, PhD, MPH, Department of Health, Behavior & Society, Johns Hopkins Bloomberg School of Public Health, 624 North Broadway Street, HH257, Baltimore, MD 21205, Telephone: (410)-955-2218/ dkerrig1@jhu.edu.

Geolocation

This research was conducted in Baltimore, Maryland. United States of America.

declined in every age group except adolescents in recent years (UNICEF, 2016). HIV deaths have actually tripled since 2000 among adolescents, making AIDS the second leading cause of death for this group, globally (UNICEF, 2017).

ART adherence among adolescents and young adults is crucial to both their individual health and ongoing HIV transmission dynamics, given that 30% of all new infections occur among ages 15–24 (UNAIDS, 2017). A recent meta-analysis documented the sub-optimal rates of ART adherence (62.3%) in this age group across geographic regions, with the lowest rates of ART adherence observed in the North American region (53%) (Kim et al., 2014). To date, limited intervention models have been shown to be effective in improving ART adherence for adolescents and young adults living with HIV.

Prior research has documented a relationship between mindfulness and increased adherence to medications for a variety of health conditions (Salmoirago-Blotcher & Carey, 2017), including HIV treatment adherence (Riley & Kalichman, 2015). In our prior research with HIV-infected youth in Baltimore, Maryland, mindfulness was shown to improve coping and life satisfaction. Mindfulness program participants were also more likely than controls to have low HIV viral loads at follow-up, presumably representing improved ART adherence (Webb et al., 2017). In addition to supporting medication adherence, there is a robust evidence base for the role of mindfulness in improving mental health and well-being (e.g., Goyal et al., 2014; Sibinga et al., 2016).

HIV is a stigmatized and chronic condition that disproportionately impacts already marginalized populations. As such, many people living with HIV may confront multiple socio-structural challenges that intersect with the experience of living with HIV (Parker & Aggleton, 2003). Socio-structural factors, such as stigma and discrimination, have been found to be associated with lower ART adherence across populations (Katz et al., 2013). Internalized stigma may be particularly salient among young people, as learning to live with HIV may occur within the context of the ongoing developmental processes of developing a healthy relationship to oneself and others (Hosek et al., 2005).

Acceptance, including learning to accept the aspects and characteristics of ourselves that we do not care for, is understood as a key component of mindfulness training. Mindfulness meditation is often understood as an opportunity to be fully present and to observe, sit with, and accept the thoughts and feelings that we have about our “imperfection,” rather than striving to fix or change ourselves (Brach, 2003). While research surrounding mindfulness and HIV behaviors, including ART adherence, has been growing in recent years, the mechanisms via which mindfulness may impact adherence have yet to be fully explored. The aim of this manuscript is to examine the psychosocial dynamics of ART adherence and the influence of mindfulness training on adherence among youth living with HIV in Baltimore, Maryland.

Methods

Parent Study

This qualitative study was embedded into a randomized controlled trial, Mindfulness for ART medication adherence in HIV-infected youth (). The parent trial is aimed at assessing the efficacy of a mindfulness-based stress reduction (MBSR) intervention on ART adherence in adolescents and young adults (13–24 years old) living with HIV (n=74). Participants were recruited from two academic clinics in Baltimore, Maryland (Johns Hopkins Hospital and University of Maryland Medical Center). The trial was originally designed with three arms. Early on, the two control arms were collapsed into one due to enrollment and sample size considerations. The final breakdown between arms was: MBSR (n=34), active control (n=32) and usual care (n=8).

Intervention Description

The MBSR intervention implemented involved a structured program designed to cultivate mindfulness, a focused non-judgmental awareness of present moment experience, and was previously adapted for youth from the widely used curriculum developed by Dr. Jon Kabat-Zinn at the Center for Mindfulness of the University of Massachusetts School of Medicine (Kabat-Zinn, 2013). MBSR has been previously shown to reduce stress, anxiety, and depression (Khoury et al., 2015; Goyal et al., 2014). The adapted MBSR intervention consists of eight 2-hour weekly sessions and one 3-hour retreat led by trained and experienced MBSR instructors with personal mindfulness practices (Sibinga et al., 2011).

The program included materials, exercises, and discussion related to mindfulness, meditation, yoga, and the mind-body connection. While participants were recruited because they were living with HIV, HIV was not an intended or explicit focus in the MBSR or health education programs, unless brought up by participants. Participants in the control conditions received either an eight-week health education program called Healthy Topics adapted from the Glencoe Health Curriculum (McGraw Hill, 2005) or usual care consisting of clinic visits and laboratory assessments every three months.

Participants

We conducted a qualitative sub-study among 20 participants from the parent study. We utilized purposive sampling to create a stratified sample of youth from the intervention (n=11) and control (n=9) arms. Among the control arm participants, 6 received the active control versus 3 receiving usual care. The sample included 11 female and 9 male participants and 11 with perinatal and 9 with behavioral transmission. The median age was 21 years (range 15–24 years), and the majority were African-American (95%). Thirty-six percent of participants reported being heterosexual. Most participants were not in school at the time of the interview. Over half (55%) were unemployed.

Data collection procedures

We conducted iterative semi-structured, in-depth interviews with study participants. We interviewed the MBSR intervention participants up to three times each (pre-intervention, immediately post intervention, and three months post intervention), and control participants

twice (pre and post intervention). In total, we conducted 44 interviews between February 2015 and August 2016. Final qualitative interviews were conducted after participants completed parent study follow-up data collection.

Participants were interviewed by a researcher trained in qualitative methods using a semi-structured field guide containing open-ended questions in key domains such as: dynamics of participants' daily lives, history living with and managing HIV, current challenges and goals including school, jobs, and social relationships, experience with providers and clinical care, ART adherence barriers and facilitators, and perspectives on and experiences with the intervention or care group to which they were assigned.

Ethical procedures and review

Participants provided written informed consent prior to being interviewed. Interviews took place in a private room within the clinical care facility where they were recruited and received ongoing care. Participants received a \$25 gift card for each interview completed. The Institutional Review Boards of the Schools of Medicine at both the Johns Hopkins University and the University of Maryland approved the study.

Data management and analysis

All interviews were audio-recorded and transcribed in their entirety. Thematic content analysis was utilized to approach the data (Miles & Huberman, 1994). Textual data was coded for both a priori, informed by the interview field guides, and emergent domains of interest within the qualitative analysis software, Atlas.ti®. Code output was synthesized and salient themes were extracted and developed into thematic memos. Quotes were selected to illustrate consistency and/or diversity within themes as relevant. We utilized unique identifiers to work with transcripts from the same participant over time and examined how their description of stressors and response to those stressors, including the management of HIV and ART use changed over time.

Results

Major themes that emerged from the analysis are presented below including the relationship between the experience of living with HIV as a stigmatized condition and mindfulness as a facilitator of self- and illness-acceptance and improved ART adherence.

Acceptance of HIV diagnosis as an ongoing process

For most participants, HIV was by far not the only significant stressor in their lives. Many reported having challenging childhoods. This included economic struggles leading to insecure housing and multiple moves, as well as parental substance use contributing to instability, incarceration, and family disruptions. For many participants, their current focus was on getting a job or trying to go back to school to get a better job.

Many perinatally infected participants reported not being told that they were living with HIV until they were teenagers and often described a confusing path to becoming aware of their status. Many of these participants felt that as a result, it was difficult understanding the role

and importance of ART. For female participants who were behaviorally infected, they commonly discovered that they were living with HIV when they became pregnant; while males who were behaviorally infected often reported discovering their status after the onset of symptoms or through an infected partner.

While there was diversity based on mode of transmission regarding the timing and initial process of discovering and dealing with HIV, there were also shared experiences. These included struggling with the reality that an HIV diagnosis was a permanent, stigmatized condition. As a result many reported battling feelings of anger and blame (towards oneself and others) and working to try and find peace with the role of the disease in their lives. The quote below describes how many participants understood the process of acceptance of an HIV diagnosis as a lifelong and ongoing dynamic.

I don't know how to deal with it. I don't know. Some people just come to grips with it and just accept it and do what they're supposed to do to stay healthy. And me, on the other hand, I still have a hard time accepting it, and it's been too long for me to not accept it, you know? So, yeah, I really do need help. I think that's why I decided to finally do the study, because I can't do it by myself, obviously.

-Female, behaviorally infected, 19 years old

The relationship between acceptance of HIV diagnosis and ART adherence

For some participants, ART adherence had become “routine” over time, but not for most. Many participants linked non-adherence with “forgetfulness” and reported missing doses here or there in a sporadic manner when “things became too hectic” in the context of competing demands and responsibilities (e.g., helping care for other family members, jobs, school, relationships). Some reported having “crashes” where they felt they just could not handle it all and in turn reported stopping their HIV medications temporarily, as there were just too many things to “juggle” or “a lot on one's plate.” But for others, there were additional psychosocial dynamics at play associated with the process of acceptance of living with HIV and having to take ART indefinitely.

Living with HIV. It has been very—I don't like it. At times I didn't like the medicine...I didn't understand why because this only pill right here is the only reason why I'm living. I see everybody else... they live on their own and they breathe on their own. They don't need a pill to just keep them alive. And yet I gotta keep a pill that just like it made me think, like everybody else's life is have more meaning than just a pill. And mine's don't... emotionally, physically. It was all just messing with me. So I didn't like it [ART].

-Male, perinatally infected, 22 years old

Several participants described not wanting to always have to think about HIV and viewed ART as a “constant reminder” of living with the illness, which provoked stress and impeded their adherence. Others reported concerns with stigma and discrimination, not wanting others to see them taking pills or having pill bottles with them if they went out or stayed over at another person's house, which was a common occurrence.

Several participants reported, however, that they had seen their non-adherence “bite them in the ass” meaning they became sick or ended up in the hospital. For some, these HIV treatment breaks and their consequences were motivators to become and stay adherent to ART, while for others these set-backs compounded ongoing struggles with depression and anxiety, substance use, and structural issues such as financial insecurity.

The role of mindfulness instruction in facilitating improvements in ART adherence

Many participants reported reduced stress and greater calm as a result of MBSR participation, including being able to better manage thoughts and emotions that would have previously caused them sadness or anger. Through mindfulness training, several participants reported gaining perspective on and relief from the pressure of living with HIV as a stigmatized and chronic condition, and as a result, they were able to often approach taking their ART medications differently as relayed in the quote below.

It used to impact my day, but now it don't...because every time that I would take it [ART], it would remind me of the situation. It reminds me that I have it [HIV], and I just be like, “Oh, I got this. Let me take these medicines. I don't want to.” But now it's just like I could just easily just get up and take them, and don't think about it. It's just like me doing something that I have to do every day, like getting him up for school. I have to do that every day, so take this medicine while I'm at it. It just don't bother me as much. I've found myself that I can do it much easier now...I'm like, ‘Just take it.’ -Female, behaviorally infected, 22 years old

For some, MBSR also offered not only a different outlook, but also specific tools and techniques to manage side effects and other discomforts associated with taking ART.

That's where I use the breathing and the meditation because I don't know how to calm my body down or my anxiety when it is off the roof. So I used the breathing technique, I use the meditation technique and once those two are down pat, I'm able to swallow two pills before I can swallow the last pill that gives me that panic. So it works okay but you have to be calm and you have to really take the time out to do it...every day now before I get too anxious, just to take the time out because I will panic, I will go--my anxiety level is just so high, I'll be out of it.

-Female, behaviorally infected, 24 years old

The psychosocial changes that many participants described as a result of MBSR participation were not only stimulated by the mindfulness strategies that they learned, but were also enabled by a trusting, non-judgmental environment within the MBSR groups. This support and solidarity was reported to facilitate acceptance of one's HIV diagnosis and oneself overall, reducing ruminating negative thoughts and internalized HIV stigma, which previously inhibited adherence. Both the individual and collective aspects of the MBSR intervention were understood by participants as contributing to reduced stress and internalized HIV stigma, making living with HIV and ART adherence more manageable.

While participants in the control arm reported learning useful strategies to take better care of their health and generally reported feeling supported by group facilitators and clinicians, as well as having a camaraderie with other study participants, the psychosocial experience of

learning how to recognize and relate to the pain and shame associated with living with HIV, that had often gone unaddressed in their lives to date, through non-judgmental awareness and acceptance, was unique to MBSR participants.

Discussion

Findings from this qualitative study among youth living with HIV underscore that the process of acceptance of their HIV diagnosis was an ongoing struggle, set within a broader socio-structural context characterized by intersecting inequalities and stigmas. Competing daily life demands and stresses (e.g., finding or keeping a job or finding or keeping a safe and stable place to live) often took precedence over prioritizing their individual health, attending clinic visits, and being adherent to ART. These challenges were often linked to depression, anxiety, and stress, and contributed to the sense that they were somehow “broken” or “messed up.” For many, ART was commonly viewed as an unwanted reminder of living with HIV, which they would prefer to forget about.

MBSR offered an opportunity to learn about new concepts and practical strategies that could help break these cycles of feeling damaged or unworthy, by learning to observe and let go of thoughts and feelings that were previously understood as permanent aspects of “who they are.” Practitioners working to integrate Western and Eastern psychological perspectives have highlighted the importance of recognizing the places where we judge ourselves and attending to and experiencing these without viewing them as fixed (Epstein, 1995; Epstein, 1999). The use of these approaches in the current intervention, and our past work with urban youth have been found to create “shifts in perspective” and a greater sense of groundedness in relation to living with HIV (Kerrigan et al., 2011).

MBSR also offered participants the perspective and tools to approach ART adherence in a new manner, making it less “overwhelming” and “more manageable.” What these findings reveal in particular is that mindfulness training does not just assist individuals to pay more attention or to better remember to do a certain behavior, but rather it may also help liberate them from patterns of thinking and difficult emotions that impede the uptake or continuation of challenging behaviors, such as ART adherence, which may be particularly important developmentally for youth and emerging adults.

Several participants also reported that the group solidarity generated through a trusting, non-judgmental environment within which the MBSR sessions took place helped reinforce this process of learning to better accept their HIV diagnosis. Previously, group-level dynamics have received less attention in terms of the mechanisms of effect of mindfulness interventions (Shapiro et al., 2006). Our findings indicate that they may be a key part of group-based mindfulness interventions, particularly for marginalized groups that may have experienced feelings of isolation. Future mindfulness research should also work to document group-level processes such as mutual trust, cohesion, and solidarity.

Study limitations include the limited time period to examine the relationship between mindfulness training and adherence dynamics. Our sample was limited to participants in a clinical trial recruited from university-based clinics, creating potential bias in terms of their

levels of motivation to engage with MBSR training and to improve ART adherence. Lastly, our relatively small sample size may not have allowed us to fully capture diversity in experiences with the intervention and control activities.

Conclusions

Study results offer important insights into how group-based mindfulness instruction may positively influence adherence for stigmatized conditions such as HIV in disadvantaged groups by creating a space for greater illness- and self-acceptance.

Acknowledgments

We would like to thank the study participants for their time and commitment, as well as, the UMMC site-PI Vicki Tepper, PhD; project staff — Tracey Chambers Thomas, Jan Stevenson, and Lindsey Webb; MBSR instructors — Tawanna Kane and Mira Tessman; and Health education instructors — McCay Moiforay and Keyya Simmons.

References

- Brach T (2003). *Radical acceptance: embracing your life with the heart of a Buddha*. New York: Bantam Dell.
- Epstein M (1995). *Thoughts without a thinker: Psychotherapy from a Buddhist perspective*. New York: Basic Books.
- Epstein M (1999). *Going to pieces without falling apart: A Buddhist perspective on wholeness*. New York: Broadway Books.
- Gonzalez A, Locicero B, Mahaffey B, Fleming C, Harris J, & Vujanovic AA (2016). Internalized HIV Stigma and Mindfulness: Associations With PTSD Symptom Severity in Trauma-Exposed Adults With HIV/AIDS. *Behav Modif*, 1;40(1–2):144–63. doi: 10.1177/0145445515615354 [PubMed: 26584609]
- Goyal M, Singh S, Sibinga EM, Gould NF, Rowland-Seymour A, Sharma R,... Ranasinghe PD (2014). Meditation programs for psychological stress and well-being: a systematic review and meta-analysis. *JAMA Internal Medicine*, 3 1;174(3):357–68. 10.1001/jamainternmed.2013.13018. Review. [PubMed: 24395196]
- Hosek SG, Harper GW, & Domanico R (2005). Predictors of medication adherence among HIV-infected youth. *Psychol Health Med*, 5;10(2):166–179. doi: 10.1080/1354350042000326584 [PubMed: 25705113]
- Kabat-Zinn J (2013). *Full catastrophe living (Revised Edition): Using the wisdom of your body and mind to face stress, pain, and illness*. New York: Bantam.
- Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, & Tsai AC (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc*, 11 13;16(3 Suppl 2):18640. doi: 10.7448/IAS.16.3.18640 [PubMed: 24242258]
- Kerrigan D, Johnson K, Stewart M, Magyari T, Hutton N, Ellen JM, & Sibinga EM (2011). Perceptions, experiences, and shifts in perspective occurring among urban youth participating in a mindfulness-based stress reduction program. *Complement Ther Clin Pract*, 5;17(2):96–101. doi: 10.1016/j.ctcp.2010.08.003 [PubMed: 21457899]
- Khoury B, Sharma M, Rush SE, & Fournier C (2015). Mindfulness-based stress reduction for healthy individuals: A meta-analysis. *J Psychosom Res*, 6;78(6):519–28. doi: 10.1016/j.jpsychores.2015.03.009 [PubMed: 25818837]
- Kim SH, Gerver SM, Fidler S, & Ward H (2014). Adherence to antiretroviral therapy in adolescents living with HIV: systematic review and meta-analysis. *AIDS*, 8 24;28(13):1945–56. doi: 10.1097/QAD.0000000000000316. Review. [PubMed: 24845154]
- McGraw-Hill. (2005). <http://www.glencoe.com/sec/health/th12005/index.php/md>.
- Miles M & Huberman M (1994). *Qualitative data analysis: A methods sourcebook* (2nd Edition). Thousand Oaks: Sage Publications.

- Parker R & Aggleton P (2003). HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Soc Sci Med*, 7;57(1):13–24. doi: 10.1016/S0277-9536(02)00304-0 [PubMed: 12753813]
- Riley KE & Kalichman S (2015). Mindfulness-based stress reduction for people living with HIV/AIDS: preliminary review of intervention trial methodologies and findings. *Health Psychol Review*, 9(2):224–43. doi: 10.1080/17437199.2014.895928
- Salmoirago-Blotcher E & Carey MP Can mindfulness training improve medication adherence? Review of the current evidence and proposed conceptual model. *Explore (NY)*. 2017 10 23 pii: S1550-8307(17)30101-5. doi: 10.1016/j.explore.2017.09.010
- Shapiro SL, Carlson LE, Astin JA, & Freedman B Mechanisms of mindfulness. (2006). *J Clin Psychol*, 3;62(3):373–86. doi:10.1002/jclp.20237 [PubMed: 16385481]
- Sibinga EM, Webb L, Ghazarian SR, & Ellen JM (2016). School-based mindfulness instruction: an RCT. *Pediatrics*, 1 1;137(1):e20152532. doi: 10.1542/peds.2015-2532
- Sibinga EM, Kerrigan D, Stewart M, Johnson K, Magyari T, & Ellen JM (2011). Mindfulness-based stress reduction for urban youth. *The Journal of Alternative and Complementary Medicine*, 3 1;17(3):213–8. doi: 10.1089/acm.2009.0605 [PubMed: 21348798]
- UNAIDS. (2016). Ending the AIDS epidemic for adolescents with adolescents. Retrieved on December 28, 2017 from http://www.unaids.org/sites/default/files/media_asset/ending-AIDS-epidemic-adolescents_en.pdf
- UNAIDS. (2017). UNAIDS DATA 2017. Retrieved on December 28, 2017 from http://www.unaids.org/sites/default/files/media_asset/20170720_Data_book_2017_en.pdf
- UNAIDS. (2017). Overcoming HIV-related stigma and discrimination in healthcare settings and beyond. Retrieved on December 28, 2017 from http://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf
- UNICEF. (2017). Children and AIDS. Statistical Update. December 2017. Retrieved on December 28, 2017 from <https://data.unicef.org/wp-content/uploads/2017/11/HIVAIDS-Statistical-Update-2017.pdf>
- Webb L, Perry-Parrish C, Ellen JM, & Sibinga EM (2017). Mindfulness instruction for HIV-infected youth: a randomized controlled trial. *AIDS Care*, 10 26:1–8. doi: 10.1080/09540121.2017.1394434
- WHO. (2017). HIV and Youth Updates. Retrieved on December 28, 2017 from http://www.who.int/maternal_child_adolescent/topics/adolescence/hiv/en/