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The daily lives of people with HIV infection: A qualitative study of the control group in an expressive writing intervention

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Abstract

Emotional disclosure is an expressive writing technique used in psychotherapy to process traumatic and stressful life experiences. While emotional disclosure interventions frequently use control groups, there are few qualitative analyses of these control groups. Our study's purpose was to analyze the control essays written by HIV-infected informants about their daily activities in an augmented written emotional disclosure intervention. Latent and manifest qualitative content analyses revealed prevalent contextual themes within the data. The emergent themes were socioeconomic status (SES), self-care, religiosity/spirituality, and social support. Emotional disclosure control subjects contributed substantial findings in terms of SES, self-care, resiliency, religiosity/spirituality, and social support and altruism.

Keywords

HIV; religiosity; self-care; social support; socioeconomic status; spirituality; written emotional disclosure

Emotional disclosure is an expressive writing technique used in psychotherapy to process traumatic and stressful life events. Although control groups are commonly used when examining the effect of expressive writing on health-related outcomes, few qualitative assessments of the control groups' writing exist in the literature. In fact, an expressive writing meta-analysis by Frisina, Borod, and Lepore (2004) reinforced the superiority of experimental trauma writing over control group writing when investigating health outcome variables. To our knowledge, there were no qualitative studies in the literature on HIV and

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emotional disclosure interventions that exclusively examined control writing. Our purpose was to analyze control essays written by HIV-infected informants in an augmented written emotional disclosure intervention (Ironson et al., 2013) to illuminate the substantial information attention control (i.e., daily events control writing) participants may provide about the daily lives of people living with HIV (PLWH).

Empirical evidence has demonstrated the beneficial effects of emotional disclosure in expressive writing since Pennebaker and Beall (1986) introduced the writing paradigm. Pennebaker and Beall (1986) randomly assigned individuals to disclose their deepest thoughts and emotions concerning a traumatic event (i.e., experimental, expressive writing, or trauma writing condition) or to write about neutral/trivial topics for several consecutive sessions (i.e., attention control condition). Their results revealed that confronting intimate thoughts and sentiments regarding a stressor or trauma improved physical health, as evidenced by reductions in medical visits, aspirin usage, and overall positive assessments of the effect of the experiment (Pennebaker & Beall, 1986). Since then, these findings have prompted numerous studies to examine the effect of expressive writing on physiological and psychological health outcomes in both healthy and clinical populations (Pennebaker & Chung, 2011). In 2006, Frattaroli (2006) conducted the largest expressive writing meta-analysis to date, using 146 randomized studies that implemented some variation on the Pennebaker and Beall (1986) writing paradigm. She found that written emotional disclosure (i.e., experimental disclosure) improved psychological health (e.g., depression), physical health (e.g., immune function), and overall function; successful studies tended to use participants with a health ailment or history of trauma (Frattaroli, 2006). Her review accelerated the study of the impact of expressive writing in chronically ill patient samples.

Few studies of PLWH have examined the effects of written emotional disclosure in randomized controlled trials (RCT), and even fewer have used qualitative methods to assess the written content disclosed by participants. The Pennebaker expressive writing paradigm (Pennebaker & Beall, 1986) provided an ideal avenue for PLWH to disclose their thoughts and emotions regarding the trauma and stress associated with an HIV diagnosis, the social implications of living with HIV, and disease progression. Petrie, Fontanilla, Thomas, Booth, and Pennebaker (2004) reported that experimental participants had a positive biological response with a significant increase in CD4+T lymphocyte cell counts compared to control writing; moreover, the treatment group rated their essays as more meaningful and emotionally revealing than those in the control condition. Contrasting these findings, Rivkin, Gustafson, Weingarten, and Chin (2006) examined adjustment to living with HIV in an expressive writing study and revealed that control participants (who were instructed to write contemporaneously and factually about their day) reported the process to be just as personal, emotional, and nearly as valuable as did those in the expressive writing arm of the exercise. Despite control participants not expressing as much emotion or cognitive processing as treatment participants, the control prompt enabled them to disclose information concerning their social lives (Rivkin et al., 2006). Even though the experimental condition enabled participants to address problematic emotions, strengthen self-awareness and insight, and confront reality, the control condition still allowed participants to meditate, reflect on their day, and recognize that people in their lives cared for them. Wagner, Hilker, Hepworth, and Wallston (2010) found no effects of expressive writing on psychological, physical, or pain

outcomes compared to control writing. In a computerized structured writing intervention on depressed mood for PLWH, Kraaij et al. (2010) found that respondents who followed the cognitive-behavioral self-help program improved significantly in mood but not in health outcomes. Our parent study (Ironson et al., 2013) investigated gender-specific effects between conditions and found that the women in the trauma writing group showed significant reductions in symptoms of post-traumatic stress disorder, depression, and HIV-related symptoms, compared to the women in the control group. Unexpectedly, the control condition's men showed significant reductions in depression when compared to the men in the experimental condition. Seeing that the data demonstrated evidence for an effect within the control condition, this provided an opportunity to conduct qualitative analyses on these essays to understand the daily lives of PLWH.

In order to ensure an inclusive literature review, we conducted a preliminary survey of contextual themes in our data as well as in the literature. These overarching themes were socioeconomic status (SES), self-care, religiosity/spirituality, and social support. All of these variables have shown an effect on health in chronically ill populations. In caregivers and chronically ill adults, social support has been shown to serve as a protective factor for mental health (Casale, Wild, Cluver, & Kuo, 2014). In patients suffering from heart failure, social support (particularly from the individual's family) was positively related to heart failure self-care behaviors (Graven & Grant, 2014). Additional research has shown how self-care behaviors provided an effective mechanism to reduce heart-failure patient expenses and to ameliorate negative patient health outcomes; however, those individuals with low SES still faced extenuating circumstances that exacerbated negative self-care (Macabasco-O'Connell, Crawford, Stotts, Stewart, & Froelicher, 2008). People with heart failure also suffered from disordered sleep, which had a negative impact on self-care (Redeker, 2008).

The current state of research with PLWH has shown an increase in self-management interventions that help when coping with daily life (Bernardin, Toews, Restall, & Vuongphan, 2013). In their review of HIV self-management interventions, Bernardin et al. (2013) concluded that the collaborations between health providers and clients promoted self-care, interpersonal and cognitive skills, knowledge, positive attitudes, future planning, and role management; outcomes included well being, health and illness management, and use of health services. Group-based interventions also encouraged social support from program leaders and other participants. In addition, self-management interventions have been shown to improve perceptions of sleep quality, decrease stress, and ameliorate problems with physical functioning and psychological coping (Bernardin et al., 2013). HIV-related fatigue has been the most frequent complaint by PLWH and was predominately an outcome of stressful life events (Barroso, Leserman, Harmon, Hammill, & Pence, 2015); furthermore, fatigue in HIV has impaired both basic and instrumental daily activities, especially activities related to work, family, and social life (Barroso, Harmon, Madison, & Pence (2014).

Research on the relationship between self-care and social support in HIV has been sparse; however, perceived HIV-related stigma has been found to contribute to lower perceived levels of social support (Earnshaw & Chaudoir, 2009). Zhang et al. (2014) found that teaching stigma reduction and educational interventions to augment the social support systems of PLWH (e.g., family members, friends, peers) could improve active interpersonal

coping, a form of self-care. Coping may manifest as positive or negative self-care behaviors, which suggests a link between social support and self-care in HIV. A qualitative study on the role of social support in HIV-infected refugees identified how emotional support helped people cope with an HIV diagnosis and instrumental support encouraged medication adherence (Rouhani et al., 2016). High levels of perceived social support in gay and bisexual HIV-infected men were associated with higher use of positive coping methods and actively searching for support, and low levels of perceived social support were related to higher use of self-destructive coping methods (Tate, Van Den Berg, Hansen, Kochman, & Sikkma, 2006). Coping by avoidance and conflicting social interactions were significantly related to each other, where negative interactions with others encouraged social isolation as a means of coping, resulting in poorer social function (Fleishman et al., 2000).

In a nationally representative cohort of 2,266 patients receiving care for HIV infection, respondents affirmed that spirituality (85%) and religiosity (65%) were *somewhat* or *very* important in their lives (Lorenz et al., 2005). In fact, HIV diagnoses have been known to inaugurate a re-exploration of one's relationship to spirituality. An increase in religiosity/spirituality has been shown to occur post-HIV diagnosis and that it predicted slower disease progression (Ironson, Stuetzle, & Fletcher, 2006). It is important to emphasize that we found other precursors for spiritual transformations or drastic changes in spiritual beliefs, self-views, and attitudes in HIV-infected participants. Such precursors accompanied a profoundly spiritual experience (e.g., a near death experience) or substance abuse recovery where principle themes such as education, social support, aspirations to change, confrontations with illness and death, lifestyle, helplessness, and depression were prevalent (Kremer & Ironson, 2009). In the context of religiosity, which entailed a search of the sacred within a social institutional setting, HIV-related stigma revealed a perceived disassociation between PLWH and religious institutions. These social religious organizations could have provided PLWH with a support network, but HIV-related stigma stripped this potential support system from them (Kremer & Ironson, 2009).

Regardless of this disconnection, PLWH preserved a sense of religiosity/spirituality in order to cope with the disease and manage their lives (Ironson & Kremer, 2011; Ironson, Kremer, & Ironson, 2006); therefore, religiosity/spirituality provided helpful coping mechanisms, where prayer, meditation, and giving credence to a higher power were common. Participants stressed how their beliefs in God and the role of religion helped them cope with the virus (Ironson, Kremer, et al., 2006). Spirituality facilitated constructive coping mechanisms that influenced self-care cognitions and behaviors in HIV. Prayer has been used and rated as a highly effective self-care strategy to manage HIV-related symptoms (Eller et al., 2013). In Ironson and Kremer's (2011) review on spiritual coping in HIV, the ways in which spirituality/religiosity may aid coping with HIV were elucidated: (a) it may provide hope by encouraging belief in a higher power; (b) it can foster more positive appraisals; (c) it can empower individuals with a feeling of wellbeing, tranquility, and safety during uncertainties; (d) it may encourage the feeling that one has support and is not alone; (e) it may promote a greater respect for one's body; (f) it can take a person out of the realm of suffering through transcendence; (g) it can give meaning; and (h) it may activate surrendering to a higher power (Ironson & Kremer, 2011).

The purpose of our study was to analyze the control essays written by HIV-infected informants in an expressive writing study (Ironson et al., 2013). To our knowledge, there have been no qualitative studies that solely examined control conditions from emotional disclosure interventions in HIV; therefore, our study enhances the understanding of the daily lives of these informants. The themes of SES, self-care, religiosity/spirituality, and social support reflected prevalent patterns found within these data.

Method

HIV-infected informant ($n = 119$) essays revealed how SES, self-care, religiosity/spirituality, and social support impacted the daily lives of our participants. These data came from the first time-point control group in the primary study in an augmented written emotional disclosure intervention (Ironson et al., 2013). The University of Miami Institutional Review Board approved the parent study; participants provided written consent prior to study initiation. The information reported here served as a secondary qualitative data analysis of the control condition.

Participants

Participants from the written emotional disclosure intervention were randomly assigned to write about a traumatic event (the intervention group, $n = 121$) or to write about their daily lives (the control group, $n = 123$, with attrition, $n = 119$).

Between February 2004 and January 2009, participants were recruited from southeast Florida (i.e., Miami-Dade and Broward Counties) with follow-up sessions that continued into February 2010. Inclusion criteria required participants to be within mid-range of illness (where 85% fell into a CD4+ T cell count range of 100-600 cells/mm³) and to be within 18 to 70 years of age. Subjects were excluded if they had any severely symptomatic AIDS-defining conditions in the year prior to enrolling in the study. Exclusion criteria also omitted those suffering from current alcohol or substance dependence, psychotic symptoms, or active systemic diseases or disorders (e.g., stroke or cancer, or liver, lung, kidney, or heart problems) that could potentially hamper participation or measures of disease progression. A Test of Written Language (Hammill & Larsen, 1996) also excluded those who could not read at an eighth-grade or higher level (Ironson et al., 2013). Participants were recruited from various community organizations, family health centers, physician offices, and gay social networking places (i.e., bookstores, clubs, bars, etc.), via newsletters and online advertisements, at relevant events (i.e., AIDS walk and Gay Pride), and by word of mouth. Participants received 50 USD for each writing session.

Our study examined the 119 control essays produced at the first time-point of the primary study. The age range of participants was from 18 to 70 years ($M = 41.54$, $SD = 9.36$), and included 73 males and 46 females, 19 Caucasians and a total of 100 African Americans, American Indians, Asian Americans, Hispanics, Haitians, Afro-Caribbeans, and others who considered themselves biracial (Table 1).

Procedure

For the control condition, informants were asked to write an account of their daily activities for 20 continuous minutes; instructions included writing about what they did yesterday from the time you got up until the time you went to bed. While the intervention condition focused on traumatic emotional disclosure and in-depth processing, the control prompt instructed them to *avoid writing about your emotions or opinions* but to try to be as *accurate and objective as possible*.

Data Analysis

Our study was a latent and manifest qualitative content analysis (Graneheim & Lundman, 2004), based on the work of Ironson et al. (2013). A manifest content analysis codes the apparent and measurable content of the data; a latent content analysis, on the other hand, codes the hidden and deeper structural meanings in the data. Collectively, these analyses provide a broader analysis of the data (Graneheim & Lundman, 2004).

We used qualitative descriptive analysis to develop a comprehensive overview of participants' daily life events and to obtain descriptive and interpretive validity (Sandelowski, 2000). After having transcribed a large amount of the hand-written data to electronic format over the previous years, the first author already had a firm understanding of the content. We started the analysis by reading 20 essays to gain a sense of their content. We then identified common storylines or key patterns and regularities within the data to categorize the data. With each sequential batch (20-30 essays) of data, we deduced the data's patterns into more abstract emerging themes. Latent content analysis involved an in-depth systematic reading of the meaning of the data (Graneheim & Lundman, 2004). We categorized/coded each essay, developing prevalent themes regarding daily life events. Our manifest content analysis included calculating frequencies of patterns discovered within the themes (Graneheim & Lundman, 2004). We then defined the meanings and characteristics of each theme and compared our findings to the literature.

Results

The most predominant groups in the sample were African American women and gay men. The sample was predominantly people of lower SES with a mean annual income of \$10,000. The essays ($n = 119$) contained the following themes: the effects of socioeconomic status, self-care, religiosity and spirituality, and social support (see Table 2).

Socioeconomic Status

The SES theme differentiated financially secure individuals from those who were financially burdened. Participants ($n = 46$) categorized as financially secure were those who owned vehicles, were employed, owned property, or had more education. Of the financially secure participants, 26 owned a vehicle, 17 indicated they were employed, and 6 attended classes at a local educational institution. Some participants mentioned the types of classes they were taking and their majors included mathematics, interior design, law, and architecture. These participants also described property they owned or would own in the near future, such as apartments, land, or duplexes. One employed participant mentioned an upcoming vacation.

In contrast, 13 participants described economic struggles with impoverished living conditions. Financially burdened individuals reported poor living conditions and an overall hardscrabble life marked by poverty and destitution. Such individuals reported using duct tape to repair their home window screens, walked miles to reach a bus stop to go to the physician and run errands, and were not able to buy a \$5.00 USD pair of sandals. Some talked about sitting outside on milk crates waiting for buses while it rained. One participant wrote, "I rode my bike to the bus stop to see the doctor; I had foot surgery and I had to change my bandages. I got my feet cleaned and had them rewrapped then caught the bus back home."

Financially burdened participants also mentioned living in darkness because they could not pay their electric bills: "We got to the buffet. My mother say get full because we don't have no lights." Other informants described being elated at the sight of food that their research studies supplied: "A bunch of people were there. Near the door was a table filled with sandwiches, chips, and sodas. Yummy! I was really hungry! I started scarfing down their food." Some would collect recyclable materials and garbage as a way to earn money, and some were homeless. A participant described,

[I] went to my mother's house, and she started to fight with me about my brother. She said to never come back over to her house. So I don't have anywhere to stay now; I am out on the streets. I ate sandwiches last night and nothing else so far but I feel really bad because I have nowhere to stay or nothing to eat. I am scared to tell my mother and father that I have HIV because they don't want me. They don't want nothing to do with me.

Poverty is critical when considering self-care, the next theme.

Self-Care

Of the 46 individual essays that expressed greater financial security, 42 practiced positive self-care. Self-care was defined as cognitions and behaviors that influence health maintenance and improvement, including mental, emotional, and physical well-being. Participants who performed positive self-care behaviors expressed optimistic attitudes and engaged in constructive actions that provided stress reduction for the physical body and emotional state of mind. Participants who demonstrated negative self-care behaviors wrote about self-defeating thoughts and maladaptive behaviors, which may have provided temporary stress reduction for the body, yet had a negative long-term impact on mind and body health.

A total of 114 essays conveyed positive self-care with cognitions and behaviors that provided stress reduction on the physical body and mental/emotional well-being. Mental-emotional activities ranged from creating or listening to music, singing, writing, reading, playing board games, taking time to relax, getting organized, and watching television or movies, to surfing the Internet. Activities that had a positive impact on physical health ranged from exercising and swimming, playing outdoor games, taking medications or vitamins, engaging in personal hygiene, to eating well. The participants employed additional activities that encompassed the complete emotional, mental, and physical health spectrum of

well-being. These activities included meditating, decorating, gardening, fishing, ceasing illicit drug use, attending medical or counseling appointments, and smoking cannabis.

Despite 13 participants indicating economic difficulties, some were able to access free food and inexpensive meals. Many prepared healthy meals and participated in matters of personal hygiene. Participants would take time out of their days to cook and eat fulfilling meals; some were so meticulous that they prepared their meals in advance (i.e., soaking almonds), made sure to drink sufficient amounts of water throughout their day, and occasionally rewarded themselves with treats of their favorite foods and desserts. In regard to personal hygiene, informants discussed caring for wounds to reduce the risk of infection, taking baths, taking time to prepare a nice outfit, and cleaning their living spaces. One participant even made the effort to meet with the university dean before attending his scheduled dental appointment with a student hygienist to ensure the process would occur smoothly. Only 10 exercised moderately; some walked, some went to the gym, and some swam. One informant discussed eating well and exercising while integrating social support:

Breakfast is a must; I never skip it. I ate cereal with bananas, piece of toast with butter and jam, tea, followed by [a] large glass of water. I went to the gym for 2 hours, relieves stress, good for my overall being, and like my social time with my workout buddies.

Within a small fraction of this participant's day, he successfully managed to incorporate components of positive social support (i.e., exercising with his workout buddies) with positive self-care (i.e., exercising, eating well) in order to reduce stress.

Furthermore, three participants' essays discussed maintenance of sobriety, and two of the three essays described the use of positive self-care to avoid relapse. One informant said, "I didn't stay because they did drugs so I left, went home and read a book...". After eating breakfast, engaging in matters of personal hygiene, and getting dressed, one participant wrote, "On my way to church I stopped by some people I had not seen in over 2 years. I told them that life was good without alcohol or drugs and then I drove on to church." These essays captured how positive self-care practices can act as a buffer against involving themselves in future detrimental behaviors (i.e., negative self-care) that could lead to relapse.

In terms of negative self-care, a total of 30 essays presented behaviors where individuals did not eat well, drank too much coffee, habitually smoked cigarettes ($n = 22$), and experienced disordered sleep. Two essays in this category described not eating for an entire day due to lack of food, lack of appetite, and being too busy. A total of 50 essays indicated symptoms of disordered sleep, where participants would take several naps during the day, stay up late, have trouble falling and staying asleep, and oversleep. One individual wrote,

The phone rang four different times in the morning and I finally got out of bed. I was very groggy, which is my usual state every morning because I don't sleep much during the night. My sleep is sporadic, and I am in it intermittently.

Some abnormal sleepers experienced excruciating body aches, which woke them at night. Most who had pain had to get up and take pain medications just to fall back to sleep; some would be unsuccessful. One informant described, "I awoke around 5:00 AM in pain, went to

the bathroom, and then I went to the kitchen for water and pain medication. After that, I tried unsuccessfully to go back to sleep; so I watched television.” All participants with disordered sleep watched television repeatedly throughout the day, and especially during the night before bedtime, which exacerbated their sleeplessness.

Resiliency

Resiliency was defined as patterns of positive adaptation in the context of significant risk or hardships; 38 participants expressed strong self-worth, an overall optimism despite daily negative circumstances, and positive self-care in terms of HIV management. They made an effort to smile at everyone (including strangers) and to be cordial, to engage in positive hobbies for personal enjoyment, to continue to job hunt despite previous difficulties, to schedule earned vacations, to attend health-related conventions for personal enrichment, to care for themselves despite the event of a natural disaster (i.e., hurricane), to push for their health care despite negative social contexts, and to care for children. Although one participant had served time in prison, he described:

I waited tables for 6 hours. I ran errands with a coworker and also was driving another waiter home. After doing so, the other worker and I went to the courthouse where I had to go to the probation office for a urine analysis. After that, I got my prescription medications. After the pharmacy, we got fast food - where I purchased a burger and a soda in which I scarfed the food down. Never really slept, just relaxed until about 7:00 pm and went to visit a friend to get my belongings that he kept for me while I was in prison.

Despite having been incarcerated and needing to fulfill his probation obligations, this participant expressed resiliency by attaining a job, owning a vehicle, having a strong network of social support, and engaging in positive self-care.

Religiosity and Spirituality

Depictions of religiosity/spirituality in the essays were also indicative of self-care. Of the 35 essays containing religious and spiritual behaviors, 34 also demonstrated positive self-care behaviors, showing a relationship between positive self-care and religiosity/spirituality. Religiosity and spirituality relate to expressions, thoughts, behaviors, or experiences that originated from an exploration of the divine. Religious participants indicated a system of worship and doctrine affiliated with certain religious institutions, whereas spiritual participants focused more on the transcendent by expressing faith, devotion, and reverence. A total of 35 individuals practiced religious and spiritual behaviors, which ranged from attending religious institutions (mostly church), praying throughout the day, expressing gratitude to God, to listening to gospel music. Of the 35, 26 participants engaged in prayer, both personal and intercessory, and they chanted, meditated, or praised God. One participant said, “I began every morning with my usual prayer. You didn't have to wake me this morning, but you did and I thank you Lord.” Another praised God, stating, “How good he is to me to keep me alive and be my own person.” Participants also stressed the nature of trusting in God during times of hardship. One wrote,

I called my pastor. We talk about how good God is. Then I call another friend who was sick and let him know that he will be all right. I told him to keep trusting God. So I call one of my kids to check on them. I let them know to keep the good work up in school, that I was proud of them and that I was going through something. I then pray and gave to God because I was a little down, but he work it out for me. Peace came over me.

Nine attended institutions of faith, including Sunday school, holy communion, Jehovah witness ceremonies, and chapel and ministry attendances. One informant described elements of positive self-care and altruism, while attending a religious service:

The service began and I had pie and pastries to eat. They spoke about difficulties that one may encounter: loss of job, no job, death of a loved one, and how God (Jehovah) can be there for you, his love, knowing that he will never leave you nor forsake you. It was very uplifting and encouraging.

Five read religious texts throughout the day. One participant integrated social support, personal and intercessory prayer, and Bible reading. In these essays, participants expressed elements of spirituality and transcendence while incorporating gratitude and reverence.

Finally, a few essays depicted religious and spiritual cognitions negatively in terms of coping with the disease (i.e., getting angry or rejecting God or a higher power). But most cognitive and behavioral elements of religiosity and spirituality were written within a positive frame of reference.

Social Support

The social support theme included a continuum of social support where participants depicted one of the following themes: no social support, only social interactions, some social support, or *abundant social support*. In addition to this continuum of social support, a separate category of *unsettling social support* represented the negative aspects of social interactions described by participants. A total of 115 essays were categorized into one subcategory within the established continuum of social support, and 10 of these essays overlapped into the separate *unsettling social support* category; four essays fell exclusively into the *unsettling social support* category.

Degree of social support—Essays that indicated *no social support* were devoid of any social interactions or support in daily events. Five of the 115 essays fell into this subcategory. While one participant did not provide much description in her essay, a majority of these people stayed at home all day and slept intermittently while watching television. When integrating elements of religiosity, one participant explained, “My body needed rest as much as it can. If I go out all the time I become like most people thinking about what’s going on in the streets. So I stay away from that and pray a lot.” For this participant, a paucity of social interactions or support became a positive aspect in her life because it kept her away from negative influences.

Essays categorized as having *only social interactions* were individuals who engaged in social scenarios that enabled communication and connection with others, yet did not provide any

supportive networks or relationships. Thus, these interactions did not include friendships, support groups, or long-lasting relationships. Nine participants interacted with random strangers while running errands, or went out to people watch or to be around other living beings; none of these informants fostered substantial relationships from these interactions. One informant wrote,

In route to the bus stop, I acknowledged the beach's homeless population; greeting the day with sleepy faces and hands out to request "spare change" from passersby. Another day of business for storekeepers while onlookers seemed to awaken to the smell of coffee in the air.

Despite this participant not receiving nor mentioning any significant value from his social greetings and observations, he still made the effort to engage in social interactions.

For those in the *some social support* subcategory, which included activities such as provider-patient scenarios, essays briefly mentioned dialogues with other individuals (i.e., colleagues, clients, or friends), or phone calls from friends and family. These 27 informants barely elaborated on any emotional connections with these individuals, yet were still able to network and participate in support groups or discussions. For example:

I walked to the hospital said, "Hi" to a few people I knew. I made a human immunodeficiency virus lecture and medical education class. When group time was over I spoke to a few peers that attended and went to eat lunch.

While this informant greeted some colleagues, attended his social support group, and communicated with his peers, he never spoke of the overall extent of these relationships, but still experienced some social support.

The *abundant social support* subcategory within the social support continuum represented individuals who had a great deal of social support in their daily lives. A total of 74 essays indicated receiving copious amounts of social support from family (i.e., children, grandchildren, spouses, parents, other extended relatives); pets (i.e., dogs, cats, parrots, and turtles); significant others; roommates; co-workers; community organizations; sponsors; support groups (i.e., Alcoholics Anonymous, Narcotics Anonymous, or other research study support groups); deeply-rooted friendships and neighbors; coaches; psychotherapists and counselors; and health care providers who spent considerable time with the participant. A majority of these participants openly discussed their HIV diagnosis with their loved ones. One hopeful participant wrote, "[I] play with my kids, play ball, running and sat down with my kids to talk about human immunodeficiency virus and sex [and] try to be positive." Despite the social stigma and hardships associated with HIV, this participant made the effort with his children to educate them while remaining open-minded about the topic at hand. Parents and grandparents mentioned engaging in activities with children where they braided hair, helped with homework, played games, and ate together. Two mothers with several children described heartfelt moments with their kids.

Another participant, who received social support from his dog, church community, and grandchildren, expressed gratitude for his social support network; he stated, "I want you to

know that I am doing my best but I cannot do it alone so thank you for your support.” He realized how fundamental these relationships were for his overall well-being.

In addition, some participants attended up to five distinct support group meetings provided by their treatment facilities and mentioned engaging in quality conversations with peers. They elaborated on how they cognitively processed the information provided by their meetings in order to manifest these changes in their daily lives. Many participants also discussed the substantial advice they received from therapists and counselors who helped reframe self-defeating cognitions and behaviors and improved participant quality of life. Cognitive Processing Therapy and Cognitive Behavioral Therapy were vital therapeutic methods that enhanced the quality of these individuals’ lives.

Lastly, 14 essays from the sample demonstrated *unsettling social support*. These informants emphasized complicated relationships with family members, coworkers, and roommates; some expressed vexation from landlords, neighbors, telemarketers, and people they socialized with during the day. Participants had ex-roommates steal from them, while some discussed arguments and major discrepancies with others.

Altruism—Closely related to social support, altruism for 15 participants included verbal expressions of concern and active contributions of caring for the wellbeing of others, including volunteerism, caregiving, and random acts of kindness. Altruistic participants actively helped others outside of their routine obligations despite their own responsibilities and hardships. They volunteered at food warehouses, prayed for others on phone prayer lines, babysat and attended to the needs of children who were not related to them, provided rides for people, donated money to the needy, volunteered at their local religious organizations, and lent a helping hand to random strangers they saw in passing. One participant wrote,

There were a lot of people with disabilities. The bus driver wasn't all that helpful. I tried to help a young man in a wheelchair but I couldn't get the seat up for him. No one else seemed to care. Finally the bus driver helped when he saw I took action.

Her assistance stimulated the bus driver's help, and provided the incapacitated man the service that he deserved.

Informants also engaged in caregiving for loved ones. While spending time with her mother, one informant described,

[I] went to my mother's house and talk to her about how she feel and clean up her house and give her a bath, then I made her something to eat. I call my mother on the phone when I got back home and told her that I love her and not to worry about me.

While this informant was not obligated to perform these actions for her mother, she still made the time to do so despite her own life circumstances.

Discussion

Our results revealed how qualitative analysis of control data in emotional disclosure writing interventions can contribute substantial information to the existing literature on PLWH. The written accounts of HIV-infected people's daily lives reflected the themes of SES, self-care, religiosity/spirituality, and social support. These variables illuminated influences on mental, emotional, and physical well-being in the context of HIV infection.

Our SES theme found that financially burdened individuals faced challenging circumstances (i.e., homelessness, destitution, lack of food) that stopped them from taking care of themselves, similar to the findings on low SES heart failure patients (Macabasco-O'Connell et al., 2008). Our results on negative self-care paralleled the relationship between disordered sleep and negative self-care in heart failure patients (Redeker, 2008), where disordered sleep in HIV illness was related to negative self-care influences on health. A total of 50 of the 119 participants (42%) showed symptoms of disordered sleep with maladaptive self-care behaviors, in that all of these participants watched television while trying to sleep. Perhaps, as with heart failure populations (Macabasco-O'Connell et al., 2008), low SES contributed to negative self-care in HIV. It is critical to assess quality of sleep as part of care for PLWH. Cognitive-behavioral techniques are quite successful (Butler, Chapman, Forman, & Beck, 2006) and include altering cognitions (e.g., the fear of dying from HIV) and behaviors (e.g., keeping the television illuminated out of loneliness or fear) that could be hindering regular sleep.

Regarding positive self-care, 42 of the 46 participants who were financially secure (91%) in our sample practiced healthy self-care behaviors, which was consistent with the findings of Macabasco-O'Connell et al. (2008), where high SES heart failure patients practiced positive self-care and had better health outcomes. Our self-care results showed how positive self-care practices could act as a buffer against potential negative self-care behaviors (e.g., reading a book instead of relapsing). Perhaps this was connected with resiliency; the 38 participants indicating resiliency also discussed positive self-care practices. Despite the challenges of living with HIV, these people showed a determination to prevail against all odds, took care of themselves, and were optimistic. Mexican women with HIV faced similar circumstances managing their illness, poverty, and caring for children (Holtz, Sowell, & Velasquez, 2012), suggesting that the relationships between resiliency, self-care, SES, and social support might be related and should be further examined. Future research should seek to examine the potential moderating or mediating effects of resiliency on self-care and SES in HIV, as well as its relationship to social support.

Other studies on the connection between self-care and social support have shown a significant positive relationship in people with heart failure (Graven & Grant, 2014), and social support was shown to protect against disease and increase longevity (Koenig, 2012). As high levels of perceived social support were related to positive coping methods (Tate et al., 2006) and positive coping was significantly related to an active search for social support in HIV, perhaps the participants in the positive spectrum of social support (i.e., *only social interactions*, *some social support* and an *abundant amount of social support*) practiced positive self-care. Low levels of perceived social support and negative coping methods were

related (Tate et al., 2006), as were negative social interactions and avoidance coping (Fleishman et al., 2000). Perhaps then *unsettling social support* and *no social support* might be significantly related to negative self-care in HIV. Future research should examine these relationships in the context of HIV and inspect the impact of SES in relation to social support. These measures could then be related to health/medical outcomes and other chronically ill populations.

Paralleling the results of Rivkin et al. (2006), we found that our control writing participants had people in their lives who cared for them. Thus, our descriptive results for social support revealed the importance of being cared for, loved, understood, and accepted by one's support network. This gives rise to the psychosocial construct of *mattering* (Rosenberg & McCullough, 1981), where people perceive themselves to be a significant part of the world on individual and social levels. Because feeling understood and loved mediated the relationship between coping style choice (i.e., avoidant vs. active coping) and social support in HIV (Schmitz & Crystal, 2000), self-management programs should implement strategies to detect if individuals are at a loss of *mattering* to prevent maladaptive coping strategies.

Furthermore, our descriptive results on social support showed the importance of encouraging a positive accepting conversation between PLWH and their support networks. Informants in our sample who felt secure enough to educate family members or personal friends about HIV without being stigmatized were able to cultivate those relationships, thus adding to a perceived level of positive social support. As perceived level of social support has been found to mediate the relationship between HIV-related stigma and post-traumatic stress disorder (Breet, Kagee, & Seedat, 2014), teaching and stigma reduction interventions to support networks of PLWH can help facilitate positive conversations and may, in turn, alleviate the trauma experienced with living with HIV. Zhang et al. (2014) found that education and stigma reduction interventions were related to active interpersonal coping and that loving, understanding, and accepting environments between PLWH and their support networks may help individuals retain a sense of *mattering* and encourage positive coping methods to enhance self-care.

Our results on religiosity/spirituality were indicative of self-care, where 34 of the 35 religious/spiritual essays (97%) also demonstrated positive self-care cognitions and behaviors. The results paralleled the findings of Ironson and Kremer (2011) on how religiosity/spirituality helped people cope in the context of HIV when participants felt uplifted and empowered by believing in a higher power. Informants in that study were able to apply meaning and purpose to their lives by reading passages from holy texts. People who were high in religiosity/spirituality endorsed more positive appraisals of the self (Ironson & Kremer, 2011); informants saw each day as a blessing. Informants surrendered their worries to a higher power and gained a sense of harmony, encouragement, and well-being in the face of major difficulties, such as the loss of a job, joblessness, social isolation, or the death of a loved one. Participants never felt alone; they continuously felt an omnipotent presence, support, and guidance (Ironson & Kremer, 2011). Some informants even prevented themselves from relapsing into drug use by leaving environmental triggers and attending church services. Religious/spiritual beliefs helped shape a greater respect for their bodies, thus promoting good nutrition and motivation to engage in constructive coping methods

(Ironson, Kremer, et al., 2006; Ironson & Kremer, 2011). Because an increase in religiosity/spirituality occurred post-HIV diagnosis and predicted slower disease progression (Ironson, Kremer, et al., 2006), future research should examine the relationship between self-care and religiosity/spirituality. Positive self-care may be significantly related to religiosity/spirituality in HIV, thus negatively impacting disease progression.

Additionally, participants who wrote about religiosity/spirituality expressed cognitions and behaviors within a positive frame of reference toward a higher power when coping with their daily lives and illnesses; a positive view of God has been shown to predict slower disease progression in HIV (Ironson et al., 2011). Psychodynamic techniques have recognized God as a projection of self-beliefs (Freud, 1957), while self-beliefs and a person's image of God were significantly related (Lawrence, 1997), so our results suggest that self-care may be a manifestation of one's self-beliefs and one's image of God. Future research should examine the relationship between a view of a higher power and self-care; a positive benevolent view of a higher power may predict positive self-care. Furthermore, because many of our religious/spiritual participants expressed a benevolent view of a higher power, they may have reaped health benefits as well (Ironson et al., 2011).

Our results on altruism in HIV showed how social behaviors can lead to human support and encourage actions of kindness, volunteering, and caregiving. In a longitudinal study, Ironson (2007) found that acts of altruism were associated with better HIV prognosis and that these health outcomes were more strongly related to the report of active altruistic behaviors rather than expressions of concern. Her findings can be applied to our results, where 15 participants actively helped others outside routine obligations. While altruistic acts were not overwhelming, those people benefitted both mentally and physically, particularly in terms of longevity (Post, 2005).

Limitations

We reported data on the first time-point control essays only here; more information can be found by examining the remaining three control time-points in the primary study (Ironson et al., 2013). A minimal loss of data when transcribing content from paper to electronic format may have occurred due to illegibility. Despite these limitations, our results illuminated the substantial information that control writing of daily life activities can add to the literature on HIV and other chronically ill populations.

Conclusion

We have highlighted the potential impact of using qualitative research methods in emotional disclosure interventions, which can be quantitatively investigated further in relation to health outcomes. We hope that our results will inspire researchers to investigate expressive writing control data and the rich information it may provide about people's daily lives.

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Key Considerations

- Because disordered sleep negatively influences self-care in people living with HIV infection (PLWH), their quality of sleep should be routinely assessed. Cognitive-behavioral techniques may successfully treat disordered sleep.
- HIV interventionists should address low self-perceptions of mattering in PLWH because it mediates the relationship between coping style (active vs. avoidant) and social support.
- The quality of social support should be routinely assessed in patients with HIV infection.
- Religiosity/spirituality is associated with self-care for PLWH, and those who are religious/spiritual may reap health benefits. Furthermore, although it is controversial for health professionals to discuss religiosity/spirituality with clients, those who want to connect with religiosity/spirituality could be encouraged to discuss it with their religious/spiritual guides.
- Despite significant hardships, PLWH are often able to positively adapt and show resiliency.
- Socioeconomic status is an important factor that impacts the lives of PLWH.

Table 1

Demographics

Characteristic	Control (<i>n</i> = 119)
Age	41.54 ± 9.36
Race	
• African American	66 (55.5%)
• Hispanic	20 (16.8%)
• Caucasian	19 (16.0%)
• Afro-Caribbean	5 (4.2%)
• Haitian	3 (2.5%)
• Other	3 (2.5%)
• Bi-Racial	2 (1.7%)
• American Indian	1 (0.8%)
• Asian American	0 (0.0%)
Marital Status	
• Not Married	93 (78.2%)
• Married - Monogamous	26 (29.8%)
Sexual Orientation	
• Exclusively Heterosexual	63 (52.9%)
• Exclusively Gay	37 (31.1%)
• Bisexual	10 (8.4%)
• Predominantly Heterosexual	5 (4.2%)
• Predominantly Gay	4 (3.4%)
Years of Education	
• Less than 8th Grade	5 (4.2%)
• Some High School	32 (26.9%)
• High School Graduate	25 (21.0%)
• Trade School	35 (29.4%)
• Some College	19 (16.0%)
• College Graduate	3 (2.5%)
• Graduate Degree	0 (0.0%)
Employment Status	
• Employed (Part-time/Full-time)	78 (65.5%)
• Student	21 (17.6%)
• Unemployed/Other	20 (16.9%)
Household Income (Annual Total)	
• \$5000 or less	51 (42.9%)
• \$5001 – \$10,000	23 (19.3%)
• \$10,001 – \$20,000	18 (15.1%)
• \$20,001 – \$30,000	6 (5.0%)

Characteristic	Control (<i>n</i> = 119)
• \$30,001 – \$40,000	6 (5.0%)
• \$40,001 – \$50,000	2 (1.7%)
• \$50,001 – \$60,000	5 (4.2%)
• \$60,001 – \$70,000	1 (0.8%)
• More than \$70,000	6 (5.0%)

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Table 2

Daily Activity Essays Themes

Theme	Indicators
Socioeconomic Status (SES)	
<i>Non-Struggling Indicators</i>	Vehicle Ownership Property Ownership Job Employment Status Ability to Take a Vacation Higher Levels of Education
<i>Struggling Indicators</i>	Poverty and Report of Poor Living Conditions Homelessness Struggling to Pay Bills
Self-Care	
<i>Positive Self-Care</i>	Expressing positive cognitions and engaging in positive behaviors that improve health maintenance
<i>Negative Self-Care</i>	Expressing negative cognitions and engaging in negative behaviors that weaken health maintenance
<i>Resiliency</i>	Patterns of positive adaptation in the context of significant adversity or risk on more than one account within the essay
<i>Religiosity and Spirituality</i>	Expressing thoughts and behaviors that emerge from an exploration of the sacred
Social Support	
<i>No Social Support</i>	Solitary essay devoid of any social interactions or support
<i>Only Social Interactions</i>	Positive scenarios that promote brief communication and simple interactions
<i>Some Social Support</i>	Few positive supportive networks and social relationships
<i>Abundant Social Support</i>	Profuse amounts of positive social support
<i>Unsettling Social Support</i>	Negative social interactions and support Complicated relationships
<i>Altruism</i>	Actively caring and contributing toward the wellbeing of others