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Discovery of Meaning and Adherence to Medications in HIV-infected Women

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Abstract

Discovery of meaning in response to illness has been linked to positive health outcomes. The mechanisms through which this occurs are unknown. This study tests a previously unexamined mechanism, engagement in healthier behaviors, which has been left uncontrolled in most studies. Forty-one HIV-infected women completed a one-month writing intervention. This writing was coded for signs of discovery of meaning. Adherence to medications was measured before (Time 1) and after (Time 2) the intervention. Women whose writing indicated that they had discovered meaning showed significantly greater adherence to their medical regimens at Time 2, controlling for Time 1 adherence. Discovery of meaning may result in positive health outcomes by leading individuals to engage in healthier behaviors.

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- *discovery of meaning*
- *HIV*
- *patient adherence*

A DAILY challenge for individuals with HIV is taking all of their medication as directed. One current HIV treatment involves antiretroviral therapy, which has proven effective in reducing viral load and inhibiting viral replication. Treatment success, however, is dependent upon almost perfect medication adherence; several studies have found that even minor lapses can result in significantly higher viral load and treatment failure (e.g. Bangsberg et al., 2000; Casado et al., 1999; Montaner et al., 1998).

Women with HIV may find adherence to a complicated antiretroviral medication regimen especially difficult, particularly if they live with small children or have high levels of stress in their lives (Murphy, Greenwall, & Hoffman, 2002). Women with few financial or personal resources may not be able to concentrate on maintaining their treatment regimens because their energy is focused elsewhere. In addition, lower socioeconomic status (SES) women are often unable to take advantage of counseling or support groups designed to assist HIV-positive individuals, due to financial limitations or childcare concerns. Writing interventions, however, in which people disclose their private thoughts in several sessions over a period of time, are ideal for this population, as writing is low-cost, short-term and can easily be done at home.

The benefits of writing interventions on health are now widely known (for a review, see Smyth, 1998), and such interventions are proliferating, even as researchers attempt to pin down the exact mechanisms by which they operate. Proposed mechanisms include the releasing of pent-up emotions, gaining insight or cognitive processing of events or emotions. However, most studies have focused on writing about negative or traumatic events, and writing about such traumatic events has an emotional cost. Interestingly, King (2001) found similar health effects for people who wrote about positive futures, in particular their life goals, suggesting that it is not necessary to focus on negative events to benefit from writing tasks. She proposes that writing about life goals or focusing on positive outcomes of traumatic events (King & Miner, 2000) may spark a reorganization of priorities or values, increase insight and facilitate a feeling of a greater purpose in life, thereby leading to improved physical health through increased control and self-regulation of emotions.

These changes in priorities and values, and renewed appreciation of life and feeling of purpose have been conceptualized as *discovery of meaning*. There are many terms used in the literature for this

ability to find positive outcomes after a stressful event, including stress-related growth, posttraumatic growth, benefit-finding and discovery of meaning. We believe these various terms and definitions tap into one overarching general construct, and we use the term discovery of meaning to refer to it.

Discovering meaning from a challenging event (such as being diagnosed with a serious illness or losing a loved one), has been linked to increased psychological well-being and better perceived health in women with breast cancer (Sears, Stanton, & Danoff-Burg, 2003), reduced distress associated with cancer treatment (Johnson et al., 2001), increased natural killer cell cytotoxicity in bereaved women (Bower, Kemeny, Taylor, & Fahey, 2003), and better physical health and reduced mortality in men with HIV (Bower, Kemeny, Taylor, & Fahey, 1998).

The mechanisms by which discovery of meaning impacts health and well-being are not clear. In the current study we explore the possibility that discovering meaning leads individuals to engage in healthier behaviors, such as increased adherence to medication regimens. This behavioral route has not been explored in the research literature on finding meaning. Studies generally do not measure changes in health behaviors when exploring the effects of discovering meaning (e.g. Sears et al., 2003), or they measure these changes but do not conduct analyses that would assess whether those changes mediate the effects of finding meaning on health outcomes. Studies that do measure changes in health behaviors often do so with a single dichotomous item (e.g. Bower et al., 1998), which may not be sufficient to detect such changes. In addition, some studies confound discovery of meaning with healthy behavior change by including improvements in health behaviors or reported health-related benefits as indicators of discovering meaning (e.g. Siegel & Schrimshaw, 2000; Updegraff, Taylor, Kemeny, & Wyatt, 2002). Because improved health behaviors may be a mechanism through which discovery of meaning leads to better health outcomes, the definition of discovery of meaning should not include changes in health behaviors.

Correlates to discovery of meaning

Discovery of meaning has been linked to a variety of positive health outcomes, so it is important to understand the thought processes that make it more likely, as well as the types of individuals who are likely to

discover meaning during times of trauma. Cognitive processing is defined as thoughtful reflection on an event, including awareness of the emotions it evokes and the effect it might have on one's future (Bower et al., 1998). If individuals engage in cognitive processing about a stressful event, they may be more likely to discover meaning than individuals who do not engage in this contemplation.

Disclosing private thoughts in either writing or interview formats, particularly for chronically ill individuals, may encourage cognitive processing. Cognitive processing appears to lead some individuals to make sense of their lives and discover a sense of purpose or meaning, while others do not discover meaning and may become ruminative (Pennebaker & Suedfeld, 1997). In one study, for example, all participants who discovered meaning engaged in cognitive processing, but not all participants who engaged in cognitive processing found meaning (Bower et al., 1998). Thus, it appears that cognitive processing may be a necessary step toward discovering meaning, but not a sufficient step.

Individuals who are optimistic seem to be more likely to discover meaning during difficult times than individuals who are pessimistic. In a large study of HIV patients, optimism was positively related to posttraumatic growth, while pessimism showed the reverse relationship (Milam, 2004). A study of mothers with children undergoing hematopoietic stem cell transplantation found that dispositional optimism was a moderator between finding benefit from the health crisis and psychosocial adaptation six months later (Rini et al., 2004).

Present study

The present study sought to examine one mechanism through which discovery of meaning might influence health outcomes, namely, by leading to healthier behaviors. We also sought to examine two potential correlates of discovery of meaning: engaging in cognitive processing, and being an optimist. We asked HIV-infected, low SES women to engage in a writing task twice weekly for one month. We randomly assigned half of the women to write about the best future they could imagine. Because optimism is defined as having positive expectations about the future, and because cognitive processing involves thinking about the effect an event might have on one's future, we thought this task would lead to both enhanced optimism and to cognitive processing. The other half of the women were

assigned to a control writing condition in which they were asked to write about a neutral topic—something they had seen on TV or read in a book—rather than about themselves, or their expectations for the future. We used content analysis to code all the essays for signs of cognitive processing and discovery of meaning, and we measured participants' adherence to their medication regimens before the writing task was assigned and after doing the writing task for one month.

We hypothesized that participants in the future writing group would show increased treatment adherence after the four-week writing intervention compared to participants in the control group. We also hypothesized that participants whose writing demonstrated discovery of meaning would have increased adherence to medications compared to participants whose writing did not show signs of discovering meaning. Finally, we explored psychological differences between individuals who were able to find meaning and those who were not. We hypothesized that individuals engaged in cognitive processing would be more likely to find meaning than those who did not engage in cognitive processing, and that participants high in optimism at baseline would be more likely to find meaning than individuals who were low in optimism at baseline.

Method

Participants

Women who were on combination therapy for HIV were recruited at a routine medical appointment from a healthcare clinic serving low-income women in the Los Angeles area. To be eligible to participate, women had to be at least 18 years old. Four individuals who were approached to participate in the study declined to do so. Of the 41 eligible individuals who agreed to participate, 20 were randomly assigned to a future writing condition and 21 to a neutral writing condition. Participants were between the ages of 26 and 57 ($M = 40.85$, $SD = 7.44$), and 71 percent had graduated from high school. Of the participants, 58 percent were African-American, 32 percent were Latina, 8 percent were Caucasian and 2 percent were Native American. Eleven participants (27%) completed all assessments (and journal entries) in Spanish. Thirty-two percent of the participants had never been married, 13 percent were currently married, 26 percent were separated, 18 percent were divorced

and 11 percent were widowed. Eighty-four percent of the participants had children, but only half of these participants currently resided with their children. At the time of recruitment, 56 percent had been diagnosed with AIDS.

Procedure

Eligible participants gave informed consent, completed the baseline assessment and then were shown an assortment of nicely bound blank books and instructed to select one to use as their journal over the next month. They were asked to write in their journals twice a week for four weeks, for at least 10 minutes each time. Participants were then randomly assigned to either the neutral writing task or the future writing task. Participants assigned to the neutral writing condition received the following writing instructions:

Write about something interesting! Here's what you should write in your journal: describe something you saw on TV, read in the newspaper, saw in a magazine, read in a book or something in a movie you saw. This thing you describe should be something that happened to another person, but not a person that you know. It can be something you read about or saw in the past, or something you read about or saw on the day you write.

Participants assigned to the future-writing condition received the following writing instructions:

What is your dream for the perfect future? Write about the *most perfect future* that you can imagine. Think very hard about that future. What will that future be like for you? In what ways will that time be different from now? How will you feel? What will a regular day be like? You can: jot down thoughts, make a list, write a poem, tell a story or describe a dream. This is your journal, for your thoughts. So you can write about your perfect future however you want. It's up to you.

Participants were told not to worry about punctuation, spelling or grammar, and to write in the language they felt most comfortable with. In addition, participants were informed that researchers would copy their journal entries at the end of the study, and that the copies would be stored without any identifying information. After going over the writing instructions, participants were left alone for 10 minutes while they wrote their first entry. This was done to ensure that they understood the task, and to demonstrate how easy it was to write for 10 minutes.

Participants then scheduled a follow-up session approximately one month later. During that month,

they were sent weekly postcards reminding them to write in their journals. At the follow-up session, participants completed the assessments again, and had their journal entries photocopied. Participants were paid \$5 for each entry (for a maximum of eight entries), and were reminded of how important it is to take their medications as directed.

Measures

Demographic and illness variables Upon entry into the study, participants described their ethnicity, marital status, number of children, degree of religiosity, dates of their diagnosis with HIV and AIDS (if applicable) and details of their current treatment regimen.

Dispositional optimism Dispositional optimism was assessed with the Life Orientation Test Revised (LOT-R; Schiver, Carver, & Bridges, 1994), a six-item measure that includes items such as: 'I rarely count on good things happening to me' and 'I'm always optimistic about my future.' Respondents indicate the extent of their agreement to each item on a five-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree). To form an index of optimism, positively worded items were reversed and all items were then averaged, so that higher scores indicate more optimism. The scale had a Cronbach's alpha of .58 at Time 1 and .65 at Time 2.

Situation-specific optimism Situation-specific optimism was assessed with six items adapted to apply specifically to having HIV (Segerstrom, Taylor, Kemeny, & Fahey, 1998). This scale included items such as: 'It's likely that I will remain healthy' and 'I feel confident when I think about the effectiveness of my medications.' All items were positively worded, and were completed using five-point Likert scales ranging from 1 (strongly agree) to 5 (strongly disagree). All items were reverse-scored and averaged, so that a higher score indicated more situation-specific optimism. The scale had a Cronbach's alpha of .81 at Time 1 and .83 at Time 2.

Adherence Treatment adherence was assessed with a five-item general adherence measure from the RAND Medical Outcomes study (DiMatteo, Hays, & Sherbourne, 1992), which includes items such as, 'I followed my doctor's suggestions exactly' and questions such as, 'In general, how often during the past four weeks were you able to do what the doctor told you to do?' In addition, we included three items

Table 1. Sample cognitive processing and discovery of meaning statements

| Category | Example |
|----------------------|--|
| Cognitive processing | <p>'God only knows that I am still trying to deal with the anger within about the disease.'</p> <p>'It makes me think about my own problems and what I had let myself go through in my own life.'</p> <p>'I have come to grips with the fact that I have AIDS and I am okay with it.'</p> <p>'When you have to sit by and watch a friend die—do you just feel sad because that person could be you? What does it really feel like to die?'</p> |
| Discovery of meaning | <p>'Though one is [HIV] positive, that does not take away our right to fight to get better, to feel love and feel alive, to love and be loved.'</p> <p>'Knowing what I know now about being sick makes me see life in a whole different way ... being a mother and a grandmother makes me feel real good. I have a chance to give my son and grandkids everything I can, like making their lives better.'</p> <p>'My future will be one dedicated to my family, myself, my spiritual well-being and a strong commitment to my community.'</p> <p>'... it made me realize how I appreciate life more now than I have in the past and I live one day at a time and try to enjoy each day to the fullest.'</p> <p>'I love life and have learned to value it dearly.'</p> <p>'I know that this has a lot to do with knowing what my "Higher Power God" has a mission for me. It may have taken me getting AIDS but sometimes it takes what it takes for Him to get my full attention. ... What I want more than anything else is to be able to make a difference.'</p> |

that were more specific to HIV-medications (e.g. 'I took all of my medications with the right types of meals or foods'). Participants reported their adherence using six-point Likert scales ranging from 1 (none of the time) to 6 (all of the time). Patient reports of adherence have been closely related to objective adherence measures, such as plasma levels of protease inhibitors, electronic monitoring and pill counts (e.g. Duong et al., 2001; Hugen et al., 2002; Walsh, Mandalia, & Gazzard, 2002), although some studies indicate that adherence may be somewhat overestimated in self-reports (e.g. Bangsberg et al., 2000). To form an index of adherence, negatively worded items were reversed and all items were then summed, so higher scores indicate more adherence. The summed scale ranges from six to 48 points, and in the current sample, scores ranged from 15 to 48 ($M = 34.22$, $SD = 9.6$). The mean score in the sample suggests adhering to medication between 'some' and 'most' of the time. The scale demonstrated good reliability, with a Cronbach's alpha of .79 at Time 1 and .85 at Time 2.

Journal content Journal entries were transcribed by research assistants, who also translated

Spanish entries into English when necessary. Entries were then coded by two raters who were blind to condition and to the writing instructions given to participants. We utilized a coding system developed by Bower et al. (1998) to code for both cognitive processing and discovery of meaning. We adapted the definitions of cognitive processing and discovery of meaning to apply specifically to being infected with HIV. Cognitive processing was defined as in Bower et al. as 'deliberate, effortful, or long-lasting thinking' (1998, p. 980) about having HIV. Similarly, discovery of meaning was defined as a 'major shift in values, priorities, or perspectives' (1998, p. 980) in response to having HIV. Each journal entry was coded for the presence or absence of cognitive processing or discovery of meaning statements. When there was disagreement between raters, the authors (while remaining blind to the writing condition) resolved them. Ratets were careful not to code any statements related to health behaviors (such as references to taking medications) as cognitive processing or finding meaning, so the coding was not confounded with adherence measures.

Both cognitive processing and discovery of meaning were treated as dichotomous variables,

with participants classified as 'no' on cognitive processing if they had no statements coded as such, and 'yes' on cognitive processing if they had one or more statements coded as cognitive processing, in any journal entry. Similarly, participants were classified as 'no' on discovery of meaning if they had no statements coded as discovery of meaning, and 'yes' on discovery of meaning if they had at least one discovery of meaning statement. See Table 1 for examples of both types of statements. Interrater agreement for participant classification was high for both cognitive processing ($\kappa = .76, p < .001$) and discovery of meaning ($\kappa = .95, p < .001$).

Results

One participant (in the neutral writing condition) did not turn in her journal entries, so was not included in any writing content analyses. The remaining 40 participants averaged 13.53 (SD = 5.90) journal entries each over the four-week study. They were only asked to write eight entries, so most participants wrote more entries than required. The handwriting in each journal was consistent over the month of entries, indicating that the participant wrote all of the entries (since the first entry was written at the clinic).

Manipulation check and intervention effects

Journal entries of participants were examined to see if they followed the directions of their assigned conditions. Unfortunately, participants did not always write according to the instructions given to them. Nine of the 20 control group participants wrote about personal topics, contrary to the task instructions to write about neutral topics. One control participant, for example, discussed personal feelings about her illness, pain and eventual death. Similarly, other control participants discussed topics such as contracting HIV after being gang raped, what it might feel like to die and how much they learned from past mistakes.

Participants in the intervention group were instructed to write about their best possible future. Instead, four of the 20 participants wrote about fairly negative futures (e.g. 'In these moments my thoughts toward the future are not very nice because I think that my pain could get worse and that there will not be anything that could make me better'), and four others focused on negative aspects of their

past or present lives (e.g. 'I have had a present and a past with many economic and emotional obstacles as well as many health difficulties'). It is clear that the manipulation was not successfully implemented.

We hypothesized that participants in the future writing condition would show increased medication adherence at the one-month follow-up compared to participants in the control condition. Contrary to expectations, but not surprisingly given the failed manipulation, there were no significant differences between the two conditions in a regression predicting Time 2 adherence, controlling for Time 1 adherence, ($\beta = -.157, t = -1.029, p = .311$).

Effects of cognitive processing and discovery of meaning on adherence

Of the 40 participants who turned in their journals, 30 (75%) were classified as showing cognitive processing, and 21 (52.5%) were classified as having discovered meaning. Our hypothesis that discovering meaning would lead to increased treatment adherence was supported. According to a regression analysis in which Time 1 adherence was entered first, followed by discovery of meaning, discovery of meaning was significantly related to adherence to medications at Time 2 ($\beta = .50, t = 3.695, p = .001$; $\Delta R^2 = .250$). Participants who were classified as having discovered meaning increased their adherence from Time 1 to Time 2, while those who did not find meaning decreased their adherence over the same time period (see Fig. 1). As expected, cognitive processing was not significantly associated with Time 2 adherence, controlling for adherence at Time 1 ($\beta = .10, t = .616, p = .542$; $\Delta R^2 = .009$).

Correlates of discovering meaning

We hypothesized that individuals who engaged in cognitive processing would be more likely to discover meaning than individuals who did not engage in cognitive processing, and this hypothesis was supported, $\chi^2(1, N = 40) = 12.06, p = .001$. Similar to Bower et al. (1998), all participants who were rated as having found meaning were also engaged in cognitive processing, although the reverse was not true (i.e. some participants displaying cognitive processing did not also show discovery of meaning).

In addition, as predicted, participants who discovered meaning were significantly higher in situation-specific optimism at baseline ($M = 3.58, SD = .82$) than participants who did not discover meaning

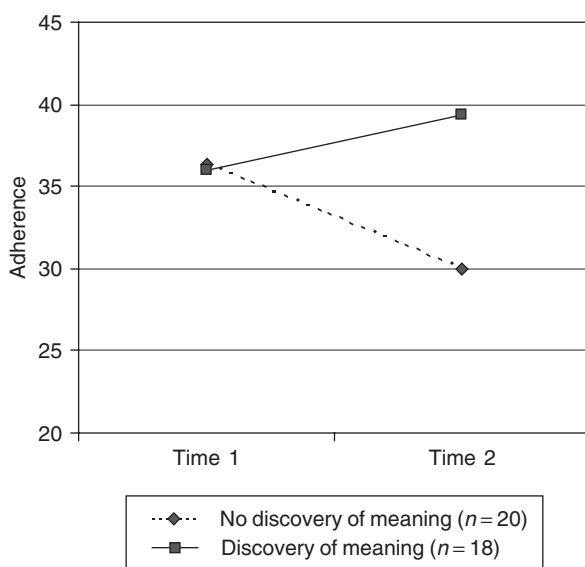


Figure 1. Adherence at Time 1 and Time 2 as a function of discovery of meaning.

($M = 2.95$, $SD = .87$), $t(36) = -2.31$, $p = .03$. They were also marginally significantly higher in optimism at baseline ($M = 3.76$, $SD = .59$) than participants who did not discover meaning ($M = 3.38$, $SD = .59$), $t(36) = -1.95$, $p < .06$. To test whether either of these forms of optimism mediated the effects of finding meaning on adherence (controlling for Time 1 adherence), each form of optimism was entered separately into the regression model described in the previous section. Including situation-specific or dispositional optimism in these models did not reduce the significance of the relationship between finding meaning and Time 2 adherence (situation-specific: $\beta = .47$, $t = 3.163$, $p = .004$; $\Delta R^2 = .185$; dispositional: $\beta = .49$, $t = 3.563$, $p = .001$; $\Delta R^2 = .236$), suggesting that they are not mediators of the relationship.

Discussion

In this study, we found that individuals who were able to discover meaning in their lives reported better adherence to their HIV medications than individuals who were not able to discover meaning in their lives. Nineteen of 40 participants were coded as having at least one discovery of meaning statement in their writing, and these individuals were significantly better at following their HIV

medication regimens at Time 2. The size of these effects is small to moderate, but it is difficult to quantify clinically as participants responded on scales, rather than giving the precise number of pills they took. According to the scales used for the self-reported adherence measures, finding meaning was associated with adhering to medications 'most' of the time, while failing to find meaning was associated with adhering only 'some' of the time.

Adherence to anti-retroviral medications is extremely important for HIV-infected individuals, but it can also be extremely difficult to maintain, as adults take an average of 14.7 doses a day (Murphy, Roberts, Martin, Marelich, & Hoffman, 2000). In addition, there are often specific dietary restrictions or instructions for different medications, and adverse side-effects are common. One study of HIV-infected women with healthy children found very low adherence rates in this population, ranging from 43 to 56 percent depending on the method of assessment employed, and adherence rates tend to decline over time (Murphy et al., 2002). Thus, it is important to explore any factor that can influence adherence rates, particularly among lower SES women who may not have many additional resources to help them cope with a complicated medication regimen. Discovery of meaning appears to be one such factor.

We also explored factors that may distinguish individuals who are likely to discover meaning from a traumatic event from those who do not. As we predicted, participants who were engaged in cognitive processing were more likely to demonstrate discovery of meaning than participants who were not engaged in cognitive processing. All of the participants who were coded as having discovered meaning also showed cognitive processing. In addition, we predicted that optimistic individuals would be more likely to find meaning during the writing task, and we also found this to be true. Higher situation-specific optimism and higher dispositional optimism at baseline were related to participants' discovery of meaning during the writing task.

One of our hypotheses was not supported. We predicted that participants in the future writing group would show greater adherence to medications at follow-up compared to participants in the control group, but this was not confirmed. Our writing content analysis shed some light on these unexpected findings. The likely reason we did not see the expected effects of future writing is that participants did not follow the writing instructions.

The tendency of participants to write about any topic they chose, instead of the topics they were assigned to write about, illustrates one drawback of community-based writing interventions; namely, that it is difficult to ensure that participants complete the intervention task as intended. Other limitations of the study include the small sample size and our reliance on self-reported adherence. Self-reports of adherence can lead to overestimates of adherence levels, though there is no reason to believe that self-reports led to systematic differences in the reports of adherence depending on whether individuals discovered meaning. Finally, this study was not a full test of the causal relationship between finding meaning and health outcomes. We measured adherence to medications, which is thought to be linked to health outcomes, but we did not measure health itself, nor did we formally manipulate finding meaning.

In summary, the results of this study suggest that discovery of meaning may affect health by leading individuals to engage in healthier behaviors. This possibility must be considered in other studies linking discovery of meaning to health outcomes, many of which do not measure whether participants who find meaning engage in healthier behaviors. At present, HIV-infected individuals are asked to alter their behaviors for the rest of their lives, adding a

complex and time-consuming medication regimen to their daily routines. Any factor that may help them succeed at these changes, such as discovery of meaning, is worth further exploration.

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