

Article

Being Diagnosed with HIV as a Trigger for Spiritual Transformation

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Abstract: How can the diagnosis of HIV/AIDS result in a positive spiritual transformation (ST)? The purpose of this sub-study is to identify special features of the experiences of individuals in whom HIV/AIDS diagnosis triggered a positive ST. We found ST triggered by HIV/AIDS to develop gradually, with a key adaptation phase after diagnosis in which the patient develops an individualized spirituality. Most participants (92%) expressed having an individual connection to a higher presence/entity. Most (92%) also described themselves as feeling more spiritual than religious ($p < 0.001$). Religious professionals did not play a key role in fostering ST. Despite experiencing stigma by virtue of certain religious views, participants accepted themselves, which supported the process that we called “the triad of care taking”. This triad started with self-destructive behavior (92%), such as substance use and risky sex, then transformed to developing self-care after diagnosis (adaptation) and gradually expanded in some (62%) to compassionate care for others during ST. Spirituality did not trigger the adaption phase immediately after diagnosis, but contributed to long-lasting lifestyle changes. Overcoming self-reported depression, (92% before diagnosis and in 8% after ST) was a common feature. After the adaption phase, none of the participants blamed themselves, others or God for their HIV+ status. The prevailing view, rather, was that “God made them aware”. Our results suggest that it may be important to find ways to support people with HIV in feeling connected to a higher presence/entity, since this leads not only to a deeper connection with a higher presence/entity, but also to a deeper connection with oneself and to more responsible and caring behavior.

Keywords: spirituality; spiritual transformation; HIV; depression; substance use

Abbreviation

AIDS = Acquired Immune Deficiency Syndrome;

HIV = Human Immunodeficiency Virus;

ST = Spiritual Transformation

1. Introduction

Since 2001, when the John Templeton Foundation funded the Metanexus Institute on Religion and Science to develop and conduct transdisciplinary research, scientific knowledge on spiritual transformation (ST) has grown remarkably [1]. The ST Program is based on the working definition of ST as a dramatic change in world- and self-views, purposes, religious beliefs, attitudes, and behaviors [1,2]. The change is often linked to a discrete experience and can occur both suddenly or gradually [1]. Pargament argued that ST should be viewed as centering on a fundamental change in the place of the sacred or the character of the sacred in the life of an individual [2]. As an initial step of the ST Program, Joan Koss-Chioino and Philip Hefner edited a book summarizing anthropological, theological, neuroscientific, and clinical perspectives of ST and healing as a complex multidimensional phenomenon [3]. Our team studied ST in the face of HIV as part of this program [4]. Being diagnosed with HIV/AIDS represents a dramatic life change, particularly before effective antiretroviral treatment (ART) became available in 1996—most of the participants of this study were diagnosed before this date, when diagnosis was considered a death sentence. The purpose of this study is to examine being diagnosed with HIV as a trigger of a positive ST.

We examined in-depth interviews of 147 people with HIV from two samples, people with chronic HIV disease (*chronic disease sample*, $n = 74$) and people with HIV who considered themselves spiritual (*spiritual sample*, $n = 73$). We identified 80 individuals who underwent a positive ST and three with a transient negative ST (see below) [5]. Positive ST was significantly associated with benefits for psychological well-being, health, and survival [6], supporting the importance of understanding how religious and healthcare professionals can foster ST.

Interestingly, in people with chronic HIV, ST occurred at the same rate (39%) [5] as life-changing spiritual experiences in the general US population (40%) and both studies were conducted at the same time [7]. In the national ST study, life-changing spiritual experiences were mainly initiated by spiritual activities (50%) and serious illnesses or accidents to themselves or a loved one (28%) [7]. Those spiritual experiences, also called religious, mystical, or peak experiences, are often accompanied by intense feelings of awe, bliss, and a sense of oneness with the universe and can lead to ST [8].

In people with HIV, positive ST was most frequently triggered by a spiritual experience (31/80, 39%) and substance use recovery (14/80, 18%). Contrary to our predictions, HIV was not the main trigger of ST. Being diagnosed with HIV/AIDS ranked third on the list of triggers (13/80, 16%). The remaining triggers included: death of a loved one, commitment to a partnership, spiritual conversion, parenthood, migration, inspirational literature, and stopping HIV medication.

Nevertheless, 26% (38/147) of participants considered HIV a key positive turning point in life [9], which included the 13 participants in which being diagnosed with HIV triggered a positive ST. The distinction between ST and a life-changing turning point is that a ST by definition has to involve a long-lasting dramatic change in all four areas—beliefs, attitudes, spiritual views and the view of the self—whereas a turning point can be less profound and does not need to involve all areas. Thus, a ST is a more profound form of a key turning point that involves spirituality.

Notably, going through a near-death experience, experiencing an increase in spirituality after HIV diagnosis, and feeling chosen by a Higher Power to have HIV, all correlated with viewing the HIV diagnosis as life's most positive turning point. In particular, interviewees felt this way when they were diagnosed at a point in their life when they were hitting rock bottom and calling on a Higher Power for help. In contrast, 11% (16/147) perceived HIV as a key negative turning point. This also included three participants that underwent a transient negative ST, which was followed by a positive turning point later on in their life. Declining spirituality after diagnosis was associated with viewing HIV as the most negative turning point in life [9].

How can being diagnosed with a stigmatizing life-threatening disease result in a positive ST? The results of our studies warrant a more in-depth examination of the 13 case examples in order to find out why being diagnosed with HIV/AIDS paved the way for a positive ST. This sub-study will identify the special features of the experiences of individuals in whom an HIV/AIDS diagnosis triggered a positive ST. Further, we will examine the role of spirituality and religiousness in fostering a ST following an HIV/AIDS diagnosis. Finally, we will discuss applications for religious and health care professionals from these examples.

2. Method

In this sub-study, we intensively examined a subgroup of 13 participants who underwent a positive ST triggered by being diagnosed with HIV/AIDS from the study of *Spiritual Transformation in the Face of HIV* [4,5,9,10]. The three participants with a transient negative ST triggered by being diagnosed with HIV/AIDS are already described elsewhere [5].

2.1. Study Population and Sampling

The subgroup was selected from 147 people living with HIV in South Florida from two samples, the chronic disease and the spiritual sample. The *chronic disease sample* ($n = 74$) included the people with chronic long-term HIV-disease from the study on Psychology of Health and Long Survival with HIV/AIDS [11-13]. Since the frequency of ST was too low in the chronic disease sample, we recruited an additional second sample, the *spiritual sample* ($n = 73$), which was a purposeful sample of HIV-positive people, self-identified as being spiritual or as having had a life-changing spiritual experience [5]. Using qualitative content analysis, we identified 80 people who underwent a positive ST, of which 13/80 (16%) reported that the HIV/AIDS diagnosis was the trigger. On average they were 42.23 years old (SD 5.90) and had been diagnosed with HIV 10.46 years ago (SD 5.17). Mean CD4 cells/ μL were 409.46 (SD 258.45), ranging from severe immune suppression (90 cells/ μL) to normal CD4 values (948 cells/ μL), and 62% (8/13) were prescribed ART, of which 5/8 (63%) had an undetectable viral load. Of the 13 participants, 62% were male, 46% African American, 31% Hispanic,

and 23% White, and 54% gay. Most (92%) had at least a high school diploma and 77% were raised with more western religious backgrounds (39% Protestant, 23% Catholic, 15% Jewish), 15 % had no religious background, and 8% another religious background.

2.2. Procedures

The IRB approved study was conducted between 4/2003 and 11/2004 and participants were paid \$50 for their participation. Details on the medical, biological and psychometric instruments used in the study are described elsewhere [4,5,9,10]. For this sub-study, we focused on the interview. The key question was whether the interviewee ever had an experience that had profoundly changed his/her life. If this was endorsed, we probed for details about the type, consequences (changes in beliefs, self-views, behaviors, and attitudes) and antecedents (asking what paved the way for those changes). We explored both sudden as well as gradual profound changes. Additionally, we asked whether spirituality and/or diagnosis of HIV were related to any of these changes. Another question explored whether the interviewee ever had a spiritual experience (e.g., communication with God or a deceased loved one, out-of-body experience, near-death-experience). We also asked if they saw a reason for having HIV within a “*larger scheme*”. In addition, they rated themselves on a scale from 1–10, with 10 being the highest, how spiritual and how religious they considered themselves. The semi-standardized interviews took about one hour and were all performed by trained interviewers, audio-taped, and transcribed verbatim. In our analysis, we also included the Beck Depression Inventory [14], which was given at the time of the interview on ST to verify if the participants were able to overcome depression in the process of the ST. Depression at the interview was defined by the cut-off points of the BDI [14]. We derived the history of depression from the participant’s interview.

2.3. Data Analysis

For qualitative analysis, the transcripts were quality controlled and uploaded into the software program atlas.ti® version 5.0.66 (Scientific Software GmbH, Berlin, Germany). We used grounded theory [15] to analyze the characteristics of ST in the subsample of 13 participants who experienced the HIV/AIDS diagnosis as a trigger, looking at antecedents, consequences, time sequences, and the role of spirituality and religiousness. Statistical software (PASW® version 18.0, Chicago, Illinois, USA) was used for descriptive statistics.

3. Results

Gradual development sets ST triggered by HIV/AIDS apart from ST that follows a spiritual experience. None of the 13 participants described a sudden change after diagnosis. Across all participants, the ST developed in four different stages: antecedents, diagnosis, adaptation, spiritual transformation. The most prominent antecedents of ST triggered by the HIV/AIDS diagnosis were heavy substance use and risky sexual behavior (11/13, 85%). Most described their life style retrospectively as risky and empty. Facing the life-threatening diagnosis of an HIV-infection caused a re-examination of their prior prevailing beliefs and views, including spirituality. Based on the interviews, the diagnosis usually triggered a period of a depression (8/13, 62%). For 11/13 (85%)

people the HIV/AIDS diagnosis was followed by a phase of adaptation preceding the gradual ST. The adaptation phase could take up to ten years and was dominated by struggle with all four areas of ST (behaviors, attitudes, beliefs, and self-view). The old self was lost, the new self not yet found. The gradual ST was characterized by an individual spiritual journey that helped to overcome substance use, sexually risky behavior and depression, and to evolve from taking care of oneself to taking care of others (8/13, 62%).

One participant described: *“It was finding out I was HIV-positive in the way that it profoundly impacted my life was that I began to realize that we need to take responsibility for our own actions and do whatever we can do to better the situation. That was really a groundbreaking experience, because I went through some really destructive behavior in order to get to more productive and healthier way of looking at myself and being positive and looking at other people in a consoling way [sic].”*

3.1. Common Features of Positive ST Triggered by HIV/AIDS Diagnosis

3.1.1. Giving up Substance Use and Sexual Risk Behavior

In our sample, 11/13 (85%) led a lifestyle using substances and practicing risky sexual behaviors prior to their diagnosis. Some described that being in a *“drug haze”* interfered with their capacity to both have spiritual feelings and *“work on their relationship to God”*. One participant stated: *“You can’t be in communion with God when you’re in that state [sic]”*. These difficulties were evident even if they had been spiritual before the onset of substance use problems. Patients used illicit drugs for recreation but not to deepen spiritual experiences. The HIV diagnosis helped them to give up substance use in the process of the ST.

3.1.2. Why Me?

All but one interviewee felt that HIV was not a punishment from God, but rather that it *“made [them] aware”* of their destructive life style. Most (10/13, 77%) accepted personal responsibility for having HIV (8 from unsafe sex alone, 2 from sharing needles combined with unsafe sex). After acceptance, they blamed nobody—neither themselves nor God—for being infected. Even if they felt an initial phase of anger toward God for permitting that to happen, they eventually viewed infection as a necessary event to *“wake them up”*. Most (9/13, 69%) saw a reason on a *“larger scheme”* why they got HIV. The three most prominent reasons on a *“larger scheme”* were: being selected by God (5/13, 38%), feeling part of a divine plan, destiny, or God’s will (5/13, 38%), and to grow spiritually (4/13, 31%).

3.1.3. Overcoming Depression

According to the interviews, self-reported depression was very prevalent directly after diagnosis (12/13, 92%), which was accompanied by self-destructive behavior including substance use and risky sex. However, most participants (8/13, 62%) described depressed feelings and self-destructive behavior even before being diagnosed with HIV. The depressed mood state might have driven individuals into heavy substance use and risky sex, which in turn led to the HIV infection (11/13, 81%).

Most (11/13, 81%) of the participants were diagnosed before the advent of effective ART. Thus, the disease was perceived as a death sentence and many of their friends with HIV passed away.

Spirituality alone was sometimes not enough to overcome the hopelessness of their situation. The availability of an efficient ART and the prospect of a longer life expectancy was another main contributor in overcoming depression.

The BDI scores at the ST interview showed that only one (8%) was severely depressed (total score of 45 on the BDI), whereas 12/13 (92%) scored below 20; 9 (77%) showed no signs of clinical depression (score below 10), and 3 (23%) mild signs (score 10-18).

3.1.4. The Triad of Care Taking

The positive ST followed a pattern that we called the “*triad of care taking*“. In the first stage, before being diagnosed, 11/13 (85%) people stated that they did not care for themselves, an important antecedent of the dramatic change. An African-American woman described her life before the diagnosis, “*I was ignorant and irresponsible. I was in denial. I wasn’t caring or getting educated that anyone can get it and I thought that I was immune of something [sic].*” The diagnosis changed her life: “*It actually shocked me at first and I did decide to make changes because I used to use drugs...I started taking care of myself by not being promiscuous.*”

In the second phase, the adaptation phase after diagnosis, care-taking behaviors were mostly limited to themselves (11/13, 85%), e.g. starting ART, stopping substance use, seeking social support, and seeking psychological treatment.

Self-care is the most important aspect for the second phase of ST. One participant described: “*I hate to say this; sometimes you have to be selfish, you have to help yourself, so you can help others. If you neglect yourself and you get sick, how can you pretend to make difference and be an active person? Sometimes it’s great that you want to help the world, but in doing that to an extreme, it affects your health and your job, you become disconnected from society [sic].*”

None of the participants started to take care of others during the adaption phase. The third phase, the gradual onset of ST, is marked by the expansion to caring about others, which was not limited to close ones, like the family but more a general feeling of love and compassion for others. Of the 8/13 (62%) who started to take care of others, one gay African American man stated: “*The first thing that comes in mind was a desire, to love myself, and extendedly was more of a desire to really encumber unconditional love, which I think is a constant practice, a constant maintenance [sic].*” Another gay man described “*Finding out I was HIV positive made me less selfish; it made me more self aware.*” The expansion from self-care to taking care of others appears to support a long-lasting ST. Typical are statements such as: “*I’m much more compassionate and I try to help anyone with this disease that I can.*” Patients experiencing a ST do not seem likely to fall back into old, selfish, and self-destructive patterns.

3.2. Role of Spirituality and Religiousness

Four themes regarding ST triggered by being diagnosed with HIV/AIDS emerged from our analysis: spiritual practices, spirituality vs. religiousness, stigma of HIV/AIDS, and the development of an individualized spirituality.

3.2.1. Spiritual Practices

All participants indicated an increase in spiritual practices following diagnosis. For example, one stated: *“I started to meditate more, to ask for help.”* The main spiritual practices included prayer and meditation. Most (10/13, 77%) indicated that they prayed or meditated several times daily. Besides prayer and meditation, three described receiving advice and comfort through an encounter with an angel, another participant grew up in a spiritual household, where seeing spirits was normative and only one individual mentioned special training in spiritual techniques such as meditation, healing, and channeling.

3.2.2. Spirituality vs. Religiousness

All participants were able to distinguish the terms “spiritual” and “religious.” All interviewees but one (92%) described themselves as being more spiritual than religious. On a scale from 1–10, they rated themselves as significantly less religious ($M = 3.23$, $SD 2.38$) than spiritual ($M = 8.69$, $SD 1.49$); $M \text{ diff} = -5.46$ ($SD 3.20$) on a paired samples Test $t = -6.15$, $p < 0.001$.

Some participants expressed that they felt, from time to time, the need for some formalized spirituality but this was not essential for their personal behavior. A gay man, who felt stigmatized by his Christian religion, described what helped him out of his alcohol dependency: *“Coming to a God of my own understanding ... was really influential. What helped me to overcome the fear of God and the fear of change was that I realized that no one has a monopoly on God. I could listen to people to religious people, spiritual people, people that try to do good, and I could learn from it, and I could also ask God to help me and guide me to the people and places and things that brought to my life that are a strong foundation [sic].”*

We did not find unrealistic expectation about spiritual healing; rather, the participants perceived that their spirituality significantly improved their life. They were in search of spiritual guidance, which they did not find primarily within their religious organizations. None of the participants reported that a religious institution or a religious professional was instrumental in the ST. The stigma of HIV within a religious context contributed to a pattern of individualized spirituality.

3.2.3. Stigma

With the HIV diagnosis, the stigma of being gay, a prostitute, a drug addict, a criminal, *etc.* became often even more pronounced. Being diagnosed with HIV lead to increased feelings of deviance and inferiority; the following testimony illustrates, *“I just couldn’t pick up the bible and try to do something ... or go into a church and listen to hell and damnation about our wrongs and sins and our character defects.”*

Spiritual views were helpful to overcome the stigma that religious denominations at times associate with HIV, as in the case of one person, who stated *“trying to see the good in me; that is what spirituality is about.”*

Either the participants were already open, forgiving, and non-judgmental prior to the diagnosis (1/13, 8%), or they developed in this direction after their diagnosis (12/13, 92%). Some felt unworthy of belonging to certain religious denominations. In two cases, they felt actively excluded by religious

professionals. One gay man relayed, *“I couldn’t really follow with my old Christian beliefs, because it was so against everything that my life actually stands for, my homosexuality, my belief in women’s choice.”* Another described, *“I went to a catholic priest asking for help and when he learned I was HIV- positive he was never there again [sic].”*

In our study, being gay affected the religious views of the individual. For two individuals, negative views of gays in their denomination led to a conversion from their religion to an individualized spirituality. One Latino man felt conflicted towards God for not fulfilling his wish of being “straight”. The feeling of isolation in his religious community led to an increasing independence from his minister and a constructive individual dialogue with God. The man described that God conveyed to him: *“You’re gay because that is the way I made you.” I know that I never made a choice; it was the way I was born. He [God] told me that anyone could take the words from the bible and use them for their own purposes. I have a roommate that doesn’t have legs. God told me that there wasn’t anyone in the bible who didn’t have legs, but it didn’t mean that He didn’t create my roommate, because he’s different. [sic]”* Despite experiencing stigma from certain religious views, participants accepted themselves, which was key to their individualized spirituality.

3.2.4. Individualized Spirituality

Our analysis indicated the development of an individualized self-defined spirituality as an important feature of ST triggered by HIV diagnosis. This self-defined spirituality centered on the feeling of an individualized connectedness with a higher presence/entity (12/13, 92%), rather than a search for a sacred place, items or techniques for healing. Participants mentioned neither the word “sacred” nor the word “holy.” The expression of spirituality in daily life was more salient than the search for “sacred” rituals or places.

Spiritual independence and individuality are important aspects for many participants. One manifestation of spirituality in daily life is the expression of love on both the giving and the receiving end. Decisions regarding health behaviors and medical treatment were made individually and the participants did not seek decisional support from religious authorities. No participant mentioned a particular religious affiliation as playing a role in his/her well-being. Instead, they developed a personal relationship to a higher presence/entity and created personalized codes of conduct. For those who believed in God, contact with God is individual and not mediated by a priest. For example, one gay man described, *“my true belief is God is a verb, my actions, my peripheral consciousness... I think spirituality and reaching God is so personal and who am I to say, to tell people how to do it. There are so many different paths but I think we all are going to end up the same to feel like a whole person to feel a part of and loved [sic].”* None of the participants tried to convince others about their individual spiritual viewpoints.

Changes in attitudes and self-views went hand-in-hand with the development of an individualized spirituality. For 12/13 (92%), life held more value, and their attitude towards themselves and others became more open, and less judgmental. One participant stated, *“I think once I got a lot more spiritual I became more accepting and that was the hardest thing for me. I think I became a more likable person because I started being more caring, more loving and open minded about things, ... more accepting of*

different kinds of people [sic].” The gradual ST was characterized not only by developing an individualized spirituality but also by accepting the individualized spirituality of others.

4. Discussion

Including our main study on ST [6], there is an entire body of literature supporting the benefits on mental and physical health and health behaviors of spiritual coping and post-traumatic growth in people with HIV, which we summarized in a review [16].

The purpose of this study was to explore, from our case examples, how professionals in the field of religion and health care can transform the diagnosis with HIV/AIDS into a positive life-changing experience. Our main findings were that ST triggered by HIV/AIDS develops gradually, involving a key adaptation phase after diagnosis in which the patient develops an individualized spirituality. People follow a “*triad of care taking*,” from self-destructive behavior (antecedent), to developing self-care after diagnosis (adaptation) and gradual expansion in some to compassionate care for others during the gradual onset of ST. Participants develop a new homeostatic, positive self-view and apply it to daily life—at times for the first time. Major changes involve onset of positive health behaviors, overcoming depression, compassionate care for others, valuing oneself and others at a fundamental level, and developing an individualized, non-judgmental spirituality.

These findings dovetail Pargament’s research [2], but emphasize the connection aspect of spirituality rather than the sacred component. Pargament defined spirituality as the search for the sacred and religiousness as the search for the sacred within a religious denomination [2]. However, Pargament did not restrict the sacred to a theistic object like a God or spirit. The sacred can be any object, including time and space, events, transitions, people, psychological or social attributes and roles. According to Pargament, the sacred holds divine-like qualities such as transcendence, ultimacy, and boundlessness. The search for the sacred played a significant role in ST triggered by spiritual experiences in our main study [5].

In contrast, ST triggered by the HIV/AIDS diagnosis did not take place because participants began to search for the sacred or “*see the world through a sacred lense*” (page 14) [2]. The diagnosis did not hold sacred qualities, except for some participants who described that by being diagnosed with HIV, God wanted to make them aware that they had to change their lives. Instead, we found that participants viewed spirituality as connection to a higher presence/entity, which they could not find within their religious denomination. Due to being stigmatized with HIV/AIDS as promiscuous and/or gay, participants felt disconnected from their religious denomination. Seeing themselves as more spiritual than religious, some of the interviewees sought a spirituality that matched their individual needs, such as inclusiveness of gay people. The connectedness to a higher presence/entity was not only expressed in relation to something transcendental (e.g., God/Higher Power), but also to oneself and to others. Therefore, individualized spirituality seems to have an integrating function, which reframes the often troubled past of the participants in a positive manner. A complete transformation did not lead to just praying without acting. Interestingly, connectedness did lead to acceptance of self-responsibility, although in some cases participants felt chosen to get infected for some purpose. In general, the word “connectedness” can be replaced in many instances by the words “integration” and even “acceptance.” In this sense, interviewees personally accepted responsibility for being infected with HIV. Most

importantly, they perceived God not as punishing but forgiving, and participants looked for a religion reflecting this view.

Since the adaption phase often took many years, interventions targeting the sense of connectedness could speed up the development of individualized spirituality. One extremely important aspect was forgiveness, which allowed acceptance of even very unpleasant issues, such as being infected. Their spirituality allowed them to step back and look at their lives from the perspective of a “*larger scheme*”. This together with the feeling of being embedded into a higher presence/entity helped them to perceive themselves as being meaningful and integrated, and to quell loneliness.

Limitations

This study is limited by the small number of participants and its retrospective character. Participants were diagnosed with HIV on average a decade ago and there is a recall bias. Furthermore, we do not have BDI scores before the ST and during the adaptation phase. The impression that the participants were able to overcome depression during the course of the ST is based on absence of depression according to the BDI at the interview and the participants reporting that they felt depressed before or immediately after being diagnosed with HIV/AIDS.

5. Conclusions

Being diagnosed with HIV/AIDS can, in some cases trigger a gradual onset of a ST that has dramatic, long-lasting, beneficial effect on mental and physical health behaviors. However, for the participants in our study, neither religion nor professionals in the field of religion and health care play a key role in fostering ST. Since the development of an individualized non-judgmental spirituality is a special feature of ST following HIV/AIDS, this might be a missed opportunity. This study demonstrates that there is a potential for religious professionals to foster ST. Religious professionals could play a special and highly efficient role in integrating “outsiders” by being cognizant of potentially judgmental and stigmatizing behavior. Our results suggest that finding ways to support individualized spirituality in HIV-positive individuals could be important in fostering feelings of connectedness to higher presence/entity. Feeling individually connected to a higher presence/entity leads not only to God, but also to connectedness to oneself and others, and thereby to an overall responsible and caring disposition. Inclusive religious or spiritual approaches that promote the individual connectedness to a higher presence/entity may help people who struggle with HIV, substance use and sexually risky behavior not only to overcome the depression and to change their health risk behavior, but also to increase self-care and positive behaviors towards others.

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