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# **Research Article**

# The Impact of a Holistic Intervention on Self-Efficacy and Risk of Depression in HIV-Infected Individuals in Denmark

#### **Abstract**

Introduction: Human immunodeficiency virus (HIV) infection is a stressful disease, and depression is frequently experienced by HIV-infected individuals. The aim of this pilot study was to investigate whether a holistic intervention could improve coping self-efficacy strategies and have a positive impact on the mental health of HIV-infected individuals 12 months posterior to the intervention.

Method: From January 2010-January 2011, a total of 30 HIV-infected individuals at the Department of Infectious Diseases at Aarhus University Hospital, Denmark were included in the study. The intervention was a group intervention and was facilitated by an educated coach. It was organized as a three day residential course as well as 6 single day follows up events spread out over 6 months.

The main outcome measures were coping self-efficacy (self-efficacy as defined as the belief in one's ability to perform a specific behavior) and depression. The intervention was evaluated 12 months after the end of the intervention.

Results: Twenty individuals completed the intervention. Coping self-efficacy and psychological health improved overall, and there was a significant decrease in depression (p=0.0017). The qualitative interview results supported the questionnaire results, displaying changes in bodily sensation, in awareness, in understanding and insight, in behaviour and in actions as well as the development of new competences. The individuals felt more in balance (e.g. emotional stability), and this feeling of being more competent in terms of managing the disease was maintained at the 12-month follow-up.

Conclusion: These results will be useful for developing effective interventions that help individuals manage the acute and chronic stress of living with HIV and increase coping self-efficacy, thereby preventing depression. These results merit further investigation in a randomized controlled trial.

### Introduction

Due to the successful treatment of human immunodeficiency virus (HIV) with highly active antiretroviral therapy (HAART) [1,2]. HIV infection is now considered a chronic condition, and the life expectancy of HIV-infected individuals is approaching that of the background population [2]. Sub-optimal adherence to antiretroviral therapy is the most common cause of virologic failure and will, in the long-term, lead to an increased risk of drug resistance and disease progression [3-7]. Furthermore, concerns about the consequences of inadvertent disease disclosure can interfere with self-care efforts [8-10]. Depression is the most common form of psychological distress experienced by those living with HIV, and depression is both under-diagnosed and under-treated within this population group. Up to one third of persons livings with HIV have mood disorders or clinically significant depressive symptoms [11-13]. Depressive symptoms and stress have been linked to HIV disease progression,

but the association between HIV and depression is unclear [14-16]. Depression is attributed to multiple factors, including physical factors (e.g. the progression of HIV-related symptoms) and psychological factors (e.g. prior psychiatric history and stress); factors specific to the patient and those related to antiretroviral treatment [17-19]. Several studies that examined depression at the initiation of HAART found that individuals with depression exhibited over five times the risk of clinical progression to AIDS, [13,20] slower viral suppression [21,22] and a decreased survival rate [22]. We previously investigated the prevalence of depression in HIV-infected individuals and identified factors that were associated with the risk of depression in a Danish setting [23,24]. Our studies confirmed that depression is both underdiagnosed and under-treated. In addition, our findings showed that living with HIV is as much a psychological and social concern as a medical concern. Disclosure is a continuous challenge and a potential HIV-related stressor [25]. It has independently been shown that positive psychological states aid a less rapid HIV disease progression



[26-36] and that a positive psychological adjustment to chronic disease leads to an increased participation in self-management and increased self-efficacy [36]. Self-efficacy is here defined as the belief in one's ability to perform a specific behavior [37-39]. Individuals with high self-efficacy are better able to motivate themselves and to persevere when difficulties arise, should be less vulnerable to stress and should be more resilient after aversive stimuli [40]. Coping has been the focus of research in the social sciences for a long time and is understood as a complex multidimensional process that is sensitive to the environment (i.e., to environmental demands and resources) and to personality dispositions that influence the appraisal of stress and coping resources. When people achieve a good 'fit' between stressful events and their coping strategies, they experience fewer psychological symptoms than when there is a lack of fit. Specifically, a person's belief in their efficacy determines which knowledge they acquire and thus on which foundation they base their skills [38]. This also determines the likelihood that knowledge and skills will be translated into adaptive behaviors.

Coping is considered one of the core concepts in health psychology and is strongly associated with the regulation of emotions in response to social and environmental stressors. Coping self-efficacy is based on the idea that people need to have coping self-efficacy in order to effectively engage in adaptive coping behaviors [41]. Several studies have concluded that, overall, stress-management interventions can substantially improve the mental health and quality of life in HIV-infected persons [26,42,43]. However, few studies have investigated whether the benefits of such interventions are maintained in the long-term [26].

The aim of this study was to investigate whether a holistic intervention (considers the whole person physically and psychologically, in the quest for optimal health and wellness) could improve the coping self-efficacy strategies of HIV-infected individuals, have a positive impact on mental health and be maintained 12 months after the intervention.

# Methods

## Study group

From January 2010–January 2011, a total of 30 HIV-infected individuals (8 women and 22 men) were recruited for the study. The outpatient clinic at the Department of Infectious Diseases at Aarhus University Hospital provides care for 14% (N = 4627) of the total HIV-positive population in Denmark.

Inclusion criteria were as follows: aged 18 years or older; the occurrence of two or more missed scheduled quarterly appointments; and the presence of physical problems (e.g. pain, side effects, low adherence), psychological problems (e.g. depression, anxiety, non-disclosure of HIV status, stress, loneliness, divorce) or social problems (e.g. economy, unemployed). We screened the patient group according to the above mentioned inclusion criteria and found 50 HIV-infected individuals who were eligible for the study. They were invited to participate in the study and to attend a meeting with more detailed information. 30 individuals asked to be enrolled and they were divided into two groups (15 persons in each group) according to which dates that suited the persons best. The study was

approved by the Aarhus Health Human Research Ethics Committee and the Danish Data Protection Agency.

#### Intervention

The intervention was a group intervention facilitated by an educated coach. Both groups were offered the same intervention. The framework was a three-day residential course plus six single-day/eight hour follow-up events/monthly. The total length of the intervention was 6 months. Table 1 shows the main framework for and content of the intervention. The focus of the intervention was to improve each person's coping self-efficacy in order for them to gain an improved balance in their lives (a stable mental or psychological state; emotional stability). The intervention was based primarily on a Native American philosophy of life [44] and its understanding of how changes affect human beings and create imbalance. According to this philosophy, change can be understood as a dynamic force that moves people from one point to another. However, it also acknowledges that people have different ways of facing change. The 'Wheel of Change' (Figure 1) illustrates the movement from denial over reaction to acceptance and finally to action and shows how the stages are connected to conscious and unconscious behavior. The Wheel of Change is the core starting point for the intervention. The intervention offers various tools and principles that focus on whether a person chooses 'warrior 'or 'victim' behaviors when facing challenges in his/her daily life (Figure 2). The way in which people deal with challenges determines whether, in a given situation, he or she assumes the stance of warrior or victim. The source of the warrior is love and courage while the source of the victim is fear. Once it is clear that the source of certain reactions is fear, the person becomes more conscious of how he or she reacts and is then able to develop a new ability to act. The focus of the intervention is on how to accept and recognize one's current situation and find one's own tools to act as a warrior [44].

# Questionnaire

Participants filled out a self-reported standardized questionnaire before starting the intervention (baseline) and 12 months after the intervention was completed (follow-up). The following data was recorded: gender, age, educational level, current job, marital status, current HIV treatment and adherence, current financial situation, route of infection, HIV exposure group, sex life, co-morbidities, smoking and drug habits, depression, alternative treatment, coping self-efficacy, disclosure and psychological factors associated with living with HIV, The Short-Form Health Survey (SF-36), The Sense of Coherence (SOC) Scale, The coping self-efficacy scale (CSE), The Beck Depression Inventory II (BDI).

The Short-Form Health Survey (SF-36) [45] is a multi-purpose, short-form health survey with 36 questions that yields an 8-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index. The Sense of Coherence (SOC) Scale [46], the SOC, is defined as: "The extent to which one has a pervasive, enduring though dynamic, feeling of confidence that one's environment is predictable and that thing will work out as well as can reasonably be expected." It includes three components: 1) Comprehensibility (the extent to which stimuli from one's external and internal environments are structured, explicable



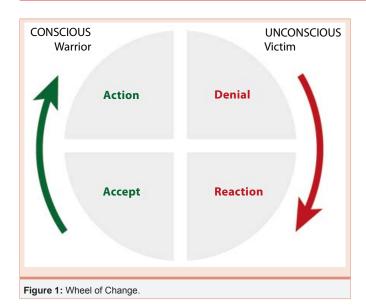
Table 1: Main frame and content of the intervention.

	Themes	The setting
Three day residential course	The Wheel of change (Figure 1) The Wheel of Change is the the essential starting point for the intervention. When you meet a challenge you go through a process in order to gain balance again. The movement goes from denial over reaction to acceptance and finally to action, but it is not necessarily a straight forward process. The stages are connected to conscious and unconscious behavior. The purpose is to be aware of your unconscious behavior which causes unbalance in order to be able to do something to regain balance in life.  The task and challenge is to learn to become conscious of the unconscious  Warrior/Victim (Figure 2) The intervention focuses on various tools and principles that primarily intend to shed li9ght on whether a person chooses 'warrior' or 'victim' behavior when handling challenges in daily life. We are not either a warrior or a victim — we contain both The source of the warrior is love and courage, while the source of the victim is fear.  The task and challenge is how one can accept and recognize the current situation and find the tools to act as a warrior  "The five questions" (The warrior's weapon) Understand that the fear is not an enemy. The fear is teaching us a lesson. It is trying to teach us what I have to do. You don't get rid of it — you integrate it.  When you face fear:  1) Breathe  2) Connect, feel, accept  3) Ask the five questions and identify the fear Who; am I afraid of? What, am I afraid of? What, am I afraid of? Where, do I feel the fear? When; does the fear occur? How; does the fear occur? How; does the fear fect me?  4) Learn the lesson, integrate You cannot change the other person — you can change yourself	To create the setting, the coach first of all ensured a safe environment of trust and respect, which is crucial and the main condition to be able to open up and work with private challenges.  The participants were seated in a circle. The circle is the pattern of harmony, according to the native Indians. Initial a feather was send from one person to the next in the circle and the person with the feather was speaking and the rest were listening. This was how all gatherings started.  On the first day the coach was introducing the participants to do small grounding exercises. The coach mainly used own cases as examples. Slowly the participants were getting more involved and was bringing in own experiences and examples.  On the second day the coach was asking for the participant involvement and slowly during the day they brought in more cases and examples. No one felt forced to bring it is and only at the end of the day they were asked to make an exercise, where they were paired two and two and had to tell about own experience of tear to each other.  The exercise was marking a shift in the intimacy of the group. The coach to the participants, that the name of the course really was 'I How to grow up and be an adult'  There had been build up an atmosphere of confidence in the group and the participants got more and more involved in exercises and
Six single days follow up	The six follow up days all put layers to the central themes the participants were introduced to during the residential course. They were introduced to new grounding and mediation exercises, which gave participants a variation of exercises to choose from.  They gradual recognize that they have the resources themselves – they just have to rediscover them.  The participants were constantly being reminded of the value of practicing and facing challenges and learn from it.	
Practice in between	What you train- is what you do  Exercises of own choice: Breath work, Grounding, Getting conscious of the unconscious, Face fear etc.	The participants effort of exercising differed as did the speed and depth of change.

and predictable), 2) Manageability (the extent to which resources are available to a person to meet the demands posed by these stimuli) and 3) Meaningfulness (the extent to which these demands are challenges worthy of investment and engagement). SOC is strongly related to perceived health, especially mental health, and having a strong SOC may protect against depression, so SOC can be useful for identifying people who can be helped by psychological interventions. The SOC scale has a seven-point Likert scale format with two anchoring responses, 'never' and 'very often'. The points that were measured were perceived comprehensibility, manageability and

meaningfulness. The score ranges from 13–91, a high score indicating a strong SOC. *The coping self-efficacy scale (CSE)* [47] provides an alternate approach to the measurement of adaptive or positive coping for intervention studies. The CSE scale assesses a person's confidence with respect to carrying out various key coping behaviors (adaptive), such as seeking social support and finding solutions to problems, so that the CSE score reflects the individual's confidence regarding his or her ability to effectively cope with or manage problems. The CSE was assessed with a 26-item measure of perceived self-efficacy for coping with challenges and threats. Subjects were asked to use





Warrior	Victim
Takes responsibility	Blames others
Proactive	Reactive
Makes life happen "Change"	Life happens
Open, flexible	Closed, rigid
Sees choices and options	Is stuck, has exuces

an 11-point scale to rate the extent to which they believe they could perform behaviors that were important to adaptive coping, such as 'differentiate between what can be changed and what cannot be changed', 'break an upsetting problem down into smaller parts', 'look for something good in a negative situation' and 'receive emotional support from friends and family'. Anchor points on the scale were 0 ('unable'), 5 ('moderately able') and 10 ('certainly able'). The Beck Depression Inventory II (BDI) [48] was used to assess the prevalence and severity of depressive symptoms. The BDI has shown high validity and reliability in measuring depressive symptoms and has acceptable test-retest reliability in a nonclinical population. The respondents rated 21 items on a scale from 0 to 3 according to how they had felt during the preceding 2 weeks. The BDI focuses on both the cognitiveaffective symptoms of depression, e.g. pessimism and diminished self-esteem as well as on the somatic symptoms of depression, e.g. weight loss. A BDI score ≥14 is widely accepted as an indication of depression. In this study, the BDI score categories were interpreted as follows: 0-13, no/minimal depression; 14-19, mild depression; 20-28, moderate depression; 29-63, major depression.

#### **Qualitative interviews**

Semi-structured in-depth interviews were conducted with each participant at the end of the intervention by a trained anthropologist. The interviews inquired about the following topics: the motivations for participating in the intervention, what had been the best qualities of the intervention, considerations about joining a group

intervention, cognition gained from participation and changes in one's own behavior as perceived by oneself and as perceived by one's friends and family. The qualitative data was analyzed using a thematic framework analysis [49].

#### Statistical analysis

The statistical analyses were performed using STATA 10 [50]. All data from the questionnaires was double-entered. All statistical analyses were non-parametric as the sample size was too small to assume that the sample data was normally distributed. All parameters were analysed as paired data (baseline versus follow-up), and we used the Wilcoxon matched-pairs signed-rank test to show changes in depression. A p-value <0.05 was considered statistically significant. When comparing two parameters, linear regression was used to test for correlations.

#### Results

In January of 2010,  $30\,\mathrm{HIV}$ -infected individuals,  $8\,\mathrm{women}$  and  $22\,\mathrm{men}$ , were enrolled in the study.

These individuals have lived with their HIV-status for anywhere between 2-26 years. Twenty participants completed the intervention but only 19 turned in questionnaires filled out at baseline and at the 12-month follow-up. Seven participants stopped after the three-day residential course. The reasons for stopping were as follows: two had severe psychological problems; three concluded that the intervention was "not right for me"; and two began new jobs. Three participants almost completed the intervention but stopped before the last follow-up day due to practical reasons.

The questionnaire results, qualitative interview results as well as their associations with the outcome of the intervention are reported below.

#### Questionnaires

The participants were mostly male (74%), and 58% were between 41 and 50 years old (Table 2). Overall, 58% had co-morbidities (hypertension, diabetes, hepatitis B/C, asthma or mental illness). The prevalence of symptoms of depression is shown in table 3.

At baseline, 5 individuals had a BDI >20, indicating moderate to severe depression. At follow-up, this number decreased by 80%, and only 1 individual was depressed. The median BDI score was 11 at baseline and 4 at follow-up. A Wilcox on matched-pairs signed-rank test showed a significant decrease in depression from baseline to follow-up (p=0·0017; Figure 3). A total of 53% of the individuals had diagnosable depression at some point in their lives. The median BDI scores both at baseline and at follow-up fell into the lower range (0–13), indicating minimal depression. Looking at the interquartile ranges, the upper quartile was 19 at baseline and 9 at follow-up. Five individuals had moderate to severe depression at baseline, while only one had moderate to severe depression at the follow-up.

There was an overall improvement from baseline to follow-up as there was a decrease in the influence of emotional factors on dayto-day life with HIV. In terms of coping self-efficacy, there was an overall increase in self-efficacy from baseline to follow-up, indicating increased confidence in performing coping behaviors when faced



with life challenges (Figure 4). The participants reported a better self-rated health at follow-up (SF-36) and overall results indicated improved psychological health and unchanged physical health (SF-36) at follow-up as compared to that at baseline. The participants also reported an increased SOC.

#### **Qualitative interviews**

In-depth interviews were conducted with the 20 participants that had attended all sessions and the 3 participants who stopped before the last session (77 % of the participants). Overall, participants

 $\textbf{Tabel 2:} \ \ \textbf{Characteristics of the 19 HIV-infected individuals in the interventional study.}$ 

	N	
	19	%
Gender		
Men	14	74
Women	5	26
Age		
31-40	3	16
41-50	11	58
51-60	4	21
60+	1	5
Etnicitet		
Denmark	19	
Education		
A few years of higher education (1/2 year-2years)	3	16
More years of higher education (3-4 years)	14	74
Completed or almost completed higher education (more than 4 years)	1	5
No education after secondary school	1	5
Work		
Employed	11	58
Rehabilitation, social security, sickness or disability support pension	3	16
Incapacity benefit	3	16
Other	3	11
Married/has a partner		
Yes	11	58
Children		
Yes	11	58
HIV exposure groups		
Homosexual	8	42
Heterosexual	10	53
Bisexual	1	5
Co-morbidity		
Yes	11	58
Hypertension	2	
Hepatitis B,C	3	
Asthma	3	
Mental diseases	4	
Decreased lung function	1	

<sup>\*</sup>Twenty participants completed the intervention but only 19 turned in the questionnaires at baseline and follow-up.

**Table 3:** The prevalence of depressive symptoms and diagnosed depression among the 19 HIV-infected individuals in the interventional study.

Becks Depression Inventory II		Baseline		Follow-up	
Score		N		N	
		19	%	19	%
Minimal	0–13	11	58	17	90
Mild	14–19	3	16	1	5
Moderate	20–28	3	16	1	5
Major	29–63	2	10	0	0
Previous diagnosed with depression		10	53		
Pre HIV-diagnosis		3	16		
Post HIV-diagnosis		6	32		

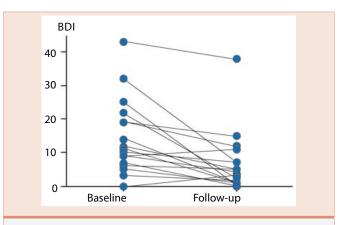
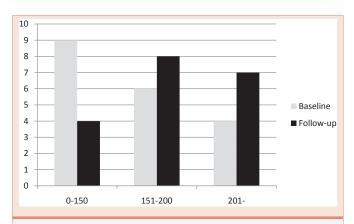


Figure 3: BDI Score.



**Figure 4:** Coping Self-efficacy Scale scores for the 19 HIV-positive subjects in the interventional study at baseline and at a 12-month follow-up. This 26-item scale measures one's confidence in performing coping behaviours when faced with life challenges.

indicated changes in body sensation; in awareness, understanding and insight; in behaviour; in actions; and in the development of new competences as one's own "HIV-manager". Many of the participants emphasised that they had become more conscious of how they behave in different situations. This consciousness of how they react to various obstacles and unpredictable situations presented



an opportunity to change their behaviour and gain control of their daily life. This new awareness was supported by various tools and techniques of meditation and breathing exercises. The techniques of gaining control were implemented in daily life situations and did not call for withdrawal. Each participant found what suited him or her best and this was one of the strengths that participants emphasised as unique for this intervention; that there wasn't one right solution to follow; instead you had to find one that worked for you. As they reclaimed control over their lives, some also gained the courage to tell relatives about their HIV status, others realised they had to change profession and some stopped using anti-depression drugs. Of the 20 persons that completed the intervention, all mentioned changes that they themselves had felt, and for half of the group people close to them had likewise noticed a change, that they had become more optimistic and more straight-forward. The intervention made it clear to the participants that many of the obstacles they were facing were not due to their HIV status, and that by accepting HIV as a condition they had to cope with, the disease became just an element of their personal story rather than an overshadowing identity. Although they still experience their HIV as a stigma in society, they have gained strategies to cope with their situation.

#### Discussion

Our findings indicated that a holistic intervention improved the psychological health (SF-36) and the coping self-efficacy strategies (CSE) of the HIV-infected individuals in this study. In addition, there was a significant decrease in depression (BDI-II). The participants reported unchanged physical health (SF-36); thus we conclude that the intervention did not do any harm. In addition, the subjects' SOC improved. Notably, this scale can be thought of as a prognostic indicator of the outcome of the individual's rehabilitation process. The result indicates a gain in balance and emotional stability and a stable mental or psychological state in terms of living with HIV. The SOC measures the internal capacity to manage changes in life situations without neglecting one's health. The consistency between the SF-36 and the SOC responses supports this conclusion.

The intervention had a positive impact on the severity of depression as measured by the BDI-II score. A review by de Ridder et al. [36] concluded that to promote psychological adjustment, patients with chronic diseases should remain as active as is reasonably possible, acknowledge and express their emotions in a way that allows for them to take control of their lives, engage in self-management and try to focus on potential positive outcomes of their illness. Patients who can use these strategies have the best chance of successfully adjusting to the challenges posed by a chronic illness. The decrease in depression might be due to increased coping self-efficacy as, in general, a person with a strong SOC is more likely to feel less stress and tension and to believe that he or she can meet the demands of daily life; thus, a strong SOC is a protective factor against depression [51]. As a strong SOC may protect against depression, SOC may be useful for identifying individuals who are likely to benefit from psychological interventions [52,53]. The participants reported a better self-rated health at the follow-up. Self-rated bad health has been linked to being a strong predictor for mortality in HIV-infected individuals [54].

A meta-analysis conducted by Chida et al. [55] showed that personality types or coping styles and psychological distress were more strongly associated with greater HIV disease progression than stress stimuli per se. Other studies found that for HIV-infected individuals coping with stressors, avoidant coping and disengagement coping styles were related to increased anxiety and depression [56,57], while decreases in avoidant coping following interventions were related to decreased depression and grief [58,59]. We conducted a study investigating the relationship between coping self-efficacy levels, as determined by the CSE, HIV status disclosure and depression in a Danish cohort [60]. The study revealed that those with low CSE scores were more likely to report living secretly with HIV and to be depressed. Disclosing HIV may constitute a social stressor, and a lack of coping self-efficacy may increase the likelihood of non-disclosure and depression.

Results from the qualitative interviews supported the questionnaire results and indicated that the participants experienced:

1) Changes in body sensation (e.g. decreased symptoms of depression, increased quality of life, increased self-reported health);

2) Changes in awareness, understanding and insight (including being able to understand HIV in ways that differed from their biomedical understanding);

3) Changes in behavior and actions and the development of new competences in their role as "HIV manager" (e.g. increased coping self-efficacy, increased SOC, decreased HIV-related stressors, developing their own resources/motivations, more tools to handle life situations, greater knowledge and more tools to help prevent symptoms and promote health).

This study was a pilot study of a complex intervention and is, to our knowledge, the first study to use a Native American Philosophy approach. The definition of a complex intervention is one that is "built up from a number of components which may act both independently and interdependently" and early phase research is needed to define the "active ingredients" of the intervention [61,62]. It is difficult to evaluate a complex intervention due to problems inherent in developing, identifying, documenting and reproducing the intervention. Complex interventions are directed at the person as a whole and require use of both qualitative and quantitative evidence [61,62]. We used both qualitative and quantitative methods to measure aspects of the changes that took place during the intervention. Furthermore, the results of the intervention depend on both the contextual and communicative aspects of the intervention, the resources of the individual such as the body's ability to heal itself and the impact of the individual's situation. Therefore measurement of the outcome is not a single endpoint with a linear cause. Rather, the individual is an active agent who will interact with an intervention in ways that produce individualised changes. Changes in immune status may emerge over longer periods, and randomised controlled trials (RCT) with sufficient statistical power should include longterm follow-up assessments to conduct more definitive tests of the effects of the intervention on HIV disease markers [63]. The assumptions that underlie the intervention should be identified as well as its process and context. This is beyond the scope of this study but should be explored further in an RCT as the next step in developing an intervention [60,61]. There is insufficient evidence to draw conclusions regarding the long-term outcomes of HIV-



specific self-management interventions [26]. We believe that these results offer information that can be valuable for developing effective interventions.

The study has some limitations. One limitation is the small number of participants: 20 HIV-infected individuals (67 % of the study group) finished the intervention at the 12-month follow-up. The small size of the study decreases the statistical power of the analysis of the results of the questionnaires and increases the likelihood of bias, but the qualitative data supports the quantitative findings. The lack of a control group is a considerable limitation as the results could be attributed to natural fluctuations, improvements of individuals over time, changes in treatment, the characteristics of the participants (e.g. age, gender, amount of time living with HIV-status, ethnicity) and other uncontrolled variables.

In conclusion, the findings from this study are useful for developing effective interventions that help HIV-infected individuals to increase their coping self-efficacy and thereby prevent depression over the long term. These findings add to our understanding of a more holistic approach to patient care and might lead to an increased coping self-efficacy for patients as well as an increased involvement and responsibility for patients' own health. This merits further investigation in an RCT.

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### **Conflict of interest**

All authors declare that we have no conflict of interest and conformed to the Helsinki Declaration concerning human rights and informed consent, and that I followed correct procedures concerning treatment of humans and animals in research.

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