

## ARTICLE

# “I am a whole person, not a diagnosis” - A mind-body intervention to improve the mental wellbeing of HIV-infected individuals in Denmark

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### Abstract

**Background:** Depression is the most common mental health co-morbidity experienced by people living with HIV. We developed an intervention to improve mental health among HIV-infected individuals. The aim was to improve each person's balance in life, making each person conscious about their own behavior and activating their own resources. The participant worked with their individual process within the group and practised techniques to address fear/stress management. Mental health improved overall and there was a significant decrease in depression. The effect was maintained at 12-months. This study aimed to gain insight into factors that mediated the effects observed.

**Methods:** Semi-structured interviews were conducted with each participant at the end of the intervention. Digital audio-recordings of the 48 interviews were transcribed and analyzed using thematic analysis.

**Results:** The following themes were identified as facilitators: *Context, Participant, Coach, Intervention approach* and *Sense of Community*. Three themes explained the experienced effect: *Transformation, Internalized Stigma Changes* and *Integrity*. We observed that fear no longer controlled the lives of the participants, as the individuals acquired new skills to handle disclosure and internalized stigma. Living with HIV became an integrated part of their life.

**Conclusion:** Interventions designed to practise and strengthen patients' insight into the mental and physical contexts of their condition reduces depression, improves mental health and quality of life and should be offered in conjunction with HIV medication and be a fully integrated aspect of HIV care. Thus, treatment calls for a holistic and person-centered approach to patient care, acknowledging that viral suppression is not necessarily the ultimate goal of effective treatment.

### Keywords

Complex intervention, depression, disclosure, HIV, holistic health, mental health, mind-body, patient-centered care, person-centered healthcare

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## Introduction

Improvements in HIV treatment mean that many people who are infected in both high and low income countries now have a life expectancy comparable to the general population [1]. Although antiretroviral therapy (ART) has transformed HIV from a terminal illness to a chronic condition, public views of the disease have not markedly changed [2]. HIV remains highly stigmatized throughout the world, including Denmark [3]. Stigma-related experiences of people living with HIV may contribute to stress and difficulties adjusting to a new life scenario [4,5]. Indeed, HIV-positive individuals may respond to the stigma by concealing their disease from others and

concerns about the consequences of inadvertent disease disclosure can interfere directly with efforts at self-care [6].

Continuously making individual decisions to determine the best possible way to disclose their HIV diagnosis to others is a preoccupation of infected individuals [7] and impacts their mental health and quality of life. Depression is the most common form of psychological distress experienced by people living with HIV [8]. In a Danish setting, we previously found that 26% of an HIV-infected population had symptoms of major depression [7,9,10] and disclosure of HIV status is a continuous challenge and potential social stressor [11]. Furthermore, we found that lack of coping self-efficacy may increase the likelihood of

non-disclosure and depression [12]. Living with HIV today is as much a psychological and social phenomenon as a physiological and medical concern. Thus, treatment calls for a holistic and person-centered approach to patient care, acknowledging that viral suppression is not necessarily the ultimate goal of effective treatment.

Healthcare systems need to become more integrated and person-centered to meet the needs of HIV-infected individuals [13] and to adapt to the needs of this aging population. A holistic approach considers the whole person, physically and psychologically, in the quest for optimal health and wellness, acknowledging the interplay between biological, behavioral and psychosocial factors (health and behavior) [14]. Mind-body medicine focuses on the connections between the mind and body and on the effects of changes in physiology and behavior on health and disease. Mind-body interventions are widely considered safe and have been shown to improve symptom management in a wide variety of illnesses [15]. Mind-body medicine programs are effective at reducing and managing the clinical manifestations of stress, reducing anxiety and increasing patient resilience [16-18]. Higher resilience is associated with lower psychological distress and higher perceived quality of life, both physically and mentally, among HIV-infected individuals [19,20].

There is a lack of studies establishing the long-term efficacy of self-management programs with a general focus on living with HIV/AIDS [21,22] and to meet the needs of living with HIV across a lifespan. We developed an intervention to increase mental health among people living with HIV. Mental health improved overall and there was a significant decrease in depressive symptoms, with the effect maintained at 12-months [23,24]. This study aimed to gain insights into the factors that mediated the effects observed.

## Materials and Methods

### Development of the Intervention

We used the model from the UK Medical Research Council (MRC) for the development of complex interventions [25]. 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 [25,26]. It is difficult to evaluate a complex intervention due to the challenges inherent in developing, identifying, documenting and reproducing an intervention. Complex interventions are directed at the person as a whole and require the use of both qualitative and quantitative evidence [15,26]. We used both qualitative and quantitative methods to measure the aspects of changes during the intervention. Furthermore, the results of the intervention depend on both the contextual and communicative aspects of the intervention, as well as the physical and mental resources of the individual. Therefore, measurement of the outcome is not a single endpoint with a linear cause; the individual is an active agent who will

interact with an intervention to produce individual changes. The current article presents the qualitative data, with the quantitative data having been presented elsewhere [23,24].

### Participants

The inclusion criteria were age  $\geq 18$  years, psychological problems (e.g., depression, anxiety, stress, loneliness) and motivated to work on personal challenges. Patients with an untreated mental illness were excluded. Each patient received information about the study by mail and an invitation to attend a meeting for more detailed information. Before inclusion, all patients confirmed their motivation for working on personal challenges and provided written informed consent. We conducted 4 courses (15 persons/course) with 60 HIV-infected individuals in total and 80% completed the intervention (Table 1). The participants had been infected with HIV for 2 to 33 years and had different expectations or wishes for change that motivated them to join the intervention (e.g., regaining joy in life, a need for regaining balance, breaking out of isolation, a possibility to focus on themselves and meeting other HIV-infected people).

### Intervention Content

The intervention was a group intervention facilitated by an educational coach taking the form of a 3-day residential course plus 2 single-days/8-h. The overall focus of the intervention was to improve the life balance of each individual (i.e., stable mental or psychological health and emotional stability), making each person conscious of their own behavior and how to activate their own resources. The mind-body approach in the intervention took into account the effect of the mind on physical processes, including the effects of psychosocial stressors and conditioning. The intervention was based primarily on a Native American philosophy of life and its understanding of how changes affect human beings and create imbalance [27,28] with different mind-body approaches. The following components were addressed: warrior/victim behavior, personal limits and boundaries and techniques to address fear/stress management. The intervention offered the participants a variety of techniques and was then adapted to an individual approach; the participants were not obliged to work with all techniques to gain an effect. The main framework and content of the intervention is shown in Table 2. The way an individual deals with challenges determines whether he or she assumes the stance of warrior or victim. The source of the warrior behavior is love and courage, whereas the source of the victim behavior is fear. Once the person becomes aware of how he or she reacts in stressful situations, a new ability to act is developed. When an individual becomes aware of his/her fear behavior, strategies can be employed to switch from a stress response to a relaxation response in order to achieve balance [29]. Participants performed exercises at home by their own choice, listening to audio files (the same as they were introduced to during the intervention) focusing on the

Table 1 Sociodemographic characteristics

Characteristics	Completed (n=48)		Did not complete (n=12)	
		%		%
<i>Gender</i>				
Male	32	67	9	75
Female	16	33	3	25
<i>Age</i>				
30-40 years	9	19	4	33
41-50 years	20	42	3	25
51-60 years	16	33	3	25
60+	3	6	2	17
<i>Ethnicity</i>				
Etnic Danish	44	92	10	83
Other European country	1	2	2	17
Africa	1	2		
South/Central America	2	4		
<i>Education</i>				
Short cycle length of higher education	12	25	3	25
Medium cycle length of higher education	27	56	7	58
Long cycle length of higher education	6	13	2	17
No education	3	6		
<i>Employment</i>				
Employed	29	60	6	50
Unemployment benefit, social security	6	13	3	25
Sickness or disability support pension	8	17	3	25
Maternity leave				
Other, pension, orlov	5	10		
<i>Married/Partner</i>				
Yes	15	31		
<i>Sexuality</i>				
Homosexual	21	44	8	67
Heterosexual	25	52	4	33
Bisexual	2	4		
<i>Co-morbidity</i>				
Yes	22	46	5	42
High blood pressure	3		1	
Hepatitis B, C	5			
Mental illness	4		2	
Cancer	1			
Diabetes	1			
Asthma	3			
Osteoarthritis	2			
Other	3		3	

Table 2 Intervention framework and content

Approach	Schedule	Components	Tools and techniques
<b>Creating the setting</b>	<b>Module 1</b>		
The coach ensures a safe environment of trust and respect, which is crucial to the main condition of being able to open up and work with private challenges	Three-day residential course	1.Warrior/victim behavior	Various tools and principles that focus on whether a person chooses warrior or victim behavior when facing challenges in his/her daily life
	Anonymous place outside the hospital		
	Homework		
<b>The circle</b>	Train skills, mediation	2.Personal limits and boundaries	Mix of teaching/reflection within the group, in pairs, or individually
The participants are seated in a circle	Buddy talk		Reflective discussion to develop emotional intelligence and accurate thinking
The circle is the pattern of harmony according to the Native Americans In the center of the circle was an arrangement of flowers and candles	Exercises of own choice		
<b>Talking stick</b>		3.Techniques to address fear/stress management	Breath awareness
All gatherings start with a talking stick being passed from one person to the next in the circle - the person with the talking stick has the right to speak and the rest are obliged to listen			Mindful awareness
	<b>Module 2</b>		Guided meditation
	One day (8 hours)		Imagery
	Anonymous place outside the hospital		Body scan
	Homework		Grounding
<b>Attitude</b>			Self-awareness
Welcome with all that is you	Train skills, mediation		Physical exercises: walk in nature, yoga
No specific plan - you make the plan, we serve you	Buddy talk		
	Exercises of own choice		
	<b>Module 3</b>		
	One day (8 hours)		
	Anonymous place outside the hospital		

following techniques: breathing awareness, mindfulness awareness, body scan and imagery.

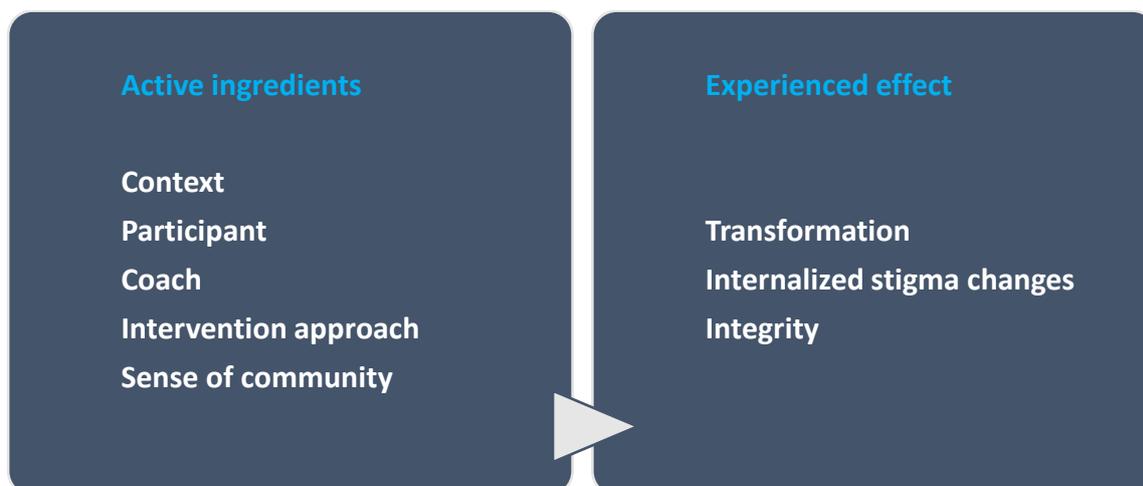
### Data Collection

Most participants referred to the 3-day residential course as the time when they were convinced that this course had addressed what they were seeking. Those that experienced otherwise left the residential course or considered leaving and then dropped out immediately afterwards. Of the 60 participants, 12 did not complete the intervention for varying reasons. Two did not start at all for practical reasons and the overall reasons for stopping were severe psychological problems (n=2), deciding the intervention

was “not right for me” (n=3), beginning a new job (n=2) and stopping before the last follow-up day due to practical reasons (n=3). This resulted in 48 semi-structured interviews.

Individual semi-structured, in-depth interviews were conducted at the end of the intervention by a trained anthropologist on the following topics: motivation for participating in the intervention, cognition gained from participation, changes in self-perceived behavior, the best experiences of the intervention and considerations about joining a group intervention. Each interview lasted approximately 1 hour and took place at the hospital in a separate room to protect patient confidentiality.

Figure 1 Overall model of findings of the intervention



## Data Analysis

Using the 6 phases of thematic analysis of Braun and Clarke [30] data were analyzed to discover meaningful patterns. The phases were: familiarization with the data, generating initial codes, searching for themes among codes, reviewing themes, defining and naming themes and producing the final report [30-32]. Digital audio recordings of the interviews were transcribed *verbatim* and coded thematically using NVivo 11 (QSR International, Melbourne, Australia). The analysis was carried out primarily by the anthropologist who conducted the interviews, but the outline and the analytical progress was discussed with the first author (Rodkjaer) to rule out misunderstandings and maximize rigour and validity.

## Ethical Issues and Approval

Each patient provided written informed consent prior to participation. The study was approved by the Aarhus Health Human Research Ethics Committee and the Danish Data Protection Agency.

## Results

Three themes emerged to explain the patients experienced effect of the intervention and 5 themes and 8 sub-themes explained the 'active ingredients' that the patients experienced as facilitating this effect (Figure 1).

### Experienced effect

#### Transformation

The participants became curious when exploring their own patterns of behavior and while having the opportunity to change unconscious behavior into conscious action. Working on the warrior or victim stance and on

warrior/victim values, was at the core of the courses; being part of all meditation/mindfulness exercises, during silent walks in nature and throughout the intervention. Between courses, the participants were trained to spot their own behavior according to these values. As a result of getting to know their own patterns of behavior and way of thinking, the participants were familiarized with the experience of fear that had been controlling them in certain situations, especially that of being stigmatized due to their HIV status. When they identified their own patterns of behavior and were aware of when the fear was controlling these patterns of victimization, the participants started to become conscious of themselves. By confronting the fear, they had the opportunity to change their own patterns of behavior.

#### Internalized Stigma Changes

The issue at stake was hardly ever about HIV, but rather how to deal with the fear of being disclosed as HIV-infected. Many disclosed their HIV status to friends or family during or after participating in the study, even though it was challenging to do so, referring to tools gained during the course that helped them deal with associated stress (e.g., respiratory, or grounding, exercises), experiencing a relief in being open about it. One participant said:

“In relation to participating in the course, I have experienced that I have become more open to people that I haven't told about my disease before. I feel safe and more in balance.”

During the intervention, the diagnosis became less important with respect to restricting one's life when the participant had decided to live more or less anonymously or open with the diagnosis. The major change for everyone was to reconcile that they had been infected with HIV and had to live with HIV, where HIV had become an integrated part of the individual's life story and no longer controlled them. One participant said:

“I am not ill anymore ... That is my new conviction. I have to take some pills in the morning to prevent myself from falling ill. It’s not important anymore.”

## Integrity

The ability to handle unforeseen challenges improved for most participants. They obtained tools, such as respiratory techniques and grounding exercises, that helped them stay calm in most situations. They regained self-confidence and made peace with the past. One participant explained the change as such:

“I have learned to let go of things. When I look back on my life certainly, there are a lot I today would have tackled differently, but it is too late to change now, so I choose not to worry about it. I take it from here and I rather look forward.”

The participants became aware of how HIV had become the overall explanation when something in daily life was challenging and they felt sad and depressed. It became obvious that patterns of behavior originated from what had happened throughout their life and that only by spotting these patterns and becoming conscious of them could they behave differently. This new knowledge was the main benefit of taking part in the intervention. Some participants said:

“During the courses the coach has made us understand that we haven’t improved as human beings. We already are the best version of us, but we have found it hard to believe. We constantly try to be a better person than what we think we are. So you actually learn to see how competent you already are and through that you spot your self-efficacy.”

## Active ingredients

### The Context

The context was an important facilitator; the residential course and follow-up sessions occurred at remote and quiet locations outside the hospital. Thus, the focus was moved from the disease to a more holistic view of the person. As one participant described:

“It means a lot that we meet in a nice and quiet place, where you can enjoy a walk in the nature and we are the only ones staying in this place, as I then do not have to consider, what to say if I meet someone that I know.”

The fact that the department at the hospital had taken the initiative to offer the intervention made them comfortable to participate and many had chosen to participate because the hospital staff had encouraged them to do so.

### The Participants

Participants were motivated to work on personal challenges and had a desire to change some areas in their

lives. The wish for change, according to the participants, had to be deeply rooted:

“It all depends on yourself. How much are you willing to invest in this change? The more you invest, the more you gain from being part of the intervention.”

Most participants were not clear as to what exactly they expected from participating, but all hoped that it could move their life in a more positive direction.

### The Coach

The coach established a safe environment of trust and respect for the participants, which he did by emphasizing confidentially pointing out that ‘what was said in the room stayed in the room’. The coach facilitated each participant to let go of the fear of not feeling good enough, which is crucial in order to work with one self. This was highlighted by many participants as being crucial to the nature of the personal issues raised in the group and to participation. Further the participants emphasized that it was important for the credibility of the coach that he was actually practising what he had confirmed. One participant said:

“The coach means everything. He has an amazing personality and he is really good at communicating the topics and he himself is personally very engaged in what he teaches. He gives as much of himself as we do.”

The coach facilitated an individual process in which participants did not have to achieve a specific goal and could adopt the skills they found useful. Each participant worked at their own pace and was the one to judge which decisions were right for them and their life. Indeed, a non-prescriptive approach by the coach, through not determining what would work for each and every one, has been an essential component of the intervention.

### Intervention Approach

The intervention approach focuses on the person. This was experienced as being met as a unique individual and not just as a patient:

“You feel that you are seen as a person with an individual life story and not just some HIV disease.”

The focus on being HIV positive lessened as the intervention progressed. What was shared by all was the reason why they had chosen to participate in this intervention. Some participants said:

“During the intervention, we focus on how we deal with different matters personally and, of course, also how we deal with being HIV-infected, but actually not that much. It is not really about how we deal with HIV, but it is how we deal with life ...”

The participants began to understand themselves as individuals with unique stories, in which living with HIV was just one aspect of life and to address themselves as

persons who are responsible for their own lives. The intervention invited the participants to explore themselves using different tools, instilling the essential wisdom that only the individual can get insight into what drives him/her and decide what is important in life.

### Sense of Community

The participants experienced a sense of community, as everybody was HIV positive. First and foremost, however, they shared the motivation and desire for changes to life in general. Many had lived secretly with their HIV status and were not familiar with being together with other HIV positive individuals. HIV became secondary and the focus is on personal issues in general. As one participant expressed:

“HIV is what connects us, and it is with this in common that we do open up to each other. We actually hardly speak of HIV.”

During the intervention, the participants were simultaneously introduced to new concepts and exercises. Although different aspects may mean something different to each participant, they all shared a common way of participating. They all accepted the premise and the exchange of experiences while interpreting the new concepts and exercises. This strengthened the feeling of constituting a community. The intervention, being a group intervention, was of great importance to most participants. They emphasized that listening to other participants' stories and experiences, and seeing how they worked with the tools in practice, was essential to the individually experienced effect.

### Discussion

To our knowledge, this is the first mind-body intervention for people living with HIV that combines different tools to practise and strengthen the person's insight into mental and physical contexts associated with long-lasting benefits. We contend that the overall experienced effect can be considered a causation chain, starting with (a) motivation to learn new practices, tools and techniques in a community of practice, (b) building up both an inner bodily awareness and a consciousness about one's reactions, (c) practicing techniques that work, slowly change habits according to the new awareness, leading to (d) a more conscious behavior with increased self-care, less stress and increased resilience.

This was a group intervention promoting vicarious learning from others which strengthened the experienced effect. To make this group a community of practice, participants had to meet and practise in a safe environment. According to Wenger [33], this is central to how people actually learn new skills and sustain changed behavior. All participants had to take part in the negotiation of meaning. Wenger underlines how duality of participation and reification has to balance so that individuals see themselves as participants and see others as participants

through membership, acting and interacting. Communities of practice [33] are an integral part of daily life and each person is part of different communities of practice, such as, for example, their family, at work, the football club, and others. The intervention course was just one to which the participants belonged. Most participants referred to the 3-day residential course as the time when they were convinced that this course addressed what they were seeking. Thus, it seems that the community of practice was established during this phase. The fact that all participants had the same disease encouraged people to attend and participate. Importantly, all of the participants pointed out that they hardly talked about living with HIV during the sessions; therefore, it appeared that the sessions did not simply afford the participants the opportunity to talk to others about having a chronic condition, but that it enabled more than just this.

A variety of stress management interventions have been designed and evaluated to improve ability of patients living with HIV to cope with stress. However, results have been mixed for coping and health status outcomes and a majority of studies have employed only brief follow-up periods focused on HIV-infected men who have sex with men (MSM) and have not addressed HIV-specific stressors. A systematic review concluded that the development of multifaceted interventions could reduce the impact of HIV-related stigma on the health and wellbeing of people living with HIV [34].

Compared to other chronic conditions, stigma and disclosure stand out as being particularly challenging for self-management of HIV positive status. Decision-making concerning disclosure is shaped by factors specific to the individual, as well as factors specific to the social environment [34]. The person has to cope with both internal and external HIV-related stigma. HIV-related stigma has a detrimental impact on a variety of health-related outcomes in people with HIV.

Fear was a common reaction among the participants and something they struggled with, but for different reasons, in which disclosure was a general theme. To address disclosure on an interpersonal level, the intervention needs to be individually tailored, but within a group to benefit from promoting vicarious learning from others, knowing and being comforted by the fact that others experience similar difficulties and practising in a safe environment.

Working at one's own pace in a setting free of performance anxiety facilitated an intrinsic motivation pivotal for changing behavior, thereby increasing self-care, personal growth and resilience. They did not have to follow a particular program or gain a specific effect. Resilience may mediate the associations between stress and physical and physiological wellbeing [35]. Future studies should include longer follow-up in order to assess long-term efficacy and should target the unique stressors faced by individuals living with HIV, such as levels of stigma and discrimination that could be targeted in stress management interventions for this population

This intervention employed in this study recognized the need for a more holistic approach that also acknowledges the mental challenges faced when diagnosed with HIV. Our findings further underline the need for healthcare

systems to become more integrated and person-centered to meet the needs of people living with HIV. Our findings further highlight the benefits of conducting both qualitative and quantitative explorations of process data alongside with feasibility studies of complex interventions. Only focusing on the quantitative outcomes would not have explored the mechanism that explained the experienced effect. However, there are some limitations to the intervention. To participate in the intervention, a patient has to be motivated to work on their own personal challenges, which requires the necessary skills to be able to reflect on one's own behavior to some extent. In addition, a potential participant not only has to possess these skills but also to be comfortable with working in a group. Therefore, the intervention limits participation according to these criteria.

## Conclusion

In conclusion, we urge that interventions designed to practise and strengthen a person's insight into mental and physical contexts should be offered in conjunction with appropriate HIV medication regimens and clearly not as substitute for them, thus becoming fully integrated aspect of a properly person-centered HIV care.

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