

# Social-Ecological, Motivational and Volitional Factors for Initiating and Maintaining Physical Activity in the Context of HIV

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**Abstract:** Sport and exercise can have several health benefits for people living with HIV. These benefits can be achieved through different types of physical activity, adapting to disease progression, motivation and social-ecological options. However, physical activity levels and adherence to exercise are generally low in people living with HIV. At the same time, high drop-out rates in intervention studies are prevalent; even though they often entail more favourable conditions than interventions in the natural settings. Thus, in the framework of an intervention study, the present study aims to explore social-ecological, motivational and volitional correlates of South African women living with HIV with regard to physical activity and participation in a sport and exercise health promotion programme. The qualitative data was produced in the framework of a non-randomised pre-post intervention study that evaluated structure, processes and outcomes of a 10-week sport and exercise programme. All 25 participants of the programme were included in this analysis, independent of compliance. Data was produced through questionnaires, participatory group discussions, body image pictures, research diaries and individual semi-structured interviews. All participants lived in a low socioeconomic, disadvantaged setting. Hence, the psychological correlates are contextualised and social-ecological influences on perception and behaviour are discussed. The results show the importance of considering social-cultural and environmental influences on individual motives, perceptions and expectancies, the fear of disclosure and stigmatisation, sport and exercise-specific group dynamics and self-supporting processes. Opportunities and strategies to augment physical activity and participation in sport and exercise programmes in the context of HIV are discussed.

**Keywords:** Culture, disadvantaged, disclosure, exercise therapy, HIV, motivation, sport, stigmatisation.

## INTRODUCTION

Sport and exercise can have several health benefits for people living with HIV. For instance, aerobic and resistance training can have a positive impact on cardiovascular fitness, fatigue, body composition, psychological well-being and quality of life [1-5], in addition to reducing the health risks and diseases associated to a sedentary lifestyle. These benefits can be pursued through a wide range of different types and levels of physical activity, adapting to disease progression, individual motivation and social-ecological options [6].

Despite many of these benefits [7, 8], the physical activity level and adherence to sport and exercise are generally low in people living with HIV [9]. At the same time, high drop-out rates in intervention research are prevalent even though they often have more favourable conditions than interventions in the natural setting of people living with HIV [6, 9-12].

Studies about the underlying reasons for the low physical activity level in people living with HIV are scarce [6].

Research in other population groups has identified several correlates, both psychological and social-ecological ones, for initiating and maintaining physical activity. Psychological determinants include, for instance, evaluation of previous experiences; outcome expectancies; awareness of risks, vulnerability and need to change; control beliefs, i.e. self-efficacy; intention strength and self-concordance; and perceived barriers and resources [10, 13-16]. Several models describe motivational and volitional processes covering the building of intentions, action and coping planning, initiation and maintaining action [17-22]. However, various authors [23, 24] criticise adopting a mere psychological-behavioural approach, and focusing only on individuals' lifestyles as a primary cause for disease, especially as individuals take choices in the social-ecological context. "While most observers acknowledge that social forces influence these choices, most interventions focus on changing individuals" [23]. Social-ecological correlates include, for instance, family and friends; social-cultural beliefs, norms and practises; perceived environment, such as safety; living and work conditions; policies; and the use of the space and infrastructure [24-28].

This article aims to explore the correlates of motivational and volitional processes of women living with HIV with regard to physical activity and the participation in a sport and exercise health promotion programme. This was done in the

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framework of an intervention study in a low-socioeconomic, disadvantaged setting in South Africa. Hence, individual psychological correlates are contextualised, and the role of social-cultural, environmental and gender-specific influences on perception and behaviour are investigated.

## METHODS

### Design

Two qualitative case studies were performed in a disadvantaged urban setting in South Africa, in order to conduct the research at community level with people living with HIV. One was placed in a university setting and the other in a nearby disadvantaged community. The data was produced in the framework of a 10-week sport and exercise health promotion programme that was evaluated in a non-randomised pre-post study design [29]. Study inclusion criteria were for participants to be HIV-positive and willing to participate in the exercise programme. Exclusion criteria were acute infection (e.g., active tuberculosis), pregnancy, uncontrolled hypertension, and any other disease or infection that was contra-indicated for sport and exercise participation. No selection to the project was based on HIV stage, disease progression, medication use or associated illnesses or physiological changes. Although regular reminders were sent to the 50 persons who were initially interested, only 36 arrived for baseline testing. Of these, three were without HIV-infection but were allowed to participate in all activities together with the other participants (in order to avoid stigmatisation and to secure the support of friends), but these participants were precluded from the data analysis. Another five of the participants were excluded from the project because of acute tuberculosis (n=1), a recent operation (n=1), pregnancy (n=1) and uncontrolled high blood pressure (n=2). Of the 28 HIV-positive participants remaining, all were asked to participate in the final measurement independent of their compliance. Five participants were not available for the final testing, because of relocating to another suburb (n=3) and not being contactable (n=2). All 25 female participants of the programme were included in this analysis, independent of compliance to the programme.

### Participants

All participants lived in a disadvantaged setting characterised by limited choices in daily life, limited options for individual and social-economic development, and high stigmatisation of people living with HIV. Group A was less disadvantaged than group B in the sense of having access to institutional knowledge and academic support. The subjects' ages ranged between 20 and 44 years. CD4+ cell count and percentage ranged from 155 to 1315 cells/ $\mu$ l (M = 535.32; SD = 256.064) and 9 to 41% (M = 25.77; SD = 9.402), respectively. At baseline, 13 participants were taking antiretroviral medication and their viral load was not detectable. The viral load of the other participants was between 1751 and 152063 RNA cps/ml (M = 16676.5; SD = 36729.41). Ten participants were classified by the medical doctor in WHO stage I; six in WHO stage II; five in WHO stage III and two in WHO stage IV.

## Research Procedures and Measures

After ethical clearance was obtained from the university's research committee (Reg. N<sup>o</sup>: 11/4/17+18) and the municipal health committee (Reg. N<sup>o</sup>: 10258), participants were recruited either through a collaborating community clinic, health forum or non-governmental organisation (NGO). They were informed about the research by oral presentation and a written information sheet, available in Xhosa and English. Bilingual researcher assistants and translators were present at all times and used when the participants wished. All participants gave their informed consent.

Before starting the programme, a short questionnaire was attached to the registration form that included questions regarding motivation and goals to participate in the physical activity programme, as well as preferences regarding time, type of physical activity and organisation.

This was followed by a participatory group discussion in which participants discussed needs, perceptions, expectancies and preferences with regard to intervention setting, conditions and contents of the programme. Extensive notes were taken by the principal researcher and checked and completed by the bilingual research assistance.

Furthermore, eight body image pictures were used in the study to deepen the participants understanding on related goals and perceptions. This research tool was validated in the South African context and used in a very similar context [30, 31].

A survey was developed containing questions (a) assessing psychological-behavioural determinants, such as outcome expectancies, self-efficacy, implementation intentions and planning, predominantly adopted from studies on the Health Action Process (HAPA) Model [22, 32] and the Motivation-Volition (MoVo) model [20, 33], and (b) assessing social-ecological influences on cognitions and behaviours [24, 34].

A questionnaire was administrated at the end of the programme to evaluate the outcome experiences and perceived changes in the participants. It also allowed for detecting further barriers and challenges that were not mentioned at the beginning of the intervention.

The principal researcher and facilitator recorded research diaries based on their participatory observation during the period of the intervention. The researchers' participation in the intervention allowed them to establish a trustworthy relationship with the participants in order to produce rich and comprehensive data and to obtain a deeper understanding of the emotions, cognitions and behaviours of the participants. Furthermore, the two participatory observers contrasted their observations among each other continuously and with the research team as well.

Individual semi-structured interviews were conducted. The questions dealt with participation, motivation for participation, anticipated future participation in physical activity, the challenges and barriers to participation and any recommendations for future projects.

During the period of the intervention, compliance was monitored in both groups by keeping a register of

attendance. Non-compliance was assigned when a participant took part in the programme on average less than once a week, that means, less than one third of the total sessions.

### Data Management and Analysis

All interviews were recorded and later transcribed into written records. Group discussions were captured by means of extensive notes. Participatory observation was recorded in research diaries, while open-ended questions were answered in the questionnaires. All qualitative data was analysed according to the themes that emerged from the data (inductive coding) and the theory (deductive coding). If differences among the two intervention groups were detected, data referring to group A (University setting) and B (Community setting) was marked accordingly in the text.

### Research Challenges

The research is based on a limited number of participants and a high drop-out rate in the intervention. Getting people living with HIV to participate in the intervention study was very challenging. However, recruitment problems are also mentioned by other researchers in the field: *"In an attempt to recruit enough participants, the discovery was made that HIV is still a highly stigmatised disease in both Mpumalanga and Gauteng. After eighteen months of negotiations with AIDS clinics, mine groups and a newspaper advertisement, only three participants were enrolled"* [35]. In our case, we consider the following reasons as predominant: mistrust about participating in intervention studies; fear of HIV disclosure; competing immediate priorities and daily-living challenges.

The high drop-out is also discussed in the literature [10]. Regarding a 40% loss of exercise participants with HIV in an individualised 12-week exercise programme, Neidig *et al.* [12] stated that "individuals who were lost from the study were often among the working poor and reported abrupt changes in employment, unreliable transportation, and increased family responsibilities." Apart from socioeconomic and socio-cultural constraints, non-adherence to treatment or health programmes are often related to individual factors, such as self-efficacy, depression and psychosomatic diseases. Petroczi *et al.* [9] mentioned that "actual physical fitness level or other physical characteristics" seem to be less influential on adherence to physical activity. Conversely, Stringer [36] suggested that "patients with chronic diseases such as HIV sometimes have decreased motivation to perform regular aerobic exercise.... This lack of activity results in a vicious cycle of decreased exercise, pain, slow recovery from activity, loss of lean body mass, anxiety of exercise, de-conditioning, and reduced gain from aerobic exercise sessions."

Another research challenge was the heterogeneous composition of the group, representing a broad diversity with regard to disease progression, medication, signs and symptoms and living situation.

## RESULTS AND DISCUSSION

### Perceptions and Expectancies Regarding the Social Environment and Programme Structure

The initial participatory group discussion captured the perceptions and cognitions regarding the intervention setting and conditions with reference to the environment and social-cultural beliefs.

The discussion was strongly dominated by worries about serostatus disclosure and HIV-related stigma. Most of the participants were not living openly with their HIV status. Serostatus was hardly disclosed in the most intimate circles, such as partners, family members or close friends: "only my partner knows"; "I don't speak with anybody about it"; "only my best friend, she knows". As a reason they discussed that stigmatisation of people living with HIV is very high in the community: "In my community, they call you with bad names if they know that you have HIV"; "they change their behaviours towards you" [cf. 37-39]. Hence, there was consent among the participants in the present study that disclosure of serostatus must be avoided by all means: "nobody must know it"; "not to speak about it".

In dealing with the risk of serostatus disclosure, two different "voices" were identified amongst the participants. One "voice" was concerned about who should participate in the physical activity group. Some participants argued that everybody should take part "independent of HIV" or "without questioning HIV status", hence "to take part as anybody else". Therefore, the programme should be open for both HIV-positive and HIV-negative participants. Some expressed that they would not take part in a programme *only* for people living with HIV. These arguments were related to the perceived risk of disclosure. However, there was also the second "voice" that argued for not wanting to get labelled or to be treated as "ill" or "different". It was argued that they should be able to play and exercise the same as anybody else. Consequently, these fears and concerns were an appeal for *mainstream* physical activity opportunities, such as recreational sport teams, to be available for all and that do not isolate and deal specifically with HIV.

Conversely, some participants also voiced the wish to speak about their problems and concerns, which would only be possible for them in a group of people, all living with HIV. This was more prevalent in the group B (Community group) where the need for mutual support was more voiced by the participants. This wish calls for specific physical activity opportunities, such as supportive sport and exercise groups, that deal with challenges related to HIV and where members can share experiences and support each other.

In the group discussion, the participants stressed, in a common voice, the need to preserve confidentiality at all times. "HIV-status must neither be revealed in the group nor outside the group". If a participant wanted to disclose his/her status, he/she could do so personally in the group or to a member, but "it must be your own choice to speak about it",

thus “nobody must speak about it” and, for example, “the trainer should not know why I am coming to exercise”. In that regard, the only participant who was living and talking openly about her status had the following to say in an interview: “I don’t greet the others [participants], unless they first greet me. People know my status. I tell them [the other participants] that it is up to them to come to me. It is their decision”. She first gives the choice to the participants, who can then act in that situation to avoid the possible stigma of being associated with HIV. Also one researcher argued that: “I always stress to everyone that I do research on health promotion, and that I have several projects, inclusive of HIV. If people know that I am working only with people living with HIV, they might question the status of those I am walking and/or talking with during work time”. Bearing this in mind, the research programme was not presented as an HIV programme, but rather as a general *sport and exercise health promotion* programme for all who were interested in participating. The participants agreed that, for research purposes and for giving individual feedback and advice, the principal researcher and the participating doctor should know their HIV-status. Those who wanted an HIV-specific group especially articulated the importance that all members of the group must take personal responsibility and commit to treating all information as confidential, and not to talk to people outside of the programme about happenings in the programme: “it must stay in the group”; “not to speak about it outside”. These disclosure-related concerns were also to be observed in other contexts, such as in relation to who should participate in the HIV-related support groups, and what setting and conditions were needed in the HIV-specific support groups.

Thus, two different programme settings were identified in the discussion. The participants of Group B preferred to train in a group setting. The programme setting was a school within the community, who kindly made their premises available for the *sport and exercise health promotion programme* in the afternoons. Conversely, participants of Group A preferred to train individually in a fully-equipped training centre in a university setting. The reasons mentioned by these participants were that they had predominantly diverse times of availability, and also expressed doubts about the maintenance of confidentiality in the group setting. Although the physical activity intervention consisted of individualised exercise training, it was proposed that they go for training in small groups in order to boost exercise adherence. In fact, some expressed being “motivated by training together in pairs”. However, training in small groups was also challenged by the diverse times of availability. Thus, several participants asked if they could bring along a friend (even if they were HIV-negative) as that would improve their participation, and two of the participants did so. This indicated the need for social support or peer-support, but essentially trustful and confidential support, from a good friend.

Fear of disclosure was repeatedly an issue also throughout the duration of the programme (see below discussion about barriers for participation and drop-out).

## Motives, Intentions to Initiate Physical Activity and Outcome Expectancies

At the registration of the programme, a questionnaire was used to capture the initial motives and interest for participating in the physical activity programme. These were further discussed in the initial participatory group discussion, especially their expectations, as well as the programme content and types of physical activities to include.

The participants’ main motives were health-orientated: “I want to improve my healthiness”; “I want to live a healthy lifestyle”; “To build up my immune system more”; “To stay healthy”; “To improve my health, immune system + and to be happy”; however, frequently they included a special reference to the body and appearance: “I want to keep my body healthy”; “To [be] physically fit”; “I want to get strong”; “to lose weight”; “lose some weight, as I have gained a lot since last year”; “I want to look and feel healthy, physically and mentally”. Participatory observation throughout the programme confirmed the paramount importance that appearance was given. Appearance was important in the participants’ strategies of avoiding HIV-related stigma. “In our community, people who are very thin are thought to have HIV”; “if you are thin, people will think that there is something wrong, that you are ill” [30, 40, 41]. A researcher remarked in his diary: “One participant told me concerned that she already perceives the effects of the ‘gyming’, that she is losing weight. I was surprised, as the training only just started a few weeks ago and I suspected other reasons for the weight loss; and as I saw her concern, I asked her if that would not be a good result to lose weight. She replied that she is afraid of losing too much weight”. In conclusion, most of the participants, “Want to reduce weight in the stomach area, but not to be thin”.

Perceptions of appearance was also analysed by means of a questionnaire showing a normed sequence of eight pictures of a female body with gradually increasing body dimension [30, 31]. The questionnaire served two purposes. Firstly, it was used to analyse appearance and weight-related goals by asking them, individually, which picture represented them best at the moment and, secondly, it was used to identify which picture they aimed to be. Their perception on which picture represented them best was compared with the anthropometric measurements actually taken, i.e., height and weight that were used to calculate Body Mass Index (BMI). In addition, they were asked which picture represented a healthy person. The results showed a concurrence between subjective perceptions and objective anthropometric measurements. The *goal body picture* identified by the participants ranged mainly between a healthy perceived person (with a *normal* BMI following WHO classification) and a slightly overweight person (BMI between 25 and 30 kilograms per square metre). These results confirm the above-stated goal for a number of participants which was not to lose too much weight, but rather to stay a little bit more overweight. These results are also in agreement with other studies that conclude that fear of HIV-related stigma, encourage black African women to be rather “slightly

overweight, but not obese, than thin and having people think they were infected with HIV or they had AIDS" [30]. In South Africa, where 29% of men and 56% of women are classified as either overweight or obese [42], the stigma related to HIV "may be responsible for fuelling the obesity epidemic among black African women" [30]. It definitely influences behaviour and goal setting with regard to physical activity.

Finally, the potential to gain knowledge was another motive for participation; "I want to know how exercise impacts upon my health status". While most participants were expecting positive outcomes, some participants, were less convinced ("I really would like to see the outcomes"). Therefore, feedback on their progress was given continuously and, most importantly, after the medical and fitness assessments at the beginning and end of the 10-week research period. The participants showed much appreciation for the feedback. Most of them asked many questions, which demonstrated a keen interest in gaining knowledge.

According to these motives for participation, the physical activity programme included moderate aerobic exercise and progressive resistance training. In addition, in group B, modified sports and games were played. Members of group A trained individually. In both groups, the intention was to train regularly, ideally three times or more, but at least twice a week, and to learn and build up skills and habits that facilitated the inclusion of physical activity in daily life.

### **Self-Concordance and Strengths of Intentions**

The intention to participate in the programme and to exercise regularly was mainly determined by their motivation to look and to live healthy. Firstly, exercise in order to look healthy, was constructed mainly on their motivation to protect themselves from external HIV-related stigma and to avoid discrimination. This motivation was particularly strong. Thus, the physical activity training, specifically the resistance training or "body-building exercises" seemed for them to fit in well with this motivation. Their motivation was especially high for these kinds of exercises. Then, secondly, exercising in order to live healthy, seemed mostly intrinsically motivated, such as "I always have been interested in exercise, but I just do not have the time". However, others showed more extrinsically motivated intentions to exercise, for example, a woman referred to her intention to participate, "when I heard that the programme was going to be helpful for our health". Some also expressed doubts, for example, "I really would like to see the outcomes" and asked many questions in the initial group discussion about how physical activity would help them.

It is noteworthy to mention briefly, in this context, that the women were not motivated through the environment or through the community to exercise and to be physical active. In the disadvantaged community, for example, women generally are not seen running in the street for exercise and health reasons. This situation might be due to a lack of safety and security in such areas, but also due to social-cultural norms and attitudes about women in the black African community [41, 43-45]. On the one hand, women are not supposed to play, since only young girls play, but once they

reach adulthood they have to fulfil their family duties and responsibilities. Sport is mainly engaged and dominated by young men and children. As a consequence, the group B (Community group) was conducted in the afternoons in the inner yard of a school in order to be less visible from the community and, in that way, reduce possible inhibitions in the participants to play or to train. On the other hand, with the transitional changes (urbanization, socio-economic growth, etc.), being sedentary has become a luxury. So far, walking was used as a coping strategy in daily life, for example, to walk long distances in order to get water. In the black African community, being sedentary might be perceived as a symbol for social-economic wellbeing. Therefore, we consider that the social-cultural and environmental situation were not directly motivational for women to exercise. Although, indirectly, the HIV-related stigma, might have stimulated the motivation to exercise in order to look healthier.

The motivation and intention to fulfil the set goals were perceived as very high in the beginning: "participants were quite happy to join, laughed and seemed very motivated"; they expressed positive emotions about the programme; "it is refreshing", "feeling good exercising"; "it really reminded me of the good old days when I used to be an athlete, handball player, netball player, so it was fun". Most participants felt that physical activity was high on their priority list. However, throughout the duration of the programme, it seemed that the reality of daily life was overwhelming, and gradually the participants mentioned steadily increasingly competing priorities, such as studies (in group A, especially during exam time) and the need for getting financial income (work or getting bursaries, especially in group B); or "something urgent that I need to attend to". For example, a participant wrote an email to the principal researcher: "Good morning, I'm sorry for not having been available at gym this week but I was struggling in terms of school work; it was a hectic week for me, but I promise next week I will be there during my time slots; I'm sure I will at least be above the water then, because as of now am slightly sinking. Thank you for your concern". Further barriers and time management challenges are discussed later on; here, we conclude that the intention to achieve the goals were generally perceived as very high but, nevertheless, standing in direct opposition to the emerging priorities and challenges of daily life.

### **Barriers for Participation and Drop-Out During the Intervention Process**

During the sport and exercise intervention programme, expressions of fear and continuous avoidance of HIV disclosure by participants were dominant and were considered as obstacles for participation: "Before going to the gym, if I was with friends, they would ask me where I was going. So, sometimes, it was difficult to go to the gym"; "My friends asked about why I go to gym"; "Others asked me, what was the programme for"; "My neighbour was asking where I go, and then also if she can join me, and I didn't know how to say no". In fact, twice a neighbour was brought along in group B, which created an uncomfortable situation among the participants. They discussed it and decided that we have to declare the group full, in order to

avoid any disturbance by new and unknown members, as well as to avoid disclosure and stigmatisation of the group.

Other challenges experienced were concerns with time management or competing priorities (“Not enough time”; “Sometimes I had something urgent to attend to. If it happened that I finished on time where I am was going, I can even come by later, before the gym closed, because I would really feel bad if tomorrow's session would go to waste”; “I had to get the bursary”), family responsibilities (“I have a child that I have to take care of”; “I got pregnant”; “The last two weeks I was not feeling well, I was not even able to come to the gym, I was vomiting, having severe pains. I decided to go and see the doctor only to find out that I'm pregnant. So, me and the father of the baby decided together to abort the baby, that will be on the 5 September, so please I would like you to give me a week or 2 weeks so that I could recover this, as I'm not gonna be able to start with gym immediately after I have done this”) and illness (“Sickness”; “flu”, “vomiting”, “pain”, “too tired” (fatigue); “I was stressed”; “Participants suffer from different illnesses and were getting sick during the period of the programme”). One participant explained that the reason for dropping-out was because of the change in her work situation, and another one stated that she had to miss out due to traveling (“I am sorry I could not come to the training last week, because I went home and its far for me to travel”). Transport problems were mentioned in group A, because it was a challenge to come to campus in holidays due to lack of funding (“The school is closed and my aunt is not giving me money for transport, and in that way I can't be present at the gym”).

Discomfort from exercising (“pain after training”, “pain the next day”) was mentioned, but was seldom. The discomfort due to the exercising setting in the gym (“noisy”, “people watching”) was reported more frequently. Others, however, in converse, stated that it was comfortable in the gym where they were “exercising just as anybody else”.

Participation was also influenced by the changing situation during the month; “having to stand in lengthy cues for getting bursaries at the beginning of the month” and “having more money available at the end of the month, after being paid” were mentioned.

Approximately 50 % of the participants were non-compliant, attending on average less than once a week. Drop-out was higher in the individual exercise group A (80 % drop-out) than in the group intervention B.

### Control Expectancies

Compliant participants showed a higher task self-efficacy (“I am confident that I can be physically active 5 times a week”) ( $t = 2.191$ ;  $p = 0.04$ ) than the non-compliant participants. They also expressed more often having a coping plan (“I have a plan about what to do in difficult situations in order to stick to my exercise intentions”) ( $t = 2.435$ ;  $p = 0.025$ ).

Most of the participants were confident that the challenges and barriers of participation would decrease in future, and that “next year it will be easier”. Some of them expressed that even though they could not attend regularly “it was the first time they had joined a gym” and that this

first step was important in order to join a gym in future and to maintain an active lifestyle.

### Outcome Experiences and Perceived Results (After the Programme)

Once the programme ended, most participants in group A (individual training) expressed the wish to participate in a group intervention in future: “I don't want to exercise alone”; “Next time, we would like to do it in a group”. In this group, there was hardly any interaction observed among the participants, even though some of them trained at the same time.

In the group intervention (group B), mutual support was observed. They often exchanged experiences and opinions about ARV medication, avoidance of side-effects, coping strategies and nutrition. They also discussed concrete plans of together building a gardening project to plant vegetables, as this produce was too expensive for them to buy (“Even if we know what to eat, we cannot afford it. Healthy food is too expensive”). Participants in this group made friends and supported each other even outside the programme. They often collected each other in order to come together to the programme. They also left together and walked together to their homes. When one of the participant died one year later, the other participants went together to visit the deceased's family and assisted with the funeral. These self-supporting processes were possible, as this group was only for members living with HIV and, thus, they could disclose status to each other, if they wanted to, and be able to speak about HIV-specific challenges without fear of repercussions.

In general, the programme was perceived as “refreshing”, they were “feeling good exercising”, and “enjoying every moment”. One participant stated that “it really reminded me of the good old days when I was an athlete, handball player, netball player, so it was fun”. Enjoyment was an important motivational factor for the participants as a way of opposing the daily hassles and challenges of living with HIV.

Statements regarding the perceived changes from participating in the programme were quite diverse: “I disliked food before, but now I eat a lot, I like that”; “weight loss”; “I feel more energetic”; “small increase in muscle mass”; “feel more power”; “my appearance improved”; “I feel so strong about myself”; “to be able to face life challenges, having a positive attitude towards life, and the most important thing is that I accept myself”; “the way in which I feel about myself”; “before the programme, I was always exhausted, but while I was on the programme I did not get exhausted at all”; “the programme made me more interested in exercising”; and “eager to make friends”. These aspects indicate a trend towards several psychosocial improvements.

One recurrent perceived change concerned the subjective improvement of strength. This was in agreement with the observed high motivation for the resistance training exercises. Bearing in mind the relatively short duration of the programme (10 weeks) and the irregular pattern of participation, strength improvements were more likely to be visible than other physical changes. In fact, the results of further physical measurements were also reported in another publication [29], which showed that in the compliant group,

strength improved significantly more than in the non-compliant group (ANCOVA  $F=4.516$   $p=0.047$ ); meanwhile no significant changes were observed with regard to any other physical measurements, such as fatigue (time on treadmill). The improvement in perceived strength has psychosocial importance, because appearing physically strong is perceived as beneficial in protecting oneself from forced HIV-disclosure. Thus, the improvements are aligned with the participants' goals. Therefore, muscular strength training may be an important element of physical activity programmes with people living with HIV, not only in order to achieve health outcomes, but also to motivate participation and adherence.

Nevertheless, some of the participants also expressed the concern that they had not achieved what they wanted or expected: "Because I was not attending the gym regularly, I am not completely fit as I want to be."; "I have [changed], but if the programme had started earlier, I would have lost more weight."; "the days when I was absent, played a big role in my levels."; "physical strength, it didn't change much, because I stopped attending".

## CONCLUSION

In order to plan and implement the sport and exercise programme in accordance with the motives, intentions and expectancies of the participants, the intervention study took on an evolving and participatory approach, continuously dialoguing and adapting according to the progressively emerging results. Such an approach is convenient, as it facilitates a more appropriate and subjectively meaningful intervention, as well as more active involvement by the participants.

The motives to exercise were strongly influenced by HIV-related and social-ecological perceptions and cognitions. The participants mostly wanted to lose weight, but not too much, rather to be a little bit overweight rather than too thin, because it might mistakenly be associated with HIV. Thus, the main motive to exercise was to be strong and obtain a healthy appearance. Accordingly, the sport and exercise setting and participants' behaviour were strongly dictated by self-protection from HIV stigma and the fear of disclosure of HIV serostatus. Two different intervention groups were implemented: one was a *main-stream* intervention where participants exercised, just as any other person, in a gym-setting at the university, while the other was a group intervention in the community, where the self-supporting processes were facilitated through an 'only people living with HIV' group. The latter one seemed to be more successful, as compliance was higher, mutual support was evident and the group dynamic was highly valued.

Strength training was important in both groups. Objective and subjective strength improvements were perceived and may have affected the motivation to exercise, as it is concordant with the goals of looking stronger and healthier and avoiding HIV disclosure.

Nevertheless, the high motivation to initiate a sport and exercise intervention was opposed by strong challenges of daily living and compounded by several barriers to maintaining participation. During the sport and exercise intervention expressions of fear and continuous avoidance of

HIV disclosure were dominant, and were considered as obstacles to participation. Further reasons for non-participation were competing personal priorities: family, studies and work duties, challenges with time management and coping with daily hassles and problems, changing circumstances throughout the month and sickness (ranging from fatigue to disease progression and comorbidities). Feelings of discomfort from exercising were seldom mentioned; but some discomfort was mentioned by the participants due to the exercise setting. Compliant participants showed a higher task self-efficacy and expressed a higher degree of planning than the non-compliant participants. Therefore, it would be crucial to increase the knowledge, action planning and coping skills that are in concordance with the personal and social-ecological situation. At the same time, the sport and exercise programme should put more emphasis on facilitating experiences that promote self-efficacy.

Furthermore, the results show that both psychological and socio-ecological perspectives should be combined, and that multi-level interventions are needed. Such interventions should also respond to the individual situation and living condition, as well as to the social perceptions and cognitions regarding people living with HIV and regarding exercising. Participatory approaches offer valuable opportunities in this complex field of research and intervention.

## CONFLICT OF INTEREST

The authors confirm that this article content has no conflict of interest.

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