THE THERAPEUTIC IMPACT OF HIVITYALITY RETREATS

H. P. King,
School of Health Wellbeing and Social Care
October 2022
THIS YEAR MARKS THE 30TH ANNIVERSARY OF ‘LIVING PROOF’ RETREATS

Since these retreats started in 1992, the meaning of a positive HIV diagnosis has in many ways, changed radically. Effective treatments keep us well and we cannot pass it on, but, as we all know, HIV is still a difficult thing to live with. It can affect our health, especially if we’ve had it a long time, or have other conditions to manage alongside it. Above all, we know, it remains difficult to talk about openly...

That’s where HiVitality comes in

HiVitality is the only peer-run organisation in the UK that helps people living with HIV via the provision of regular multi-day wellbeing retreats. All ‘members’ sleep onsite, take meals together, and take part in a programme of discussion groups, complementary therapies and social activities. Each retreat lasts 2-3 days, and around four are held each year at countryside locations exclusively hired and only open to positive people. Around 25-30 people attend each retreat. Members are welcome to contribute to the running of events, feeding into the ‘group of friends’ ethos that has developed over many years.

HiVitality has been working with the Open University over the last year to understand more how retreats serve the needs of members. Between May 2021 and July 2022 we codeveloped a new programme incorporating psychoeducation and drawing on principles of person-centred therapy, carried out research, and engaged in strategic analysis to explore our charity’s potential.

HiVitality has been working with the Open University over the last year to understand more how retreats serve the needs of members. Between May 2021 and July 2022 we codeveloped a new programme incorporating psychoeducation and drawing on principles of person-centred therapy, carried out research, and engaged in strategic analysis to explore our charity’s potential.

Within these pages you will find an overview of the project and what it’s shown us about how retreats help people living with HIV. We hope you enjoy reading and encourage you to get in touch with any comments or queries – HIV@open.ac.uk
Featuring 1 large exotic fish, 2 fluffy alpacas, 2 naughty goats, and too many peacocks/chickens/pigeons to count.

This year in numbers:

- 112 people helped across 4 HiVitality retreats.
- 192 HiVitality retreat hours provided.
- Each lasting 48 hours.
- Giving 5376 hours of memorable member experiences.
- 672 sit-down meals eaten.
- 48 hours of facilitated group discussions.
- 10 Number of HiVitality volunteers who made this happen.
- 6 Number of complementary therapists.
- At 2 beautiful countryside venues.
- Cost of delivery £24k.
- 40% National Lottery grant.
- 25% charitable grants.
- 25% member fees.
- 10% community fundraising.

Number of HIVitality volunteers who made this happen 10.
Throughout 2021 and 2022 HiVitality trustees and researchers from the Open University worked together (supported by the Cranfield Trust) in order to achieve four aims:

1. Enhance the therapeutic value of HiVitality retreats
2. Evaluate the effect of retreats for participating members
3. Improve our understanding of internalised HIV stigma
4. Understand the operational functions and environmental context HiVitality works within

One result was the ‘My Beautiful HIV’ programme, a combination of psychological education, themed discussions and structured activities delivered across six sessions (60 minutes each) at existing HiVitality retreats. Group members were encouraged to attend all sessions so that turnover was minimised, and the group developed deeper bonds throughout the course of a retreat. The format of sessions was flexible and adapted in real-time to accommodate emergent topics and conversations which needed longer to blossom. An ‘open’ group ran at the same time for members who preferred not to participate in My Beautiful HIV. Participation in any group was optional.

Each session included a learning section with short presentations on academic topics such as ‘internalised stigma’, ‘post-traumatic growth’, ‘self-actualisation’, ‘self-conceptual positivity bias’ and ‘self-compassion’. Facilitated discussions drew upon principles of person-centred counselling, with the primary focus being on the creation of a safe relational environment and increasing group members empathetic understanding to boost personal growth. Retreats were evaluated through analysis of data from focus groups, semi-structured interviews, participant observation, an internet-hosted survey, and situational analysis. This report draws mostly on qualitative data- that is, what members/trustees/stakeholders said and the subsequent themes which were revealed. The project was reviewed and received a favourable opinion from The Open University Human Research Ethics Committee HREC reference number 4315.
There are currently around 105,000 people living with HIV in the UK. We still experience stigma and discrimination and many of us keep our HIV status a secret. Only some of us can access mental/social support, and our healthcare providers are not always very knowledgeable about HIV.

**SOCIAL CONTEXT OF RETREATS**

Members we spoke to considered HiVitality retreats in relation to other HIV charity services they’d accessed. People commented that other support services tend to ‘specialise’ and are targeted towards certain demographic groups (e.g. African, Gay, women, newly diagnosed). Some mentioned that conversation topics at other groups are less ‘intense’, ‘deep’ or ‘free-flowing’ than retreats, because “…in the charities, it’s often around medication or around U=U… it’s led by what we’re commissioned to do… Even the peer mentoring, it’s very structured… around certain specific goals…”

It was noted that sometimes “…there’s such a focus of putting a positive light on HIV that… you don’t necessarily feel that you can express the difficulties you might be experiencing”. One person said there were constantly new people joining other services, and that being in different sessions with new faces meant “…we’ll have to talk again-sometimes you have to repeat some things”. One member who lived in a rural location there were no similar HIV-specialist services to compare to at all.

Several members mentioned accessing psychotherapy or talking therapies, either in the past or in the present. More than half self-reported a type of mental health problem such as anxiety, depression, bipolar or other non-disclosed severe illness they were dealing (or had dealt) with.

Almost all members that we spoke to revealed examples of stigma they’d experienced, including being shunned by their families and communities, or overhearing people saying “…really awful, ignorant things” about HIV. Awareness of people who “…won’t say it direct but they will show it with their body language” had made some members feel unsafe and was described by one as a “…kind of trauma”.

One person admitted initially feeling negative towards other people living with HIV, saying at their first retreat “…I thought ‘oh my God, look at all these broken people’”. This person shed their own stigmatising feelings by getting to know other people at the retreat. Another member described their frustration that having HIV was perceived nowadays as “fine-just take one tablet and everything’s fine” despite their experience showing everything was not fine due to ill-health and ongoing stigma.

A significant issue referred to by numerous members was keeping their HIV diagnosis secret, as “…most of us we go round our everyday lives and so on and everyone just feels they’ve got a big secret inside that they cannot tell anybody.” Some members had not told close family/friends, whilst others who had contracted HIV vertically did not discuss it with their parents. One member advised they managed their status through “…suppression… what people see of me, on the outside, doesn’t reflect who I am on the inside at all”, and another spoke of “…navigating this world invisibly”.

Members recognised that “…sometimes you keep things inside, and… keeping things inside is not good. It’s not healthy because you carry them all the time, and then they can affect your emotions. They affect your lifestyle. They just affect the whole of you. Sometimes, you have sleepless nights, you lose appetite, you can’t get on with life.”. In comparison, “…at the retreat you don’t have those secrets, you didn’t have nothing, everybody is there on the same thing.”
HiVitality retreats take place over 2-3 days at a countryside location. There's a fixed timetable. Retreats begin with an opening circle which involves the lighting of a candle, a welcome talk and group introductions. Following this a group meal is shared and then members socialise. Music is played and friendships built. Discussion groups start the next morning. There are two groups that run simultaneously. One is known as the 'open' group, and here members discuss whatever arises in the moment. Each session stands alone, and members can attend each group meeting as they please. The other group is the 'closed' group, and this works with the same groups of members throughout the whole retreat. The My Beautiful HIV programme (MBH) ran as a closed group. Members told us about features that they felt were important to their experience of retreats and the MBH programme.

**Venue:** A few members noted the ‘ambience of the house’ was significant to their experience, saying this was ‘homely’ and ‘hospitable’. Many members simply appreciated “... time away from home” and how this meant “...there was an element of revisiting in a different space, which allowed me to see things a bit differently”. The residential format where everyone stayed “... on the same premises” was also felt to directly contribute to the ‘intensity’ of conversations as it encouraged ‘bonding’ and means “...you can form those relationships and feel more comfortable doing that.”

**Group sizes:** Approximately 15 people attended each discussion group. Some members said that this size group was sufficient for people to ‘open up’ but in a ‘time-limited’ way. It was noted that all need an opportunity to contribute and smaller groups offer more time for individuals to speak.

**Downtime:** Members did not identify specific social activities as being important to their experience, but instead talked of ‘downtime’ and ‘mealtimes’ as being highlights. For one (relatively newly diagnosed) member attending a retreat for the first time, mealtimes were a calmer way of “… dipping your toe into the pool... just gently breaking the iceberg with a small set of people and like the ripple effect of then getting to know the others gradually... breaking them little barriers”.

**Exclusively for people living with HIV:** One key feature all members mentioned was the fact retreats are exclusively for people living with HIV. Being in “…a house full of people like this” was ‘freeing’ and ‘liberating’ and meant members could be “…completely 100% open, knowing that everyone is the same as you, and so there’s literally nothing you have to hide from anyone.”.

**Openness:** Members valued being open, as “…if you don’t have to cover up, you don’t have to... worry if I ever say anything here or anything there”. Openness by certain members had the ability to influence others, as “…hearing how other people had suffered and the stuff they went through... was like, ‘oh bloody hell this is a completely open conversation’, which put me at ease because then I thought ‘well if people are willing to share that sort of thing in depth then I can as well’.

**Non-judgmental:** Having a ‘non-judgmental’ atmosphere where “…we are all equal” enabled members to talk about HIV “…without thinking of somebody judging you or criticising you.” For one member, this was “…the first time I was at peace talking about HIV...with no fear that someone was going to judge me or I’ll meet someone who knows me...”. Retreats are seen as “…a very safe space to just talk and be yourself”. This is important because “…you need that platform where...it is safe to bring out this information and talk about it”. It reduces isolation since “…when people talked to you it made you realise you’re not alone, you’re no longer alone”.

**Mixed group:** Members valued the demographic mix, with no restrictions on age (18 years of age and older), gender, sexuality, ethnicity, religion, nationality, education, time since diagnosis, mode of transmission etc.
"I’ve never really been in a group of mixed people to share our ideas together…. Now, hearing different sides, we all have the same experience…"

“It was amazing. It’s something you can hardly see out there. People hardly sit down together… it’s rare to find that combination. And the fact that we just blended like a big family was… amazing”

“If somebody had mentioned to me before about HIV I would have naturally come to the conclusion of either black or gay. But being there at the weekend… I was like, this isn’t an illness that is discriminatory, everybody’s susceptible to it…"

“You can get tunnel vision… there’s no one bringing an alternative perspective… like an echo chamber, focusing in very specifically on certain issues… (whilst) different communities… broadens discussions”

“My frame of reference for HIV was dirty, promiscuous… very negative… So being surrounded by people who had contracted it by birth… was a revelation. And how their identity had been constructed… was more positive. There was no guilt. There was no shame… for me that was very almost liberating”

“We are all equal in a way, no matter where we come from… no matter our experiences in life. If you are living with HIV, we are all facing the same challenges…”

**Structured MBH content:** The MBH programme design included psycho-educational elements and structured activities which ‘stimulated people’, went ‘really in depth’, enabled ‘challenging topics’ and ‘unpacked’ what was going on for people. It was highlighted that “…the real, valuable thing about those topics is the discussion that it opened (they)... steered people in a certain direction… like a door”, Academic content produced ‘deep meaningful’ and ‘illuminating’ discussion, and encouraged “… questions about what it means for how we exist in the world”. They also provided an opportunity for people to talk about ‘negative experiences’ which “we don’t explore a lot… due to stigma”.

**Flexible MBH format:** Flexibility in the programme allowed “free-flowing discussion” which “…developed by itself” and went “…off-topic a little bit”. Letting ‘spontaneous’ conversation threads take hold meant “…the structure became organic, it blended out, it bloomed like a flower”, so enabling ‘deep dives’ around living with HIV “…in a different capacity”. Members were free to “…input or to stay silent and observe”. They knew “…if we need a break from a session, if we just need to do our own thing… that’s up to the individual”, and there were “…alternatives for other people to go to”. This was especially needed “…if it gets too overwhelming, you can give yourself a break.”.

**MBH facilitation style:** The person-centred approach gave members “…space as well to express myself… allowed to say what I want to say, and given the time to say it”, and meant “… nobody was talking over one another, everybody was listening to everybody and what they’ve got to say”. The HIV+ facilitator used examples from their lived experience to illustrate points and deepen conversation which “…really worked in helping other people open up, because you were so honest. You weren’t oversharin… It was such a kind of honesty and vulnerability that allowed other people to then do it”.

**MBH closed group:** Group members were encouraged to come to all six MBH sessions. This meant “…having almost the same people, it’s like you are building a family. Because the first time in the first session, it’s like you’re getting to know each other, and then the stories start. And when you meet the next session, it’s like now you are following up from the last one, and you still remember people by some of the stories they gave. You are getting to know them better. So, throughout the sessions, you get to know the people better. By the time you get to the end, it’s like you’ve built a family…”.
Essentially, all people living with HIV have a store of experience relating to this, and this is what we bring to discussion groups. In the circle, we offer from our experience via the telling of stories and the sharing of ideas. The process of sharing can itself be beneficial.

“When I spoke up and shared my own experiences it was really appreciated. And people really liked hearing what I had to say, and that made me feel good about myself, and also more confident to want to speak up more and share other stuff as well”

“...sharing what I’ve been through just helps come to terms with it”

Sometimes (due to concealment) we have never shared our stories and the circle becomes the first sharing. Some stories are traumatic. This can increase the intensity of feelings during sharing.

“Some people cannot talk about themselves or they cannot talk about anything at all. So, the fact that we were there and we were talking about ourselves, releasing what is inside us and hearing other people being emotional... it means they were burning whatever thing that was...releasing it...”

“...just very deep and personal stuff, and afterwards there was that heavy feeling and, I don’t know, I really felt for everyone else and the situations they were in. And it made me feel a little sad because a lot of them were really scarring traumatic experiences...”

People then respond from their own store of experience. Responses are sometimes in the form of related stories, the sharing of which can also be beneficial.

“Sharing my story, my experiences... gives them confidence as well...And to know that somebody got their strength from sharing my story, our stories, makes me feel good.”

“I need to talk about (my life) because it could help someone here.”

Other group members hear our stories.

“I asked myself... why am I being quiet? And it was very much the answer, because it’s okay to be quiet. It’s okay to listen. It’s okay to absorb that.”

“I just needed to hear the stories to understand that you just have to listen and support...”

Other times members give direct feedback on a story that’s been shared. This feedback is intended to be helpful and supportive and can be deeply insightful.

“Everybody sees... where they can be of assistance and help and get rid of the stigma"
We can use what we hear as a basis for self-reflection, including to reorganise our own stores of experience. Reframing things that happened to us allows us to understand them in a different way.

"Every story I could reflect on…. I could reflect on a situation I'd been in, which if not the same something similar. It helped me come to terms with certain things with myself..."

We learn improved ways of coping and occasionally have a radical shift in perspective - an 'awakening'

"...if I keep reflecting back and reflecting on the differences we have with each other, it helps me to improve in the way... how I deal with situations and how I deal with people."

"You look back in the past and then you remember and ask yourself, is it me who went through all this. And now I am here!"

In the circle emotions are generated, and sometimes we experience a sense of emotional release.

"...discussing the trauma bit, that was intense. I felt quite emotional a bit at times"

"It was a great release... and then I burst into tears, and I couldn't continue anymore... I just burst into tears and put my head down"

We can use what we hear as a basis for self-reflection, including to reorganise our own stores of experience. Reframing things that happened to us allows us to understand them in a different way.

"Every story I could reflect on.... I could reflect on a situation I'd been in, which if not the same something similar. It helped me come to terms with certain things with myself..."

We learn improved ways of coping and occasionally have a radical shift in perspective - an 'awakening'

"...if I keep reflecting back and reflecting on the differences we have with each other, it helps me to improve in the way... how I deal with situations and how I deal with people."

"You look back in the past and then you remember and ask yourself, is it me who went through all this. And now I am here!"

In the circle emotions are generated, and sometimes we experience a sense of emotional release.

"...discussing the trauma bit, that was intense. I felt quite emotional a bit at times"

"It was a great release... and then I burst into tears, and I couldn't continue anymore... I just burst into tears and put my head down"

We listen to the responses from our peers and can learn from them, as we build our knowledge about living with HIV.

"...we learn how to individually deal with our own problems through other people's problems"

"...I learned some things... if I might happen to face these kinds of challenges in future I will definitely know who to contact for help"

"Around the 80s and 90s and stuff when it was this really huge, big thing and it was really bad and stuff like that... and there wasn't any medication at the time. I didn't know any of that stuff I really didn't.... I learnt all of that from the retreat about what it was like in the beginning..."

Emotional energy is realised into the circle and group members connect with it (and each other) via empathy. We absorb and process each other’s emotional energy and provide stability to others.

"...you felt empathy for everybody in that room... because everybody was in tune, everybody could feel each other's pain, everybody could feel each other's distress..."

"It was emotional. I could feel the tears about to come, and I was holding them back, and I was fighting it. Because the stories that I heard... just disturbed me. It was very disturbing, this time round. I felt... Found myself empathising with them, and I think that's what almost make me break down."

"I really wanted the best for them and just hope that they would be able to feel better about themselves despite those situations."

The benefits from circle work were accredited by members to different dimensions of the group work, such as the 'group dynamics', 'bonding', and being in the 'same boat'. Above all, we get a sense of normality from retreats, through talking to, listening, seeing and being around others living with HIV.

"Just normality, really, normalising it, usualising it."

"...without having to explain yourself, without having to apologise for your diagnosis. I'm sorry, I'm HIV positive, is that ok? Talking to other people, no explanation, no apology... normality, I suppose."

"I was sat with the older people that was just general normal conversation as if HIV just wasn't a thing, like it was just normal conversation."

"You look and you think, wow, you're all, this sounds really naive, but yes, you're all human beings, you're all normal, you're all... You couldn't tell."

"It's just weird. Everybody has this thing but we look quote unquote 'normal'. We're normal but we just look like someone... a person on the street, and I just thought they were like a normal person."
We live in a time where the HIV epidemic could end. We know that being ‘virally suppressed’ means we cannot pass HIV on (U=U). This means if everyone carrying HIV knew they had it and received effective treatment, there would be no new cases. Creating this reality will require overcoming stigma and persistent inequalities.

**IMPACT OF RETREATS**

Part of the problem is that HIV affects certain groups more than others, and these groups are already marginalised by society. This is a broader issue. But stigma is also something we need to address within ourselves. Sometimes we adopt other people's negative ideas about HIV and apply these to our own way of thinking. This can affect how we view ourselves, how we think about others, and how we interact.

Retreats can help us to process and overcome stigma.

“I think I still had a little bit of self-stigma. I thought I got rid of it, but I realised then I still had a little self-stigma inside of me. And coming away from that workshop I just felt freer and as I say, ‘to hell with the world, I’m not doing anything to hurt the world, to hell with it, I don’t care what they say or what they do I’ll always be me.’”

“The more variety it is, it helps people learn more. Because sometimes, people have issues in their mind or beliefs, even stigma around different kinds of people. But the more you mix with people, the more you get to learn the differences, and the similarities, and how to handle people and get on with them.”

Retreats can also help us to see ourselves as strong, capable and a valued member of society.

“The sessions gave people a sense of power, empowerment, and that’s what we’re all about giving each other empowerment.”

“It is a new lease on life. A new chapter is about to open.”

“I can still make sure that I can complete my degree and I can contribute to society, regardless of people knowing that I have HIV or not... I can still go to university just like my peers can go to university and yes, make a difference just like my peers can also make a difference... they also have a place in being able to contribute to society and I also have my place as well.”

Retreats can help us to get a new perspective on our condition, and to reach a place of acceptance.

“...it made me realise, it’s not the worst thing that could happen. There could be worse things that could happen to you, it’s just how you deal with your problems as they come, how you deal with it.”

“I hadn’t been on a retreat before... I think it helps... with owning what I have and myself and stuff. So this retreat was really necessary for me to go and have the experience and just acknowledge, just acknowledging this is me, this is part of me and I’m fully accepting it.”

“...knowing that, yes, I have it but also it’s not the end of the world. And I can realise how that affects all parts of me, and I can just give myself more kindness in the world... just accepting this... part of me even more.”
For some members, the retreat helped to reduce anxiety and feel good in themselves.

“I do suffer from anxiety and depression, severe both ends. And since I’ve come back I’ve just felt more relaxed, more positive with life.”

“it’s like the anxiety of it just disappeared after listening to everybody else, and having spoke about it. The anxiety disappeared because we’re all in the same boat.”

For some, the effects of the retreat have been life changing.

“…afterwards, like I’ve come out publicly now as being HIV positive because of the retreat…. that’s how much of a profound affect your workshops had on me….for me, it was like ‘I’m empowered. I’m not bothered what people think about it anymore.’

Key to this is connecting with other people living with HIV.

“By the time you get to the end, it’s like you’ve built a family, which feels good.”

“I definitely left with good experiences and definitely a lot more friends and people to be able to talk to about stuff.”

Demand for retreat places is increasing and more people living with HIV apply for places than are available. The charity relies solely on the help of volunteers to make retreats happen. There are no paid staff, and no division between those than run retreats and those that attend them. Charity trustees have multiple roles – including strategic governance, operations management, and members.

In order to grow and offer more retreat places, the charity needs more volunteers to help with organisation. The Open University is continuing to work with HiVitality to explore ways to assist.
HiVitality is the only peer-run organisation in the UK providing regular multi-day wellbeing retreats to people living with HIV.

The charity’s ‘group of friends’ approach runs through the entire organisation—from peer support to strategic decision making. Outside people conceal their medical condition whilst retreats enable authenticity and openness with healing consequences.

Over the last year HiVitality have been working with the Open University on a coproduced retreat programme, and research to explore how retreats serve members’ needs.

This report details findings from this programme, and gives insights into the contexts, core features, and healing processes which ultimately benefit people living with HIV.

“It was a very safe space to just talk and be yourself”

“Talking about HIV, it means healing to both sides, to the person I’m talking to and to myself. I feel better when I talk about it, because it’s not something we talk about every day…”

“…there was something real about it. There was something tangible. But also humbling. And also a self-acknowledgment of ‘it’s okay’. You’re not on your own, you’re not alone.”

“The more people opened up, they felt bonded. We all felt bonded to one another, and it made no difference your sexuality, your ethnicity, your religion, it made no difference”

“…you were asking questions about what it means for how we exist in the world… And some of the other things that we looked at in that kind of deep meaningful way… That kind of free-flowing discussion with the topics allowed for those kind of deep dives, and for people to think about themselves as positive people, but in a different capacity.”

“…it was cathartic when I sat down and I was able to disclose for the very first time publicly that I was HIV positive. To me, that was relief, because I couldn’t stop crying. And it just kept on coming. Every time I looked at someone in that circle, I just wanted to cry again. And when I was talking to one of the members, I looked in her eyes, and I just, I don’t know, it just set the waterworks off again.”

“…I was very nervous in the beginning, nervous, slightly anxious. But then leaving I felt content. I felt like it was a good weekend that it was well spent, and I appreciated every moment of it.”

The Open University
Faculty of Wellbeing, Education and Language Studies,
Walton Hall, Milton Keynes MK7 6AA
HIV@open.ac.uk