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“HIV has taught us that you can survive anything”: findings from auto-ethnographic video diaries exploring resilience among people living with HIV during the Covid pandemic in five countries

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ABSTRACT

This study aimed to elucidate the intrinsic and extrinsic resilience resources among people living with HIV (PLWH) during the Covid pandemic. Autoethnographic video diaries from 29 PLWH from Argentina, UK, Philippines, Zimbabwe, and Trinidad and Tobago were included. Data were thematically analysed and validated with community partners and a video was co-produced. PLWH displayed a readiness to adopt healthy behaviours and engage in optimistic and constructive thinking about the future. Hobbies and daily activities, supportive relationships with peers living with HIV, family and friends, opportunities to mobilise and contribute to their communities in meaningful ways, supportive healthcare providers and reliable access to antiretroviral treatment helped foster psychological resilience among PLWH. The extrinsic resilience resources also supported positive physical health outcomes among PLWH through improved medication adherence.

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Resilience; Covid; HIV; video diary; mental health; antiretroviral treatment

Introduction

Similar to Covid, the early days of the HIV/AIDS pandemic were characterised by serious threats to physical and mental health, as well as distinct resilience and community mobilisation (El-Sadr, 2020; Illanes-álvarez et al., 2021). Resilience is defined as adaptation and post-traumatic growth in the face of serious adversity (Dulin et al., 2018), such as pandemics. Resilience is a dynamic, longitudinal process of adaptation, influenced by people's intrinsic traits, environments and experiences (Dulin et al., 2018; Gillespie et al., 2007).

Notable gaps in research on resilience during pandemics remain. First, research on both HIV and Covid has been largely “damage-centered”, documenting losses without robust reference to markers of strength, resilience and agency (Tuck, 2009). “Community wealth-centered” research is required to inform the design of empowering interventions that recognise people's potential, work with their capacities and foster resilience (Fránquiz & Ortiz, 2018). Second, definitions largely situate resilience among PLWH as an individual-level phenomenon (Dulin et al., 2018), overlooking the social contexts in which resilience and stress occur

(Earnshaw & Quinn, 2012). Important resilience resources have been identified among PLWH globally, including self-efficacy, religiosity, and mindfulness at the individual level; parental monitoring for adolescents, supportive family and marital relationships, and functional social support at the inter-personal level; and access to support groups within one's community (Amiya et al., 2014; Boyes et al., 2019; Casale et al., 2019; Dalmida et al., 2013; Gonzalez et al., 2016; Huang et al., 2018; Liu et al., 2013; Oppong Asante, 2012; Safiya et al., 2009; Steglitz et al., 2012; Woollett et al., 2016). However, evidence is lacking on how PLWH cope with emerging macro-level crises, such as pandemics (Dulin et al., 2018), as well as how they might be supported or hindered by health and other policies at the structural level. In a recent UK-based survey ($n = 653$), 83.3% of PLWH reported that living with HIV had equipped them with strength to adapt to the Covid pandemic (Pantelic et al., 2022). However, the resources that foster this resilience remain unknown.

This study aims to address the aforementioned gaps in research by elucidating the multi-level resilience resources among PLWH during the Covid pandemic.

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Method

Design and setting

Participant-recorded audio-visual diaries were used to enable a bottom-up, constructivist and interpretivist approach (Schwandt, 1998). The video diary method allowed PLWH to take control of their data and engage with the research in their own time and space (Buchwald et al., 2009). PLWH framed their own stories, sharing or withholding as much as they felt comfortable doing (Bates, 2020).

The study was a partnership between the University of Sussex and three global networks of PLWH: Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV (ICW), and the Global Network of Young People Living with HIV (Y+). Partners selected five participating countries: Argentina, the Philippines, the UK, Zimbabwe, and Trinidad and Tobago.

Participants

To be eligible, participants had to be 18 or older, live with HIV, reside in a participating country, and consent to participate in the study.

Procedures

Participants were recruited through partner civil society organisations and social media. Interested individuals were invited to fill a Microsoft Form, after which they were emailed study information. Virtual meetings were conducted with a member of the study team for informed consent procedures.

Between February and July 2021, eligible participants were invited to film 15 min of footage over a three-week period using their phones. During these three weeks, participants had autonomy over submission and withdrawal of data using a university-encrypted drive until they were comfortable with the resulting video content. Instructions detailing how to film and upload, as well as prompts suggesting topics “in case you get stuck” were emailed to participants prior to the filming and submission period. The topic prompts were co-designed with partners and included: (1) Impact of the Covid

pandemic on your daily life, healthcare and ART access, and community services; (2) Impact of the Covid pandemic on mental health; (3) coping strategies used during the Covid pandemic; (4) anything that has helped you navigate the pandemic; and (5) how everyday life has changed for you.

Data analysis

Thematic analysis was used to analyse transcripts in the following six phases (Braun & Clarke, 2006): familiarisation with the data, generating codes, generating initial themes, reviewing themes, defining and naming themes and write-up. An inductive strategy was used to produce themes and ideas by two independent coders (ZC and PB), and discrepancies were resolved via discussion with an additional analysis by MP. In addition to these analyses, a summary video illustrating emergent themes was co-produced with civil society partners.

Data validation

In collaboration with GNP+, three data validation sessions were conducted with HIV community representatives and PLWH during data collection and analysis to ensure that emerging themes accurately captured the content and context of participants’ video diary entries. These sessions were one hour long; a 20 min presentation of emerging themes and 40 min discussion. At the end of the project, participants were sent a summary of the findings in the form of a co-produced video for feedback prior to the writing of this paper.

Ethical considerations

The study procedures were approved by the Brighton & Sussex Medical School Research Governance and Ethics Committee (approval ref no: ER/BSMS9GXW/2). Information sheets clearly stated that participants did not need to film their faces or their homes unless they explicitly wanted to and felt comfortable doing so. None of the participants recorded other individuals. Participants could opt out of using their data visually and/or aurally for the final summary video while still contributing their data to the research project. Each participant was compensated £20 for the communications expenses.

Results

A total of 29 PLWH in the UK, Zimbabwe, Philippines, Trinidad and Tobago, and Argentina took part in the study, of which: 12 identified as male and 17 as female, including one transgender woman. The distribution of

Table 1. Sample characteristics.

Country	n	Age range	Length of footage
Argentina	5	30–50 years old	47 min and 29 s
UK	5	50–70 years old	49 min and 12 s
Zimbabwe	5	20–50 years old	42 min and 36 s
Trinidad & Tobago	6	40–60 years old	69 min and 42 s
Philippines	8	20–50 years old	86 min and 31 s

countries, participant ages and footage length are summarised in [Table 1](#). The co-produced summary video is available at <https://youtu.be/4RdQF1-6sUU>.

[Table 2](#) outlines the themes and subthemes that emerged from the data. The section below utilises participant quotes for illustrative purposes, followed by participant number, gender and country.

Theme 1: daily activities affecting resilience

Several new daily activities were found to be helpful for PLWH across contexts, including art, gardening and exercise.

What I have done to help me cope really is I've started my own little home garden, I like digging in the dirt it relaxes me, especially when I see what I planted and it helps me cope ... (P27, F, Trinidad and Tobago)

Social media was a stressor for some participants, both because it distracted them from nurturing activities and because it was a source of misinformation.

[...] myths about Covid-19, myths about people dying with HIV from taking vaccines – it was a scary issue for people like us living with HIV and it was difficult [...] because every type of fake news were all over the internet and they brought insecurity to us – saying that people living with HIV had died [...] (P14, 22, M, Zimbabwe)

Theme 2: community mobilisation

Community mobilisation – both within and outside the HIV sector – was a valuable source of empowerment for PLWH. A female participant described the impact of connecting with other women living with HIV.

Working with [other women living with HIV] gave me the courage and the opportunity and the strength to share my story and be involved in advocacy and just do more [...] as a young person living with HIV [...]

Table 2. Emerging themes and subthemes on resilience among PLWH during Covid.

Theme	Subtheme
Daily activities that foster or hinder resilience	Hobbies Social media
The importance of communities	Peers living with HIV Family and friends Community mobilisation
Structural barriers and facilitators for resilience	Resources within the healthcare system Income (in)security Inequities between contexts Exposure to HIV stigma due to travel restrictions
HIV as a source of resilience in the context of Covid	Appreciation for life Adoption of healthy behaviours Future mindedness

It's been a really interesting experience for me and even though I am home and don't really go anywhere [...] I use that time to focus on advocacy and learn as much as I can about being a PLWH and how I can help better my community and what I can do to advocate for my PLWH community which I am a part of. (P25, F, Trinidad and Tobago)

Theme 3: resilience resources and barriers at the structural level

Participants lived in vastly disparate policy and income contexts, which impacted their ability to cope with the stressors of HIV and the Covid pandemic. In the UK, a relatively well-resourced national health service (NHS) and reliable ART stock enabled participants to confidently navigate HIV services:

Obviously in-person visits to the clinic stopped and it was all done via telephone. I have an extremely good relationship with my HIV doctor and I know I can email her at any time and she will respond and there had been a couple of issues through the first lockdown where I had some anxieties. I was undergoing treatment for stomach ulcers and a quick email to her resolved the issues that I had and I haven't had any issues getting access to treatment. When the first lockdown started she suggested I get 6 months-worth of meds and that's what I did so there was never any anxiety about running out of medication during this whole experience. (P3, F, UK)

This was in stark contrast to experiences of PLWH in low-income settings, where unreliable stocks and costs of ART hindered access.

I have just received my antiretroviral medication, in an opened jar. A pity, really, and it is also not the medication that I had been taking. Ah, so well, here we are, now I have to make a complaint. (P12, 36, F, Argentina)

It was so scary when our forum, the virtual forum of women living with HIV, every day I'll hear someone crying out 'I'm ill, I don't have the money to go to the hospital' and it costs 500 US dollars to be admitted on a daily basis in some of the hospitals [...] (P5, Zimbabwe)

Several participants from the Philippines spoke about being diagnosed with HIV during the pandemic, which introduced new expenses for daily ART at a time of unprecedented financial insecurity. This affected both their mental health and ability to manage HIV:

I have not started [ART] yet [...]. The problem is the medicine is too expensive and I can't afford it. Then, I am also the breadwinner of our family. We have many needs. Without me working, I can't really support myself. (P19, M, Philippines)

In Zimbabwe, COVID related travel restrictions inadvertently increased the risk of stigma and interruption of ART for PLWH who were not comfortable disclosing their HIV status:

Collection of medicine at any clinic was tough as we were not part of the “essential” clients. It took more than one day to collect medication. We had to disclose our reason of travel and it felt unsafe to do so. (P6, F, Zimbabwe)

Theme 4: lessons from HIV

Despite the challenges of living with a life-long stigmatised condition, PLWH across contexts reflected on valuable lessons from HIV, particularly in relation to adapting to the Covid pandemic. Both long-term survivors and recently diagnosed participants reflected on how HIV gifted them with a new appreciation for life:

I think for me experience of the 80s into the 90s and sort of living with the HIV outbreak then, the lesson very much was about enjoying today – not in a hedonistic sense but in that you didn’t really know about the future, you didn’t know what the future held ... There was a period of attending so many funerals y’know of friends, ex-lovers and it wasn’t possible to really live with that constant anxiety about the future ... So you had to really learn just to enjoy today within the reigns of course of being sensible about your health et cetera and I think really that has carried forward with the Covid-19 pandemic and possibly being able to cope with the lockdown and being able to see oneself through a whole year really of changing situations. (P4, M, UK)

For me, this [life after initiating ART] is my second life, I said before, don’t waste your second life. Just give your life to the people you love, because you won’t be able to do it when you’re dead. (P15, M, Philippines)

Many participants spoke of the ease with which they adopted preventative measures such as mask wearing and social distancing, as well as measures to support their immune system:

That is life for us, people with HIV, we have to do the things we love so that we don’t spend time thinking about the problem, thinking about negativity or stigma so this is one thing I do most times. I go outside I take walks I just appreciate the world and voila I am changed I have boosted my confidence and my wellbeing. (P14, M, Zimbabwe)

I haven’t found the pandemic with Covid as challenging as perhaps someone who hasn’t been through an experience like HIV and therefore I think I’ve coped pretty well I haven’t felt my mental health has suffered largely because I have had the tools at my fingertips ... y’know I knew what worked for me in terms of helping with my wellbeing, hence why I started to become creative again and maintained physical exercise. (P3, F, UK)

Participants also noted how HIV instilled future mindedness:

One thing that actually really helped was the way I’d prepared financially to deal with getting ill through HIV was to save money every month and so when the work dried up because of Covid, I was incredibly lucky to have my nest egg that meant I wasn’t going to be concerned financially about coping with a reduction in my income. (P3, F, UK)

All the uncertainty at the beginning of the Covid pandemic felt very familiar and [...] that gives you a certain resilience because you know that at some point [...] they will find out more information, more data will be collected more will be known about it, risk will be better understood [and] therefore prevention will be better understood. (P1, F, UK)

HIV has taught us that you can survive anything. (P8, F, Zimbabwe)

These reflections challenge dominant narratives, which generally construct HIV as an adversity. As illustrated in the quotes above, many PLWH in this study portrayed the experience of living with HIV as an asset within the context of a novel pandemic, without having been prompted to reflect on it.

Discussion

In the midst of the chaos and uncertainty caused by the Covid pandemic, PLWH in this study constructed meaning from living with a lifelong stigmatised condition and from the grief of losing loved ones to AIDS-related causes. PLWH displayed a unique appreciation for life, a readiness to adopt healthy behaviours and an ability to engage in hopeful and constructive thinking about the future of the Covid pandemic. Findings suggest that nurturing hobbies and daily activities, supportive relationships with peers, family and friends, opportunities to mobilise and contribute to their communities in meaningful ways, supportive healthcare providers and reliable access to ART may help foster psychological resilience among PLWH. Structural-level resourcing of healthcare systems and reliability of ART stocks considerably impacted the ability of PLWH to cope with adversities. Notable inequities in access to life-saving ART were observed between the global north and more resource-limited contexts, and these inequities seem to have been exacerbated by the Covid pandemic.

This study had several strengths and limitations. Only PLWH with access to the Internet and technology were able to participate, which is likely to have excluded the most marginalised. However, the video diary method allowed for inclusion of participants who

would not have the time or motivation to participate in more conventional interviews or focus group discussions, e.g., people with inflexible work hours and/or caring responsibilities (Taylor et al., 2020). Only audio transcripts were analysed, but the video diaries were an important element for data validation with people living with HIV and dissemination to lay audiences. There were substantial discrepancies in the amount of data submitted between participants. This may be a reflection of the methodology, which sought to equalise the relationship between researchers and participants (Litovuo et al., 2019): participants chose how much, when and under what circumstances to share their stories.

This study makes an important contribution to existing literature on resilience among PLWH by including perspectives from divergent policy and pandemic settings and those underrepresented in HIV research. This enabled the much-needed documentation of resilience promoting and hindering mechanisms at the structural level. Our findings suggest that some public health measures have had harmful effects on PLWH – in particular restrictions that interrupted access to ART and exposed people to stigma. In the event of future emergencies such as the Covid pandemic and lockdowns, it is critical to ensure that PLWH have uninterrupted access to ART. This can be done through six-month dispensing of ART (Hoffman et al., 2021) whenever travel restrictions and curfews are imposed, free ART, support for other basic needs and sensitive travel restrictions that do not force people to disclose their HIV status. It is estimated that without efforts to mitigate interruptions in health services during the Covid pandemic, a six-month disruption of antiretroviral therapy could lead to more than 500,000 preventable deaths annually from AIDS-related illnesses (Jewell et al., 2020).

Important affective, cognitive and behavioural assets that have the potential to foster the resilience of PLWH were identified: appreciation for life, future mindedness, and readiness to adopt behaviour change for public and personal health. Participants suggested that these resources were developed through the experience of living with HIV. PLWH should therefore meaningfully be included in the design of psycho-social support interventions for people more recently diagnosed with HIV or potentially other life-long stigmatising conditions. Such initiatives are already being organised by networks of people living with HIV (GNP+ et al., 2020), and more research is needed to evaluate effectiveness. Evidence from Nepal (Bhatta & Liabsuetrakul, 2017) and India (Ghosal et al., 2017) suggests such interventions reduce self-stigma and improve self-worth, with onwards

effects on health-seeking behaviours. Empowering PLWH to know and assert their rights within rapid policy shifts such as those seen during the Covid pandemic is essential.

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Author contributions

MP, CL, GC, AS and JW conceptualised the study. PB and ZC facilitated data collection and transcription. PB, ZC and MP analysed the data. All authors contributed to the interpretation of findings and manuscript write-up.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Ethics approval

Ethical approval was granted by the Brighton and Sussex Medical School Research Governance Ethics Committee (Approval ref no: ER/BSMS9GXW/2).

Data availability statement

Data are not currently available due to restrictions with consent and ethical agreements on sharing data.

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