

"A tool to be okay": experiences of and attitudes towards starting antiretroviral therapy amongst people with recently acquired HIV in Greece, Spain and the UK

Emily Jay Nicholls¹, Julián Puente², Arygro Karakosta³, Inés Suárez-García^{4,5}, Inma Jarrín⁶, Nicoletta Policek⁷, Bruno Spire⁸, Alain Volny-Anne⁹, Kholoud Porter¹, Fiona Burns^{1,10}, Shema Tariq^{1,11}, CASCADE Collaboration

¹Institute for Global Health, University College London, London, UK, ²Independent, Madrid, Spain, ³Medical School of Athens, Athens, Greece, ⁴Hospital Universitario Infanta Sofia, Madrid, Spain, ⁵CIBERINFEC, ISCIII, Madrid, Spain, ⁶National Epidemiology Centre, CIBERINFEC, Instituto de Salud Carlos III, Madrid, Spain, ⁷European AIDS Treatment Group, Brussels, Belgium, ⁸Aix Marseille Univ., Inserm, IRD, SESSTIM, ISSPAM, Marseille, France, ⁹Independent, Paris, France, ¹⁰Royal Free London NHS Foundation Trust, London, UK, ¹¹Mortimer Market Centre, Central and North West London NHS Foundation Trust, London, UK

Background

Most national guidelines recommend rapid initiation of antiretroviral therapy (ART) for those with recently acquired HIV. However, a 2023 qualitative systematic review on recently acquired HIV¹ identified only two studies on initiation of ART in people with recent HIV infection^{2,3}. Participants in these studies were motivated to start ART to relieve acute symptoms² while reducing the risk of onwards sexual transmission³. For cis women, ART also allowed them to fulfil a maternal role through the prevention of vertical transmission or by staying well due to medication².

There remains a gap in our understanding of the broader motivations and concerns regarding ART initiation in this group, as well as adherence and clinic support.

Aim

To explore experiences of and attitudes towards starting ART amongst people with recently acquired HIV in Europe.

Methods

We conducted semi-structured interviews (SSIs) with individuals from Greece, Spain and UK who had recently acquired HIV (HIV-negative to HIV-positive ≤ 1 year or other laboratory evidence of seroconversion) as part of CASCADE, an international longitudinal mixed-methods study of recently acquired HIV.

Data were summarised in English and synthesised across countries using Rapid Assessment Procedure (RAP) sheets⁴ and analysed thematically.

Results

23 people with recently acquired HIV participated in SSIs; 21 were cis-gender men and 2 cis-gender women. Interviews were conducted in Greece, Spain and UK.

	Greece (n=8)	Spain (n=6)	UK (n=9)
Age			
16-25	3	1	2
26-35	3	2	3
36-45	1	2	2
46-55	1	1	1
56-65	0	0	1
Gender			
Man	8	5	8
Woman	0	1	1
Sexuality			
Gay or bisexual	8	5	8
Heterosexual	0	1	1

Key findings

- Overall, participants were highly motivated to start ART
- Where there had been delays in ART initiation, this was not intentional on the part of participants; rather this reflected clinical decision-making (e.g. to identify the best treatment regimen)
- The primary motivation for starting ART was viral suppression
- Some participants reported concerns about long-term side-effects but this did not impact their decision to start ART.

Motivations to initiate ART

Interviewees started ART soon after diagnosis (with varying lengths of time). Motivating factors included:

- Restoration of health
- Becoming virally suppressed
- Returning to normalcy
- Regaining control over one's health

Once [the doctor] explained the tablets to me... I mean it's just kind of like PrEP in a way. I think it's got one of the drugs that are PrEP in it. I just wanted to start it [...] I started on a really positive, motivational wave. Like now I've got it, now's my time to make a change for the better. So I was just [...] "give me whatever medication I need to take. Tell me what I need to do. Let's just crack on with it and get the viral load down."

Concerns about initiating ART

Key concerns included:

- Long-term side effects
- Potential for interactions with other medications
- Lifelong nature of treatment and adherence
- Effectiveness

I think some underlying concerns about kidney health and liver health, given that I could be on, well I will be on, this medication for the rest of my life [...] what does this look like when I'm 60 or when I'm 70? So some of those longer term views [...] started to crop up after the initial shock and the denial [of diagnosis].

1 month after diagnosis, I started the medication. I was mostly afraid of the side effects, because I was also on anti-depressant medication. I also worried whether the medication will be effective or not.

Role of clinic

- Participants reported positive experiences of support from their clinic
- ART initiation was perceived to be a joint decision with HIV clinicians, encompassing discussions about potential side effects and regimens tailored to their individual needs
- Some participants anticipated future challenges, but were confident that they could rely on their clinician to support them and adapt their regimen if needed.

I knew I wanted to have access [to medication], and I got offered [it] pretty much straight away. [The clinic ran] all the blood tests to know how my bones, how my kidneys, the viral load, my CD4, all that, and then [offered] me the best treatment [...] they took all the right steps. And they involved me as well in the decision making process [...] I think that was pretty great.

Adherence to ART

- The majority of participants reported adhering to ART
- Some found it challenging and/or felt anxious about forgetting.
- Those experiencing challenges tended to use adherence aids such as dosette boxes or phone reminders

I find myself getting into a schedule, a rhythm of taking that one medication every day at two o'clock, and then suddenly I'm on a new contract [...] so I need to change the timing to another point. So it was often a few missed medication days when that schedule had to keep changing. It's just changed again [...] so I'm still trying to work out timing wise what's best for me at the moment.

I'm not a person of routine. The fact that I have to be consistent with the medication was very stressful for me. I know that it is important and in order to be consistent, I've set a reminder.

Conclusion

In this study people with recently acquired HIV who were linked to HIV care were **highly motivated to start ART**, with concerns largely outweighed by the **desire to return to health** and to **achieve virological suppression**. Commonly reported **concerns** included **long-term side-effects** (in particular, hepatic and renal toxicity), and **uncertainty about effectiveness**.

Recommendations

Healthcare providers and others supporting people with recently acquired HIV should proactively discuss effectiveness and side-effects when initiating ART in order to address potential anxiety and to maximise adherence.

References

- Nicholls EJ, Policek N, Volny-Anne A, Spire B, Burns F, Ruiz-Burga E, Tariq S. A systematic review of qualitative research on recently acquired HIV. *AIDS* 2023;37(14):2199-2212
- Van Der Elst E, Kombo B, Mugo P, Thiong'o A, Kanungi J, Wahome E, et al. Adjustment to acute or early HIV-1 infection diagnosis to prompt linkage to care and ART initiation: qualitative insights from coastal Kenya. *Psychol Health Med* 2019; 24:631-641.
- Grace D, Steinberg M, Kwag M, Chown SA, Doupe G, Trussler T, et al. Diagnostic technologies in practice: gay men's narratives of acute or recent HIV infection diagnosis. *Qual Health Res* 2015; 25:205-217.
- RREAL Research, Evaluation and Appraisal Lab (RREAL). RREAL sheets-a quick guide. 2021. Available: https://c06b0ae7-7006-4c4d-8f3c-d3255fe5b08d.filesusr.com/ugd/e7949e_98b9fe553719481bb860025be83cd588.pdf

Acknowledgements

This study is funded by ViiV Healthcare UK, Janssen Pharmaceutica NV, and Merck Sharp & Dohme Corporation.

Ethics approval: IRAS 306443, REC 22/YH/0114, EDGE 148237

CASCADE Collaboration

CASCADE Executive Committee: Santiago Moreno (Chair), Fiona Burns, Rafael Eduardo Campo, Harmony Garges, Cristina Mussini, Nikos Pantazis, Barbara Pinto, Kholoud Porter, Caroline Sabin, Shema Tariq, Giota Touloumi, Vani Vannappagari, Alain Volny Anne, Lital Young

CASCADE Scientific Steering Committee: John Gill (co-chair), Kholoud Porter (cochair), Christina Carlander, Rafael Eduardo Campo, Harmony Garges, Sophie Grabar, Inma Jarrín, Laurence Meyer, Barbara Pinto, Giota Touloumi, Marc van der Valk, Vani Vannappagari, Alain Volny Anne, Linda Wittkop, Lital Young

CASCADE Social Science Sub-Committee: Shema Tariq (Chair), Agnes Aisam, Diana Barger, Fiona Burns Udi Davidovich, Marie Dos Santos, Lars Eriksson, Eli Fitzgerald, John Gill, Sophie Grabar, Inma Jarrín, Argyro Karakosta, Hartmut Krentz, Cristina Mussini, Emily Jay Nicholls, Nicoletta Policek, Elisa Ruiz-Burga, Chris Sandford, Bruno Spire, Inés Suárez-García, Giota Touloumi, Alain Volny Anne