

1. Background

- Evidence suggests that engagement in care (EIC) may be worse in young people living with perinatally-acquired HIV (YPLPHIV) than in adults or children living with HIV. However, few studies from YPLPHIV in Europe exist.
- We explored EIC from the perspective of YPLPHIV in the UK. Findings from a quantitative analysis of EIC predictors in the Adolescent and Adults Living with Perinatal HIV (AALPHI) cohort were explored in focus group discussions (FGD) with YPLPHIV.
- The study aimed to gain young people's perspectives to help interpret and contextualise the quantitative findings and gain a deeper understanding of YPLPHIV's experiences and influences on EIC.

Box 1: Previous quantitative analysis discussed in focus groups:

- A flexible new approach to measuring EIC was developed which took into account participants changing health care status
- Clinic appointment data were not available. Recorded viral load, CD4 count, weight, height and changes to ART regimen were used as proxy markers for clinic appointments
- The relationship between a range of exposures and EIC was carried out in AALPHI participant using quantitative analysis. Factors found to be associated to EIC were: older age, Asian/mixed ethnicity, self-harm, worse adherence/not on ART, and viral load >50c/mL

2. Methods

- Three FGDs with YPLPHIV (aged 16-26) were conducted in 2019 at voluntary sector organisations and events.
- Participants were asked to reflect on the reasons they attend clinic visits and whether findings associated with poorer EIC in the quantitative analysis resonated with their experiences.
- Focus group data were analysed using thematic analysis
- Ethics approval: East Midlands–Leicester Central REC, London School of Hygiene & Tropical Medicine. All participants gave consent to participate.

3. Findings

Characteristics of Focus Group Discussion participants

- Of 16 YPLPHIV who participated in the FGDs, 11 were male; median age was 20 (16 - 25); 13 were of Black, 2 of White and 1 of mixed ethnicity; most participants were UK based with one based in Ireland.

1. Participant feedback on use of proxy markers and quantitative predictors of EIC

- Young people largely agreed with the use of proxy markers (Box 1) for clinic appointments in the quantitative analysis but highlighted how using this method would miss some other important reasons for visiting or not visiting clinic. Participants most commonly cited clinic attendances for mental health or psychological reasons.
- Young people reported that the quantitative findings largely resonated with their experiences of EIC.
- However, discussions highlighted a much more nuanced range and dynamic nature of the different explanations for the individual predictors of EIC from the quantitative model.

'I remember I had a rough patch and they were like 'we want to keep an eye on you for a while'. But a lot of it was mental health and to maintain stability.' (male, 18 years old (yo))

2. Self-management and shared decision making

- Young people had different views on whether increased responsibility due to their age made attending appointments harder or easier.
- Young people who reported that healthcare workers communicated to them clearly about their health and about how often they needed to be seen in clinic had more positive experiences of shared decision-making and better EIC.

'I say for me when I was younger I probably messed up a lot more than when I got older. Because when I was older, I was a lot more independent and more in charge of my medication and my appointments.' (male, 23 yo)

'When I was young, my grandparents helped me. So I was taking medicines twice a day and I was always taking it on time every day because they always reminded me. Then as I got older, because it was my responsibility I kept forgetting it a lot.' (male, 21 yo)

'I feel like for me, if I am undetectable (viral load <50 c/mL), it's just like usually just say come in whenever my meds start finishing, but because I have been at University for 3 or 4 years, they just try to fit in when I am back from holidays basically. And it's just worked out fine.' (male, 23 yo)

2. Judgement and internalisation of responsibility

- Participants reported that communication with clinic staff about problems with adherence to ART were usually reactive (they were scolded and told off) and there was little acknowledgment of the wider context of managing their HIV treatment. Some YPLPHIV reported they would actively avoid clinic if they had a period of non-adherence and thought their viral load would be high.
- For some of the participants, any problems they had taking their medicines and attending clinic as entirely their own fault therefore attributed all the blame to themselves.

'Because by the time you go to the hospital, they are just going to say the same thing like 'Take your meds' so why should I go if they are just going to say the same thing.' (male, 20 yo)

'The nurses are like, 'If you don't take your medication you're are going to die the next time.' (female, 21 yo)

'I think for me it's a personal thing I think. So it's like, I know I need to and I tell myself I need to, I just don't. For me, I think that is something for me I am just trying to figure out why I don't even though I know I need to.' (female, 20 yo)

'It's not hard! It's not hard! No I mean some people make it harder than it seems. Because there are people who are using it who have more than me ...and that there are younger kids who are using it better than I can.' (male, 18 yo)

4. Conclusions

- Findings highlight the importance of including young people's views in healthcare research using mixed methods. Without the FGD findings, the range and dynamic nature of the different explanations for the individual predictors of EIC from the quantitative model would be lost.
- FGD results highlight the need for staff training in the challenges in this population especially around communication. Further research understanding staff perspectives on adherence in YPLPHIV would complement these findings.
- Limitations: i) ethnicity as a predictor was not discussed in the FGDs, so contextual understanding is limited; ii) all participants were purposively selected from pre-existing groups of young people already engaged in voluntary sector services and therefore may not be representative of young people who are disengaged from all services; iii) young people in the first focus group had been involved in the voluntary sector for a number of years and may be more used to critically thinking about health care than other young people.

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