Supporting antiretroviral therapy and adherence for people living with HIV in Aotearoa New Zealand

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Background

- **Effective antiretroviral therapy (ART) has dramatically reduced morbidity and mortality in people living with HIV.**
- **UNAIDS aim to end the AIDS epidemic by 2030, with 95-95-95 HIV testing, treatment and VL suppression targets.**
- **Current situation in Aotearoa NZ (people notified with HIV 2006-2023)**
  - 2348 PLHIV; 98.5% on ART (95% CI 97.9-98.9); 91.7% (95% CI 90.5-92.8) virally suppressed.
    - No difference in the proportion of people on ART by gender, age, ethnicity, mode of acquisition or year of HIV notification.
    - A lower proportion with undetectable VL in:
      - Māori (82.9%; 95% CI 77.5-87.6)
      - Pasifika (87.8%; 95% CI 80.4-93.2)
      - those aged under 30 years (88.3%; 95% CI 82.4-92.8)
      - those with a mode of acquisition other than MSM (89.2%; 95% CI 81.5-94.5)
- **UNSDG: Leave No One Behind (LNOB) - there is need to better understand experiences of people who experience challenges being on, or staying on, ART.**

Aim

To identify barriers and facilitators to ART uptake and adherence and to gather views on how these barriers might be removed to ensure that all people living with HIV in Aotearoa NZ are supported, and have access to the appropriate treatment and care for them to stay well.

Methodology

- Qualitative.
- Semi-structured interviews with People Living with HIV who self-identify as not being on ART, or having experienced difficulty staying on ART (n=8).
  - Ethnicity: 4 Māori, 4 non-Māori
  - Gender: 6 Male, 2 Female
  - Age range: 29-63, Average Age: 46
- Interviews were conducted via Zoom, telephone or face-to-face, and were audio-recorded, and transcribed verbatim.
- Transcripts thematically analysed using the framework method.

Barriers to ART uptake and adherence

Mistrust of health professionals, often grounded in experiences of stigma, discrimination and trauma

“When I got diagnosed, and I had to go into the doctor, I mean, she just looked at me like, “why did you do that for? You should know not to do that sort of thing.” You know, I had a big lecture of it. So I thought, “fuck you, bitch.” And I walked out. And I didn’t go and get any healthcare for quite a long time after that.” (Blake)

Lack of “fit” with support services

“I've probably spent two years trying to get services to help me out, I was just preyed upon, mate… it was fucking hideous. They all assumed the wrong thing about me. Being diagnosed with HIV – they thought, “well, he must be gay.” Or “he’s Māori, he must be on drugs.” So they sent me a gay Māori, and in the matter of not even one calendar week he had embedded himself into my life , tried to turn me into his gay little pet… and then um, [a different support service] comes along, but same thing, very focused on gay men. So, I’m just thinking to myself, “is there fucking nowhere for a guy like me, who’s straight, who doesn’t do needles, who’s never even had an STD for Christ’s sake.” But now, after 2 years of being in the system, they have realised that I’m obviously not gay, that I’m not on drugs, and everyone’s just sort of left me alone, which is fucking great. But, again, it’s sort of a bit sad because there's no support there for me.” (Jordan)

Fear of disclosure

“So, I went in [to the pharmacy] to go and pick up my meds, and [the pharmacist is] like, “oh, you're on antiretrovirals.” …And I had my kids with me. And he doesn’t know that my kids know, or that they were even *my* kids. And then there were other people around too, people who could have known me, and he said it loud enough…The stigma, and then the out-of-control’ness of it, that he just, just said that, and I had people with me. I didn’t want to go back and pick up my meds.” (Casey)

Desire to maintain power and agency over diagnosis and treatment

“I’m not a night pill person. Never have been. And they’ve always said, “well, you’ve got to change.” I said, “no, you’ve got to change, the system has got to change.” It’s like the drug companies are trying to force us onto their schedule. I've always been adamant that I’m, I’m not taking meds more than once a day. I take my meds in the morning. That's it…” (Blake).

“I think it’s that sense of powerlessness that's the hardest thing to grapple. Sometimes I skip my meds to alleviate that sense of powerlessness, to regain that sense of control, of power, and choice.” (Drew)

ART a daily reminder of HIV

“I really know that I fucking need to [take my medication], because I don’t want to die, mate. But these pills say to me “you fucking have HIV” every fucking day! Sometimes I just want to hide from that reality, hide it from myself anyway, until I can sort of claw back some sort of self-esteem.” (Jordan)

Mental Health Challenges

“I had a really severe breakdown. Like, I was quite bad, like, um, you know, almost bordering on sort of psychotic. Like, um, if my partner wasn’t around I probably would’ve been put in the unit - like, really, really bad. And when I was sort of going through it, I couldn’t remember whether I'd taken my medication, whether I hadn't, I didn’t know what was going on. So… like, I'd take them, and then, you know, then I'd worry I hadn't taken them. So, I'd take them again.” (Casey)

Concerns around long-term impacts of ART

“I think of my friends that were dying of HIV, you know, going to their funerals, you know, things like that. And they all started to have other issues before they died, like their kidneys, and diabetes, and so I do worry that that’s the side effects of this medication over time.” (Alex)

“It’s something I really struggle to get my head around…you have to be on medication forever…like what is it doing to my body” (Jessie).

Physical challenges of taking medication

“I turned around and said to [name of clinician], “these are big horse tablets.” And I turned around and says, “they're about the same size as the suppository tablet, and I've got to stick that down my throat?” And I kept on complaining because I was getting depressed because I've got these big tablets that I’m struggling to swallow.”(Alex)

“I am having side effects now, which is nausea, and, um, you know, I haven't had a solid bowel motion for about, you know, close to 4 years. They just go in one way and it comes out the other. And it’s… yeah. And, you know, like, some stomach upsets, and, you know, things. I had quite a rounded face. And it’s, you know, got very thin, quite drawn and, you know. And, like, the little hump thing, and the fat distribution around the waist, those side effects also kind of make you a little bit put off the drugs, you know, not wanting to take them.” (Jessie)

Access to pharmacy and health services

“[Name of place] is a small town, I mean there isn’t even a pharmacy here. There are a couple of pharmacy’s in [name of closest city] that stock the meds I’m on, but it’s 45 minutes away on public transport, and they close at 5.30pm… So yeah, I haven’t managed to get into, to the pharmacy, um, in September at all. I mean, and now I’ve missed the rest of the month’s worth of medicine. I mean, I think I’ve tried to, but just been busy with work and other stuff.” (Drew)

Having to plan ahead

"I get my HIV meds from my local pharmacy, here at [name of town] which is just a few minutes' walk from my place. The pharmacist told me that I need to ring them and tell them at least two days before I needed to pick them up, because they don't stock them and need to order them from their wholesaler, which I think they said their wholesaler is in Auckland. But it's not always top of mind until I actually run out, so there is often a lag of a few days." (Finley)

Competing priorities

“I think, looking back now, there have been times I was too busy getting drunk, and late, late nights, long hours of enjoyment, but it took a toll on my body. But there have been times I remember thinking “I can't be bothered with the drugs anymore…the side effects are destroying my nightlife.”” (Billy).

“I was working in the hospital then too, so, I didn’t really want to have any side effects – it would affect my work.” (Blake).

Changes in daily routine

“It’s very difficult when my routine’s changed, like today coming up here. It’s different from my normal routine, and that’s when I miss a dose.” (Billy)

“I'd just get busy, and if I was doing anything that was outside my normal routine, or if my routine was changed for some reason, or I got distracted, you know, like, um, the phone rings, or, I don't know, the dogs have to get put outside, that’s when I start to miss some doses.” (Jessie).

Fatigue associated with chronic daily medication

“You start out really, really well, and you take them every day, then, all of a sudden, you think, “ooh, did I take that yesterday?” I don't know what that’s about, because you'd obviously think that the longer you do it, the easier it would get… you'd get into your groove, eh, but, um, more often than not these days I think to myself when lunchtime comes, or 2 o'clock. I think, have I taken those pills (Finley).

Facilitators to ART uptake and adherence (realised)

Good relationships with clinicians, pharmacists, support services, and community

“I have a good specialist. You know, he is very good. There was a time when I got depressed and I didn’t take my medication, and then I got sick. And, so, he put me in hospital and looked into my medication, and got me back on track. I also have good support from [support service provider], So, yeah, I have a good wraparound service. Which is good.” (Alex)

“The people I keep in touch with are really, um, supportive when I’m struggling [with adherence]. You’ve got the men’s retreats, and the women’s retreats, which is a unique thing for our community because it’s so small, and we’re so, um, connected.” (Drew)

Availability of medication at wider range of pharmacies and home delivery

“Just having them delivered, having the medications delivered is helping. There used to be only one pharmacy I could go, way across town, but now they deliver, a courier delivers straight to my house.” (Blake).

Blister packs

“[I had] all this sort of anxiety around medication, it was huge. You know, it would really trigger me off. So that was quite upsetting. In the end, the specialist said, “oh, if you go to this particular pharmacy, you can get your medications in a blister pack.” …That made a *huge* difference. Now I know, you know, like, I just check my blister pack, then I'd know I've taken that one or not. And I wouldn’t worry about it – I could just leave it. And it was, that was quite life-changing, actually.” (Casey).

Facilitators to ART uptake and adherence (imagined)

Long-acting injectables

“If that 6-monthly injection could be available for me – I want it. Today! It would be a game changer, mate. It would be a game changer on so many levels…injectables over edibles… definitely.” (Jordan)

“[Injectables] has been a big topic of discussion recently with a lot of the women that I keep in touch with, and everybody wants it… For those that struggle with adherence, like I have myself, it definitely would be amazing. Like, set and forget.” (Jessie)

More information/support about ART

“I always thought… because my specialist kind of put the fear of God in me that “if you don’t take your medication on time, then, you know, that's bad.” …but someone sort of sat down at a women’s retreat one day and explained to us the how the medication actually works, and that it kind of slowly leaves your system over a period of time. And even if you were to take your medication, like, 2 days late, or a day late, there still would be a little bit of medication in your body, and that's, you know, you can take it 3 or 4 hours later one day; you don’t have to take it at 9 o'clock every morning. And that made a huge difference, I think, to a lot of women too, knowing that, that fear around, you know, maybe if I go to work and I forget to take my meds, I can still take them after work. And it’s not going to be, like, “oh, my God,” you know, like, the shit’s going to hit the fan because I haven’t taken them… but it’s a fine line between knowing that it’s OK to take them a little bit later but not having that complacency that…”(Casey)

App-based solutions

“But even if there's like a, I don't know, apps – I’m sure there's probably an app thing that would send you a little reminder or something, that might help.” (Jessie)

“Maybe an App, because we’re all on phones these days. It’s a hard call. I mean, do we turn to technology to help us bridge that gap of reliability with our new habits, or do we look to ourselves and hope that we are just adult enough to be able to maintain and manage a regime… probably a bit of both.” (Jordan)

Remove stigma and discrimination

“We, the community, are kind of left with the task of educating and sorting out the stigma and that, I find that frustrating…I’m not blaming the people that have the reaction, because I can understand that, I'd probably be freaking out too…I mean, you get stigma, and then you get self-stigma, so I understand. But you know, like, we’re 2024 now, this isn’t good enough…so um, yeah, if others don’t have to experience [stigma] like I have, that would definitely help [with adherence].” (Casey)

Concluding thoughts

- Participants in this study identified a range of barriers and facilitators to ART uptake and adherence in Aotearoa New Zealand.
- Better understanding these barriers and facilitators could help Support Services improve their support for those struggling with treatment uptake and adherence, and guide Infectious Disease Clinicians in the management and care of their patients.
- Strong appetite for long-term injectables, so continued advocacy for this to be funded and widely available, could lead to improved uptake and adherence.

Ngā mihi maioha!

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