



Young people and self reported adherence to antiretroviral therapy: A HYPnet survey

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Introduction

During the early stages of developing these guidelines, the writing group felt that it would be very valuable to get information from young people themselves about taking antiretroviral treatment. A self reported adherence questionnaire was designed to collect treatment adherence information from young people living in the UK who were currently on HAART. This was a project that involved collaborative working between multidisciplinary professionals and voluntary sector representatives who work closely with adolescents and young adults living with HIV. The broad aims of the adherence questionnaire were as follows:

1. To gain a better understanding of how young people are currently adhering to their HIV treatment.
2. How many young people are familiar with the blood tests that assess how effective their treatment is
3. What strategies young people already have in place to help them to take their treatment
4. What they identify as being barriers to treatment adherence (if any)
5. What their views are about what might help them to adhere to their treatment (if any)
6. A snap shot of how important this is for them currently
7. How confident they feel about managing to adhere to treatment currently.
8. Does peer support help with treatment adherence

Summary data was presented at the BHIVA spring conference in 2011 is discussed in more detail in the following article.

Young people and self reported adherence to antiretroviral therapy: A HYPnet survey BHIVA 2011 [P169]

McDonald S, Levitt D, Tanner N, Griffiths J, Foster C.

Background: Cohort studies have shown that young people (aged 12-24) living with HIV, infected either perinatally or sexually, have poorer adherence to highly active antiretroviral therapy (HAART), resulting in reduced rates of optimal viral suppression (VL <50 c/ml) when compared to either adults or younger children. As part of a wider collaborative approach to developing adolescent adherence guidelines on behalf of HYPnet, a self report questionnaire was designed to collect treatment adherence information from young people currently on HAART.

Methods: An adherence questionnaire designed by multidisciplinary health professionals and voluntary sector representatives was piloted by two HIV positive young people, gained ethical approval and was distributed to 28 hospitals and voluntary sector sites across the UK between September 2009 and March 2010. Participation was anonymous, voluntary and inclusion criteria included: age 12-24 yrs, HIV infected (any route of transmission), aware of status and currently on HAART. Completed forms were returned by post.

Results: 138 young people responded from 14 sites, median age 16 yrs (IQR 15-17). Of participants responding to each question; 67/111 (60%) were female, 50/96 (52%) were born abroad and 95% were living with family. 83/131 (63%) self reported good adherence defined as >95% HAART doses taken in the last month. 79/138 (57%) reported their latest VL result, 41 (52%) with a VL <50 c/ml. 72/138 (52%) reported a CD4 count, 52% with > 350 cells/mm. Of HAART regimens taken: 67% once daily, 59/136 (43%) 4+ pills/day and 76/135 (56%) had been on HAART > 4 yrs. Factors identified as supporting adherence: reminders from family/carers (45%), peer support (45%), memory aids (35%), regular routine (27%) and health benefits (20%). Barriers included: forgetting (46%), too busy with other activities (28%), keeping HAART secret from friends/family (17%), side effects (14%), pill fatigue (14%) and a daily reminder of HIV (9%). Reported views on what might further improve adherence were; once daily regimens (35%), less (34%) and smaller pills (24%), no side effects (21%), being able to share with friends (12%) and talking to someone else on HAART (8%).

Conclusion: Despite increasing independence associated with adolescence, the role of the family remains as important as that of peers in supporting adherence for this cohort. Stigma and secrecy remain a barrier to adherence for one in five of the young people surveyed.

Methods

Ethical considerations: The questionnaire and an outline of the aims were discussed with Imperial College Healthcare Research Ethics committee. They concluded that this was a voluntary anonymous survey to support the development of guidelines which were aiming to improve patient services. They concluded that it did not require ethical review by NHS Research Ethics Committee.

A self reported adherence questionnaire was designed to collect treatment adherence information from young people living with HIV (YPHIV) in the UK who were currently on HAART. This was a project that involved collaborative working between multidisciplinary professionals and voluntary sector representatives who work closely with adolescents and young adults living with HIV.

Pilot questionnaire: An initial questionnaire was piloted by two HIV positive young people (aged 17 and 18 years old). They both reported the questionnaires were easy to follow, relevant and did not take up too much of their time. Based on these findings the questionnaire was distributed to all collaborating centres.

Contacts of health care professionals working in HIV paediatric and young person clinics, the community and voluntary sector were primarily found through HYPnet. A named person was allocated to each site and a letter outlining the project along with the questionnaire was sent via email to each individual site. 28 sites were contacted across the UK between September 2009 and March 2010. Participation was voluntary and anonymous. Inclusion criteria included: age 12-24 years, HIV infected (any route of transmission), aware of HIV status and currently on HAART. Completed forms were returned by post.

Results

A total of 138 young people responded, from 14 different sites, median age 16yrs (IQR 15-17).

Demographics:

Age (yrs)	12-14	15-17	18-24
	36/138 (26%)	53/138 (38%)	49/138 (36%)
Gender	Male	Female	
	44/111 (40%)	67/111 (60%)	
Birth place	UK	Abroad	
	46/96 (48%)	50/96 (52%)	
Living situation	Family	Friends/flat share	Living alone/other
	112/135 (83%)	9/135 (7%)	14/135 (10%)

Treatment regimen related questions:

1. How long have you been taking HIV treatment for? 133/138 responses

- don't know 15/133 (11%)
- less than 6 months 9/133 (7%)
- 6 months – 1 year 3/133 (2%)
- 1-2 years 4/133 (3%)
- 2-4 years 28/133 (21%)
- 4-6 years 13/133 (10%)
- 6-8 years 11/133 (8%)
- over 8 years 50/133 (38%)

2. How many times a day do you take HIV treatment? 137/138 responses

- once a day 91/137 (66%)
- twice a day 44/137 (32%)
- more than twice a day 2/137 (2%)

3. What kind of treatment do you take? 135/138 responses

- tablets/capsules 130/135 (96%)
- liquid 1/135 (1%)
- both 4/135 (3%)

4. How many HIV tablets/capsules do you take a day? 136/138 responses

- one 33/136 (24%)
- two 14/136 (10%)
- three 30/136 (22%)
- four 15/136 (11%)
- five 26/136 (19%)
- six 7/136 (5%)
- seven 2/136 (1%)
- eight or more 9/136 (6%)

5. Do you take your HIV treatment? 136/138 responses

- with or just after food 60/136 (44%)
- no food 23/136 (17%)
- sometimes with/after food 53/136 (39%)

6. Do you use a PEG tube (tube in your stomach) for treatment use?

133/138 responses : Yes 1/133(1%)

7. Have you ever used a PEG tube (tube in your stomach) for treatment use? 131/138 responses: Yes 6/131 (5%)

Treatment interruption.

1. Have you ever stopped taking your HIV treatment? 126/138 responses

- Yes 53/126 (42%)
- No 73/126 (58%)

2. If your answer is yes, the last time you stopped, how long did you stop for? 61/138 responses

- less than 3 months 21/61 (34%)
- 3-12 months 9/61 (15%)
- more than 1 year 19/61 (31%)
- don't know 12/61 (20%)

3. Why did you stop treatment? 64 /138 responses

Doctor stopped it 17/64	Fed up taking treatment 16/64	Didn't want to take it 12/64
Treatment side effects 11/64	Don't know 9/64	Too many pills 6/64
Felt well 5/64	Didn't think it was helping 2/64	Part of a trial 2/64

Additional comments:

" VL was undetectable"
"To ill to take x2" NG tube at present
"CD4 count was high"
"Thought and still think that Christ is my healer and has healed me"
"Feeling depressed. There are times when you don't feel like taking them because you feel well and when you take them you feel ill"
"I had problem taking them. I don't feel comfortable"
"Homeless"
"Tablet size I chose not to take them"
"Forgot"
"Felt I had nothing to live for"

Adherence related questions

1. How many times have you missed taking your HIV treatment in the last week (per dose not per day). 131/138 responses

- did not miss any 78/131 (60%)
- one dose 20/131 (15%)
- two doses 9/131 (7%)
- three doses 3/131 (2%)
- four doses 4/131 (3%)

- don't know 17/131 (13%)

2. How many times have you missed your HIV treatment in the last month? 132/138 responses

- did not miss any 56/132 (43%)
- one dose 20/132 (15%)
- two doses 12/132 (9%)
- three doses 12/132 (9%)
- four doses 3/132 (2%)
- more than 4 doses 3/132 (2%)
- don't know 26/132 (20%)

Good adherence based on > 95% adherence rates (Paterson et al 2000) worked out based on daily or twice daily regimen.

- >95% adherence 82/132 (62%)

Immunology/virology assessing treatment effectiveness.

1. If you know your latest viral load result please choose from the following: 127/138 responses

- don't know 48/127 (38%)
- I< 50 (undetectable) 52/127 (41%)
- 50 – 1000c/ml 18/127 (14%)
- more than 1000 c/ml 9/127 (7%)

2. If you know your latest CD4 count result please choose from the following 129/138 responses

- don't know 57/129 (44%)
- less than 200 26/129 (20%)
- 200-350 cells 12/129 (9%)
- more than 350 34/129 (27%)

Treatment strategies and barriers to adherence.

1. What helps you to take your HIV treatment? Please tick as many as apply: 135/138 respondents

Parent/carer reminds me 59/135	Nothing I just always remember 58/135
Having a routine 38/135	I know it helps me look after my health 27/135
Pill box 22/135	I keep them in a place that reminds me to take them 21/135
	Brother/sister reminds me 19/135

Mobile phone 20/135	
Having a specific goal 8/135	Other alarm system 6/135
Carry them with me all the time 6/135	Friends remind me 4/135
Staff and the clinic remind me 3/135	Having a plan developed with the staff at the clinic 1/135
Home visits from nurse/social worker 0/135	Adherence diary 0/135

Additional comments:

"Tired at night so dad reminds me"
"If the side effects are not so bad I don't feel ill"
"Bedtime - like doing your teeth"
"Persistence"

Reminders from family/carers (parent/carer/brothers/sisters) 63/135 (47%)

- Parents/carers 44/63 (67%)
- Brother/sister 4/63 (6%)
- Both 15/63 (24%)

Reported adherence support memory aids for 49/153 (36%) included pill box, "place reminds me", mob phone, other alarm, "carry with all time"

**2. If you missed treatment doses, why do you think this happened?
Please tick as many as apply. 134/138 Responses**

Forgot 64/134	Busy with other activities 39/134
Did not miss any 24/134	I was with family/friends 24/134
I did not have the treatment on me 20/134	Side effects 20/134
Fed up taking treatment 19/134	Treatment reminds me of HIV 13/134
On school trip 12/134	Treatment makes me feel different 11/134
Don't know 10/134	On holiday 7/134
	Difficult to take treatment when well 5/134

I don't want to take this treatment 7/134	
It doesn't matter if you miss doses 2/134	People were nagging me too much 2/134
Not sure why I am taking this treatment 2/134	Don't believe in taking HIV treatment 1/134
I don't think this treatment helps 1/134	My family don't encourage me to take the medication 1/134

Additional comments:

" Missed 1 dose because fell asleep early, unsure about whether developing a plan with staff in clinic"
" Side effects - bad dreams"
" Rushing for school"
"The smell of the medicine affects the mood but I try hard to take it because it helps me a lot"
"Just do want to do so "but only once"
"Fell asleep (take first thing in the morning if possible)"
"Can't be bothered sometimes"

3. What do you think could be helpful taking your HIV treatment better? (please tick as many as apply) 127/138 responses

Treatment once a day 48/127	Less tabs/caps 47/127
Smaller tabs/caps 33/127	If I didn't have to keep them a secret 32/127
No side effects 29/127	If I was able to share this with my friends 17/127
Somebody to remind me 13/127	Text reminder 12/127
Talking to somebody else who takes this treatment 11/127	Having my own goal 11/127
If I could see the benefits 10/127	If I understood better why I was taking it 5/127
If I could develop a plan with a family member 3/127	Visits at home from my nurse 2/127

If somebody gave it to me everyday 1/127	Developing a plan with staff from the clinic I attend 0/137
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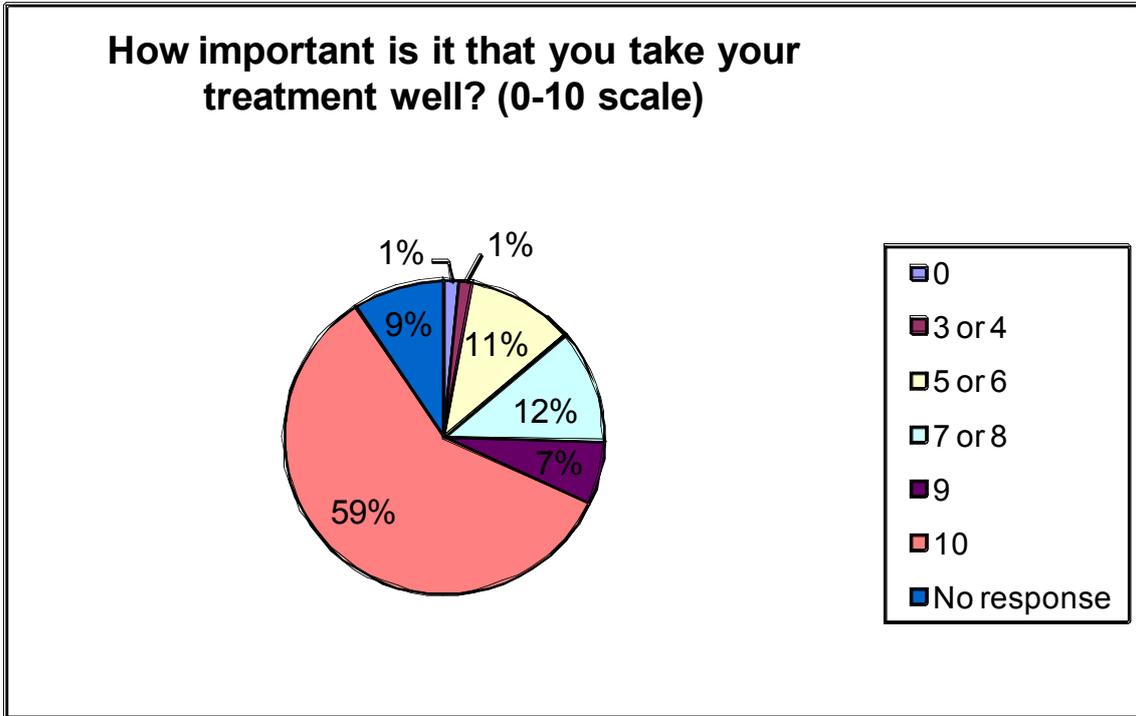
Additional comments

"Don't know"
"Being in charge"
"None of the above it's just normal now"
"I don't know really, I like the challenge, every day's a victory, peer support has given me insight"
"Smaller pill box"
"Treatment once a week/month"

Importance and Confidence scales

1. On a scale of 0-10, how important is it to you that you take your treatment well. Please circle 125/138 responses

(0 – not important 10 – very important)

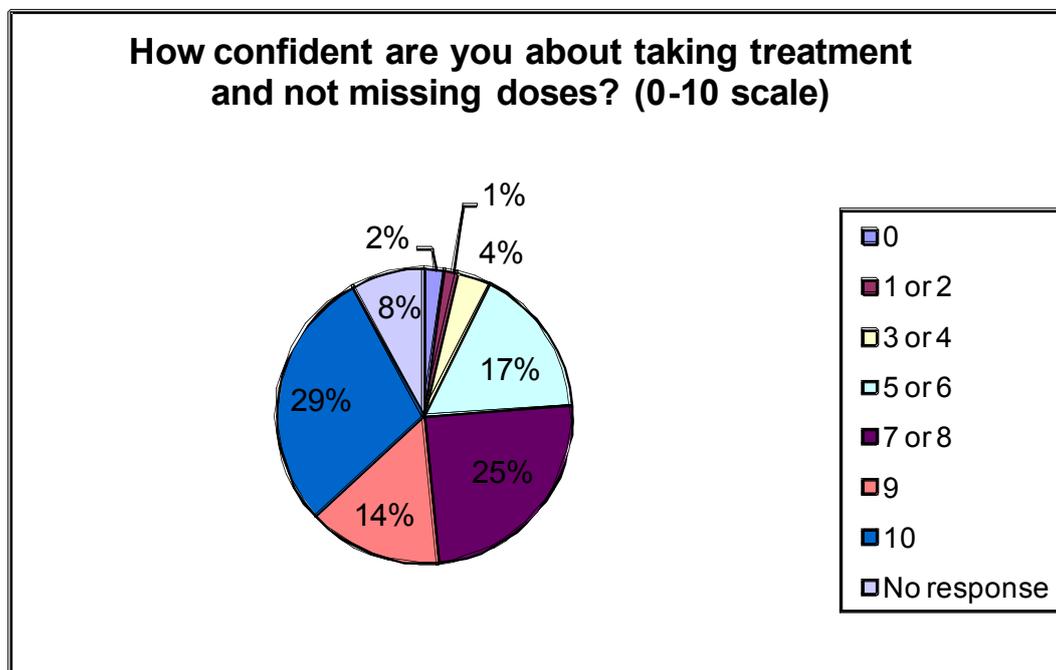


Additional comments:

"It's my life; treatment and my health is my number one priority"
"Not very coz I'm going to die anyway"

2. On a scale of 0-10, how confident do you feel at this time about how you are managing to take your HIV treatment and not miss doses?
Please circle 127/138 responses

(0 – not confident 10 – very confident)



Peer and community support

1. Do you access any peer support groups (meeting other HIV positive young people) such as teen spirit or positive vibes? 122/138 responses

- Yes 56/122 (46%)
- No 66/122 (54%)

2. If you have ever attended peer support do you think going to a group and meeting other HIV positive young people has been helpful for you? 98/138 responses

- Yes 68/98 (69%)
- No 30/98 (31%)

3. In peer support, do you think talking to other young people who are going through similar things has helped you in terms of taking your treatment? 97/138 responses

- Yes 62/97 (64%)
- No 35/97 (36%)

Additional comments:

“Peer groups reminds me of HIV”

“Not for me personally as I am comfortable with my status. I haven't been but I think it is very useful to be able to speak to someone”

4. Do you have a nurse that visits you at home? 130/138 responses

- Yes 19/130 (15%)
- No 111/130 (85%)

Conclusion

Despite increasing independence associated with adolescence, the role of family remains an important factor in supporting adherence. Simply forgetting medication was the commonest cause of poor adherence, although stigma and secrecy remain barrier to treatment for one in five.

Once daily therapy with fewer and smaller pills was perceived as being important to this group. Peers have been identified as a means of adherence support for two thirds of those who access such groups.

