Expectations of perfect adherence: a qualitative study to explore treatment failure amongst Malawian adolescents living with HIV

R. Burns[1], D. Magalasi[2], T. Zimba[2], R. Keango[2], T. Kalua[3], P. Blasco[4], E. Szumilin[4], B.Schramm[1], E. Pasquier[4], A. Wringe[5]

1. Epicentre, France, 2. Médecins sans Frontières, Malawi, 3. Ministry of Health, Malawi, 4. Médecins sans Frontières, France, 5. London School of Hygiene and Tropical Medicine, UK

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Depiction of a young person with HIV drawn by a study participant

Background and aims

- Very high rates of 1st line treatment failure (~30%) among ALHIV in Chiradzulu, Malawi despite a well-supported HIV treatment programme and good outcomes among adults.
- Limited evidence base for developing programmes to support adolescents' ART adherence.
- Knowledge gap: How social and contextual factors shape treatment adherence from the perspectives of young people and their carers

Overall aim: To explore how individual, social and programmatic factors influence ART adherence among ALHIV in order to inform adherence-promoting interventions

This analysis aimed to explore the social interactions of ALHIV within the clinic, at home and in the community and consider how these influence their adherence to ART

Methods: data collection

Method		Male	Female	Total
In-depth interview (IDI)	ALHIV (2 IDI each)	8	8	16
	Caregivers	4	12	16
	Community persons of influence	7	0	7
	Health workers	5	1	6
Group activities using	Adolescents of unknown status (6 grps)	22	21	43
participatory methods	ALHIV (2 grps)	4	7	11
	TOTAL	**50**	**49**	**99**

Methods: data management and analysis

- Recording, transcription and translation of interviews and group discussions
- Other data included: photos of output from group activities, fieldworker diaries and observations in health facilities, social events
- Data were inductively “coded” to categorise the emerging concepts and themes from the data
- Thematic analysis to understand the relationships between the codes
- Ethical approval was obtained from NHSRC (Malawi) & LSHTM (UK)

Findings

- ALHIV: generally very good knowledge about HIV & ART; good adherence intentions.
- But their intentions were sometimes undermined by social norms and expectations of young people in **HIV clinics, at home, and in the community**
- In each setting, adolescents' behaviours were regulated by strict rules and obligations with threats of negative consequences, disciplinary action or punishment for non-compliance.
- Attempts to exert control over ALHIVs behaviours in these settings could undermine their adherence intentions.

In health services

- Health messages focused on ART “rules” and need for very strict adherence
- Counselling focused on treatment literacy, and sometimes “testing” patients for “mistakes” in their knowledge.
- Consequences of poor adherence sometimes overstated by health workers
- Many patients appreciated health workers’ support to adhere, but some reported being scolded or chastised which undermined care engagement.

For example the medicine is supposed to be taken at 6:15 and instead one takes at 6:30. The medicine in this case does not work properly and the viruses keep on multiplying and the medicine does not work at all …..

[Caregiver at orphanage]

Other doctors are better off but the kind we have drawn, are those ones [that] cannot manage to stay for 10 minutes [while] explaining to them about your problems. They would even shout at you for delaying them…..

Drawing of a doctor by ALHIV

In health services

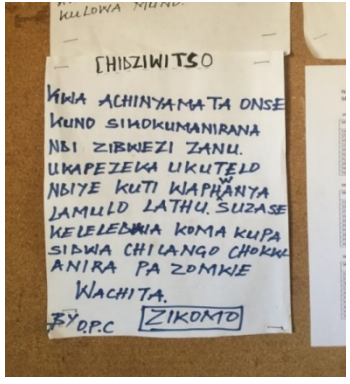
- Little opportunity to frankly discuss adherence challenges or potential solutions with health workers.

…a patient came and …he was told the names of the medicine but it was not enough. I wish [healthworker] could try to encourage the patient other than just giving medicine names. I wished he could engage the patient in a dialogue.. ask the patient how he is feeling and how he thinks the medicine will work .. And even involve him in deciding the best time to take the medicine.' (ALHIV, male)

- Some measures to improve adherence deemed punitive: e.g. additional pill-counts, longer waits, extra appts etc

if you come and get medication for 2 months in advance they would deliberately give you medication worth only a month so as to punish you ..so we end up wasting transport money and other costs (ALHIV, male)

- These attitudes were also reflected in other services e.g. so-called "youth-friendly" clinics



Notice on youth-friendly clinic door

NOTICE: To all youths, this is not a meeting place for you and your lovers. If found doing that, then you have broken our law. You will not be tolerated, but given a punishment proportional to the crime you committed. Thanks **By OPC**

At home

- Caregiving arrangements often fluid, precarious
- Children often instructed to hide pills from siblings; fears of disclosing parents' status.
- Caretakers rarely engaged in conversations about HIV reinforcing it as shameful.
- Dose reminders often directive; sometimes with threats, reprimands, punishments. Led to hiding missed doses, throwing away pills
- Contributed to feelings of isolation, anxiety, confusion, self-stigma which undermined pill-taking

Can you tell me where you hid the medicine? *Okay this is how I hide, there is a drum and inside that drum there are .. books and that is where we get these chairs and so no one will be interested to remove all those things in such a place, I also place the mattress on top .. no one will step a foot in there.* (Caretaker)

Like when I come late I would find everyone asleep …so sometimes I would take and sometimes I would not take [ART], sometimes I would just shake the bag so that they would think that I have taken..when I had not taken anything. (ALHIV, male)

Wider community

- Influential community members often held strong views about young peoples' social lives and adherence behaviours
- Many expressed responsibility to address stigma or encourage adherence to ART
- Far-reaching powers to influence and regulate social behaviours:
  - E.g. *imposition of curfews, fines, organisation or cancellation of social events such as football matches, dances*
- These attempts sometimes served to undermine adherence

There others who when they take the medicine and see that they are good, they stay without taking medication, they just stop. So when we find such things we give them a threatening advice that if they do that, they won't be received at the hospital and also we won't write those letters….
(Community member)

Discussion

- **Good adherence intentions among ALHIV often undermined by:**
  - inability to conform to unnecessarily strict rules and expectations of perfect adherence
  - fear of consequences if seen to be non-adherent in social settings
  - lack of safe spaces and opportunities to talk about HIV, ART and pill-taking strategies
- **Interventions should :**
  - Occur where pill-taking occurs: in the home ***e.g. home visits***
  - Be family-focused; support family disclosure, address stigma: ***social workers, counsellors***
  - Move beyond ART literacy, include problem-solving, build resilience ***e.g. age-specific peer clubs, counselling cadre***
  - Ensure health worker training on messages, counselling style, disclosure processes
- **Revised model of ALHIV care is under development in Chiradzulu**
- Key strengths: range of perspectives; limitations: social desirability bias

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