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## Background

- Over 2 million adolescents living with HIV (ALHIV) in sub-Saharan Africa<sup>1</sup>
- 50% increase in HIV deaths among ALHIV between 2005-12 due to poor antiretroviral therapy (ART) access and adherence<sup>2</sup>.
- Growing recognition that ALHIV adherence is shaped by social factors including caregivers’ support<sup>3</sup> but, few studies consider how caregiving dynamics are influenced by social circumstances (e.g orphanhood) and the consequences of caring for ALHIV (e.g stigma, financial costs).
- Caregivers are often overlooked from interventions that are designed to support adherence among ALHIV

**Aim: To explore the interplay between caregiving dynamics and ART adherence among ALHIV in rural Malawi**

## Study setting

- Chiradzulu District, southern Malawi; HIV prevalence 17%. Most residents engage in farming, petty trade.
- Medecins sans Frontieres supporting the Ministry of Health to provide HIV care in 11 facilities including 1150 ALHIV on 1<sup>st</sup> line ART.
- Virological failure estimated at ~31% among ALHIV on 1<sup>st</sup> line ART > 6 months<sup>3</sup>
- ALHIV guidelines recommend incremental HIV disclosure with full disclosure by age 12



Photos: The study setting and HIV clinic in Chiradzulu

## Methods

- Repeated in-depth interviews (IDI) with 16 ALHIV on 1<sup>st</sup> line ART and IDI with 16 caregivers (see table 1)

Variables	Category	Total
<b>ALHIV (n=16)</b>		
Age (years)	10-13	7
	14-16	4
	17-19	5
Sex	Girls	8
	Boys	8
Viral Load	Detectable	10
	Undetectable	6
<b>Caregivers (n=16)</b>		
Disclosed to ALHIV	Yes	8
	Partial	8
	Relationship	
	Parent	9
	Relative	6
	Other	1

- IDIs covered ALHIV and caregiver experiences of ART, caring and HIV disclosure.
- IDIs recorded, transcribed, translated into English.
- Data coded inductively and analysed thematically.
- Ethical approval from the National Health Sciences Research Committee (Malawi) and LSHTM (UK)

Table 1: Participant characteristics

## Conceptual perspective

We draw on Kleinman’s theory of social suffering<sup>4</sup> as a lens through which to explore how:

- Adherence can be viewed as a product of socioeconomic and sociopolitical circumstances which are often dire for ALHIV
- The family, viewed as a social institution, has potential to support or undermine ALHIV’s adherence;
- Caregivers may also suffer through the burden of caring for ALHIV which may further undermine young peoples’ adherence

## Caregiver-adolescent relationships influence adherence behaviours

The nature of the caregiver-adolescent relationship in turn influenced their adherence to ART:

- Supportive relationships with caregivers facilitated pill-taking:

*can you also explain how you as the mother help her? Alright, we help this child in various ways encouraging her to work hard in school and...in terms of adherence to medication and telling her how she got the virus ...and being open with her so that she knows. And we tell her that if she is suffering from illness she should let us know so that we can help (caretaker)*

*Because when your parents are taking part, it becomes so easy..... (ALHIV)*

- In contrast, when caregiving relationships broke down, ALHIV were susceptible to feelings of anxiety and stress. Those with precarious living arrangements, multiple caregivers and little emotional support often experienced challenges in adhering to ART.

*R: Yes because there was a time when he stopped taking the medicine and this will be like the second time. T: hmmm, why did he stop?*

*R: Problems with the shortage of food, lack of proper care.... So it is like he just threw his life away and he says I should just die and a lot of other things. Hee I should just die, you do not give me food, and all sorts of things (caretaker)*

- In turn, poor adherence further undermined caregiving relationships

*His siblings just left him since he was not listening to them when they said that “you should remain here and be taking your medicine right here (caretaker)*

## Results

### Social circumstances and the responsibility of care for ALHIV

The social circumstances surrounding the ALHIV-caregiver dyadic were instrumental in shaping caregivers’ attitudes towards care:

- Responsibility for orphaned ALHIV was often perceived as a drain on time or financial resources:

*I can’t say that I can take a good care of him.. the way I live here its hard ... I have nothing, and so I think to myself: what if I take him? But then what am I going to give him? I already have 4 other children...(caretaker)*

- The caregivers’ HIV status also influenced the disclosure process and could represent an emotional burden. For some parents, a sense of guilt about the child’s infection could hinder disclosure. Conversely, many HIV-negative caregivers did not know how to broach the topic:

*“Ok was the child told that she had the virus? No, but now she knows that she takes the medicine but she has not been told...Aaah I just feel like she got a sense about it when taking the medicine. But still now..I don’t know what to say - it [HIV] is hard to explain (caretaker)*

- However for some ALHIV with HIV-infected caregivers, disclosure was facilitated by the shared experience of pill-taking:

*D; So the time that you were explaining to her this news (disclosure), how did she react?*

*R: She didn’t get sad because she was also seeing me taking medicine, so she wasn’t upset (caretaker)*

- Caregivers HIV status also impacted on HIV stigma in the household: some ALHIV were told to hide their HIV status and pills in the house to prevent deductive disclosure of the parents’ status.

## Discussion

- Social circumstances underlying caregiving arrangements and their social consequences influence the caregiver-ALHIV dynamic which in turn influences adherence (figure 2)
- Caregivers were often poorly resourced to manage the responsibility that caring for an ALHIV entails which undermines adherence.
- Counselling for caregivers should address guilt, emotional burnout, and offer support with disclosure, communication and care for ALHIV.
- Family-level interventions, including home visits by lay or professional counselors may support ALHIV and caregivers and improve adherence.

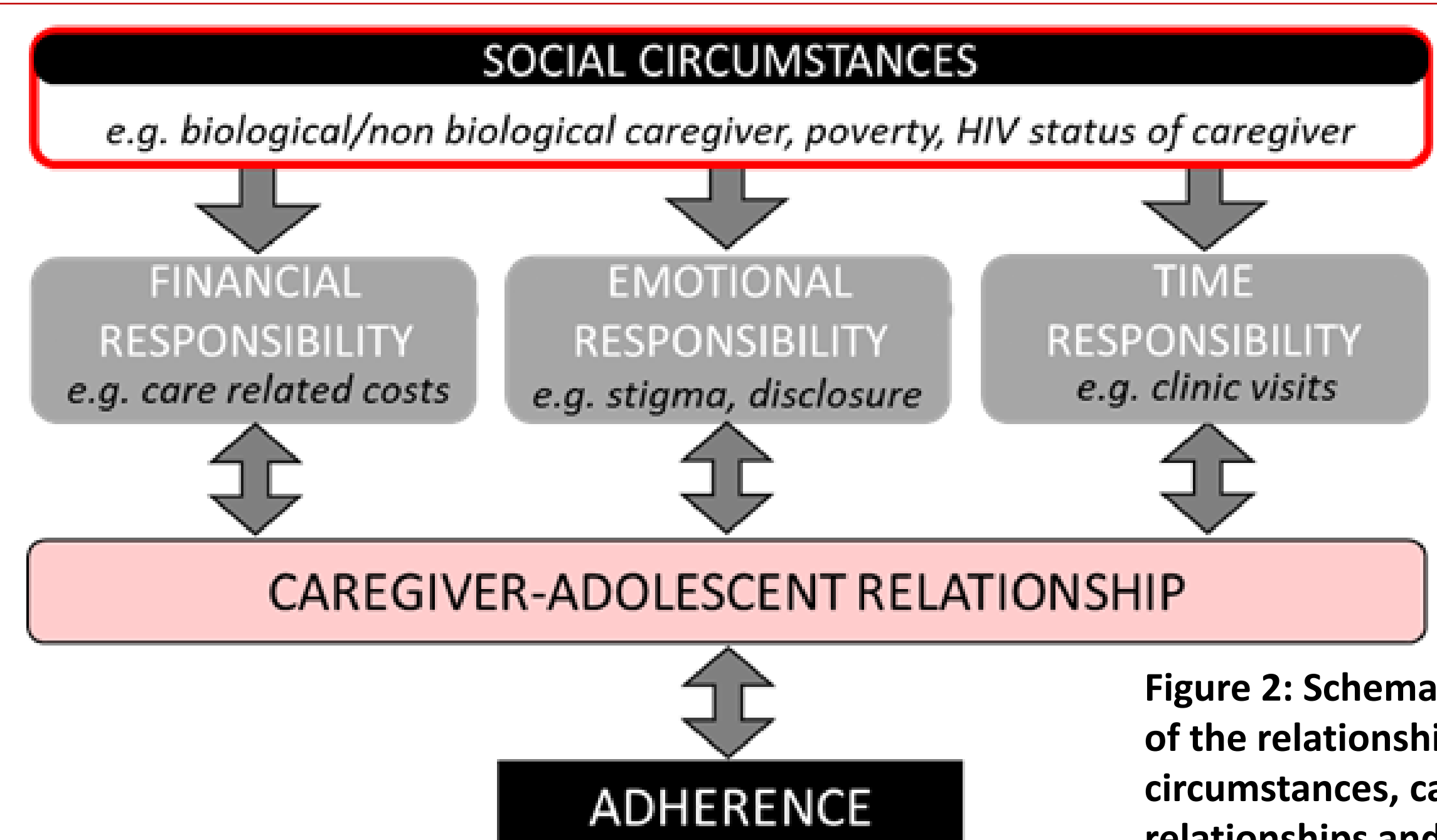


Figure 2: Schematic representation of the relationship between social circumstances, caregiving relationships and ALHIV adherence.