



Conceptualising adolescent HIV self-management in a South African context

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Goals and objectives

- ▶ Session goal

- ▶ To provide the background, methods and findings of a qualitative study that aimed to conceptualise adolescent HIV self-management in a South-African context

- ▶ Session objectives: To

- ▶ Provide a background to the study
 - ▶ Explain the study methods
 - ▶ Present and discuss the study findings

Adolescence

- ▶ Latin *adolescere* – to grow up or to grow into maturity (Lerner & Steinberg, 2009)
- ▶ Development: Cognitive, psychosocial and moral
- ▶ World Health Organisation defines as age 10 – 19 (WHO, 2014)



Self-management

- Behaviours and/ or processes that patients (adolescents) engage in (individually or in collaboration with caregivers or health workers) that will contribute to their health, well-being and control of their chronic condition (HIV) (Sattoe et al., 2015; Webel et al., 2012)



Adolescence vs self-management: is it possible?

- ▶ Adolescents have the ability to exercise agency in order to achieve health and well-being (Skovdal & Daniel, 2012)



Background

- ▶ Many adolescents living with HIV in South Africa (15% of global population, approx. 300 000) (De Wet, Oluwaseyi & Odimegwu, 2014; UNICEF, 2013)
- ▶ Most acquired HIV perinatally and are on ART since childhood
- ▶ Challenges of managing HIV related problems as well as physical, and psychological changes during adolescence (Mofenson & Cotton 2013)
- ▶ HIV a chronic condition for people who access ART
- ▶ Self-management important component of chronic care (Modi et al. 2012)

Rationale

- ▶ Adolescents living with HIV in low resource settings are exposed to various context specific issues (Agwu & Fairlie 2013)
- ▶ Knowledge of how adolescent HIV self-management is realised in this context may help clinicians to tailor interventions to their needs
- ▶ Evidence indicate that self-management is associated with clinical outcomes such as treatment adherence and quality of life (Modi et al.; Schilling et al., 2009)

Research problem

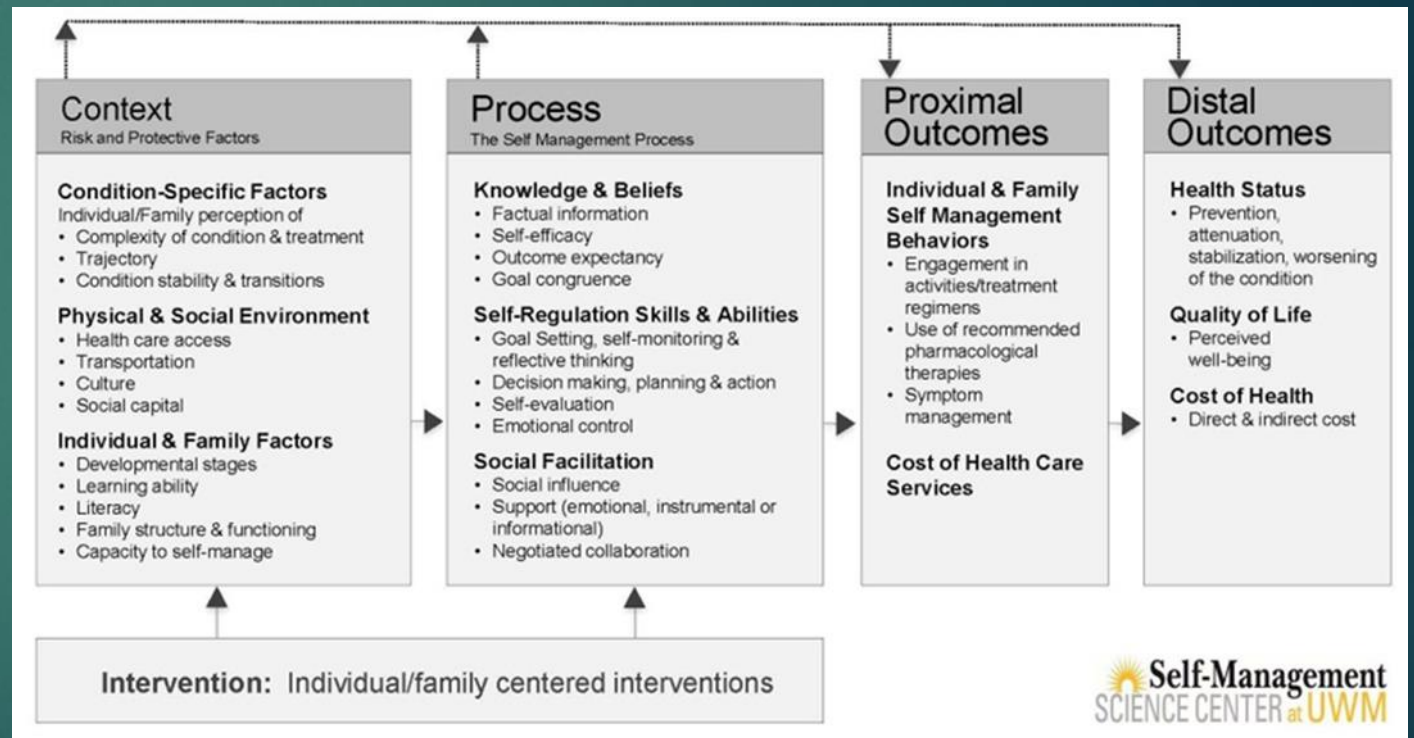
- ▶ Little is known about the healthcare needs of adolescents living with HIV in low resource, high HIV burden settings
- ▶ Adolescent-specific care is lacking
- ▶ Treatment adherence during the adolescence period is problematic

Objective

- ▶ To explore the realisation of adolescent HIV self-management from the perspectives of adolescents, caregivers and healthcare workers in a South African context

Theoretical underpinnings

- ▶ Ecological Systems Theory and Bioecological Model (Bronfenbrenner, 1979; 1994)
- ▶ Stages of Development (Ericson; Piaget; Kohlberg)
- ▶ Individual and Family Self-management Theory (Ryan & Sawin, 2009)



Methods

- ▶ Qualitative interpretive (hermeneutic) phenomenological design
- ▶ Setting & population: Cape Metropole, Western Cape, South Africa
- ▶ 1 962 adolescents between the ages of 13 and 18 on ART and receiving care at primary health care clinics in the Cape Metropole



Population & sampling

- ▶ Purposive sampling – two healthcare facilities: one hospital, one community health clinic that have adolescent services
- ▶ Individual interviews: 6 adolescents aged 13 to 18; 6 caregivers; 6 health workers
- ▶ Focus groups: Five adolescent focus groups of 5 – 9 adolescents in each
- ▶ Total of 56 participants



Ethics & data collection

- ▶ Ethics Committee approval & Department of Health approval
- ▶ Adolescent assent and parental written / telephonic consent
- ▶ Individual interviews and focus groups (Eng/Afr/Xhosa)
- ▶ Field worker to assist with Xhosa speaking participants
- ▶ Separate male and female focus groups for adolescents for 4 of the 5 groups
- ▶ Older and younger adolescents separated
- ▶ Data collection took place from July 2015 – December 2015

Data analysis

- ▶ Software: Atlas ti
- ▶ Steps described by Christ and Tanner (2013)
 - ▶ Early focus and lines of enquiry
 - ▶ Central concerns, exemplars and paradigm cases: engaging with philosophy and theory
 - ▶ Shared meanings: thematic development
 - ▶ Final interpretation



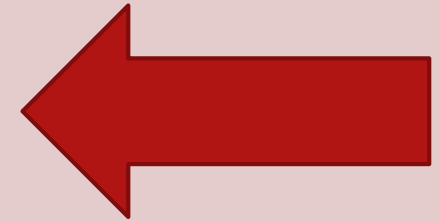
Rigour

- ▶ Trustworthiness
 - ▶ Credibility
 - ▶ Confirmability
 - ▶ Dependability
 - ▶ Transferability



Findings

Themes		Sub-themes
1	Self-management processes and behaviours	<i>Knowing and understanding</i> <i>Believing and valuing</i> <i>Self-regulation</i> <i>Self-management behaviours</i> <i>Coping</i> <i>Communication and disclosure</i> <i>Social facilitation</i>
2	Caregiver challenges	Knowledge and skills; Socioeconomic difficulties; Responsibilities
3	Putting the spotlight on HIV	Stigma; Fears of rejection; Telling lies
4	Health care system	Adolescent preferences; Clinic/hospital functioning; Health care worker attitudes
5	Factors influencing self-management	Disease and treatment characteristics; Individual differences Family context; Health system structure and functioning; Community influences



Knowing and understanding

- ▶ *She must understand how she lives, know that she is HIV+, that should stay in her mind, I don't mean it should disturb her but she must know that she is not different from other people who have illnesses, she must not think that "maybe I'm going to die tomorrow, " but she must care for her health and know that "I'm living like this now."'* [Caregiver 5, mother]
- ▶ *'Yes I know all my tablets, how they look and their names.'* [Female adolescent, focus group 3].
- ▶ *'I think if you are not taking your pills the virus increases in your body'* [Female adolescent, focus group 3]

Believing and valuing

- ▶ *'So nowadays when I take my medication, I don't see myself as different. I am just an individual. Yes, I have to like take these pills, but nothing about me changes. It doesn't change my name, my fingerprints, you know, I'm still the same when I look in the mirror and stuff like that.'* [Male adolescent, focus group 1].
- ▶ *'But the thing is, you feel perfectly normal during the day, and then seven o'clock strikes and you're like okay, I'm different. So you don't drink it because you want to go on living life like a normal person.'* [Female adolescent, focus group 1].
- ▶ *'I do understand but I always have questions when I'm alone, "why me God" I don't blame God, don't make me like that mean childlike. I always like ask why me, why shouldn't be anyone that has this kind of sickness that I have. But in reality I agree that I do have it and it will last forever and ever, until I die.'* [Female adolescent, focus group 2]

Self-regulation

- ▶ *'Adolescents don't tend to think about consequences. If this is what I want, this is what I want to do, I am going to just do it. Only as you get older and you start learning about the consequences of your actions, you tend to get a bit more responsible.'* [Healthcare worker 3]
- ▶ *'I have to be after him reminding him, do you hear that I said he is 15 years now, but I still have to be after him, it was better when he was 10 and younger, he was using it properly, but as he grows I need to be after him all the time.'* [Caregiver 4, mother]
- ▶ *'I said I'm not going to worry now, and they were drinking and so on, I was just talking the whole time there. It was for four days I didn't drink my tablets. I decided I'm not going to worry about it.'* [Female adolescent, focus group 1]

Self-management behaviours

- ▶ *'Because I trust my viral load, so if I don't have a condom right now, I have to get going.'* [Male adolescent, focus group 5]
- ▶ *'Nobody reminds me, I'm used to it, because seven o'clock I know it's my time to drink pills.'* [Male adolescent, focus group 5]
- ▶ *'I have a calendar actually in my cupboard, and every time I write down the date.'* [Female adolescent, focus group 1]

Coping

- ▶ *'There will always be people talking positive and negative things, so you don't have to care too much because you will end up being in trouble, you need to take care of yourself.'* [Male adolescent, 16 years]
- ▶ *'You don't like think about I have HIV and stuff, and then you don't, like when you play, you just don't feel that thing, that pain that you have HIV.'* [Male adolescent 2, 14 years]
- ▶ *'...don't try to kill yourself because you have HIV. I would advise him or her don't try to do drugs, because drugs won't help you. Even if you smoked a lot, drugs won't help you. They won't change the world.'* [Male adolescent, focus group 5]

Communication and disclosure

- ▶ *'These parents do not talk to these children, and these children do not talk to their mothers, she says we last speak here at the clinic and it ends there, we just keep quiet as if nothing has happened.'* [Healthcare worker 4]
- ▶ *'Sometimes I have 2 or 3 girls and see their personalities, what kind of people they are, and start a topic by asking them "what would you do if I could have this thing, one will say "no I would continue dating you because it is not the end of life you'll just need to take care of yourself," others would say "no I would dump you" then you can see that this one good than that one, but that one is more valuable than that one, you can see.'* [Male adolescent 4, 16 years]

Social facilitation

- ▶ *'You stay with people you love, then they will make you happy, then you will even forget that you are HIV positive. So, it's where you gain weight, it's where you gain health.'* [Male adolescent, focus group 5]
- ▶ *'My father will say "my child I'm going out now" and he will go and drink and then he will come back and ask me "why didn't you take your pills" and then hit me.'* [Female adolescent, focus group 3]
- ▶ *'In this group, you can share your feelings, like how do you feel about the illness, and like outside you can't share it because you don't know who to talk to, and people will judge you.'* [Female adolescent, focus group 1]

Conclusion

- ▶ HIV self-management in adolescents is a complex phenomenon
- ▶ Several self-management processes and behaviours were identified and contextualised in a South African setting
- ▶ Based on the qualitative findings, the researcher is currently in the process of developing and validating an instrument to measure HIV self-management in adolescents



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