Poverty reduction strategies in a public health perspective

HIV/AIDS, the disability grant and ARV adherence

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Overview

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- Ramifications of the disability grant for PLWHs
- Disability grant termination and ARV adherence
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Abbreviations

ARV:	antiretroviral
FGD:	focus group discussion
KSPS:	(Khayelitsha) panel survey
KPS:	control panel survey
PLWH:	people living with HIV/AIDS
PMTCT:	prevention of mother-to-child-transmission of HIV
STI:	sexually transmitted infection
ZAR:	South African rand

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Background

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HIV in South Africa

- ✓ 5,7 million people are living with HIV in South Africa
- ✓ Highest HIV prevalence among the black majority of the South African population
- ✓ This group also have the highest rate of unemployment (25,9%) and the lowest per capita income of the racial groups
- ✓ HIV has a gendered face - the burden of HIV affects women disproportionally more than men

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The disability grant

- ✓ South Africa's social security system, such as the provision of social grants, is aimed at empowering people to take active part in the social and economic life
- ✓ South Africa has one of the world's largest non-contributory social security systems
- ✓ Despite high unemployment, this welfare system is premised on full employment, i.e. there is no support system for the unemployed

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The disability grant

- ✓ The disability is intended for people between the age of 18-64 years, who due to mental and/or physical disability, need full time care + people sick with AIDS
- ✓ After 2000, the number of people receiving disability grant has more than doubled, rising to there has been an increase in the use of disability 1,2 million (10% of social grant recipients)
- ✓ This growth is attributable to the increasing number of people sick with AIDS
- ✓ The grant is now 1010 ZAR* per month

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The roll-out of ARVs

- ✓ The roll-out of ARVs through public sector health care have been very controversial in South Africa, but is now on track
- ✓ Prior to the roll-out of ARV many PLWHs accessed disability grants
- ✓ Once on ARVs, many stand to lose the grant as a result of their improved health

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Issues in social services

- Grants does not only support the individual, but the whole household might be dependent of the grants
- This has created a debate about trade-off between access to ARVs and the use of disability grant
- There is a concern that some PLWHs will stop taking ARVs in order to remain eligible to disability grant
- There has been a debate about establishment of a basic income grant

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Main objectives

- ✓ To assess the effect of the disability grant on individual and household welfare
- ✓ To explore whether PLWH reduced or stopped taking treatment to remain eligible or requalify for the grant
- ✓ To explore potential dilemmas in this trade-off from the perspectives of PLWH and health professionals
- ✓ To investigate if women and men had different approaches to HIV prevention and health care in general

Methods & Participants

- In-depth interviews with 29 PLWH and 8 public health doctors (Xhlosa-English)
- Three FGDs with programme managers/stake holders, HIV+ men and women
- A panel survey (KSPS) of 216 PLWH accessing ARVs
- A control panel-survey (KPS) of 517 people.

The study was conducted in peri-urban townships in the Cape Flats, Cape Town, in 2007 - 2009

Presentation of results

Khayelitsha

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Ramifications of the disability grant for PLWHs

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Employment, economy & the disability grant

- ✓ 50% of the KSPS sample was unemployed, and 46% of the KPS (control group)
- ✓ 78% of households in the KSPS sample received some kind of grant as part of their of their income
- ✓ 98% of KSPS respondents reported using the disability grant to cover general living expenses
- ✓ The qualitative data indicates that the disability grant in most cases is the only source of income for the extended family. This put PLWHs under pressure.

Employment, economy & the disability grant

"I am fine. I can work. The government must produce more tablets … The people [PLWH] must get stronger. The government must accept us [PLWHs]. We are HIV infected – everybody must accept us! We are not dead already! […] They must accept us, they must give us jobs, and they must treat us like anyone else. They must not think that an HIV+ person is going to die tomorrow. They are not giving us [PLWHs] opportunities to be somebody! […] So the government must not wait for somebody to die. The government must not wait until a person's CD4 count is less than 200, because that person cannot do anything! You understand? They [the government] must look after and support us [PLWHs][...] I can get sick two, three times a week, but I do not want to be sick. I do want to get a job"

(HIV+ man, 44 years)

Use of the disability grant

- 98 % of the HIV+ participants (KSPS) who received the disability grant used it to cover general household expenses
- In many cases it covers the expenses of the extended family
- This puts pressure on the person who is '*granting*'

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Loss of the grant leads to stress

"Last month we did not pay our bills. Problems will come up next month because we are going to pay [our bills], but we do not know what we are going to eat"

(HIV+ man, 42 years)

"The problem is that we have over-crowded families with huge numbers of children who are depending on one person who is 'granting'. Our parents are both 'granting', and it is the same situation. My mother is retired, but it is not easy for her to support because there are other people she lives with." (HIV+ man, 35 years)

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Disability grant termination and ARV adherence

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Loosing the grant

- 42% of the KSPS respondents had experienced losing their disability grant
- 90% of the KSPS respondents who had their disability grant terminated reported that it had a large impact on the household economy, while 8% reported that it had moderate impact
- The qualitative interviews clearly revealed that loss of the disability grant as a result of improved health had a significant impact on physical and emotional health and also led to high levels of stress

Loosing the grant

"You become sick once you loose your grant, because you become depressed and after that your CD4 count drops because you don't know what you're going to eat. People become sick all the time, because you need to take your medication. But, if you don't have food, it's difficult, and you cannot go back to your family. No one will help you. If you are unemployed, you will experience problems, because you have to buy food and clothing and pay for funerals with that grant."

(HIV+ woman, 28 years)

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Adherence to ARVs

- 3 % (n= 6) of the PLWHs stated that they had stopped taking ARVs (KSPS)
- 99% of the KSPS respondents would not stop taking ARVs in order to keep or renew the disability grant.
- Discontinuation of ARV in order to maintain or requalify for the disability grant was not a common strategy
- The qualitative data confirmed that PLWH would give priority to their health and risk losing the grant
- But sometimes the participants complained that it was difficult to take the drugs on an empty stomach

Adherence

- ✓ 10 % of the KSPS participants agreed that "it is a common strategy for HIV infected people to stop taking ARVs in order to get sick and get the disability grant back"
- ✓ There were subtle ways in which PLWHs may '*tip the scale*' to lower their CD4 counts
- ✓ Some doctors were of the opinion that low adherence was a strategy to prolong the eligibility for the disability grant period

Adherence to ARVs

"My patients don't take the tablets every day; they play with their health. The cleaners here at the clinic find lots of tablets dumped daily, in the yard, toilet. It is almost every day that one of my patients will tell me that they saw someone in the bathroom who dropped a handful of tablets in the toilet. Sometimes, I hear them when they discuss outside about manipulating the number of tablets. They calculate how many tablets they should be left with and they educate one another outside. They discuss among themselves that if you take your tablets every day, you will get better and your CD4 count will go up and that's when the grant will stop. So they play with their health." *(Male doctor)*

Adherence

"I just tell them [doctors], sometimes, when I am hungry, I just leave the ARV treatment, I don't take the drugs, I just leave it lying there… and then I'll see [if I have any food to eat] the following/next day." *(HIV+ woman, 30 years)*

Incentives to trade off health for income

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Trade off health for income

Descriptive statistics for health and income by year and by employment status for those who lost disability grants between 2004 and 2006

Sample	2004/2005		2006		2007	
	Employed	Unemployed	Employed	Unemployed	Employed	Unemployed
Sample size	22	43	28	37	33	22
Average individual income ($ US/month)	331	126	194***	9***	198***	28***
Average household income ($ US/month)	429	265	367	173**	307**	194*
Self-reported health (1–5 scale, 5–excellent)	4.22	3.74	3.89	3.45	4.30	3.88
Self-reported side effects (number experienced)	3.74	2.37	1.57	3.76**	1.37	1.68

Significant values are for T-tests comparing outcomes from 2006 and 2007 to those from 2004/2005 wave *within* employment status groups

*** $P < 0.01$, ** $P < 0.05$, * $P < 0.10$

Trade off health for income

- Loss of the grant has a substantial impact on socio-economic status and health
- Also the quantitative data confirms that the participants are not willing to sacrifice health for access to the disability grant

Trade off health for income

"Oh no, I take my drugs every day, because I do care about my treatment and all that since I started to take my treatment……. It is about my life." (HIV+ man, 44 years)

"The situation of grant, people are talking. I understand them sometimes, me too. I am staying with them and some of them they say "I wish I get HIV so that I can have a grant". […] I had a job and I used to get R2500 a month, but now I am getting less, R870. It's stress to me you understand, it's bit stressful for me. I was getting my life forward you understand […], but with R870 I can't. People who are living with HIV must have a grant […]. If the government will give each and every people with HIV a grant we can be safe.

(HIV+ man 39 years)

Doctors' role and their relationship with PLWHs

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Criteria for grants and eligibility

- ✓ 51% of those who had lost the disability grant stated that the reason was that their doctor indicated that they no longer qualified for it, while 29% stated that their application was refused.
- ✓ Some doctors confessed that they used social criteria as well as health criteria when deciding who qualifies for a disability grant
- ✓ Doctors' criteria for assessing disability eligibility were obscure, resulting in an *ad hoc* distribution and duration of the disability grant
- ✓ The system does not work as intended – people who should receive it did not and people who should not receive it did

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Criteria for grants and eligibility

"First of all, nationally there are no clear guidelines. It varies from province to province, and even in this province, it varies from doctor to doctor. Some doctors are hesitant to write a disability grant while others give just about anyone a disability grant. Some doctors still prescribe permanent disability grants (duration five years), while other doctors never do it. Locally, there has been some sort of agreement, if your CD4 count is less than 200 then you qualify for a grant; however, some doctors will give it to you for six months and other doctors will give you a 12-month grant."

(Female HIV-doctor)

Criteria for grants and eligibility

"The most difficult thing about being a doctor, is that you have to write disability grants. It is like you are God; you just have to look at the person's face and decide whether they qualify or not" *(Male HIV doctor)*

"Who else is there to judge? [talking about the eligibility of the disability grant]….. You are the final obiter dictum and that makes your life harder……"

(Male HIV doctor)

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Doctors under pressure

- ✓ Patients classified doctors as '*good*' or '*bad*' in relation to their attitudes towards and practices of making disability grants
- ✓ This puts doctors under pressure to balance the biomedical criteria for grant eligibility against other forms of knowledge such as the individual's circumstances, unemployment and poverty

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Doctors under pressure

- The rational for prescribing grants differs from doctor to doctor
- Some doctors believed that some of their patients used HIV as a way to get the grant, while unemployment was the real problem and that the measures therefore should focus on unemployment
- The doctors were also aware that the disability grant gave new opportunities to PLWHs in everyday situations.

Pressure & expectations

"*It depends of the heart of the doctor sometimes…. [talking about extension of the original disability grant time period]. If the doctor has got your sympathy then he can do that.*"

(HIV+ woman, 28 years)

"*The most difficult thing about being a doctor, is that you have to write disability grants. It is like you are God; you just have to look at the person's face and decide about whether they qualify or not.*"

(Female doctor)

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Pressure & expectations

"Sometimes when they bring their kids and you can see that they are hungry. But then again, the guidelines state that you cannot give this person a disability grant. You know what is going on at home and that there are no social workers to take care of the person. You know that you can help, but then at the same time you do not want to be seen as the fraudulent doctor. [...] But honestly speaking, I have been fraudulent, two or even three times, not a lot; I mean I am very careful. They think I have empathy and understanding, because where they come from is probably where I come from." (Female doctor)

Gender & HIV

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Prevention

- ✓ Traditional gender constructions and masculinity act barriers to HIV prevention
- ✓ Dominant notions of traditions that validate unsafe sex, where the use of condoms (‘plastic’) is against the traditional sex practices of feeling flesh-on-flesh (i.e. unsafe sex)

“[A] thing which is a barrier it is a tradition that men believe that they would not have sex with plastic - it is a taboo. Tradition becomes a barrier. Men want flesh to flesh; they believe that what makes man is a flesh to flesh.” *(Men’s FGD)*

Prevention

- ✓ Women are biologically more susceptible to infection than men, but findings indicate that men take up a defensive position of invulnerability to illness which reinforces unsafe sex, undermines testing and delays treatment initiation
- ✓ Men perceived themselves as invulnerable to HIV infection compared to women (constructing masculinity)

"*You know I have got a problem. My experience is that each and every boyfriend who I tell: 'If you love me, can you go to the clinic to test?' He says 'OK, I will go tomorrow' and then I won't see him again*."

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HIV-testing

- ✓ Women get access to health care (through participation in PMTCT programmes) when pregnant, and through this process they test for HIV
- ✓ Most men did not volunteer for HIV-testing, but practised a form of ‘*proxy testing*’ through their pregnant partners
- ✓ Women are usually the first one to test for HIV and the knowledge of their status gives them the responsibility for enacting behaviour change, and thus take the risk of being blamed of ‘*bringing HIV into the home*’ and possibly stigmatised

HIV-testing

"Men won't go for HIV-testing. They want to make their partners pregnant. Then if the partner comes back from the clinic and says that 'I'm negative', he will be happy because he thinks he is negative. But if the partner says 'I'm HIV+', that will create domestic violence. He will say, 'You are the one who came with this thing. You were sleeping around'."

(Men's FGD)

"I was talking to women. One said they [men] actually prefer the women to get pregnant. They [men will] get to know her HIV test rather than go themselves. Then ... the woman comes back and tells them that they are HIV infected... They don't want to believe it".

(Female doctor)

Disclosure and treatment

- ✓ Balancing risks and benefits: antenatal and postnatal care & HIV-testing entails decisions around disclosure that balance the risks (stigma, rejection, re-infection through unsafe sex, reduced ARV adherence) and benefits (support, behaviour change, initiation on ARVs, adherence, informed choice on infant feeding practices)
- ✓ Thus, secrecy is a double-edged sword: disclosure runs risk of stigma, non-disclosure increases risk of re-infection and undermines recommended infant feeding practices and ARV adherence.

Disclosure and treatment

"You know last year when I was dealing with PMTCT, I discovered that most of the mothers never disclosed to their boyfriends… It's like there are many people staying together now but the problem is that it's hard to disclose your status to your boyfriend because this boyfriend might think you are the one brought that disease in to the house." (NGO FGD)

"I was suffering, you know? Because I didn't have money for this child of mine. And the father of this child ran away when I told that I am HIV Positive. I have never seen him again." (HIV+ woman, 26 years)

Infant feeding and stigma

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Infant feeding and stigma

- ✓ Women who chose to use formula milk instead of breastfeeding were concerned about being identified as HIV-positive by other mothers, and stigmatised in their community
- ✓ It was difficult for women who had not disclosed to adhere to the infant feeding method they had opted for

Infant feeding

How did you or your partner feed your last-born child for the first month? (KSPS)

	Frequency	Percentages
Exclusive breastfeeding	58	30.5
Mixed feeding (infant feeding formula, cow's milk and breast milk)	19	10.0
Purchased infant feeding formula	31	16.3
Free clinic supply of infant feeding formula	79	41.6
Other	3	1.6
Total	190	100.0

Infant feeding and stigma

"[Women] have to go to the clinic to get that Pelagon. I think it's a stigma for them. And sometimes these people are not ready to disclose." *(HIV+ woman, 30 years)*

"She used to go to the clinic to take [infant] milk and carrying this milk people will ask her, 'Are you breast feeding?' And she will say, 'No, I am not breast feeding.' And they … will tell others that she has got HIV [because] she is not breast feeding ... They will visit her at home and … see a lot of milk lying around, then say, 'Ok she is HIV positive." *(HIV+ woman,26 years)*

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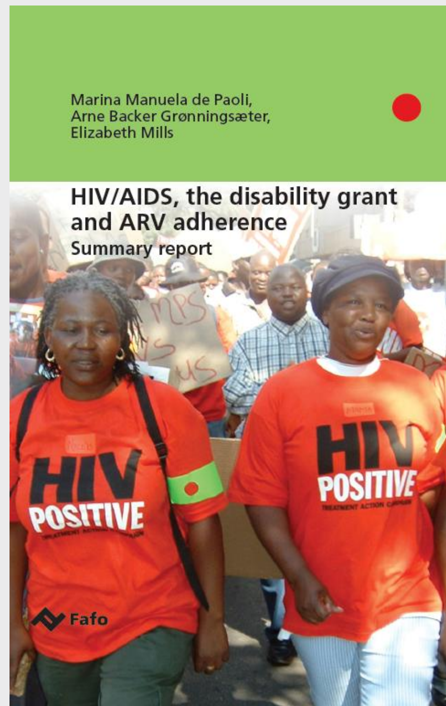
Infant feeding and stigma

“We have this funny policy that all infants *[of mothers who are HIV+] get Pelagon. It is some particular kind of formula in an orange tin. Everybody who sees a mother with an orange tin knows that the mother is HIV+…. It does put some moms off, and some will actually buy Nan, so that nobody knows that she is HIV+”* (Female doctor)

Conclusions



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Conclusions

- ✓ Given the *importance* of the public sector ARV roll-out, it is crucial for the state to provide sustainable economic support and/or to create employment to make '*positive living*' a reality for PLWHs
- ✓ Social, financial and psychological support network are invaluable for PLWHs as they promote overall health and well-being among PLWHS
- ✓ Loss of disability grant had significant implications for household income, and access to basic nutrition; this in turn affected the participants' ability to adhere to their treatment

Conclusions

- ✓ Alternatives to disability grants could be an unemployment grant, a chronic illness grant or a basic income grant
- ✓ The absence of a coherent national grant-awarding framework allows for greater flexibility on the part of the doctors, but also increases pressure on doctors and offer scope for abuse

Conclusions

- ✓ HIV-testing and disclosure are gendered, have different implications for men and women, and require tailored interventions to challenge stigma and to encourage both men and women to test
- ✓ Gender-sensitive strategies are necessary to encourage men to test for HIV, and to encourage earlier initiation on ARVs
- ✓ The PMTCT programmes put the responsibility of preventing vertical transmission on women, and this makes it difficult for the women, especially in the postnatal period

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Thank you!

The project was funded by the Research Council of Norway