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SHAPING A SUSTAINABLE FUTURE

MOTIVATIONS FOR BLOOD DONATION BY HIV-POSITIVE INDIVIDUALS ON ANTIRETROVIRALS IN SOUTH AFRICA: A QUALITATIVE STUDY

Karin van den Berg^{1,2,3}, Edward L Murphy^{4,5}, Vernon Louw⁶, Gary Maartens⁷, Shana Hughes⁵ for the NHLBI Recipient Epidemiology and Donor Evaluation Study-III (REDS-III).



1. Medical Division, South African National Blood Service, Roodepoort, South Africa
2. Division of Clinical Haematology, Department of Medicine, University of Cape Town, Cape Town, South Africa
3. Division of Clinical Haematology, University of the Free State, Bloemfontein, South Africa
4. Departments of Laboratory Medicine and Epidemiology/Biostatistics, University of California, San Francisco, USA
5. Vitalant Research Institute, San Francisco, USA
6. Division of Clinical Pharmacology, Department of Medicine, University of Cape Town, Cape Town, South Africa

Conflict of Interest:

- The authors have no conflicts of interest to declare

Background

SANBS previously identified the phenomenon of persons with HIV already on treatment donating blood.

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BRIEF REPORT

Discovery of False Elite Controllers: HIV Antibody-Positive RNA-Negative Blood Donors Found To Be on Antiretroviral Therapy

Wendy Sykes,¹ Karin van den Berg,² Genevieve Jacobs,³ Adam Jauregui,⁴ Nareg Roubinian,⁵ Lubbe Wiesner,⁶ Gary Maartens,⁶ Ronel Swanevelder,³ Brian Custer,⁴ Michael Busch,⁴ Ute Jentsch,³ Edward L. Murphy,^{4,5} and Marion Vermeulen³, for the NHLBI Recipient Epidemiology and Donor Evaluation Study-III (REDS-III)

¹South African National Blood Service, Durban, South Africa; ²South African National Blood Service, Port Elizabeth, South Africa; ³South African National Blood Service, Johannesburg, South Africa; ⁴Vitalant Research Institute, San Francisco, CA; ⁵University of California, San Francisco, CA; ⁶Division of Clinical Pharmacology, Department of Medicine, University of Cape Town, South Africa

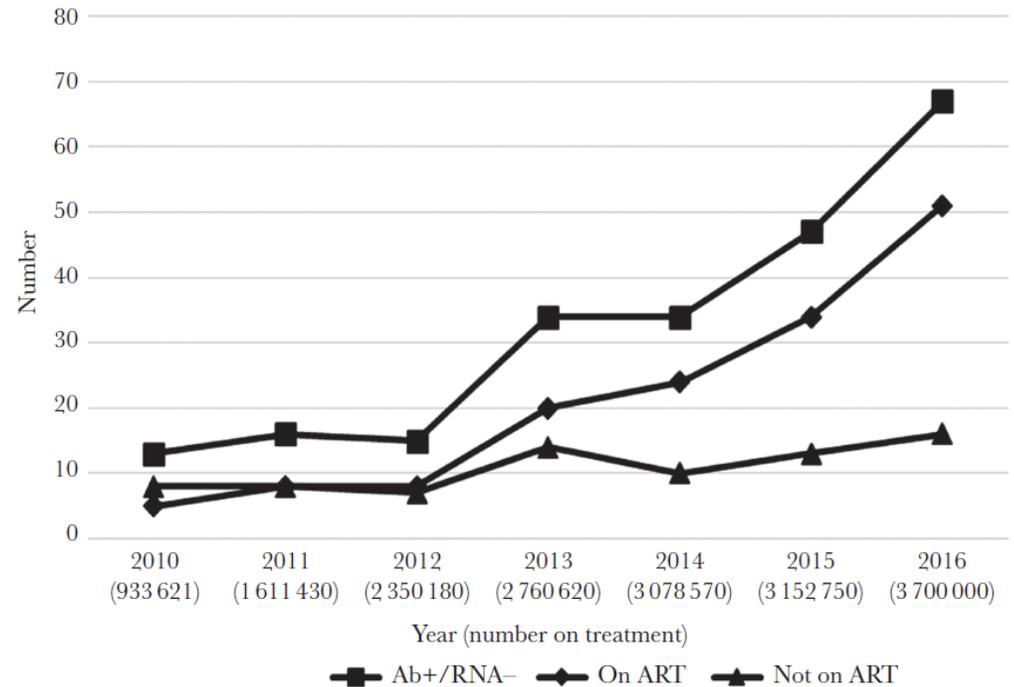
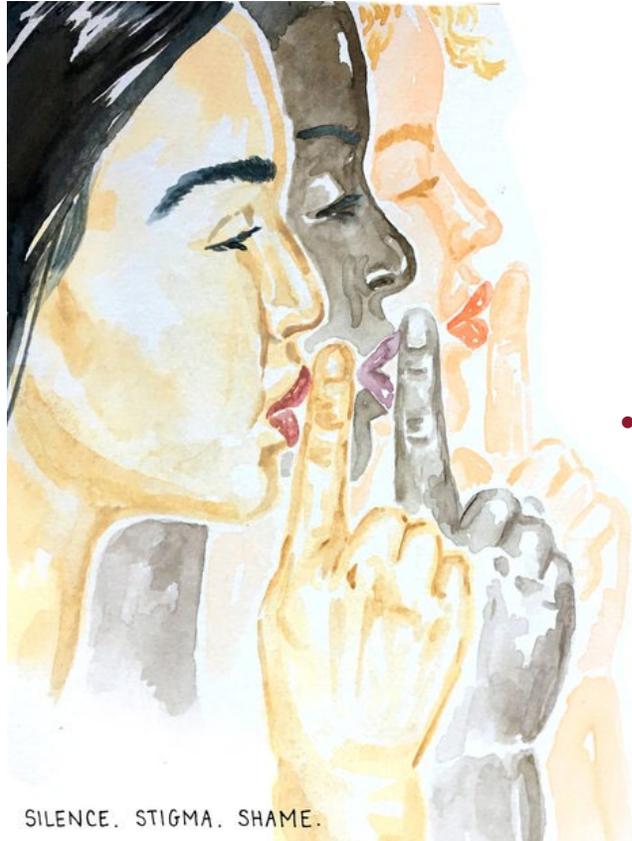


Figure 1. The number of South African National Blood Service blood donations found to be potential HIV EC (Ab⁺/RNA⁻, squares), false presumptive EC (on ART, diamonds), and true presumptive EC (not on ART, triangles) between 2010 and 2016. The estimated number of persons on ART in the general South African population is given beneath the x-axis [1]. Abbreviations: Ab, antibody; ART, antiretroviral therapy; EC, elite controller; HIV, human immunodeficiency virus.

Background:

- **Previously published findings of donors with known HIV-positive status and ARV use presenting to donate blood.**
 - Almost 10% of SA blood donors who test HIV-positive were found to be on ARV treatment
 - Similar study in the USA by Custer et al, found even higher rates of ARV use among American blood donors who tested HIV positive.
- **The higher prevalence of non-disclosure among first-time donors was expected, but non-disclosure among repeat and lapsed donors suggests a failure in donor education and assessment.**
 - Donors are informed of HIV testing to be performed on all donations
 - Specific questions on donor health questionnaire on HIV status and ARV use



Undisclosed HIV status and antiretroviral therapy use among South African blood donors

Karin van den Berg^{1,2,3} | Marion Vermeulen^{3,4} | Vernon J. Louw² | Edward L. Murphy^{5,6} | Gary Maartens⁷

| | ARV negative | | ARV positive | | Total | p-value |
|---------------------|--------------|-------|--------------|------|-------|---------|
| | N | % | N | % | | |
| Total | 1128 | 90.2 | 122 | 9.8 | 1250 | |
| Gender | | | | | | .205 |
| Female | 808 | 89.6 | 94 | 10.4 | 902 | |
| Male | 320 | 92.0 | 28 | 8.0 | 348 | |
| Ethnicity | | | | | | .505 |
| Asian/Indian | 10 | 90.9 | 1 | 9.1 | 11 | |
| Black | 1021 | 90.2 | 111 | 9.8 | 1132 | |
| Colored | 30 | 85.7 | 5 | 14.3 | 35 | |
| Unknown | 29 | 87.9 | 4 | 12.1 | 33 | |
| White | 38 | 97.4 | 1 | 2.6 | 39 | |
| Age category | | | | | | <.0001 |
| <21 | 290 | 93.2 | 21 | 6.8 | 311 | |
| 21–30 | 479 | 93.2 | 35 | 6.8 | 514 | |
| 31–40 | 226 | 85.3 | 39 | 14.7 | 265 | |
| >40 | 133 | 83.1 | 27 | 16.9 | 160 | |
| Donor type | | | | | | <.0001 |
| First-time | 605 | 85.7 | 101 | 14.3 | 706 | |
| Lapsed ^a | 250 | 95.1 | 13 | 4.9 | 263 | |
| Repeat | 273 | 97.2 | 8 | 2.8 | 281 | |
| Clinic type | | | | | | .012 |
| Fixed | 238 | 94.4 | 14 | 5.6 | 252 | |
| Mobile | 890 | 89.2 | 108 | 10.8 | 998 | |
| Home province | | | | | | .010 |
| Eastern Cape | 100 | 91.7 | 9 | 8.3 | 109 | |
| Free State | 94 | 89.5 | 11 | 10.5 | 105 | |
| Gauteng | 406 | 91.2 | 39 | 8.8 | 445 | |
| KwaZulu Natal | 199 | 85.0 | 35 | 15.0 | 234 | |
| Limpopo | 65 | 97.0 | 2 | 3.0 | 67 | |
| Mpumalanga | 196 | 88.7 | 25 | 11.3 | 221 | |
| North West | 58 | 100.0 | 0 | 0.0 | 58 | |
| Northern Cape | 10 | 90.9 | 1 | 9.1 | 11 | |

Background:

- **Donor motivation for non-disclosure of known HIV infection and ARV use needs further investigation:**
 - Early ARV initiation or infection while on PrEP could lead to low Ab and RNA levels
 - Such perturbed test markers could lead to failure to detect HIV-infected donations
 - Potential increased risk of transfusion-transmitted HIV



I just don't feel as though [my other friends] should know. Like not that I don't trust them, I just..it's not me. It's something I have but it doesn't make me, me.

—Anonymous, 24

- **Aim of the study:**
 - Designed a mixed-methods study to explore motivations associated with HIV+/ARV+ donation, with the aim of identifying potential strategies to reduce this behavior and mitigate risk for blood recipients

Methods:

- **Mixed-methods study**
 - UCT & SANBS HREC approved
- **Previously identified eligible, consenting HIV+/ARV+ participants were invited to:**
 - Complete a survey:
 - which included a validated 12-item stigma scale,
 - administered through audio computer-assisted structured interview technology, and
 - an individual, in-depth qualitative interview (IDI).
- **The Social Ecological Model (SEM) provided the conceptual framework for this study**
 - Frequently used in qualitative health research and
 - Posits a complex interplay between multiple levels of influences and human behaviour and health outcomes,
- **Data management:**
 - Stigma scores were summed and dichotomized (high or low stigma).
 - De-identified verbatim transcripts from interviews underwent inductive and deductive thematic analysis, following a modified Grounded Theory approach.
 - Applied narrative analysis to interviewees' accounts of their study-qualifying donations to better grasp their experience as a whole.

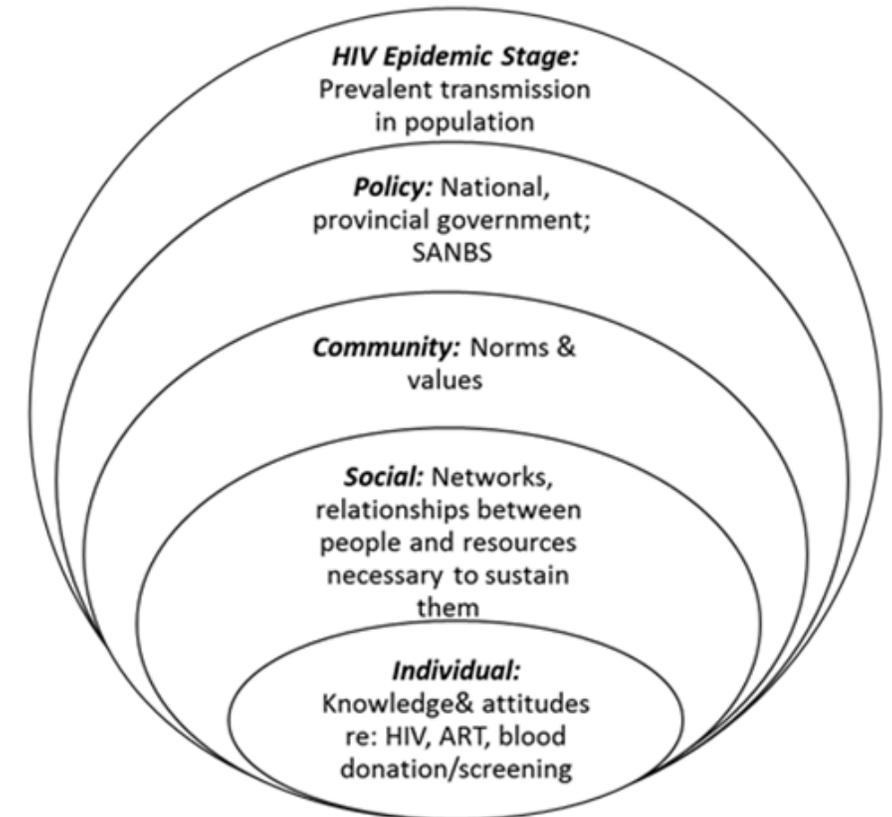


Figure 2: Levels of influence on decision by HIV+/ART+ individual to donate blood (adapted from Baral et al. 2013)

Results:

Table 1. Participant demographics, disclosure practices and stigma scores

| | N/Median | %/(IQR) [†] |
|--|----------|----------------------|
| Total | 25 | 100 |
| Ethnicity | | |
| Black African | 23 | 92 |
| Coloured | 2 | 8 |
| Gender | | |
| Female | 18 | 72 |
| Male | 7 | 28 |
| Donor Type | | |
| First Time | 17 | 68 |
| Lapsed | 5 | 20 |
| Repeat | 3 | 12 |
| Age | | |
| Median | 32 | (24-39) |
| Province | | |
| Eastern Cape | 2 | 8 |
| Free State | 4 | 16 |
| Gauteng | 10 | 40 |
| KwaZulu Natal | 5 | 20 |
| Mpumalanga | 4 | 16 |
| Clinic Type | | |
| Mobile | 22 | 88 |
| Fixed Site | 3 | 12 |
| Disclosure Practice[‡] | | |
| Extremely restricted | 3 | 12 |
| Very Highly restricted | 5 | 20 |
| Highly restricted | 8 | 32 |
| Moderately restricted | 8 | 32 |
| Least restricted | 1 | 4 |
| Stigma Scores | | |
| Overall | 22 | (16-29) |
| Disclosure Concerns | 6 | (4-9) |
| Public Attitude | 7 | (3-10) |
| Self-Image | 4 | (3-6) |

- **Enrolled 25 participants:**
 - 11 classified with high stigma
 - Only 1/3 had ever disclosed their HIV status to more than three people
- **The most commonly reported motivation was altruism (N=12).**
 - We identified two sub-themes:
 - 1) a general wish to help others (N =4) and
 - 2) donating blood specifically for other people living with HIV (N=8)

One interviewee, on ARVs since 2012, said of her blood:

“I think it is better than the people who have just found out that they are HIV positive.... because I am drinking the medications regularly and then my health is fine. It will help the people who are HIV positive, especially the ones with low CD4 count”

Results:

- **The other primary factor (N=10) was a lack of privacy.**
 - Interviewees reported that donation opportunities arose when they were with others (friends, partners, employers) to whom they had not and did not plan to disclose their HIV status;
 - Most were highly confident their donations would be identified as HIV+ and discarded.
- The donation stories from these donors, featured a series of **decision points**, all experienced as threatening to interviewees' privacy.
 - The first involved presenting for donation. Interviewees generally felt **unable to opt-out of attempting** to donate without prompting questions and raising suspicion.
 - The second revolved around **discussing HIV status or donation eligibility with SANBS staff**. Most interviewees reported there was no private place to have such a conversation (though some had gone to the donation site with precisely this intent).
 - The third decision point involved answering the DHQ. Interviewees felt unable to disclose their HIV status on the DHQ, either **due to the proximity of co-workers and friends, or because they believed the confidentiality of their answers might be compromised.**



Results:

- The above is well-illustrated by a specific participant's account. She explained that SANBS ran a blood drive at her workplace:

“Everyone, most of the people in the office, they were going to donate...and yah, so I didn't have much of an excuse as to why I shouldn't go” (presenting for donation). She thought that *“when I get there, I will [be] able to speak, maybe it will be in private ...but it was in the boardroom and you know they had the beds and stuff so we all just filled in the forms in one table”* (discussing eligibility).

Regarding the screening questions, she *“didn't answer them truthfully” because her co-workers were close at hand* (answering the DHQ). In addition, she observed that being deferred from donation attracted undue attention to her as the donor, which was exactly what she was trying to avoid.: *“Everyone was looking at each other ... it was like a joke because even those who had iron problems and [were] turned away... people were, like, talking like, 'Oh why have [they] been turned away?’”*

Conclusions

- We uncovered two primary motivational paths to HIV+/ARV+ blood donations: **privacy and altruism**.
 - The latter included a motivation not previously reported in the literature: the specific desire to donate for other PLWH.
- Slotting these findings into our adapted version of the SEM reveals a **complex interaction** between
 - individual, social, cultural, and structural/policy factors in blood donations by PLWH who take ARV.
- **Recommendations to limit HIV+ARV+ donations include:**
 - 1) Targeted communication strategies to increase knowledge among PLWH of their deferral from blood donation—without increasing stigma, and
 - 2) Development of procedures to assist those who feel unable to opt-out of donation due to peer pressure and privacy concerns.

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