Towards HIV Cure
Community Perspective

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Towards HIV Cure
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Introduction

• My community

• Why communities need cure now

• Way forward

• Conclusion

• Acknowledgements
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The late 90s – late 2000s

- Peak of HIV and AIDS
  - Funerals everywhere (tents)
  - Confusion
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Evidence

• A = 9 graves (includes 2 grandchildren)

• B = 8 graves (all the children)

• C = 11 graves (2 double funerals)

My ‘Resilient Sheroes’
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Introduction of ARVs

• Thank you so much to:
  – Researchers and communities that participated in ARV Research (hat off)
  – AIDS activists and many organizations that exerted pressure about treatment. (TAC, AVAC)
  – CAPRISA who brought back so many people back to life in Vulindlela

• Acknowledge latest development of 1 pill a day!
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New challenge - Defaulting on ARVs

- Increase in Viral load
- Contributes to an increase in new infections

Numbers of new HIV infections are completely unacceptable
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Conversations with grandparents:

• *I have 3 grandchildren on ARVs. They are careless. They take them today and not tomorrow. Give them something which will finish everything in the blood until the blood is clean.* (84 year old granny)

• *I do not want to go back to what I have been through...no more.* (80 year old granny)
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Conversations with PLWHA (23-30)

Eventually you get tired. I have done this for 5 years. Now and again I cheat. I just, just do not feel like it. ... it has been a long time (woman, 24 years)

When people are happy. I must look at the time. Always. If not, my life is in danger. I live with constant threat. I cannot relax completely. Like I did something wrong. (male, 28 years)
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Conversations with PLWHA (23-30)

- Women on contraception take a break when they are pregnant, why can’t we be allowed to? *(woman, 29 years)*

- Sometimes it feels like my rights to live freely are interfered with. Come 6 o’clock... I panic. An hour left. 30 minutes. Time up ... ayi, it is tiring! *(male, 27 years)*
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We desperately need a cure now!!!.

‘Take your treatment for so many months. Finish. You are now HIV free!!!’.
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Thank you so much researchers!

You did it for TB

You did wonders for MTCT
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As communities we know that:

You can do it for HIV!!!
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• Way Forward: very simple
  – Investments
    • More funds for Drugs
    • More funds for research
    • More funds for community work
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• Way Forward

  ▪ Meaningful partnerships

    » Working with local organisations on a structured manner (establish one)

    » Ask for advice from the community (act)

    » Listen to them. (lesson)

    » No window dressing, please! (CAB)
Way Forward

– Deal with the clinics.
  » Separate entrance
  » Different colour files
  » 5 hour waiting time

– Address stigma and discrimination

– Other factors contributing to HIV infection
Conclusion

Researchers and communities need each other in this journey towards HIV Cure.

None would be successful without the other. Need for meaningful partnerships.

The world needs HIV Cure, the same way the world needed TB Cure.
I thank you!!!
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• Acknowledgements

• Vulindlela Community for their participation
• Grandmothers who shared their stories and pain
• PLWHA for sharing their experiences of taking ARVs
• Quarraisha Abdool Karim for her mentorship
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