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To cite this article: Heidi van Rooyen (23 Feb 2024): A poetic inquiry: the role of the social sciences and humanities in revitalising AIDS, AIDS Care, DOI: [10.1080/09540121.2024.2319840](https://doi.org/10.1080/09540121.2024.2319840)

To link to this article: <https://doi.org/10.1080/09540121.2024.2319840>



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Published online: 23 Feb 2024.



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A poetic inquiry: the role of the social sciences and humanities in revitalising AIDS

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ABSTRACT

For the past four decades, biomedical science has transformed clinical outcomes for HIV and AIDS. However, the social, economic and gendered determinants of HIV remain largely intact. The social science and humanities offer concepts and methods for articulating why these remain intractable. I used poetic inquiry – an arts-based, qualitative approach – as I reviewed literature on the “end of AIDS, and post-AIDS”. As I did so, I considered what contribution the social sciences and humanities could make in moving us closer to these ideals. Several themes and found poems emerged in this reading: (1) how language oversimplifies complex social realities; (2) the voices of people living with HIV and AIDS must be included; (3) HIV and AIDS intersects with social inequalities; (4) social and structural issues are no barrier to HIV prevention and (5) the need for radical interdisciplinarity. The paper concludes that the end of AIDS requires responses that are integrated, holistic and that radically challenge our silo’d disciplinary boundaries and frames. The social sciences and humanities are key to this charge.

ARTICLE HISTORY

Received 16 August 2023
Accepted 10 January 2024

KEYWORDS

Social science and humanities; HIV and AIDS; interdisciplinarity; social determinants of health

SUSTAINABLE

DEVELOPMENT GOALS

SDG 10: Reduced inequalities

There are years that ask questions and years that answer
– Zora Neale Hurston

Introduction

While the social sciences have made critical contributions, biomedical science continues to dominate advances in the global HIV evidence base (Sprague et al., 2020). The biological model of disease translates into public health interventions such as treatment as prevention, U = U and talk about chronicity, the end of AIDS and post-AIDS (O’Connell, 2020). Biological ways of seeing, steeped in disease exposure, elimination and control, centred on the individual, allow for clear, unequivocal criteria of success but avoid complex and difficult realities of what it means when a virus lives in a human body (Clarke et al., 2019; Davis, 2021). While biomedical interventions in the past four decades have transformed clinical outcomes, the social, economic and gendered determinants of HIV remain largely intact (Walker, 2020). The social science and humanities offer concepts, theories, methods and tools for articulating why these remain intractable and offer an opportunity to reimagine a future where AIDS may not exist.

Arts-based research fuses the arts and humanities with scientific inquiry to articulate rich contextual and affective realities in evocative ways (Richardson, 2003). Poetic inquiry is an “umbrella” term used to describe a field of arts-based inquiry that integrates qualitative research and poetry (Prendergast, 2009). The method is used in many ways and at various stages of qualitative research, from coming up with a research question to generating data, analysing it, and sharing the conclusions. I used poetic inquiry when reviewing recent literature discussing the “end of AIDS, and post-AIDS”. As I engaged with this work, I considered what contribution the social sciences and humanities could make in moving us closer to the end of AIDS.

Methodology

As I read, several recurring themes emerged. Under each theme, I noted key ideas, words, images, and phrases that captured the essence of that theme (Glesne, 1997; Richardson, 2003; van Rooyen & D’Abdon, 2020). Found poems were developed under some themes. Found poems are created by taking words, phrases, images from a theme and using “poetic licence” to

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shape them into poems through the use of space, lines, adding or deleting text, and the use of repetition (Butler-Kisber, 2010). Five themes emerged and are discussed below. These were (1) how language oversimplifies complex social realities; (2) the voices of people living with HIV and AIDS must be included; (3) HIV and AIDS intersects with social inequalities; (4) social and structural issues are no barrier to HIV prevention and (5) the need for radical interdisciplinarity.

Language matters

How we use language matters. Think back to terms such as “The gay plague”, “GRID”, the “African disease”. Recall how these were used to harm, marginalise and stigmatise. We should be mindful of our current language and the unintended consequences of it. As Walker (2020) observes, talk about the end of AIDS or post-AIDS starts with the biomedical, with antiretroviral treatment and other technologies central to them. The human, social and structural conditions to get us to those points, loud in their silence. Based on a narrative of “positive progress” they uncritically oversimplify highly complex social realities.

the embodied
everyday sense
of risk,
the daily tasks
of living with
HIV and AIDS,
its stigma
the uncertainty
anxiety
the economic drain
and social tumble
through life
with an illness
with no cure
this story
my story
our story
silenced
by your
post-AIDS talk

The language of international health policy at odds with the lived experience of many around the globe. The end of AIDS is closer for some, but a distant reality for many; despite our progress, the epidemic impacts negatively and unevenly on individuals, families, communities and countries (O’Connell, 2020; Walker, 2020). Similarly, for men who have sex with men, black people in the US and South Africa, for certain populations, in certain places, it’s premature to insist we manage HIV as a chronic disease just like diabetes

and asthma (Sangaramoorthy, 2018) or fail to acknowledge that HIV carries continuing and residual stigma in certain bodies, communities and health care services (Walker, 2020).

Nothing about us, without us

Diallo (2021) refer to the landmark documentary, “Nothing Without Us: The Women Who Will End AIDS”, where reproductive justice activist Gina Marie Brown stated unequivocally that she was the woman who will end AIDS.

without women
girls
femm;es
trans-gender
queer or questioning
intersex asexual plus
people
incarcerated individuals
and people who inject drugs.
without women
of African descent
black women
around the world
no one gets to the end
the epidemic ends with me
the epidemic ends with WE

The needs and lived realities of marginalised groups will not be addressed until their voices are acknowledged and acted on. Not only is it important to engage Black communities in HIV prevention efforts, but it is equally important that Black scholars are centred in research that unpacks and finds solutions for the addressing the social determinants of health and their impacts on HIV outcomes (Carter, 2021). Many Black scholars experience marginalisation in ways that mirror communities most impacted by HIV; these perspectives are invaluable for understanding and appropriately addressing HIV inequities (Carter, 2021; Diallo, 2021; Phillips, 2021).

Creative approaches from the arts and humanities (visuals, stories, dance, theatre, poetry) have intrinsic value as they are central to and expressive of the human experience. They help us to think about ourselves and others, about culture, family, ethics, conflict life and death, the world around us and the world within (Langdrige et al., 2019). Embedded in our research they offer a language and experience that people can recognise, engage, understand and relate to. They aid comprehension, simplify, create resonance. When we do so, we engage people not just in our science but re-energise them in their lives. In the process, we revitalise ourselves and our work. This is good for study outcomes

and impact, but good for people too. This is science for the greater good. Science that makes a difference.

Unless we commit to this, intentionally and consistently, we will not improve access to HIV research, care, and prevention services to meet the needs of diverse and marginalised people living with HIV and AIDS, we will not have an end to AIDS, we could not embrace a post-AIDS world.

HIV and AIDS intersects with social inequalities

Rooted in black feminist activism and scholarship, intersectionality outlines how social identities – such as gender, sexuality, age, race, class, and (dis)ability, amongst others— are interconnected and create unique experiences of oppression and discrimination for marginalised persons (Crenshaw, 1991). Intersectionality names how: (1) structures such as racism, sexism, classism build on each other and (2) that these are interrelated and shape who we are and (3) that one category cannot be understood without also understanding other groups to which we belong (Gkiouleka et al., 2018; Settles et al., 2020).

name it
call out the hands
that have ached your life
and mine
listen to how
this gender
race, sexuality
disability, class
come to
live in this body
on this face
in this hair
see my
complex colours
name them
where there's no name
you can't see it
you can't see me

Health inequities have some degree of social causation (Carter, 2021). The environments in which we are born, live, learn, work, play, worship, and age – these social determinants – significantly impact our health outcomes (World Health Organisation, 2008). Viruses attack vulnerabilities (Phillips, 2021). Historical, long-standing stacks of them. While they don't discriminate, viruses thrive in bodies familiar with structural and systemic racism, income inequality, poverty and unemployment, migration (Landers et al., 2021; Phillips, 2021; Sprague et al., 2020). In South Africa, we see how these social determinants of health interact with socio-cultural norms, gender and HIV risk and impact

the diagnosis and management of HIV, AIDS and TB in particular ways (El-Sadr, 2021). Sprague et al. (2020) show how the virus, poverty, race and stigma work in concert to exert combined negative effects on HIV-positive African Americans' health and outcomes. The impact of COVID-19, HIV and chronic diseases for certain communities is not equal (Jassat et al., 2022).

The social is no barrier

More than a decade ago, Kippax warned that social and structural factors are not a barrier to successful biomedical HIV prevention; the social is the medium of its realisation (Kippax, 2012). Then and more so now as we talk of ending AIDS, these words take on deeper significance. It's not the case of finding a way over or around social barriers but recognising how central these are to a comprehensive HIV response. Kippax and Stephenson (2012) advocate for a social public health approach that moves beyond an over-reliance on individual capacities or views social determinants as separate entities that exist outside the individual. For them, human behaviour is intimately tied to the enabling (or disabling) set of social norms, practices and institutions we live and move in. These are shaped by what occurs in macro policy environments and transformed or modified by community mobilisation and social movements (Kippax & Stephenson, 2012).

Radical interdisciplinarity

Unpacking the relationship between social contexts and individuals is the work of ethnographers, sociologists, anthropologists, political scientists and humanities scholars. This work must integrate with the methodological, conceptual and cognitive resources of the biomedical and behavioural to address HIV and AIDS. Clarke et al. (2019) believe this requires radical interdisciplinarity. Not social science added on as afterthought, as a thin veneer to the main biomedical course, but integrated as we frame the questions, design and implement the science.

Interdisciplinarity requires valuing and integrating all forms of knowledge. It will require boldness – shifts in the politics of what is valued, and what gets funded. No more funding for magic bullets! We have enough. It's time for translation into life – effectiveness studies and implementation science, interdisciplinary bio-social/social-bio studies that address complexities. It's time to reignite conceptual and methodological conversations about the limiting gold standards of efficacy, to find a way to conduct and value science that addresses the fullness, the messiness of life. More qualitative

studies such as those conducted by Sprague et al. (2020) that demonstrate social science understandings of the social determinants of health and poor HIV outcomes in socially excluded groups. Only by joining disciplines, can we produce the knowledge, concepts and insights that help account for the complexity of health and disease, that will allow us to build sustainable interventions (Clarke et al., 2019). When combined with social theory, such evidence can identify entry points to better policy, practice and interventions to address socially produced health inequities that may lead to the end of AIDS (Sprague et al., 2020).

Conclusion

At the heart of the social sciences and humanities, is imagination. As my colleague Lesley Banks says, the value of imagination is needed now to produce innovative science, imagination is required to reimagine our broken world, to revitalise our science and ourselves.

“There are years that ask questions and years that answer” says Zora Neale Hurston. The world looks to the social sciences and humanities to take up its place alongside biomedical science in addressing and designing contextually appropriate responses that address the social and structural determinants that keep HIV and AIDS entrenched for certain marginalised people and places around the globe. It requires responses that are integrated, holistic and that radically challenge our silo’d disciplinary boundaries and frames. The social sciences and humanities must lead this charge to ending AIDS, but it will require us to come out of the shadows, to take the lead, to be bold and confident in our science, theories, and methods, to be engaged, creative and imaginative as we do so.

there will be no end to AIDS
the epidemic ends with ME
the epidemic ends with WE
with US

Disclosure statement

No potential conflict of interest was reported by the author(s).

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