



Experiences of HIV diagnosis: Emotion work in the clinical encounter, and the pursuit of undetectable viral load

Dean Murphy | 17 Sept 2019

Acknowledgements

Participants in *RISE Study*

Investigators

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Partners

ACON, AIDS Action Council of the ACT, Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM), Living Positive Victoria, New South Wales Ministry of Health, Northern Territory AIDS and Hepatitis Council (NTAHC), Northern Territory Department of Health, Positive Life NSW, Queensland Department of Health, Queensland Positive People (QPP), South Australia Mobilization + Empowerment for Sexual Health (SAMESH), South Australian Department of Health and Ageing, Tasmanian Council on AIDS, Hepatitis and Related Diseases (TasCHARD), Tasmanian Department of Health and Human Services, Victorian Department of Health and Human Services, Western Australian AIDS Council (WAAC), Western Australian Department of Health.

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Advisory group

Jeanne Ellard, John Rule, Suzy Mulholtra, Chris Howard, Lisa Bastian, Lisa Tomney.

Overview

- 'Emotion work'
- Background and study design
- Methods and participants
- Diagnosis
 - Anticipation
 - Responsibility
 - Treatment
- Summary

Emotion work

- Managing emotions according to what is culturally acceptable ('feeling rules') within a particular situation or relationship (Hochschild, 1979).
- Social interactions involve emotion work – is a form of gift exchange.
- 'Emotional labor' – emotion work undertaken in professional setting (important feature of specific work roles [Hochschild, 1983]).
- Work undertaken by 'patient'/client
- What cultural scripts (expected/acceptable narratives) are available to inform how one ought to respond to diagnosis.
- Examples:
 - Surprise
 - Assuming responsibility for infection
 - (Enthusiasm for) HIV treatment

Methods and participants

- Optional component of RISE Study.
- Eligibility criteria:
 - Aged at least 16 years
 - Currently residing in Australia
 - Diagnosed in 2016 or later
- In-depth interviews (conducted face-to-face or by telephone/videoconference).
 - Focus on diagnosis event
- First 16 participants:
- 14 men (11 gay/bisexual, 3 heterosexual) and 2 women
- 11/16 born in Australia
- Average age 35.4 years (range 27 to 50)

Diagnoses

- Diverse settings, often outside sexual-health and s100-prescriber networks.
- Often spread across time and space –reflecting changes in technologies and testing patterns – so not always possible for participants to describe their diagnosis as a single event.
 - Jurisdictions – different states, countries.
 - Sites/services – suburban/regional GP, walk-in bulk-billing practices, hospital emergency department, other health services, HIV specialist, visa/insurance settings.
- Being informed about diagnosis varied, and was not always revealed in the way intended.
 - Technologies – email, phone, letter, printed documents.

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I got a printout of all my results and when I got home, started flicking through them. The HIV serology came back with 'indeterminate'. I rang the lab and they thought I was the doctor. (Hamish, male, gay, 35 years)

Anticipation

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On the Thursday morning I got a call off the GP just to come in to discuss the test results, which, as soon as she said that, I just knew straight away. And then, so, when I went in there, she was like, “Oh, did anybody drive you here?” And I was like, “Oh well, now I definitely know.”

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And I remember her saying, “Oh, what do you think I’m going to tell you?” And I was like, “Oh, that I have HIV.” And she was like, “Yes, well, the first test did come back positive.”

That’s an interesting line: “What do you think I’m going to tell you?”

Because I think she knew that I already had figured it out.

(Rufus, male, gay, 28)

Anticipation

I guess she just thought I had an expectation that I might have it. And maybe that's why she thought I'd asked to go on PrEP.

Can you take me through with a bit more specificity exactly what happened? What exactly did she say to you?

She said something along the lines of, "I imagine you know why I called you back in." And I said, "No, I, I don't." And that's when she said, "I just wanted to let you know that you have, your test has come back positive for HIV." And, and, at that stage, I was, obviously, a bit in shock.

(Tobias, male, gay, 47)

Responsibility

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I had been getting ready for that moment for my entire adult life, but nothing could really prepare me for that moment. I was heartbroken that I had let myself down. [...] One of my thoughts was, “Oh, it actually happened.” I think as gay men we all, in some respect, expect to become HIV positive or at least we mentally prepare ourselves to become HIV positive. You know, that’s definitely a legacy of the epidemic. So, in that way I was like, “Oh wow, okay, so this thing since I’ve been expecting since I was 16 has happened.”

(Flynn, male, gay/bisexual, 27 years)

Treatment

Treatment

I just want to talk about how you were feeling at the time that they told you you had HIV.

I was pretty calm. I knew about the treatment before, like as in I was on PrEP a year before that. And then I stopped. So I'd heard about PEP and PrEP. So, [once] I knew about the diagnosis, the next thing I jumped to is already, "I need the treatment." That's it.

(Bernard, male, gay, 28 years)

Treatment

You said that you were sort of relieved. [Yes] Was that mixed in with any other emotions, or was it purely just relief?

Purely relief. It was good 'cause it was like, "Great. Now we know what it is. We can fix it or at least manage it." I don't like the question marks. I don't like grey areas. I don't like, you know, I like certainty, which I guess most people would. So yeah, it was just relief. I didn't, there was no emotional reaction. I didn't cry. I didn't gasp. It was nothing like that. I was kind of like, "Okay. Well, that's good that we know what it is now." Then he asked how I was feeling. I said, "To be honest, fine." Yeah. "What, what are we going to do? Like what's the next steps? Just give me ... I get hope through having next steps so tell me what we're going to do."

(Angus, male, gay, 28)

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Discussion

- Accounts of diagnosis indicated the complex ways in which participants managed feelings (e.g. evoking, shaping, suppressing) within these interactions (referred to as ‘emotion work’ [Hochschild, 1979]).
- Factors in shaping response to diagnosis: connection to the HIV epidemic, previous testing history, use of prevention technologies, and expectations of a positive diagnosis.
- Gay/bisexual men – reactions compared to expected/anticipated responses to diagnosis, and the strategies (cognitive, bodily and expressive) they pursued in reconciling discrepancies.
- Accounts of HIV diagnosis in 2019 share some similarities with earlier periods in the epidemic, but notable changes such the early antiretroviral therapy, and UVL, have changed clinical encounters.

Thank you

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