

Two sex workers' experiences of using pre-exposure prophylaxis: A narrative analysis

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This article is intended to accomplish two primary tasks: to reveal the experiences of sex workers using pre-exposure prophylaxis (PrEP), and to demonstrate how a narrative approach can contribute to the field of health psychology. Two sex workers were asked to describe and discuss their experience using PrEP, as well as their lives prior to starting on it. In order to gain a perspective on the individual experiences of sex workers using PrEP, a narrative approach to gathering and analysing data was taken. The results are reported by means of two descriptive narratives. The narratives of the sex workers described in the article show the ways in which social support is neither predictable nor consistent at the individual level. Sex workers, like all people confronted with HIV, have diverse experiences, and are influenced by a wide array of personal and societal factors.

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In South Africa (SA), in contrast with the non-communicable diseases, there are promising signs that the HIV/AIDS epidemic is declining.^[1] For example, the number of people newly infected with HIV decreased from 2.2 million in 2001 to 1.8 million in 2009. The annual HIV incidence among people aged 18 years decreased from 1.8% in 2005 to 0.8% in 2008, and more than halved among women aged 15 - 24 years, from 5.5% in 2003 - 2005 to 2.2% in 2005 - 2008.^[1] Further evidence from more recent statistics shows that between 2002 and 2008, HIV prevalence was relatively stable, ranging from 10.6% in 2002 to 11.4% in 2008.^[2] Zuma *et al.*^[2] state that the estimated overall HIV prevalence rate in SA is approximately 12.7% of the total population. The total number of people living with HIV was estimated to be approximately 7.03 million in 2016. In adults aged 15 - 49 years, an estimated 18.9% of the population is HIV-positive.^[2]

Sex workers have long been recognised as a high-risk group for HIV/AIDS and sexually transmitted infection (STI) transmission in sub-Saharan Africa.^[3] In SA, sex work is at present illegal; however, a highly visible industry exists throughout the country, particularly in urban centres and along trucking routes.^[4] Although epidemiological research among sex workers in SA is sparse, it suggests a high prevalence of HIV and STI infection.

Narrative analysis

Stephens^[5] states that narratives are the stories that people tell about their lives. Narrators render specific life events meaningful by linking them to other such events, and by providing a temporal ordering of these events. Narratives therefore describe the context for human activity – temporal, spatial, interpersonal and societal.

Because narratives are situated within a broader sociocultural context, they reveal social structures and processes (including those relevant to race and class), and not just personal realities. Through stories, individuals actively construct identities, revise them and try out alternative configurations of self.^[5-7]

A strength of the narrative approach is that it is rooted in how human beings typically understand and represent their lives. Arguably, the world must be interpreted in narrative form in order to make sense of the temporal nature of life.^[8] A narrative approach has increasingly been used to understand the experiences of illness, and its prevention, as in the present article.^[6,9]

Murray^[8] contends that illness is a type of 'biographical disruption' that challenges individuals to reimagine their life stories. Studying the narratives of ill people consequently reveals how illness is integrated into people's lives, and how various social factors impinge upon this process. In an effort to provide structure for the analysis of narratives, a number of theorists have sought to identify narrative 'types'.^[9-11] Frank's^[9] analysis of narratives of illness espouses a three-part typology. In this typology, he first describes the restitution narrative, wherein the teller minimises the experience of illness and sees it as a temporary interruption that will be overcome. The return to pre-illness 'normalcy' is the focus.^[9] The second type that he outlines is the chaos narrative, wherein the ill person loses any sense of order, meaning or purpose, and is unable to articulate a coherent path for dealing with the illness experience. Finally, there is the quest narrative, in which illness becomes a challenge to be met. Ill people who tell quest narratives typically see themselves as on a journey, on which heroic acts will be necessary and where good can overcome evil.^[9]

Ezzy^[11] studied the limitations of such typologies, including Frank's, and proposed an alternative system to make sense of his data on HIV-infected men. He included a temporal dimension to his categories, highlighting how time is key in people's framing of their lives. His first category, restitutive linear narratives, reflects the assumption that the future can be controlled through people's actions.^[11] Baumeister and Newman,^[12] in a similar vein to Frank's restitution narratives, had earlier argued that this assumes that what is out of balance can be put back into balance; sick people who return to wellness while constructing chaotic linear narratives, on the other hand, anticipate a life that cannot be brought under control, and will result in despair and depression. The emphasis of these narratives, according to Baumeister and Newman,^[12] therefore lies in the present, with the future portrayed as uncertain and ultimately unmanageable. However, chaotic linear narratives often include spiritual experiences, and tell of increased insight and deepened self-understanding.

Methods

Participants and setting

The two sex workers in the present study were recruited from the Public Health and Reproductive Unit (PHRU) at Chris Hani Baragwanath Academic Hospital (CHBAH), Johannesburg, SA. The two are part of a group of sex workers who were recruited for clinical trials of Truvada, a pre-exposure prophylaxis (PrEP) drug. Recruitment was through the PHRU, and participants were chosen according to a number of criteria. The inclusion criteria were that the sex worker must be HIV-negative, have been on the drug for a year, could both read and write English, and finally, was actively engaged in sex work at the time. This article limits its focus to the two sex workers specifically recruited for the study.

Data collection procedures

Two in-depth, open-ended interviews were conducted with each participant. This target number of interviews for study participants was decided upon after pilot interviews revealed that the topics to be covered were best explored over two meetings. Gaps between the meetings allowed the research team to review content and identify questions that might reveal missing or unclear information. Both sex workers were interviewed at the PHRU offices at CHBAH. A black African female in her 20s conducted the interviews with both participants described in this paper.

At the initial meeting, the sex workers were asked to review and sign a consent form. Spacing between the interviews was negotiated according to the needs and preferences of participants, while also allowing sufficient time for the research team to review and discuss the interview transcripts between the first and second meeting. The series of interviews proceeded in three general phases. In the first phase, the participants were asked to describe and discuss their sex work experiences. Participants were asked about their experiences as sex workers, i.e. how they got into sex work, and the nature of the work. In the second phase, participants were asked to describe and discuss their lives prior to becoming sex workers, starting from early childhood, including early relationships with parents and family members, schooling

experiences and romantic and sexual relationships. This part of the conversation focused particularly on those aspects of the participants' life accounts that were evidently important to them. The final phase involved asking the participants to discuss their experiences, in their everyday lives, of using PrEP, and to reflect on the links between their risk of HIV infection and the sex work they engaged in. Interviews were audiotaped and transcribed verbatim. Field notes were kept to assist in the interpretation of interview data.

Data analysis and reporting

In reading the transcripts and thinking about the core aspects of the narratives, the focus was particularly on details that showed how individuals' lives were connected to social and structural systems (e.g. workplace, family, the healthcare system). I was also alert to ways in which identities were being actively constructed in the context of shifting life circumstances and issues. In the process of identifying and reporting on core aspects of the participants' narratives, we made decisions on which other aspects to leave out. This streamlined approach to narrative display is not meant to suggest that study participants are entirely consistent or straightforward. Indeed, I readily acknowledge that participants' experiences, and consequently their narratives, are complex and fractured, and embody multiple perspectives simultaneously.

Results

The results are reported through two descriptive narratives. In order to honour our confidentiality agreements with study participants, identifying details have been altered – including names of people and places, dates and ages.

Nandi

Background

Nandi was a rebellious child. This enraged her parents, and after a series of instances of misconduct and punishment, they asked her to leave the house. She was 16 years old at the time (in her late 20s at the time of the interview) and her grandmother took her in. Her parents stopped taking care of her completely, meaning that they stopped giving her material support. Her grandmother was 66 years old and relied on a state pension that could barely sustain the two of them on a month-to-month basis. She was raped a few months after having moved in with her grandmother, and did not pursue criminal charges, but settled the case out of court, receiving an out-of-court-settlement fee from the rapist. The dire economic conditions and her desire to change her life led her into sex work. She paid for her university education with her earnings from sex work, and continues with this work to this day. She has no desire for a formal job, even though she supports formalising sex work, and wants to own a sex shop in the future. She has maintained an 'I do not care' attitude since she was young, and has no quality intimate interpersonal relationships. She has no close friends, and she does not speak to any of her family members. Her grandmother left her alone in the house when she moved to Limpopo, and from this house, Nandi does sex work.

Sex work and experiences of using PrEP

When Nandi was raped, she did not know how to deal with the trauma. She felt confused during the rape, asking how it was possible for something so gruesome to be so enjoyable at the same time. She hated the idea of forming meaningful relationships with men, but felt that she could not just let them be, and stay away from them altogether. Sex work meant that she was close enough to men, but with no obligation to relate to them. Sex work therefore provided a platform from which she could continue to enjoy sexual encounters with men, but without forming any significant relationships. In addition to this, at the time she became involved in sex work, she was in dire financial straits: 'I got to this industry because of poverty, and I wanted to have money to go to school to study further'. She has carried on with sex work even though she has completed school, because 'now that I am done I still feel like eh ... its, its ... being a sex worker is part of my life uhm ... it's not, I'm not actually selling sex because of poverty now, it's because of who you are, who you become ... so I don't have feelings anymore!'

She used to work with a group of other sex workers. They were under the management of a pimp, and were forced into using drugs. Unlike the other women, she worked from her own base – her grandmother's house – and she decided to go solo. She could not continue to use drugs, given that her goal was to go to college. She has fallen pregnant twice, and has had two abortions. She does not use any contraceptives other than condoms, and these at the discretion of the client. She regularly visits the clinic for testing and to collect condoms. She is generally healthy, and she maintains an active lifestyle and often goes to gym. She has a schedule of at least three clients a day. She has experienced violent encounters with some of her clients, and she has learnt how to deal with this. She fears not being paid, so her payment is cash up-front.

Visiting the clinic so often, she found herself joining the clinical trials for Truvada, a PrEP drug, which provides prevention from HIV infection for HIV-negative people with an active sex life. She has considered having children in the future, and does not want to contract HIV.

Story-telling style

Nandi spoke in an evocative, larger-than-life manner about her role as a sex worker. She adopted an activist approach in the interview, speaking of sex work as empowering for women that choose the experience and defending her choices, in a manner reminiscent of how she may have engaged with her peers on a daily basis. Although she was willing to talk about her sex work experiences, she was not optimistic about her future and often deflected from speaking about her experiences by engaging in more abstract topics.

Buhle***Background***

Buhle is in her 30s. She has no children, but finds herself in dire financial circumstances. She has worked menial jobs for paltry earnings. She sought to borrow money from a friend, who in turn introduced her to sex work. She has been living in Soweto for about

10 years now. She moved there from KwaZulu-Natal (KZN) to find work and change her life circumstances. She rents a backroom in someone else's yard. She has no family in Johannesburg, and has only a few close friends. She has always been a source of support for her family back in KZN, both materially and emotionally. She is quite sceptical of people in Soweto; she thinks they are 'shady' and misrepresent themselves a lot. She enjoys a good time, and therefore hangs out in drinking spots where she attracts her clients and alcohol. She claims she has never bought herself a beer – she is just 'too attractive for men to ignore'. She is quite chatty and has a good sense of humour.

Sex work and experiences of using PrEP

Being broke and facing eviction from her rented backroom, Buhle found herself at her friend's mercy. The friend was willing to not only give her the needed money, but also introduce her to her ways of money-making. The friend was a sex worker. Buhle was not opposed to sex work; she had simply never considered it. She had feared the potential repercussions of the work, such as not being paid, falling pregnant, contracting HIV and being raped or exposed to violence. Buhle has been involved in sex work for just under 2 years. Her material needs mean that she sees many clients, between 5 and 8 a day in a good week. She mostly engages in 'quickies' or 'short time', which are lucrative for her. She works from her backroom apartment. She giggles, 'There is money in this industry hey, there are some guys that need us, there are those men that need us, [and] we really help them a lot ... and ... yeah, I love money. I make, like it's quick, yeah.'

Her landlord is not too pleased about it, but as long as she pays rent, she can continue to stay there. She has brought many men into the yard. She has no preferences; all she wants is money. She engages in risky sex: some clients demand unsafe sex for a higher fee, and others refuse the option of safe sex and still want the same service. She visits the clinic with her friend to test for sexually transmitted diseases regularly. She also found herself registering for the clinical trials for Truvada, the PrEP drug.

Story-telling style

Buhle was largely nonchalant about her sex-work role, and quite sarcastic about her future in it. She used humour where she might have delved more deeply into her emotions. The imagery she used to describe her sex-work experiences, and the sarcasm, suggest that she uses irony to mock or convey contempt for sex work, perhaps because she is not ready to deal with the ramifications of her actions. Her use of sarcasm may have been intended to absolve her of responsibility for the feelings she endures.

Discussion

Narrative analysis shows that people use stories to define who they are to others. For instance, Nandi and Buhle each describe their role as 'sex worker' as essential to their survival, demonstrating why it is necessary to remain in the role.^[13] Yet they are confronted with the realities of ill health and exposure to violence. The construction of sex work as meaningful labour that deserves compensation, and protection from the state, by some human rights and feminist

movements – through telling the stories of women – has led to their adoption of the identity of ‘sex workers’.^[14] The identity of a sex worker is described by such human rights and feminist organisations, modelled by members in their personal stories, and used by new members to learn the requirements of the new identity.^[15]

Narratives do not reveal an ‘essential’ self, but rather, a preferred version of self which is appropriate to the social context of the telling.^[16] Harré and van Langenhove^[17] provide a theoretical account of narrative positioning to explain the interplay of biographical identity and the social situation of the story-teller. This approach describes the shifting narrative identities of the women who justify being sex workers to others.^[17,18] Buhle’s narrative about being so beautiful that no man can resist her, and her comment that there is money to be made, reveal the roles played by social spaces and embodiment to align her preferred subject positioning as a sex worker.^[11]

Morality, in this context, is useful to understand positioning as a powerful force shaping the narratives. To be a female sex worker in many societies is to risk being seen as a threat to ‘honest women’ and the matrimonial order, and hence not a virtuous citizen; therefore, a sex worker must work harder to position herself as a good person.^[19] For example, when Nandi spoke about sex work being part of her life, this was about demonstrating her position as a virtuous member of society, in a bid to normalise what society would generally ostracise.^[20] In SA, recently, sex workers have expressed a strong wish for their work to be recognised as a ‘normal profession’, and accordingly, accounts are constructed to position sex workers as people with everyday concerns, rather than dwelling on the moral and health issues that set them apart from more conventional workers.^[21]

Story-telling is not only about embodied experience, but is an embodied performance that is constructed in accordance with the material conditions of the telling, including who is able to speak and what may be said in the situation.^[22] Stories are told to an audience, and so the construction of narrative may be understood as a joint enterprise with an active audience. Rather than being simply an account of past actions, stories include the time of the telling and the particular accomplishments of that moment. That stories are told to an audience, in this case an interviewer, makes these particular narratives co-constructions of the interviewer and participant. This does not mean that Nandi and Buhle’s stories are not valid or valuable, but that the specific relationships in this context produced certain accounts.^[20,23] It is important to always consider that interviewers are not neutral bystanders, and their direct contribution to shaping the narrative, as well as their representation of a broader social world to which the narrative is oriented, cannot be minimised or ignored. However, considering the cultural basis of dialogues in everyday life, these interviews produced narratives that are suited to the social and historical contexts in SA townships.

Using narratives is important in health psychology because, as a form of self-care, personal stories are a means by which a sick person can take control over the illness, and so bring order to a chaotic world.^[8] This is so because illness, particularly when life-

threatening, brings chaos to the everyday world of the sick person. According to Murray,^[8] the illness narrative seems to remove guilt from the narrator, or at least to assert a relative degree of responsibility. Beyond this catharsis, illness narratives are essential in the reconstruction of identity. Murray^[8] consequently describes chronic illness as a particular kind of disruptive event in the sick person’s personal biography where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Therefore, the individual begins to establish an understanding of chronic illness within the context of this personal disruption to his or her life story.

Hinyard and Kreuter^[24] bring our attention to theories through which narratives may influence health-behaviour change: behavioural modelling and observational learning, changes in cognitive readiness and perceived social norms. They suggest that through social cognitive theory, individuals can learn a behaviour and will be more likely to perform it if they see the model reinforced for the behaviour in ways that appeal to them. The use of personal experience narratives therefore promotes observational learning. Hinyard and Kreuter^[24] further argue that through the precaution-adoption process model, exposure to narrative characters who are perceived by the audience to be similar to themselves may move participants closer to taking action for a particular health behaviour. Finally, narratives told by individuals who are perceived as similar to the audience, or with whom the audience identifies, may help position health behaviours as normative.

Conclusion

In conclusion, a narrative approach to studying illness allows a more intimate and complex understanding of the experiences of ill people than more traditional health psychology approaches have realised. Although the present article is not focused on illness experiences per se, it contains narratives of health in terms of preventing illness. The narratives of the female sex workers show how the interaction of gender with health and illness is neither predictable nor consistent at the individual level. Female sex workers have diverse experiences and are influenced by a wide array of personal and societal factors. While the high risk of HIV infection makes proactive interventions advisable, such interventions will be most effective if the heterogeneity of female sex workers’ experiences is taken into account. Health psychology researchers will benefit from attending more to the stories that people tell.

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