

'Waiting at the dinner table for scraps': a qualitative study of the help-seeking experiences of heterosexual men living with HIV infection

Tony Antoniou,^{1,2} Mona R Loutfy,^{3,4,5} Richard H Glazier,^{1,3,6,7,8,9} Carol Strike⁷

To cite: Antoniou T, Loutfy MR, Glazier RH, *et al*. 'Waiting at the dinner table for scraps': a qualitative study of the help-seeking experiences of heterosexual men living with HIV infection. *BMJ Open* 2012;**2**:e000697. doi:10.1136/bmjopen-2011-000697

► Prepublication history and additional appendix for this paper are available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2011-000697>).

Received 30 November 2011
Accepted 18 June 2012

This final article is available for use under the terms of the Creative Commons Attribution Non-Commercial 2.0 Licence; see <http://bmjopen.bmj.com>

For numbered affiliations see end of article.

Correspondence to

Dr Tony Antoniou;
tantoniou@smh.toronto.on.ca

ABSTRACT

Objectives: To characterise the help-seeking experiences of heterosexual men living with HIV infection and explain these experiences in relation to the broader social relations and discourses in which they are embedded.

Design: Qualitative study using focus groups and theoretically informed constructionist grounded theory.

Setting: With one exception, focus groups were conducted in the offices of community-based AIDS service organisations across Ontario, Canada.

Participants: 40 HIV-infected heterosexual men aged 18 years or older.

Results: Heterosexual men living with HIV perceive themselves to be relegated to the margins of a health care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women living with the virus. Specifically, gay men are better positioned than heterosexual men when vying for the services and recognition of AIDS service organisations due to their social capital within these agencies, thereby benefiting by virtue of their membership with the group perceived to control the decision-making apparatuses when resource allocation and programme development are at stake. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being perceived as the 'guilty' parties in the context of heterosexual HIV transmission. As a result, the material and support needs of women have been prioritised, while those of heterosexual men living with HIV remain largely unaddressed.

Conclusions: Heterosexual men living with HIV are operating within a health and service field that has not kept pace with their increased representation among the population of persons living with the virus. Researchers, clinicians and policy makers should strive to integrate heterosexual men living with HIV in decision making and community-based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.

ARTICLE SUMMARY

Article focus

- The prevalence of HIV infection among heterosexual men in North America and Western Europe is increasing.
- Very little empirical research exists examining the help-seeking experiences of heterosexual men living with HIV.

Key messages

- Heterosexual men living with HIV are navigating a healthcare and service field that has not kept pace with their increased representation among the population of persons living with the virus.
- Lacking in the symbolic appeal of heterosexual women living with HIV and the social connections of gay men, heterosexual men living with HIV have neither the requisite composition nor the volume of capital required to benefit fully from or improve their positions within the existing HIV-related health and service field.
- In keeping with the principle of Greater Involvement of Persons with HIV, heterosexual men living with HIV should be integrated in programmatic development that addresses the support and health needs of this group.

Strengths and limitations of this study

- This is the first in-depth critical examination of the help-seeking experiences of heterosexual men living with HIV.
- We did not include the perspectives of HIV researchers, clinicians, policy makers or staff of AIDS service organisations.

INTRODUCTION

Globally, approximately 34 million people are estimated to be living with HIV.¹ Although unprotected sex between men remains the predominant mode of transmission in most of the developed countries of North America and Western Europe, the number of new infections attributable to heterosexual transmission has been steadily increasing in these

jurisdictions over time.¹ However, despite the increasing importance of heterosexual transmission in sustaining the HIV epidemic in developed countries, very little empirical research exists describing the health and help-seeking experiences of heterosexual men living with the illness.^{2–7} This gap in the literature is important for several reasons. First, there has been a marked increase in the prevalence of HIV infection among men infected through heterosexual transmission, such that approximately 18.8% of patients accessing HIV-related care in UK in 2009 were men infected via heterosexual sex.² Similarly, though this group accounted for <5% of all cases of HIV prior to 1990 in the province of Ontario, Canada, heterosexually infected men represented 13.8% of HIV diagnoses among men in 2008.³ These trends are likely to continue in parallel with the increasing numbers of HIV-infected individuals immigrating to Canada and UK from countries with a high prevalence of infection, the majority of whom acquire the virus via heterosexual transmission.^{2 3 8} Furthermore, the profound impact of combination antiretroviral therapy on the prognosis of HIV infection has resulted in a substantial decrease in disease-related mortality in Western countries.^{9–13} As a result of this improved outlook, the need for healthcare and support services for HIV-infected heterosexual men is likely to increase. Finally, because currently funded HIV-related health and support programmes were rooted largely in the political mobilisation of gay and lesbian communities in the early years of the epidemic,¹⁴ and informed further by subsequent socio-political action on the part of women living with HIV,^{15 16} the existing array of services may be ill equipped to provide care and support for the increasing numbers of heterosexual men living with the virus. However, empirical research examining the experiences of heterosexual men living with HIV when navigating the available complement of HIV-related treatment and support services is presently lacking. These data have important implications for clinicians, policy makers and researchers who work with HIV-infected heterosexual men and who are involved in the planning, coordination and financing of HIV-related services.

In order to address this large gap in contemporary HIV knowledge and to inform continued policy on how best to provide care for the evolving and diverse community of people living with HIV, we undertook a qualitative study that sought to characterise the help-seeking experiences of heterosexual men living with HIV and explain these experiences in relation to broader social relations and discourses. That is, we wanted to understand what it is like to be a heterosexual man living with HIV trying to access help and theorise about the basis of any challenges associated with this process.

METHODS

Theoretical framework

The theoretical framework used to inform the analysis of our data drew upon the commensurable perspectives of Erving Goffman's pioneering work on stigma and iden-

tity management and Pierre Bourdieu's conceptual framework of 'structural constructivism' (see e-appendix).^{17–20} Structural constructivism provides an analytic framework and conceptual arsenal that relates the subjective accounts and experiences of participants with aspects of the social environment (ie, social relations) and discourses in which help is provided. By discourse, we refer to language, images, systems of thought and symbols that represent and/or construct individuals and aspects of their social world.²¹ From this perspective, we were interested in how participants drew upon and/or resisted particular discourses when characterising their experiences.

Data generation—sampling and recruitment

We conducted eight focus groups (4–6 participants per group) with heterosexual men living with HIV who were sampled with the assistance of community-based AIDS service organisations (ASOs) in Ontario, Canada. We used sampling strategies that are well established for qualitative research. Specifically, we used non-probabilistic purposive sampling to recruit self-identified heterosexual men living with HIV who were 18 years or older and could speak to the experience of seeking HIV-related care at an ASO or within the broader healthcare system.^{22 23} We set a minimum quota of two focus groups comprised exclusively of men who had immigrated to Canada from Africa or the Caribbean and altered our sampling approach mid-way through the project to focus on recruitment of men living in small urban centres lacking a strongly visible gay and lesbian community to identify concepts and experiences that might be in exception to those generated by the analysis undertaken to that point. Our sampling approach was developed to seek variation in social background and context, rather than generalisability to the entire population of heterosexual men living with HIV.^{22 23}

We used focus groups to generate the group interaction and raw accounts that would undergo subsequent analysis and interpretation.²⁴ With the exception of a single focus group held at a teaching hospital in downtown Toronto, focus groups were conducted in the offices of the ASOs. We developed our focus group guide in collaboration with a community advisory board of five heterosexual men living with HIV. Discussion among the participants was facilitated by a male researcher (TA) utilising open-ended questions regarding the availability, accessibility and quality of existing services for heterosexual men living with HIV. However, most of the conversation produced in the focus groups was instigated by the dynamic interaction between the participants. As part of the focus group, we asked all participants to complete a brief sociodemographic questionnaire. Each focus group lasted approximately 2 h and was audiotaped and transcribed for subsequent analysis.

Data analysis procedures

We integrated aspects of constructionist grounded theory with our theoretical frameworks to analyse the

focus group transcripts and conducted our analyses concurrently with data generation to both pursue concepts being developed and adapt our sampling approach to seek out cases and experiences that could deviate from emerging patterns.^{25 26}

For each focus group, one of us (TA) reviewed the written transcripts while listening to the audio recording to supplement the transcripts with notes regarding tone, silences and group interaction. Following this initial pass at the data, we used line-by-line coding and memo writing to analyse the transcripts, moving iteratively between the data and our theoretical framework. Initial codes were derived both from the words of the participants (eg, ‘gay disease’, ‘discrimination’) and from interpretations of data segments as being representative of socially constructed phenomena or identities (eg, ‘stigma’). For each section of coded data, we produced a memo that was cross-referenced by transcript, page and line numbers. Memos were written to elaborate on line-by-line coding and interrogate the participants’ accounts and group interaction with theoretically driven questions such as ‘How are participants’ identities being constructed?’, ‘How is the particular help-seeking environment discussed being characterised?’, ‘What is this segment an instance of?’, ‘What discourses are reproduced and/or resisted?’, ‘What circumstances produce this action and/or interaction?’, ‘Why this pattern of narrative?’ and ‘What are the participants doing in this segment?’. Using word processing software, similarly coded data were extracted from the entire transcript corpus and re-assembled into data clusters that were assigned analytic labels representing the varied dimensions of the help-seeking experiences of heterosexual men living with HIV and the different manners in which this phenomenon was understood by the participants. We repeated the process of coding and memo writing, cycling iteratively between the focus group data and theoretical frameworks until we had developed well-theorised concepts that related the accounts of the participants with the objective social relations and discourses in which they were embedded. In this manner, we produced an analysis that was theoretically informed but always grounded in and tethered to the data at hand.

Ethical considerations

We obtained written informed consent from all participants. Because of the potentially sensitive nature of the study, we verbally reinforced the importance of respecting the privacy of coparticipants once outside the confines of the focus group setting. We obtained approval for the study from the Ethics Review Committee of the University of Toronto and the Research Ethics Board of Women’s College Hospital.

RESULTS

Characteristics of the participants

The demographic characteristics of the participants are summarised in table 1.

Table 1 Characteristics of focus group participants

Characteristic	Focus group participants (n=40)
Median (IQR) age (years)	48.5 (42.0–55.0)
Years HIV positive (median, IQR)	7.5 (4.0–12.0)
Country/region of birth	
Canada	19 (47.5%)
Africa	9 (22.5%)
Caribbean	4 (10.0%)
Other	3 (7.5%)
Incomplete	5 (12.5%)
Relationship status	
Married/common law	12 (30.0%)
Separated/divorced	8 (20.0%)
Single	16 (40.0%)
Incomplete	4 (10.0%)
Number of dependents	
0	18 (45.0%)
1	4 (10.0%)
2	1 (2.5%)
3	5 (12.5%)
≥4	6 (15.0%)
Incomplete	6 (15.0%)
Employment status	
Full-time	6 (15.0%)
Part-time	6 (15.0%)
Unemployed	2 (5.0%)
Volunteer	1 (2.5%)
Student	2 (5.0%)
Retired	1 (2.5%)
Social assistance	18 (45.0%)
Self-employed	1 (2.5%)
Incomplete	3 (7.5%)
Highest level of education completed	
Less than grade 9	6 (15.0%)
High school	14 (35%)
Trade/technical school	1 (2.5%)
College	11 (27.5%)
University	4 (10.0%)
Incomplete	4 (10.0%)
CD4+ cell count	
>200 cells/mm ³	23 (57.5%)
<200 cells/mm ³	4 (10.0%)
Don’t know	12 (30.0%)
Incomplete	1 (2.5%)
Viral load	
<50 copies/ml	20 (50.0%)
>50 copies/ml	1 (2.5%)
Don’t know	17 (42.5%)
Incomplete	2 (5.0%)
Ever hospitalised for HIV-related illness	
Yes	15 (37.5%)
No	21 (52.5%)
Incomplete	4 (10.0%)
Current use of antiretrovirals	
Yes	35 (87.5%)
No	3 (7.5%)
Incomplete	2 (5.0%)

Concepts and findings

Spatially acquired stigma: the discrediting potential of help seeking

For most participants, the perception that HIV is an infection harboured within the 'tainted' bodies of gay men, injection drug users and sex trade workers is reproduced and reinforced among their own social networks and in the broader heteronormative social sphere. Because of this potential association with 'problematic' identities, seeking HIV-related healthcare or support services becomes potentially discrediting for heterosexual men living with HIV. That is, the stigma associated with the problematic imputations that come with being HIV positive becomes grafted upon the clinics and ASOs that provide care to individuals living with the virus. Therefore, participants are wary of being seen engaging with these sites for fear that it may inadvertently undermine their efforts at controlling information pertaining to their illness among their own social networks.

I: Do you think that could deter some people though, from coming in, like some infected guys from coming in?

P1: I hear a lot, you know, for sure, definitely. Yeah, yeah. "I'm not going there."

P2: This is one of the first groups I've ever been to.

P3: The same with thing with the hospital, like a doctor. Like, if-

P4: Dr _____, you mention his name, the first thing that people pop up, "Oh, he's an AIDS doctor."

Help seeking at HIV clinics or ASOs therefore becomes a threat to the ability to balance disclosure and manage a complex discreditable identity among heterosexual men living with HIV. However, the discrediting potential of help seeking for participants extends beyond the subversion of disclosure containment strategies. In addition, participants are fearful of potentially calamitous consequences associated with being seen entering or exiting sites that are constructed in their social circles as 'AIDS buildings'. Specifically, the participants were concerned that being seen engaging with an agency or clinic known to provide HIV-related care could prove deleterious to their livelihoods or jeopardise relationships with family and friends, a reality endorsed by some participants in the study. Furthermore, the potential for transmitting this spatially acquired stigma to children was of particular concern for participants who were fathers:

P: I, um, I won't go anywhere with a sign that says 'HIV' or 'positive'. I have kids, so I worry about parents of my kids friends, who now won't want them to play with my kids because they, because I have HIV "I don't want you to hang around, cause his dad ..." sort of thing.

In this manner, spatially acquired stigma becomes potentially transferable to children through lineage in a manner akin to the tribal stigmas of race, nation and religion described by Goffman.¹⁷ These concerns were

especially salient for men of African and Caribbean origin, for whom the stigmatising consequences of seeking help at community organisations which cater to their particular racial demographic were potentially transferable to their families both at home and abroad.

Spatial marginalisation: mismatched and poorly positioned at ASOs

Because of the centrality of ASOs in the HIV-related help-seeking arena, it was not surprising that a great deal of talk generated in the focus groups related to experiences accessing care from these agencies. The gaps in healthcare for which heterosexual men living with HIV most commonly sought the assistance of an ASO were in the realm of counselling and social support, although these sites were also occasionally utilised for accessing HIV-related care provided by physicians and nurses working on-site. However, help seeking at an ASO occurs within a network of social relations and discourses that converge to produce a perception of being mismatched and marginalised in these agencies. Specifically, participants described being out of sorts or ill at ease in the social space of an ASO, which is dominated mostly by gay men in terms of clientele, staff and decision makers, and frequently conflated these agencies with the 'gay community' at large, seeing the former as a microcosm of the latter:

P1: Support exactly what he's saying. Even the AIDS organisations that we have in Toronto, go to the offices, I don't want to mention names, but go to the offices. All the people, the staff, everybody that you get there, they're gay.

P2: Yeah, there are gay communities.

P3: It is the gay community (note: underline added to denote participant emphasis)

The perception of ASOs as an extension of the gay community is most palpable among participants living in large urban centres, where the identity of these agencies remains closely connected with the history of political activism on the part of local gay and lesbian communities that marked the early years of the epidemic.

P1: Some of us aren't going anywhere. We go to the same, the organisation.

P2: The same gay organizations.

P3: Yeah, we go to the same organizations, but you can't blame them, they created this stuff. They were the ones in the crisis, you know? It's like, they were the ones who needed it and they fought for it. And now we're looking to them for helping right?

When viewed in concert with other data (eg, 'this space is for gay people') and filtered through a constructionist lens, heterosexual men are reconstituting and reproducing ASOs as 'gay terrain', or spaces in which they do not 'really fit in' or belong, and are therefore not comfortable availing themselves of the various counselling or supportive services provided by

the predominantly gay male staff. The men describe this perception of ASOs as 'gay terrain' as being prevalent in the heteronormative social world in which they usually reside and sustained by durable perceptions of HIV as a 'gay disease' within their social circles.

P1: It was just, you're just labelled 'gay'. You know, if you tell anybody you come here, they just think, for sure, you're a hundred percent gay ...

P2: Yeah, must be gay.

P3: Yeah.

P2: ... because you gotta be.

P1: Yeah, a hundred percent.

P2: You just gotta be. You know?

P3: Yeah. How else could you have gotten it?

Importantly, the men believe that ASOs are reinforcing this association by developing HIV-associated programmes and educational materials that target principally the gay community.

P: So the public out there, they even, now they have all the gay men club, gay men this, gay men club, even the ASO also think that, ah, the disease is for gay men. So they have programs for gay men, they don't, they don't, they don't think outside of the box, ah, the disease is no more a gay man disease.

As a result of the construction and perception of ASOs as 'gay terrain', a lack of congruence develops between the distinctive set of heteronormative 'masculine' dispositions acquired and internalised by the focus group participants throughout their personal histories and the social environment they must navigate when seeking HIV-related help. In effect, there is a mismatch between the social constitution of heterosexual men and the social space of an ASO. In response to this mismatch, participants would frequently draw upon discourses of a hegemonic masculinity to create a social context within the focus group that is more closely aligned with their heterosexual disposition.²⁷ For example, in the following segment, the men 'do' gender by transforming the ambivalence of P1 at receiving a massage from a 'gay guy' into an opportunity to reassert a group masculinity by convivially invoking gendered and sexualised stereotypes of the 'female masseuse':

P1: Like for myself, I haven't actually used any of those services. I've looked, and I thought it would be nice to go get a massage, and I've said "Okay, except, this would be awfully weird, to go, you know, have a massage by a gay guy and then be all ..." And I was looking, don't bother, right?

P2: You're assuming that it's a male ...

P1: Yeah, ah, or, it's just that, ah, I just thought, okay, it's too weird ...

P2: Cause there is women that do it too—just saying

P4: Oh yeah, that's nice ...

(laughter)

In effect, the men utilise language and imagery to reconstruct the focus group as a 'masculine space',

thereby demarcating, albeit transiently, a heterosexual zone within the gay terrain of the ASO that more closely resembles a social milieu with which they are accustomed and at ease. These actions are enacted both in the local context of the focus group (and perhaps 'performed' in reaction to the presence of the male researcher) and mirrored by attempts to claim designated space and time within ASOs that could be allotted for peer support groups and social functions that provide opportunities for connecting with other heterosexual men living with the virus, much in the same manner that gay men and heterosexual women are able to secure these same opportunities for social connection within these organisations. However, efforts to satisfactorily carve out such space and identity within an ASO are undermined through spatial intrusions by heterosexual women and gay men during structured activities that are designated for heterosexual men only, incursions that they feel would be met with repercussions if repeated by them:

P: But if you try to walk in a women's group, or a gay men's group, oh, you're gonna hear about it. But us, it's like, ach, they're just six straight guys, don't worry about them.

Participants believed that, short of receiving government funding for an ASO that caters to the concerns of heterosexual men and their families, their best chance for securing a share of resources allotted to existing agencies is contingent on improving their position within the social hierarchy of these organisations. However, the mismatch between the identity of a heterosexual man and the social space of an ASO also has consequences when these men attempt to improve their social and political positions within these organisations. For example, concerted attempts by heterosexual men to increase their group visibility and affect programmatic change within an ASO through volunteering are seen as being largely in vain, given their perceived lack of access to the decision-making apparatuses controlled by the dominant social network of gay male staff within these organisations:

P: Instead of having one particular, ah, ah, status of people dominating the entire services, controlling what the policy. And therefore, they have very little for us, without us having an impact.

A similar problem ensues when seeking paid positions within an ASO. Although heterosexual men do not describe overt discrimination based on questions about sexual orientation when applying for jobs at an ASO, social disadvantage is created during this process through the use of interview questions eliciting the degree of comfort with doing outreach work at bathhouses or counselling gay male clients about safer sexual practices. Thus, heterosexual men see themselves as tacitly lacking in the social qualifications required to compete for work at an ASO, even if all other criteria in terms of

educational background or skill are met. In the segment that follows, the disadvantage becomes embodied, in that gay men are perceived to have acquired a corporeal knowledge that provides a practical edge in the social space of an ASO when materialised as body language:

P: We got the same NGO, but the environment, even people, the hiring committee are all gay men. So they know their partner; they know the body language of a gay man, all these things. They serve as an indicator that.

Without the social connections and qualifications considered essential for improving their position within ASOs, heterosexual men perceive themselves as being relatively powerless when attempting to gain any traction establishing social support programmes for their respective demographic. As a result, these agencies can become sites of contention and frustration for heterosexual men living with HIV.

P1: And we wanted something here.

P2: I think it was a fight for funding.

P1: Yeah. But we just, like, he says, we feel like we're the minority. And now we're like the gay men back in the early seventies, that we're fighting for whatever we can get.

P3: Yeah.

P1: If we get it, we get it. If not, well, we're, there's not enough of us to fight.

'I'm in a safe environment now': the modifying effect of social context

A less tense relationship between ASOs and heterosexual men living with HIV is apparent in the narratives of participants living in cities where these organisations are less closely identified with gay political activism. In these smaller urban centres, the identity of the ASO itself is managed in a manner that disentangles the agency from both HIV and the local gay and lesbian community.²⁸ For men living in these cities, ASOs are less likely to be perceived as 'gay terrain' and are instead viewed as sites of asylum from a 'mainstream' social world in which the consequences of disclosure and its resultant association with problematic identities could be devastating. Therefore, while help seeking can still be discrediting for these men if they are seen using the services of an ASO, these agencies were less often characterised as sites of contention by participants living in these cities and were instead seen as safe spaces in which refuge could be found from a world in which they risk being judged and socially 'othered'.

P: I came in here and nobody said they have HIV. Nobody asked me if I had HIV. Somehow they are, I think I may have went through the HIV thing one time, to file or whatever. But after that, everything was like, 'Okay, I'm in a safe environment now. And these people then are going to try to look after me.' So I felt comforted there.

However, participants in these cities still lamented on the lack of positions and services for heterosexual men

living with HIV within ASOs. Like their counterparts from larger urban centres, participants in smaller cities felt that the addition of peer support and a heterosexual male presence in the form of counsellors, support workers and prevention workers could augment the resources available to their demographic and simultaneously challenge the prevailing notion that HIV is a 'gay disease' among the mainstream social world they feel forced to hide from.

P1: But you know, we need more straight guys, filling some seats, offering the care, because it's a lot easier to talk to somebody, (laugh) who's at the same orientation. Like, it's just easier to communicate. (laugh) You know what I mean?

P2: I think it's a good idea to see HIV, like in general.

P3: Yeah, it's not a gay disease. It's an everybody disease

'Women are the heterosexual face of HIV': lacking symbolic appeal when seeking help

Heterosexual men characterise HIV-related health and support services as having been 'feminized', such that clinics and agencies privilege the needs of heterosexual women living with the virus. That is, women are perceived to receive greater priority than men in areas such as social support, housing, financial assistance and reproductive and sexual health. This disadvantage manifests itself both in ASOs and within the healthcare system, where specialised services for women living with HIV are seen to have proliferated.

P: We've got the Women's Hospital, the women's clinics, everything here is about ah, women, women all the time. And I think it's now time that, ah, really we men are also address the ah, I feel honoured that I'm participating in this group. Thank you.

However, in contrast to their poor positioning relative to gay men, it is not lack of membership in a dominant group that fuels disadvantage in the help-seeking arena, but rather contextual transformation of the identity of heterosexual men into the 'problem' of HIV infection in women. That is, heterosexual men have taken up and in some cases, internalised the discourse of the 'vulnerable' woman in the field of HIV help seeking. The vulnerability discourse, or paradigm, recognises the role of gender inequality and structural disadvantage (eg, poverty, violence) in driving the risk of HIV acquisition among heterosexual women, particularly in the developing countries of the world.²⁹ While this discourse has been instrumental in advancing the social and medical concerns of women living with HIV, the images and language used to construct the 'vulnerable' woman have positioned heterosexual men as categorically responsible for HIV infection in women.

P1: It's equated with, ah, women. So like there was recently, I saw this list, of like, priorities for some, it was some policy research thing. And, they listed all the different areas of priority and all the different groups. So,

um the you know, when it comes to sort of the category of heterosexual, the only thing that was represented was just women. But you see gay men, MSM, ah,—but women are, women are the heterosexual face of HIV in some way.

P2: Yeah.

P3: Mmm-hmm.

P4: Yeah.

I: How do you think this has happened, like how has that -

P3: Because they are, they are classified and they are always the victims. And we are the ones to blame. We have all brought it home.

It was fairly common for heterosexual men to take up a discourse where women were ‘victims’ and they were constructed as ‘predators’ or ‘victimizers’ in the context of the continued heterosexual transmission of HIV. Thus, while both heterosexual men and women may be stigmatised by HIV infection, heterosexual men also become morally ostracised through their discursively constructed identity of being ‘guilty’ of creating HIV-positive ‘victims’ for whom sympathy and protection are warranted. Although some men in the focus groups resisted this identity for themselves, the construction of the heterosexual female ‘victim’ was nonetheless largely accepted as pervasive in the HIV service field by the men and interpreted by them as the underlying reason for which women have become ‘the heterosexual face of HIV’. Because of the negative image imparted to heterosexual men by this discourse, the participants perceive themselves to be poorly positioned relative to women when seeking help in an environment that affords the latter group greater symbolic appeal than the former. Heterosexual men therefore become aware of and describe their sense of place relative to women.

P: But I’m saying men are last. And when they say men last, they don’t mean all men. They mean heterosexual men are last. You know what I mean, they don’t look at men, heterosexual men as men with families, and men that, they’re responsible. We’d looked as men that, that we carry the worst of everything.

Consequently, because of their greater symbolic appeal, women are perceived by men to receive greater priority by funding bodies, community-based researchers and providers when health and support services for heterosexuals living with HIV are developed. That is, for these participants, their material and support needs as heterosexual men who are also fathers, husbands and, in many cases, socially isolated remain largely unaddressed while similar concerns for women become prioritised by HIV researchers, clinicians and policy makers.

I: But why do you think there are more services for straight women than men?

P1: It’s more accept, it’s accepted a lot more by mainstream community, a HIV positive woman, [I: Okay] than, than an HIV positive man.

P2: Yeah, it’s like, it’s kind of like you don’t help the guilty, you, you help the, victim.

Capital and strategic practices

Considered as a whole, heterosexual men describe a help-seeking field in which their composition and volume of capital positions them poorly in relation to gay men and heterosexual women living with HIV. Specifically, gay men are better positioned than heterosexual men when vying for the resources and recognition of an ASO due to their social capital within the space, thereby benefiting by virtue of their membership with the group that occupies the decision-making positions within these agencies. Relative to women, heterosexual men are poorly positioned due to their negative symbolic capital, derived from being produced as the guilty parties in the context of heterosexual HIV transmission. The net effect of their poor configuration of capital relative to both heterosexual women and gay men is that heterosexual men perceive themselves to be an afterthought when funding for health services or ASO programmes is at stake. As a result, these men resign themselves to accepting whatever they can get in the way of services after the priorities of gay men and heterosexual women are addressed. Lacking in the social capital of gay men and endowed with negative symbolic capital in relation to heterosexual women, one participant summarised the lot of heterosexual men seeking help as follows:

P: This might be a little extreme, but I feel like the dog waiting at the dinner table for scraps, cause that’s all we’re getting.

In response to their poor positioning in the help-seeking field, participants pursued several strategies that can be interpreted as efforts to accumulate the capital required for improving their position. For instance, in an effort to acquire the social capital necessary to improve their positions within ASOs, heterosexual men volunteer within these organisations to increase their visibility as a group and gain recognition from the predominantly gay male staff perceived to control the decision-making apparatuses within these agencies.

P1: We all volunteer, almost every straight guy that’s here, volunteers here. That says a lot.

P2: But that’s the way we can also get attention, is by being here and doing stuff like that. That’s how we get recognized by the staff.

In contrast to gaining social capital through volunteering, other men seek to acquire the embodied capital of gay men. That is, some participants attempt to emulate corporeal traits and gestures perceived to be hallmarks of the body language of gay men, thereby trying to gain ‘membership in the club’.

P: It’s, it’s smart. You’re like, like, when some benefit will come, say for gay men, and they ask “Okay. Are you gay?” Myself, sometimes, I, yeah, I do sometimes lie. Because like, I got dozens of gay friends, I go to the gay village; I watch the way they talk and move. So when I will go

somewhere, and they say “Oh, this service is for gay men”, I can act gay, (laughter), because I have no option eh? If I don’t lie, I won’t benefit from that opportunity there.

These men characterise this form of identity management as a survival strategy within the social space of an ASO, as ‘like takes care of like’. Strategies directed at countering negative perceptions about the implied culpability of men in the heterosexual transmission of HIV were not apparent in the data.

DISCUSSION

The results of our study indicate that heterosexual men living with HIV are relegated to the margins of a health-care and service field that was developed historically within a context that privileges the priorities of gay men and heterosexual women. Furthermore, without the symbolic appeal of women and the social connections of gay men, heterosexual men have neither the requisite composition nor volume of capital required to benefit fully from or improve their position within the HIV health and service fields. Consequently, these men do not benefit fully from the existing array of services developed for other groups living with HIV and lack the capital necessary to advocate for more recognition from the clinicians, researchers and ASO staff perceived to influence decisions about funding and policy.

Our study has several important implications. In keeping with the principle of Greater Involvement of Persons with HIV (GIPA), a declaration signed by 42 countries including Canada and the UK, researchers and policy makers should strive to involve and integrate heterosexual men living with HIV in decision making and community-based research initiatives that build capacity among this group while simultaneously generating a research and policy agenda specific to the concerns of this growing demographic.³⁰ The benefits of contributing to research and policy formulation among individuals living with HIV are well documented and include establishing feelings of self-worth, mitigating stigma and increasing independence and personal empowerment.^{31–35} We argue that the same opportunities to realise these benefits should be extended to heterosexual men living with the virus. Furthermore, ASOs should invest in the creation of peer support, educational programmes and prevention initiatives that are staffed by and speak to the heterosexual community of men affected by or at risk of HIV infection. Such initiatives may begin to challenge mainstream constructions of HIV as a ‘gay disease’ and perceptions of ASOs as ‘gay terrain’. The establishment of such initiatives will also grant these men the opportunity to reproduce the camaraderie cited as a highlight of participation in the focus group by participants in the study. Frequently, these men contrasted their own isolation with the numerous structured opportunities for social engagement available for women and gay men living with HIV and voiced their desire for similar opportunities for

bonding and peer support. Additionally, it is imperative that the identity of heterosexual men living with HIV become emancipated from the image of the HIV predator that was perhaps inadvertently created by the ‘vulnerability’ paradigm and is currently reinforced by media constructions of the HIV ‘monster’ when characterising men who are convicted of transmitting the virus to unknowing partners.³⁶ It is noteworthy that strategies directed at countering the problematic construction of heterosexual men in relation to women were not evident in the talk of the participants. This may reflect a difficulty in openly challenging a discursive construction that is embedded in language and imagery, and to some extent, internalised by the participants themselves. We therefore encourage providers, researchers and policy makers to acknowledge the plural identities of these men, such as fathers and husbands, when considering the support and healthcare needs of this group, and confront a prevailing discourse in which heterosexual men living with HIV are categorically constructed as a threat to their communities.

Several strengths and limitations of our work merit emphasis. First, our study was intraparadigmatically congruent, in that internal consistency was maintained between our critical ontology, relativist epistemology, theoretical framework and methods of data collection and analysis. Intraparadigmatic congruence is considered the cornerstone of designing and executing rigorous qualitative research.^{37–38} As with all qualitative studies, our research is not intended for statistical generalisability. However, we believe that our concepts of spatially acquired stigma, spatial marginalisation and negative symbolic capital are contextually transferable and would be applicable in other jurisdictions where the development of HIV-related services is historically linked with that of gay activism and the symbolic appeal of helping women living with HIV. In addition, our concepts may be transferable to the study of other illnesses where there is a mismatch between the gendered dispositions of heterosexual men and the fields and contexts in which help is available, such as for men living with breast cancer and fibromyalgia.^{39–41} Because we did not interview HIV researchers, clinicians, policy makers or ASO staff, we are unable to consider the perspectives of these stakeholders as they pertain to the HIV service arena and heterosexual men living with the disease. However, we elected to focus on the experiences of the men because this topic is unexplored and un-theorised in the current literature.⁵ To our knowledge, this is the first indepth critical examination of the help-seeking experiences of heterosexual men living with HIV. In addition, our sample was comprised of men who use existing HIV-related services. Our findings may therefore not be transferable to heterosexual men who are less engaged with ASOs or the healthcare system. Finally, it is possible that some accounts and interactions between participants were influenced by the presence of the male researcher facilitating the focus groups.

However, our paradigmatic and theoretical assumptions posit that all accounts are coconstructed through interaction and contingent on context. Therefore, rather than attempting to 'control' for the presence of the male researcher, an otherwise impossible endeavour, such interactions were incorporated in the analysis by interrogating the group interaction itself (see earlier 'masseur' example).²⁴ In this manner, the group dynamic and manner in which the men portray themselves becomes as integral to the analysis as their actual words.

As the epidemiology of the HIV epidemic evolves, it is imperative that health and support services do not lag behind changes in the demographic composition of individuals living with the virus. The strong tradition of community involvement in policy and programme development is a distinctive feature of the response to the HIV epidemic in Western countries and has been instrumental in designing a health and support field that has been appropriate for the individuals historically burdened most with the physical and symbolic weight of the illness. Our findings indicate that heterosexual men living with HIV are operating within a service arena that has not kept pace with their increased representation among the population of persons living with the virus. In keeping with principles such as Greater Involvement of Persons, policy makers, researchers and ASOs should endeavour to involve heterosexual men living with HIV at decision-making and policy-making levels by supporting training and capacity building among this group. Such partnerships will represent an important step towards greater parity within the HIV service arena and the generation of a research and policy-based agenda grounded within the concerns of heterosexual men living with HIV.

Author affiliations

¹Department of Family and Community Medicine, St. Michael's Hospital, Toronto, Ontario, Canada

²Leslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Ontario, Canada

³Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

⁴Department of Medicine, University of Toronto, Toronto, Ontario, Canada

⁵Women's College Research Institute, Women's College Hospital, Toronto, Ontario, Canada

⁶Institute for Clinical Evaluative Sciences, Toronto, Ontario, Canada

⁷Dalla Lana School of Public Health, University of Toronto, Toronto, Ontario, Canada

⁸Centre for Research on Inner City Health, St. Michael's Hospital, Toronto, Ontario, Canada

⁹Department of Family and Community Medicine, University of Toronto, Toronto, Ontario, Canada

Acknowledgements We are grateful to the participants of the study for their time and contributions and to the staff at the participating AIDS Service Organisations in Ontario for supporting this study.

Contributors Study concept and design: TA (guarantor), MRL, RHG, CS. Analysis and interpretation of data: TA, MRL, RHG, CS. Acquisition of data: TA. Drafting of the manuscript: TA. Critical revision of manuscript: TA, MRL, RHG and CS. Administrative, technical or material support: TA.

Funding This study was supported by research funds from the Canadian Institute for Health Research (grant number CBR-99149). The sponsor had no

role in the design and conduct of the study; in the collection, analysis and interpretation of the data or in the preparation, review or approval of the manuscript. The opinions, results and conclusions reported in this paper are those of the authors and are independent from the funding sources. TA is supported by a post-doctoral fellowship from the Ontario HIV Treatment Network and a fellowship from the Primary Health Care System Program. CS and MRL are the recipients of salary support from the Ontario HIV Treatment Network and the Canadian Institutes for Health Research, respectively.

Competing interests During the past 3 years, TA has received unrestricted research grants from Glaxo-Smith-Kline Inc., Merck and Pfizer for different studies and MRL from Abbott Laboratories, Merck Frosst Canada Ltd, Pfizer and ViiV Healthcare.

Patient consent Obtained.

Ethics approval Ethics approval was provided by Women's College Hospital and University of Toronto.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data available.

REFERENCES

1. Joint United Nations Programme on HIV/AIDS. *Global Report: UNAIDS Report on the Global AIDS Epidemic*. 2010. http://www.unaids.org/globalreport/documents/20101123_GlobalReport_full_en.pdf
2. Health Protection Agency. *HIV in the United Kingdom: 2010 Report*. Vol. 4. Health Protection Report, 2010.
3. Remis RS, Swantee C, Liu J. *Report on HIV/AIDS in Ontario 2008*. Ontario Ministry of Health and Long-Term Care, 2008.
4. Doyal L. What do we know about men living with HIV and dying with AIDS? *J Men's Health* 2009;6:155–7.
5. Doyal L, Anderson J, Papparini S. 'You are not yourself': exploring masculinities among heterosexual African men living with HIV in London. *Soc Sci Med* 2009;68:1901–7.
6. Nobleman R. *To be a Man: Exploring Masculinity and HIV Service Needs Among African Men in London*. <http://idoitright.co.uk/wp-content/uploads/2011/09/To-be-a-man-Exploring-masculinity-and-HIV-service-needs-among-African-men-in-London.pdf>
7. Persson A, Barton D, Richards W. *Men and Women Living Heterosexually with HIV: The StraightPoz study*. Vol. 1 (Monograph 2/26). Sydney: National Centre in HIV Social Research, The University of South Wales, 2006.
8. Rice BD, Sinka K, Patel B, *et al*. The changing epidemiology of diagnosed prevalent HIV infections in England: greatest impact on the London environs. *Epidemiol Infect* 2007;135:151–8.
9. May M, Gompels M, Delpech V, *et al*. Impact of late diagnosis and treatment on life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) Study. *BMJ* 2011;343:d6016.
10. Bhaskaran K, Hamouda O, Sannes M, *et al*. Changes in the risk of death after HIV seroconversion compared with mortality in the general population. *JAMA* 2008;300:51–9.
11. Zwahlen M, Harris R, May M, *et al*. Antiretroviral Therapy Cohort Collaboration. Mortality of HIV-infected patients starting potent antiretroviral therapy: comparison with the general population in nine industrialized countries. *Int J Epidemiol* 2009;38:1624–33.
12. Jaggy C, von Overbeck J, Ledergerber B, *et al*. Mortality in the Swiss HIV Cohort Study (SHCS) and the Swiss general population. *Lancet* 2003;362:877–8.
13. Lohse N, Hansen AB, Pedersen G, *et al*. Survival of persons with and without HIV infection in Denmark, 1995–2005. *Ann Intern Med* 2007;146:87–95.
14. Cain R. Devoting ourselves, devouring each other: tension in community-based AIDS work. *J Prog Hum Serv* 2002;13:93–113.
15. Anastos K, Marte C. Women—the missing persons in the AIDS epidemic. *Health PAC Bull* 1989;19:6–13.
16. Hankins CA, Handley MA. HIV disease and AIDS in women: current knowledge and a research agenda. *J Acquir Immune Defic Syndr* 1992;5:957–71.
17. Goffman E. *Stigma: Notes on the Management of Spoiled Identity*. New York, New York: Simon & Schuster, Inc., 1963.
18. Bourdieu P. *Pascalian Meditations*. Stanford, California: Stanford University Press, 1997.
19. Bourdieu P. *Language and Symbolic Power*. Cambridge, UK: Polity Press, 1991.
20. Bourdieu P. *Distinction: A Social Critique of the Judgement of Taste*. Cambridge, Massachusetts: Harvard University Press, 1984.

21. Clarke AE. Turning to discourse(s). In: Clark AE, ed. *Situational Analysis: Grounded Theory After the Postmodern Turn*. Thousand Oaks: Sage Publications Inc 2005:145–79.
22. Patton MQ. Designing qualitative studies. In: Patton MQ, ed. *Qualitative Research and Evaluation Methods*. Thousand Oaks: Sage Publications Inc 2002:209–57.
23. Kuzel A. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, eds. *Doing Qualitative Research*. Newbury Park: Sage Publications Inc, 1992:31–44.
24. Barbour RS, Kitzinger J, eds. *Developing Focus Group Research: politics, theory and practice*. Thousand Oaks, California: SAGE Publications Inc, 1999.
25. Charmaz K. *Constructing Grounded Theory: a Practical Guide through Qualitative Analysis*. Thousand Oaks, California: SAGE Publications Inc, 2006.
26. Charmaz K. Grounded theory. In: Hesse-Biber SN, Leavy P, eds. *Approaches to Qualitative Research: a Reader on Theory and Practice*. New York, New York: Oxford University Press, 2004.
27. Connell R. *Masculinities*. 2nd edn. Berkely, CA: University of California Press, 2005.
28. Cain R. Managing impressions of an AIDS service organization: into the mainstream or out of the closet? *Qual Soc* 1994;17:43–61.
29. Higgins JA, Hoffman S, Dworkin SL. Rethinking gender, heterosexual men, and women's vulnerability to HIV/AIDS. *Am J Public Health* 2010;100:435–45.
30. Joint United Nations Programme on HIV/AIDS (UNAIDS). *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS, 1999.
31. Solomon P, Guenter D, Stinson D. People with HIV as educators of health professionals. *AIDS Patient Care STDS* 2005;19:840–7.
32. Ramirez-Valles J, Brown AU. Latinos' community involvement in HIV/AIDS: organizational and individual perspectives on volunteering. *AIDS Educ Prev* 2003;15(1 Suppl A):90–104.
33. Cox LE, Rouff JR, Svendsen KH, et al. Community advisory boards: their role in AIDS clinical trials. Terry Bein Community Programs for Clinical Research on AIDS. *Health Soc Work* 1998;23:290–8.
34. Flicker S. Who benefits from community-based participatory research? A case study of the Positive Youth Project. *Health Educ Behav* 2008;35:70–86.
35. Meyer P. Consumer representation in multi-site HIV, mental health, and substance abuse research: the HIV/AIDS treatment adherence, health outcomes and cost study. *AIDS Care* 2004;16(Suppl 1):S137–53.
36. Persson A, Newman C. Making monsters: heterosexuality, crime and race in recent Western media coverage of HIV. *Social Health Illn* 2008;30:632–46.
37. Morse JM, Barrett M, Mayan M, et al. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Methods* 2002. <http://www.ualberta.ca/~ijqm/> (accessed 11 Oct 2011).
38. Carter SM, Little M. Justifying knowledge, justifying method, taking action. Epistemologies, methodologies, and methods in qualitative research. *Qual Health Res* 2007;17:1316–28.
39. Iredale R, Brain K, Williams B, et al. The experiences of men with breast cancer in the United Kingdom. *Eur J Cancer* 2006;42:334–41.
40. Donovan T, Flynn M. What makes a man a man? The lived experience of male breast cancer. *Cancer Nurs* 2007;30:464–70.
41. Paulson M, Danielson E, Soderberg S. Struggling for a tolerable existence: the meaning of men's lived experiences of pain of fibromyalgia type. *Qual Health Res* 2002;12:238–49.