**ORIGINAL ARTICLE**

SOCIOLOGY OF HEALTH & ILLNESS

# Imaginaries of patienthood: Constructions of HIV patients by HIV specialist health professionals

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**Abstract**

This paper explores the ways in which HIV specialists based in the United Kingdom (UK) construct, conceptualise and imagine their patient group via the concept of the 'imaginary', a notion encompassing the symbols, concepts and values through which people make sense of their social environment. In discussing their work with men who have sex with men (MSM), practitioners described patients as knowledgeable and highly adherent to treatment, yet apt to pursue hedonistic lives involving sex and recreational drugs. Recent innovations in treatment were formulated in terms of optimism and progress and the ascent of biomedical approaches was cast as an advance over former emphases on psychosocial interventions and attempts to facilitate behaviour change. In contrast to the imaginary of patients who were well-informed and highly compliant with treatment, participants also sought to explain those who were not easily enfolded within modern treatment regimens or who were seen to be overly emotional. These patients, it was said, had some pre-existing psychological problem or perhaps were especially vulnerable to societal pressures. Overall, the imaginary of the public was

pervaded by therapeutic optimism, a sense of progress and an invigoration of biomedical themes in overcoming the challenges of delivering services to MSM.

Since its first clinical observations in 1981, HIV/AIDS has evolved from being an almost invariably fatal disease to a now manageable chronic condition due to the advent of effective antiretroviral therapy. In the United Kingdom (UK), gay, bisexual and other men who have sex with men (MSM) have been disproportionately affected by HIV and thus remain a major focus in treatment and prevention interventions. Considering the UK, Brown et al. (2018) report that there has been a decline in both new diagnoses and overall incidence according to Public Health England data. This was attributed to increased HIV testing in those at highest risk of infection, the availability of effective pre-exposure prophylaxis (PrEP) and timely initiation of antiretroviral therapy among those diagnosed with HIV rendering them uninfectious. There are many social, cultural and psychological factors that determine people's engagement with healthcare (see Jaspal & Bayley, 2020), including the quality and nature of engagement with healthcare practitioners (Jolley & Jaspal, 2020). It is thus important not only to examine patients' meaning-making in relation to HIV care, as has been the case in much previous research (e.g., Jaspal, 2018; Rowan et al., 2014) but also to explore the ways in which HIV specialist health professionals, most notably the physicians who engage, design and implement healthcare, relate to their patients. Accordingly, the key research question framing this article concerns how HIV specialist health professionals construct, conceptualise and imagine their patient group.

## THE SOCIAL 'IMAGINARY'

We explore HIV specialists' constructions, conceptualisations and imaginations of their patient groups via the concept of the 'imaginary'. For one early theorist of the notion, Thompson (1984, p. 6), the social imaginary is:

> the creative and symbolic dimension of the social world, the dimension through which human beings create their ways of living together and their ways of representing their collective life.

The idea of the imaginary has a good deal to offer, we believe, in enabling us to think sociologically about the kind of audience or patient group which health professionals consider their therapeutic ministrations to be directed towards. This imagined patient group, as we shall see, helps to shape the kinds of therapeutic interventions offered and how they are administered, and informs the issues addressed in clinical encounters and how they are managed. It essentially makes some interventions more available than others, foregrounding some and attenuating others.

To say that the practice of healthcare in HIV medicine is driven by an 'imaginary' is not to say that it is made up or entirely whimsical. Concerns over HIV transmission and the funding this has mobilised have led to an explosion in research on sexual life from the 1980s to the present day, particularly where MSM are concerned (e.g., Hergenrather et al., 2016; Jaspal & Bayley, 2020). Thus, the imaginary is empirically nuanced, and further rendered concrete and practical in the experience of clinical encounters between healthcare professionals and members of this particular patient group. It is this anchored into, but not entirely determined by, this empirical foundation.

The way in which people conceptualise their situation vis-à-vis others, their activities, the things which they think matter, the risks they attend to and so on are not fixed by the material constraints under which they live, but are often very flexible and diverse. Borrowing from Taylor (2002) and Welsh and Wynne (2013), we use the term 'social imaginary' to capture the capacities of social groups to frame their distinctive collective meanings, from intellectual, technical and emotional capacities in themselves. As Welsh and Wynne remind us, these are distinctive hermeneutic capacities. A social imaginary is a means of 'making sense of the practices of a society including the imagination of social existence, social relationships, normative expectations and the normative notions underpinning social life' (Taylor, 2002, pp. 91–106).

The use of the concept of an imaginary in the sociology of health to understand how people conceptualise their social environments is gaining ground, especially where the social study of HIV is concerned. For example, Smith et al. (2021) discuss the way that imaginaries of family inform the disclosure of blood-borne viruses. An imagined topography of risk characterised the accounts of MSM in Denson et al.'s (2021) study of Black men in the US deep south. Imaginaries of treatment resources were said to characterise representations of the geographies of care among gay men in Vancouver, as shown by Catungal et al. (2021), and Hassan and Tucker (2021) describe the construction of imagined communities around the risks faced by MSM in South Africa. The idea of imaginaries has been attractive because it permits a collective and politically nuanced account of how groups and individuals represent, discuss and act upon their social worlds and make topographies of risk, embodiment and community actionable.

Welsh and Wynne (2013) initiated discussion of the imaginaries of publics in discourse about science and society. For the sociology of health, the shifting understanding which professionals have of their patient group is vital to the establishment, reproduction and enactment of these emerging imaginaries. It is not just their capacity to project scientific findings and treatment outcomes onto new conceptions of the individual, or collective actions. How practitioners talk about their patient group and the socio-political and techno-scientific orders they entrain also reminds us of their role as knowledge-producers. Allied to this growing interest is the notion of biological citizenship, a notion initiated by Petryna (2002) and Rose and Novas (2005) and which links the management of individual susceptibility, vulnerability and viral load to broader societal concerns. As Rosengarten et al. (2021) argue, the increasing availability of effective therapies for HIV has led to a renewed biological and pharmacological emphasis on conceptions of the person where HIV risk is concerned. The biological optimism accompanying treatments and prophylaxis has arisen from a particular blend of activist development, government policies and medical possibilities which have enabled the development of novel citizenship projects.

It is therefore intended in this paper to extend the notion of social imaginaries to the study of healthcare practitioners working in HIV. We aim to commence a cartography of how clinicians in the field of HIV medicine produce representations of their patient base and the condition itself to construct imaginaries of their patients and the wider context of social, and political relations. These imaginaries may in turn shape the patient's experience of the therapeutic process. In

addition to examining how people individually and collectively construct knowledge in relation to this aspect of the caring process, we intend to examine how this social approach to the study of knowledge can illuminate how clinicians address the practice-based aspects of care. This may also have implications for the kinds of services which are planned and delivered and how professionals as a community of practice come to see their patients and their wider patient base (here, largely MSM) as a whole.

# METHOD

## Participants

The sole eligibility criterion was to be a practicing physician in the specialty of HIV and Sexual Health at an NHS Trust in the UK. Using a snowball sampling strategy, 23 HIV physicians were recruited to participate in an interview study concerning patient engagement with HIV care. Initial participants were recruited from within the second author's own professional networks, who subsequently informed other eligible colleagues about the study.

Twenty-one participants held the position of Consultant Physician in HIV and Sexual Health in their respective NHS Trusts; one was a Specialty Doctor and one was a Specialist Registrar. Nine participants were based at an NHS Trust in Central London; seven in East London; three at a Trust on the South Coast of England; one in South London; one in the East Midlands; one in the North East; and one in the South West. The mean number of years since full registration with the General Medical Council (GMC) was 18.6 years. The range of years since GMC registration was 2 and 46. Twelve individuals were White British, five were South Asian, three were Black African, two were of mixed heritage and one participant was White European. The interviews were all conducted in sexual health clinics between January and April 2017. The decision was taken to continue to collect data until data saturation had been reached. This occurred after the 20th interview and the last three interviews reiterated the findings of the existing sample.

## Analytic approach

Interviews were transcribed verbatim, anonymised and subjected to qualitative thematic analysis. The conversations about life as an HIV specialist and the challenges it brought were wide-ranging, but on reflecting upon the transcripts and in the interviews themselves, it became clear that these were not merely conversations about technical aspects of the work or the service delivered. In an important sense these were conversations about knowledge, thus suggesting an approach attentive to imaginaries and social epistemology might be productive. Whilst there is no generally agreed methodological format for such investigations, there are currently some attempts to configure social epistemology as an analytic approach (Collier, 2019). In outline, the approach adopted here proceeded by reading and re-reading transcripts and noting areas of interest. The idea of the imaginary was particularly useful when participants talked of the kind of patient base that they had, their collective characteristics and how these were differentiated by age and experience and how they engaged with treatments and risk mitigation strategies. Across the interviews this was readily assembled into a rich and evocative picture of the lifestyle and healthcare engagement of their patients, about how their patients were understood, conceptualised and seen as vulnerable both to particular risks and concordant with mitigation strategies.

The analytical approach takes its cue from recent syntheses of social epistemology and the sociology of imaginaries (Browne & Diehl, 2019). Following Goldman (1999), the analysis attended to group consensus about things which were considered to be true; in other words, judgement aggregation or disaggregation. Whilst some knowledge claims were indeed group-specific, others were identified by participants themselves as being more isolated and less consensual. Participants could be considered to be located in what Weisberg and Muldoon (2009) call an 'epistemic landscape'; a topography of different problems and sources of information, inhabited by epistemic communities following search rules related to their positioning in this space. Accordingly, the analysis was mindful of the worldview entrained within the knowledge that was deployed (Marsh, 2020).

Notably, a number of participants' accounts contained patterns of reflexivity (Bouzanis, 2017) about the imaginaries they were alluding to, including ideas about why particular subgroups of patients entertained some forms of knowledge and not others, how knowledge of different groups and individuals might differ and why, and what imaginaries might be suitable for different circumstances. This resonates with concerns in the literature about how knowledge suits the matters in hand through what Parkhurst and Abeysinghe (2016) term the maxim of 'appropriateness'. In line with the concerns of social epistemology too, the analysis presented here was also cognisant of how people assign credibility to different sources of evidence – own experience versus what they perceive to be the view of patients and other stakeholders. This included ideas about who knew what, about how one's own knowledge could be curated, supplemented and deployed, about how this differed from the knowledge of other groups, and even how the knowledge of other groups, such as patients, was organised and could sometimes be reconfigured to the participants' advantage. The intention of this analysis then is not to provide detailed commentary on the fine-grained linguistic aspects of the interview material but, following Brown (2021), to consider what is disclosed about the forms of knowledge involved.

# FINDINGS

In this section, the following three discursive themes are discussed: (1) The patient base: characterising hedonism, risk and sociality; (2) Therapeutic progress and the shift from psychosocial to biomedical approaches; and (3) Accounting for anomalies – the inner troubles of the patients. These themes contribute to an overarching discourse of a hedonistic yet well-informed patient. As we shall see, participants' accounts followed a narrative arc, from a characterisation of their patient base as hedonistic, yet medically well-informed and adherent to treatment, to a focus on what they saw to be a minority of patients who were believed to have psychological problems and who were thus unable to benefit fully from the services offered. As we shall argue, dividing the spectrum of patients into those who are 'good' patients and those who are incorrigible resonates with a theme found elsewhere in the history and anthropology of medicine between the curable and the incurable, the recoverable and those who are deemed to be beyond the pale. Managing this distinction has been seen as fundamental to medicine and other healing regimes (Nichter, 1992; Szabo, 2009) and is perhaps evident in HIV healthcare too.

In the presentation that follows, we use the term 'patient' rather than, for example, client or service user, as this was the term most frequently adopted by the participants themselves. All names are pseudonyms.

# The patient base: Characterising hedonism, risk and self-monitoring

In response to a question asking them to provide a brief overview of their patient group, participants were overwhelmingly likely to characterise their constituency in terms of male-to-male sexual contact:

> We have 2300 HIV positive individuals accessing care here. And the demographics bit is 90% MSM (men who have sex with men) and 10% heterosexual. I think among in terms of ethnicity split, I would say the MSM is predominantly white, British. (Jess)

In participants' accounts, forms of sociability in their patient base centred upon drinking, recreational drug use and drug use specifically in sexualised contexts (or 'chemsex'):

> And I think that drugs and alcohol taking in Brighton has a lot to do with that. And Chemsex… your unprotected sex is likely to be contributing and also the types of risk, highest sexual risk factors that these men engage in. (Jess)

Such was the supervenience of pleasure that barrier methods of risk mitigation, such as condoms, were not believed to be used regularly or effectively:

> Condoms are very useful and very good but people aren't using them. (Mike)

Participants thus constructed an imagined lifestyle (among their patients) revolving around drinking, recreational drugs and sex of the kind where barrier risk mitigation is not necessarily adopted. Also of interest is that the commonplace advice to avoid body fluid exchange and to adopt condoms for penetrative activity, which has been the mainstay of HIV education since the 1980s, was believed not to have traction with their particular patient group. This was particularly striking given the centrality of gay men and gay male culture in the promotion of safe sex earlier in the trajectory of HIV (Seibt et al., 1995). Indeed, in the present study the patient group was understood to have an affinity for risky sexual activity – certainly no participant characterised them as cautious. For some participants this was believed to extend to other aspects of their lives and health-related activity:

> HIV-positive individuals are risk takers err you know people who take drugs people who drink people who you know (.) enjoy anonymous sex whatever it may be (.) so they are different from a general population by large I mean clearly. (John)
> And later in the same interview:

> Oh they all smoke (.) and I mean we wouldn't ask [about] that. (John)

In this quote smoking is said to be so pervasive and is taken for granted to such an extent that it is scarcely worth asking about. This construction of the risks involved in the everyday lives of the patient group extended to comments concerning the nature of social life itself. For example, the risks taken were believed to occur in a climate of relentless sociability. The likelihood was perceived to be that parties were a frequent occurrence in patients' social landscape, that they would involve recreational drugs and sex and that the revellers would be disproportionately likely to be living with HIV (although the latter might already be under pharmacological control for seasoned denizens):

> Actually you might find that everyone who comes to your chemsex party is all unde-tectable and already positive. (Kam)

The party lifestyle was believed to involve a good deal of movement around the country too.

> That's, that's the issue the chaps from Leicester come down to London for a weekend (.) sex parties so I think it is very centred around London even though it spreads the epidemic elsewhere I mean as far as I'm aware sex parties tend to be in London or Brighton or whatever. (John)

Thus the presumed lifestyle was one in which sex and recreational drug use featured, where week-ends were spent travelling to other urban centres to attend parties, with consequent likelihood of unprotected, relatively anonymous sex taking place. The latter was formulated as a more or less inevitable outcome of the parties and recreational drugs, as something that would be pursued unreflectively by the patient without a great deal of deliberation over possible infectious hazard.

Again, the focus upon risk in practitioners' imaginary of the patient group is worthy of comment. Despite the focus upon safety earlier in the history of HIV the focus of our partici-pants, like a number of other authors in the contemporary era has shifted towards the hedonistic aspects of life, whether this be party culture, recreational drugs or sex itself. Practitioners and researchers are increasingly orienting themselves to this trend, for example, risk in relation to HIV and MSM (Witzel et al., 2017) and risk, recreational drug use and HIV (Chan & Tang, 2021; Jaspal, 2021). Indeed, some researchers internationally are detecting significant subgoups of risk-takers (Smith et al., 2019), so there is an emerging sense in the research community that risk-taking is worthy of attention again, and it may be that this is emerging in synergy with a focus on risk as an explanatory construct among our participants.

A further point of interest in the accounts presented by practitioners is how they construe the social lives of their patient group. Some aspects of the social infrastructure - such as the presence of parties and availability of illicit drugs - are privileged as causal factors, as if they led directly and inevitably to the transmission of infection. What is not present in participants' accounts is any question of how such encounters are negotiated, how the vicissitudes of attraction and desire – perhaps even romantic interest - are mutualised, how pairings are secured or physical aspects of a relationship are initiated and embarked upon, in even the most fleeting of encounters. Also absent is any account of the complex social choreography through which recreational drugs are manufactured, distributed, bought and sold, shared and enjoyed. These aspects of the sexual encounters in question are curiously excluded from the picture.

This absence is all the more striking because other aspects of the interior life of the patient group and the nature and function of their cultural life were emphasised. This was especially apparent when participants talked of the knowledge, attitudes and expectations of their patients vis-à-vis HIV. For example, in learning that they were HIV-positive, patients were thought of as likely to be aware of recent advances in treatment. Participants were asked what kinds of responses were likely on behalf of patients on learning of a positive test result:

> Yeah, I don't think people necessarily think they're going to die anymore. They did before. Generally speaking, I think they know they can access treatment and they tend to want to get onto treatment straightaway, most of them having heard about all the studies, perceptions. I think they worry about passing it on. They worry about transmission. (Jess)

Indeed, this knowledgeability was seen as being specific to the group of patients who engaged in same-sex activity:

> Interviewer: So what is their knowledge level? [...]
> M: So heterosexuals versus MSM I think MSM are much more knowledgeable compared to the counterparts too because it's in their literature (.) it's in magazines (.) you know when they go and talk to friends. (Mike)

And later in the same interview:

> . . . the people that go into the gay scene or hang out with other gay men (.) generally have high levels of knowledge (Mike)

The knowledge likely to be entertained by patients extended to technical detail concerning the nature of the condition.

> Most patients by the time they see me will have a grasp, will understand the basic concept of CD4 [an indicator of immunological health] and viral load. (Jess)

In tandem with this knowledgeability comes the monitoring and maintenance attributed to the patients. The men in their patient base are believed to be testing frequently:

> It looks like gay men are testing as frequently if not more frequently so STI rates aren't going down but HIV rates are going down so it's not that gay men are having any less risky sex. (Nigel)

So whilst there is a degree of risk in the lifestyle and the sexual activity, the patients are doing this from a knowing perspective and are monitoring their serological status. The knowledgeability of the patient group is not only extensive, but even new arrivals are soon 'up to speed':

> Interviewer: [...] the next question that I would like to ask (.) accessing the patient knowledge base and I would like to ask what is the level of knowledge that MSM have about HIV when they. . .
> N: Again I think the predominantly it's, it's excellent at [our clinic] and I suspect that at this centre we attract the sort of gay men who (.) are very knowledgeable anyway (.) they come with knowledge [. . .] everyone has a good knowledge apart from (.) those migrants that I've talked about who have recently arrived, they, they soon get up to speed I think. (Nigel)

This represents another curious tension in the conceptualisation of the kinds of patients encountered in this branch of healthcare. Whilst the sex in which they engage is somehow un-reflective and non-deliberative and likely to be unprotected, as in quotes from Jess and Mike above, this is nonetheless undertaken in an atmosphere of relentless monitoring and healthcare engagement. The self-aware, self-regulating citizen-subject is doing so in relation to surveillance and monitoring, but not with regard to the risky activity itself. It is as if the territory has shifted since the inception of HIV medicine. The workbench of risk management is no longer in the realm of

self-management of sexual conduct – indeed, the interpersonal complexities of this have been written out of consideration – but in the realm of testing, monitoring CD4 counts and medication.

## Therapeutic progress and the shift from a psychosocial to a biomedical frame

As described by the participants, there had been a distinctive shift from a psychosocial to a biomedical frame. First, the shift was formulated in terms of the success of medication and treatment which had rendered an HIV diagnosis less troubling in recent years:

> Interviewer: I would like to ask your opinion which which do you think are the factors that are driving HIV prevalence and incidence (.) amongst MSM in the UK?
> S: I think a lot of young gay men now are (.) too young to remember the impact of the (.) big HIV Tombstone campaign (.) And so they don't have (.) that fear of HIV that many older men and women have experienced. (Sarah)

In this quote, as with many of the interviews, fear of HIV is not seen as being as pronounced in the rising generation as in the early years when the syndrome was first characterised. Sarah, for instance, referred a lack of awareness of the challenges associated with the early days of HIV/AIDS when the disease was untreatable, terminal and destructive to communities. She referred to the UK's famous HIV Tombstone campaign which came to symbolise the death and destruction which characterised this phase of the epidemic. Moreover, diagnosis with HIV was constructed as more of a rite of passage, or even a relief:

> And I've even heard patients say that you know once they become infected they'll be relieved just because they don't have to worry about it any more. (Sarah)

Advances in treatment were identified as one of the key features which have rendered an HIV diagnosis a much less disturbing event for the people involved:

> Interviewer: [...] when you deliver an HIV positive result to an MSM what kind of reactions do you tend to encounter and how do you manage this situation.
> J: I guess that they're HIV-positive I guess that's a real possibility so I would think over 90% of them are calm, resigned (.) somewhat distressed but fairly straight forward to handle (.) very small number will act out and behave in a very err err (.) stressed way indeed but that's pretty unusual frankly (.) so when one talks to them and one tells them that there are pills that will enable them to live a normal lifespan that will enable them to have sex, children, whatever they want in due course erm there's no longer a life sentence that erm that's now widely perceived by the community as well so works pretty well as a as a (.) an issue for them (John)

Accordingly, this novel reality was said to reduce the psychological distress associated with a positive diagnosis:

> So I think very few people are very distressed (John)

The second aspect of the shift was that the growing confidence on the part of both practitioners and patients in relation to the effectiveness and tolerability of new medication regimens led to a change in the way in which people understood the diagnosis so as to render it less troubling, and also contrast the present favourably with the problems that might have been experienced in the past.

> So you know 10 years ago the tablets were horrible you know 10 tablets a day three times a day on every eight hours you know on the dot these days (Interviewer: Um) yes It used to be awful (.) You know lipodystrophy and mitochondrial disease (.)You know liver disease I mean bone disease, awful awful drugs (.) Now that they're much cleaner, much better (.) And sort of it provides a much much nicer and much more inert. (.) So the drugs actually (.) That's another thing we tell people actually you shouldn't worry about the drugs because actually they're very good. (Mike)

> The majority of MSM are probably fine with it (.) they're well educated, well informed, they know the risks, they very often know people who are living with HIV and so it's not a big thing, slightly disappointed perhaps. (Nigel)

So those who find that they are HIV-positive are seen as calm and resigned in most cases, commendably stoical, and 'fairly straightforward to handle' (John), whilst the small number who find it distressing are 'acting out' and are, in a sense, outliers. Here the technological optimism about the effectiveness of treatment regimens – the drugs are 'much nicer' (Mike) -is combined with an orientation to the patient group that emphasises the efficiency and amenability of the latter, afforded by the tolerability and effectiveness of the drugs available.

Such was the therapeutic optimism attached to contemporary medication regimes that this had led to a diminishing role for psychological support:

> I think that most people are just extremely well till their HIV diagnosis adjust to taking pills extremely well and continue with a fairly active sex life (.) really unen-cumbered by HIV and don't have made of psychological problems that's the vast majority (.) clearly there are a small minority who have considerable psychological problems these are virtually in my view all people who had them before they become HIV positive and are intimate and related to why they became HIV positive and I think the number of people who developed (.) severe severe anyway psychological problems for the first time after a diagnosis of HIV is extraordinarily low. (John)

Hence, not only has the former need for psychological support been obviated but, in most cases, patients tackle their revised life circumstances with a renewed technical efficiency:

> There are newly diagnosed courses in London and for a long time I was putting people to those but I seem to be referring people less frequently to them now but I'm also certainly aware that (.) with us starting therapy (.) more quickly in patients with HIV patients and clinicians are concentrating in getting their virus undetecta-ble and then they're sort of addressing the psychological issues a bit later so (.) very often they seem to be coming to clinic and they say my virus is undetectable now I need to think about what I want to do with my sex life how I'm going to find a part-ner so their first step is to become undetectable. (Nigel)

Notice that the need for formal support in the form of courses for people who have newly received an HIV positive diagnosis is said to be reducing, as per Nigel's comments above, and to be being supplanted by a problem-solving approach. The tutelary imperatives that animated earlier approaches to HIV – 'courses', education, raising awareness, encouraging safe sex practices and the like – appear to be ebbing away, to be replaced by a kind of analytical heuristic that emphasises becoming undetectable, managing one's sex life and partner acquisition afterward, as in the quote from Nigel, above. We will return to John's 'small minority' who have psychological problems later, for the existence of this category reveals something important about the healing imaginary.

What is remarkable is the consilience of this imaginary of the public with the medico-scientific world view. Participants conceptualise their public as being informed, steeped in the same technical language of biomarkers and treatments as the professionals. Patients are seen as likely to engage with testing, and generally do not impede the clinical efficiency of service delivery with flamboyant displays of emotion or exorbitant grief. They no longer need the laborious processes of counselling and support which were seen to characterise the old days of HIV and AIDS service provision. There may still be a good deal of talking but it is treatment focussed:

> While the patient is king at those decisions and the meeting that I mentioned, we come up with a list of options. And then the patient is booked in to see a pharmacist and we'll go through them in detail. Lots of talking. There's lots of, you know, making sure that that's what they want. And that's the right thing for them. (Jess)

Then patient base is conceptualised as being almost the ideal public from the therapeutic or scientific point of view. One which is knowledgeable, but which agrees with us, the experts. Consequently, as with Jess' quote, it is seen to be possible to agree upon a list of options and discuss their merits. There is a curious homogeneity between what participants think and their imagined public. Not only are pharmacological and psychological shifts identified but they are formulated as progress, improvement and as grounds for optimism. Let us consider further why this optimism on the part of participants and their imaginary of their public is unusual and how it contrasts with the view of the pubic in many other branches of health care.

Where patients are optimistic about many other medical procedures, it is sometimes referred to in the literature as 'unrealistic' or a 'misconception' (Jansen, 2020, p. 359) and efforts are made to revise expectations downwards towards something more readily achievable. It is seen here that the job of the practitioner is to inculcate more 'realistic' views on the part of the patient – for example, that there is likely to be some improvement but there might be continued impairment or pain, or side effects of the treatment itself. But in the case of our participants there is no such moderation. Victory over adverse side-effects has been achieved, everything is working and everyone is satisfied:

> I think generally they're (.) they're fairly satisfied (.) I think they get they get so compared to the rest of the world I think (.) probably that the UK is for the best HIV care in the world (.) They get specialised doctors. They get specialised clinics (.) They get the best drugs in the world for free (.) you know and they get lots of support around their drug use. (Mike)

This satisfaction and optimism are combined with what has been termed an 'epistemic trust' in the value of therapeutic interventions. It is said that if the client trusts the knowledgeability and authority of the practitioner then therapy – be it physical or psychological - is more likely to be

successful (Fonagy et al., 2019). The level of engagement of the patient group with the treatments offered was believed to be very good:

> Interviewer: . . . overall what's the level of engagement (.) with HIV treatment (.) with MSM
> Nikita: necessarily high medication adherence [. . . ] very high very very very high (.) So, I mean I was looking at my sort of looking at my patients who are on treatment (.) all of my patients on treatment have an undetectable viral load

Or in this example:

> Interviewer: . . . Overall (.) what is the MSM level of engagement and retention with HIV care and medication adherence.
> Aaron: On the whole, it's good (.) They tell me (.) you know the statistics speak for themselves anyway and they're not (.) It's not enormously different to what you see in Public Health (.) England itself (.) These people are more likely to be diagnosed earlier and they're more likely to adhere to medicines and they're more likely undetectable (.) than some other groups (.) But so on the whole it is good (.)

In the interviews it was generally asserted that satisfaction, involvement and adherence to the drug therapies on offer was very good, associated with the positive doctor-patient relationship, akin to Fonagy et al. (2019) concept of 'epistemic trust' above. This represents a marked contrast with other possible preventative measures or precautionary actions, such as condom use. The latter, as we have seen above, is believed to be minimal. Yet medication use is believed to be good. Partly, this might be to do with its convenience, the minimal side effects and the effectiveness imputed to it. However, the optimism here contrasts strongly with discussions of compliance, adherence and concordance elsewhere in the literature. The topic of therapeutic compliance has yielded concerns since the 1970s, as non-compliance with therapy is believed to be widespread across a variety of conditions and recommendations. Areas where therapeutic compliance is seen to be problematic include patient adherence to medication regimens but may also involve the extent to which patients adhere to recommendations about diet, exercise, or lifestyle changes (Jin et al., 2008). Whether conceptualised as compliance, adherence or concordance, medication taking by patients is often said to be limited in a variety of fields, perhaps especially in psychiatry (Chakrabarti, 2014), but also in the case of treatments for many non-psychiatric problems (Gellad et al., 2017). Yet here there are no such anxieties on the part of participants – the collectively held imaginary of the public attributes to them an extraordinary level of diligence concerning the medication available.

So far, the imaginary of the patient described by practitioners in the present study is of an almost hyper-rational individual; one who is educated, informed, technically literate and especially adherent to the prescribed medication regimens. They are conceptualised as risk-takers where sexual life and recreational drugs are concerned, and apt to have a social life featuring drinking and parties, with relatively fleeting sexual encounters. Yet these aspects of their lives are not the subject of intervention. Social and sexual life is left more or less intact, whereas the realm of intervention is directed towards factors which are microbiological and immunological and therapies which are pharmaceutical. This is akin to what has been described in the sociology of health as 'pharmaceuticalization' (Abraham, 2010) which is evident to such an extent that practitioners are seeing a reduced role for counselling or psychotherapeutic support.

Once again, there is a strong contrast here between what is found among these HIV/AIDS practitioners and the wider experience of health care. For many other conditions and fields of practice the emphasis has remained on behavioural change and personal responsibility. For example, for people who are overweight or obese (e.g., Pile, 2019) or with smoking in the mainstream heterosexual population (e.g., Pinho & Borges, 2019) there is a good deal of emphasis on responsibility, psychological and behavioural interventions to induce change, and the management of conduct as a way of tacking the problem (Brown & Baker, 2012). These examples could be multiplied over a variety of other fields, including cardiovascular health, musculoskeletal health and risk factors for diabetes. Yet in the present case, by contrast, the emphasis is on pharmaceutical solutions and a corresponding suspension of judgement over the risky activity itself – as if the latter has been ascribed as non-volitional and outside the realm of potential modification.

## Accounting for anomalies – The inner troubles of patients

So far, a picture has emerged of patients who are well-informed and generally at ease with managing their HIV status. However, a 'small minority' of people who did not fit this picture were described. How these counterexamples were accounted for is interesting because in order to sustain the imaginary of the successful patient there has also to be a way of accounting for the 'minority' of patients who respond emotionally, do not adhere to the programme and who do not conform to the model patient who sees HIV status as a technical problem to be solved. Within the history and anthropology of medicine it has frequently been observed that healing regimes make a distinction between those who are curable and those who are incurable (Szabo, 2009). This is detectable in divisions within the epistemology of bodily practice (Lock, 1993) and the way that boundaries between the dirty and the clean are constructed or maintained (Douglas, 1991). Similarly, in thinking about the way in which cultures of responsibilisation (Brown & Baker, 2012) or biological citizenship (Rose, 2009) operate, there are ways of accounting for those who apparently refuse to be responsible or repudiate the exercise of biological citizenship – they are described as incorrigible or marked by some difficult or enigmatic vulnerability.

In a similar way, among practitioners here there was some speculation about the possible reasons for the exposure to risk that the patient group undertook. After all, the risky activity may, at first glance, seem to be at odds with the hyper-rational engagement with technical knowledge, testing and treatment regimens that was espoused elsewhere in the interviews. In the case of some interviewees, to account for the areas of difficulty, an inner psychological realm of troubles was invoked, but it was seen 'through a glass darkly'. Whilst the biomolecular vital signs may be seen transparently and be shared between patient and professional, the realm of personal troubles is more or less opaque; something about which one 'wonders' rather than knows:

> And the other thing I always wonder is whether young people and mental health (.) I think there are big issues (.) And you know that a lot of young people are (.) under masses of pressure from society for various reasons (.) And there's a lot more depression and self-harm (.) And I wonder whether some of the extremely high-risk behaviour is related to (.) lack of self-respect and the sort of (.) a way of seeking a method of harming themselves. (Sarah)

Moreover, this was seen as a highly specialised realm of knowledge, outside the more general realm of HIV medicine as a whole:

> . . . very dedicated psychologists do do their best for harm reduction and look at the motivation of why people go and try and help them to you know do different things with their lives (John)

Motivation, and alternative forms of conduct were a territory for 'very dedicated psychologists'. Noticeable in these accounts was the way that this realm was not only occluded from more general clinical encounters but was somehow non-volitional and not susceptible to conscious control by the patient. Like the practice of sexual activity itself, it has been de-voluntarised and placed beyond the realm of volition. As with the comment from Sarah above, it is believed to pre-date the patients' involvement with HIV services. Unlike the early days, it is not occasioned by the bad news of a positive diagnosis, but is ontologically and chronologically prior, originating in social factors or troubles in the person's earlier life. Despite their enigmatic nature, these kinds of troubles are ready-to-hand as a means of explaining disruptions in the process of concordance between practitioner and patient:

> I mean there are a recalcitrant minority about 10% mainly driven mainly driven by drugs but (.) don't take any regimen at all but there's another small (.) 4 or 5% who have fixed (.) what I think we would call delusional beliefs that the medicine is harmful that they personally can't tolerate it they get side effects with all of it who are both a nightmare to look after and two there is little data about anything that can really help them (.) but that's a very small minority. (John)

This then deftly finesses the failures of adherence or deviations from the therapeutic trajectory. The inner troubles of the patient are responsible for their chaotic involvement with drugs of misuse and their lack of involvement with the prescribed regimen. They have excluded themselves from the therapeutic enclave by virtue of their delusional beliefs or via their being a nightmare to treat – characteristics which are placed firmly on the patient's shoulders and which are outwith the responsibility of the practitioner. In this respect, the process of accounting for anomalies resembles Pestello's (1991) process of 'discounting'. In order to sustain a particular kind of vision, imaginary or worldview, a means of making sense of items or people that do not fit is needed, and is a significant aspect of making the imaginary 'fit'; indeed this discounting process is just as important as the experiences which do fit the picture. This is not merely an afterthought to the social organisation of treatment or social policy, but fundamental to the construction of healing regimes – how to account for the minority who remain unwell or unclean (Nichter, 1992). It represents the completion of the narrative arc of this particular imaginary, from the hedonistic yet rational, curable patient to the small but distinct group of emotionally labile and hard-to-understand patients whose difficulties preclude any easy solution.

## DISCUSSION

This article has aimed to examine the imaginary of the patient base of a group of medical HIV professionals and sketch an initial cartography of how this constituency of patients was conceptualised and understood. This is important because it has implications for how services are framed, designed and delivered, and the picture – or if you will, the 'imaginary' – of patients held

by practitioners is an emerging topic of inquiry in health sociology. The notion of the imaginary has gained ground in making sense of ideas about family (Smith et al., 2021) and community (Hassan & Tucker, 2021) in relation to HIV, and the present article supplements this with a view from the perspective of practitioners as they make sense of their patient base.

Welsh and Wynne (2013) talk of what they call 'the neglected ontological stakes in the framing of scientific imaginaries of publics, and public imaginaries of science'. In other words, Welsh and Wynne's work asks: what kinds of entities do scientists consider their publics to be, for what reasons and with what consequences? As we have shown in the case of HIV practitioners here, this is clearly not a straightforward imaginary and contains a number of tensions and bifurcations. Sexual activity itself, along with recreational drug use, is seen as somehow inevitable and intractable, yet this contrasts with a picture of the self-aware, knowledgeable and highly engaged practice of patients who are said to be matter-of-fact about their diagnosis and whose adherence to treatment is believed to be very high, in contrast to that of patients in many other medical specialities. Participants were apt to characterise their work in term of the needs and lifestyles of gay men, rather than other possible groups in need of HIV services and were inclined to depict this group as risk takers. This focus of attention chimes with Denson et al.'s (2021) contention that notions of MSM and risk have driven forward the wider cultural narratives around HIV. At any rate, it is a ready-to-hand image which participants drew upon in making sense of their patients and had, like recreational drug use and smoking, the status of an unremarked 'normative mundanity' (Bostock, 2002). This may not reflect the imaginary deployed by other stakeholders in the field such as health educators, counsellors, nurses or campaigning groups, or those outside the axis of the UK encompassing the Midlands, London and Brighton. But its emergence here aligns with an emerging body of work stressing risk in relation to MSM (Jaspal & Bayley, 2020; Smith et al., 2019; Witzel et al., 2017).

The kind of imaginary described here is outstanding because it contrasts with several powerful tropes in the discussion of health, science and technology elsewhere. The picture presented by the interviewees here is one of technological modernism and optimism, according with an unbroken belief in the curative power of biomedicine. What is interesting here is that the medicalisation of social life is often seen in the literature as if it were a problem (van Dijk et al., 2016) and the related issues of control, inequality, power and domination are frequently aired by medical sociologists (Corriea, 2017). Indeed, the very notion of this Enlightenment sense of progress is subject to disillusionment and critique in many other fields (Mouzakitis, 2017). The major clinical implication of our work here is a plea for practitioners to not over-prioritise the microbiological and pharmaceutical aspects of HIV care. Biomedical tools alone are also unlikely to result in dramatic shifts in HIV incidence which are hoped for in HIV medicine, barriers to which may be social-psychological in nature – low perceived risk of infection, anticipated stigma and lack of acceptance of one's serostatus being key impediments (Jaspal & Bayley, 2020). In our study, there appears to be some disengagement from the psychological dimension of patients' wellbeing, an attenuation of its significance and a focus exclusively on the biomedical tools for treating and indeed preventing HIV.

This ambivalence towards the psychological realm extended to participants' discussion of patients they found difficult. In accounting for different and less legible aspects of the patient experience participants made use of concepts such as adverse social forces and believed a minority of patients to be troubled by hard-to-treat pre-existing psychological problems which drive their risk-taking and harbour negative beliefs ('delusions') about the available treatments. This group of patients is conceptually contained in a number of ways – they are felt to be exceptional and said to be the domain of dedicated psychologists rather than the bread and butter of everyday clinical work, or the problem is thought to originate in something that is fundamentally non-understandable anyway – a 'delusion'. This kind of demarcation between the rational,

agreeable patient and the deluded one is similar to Wynne's notion of invited and uninvited publics (Doubleday & Wynne, 2011; Wynne, 2008), where the former are the ideal public who agree with the scientists and the latter are disruptive and troubling.

The scientific aspects of HIV and AIDS care were invigorated by the factors involved being cast in technical terms (Andipatin et al., 2019) and practitioners contrasted this with former times when behavioural and psychosocial issues were prominent. In the contemporary era, characterised by effectiveness, concordance and optimism, the prominent features of this imaginary included the signs of the virus' presence, its detectability or the vital signs of the host, such as CD4 counts (an indicator of immunological health), as in Bauer and Bogner's (2020) observations on discourse about biology. Participants often compared the mitigation and treatment options available favourably to earlier, traditional treatments, characterising contemporary options as being easy to take, free of side effects and uniquely effective against the virus; more precise and efficient. In this narrative, pharmacotherapies were seen as representing scientific progress, and practitioners also frequently alluded to current treatment approaches as representing a fundamentally new era, breaking with earlier complex and potentially toxic drug regimens. In this respect, what participants are elaborating is a kind of biological citizenship (Rose & Novas, 2005) where citizens and their problems are understood in biological terms and fundamental aspects of the human condition, from the management of symptoms to the concept of persons themselves are seen via the biological imaginary.

As a relatively small-scale interview study of practitioners in the UK (based predominantly in the South East), we cannot use the information here to make large-scale claims about the general pattern of thinking and experience concerning the delivery of HIV care. Moreover, the opportunistic nature of the sampling strategy, originating in our professional and academic networks, may inflect the findings in ways that are hard to predict, and the focus on medical doctors leaves out many other practitioners from other disciplines involved in the design and delivery of HIV services.

Despite these limitations, following Fleischer (2017), our paper contributes to a broader social approach to epistemology and rationality in relation to health. Participants are performing a kind of epistemological work to formulate imaginaries of their patient group, the patients' conduct, their attitudes, their emotions and their engagement with clinical regimes, in a way which directs and enables their conceptual and clinical activity. In this respect they could be considered an epistemic community of practice (Wagner et al., 2019). They describe how they manage the condition but, in an important sense, this is the curation and management of information and socially shared knowledge that makes the realm of practice intelligible and agreeable within their realm of expertise. It is valuable to study the imaginaries of health and illness in this way, because the ideas held by practitioners of their patient group may inform their consultation style, their emotional tone and their expectations of their patients. A greater awareness of this process of conceptualising and representing patients and how this might narrow the clinical focus would be valuable in developing a more reflective practice that could be more inclusive of differing constituencies of patients and better able to encompass the diverse range of emotional responses to learning one's HIV status and living with the virus.

## AUTHOR CONTRIBUTION

**Brian Brown**: Conceptualization (lead); writing – original draft (lead); Formal analysis (lead); writing – review and editing (equal). **Rusi Jaspal**: Data curation (lead); Investigation (lead); Conceptualization (supporting); Formal analysis (supporting); Writing – original draft (supporting); writing – review and editing (equal).

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