From Sponge to Source: Health Information in the Lives of Gay Men Living with HIV

Joel Minion, Peter Bath, Kendra Albright

Abstract
Existing research into the information activities of people living with HIV has typically focused on issues of where individuals look and how they search. Little attention has been directed to understanding the meaning health information carries for those who use it or how information practices are contextualised within the social experience of living with a chronic condition. This paper explores how biomedical and experiential health information co-mediate the lives of gay men living with HIV. The discussion is based on a qualitative study of the information experiences of 24 HIV+ gay men living in the north of England. Ethnographic data were collected using unstructured interviews, health questionnaires, home mapping and photography. The findings indicate that the men’s information practices parallel the distinction drawn between disease-as-pathology and illness-as-social-experience. Participants typically passed through a limited period (not always immediately upon diagnosis) in which they became ‘sponges’ for biomedical knowledge about the virus and its treatment. The information collected was regarded as essential to understanding and managing the physical effects of HIV, with specialist doctors playing a central role in the learning process. Over the longer term, however, disease information proved secondary to illness or experiential information collected either directly from a man’s own history or from that of others like him. This second type of health information helped men inform their everyday lives while dealing with the uncertainty of their long term prognosis. Charitable HIV support agencies, in particular, served as a key information ground in which experiential knowledge was exchanged, a process that then facilitated the emergence of men regarding themselves as valuable sources (i.e. creators and disseminators) of essential health information rather than simply consumers.

Key Words: HIV/AIDS, gay men, health information, information practices.

1. Introduction
Living with HIV brings with it a host of information-related challenges. From a clinical perspective, rapid advancements in research and treatment can make staying well informed difficult and complex. In practical terms, the chronic and oftentimes unpredictable nature of HIV alongside
changes to life circumstances mean people’s information needs can vary

tremendously over time. This paper discusses a selection of findings from a

larger study into the information world of HIV+ gay men. The aim of the

research has been to understand how information practices among these men

are influenced by the social context of being both positive and gay. The

present discussion focuses specifically on the ways in which biomedical

information practices differ from and yet complement their experiential

counterparts.

This study builds on three propositions in the existing literature. First, people will avoid information they perceive as too costly in social terms
to access. They will also ignore information so long as their world can be
made to function without it. Second, understanding the world view of an
information user is vital to understanding his/her everyday information
practices. As a result, information must be defined as anything the user finds
informing. Finally, disease and illness must be distinguished conceptually,
with disease referring to pathologies of the body and illness to the social
experience of ill health. Information science research seldom draws this
distinction, with health information implicitly associated with biomedical
knowledge. The information users collect from personal experience in an
effort to understand their health is seldom regarded as comparable in
importance.

2. Related Work

Research into the information activities of people living with HIV (PLWH) is not extensive and must be referenced cautiously. Much of the
research has been conducted in the United States, the only major Western
country without universal public healthcare and one still characterised to
varying degrees by the so-called ‘culture war’ around issues such as sexual
orientation. Furthermore, the patterns of information behaviour among
PLWH likely changed, perhaps significantly, after the mid-1990s as effective
treatment transitioned HIV infection from a terminal to a chronic condition.
As a result, research conducted before this period may be of limited
applicability. Finally, many studies did not restrict their samples to gay men
or did not identify sexual orientation as a variable for analysis. As a result,
information practices specific to men who self-identify as gay often cannot be
identified.

These weaknesses noted, it is known that people diagnosed with
HIV typically learn about their condition from four sources: healthcare
professionals, social support networks, the media and Internet, and others
with the virus. Access to information is no longer considered a problem by
most PLWH. The Internet alone is generally not considered a primary
source, although white gay men with a higher education who used the
Internet had an appreciably better understanding of HIV. The Internet
also appears to allow HIV+ individuals to cope with their infection by exchanging information with one another.13

People with HIV search with greatest frequency for drug, medical and treatment information, followed by information about general wellness, relationships, and legal issues.14 They consider themselves more hopeful about their future as a result of what they find.15 White, gay men show some preference over other social groups for information taken from newsletters, educational forums and peers.16 Gay men also inform their decision about antiretroviral therapy (ART) more on the experience of friends rather than by accessing biomedical sources.17 Once on treatment, PLWH with report a high degree of satisfaction with their knowledge of medications, though finding information relevant to one’s personal circumstances remains a problem.18

3. Methodology

Three selection criteria were used to recruit participants into the study. Men were required: (1) to be at least 18 years of age; (2) to self-identify as gay; and, (3) to have lived with a diagnosis of HIV for a minimum of two years. An ethnographic approach was then used to elicit narratives about past efforts to become informed about first being gay and then being HIV+. Ethnographic methods are particularly suitable to this type of research because they are characteristically more emergent than pre-structured19 and can detail ‘the routine, daily lives of people’.20 They are also able produce ‘thick descriptions, contextual understandings and fine-grained analyses about the influence of social structures on men’s health and illness behaviors’.21 Within the ethnographic approach, interpretive interactionism was used to understand how key life experiences (coming out, testing positive, disclosing one’s status, initiating treatment) shaped the meanings given to the health information accessed.22

Data were collected during single meetings in the home. The average meeting lasted just under three hours and began with completion of a brief health questionnaire. Next, each participant was asked sketch the floor plan of his home and indicate on it anything in his home solely because he was positive. Photographs were later taken of these items in order to identify possible sources of information in the home such as HIV-related publications and health journals. The main part of each meeting was given to conducting an unstructured interview addressing each man’s experiences growing up gay, testing for HIV, and becoming informed post-diagnosis. Finally, fieldnotes were written immediately following a meeting, while the interviews were transcribed by a professional service.

A majority of the participants were recruited with the assistance of four charitable HIV agencies in the north of England. The remainder were enrolled by word of mouth. Due to a slow initial uptake and on the
recommendation of one of the agencies, an inducement was introduced retroactively following the first three meetings. Participants were offered a £10 grocery voucher, with an additional £10 being donated on their behalf to the agency through which they were recruited or to the HIV charity of their choice. The meetings were conducted between October 2007 and August 2008, with most taking place from April 2008 onwards.

4. Analysis

In keeping with the centrality of biographical and historical context in interpretive interactionism, the first stage of data analysis involved writing a short biography for each man, outlining his experience of key transitional events. These included coming out to family members, developing an awareness of HIV, negotiating safer sex practices, testing for the virus, and developing a "stock of knowledge" \(^2\) following diagnosis. These personal histories helped identify essential structures and patterns in how men sought, used and shared health information. Two distinct types of information became evident as a result: information needed to understand the pathology and treatment of HIV infection, and information needed to live with HIV on a daily basis.

Biomedical and experiential information were then each considered with respect to how the men sought and used health information. Sources of the former included healthcare professionals (primarily HIV specialist doctors), charitable support agencies, the Internet, and print materials. Not surprisingly, experiential information was collected from past personal health experiences as well as from the experiences of other HIV+ gay men, typically in the mediated setting offered by charitable HIV support agencies. NVivo software was used to classify systematically all relevant portions of the transcripts and fieldnotes into the information typology devised. The results were then reviewed for consistency in theme, with the men’s experiences summarised and key quotes identified.

5. Results

The participants. The average age of the 24 men who took part in the study was 41.9 years (range: 26.4 to 57.6 years). All of the participants identified themselves ethnically as either White British (n=22) or White European (n=2). Two reported having been raised outside the United Kingdom (one in Europe and one in Africa), while two others had lived most of their adult life overseas, returning to the UK only recently for health reasons. At the time of our meeting, the majority of the men lived either alone (n=11, 46%) or with a male partner (n=10, 42%).

With respect to education, two men (8%) had left school without any formal qualifications, six (25%) had achieved at least one O Level or equivalent, three (13%) had achieved at least one A Level or equivalent, three
(13%) had earned a certificate or diploma, seven (29%) held at least one undergraduate degree, and three men (13%) had earned postgraduate degrees. All of the men had been working or at university at the time of their diagnosis. Seven (29%) were presently in full time employment, three (13%) part time, and fourteen (58%) were living on a government disability allowance. Two of the men on benefits were also enrolled part time as students.

The average age at diagnosis had been 32.2 years (range: 23.8 to 50.1 years), with the average length of time since diagnosis 9.8 years (range: 2.3 to 21.9 years). Most men had been diagnosed in either their 20s (n=11, 46%) or their 30s (n=10, 42%). Eight (33%) had tested positive in or before 1996, the year the efficacy of combination antiretroviral therapy was announced publicly. Four men (including all three participants in their 20s) had yet to initiate treatment.

**Information as sourced.** All of the men except for one individual diagnosed in 1986 reported being aware of HIV prior to the point at which they believed they became infected. Their level of awareness varied considerably, although all of them knew that condom use during anal intercourse prevented viral transmission. Participants were asked via the questionnaire to identify their main source(s) of information about HIV in the weeks following diagnosis and then again at present. Their responses were sorted into six categories for analysis:

<table>
<thead>
<tr>
<th>Information Source</th>
<th>At Diagnosis</th>
<th>At Present</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Provider (HCP)</td>
<td>13 (54%)</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>Support Agency</td>
<td>4 (17%)</td>
<td>12 (50%)</td>
</tr>
<tr>
<td>Print Source</td>
<td>1 (4%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Internet</td>
<td>6 (25%)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (8%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>None</td>
<td>1 (4%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td><strong>Total Responses</strong> *</td>
<td><strong>27</strong></td>
<td><strong>35</strong></td>
</tr>
</tbody>
</table>

**HCP =** HIV doctor, GP, nurse practitioner, nurse, social worker, counsellor  
**Support Agency =** Staff/volunteers at charitable agencies supporting PLWH  
**Other =** friends, partner, television  
* Multiple responses result in percentages totalling more than 100%

The sources used by the men following diagnosis and at present reiterated the findings of past research, namely a preference for information...
accessed directly from individuals viewed as knowledgeable about HIV rather than through print or electronic sources. The present data did indicate, however, a sizeable shift in the men’s source preferences over time. Not only did their reliance on healthcare providers decrease, but they turned in increasing numbers to charitable HIV support agencies for their information. This transition was studied in greater detail by reviewing interview transcripts and fieldnotes for stories in which the men spoke more about the types of information they searched for, as well as when and where. Emergent patterns indicated that the men established a very different relationship over time with information about the disease of HIV than with information that allowed a man to live with infection on an everyday basis. The remainder of this discussion focuses on this distinction.

6. Biomedical Information

Biomedical information was defined in this study as anything that informed a participant about the pathology and treatment of HIV infection. In practice, biomedical information helped participants meet two principal needs. First, it supported a man’s ability to make sense of CD4 and viral load test results. Respectively, these clinical markers are used to assess immune system functioning (ART is generally started when CD4 counts fall below 350 cells/mm²) and the amount of virus in the bloodstream (ideally, viral load should be undetectable while on ART). Most of the men were being tested every two to four months regardless of whether they had initiated treatment. Understanding these numbers offered many men the comfort of a quantifiable representation of their health.

Biomedical information was also valuable in understanding ART. All of the men were aware that antiretroviral medications prevented HIV infection from becoming a terminal condition. But ART, which aims to raise CD4 levels and drop viral loads, can be complex and must be tailored to the individual. Common challenges faced by patients include side-effects, issues of adherence, and the threat of developing drug resistance. While a few men had been living successfully on one combination of medication for multiple years, almost all had needed to change combinations, many within the 12 months leading up to our meeting. The four men not on treatment had each begun investigating what was involved in anticipation of the need to make informed decisions in the short to medium term.

Beyond these two needs, all of the men had urgently sought biomedical information at some point in an attempt to answer the highly personal question, am I going to die? This search, however, was almost never long term and seldom took place more than once. Rather, men experienced a single period lasting a few weeks to a few months during which they intensively added to their stock of biomedical knowledge. Outside of this period, disease related information, such as that needed to
understand and address changes in CD4 counts and viral levels, was gathered but in a considerably less directed fashion and with far less exigency.

The men conducted the threat-of-death search at different points in time. Some did so immediately following their diagnosis. Owen (age 38, diagnosed in 2002) described himself as being like a sponge during this period, remarking how ‘no information was too small.’ Others, by contrast, waited up to several years before taking steps to learn more about the threat posed by HIV. Stephen (age 38, diagnosed in 1996) did so only after a near-death experience in 2006. The issue for men such as him was never one of denying their original diagnosis; in fact, they had all been exposed continuously to biomedical information during regular medical visits. They simply made little effort to become informed at a more in-depth level. The reasons given were varied: some men felt fine and had no HIV-related symptoms; others were too ill and lacked the energy to search; while a small number spoke of being in denial of the potential long term impact of HIV on their body.

HIV specialist doctors were the default source of biomedical information in the first instance. Many men spoke highly of their doctor’s wealth of knowledge and authority in treating HIV, with a few having developed relationships with particular consultants over many years. A more detailed reading of the transcript data, however, revealed that most specific comments about biomedical information sourced from specialist doctors emphasised their role in understanding test results and initiating ART. Questions about concerns such as mental health issues, drug side effects, nutrition, and even drug therapies in development were often cited as being inadequately or poorly addressed. A third of the men also spoke about problems in accessing HIV care that in turn limited the availability of biomedical information from this source. These included overly brief appointments and a failure to see the same doctor in consecutive visits.

Charitable HIV support agencies provided the main alternate source of biomedical information. Such agencies were often seen as being more comprehensive, personally relevant, and accessible. As Jon (age 35, diagnosed in 1996) stated succinctly, ‘If the medical system typically provides a leaflet, HIV agencies offer a book.’ Within the agencies, biomedical information was sought mainly from trained staff, including visiting or part time lay HIV educators (often positive themselves). Julian (age 56) reflected on the value of one such educator, stating:

If you talk to Terrence, he will go into great detail and it’s more sort of comfortable because he will explain everything because he will take the time. Whereas when you go to the [doctor], like I say, it’s quite technical and it’s quite a lot of jargon which I sometimes don’t understand.
As in the case of doctors, men expressly sought biomedical information through agencies only for a limited period of time, even though they frequently maintained longer associations with the groups as service users in other areas.

While approximately half the men regarded the Internet as an important, if secondary, source of biomedical information, many also viewed it with some scepticism. A key problem was the issue of overload. The sheer volume of information available was variously described by men as mind boggling, bamboozling and ‘too much and too deep’. Stephen recalled how ‘in the early days when I did use the Internet a lot, I found out too much information and didn’t understand it all so it didn’t paint a bright picture. It kind of overloaded me and I couldn’t just see the bits that I needed to.’ Andrew (age 35, diagnosed in 1999), moreover, found easy access to biomedical information on a multitude of high quality sites meant unintended exposure to things he would rather have not known. ‘What I don’t like about [the Internet] is the fact that it’s more negative information as in another thing to worry about.’

By comparison, print publications were viewed much more positively by the men. Two frequently mentioned glossy magazines provided readers with regular overviews of specific medications and announcements of new therapies or research advances. ‘I like [Positive Nation] because there are some interesting articles in there about new things which I don’t really get to know unless I start really researching – and at the moment I don’t have the time’ (Jon, age 35, diagnosed in 1996). These publications also benefited from being physically tangible as well. ‘They just seem more real than looking online’ (Adam, age 27, diagnosed in 2005). In addition, two national HIV organisations published free monthly newsletters distributed by post (as well as downloadable online) covering similar topics. Unlike the magazines, however, only one of the newsletters was aimed exclusively at PLWH; the other was written for medical professionals as well. Of it, Owen commented, ‘I can understand it, but for other people who have got no idea what blind studies mean – placebos and stuff like that – it’s very in-depth.’

7. Experiential Information

In contrast to biomedical information, the men in this study appeared to attach greater value to personal experience. If blood tests and ART kept a man alive, the ability to live productively on a daily basis underscored the need to informed by experience. In practical terms, experiential information was effectively impossible to avoid. Jerome (age 44, diagnosed 1999) summed up the reality of accumulating self-knowledge by stating, ‘You are living with your condition 24 hours a day, 7 days a week, 365 days of the year for a number of years, so that makes you
knowledgeable.’ While none of the participants kept health journals, all of them called upon personal past experience and spoke about the process by which they re-established a sense of equilibrium around their health at some point following their diagnosis. For many, there was an initial ‘propensity to get flustered and worried at the first ache, the first pain, the first niggling headache that just doesn’t seem to want to go away with an aspirin’ (James, age 45, diagnosed in 2000). But even experiential information could become overwhelming. ‘It is very difficult to monitor yourself constantly without becoming a hypochondriac’ (Pieter, age 46, diagnosed in 1989).

Experiential information underscored the importance in the men’s lives of self-management rather than the development of expertise. Participants’ focus appeared to be on striking a balance between being informed about one’s own body and getting on with life. ‘I try and put the illness to the back of my mind and get on with what I want to do. There is absolutely no point in swallowing all these tablets and going to the hospital to all these clinics if you are going to let the illness rule your life’ (Gordon, age 42, diagnosed in 1993). In this respect, living with HIV often left limited space for an ongoing influx of large amounts of biomedical information in particular.

Participants did, however, often rely significantly on the experiences of other HIV+ gay men. In some cases friends served this function, but mostly they used charitable HIV support agencies to serve as information grounds or public places where experiential information could be exchanged, often serendipitously while accessing other services such as psychotherapy, massage sessions and hot meals. But as with biomedical information practices, the use of HIV agencies to access experiential information was not necessarily most intense following diagnosis. It took Andrew, a nurse, seven years to establish contact. During this time, he had become well informed biomedically but had not discussed his experience with other HIV+ gay men:

The impact of talking to Anthony [a positive staff member] was profound. He had similar experiences, similar worries, similar anxieties. Just being able to communicate with another person that was HIV+, that had similar experiences, was just so powerful. I can’t put it into words, really, the impact it had on me. A positive impact, you know? He is a lot older than me so there is an element of seeing into the future, which is a bit scary.

Jerome, on the other hand, worked for one such agency. During a longer discussion on the purpose of the group, he said:
I think when you bring a group of people together with a multitude of conditions and you sit down and you start talking, you ask people to share their experiences, you know - the things like fatigue, depression, lethargicness that everybody experiences at some time – I think it actually helps switch the light on for quite a few people.

Although HIV agencies were typically used as information grounds for longer periods than men sought biomedical information, involvement generally did taper off. A small number of individuals shifted into volunteer roles but most maintained only limited links to an agency through occasional visits or via mail outs of newsletters. Men accounted for this distancing in a variety of ways. Liam (age 39, diagnosed in 1999) said, ‘I am not getting out of it as much as I used to. It’s a little bit negative. I am not negative anymore. I’m just getting on with it now.’ Damian (age 38, diagnosed in 2001) found too many service users took more than they gave. ‘They just want to talk about themselves so I never get a chance to relate it to me.’ And Owen captured the dependency that sometimes developed when men spent extended periods of time in agency offices. In full time employment himself, he remarked, ‘I can’t get my head around why can they not pull themselves away from it? Why do they want to live in this HIV world seven days a week?’

Ultimately, it was experiential information that allowed men to attach social value to their personal histories with HIV, therein becoming sources of information themselves. Gary (age 52, diagnosed in 1986) was the longest surviving participant in the study.

I am not banging my own drum and I am not a big headed person. But because I have been 22 years with HIV, I have seen some differences and I have listened to people and I know a lot. And I can pass that on to someone, you know what I mean?

Unlike other men, Gary still attended a support group on a semi-regular basis because it offered him a sense of purpose and personal fulfilment. Jack (age 36), who tested positive in 2004 after working for more than a decade as an HIV educator, had supplemented his encyclopaedic knowledge of HIV with personal experience of his own infection and antiretroviral regimens in order to offer something he could not have done prior to diagnosis. ‘I think my job now is to just help people to relegate HIV to a place at the back of their mind once they are convinced they are actually okay.’

Viewed from this perspective, experiential information flowed in a ‘pay it forward’ fashion, moving slowly from longer term survivors to the
more newly diagnosed. Stephen (diagnosed in 1996) spoke having arrived at a time in his life where he could now offer a shoulder to cry on only because of those who had been there for him. Outside of support groups and moments of crisis (such as a friend testing positive), however, experiential information was shared quite informally and sporadically. It tended to slip into discussions around matters unrelated to HIV. Even at the agencies, ‘we don’t sit around and talk about AIDS a great deal’ (George, age 47, diagnosed in 1990).

8. Discussion

The aim of this study was to understand the information practices of HIV+ gay men within the context of their social experience of sexual experience and being positive. Given the existing research into the information activities of PLWH, it was not surprising that participants turned primarily to healthcare professionals (notably HIV doctors) and charitable agencies for many of their information needs. The impetus behind specific information practices, however, and the manner in which they went about informing themselves both highlighted the degree to which health information cannot be approached as a homogenous entity. Rather, different types of information served distinct purposes at different points in time.

Biomedical information had meaning in large measure because it addressed the central concern of staying alive. With HIV having become a chronic and largely manageable disease, the issue of dying was more readily muted by the men than it would likely have been in the past. Once a man was able and willing to inform himself through an authoritative source that his infection was controllable, his urgent need for biomedical information was minimised. Specialist doctors were a preferred source for this purpose, but support agencies offered biomedical information that was more comprehensible and comprehensive. As a result of these information practices, most men felt that developing an overly extensive biomedical stock of knowledge offered only a quantified assessment of their state of their health that did not translate sufficiently into successful living life on a daily basis.

Experiential information, on the other hand, gave the men a better idea of what to expect in their future. The development of a personal history with the virus brought a deeper sense of meaning about the impact HIV would have on how they lived their lives. Participants added to their stock of experiential knowledge by interacting with other HIV+ gay men and hearing their stories. The value to experiential information lay not in its clinical accuracy, but in its affirmative and even predictive potential. Biomedical information, by contrast, was unable to address a man’s life concerns, issues that included such things as whether he was going to become progressively
incapacitated or whether HIV would prove an insurmountable barrier to achieving a long term relationship.

Within the information world the men constructed, it was experiential information in particular that allowed many men to add value to their lives by being able to inform others. This transition marked an ability to move beyond being simply a consumer of health information and services. As Jerome remarked, ‘I still like it when I have been able to help somebody understand, help them come to terms with their not being punished because they are HIV+. They are just, you know, they are not alone.’

Considered jointly from around the time of diagnosis, biomedical and experiential information performed overlapping and complementary functions in the men’s lives with HIV. Regardless of whether testing positive had been a surprise or a confirmation, the news set in motion a pattern of information practices aimed at reconciling oneself with one’s viral status. And where biomedical information was sought and used to re-establish a sense of control, experiential information addressed social issues such as isolation and stigma. The former was a means of keeping HIV in check; the latter, a means of developing a social context in which to live with HIV. Both types of information attended to different aspects of the men’s efforts to ‘make peace’ with their health.

The advantage of using a research approach focused more on life history was that it allowed for the identification of an arc along which the men used information to propel themselves from one understanding of their health to next. If there was an endpoint, it was achieving a set of life circumstances where the inflow of health information began to be balanced by an outflow, and where there was an overall decreased urgency (though not altogether elimination) to become still further informed about HIV. In other words, the men reached a point where their lives were again functioning with less information rather than more.

Notes

12 Hogan & Palmer, p. 435.
14 JT Huber & JM Cruz, p. 44.
15 ibid., p. 46.
16 Hogan & Palmer, p. 435.
17 RS Gold & DT Ridge, ‘“I will start treatment when I think the time is right”: HIV-positive gay men talk about their decision not to access antiretroviral therapy’. AIDS Care, vol. 13, no. 6, 2001, p. 705.
While the importance of the Internet appeared to increase markedly the longer men lived with HIV, analysis of its use as a source of health information was complicated by the fact many of the men were diagnosed prior to ready online accessibility in British homes. Only one of the thirteen men diagnosed prior to 2000 reported the Internet as a main initial source. Interestingly, even among the eleven participants diagnosed in 2000 or later, under half (n=5) reported using the Internet as a primary source of information, including two who ranked the Internet alongside a healthcare provider.


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**Joel Minion** is a doctoral student and **Peter Bath** is a senior lecturer in the Department of Information Studies at the University of Sheffield. **Kendra Albright** is an Associate Professor in the School of Library and Information Science at the University of South Carolina.