

Narratives of HIV: measuring understanding of HIV and the law in HIV-positive patients

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ABSTRACT

Objective This study aimed to identify the understanding of people living with HIV and AIDS (PLWHA) regarding the application of the law around transmission of HIV in England and Wales.

Design A questionnaire was designed to prompt participants attending a large HIV department to discuss their understanding of the law with reference to HIV transmission. The design focused on qualitative analysis as there were insufficient data available to inform a metric reflecting quantitative data on PLWHA's understanding of the legal implications of transmission.

Methods The data were collected from PLWHA attending their HIV outpatient appointment to ensure relevance of population to the analysis. The answers were analysed using grounded theory and thematic analysis to identify key themes and theories for further testing.

Results Analysis demonstrated that understanding of legal obligations and outcomes of prosecutions was poor and patchy, with behavioural restrictions often overstated. There was a strong theme of ownership of responsibility amongst PLWHA, and of reference to principles of morality beyond legal restrictions.

Conclusions PLWHA remain at risk of prosecution through poor understanding of the law. Clinical services and advocacy agencies should strive to increase understanding in order to enable PLWHA to comprehend the law and negotiate it successfully. This information should be shared as a process, not an isolated event.

BACKGROUND

In England and Wales, there have been a number of successful prosecutions for non-intentional transmission of HIV via consensual sexual intercourse. This has resulted in a number of HIV-positive individuals receiving custodial sentences

Key message points

- ▶ People living with HIV may have a limited understanding of the law which leaves them either at risk of prosecution for HIV transmission or with an overestimation of their legal obligations.
- ▶ Discussion of the legal position should occur as a process, not an event, in order to review information and comprehension.
- ▶ Individuals living with HIV may associate transmission with issues of morality and religion, and these issues should be explored sensitively.

of up to 10 years' duration.¹ As a result, the British HIV Association (BHIVA) guideline for the standard of care of HIV-positive people specifically mentions the need to address the legal implications of viral transmission.² There has been ongoing debate about the utility of such prosecutions.³⁻⁷ In the meantime, people living with HIV and AIDS (PLWHA) continue to be at risk of prosecution for non-intentional viral transmission. This is called 'reckless transmission' and is prosecuted under the Offences Against the Person Act of 1861. Broadly speaking, this occurs in England and Wales when an individual who knows they have HIV has intercourse with someone who is unaware of their partner's positive HIV status and, having taken no measure to reduce transmission risk, HIV transmission occurs. A detailed discussion of the law and advice for patients can be found in the British Association of Sexual Health and HIV (BASHH)/BHIVA position statement.⁸ Despite the risk of

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prosecution, there has been very little enquiry into the level of understanding of this risk amongst PLWHA. Our aim was to address this data gap and thereby gain a greater knowledge of what PLWHA understand with regard to HIV and the law.

METHODS

We chose to use qualitative research methods to achieve our aim. Specifically, we chose to use grounded theory in combination with thematic analysis. Grounded theory analysis enables both an understanding of the data collected, and allows the formation of theory for larger studies and ongoing research. Thematic analysis methods serve to reveal recurrent themes within the narratives of PLWHA concerning the intersection of the virus and the law.

We wished to ensure relevance of our data, and so chose to invite patients living with HIV to participate when attending for outpatient care. The sample relevance was assured, therefore, by the setting (an HIV clinic), the participants (PLWHA) and the context (attending clinic, thus engaged with active care). The data were collected via a written questionnaire. This collected demographic data and four prompts to which the participants could respond. The key prompt was “Do you understand the legal issues surrounding HIV transmission in England and Wales? Particularly consider any circumstances where it is against the law to pass on HIV, and the way that the law deals with people who pass on HIV”. The participants were invited to write as much or as little as they wished, and return the questionnaire anonymously to a marked box. They were also invited to address any questions they might have with a member of the clinical team if they wished.

Approvals

As the research was carried out on National Health Service premises, opinions were sought from both the National Research Ethics Service (NRES) and the hosting Trust. NRES did not require an ethical review, and the Trust permitted the conduct of the research.

RESULTS

Demographics

A total of 50 questionnaires were distributed, with a total of 33 completed (66% response rate). A summary of the characteristics of the participants is given in Table 1.

Codes were formed using open coding and constant comparison. The codes were then grouped to form categories and concepts, upon which the theory could be based. These codes formed the basis for the thematic analysis. Using open coding we identified 59 codes. At this point, data saturation was reached for our purposes and no more participants were invited. The participants were from diverse groups as reflected by the responses collected.

Table 1 Demographics of study participants

Gender	Male: 28 (85%); Female: 5 (15%)
Age	Mean 36 (range 19–53) years [$n=29$ (88%), no age recorded for 4 individuals]
Sexuality	Heterosexual: 10 (30%); Homosexual: 21 (64%); Bisexual: 1 (3%); No answer: 1 (3%)
Ethnicity	British: 22 (67%); African: 7 (21%); Asian: 1 (3%); European: 1 (3%); West Indian: 2 (6%)

The categories were broadly divided into categories formed as a direct answer to the prompts (i.e. understanding of the law and related practice) and emergent themes.

Direct concepts

Understanding

Participants were asked directly if they understood the legal issues surrounding HIV transmission. Four categories arose that related to understanding: those who did not feel they understood and did not describe the law accurately; those who felt they did not understand but described the law accurately; those that felt they understood but inaccurately described the law; and those who felt they understood and did describe the law accurately. This follows closely the classical skilled practitioner model of the confident/competent paradigm (i.e. unconfidently incompetent through to confidently competent), however diverges at an important point. Participant 9 (P9) (Female, 40, African) states, “I don’t know much about the law (...) I am aware it is essential to disclose to your partner before entering a relationship”. P9 demonstrates a lack of confidence, however although the understanding is not accurate, the practice of disclosure is likely to be a defence in any proceedings.⁸ Therefore although not confident, P9 would be protected from prosecution by accidental competence.

The law was poorly understood in general. There were participants with no understanding of the law, such as P33 (Male, 38, European) who had “No idea”, and participants with an overestimation of the burden of the law on people living with HIV. Some illustrative quotes include:

“I understand it is unlawful to pass on HIV.” (P17, Male, 36, African)

“I understand it is illegal to have unsafe (...) sex when you know you are HIV+.” (P22, Male, 45, British)

Neither of these statements is entirely accurate, and need further qualification to be deemed ‘correct’. In addition to this overestimation, legal punishments were poorly understood when mentioned. P49 (Male, 24, Asian) believed “... prosecution and [being] charged with attempted manslaughter or murder” occurred in the event of conviction. These results demonstrate clearly that even amongst those for

whom the law could have a direct impact, accurate knowledge is not universal. Furthermore, the perceived restriction of behaviour and severity of punishment that our participants perceive could contribute to feelings of stigmatisation and marginalisation. Some of the participants, however, were able to demonstrate a working knowledge of the law. P1 (Male, 24, British) describes two situations that are potentially illegal: “where the other party (...) is not made aware you have the virus...” and, “when you deliberately aim to infect someone else”. Although P1 has not elaborated that transmission would need to take place, which is a requisite in England and Wales, the concept of disclosure is central to his understanding.

These findings can inform a concept that not all PLWHA have an accurate or useful understanding of the impact of the law. This is despite being actively engaged in care; and in fact they might overestimate the circumstances in which they might be liable for prosecution and the severity of the charges. The responses support the theory that living with HIV does not necessarily mean that a person will engage with legal concepts relating to the virus.

Practice

Intrinsically linked to understanding of the law is sexual practice, and participants contributed substantially to this theme. HIV post-exposure prophylaxis in the event of condom breakage was cited as important, in keeping with the latest BASHH/BHIVA position statement,⁸ with P2 (Male, 36, British) discussing pre-exposure prophylaxis as a useful prevention strategy. P13 (Male, age unknown, British) felt they did not need further information as they were “(...) in a long-term relationship with a negative partner who knows my status”. The theme of unprotected sexual intercourse recurred frequently, with some participants believing that any unprotected intercourse could be considered illegal. Other participants related risk of prosecution to the risk of HIV transmission, for example P39 (Male, 19, British) asked: “If it is a low risk activity, what is my risk with the law?”. Disclosure to partners was another recurrent theme, with many participants linking illegality with non-disclosure of status. P28 (Male, 29, British) felt they would like extra information about the best time to disclose their positive status to a sexual partner. Although not all participants related legality of transmission to sexual practices and disclosure practices, many did; this represents the concept of locus of responsibility in HIV transmission. Sexual and disclosure practices were described in relationship to the responsibility borne by the PLWHA and not in the context of the uninfected participant taking measures to protect themselves.

Relationships

Status of relationships and their importance to risk of prosecution was explored in several ways. As in the

example from P13 earlier, they saw no need for further information as they were in a steady relationship within which disclosure had occurred. P44 (Male, 33, British) was unsure if the obligation to disclose extended beyond sexual partnerships, asking for information about: “If I am obliged to inform people – not necessarily sexual partners”. P9 states: “It is essential to disclose...your status before entering a relationship”, signifying the conceptualisation of a watershed beyond which disclosure must take place but also demonstrating that it is the status of the relationship that is the determining factor for this person, not the risk of transmission. This concept of relationship status having a direct bearing was articulated by P40 (Male, 53, British) who stated: “Not clear about disclosure and the law and if there (in particular) [is] a difference between casual encounters and regular partner sexual activity”. Clearly, some PLWHA are viewing need for disclosure in terms of the strength of the personal relationship in which they are engaging rather than absolute risks of transmission. This indicates a concept of duty towards a sexual partner that is based on the longevity or importance of the relationship, perhaps where the duty to a regular partner is stronger or more tangible than a duty to a casual partner.

Information sources

Participants were asked directly if they had ever had the law discussed with them in clinic. Many answered simply “No”. P7 (Male, 43, British) revealed that their main source of information had been from George House Trust, the local charity supporting PLWHA. Furthermore, P37 (Male, 37, British) stated: “No, other than this questionnaire”. Many of the participants did say that they had discussed the law during a clinic visit; however, it was clear from the responses that there were people who did not feel that the law had ever been discussed. The reasons for this are explored later in this article.

Emergent themes

The results revealed a spectrum of understanding of the law and how PLWHA perceived the law relative to their relationship status as well as potential infectivity. These concepts were derived from direct answers to the stem questions. A number of new themes emerged from the responses.

Morality

Morality featured strongly in some of the responses. When asked about understanding of the law, some participants referred directly to morality and moral standards, and even religion. Example statements included:

“I feel it is immoral to knowingly pass on HIV.” (P8, Male, 34, West Indian)

“Not a good idea to pass on your own HIV to innocent people. Pass it on to others is ungodliness.” (P43, Male, 36, African)

“...legal responsibilities and where these agree/disagree with moral ones.” (P48, Male, 44, British)

Although asked about legal responsibilities, these people feel that the passing on of HIV is a moral question, with P48 differentiating between legal responsibilities and moral responsibilities. In these PLWHA, it is a moral rather than legal restriction that influences decision making and sexual behaviours. This does not mean that those who do not articulate moral arguments are not influenced by them, but for some PLWHA moral arguments appear to take precedence over legal ones.

Rights and responsibility

Responsibility was another concept that had many forms within the responses, and is related to the morality concept. Those who felt a moral obligation felt responsibility to prevent onward transmission. P2 articulates a need to “Understand where I stand in terms of responsibility”. P37 asks for “communication about the rights of an individual”, and P48 asks about “legal responsibilities”. As a concept, responsibility is nebulous; however, it is an unsurprising feature in discourse on the law. It is a noteworthy result that all the respondents who mentioned rights and responsibilities mentioned these in the context of themselves: what are ‘my’ rights and ‘my’ responsibilities as a person living with HIV. Rights and responsibilities are therefore framed as self-owned responsibilities and rights.

Prosecution and discrimination

Some respondents demonstrated diametrically opposed views, with some feeling that prosecution was an appropriate response to HIV transmission (P8, Male, 34, West Indian and P27, Male, 31, British), and yet others felt it was inappropriate and would “compound stigma and discrimination of HIV-positive people” (P20, Male, 42, British). P37 wanted more information on “discrimination rights under the law”. Many respondents did not offer an opinion on the impact or justness of prosecution, but these results show that even amongst PLWHA, attitudes towards the law continue along the whole spectrum from appropriate and just through to inappropriate and discriminatory.

DISCUSSION

Using a combined grounded theory and thematic analysis approach we were able to identify several important concepts within the data, and to form related theories. All of the concepts can be shown to be related to self or personhood, from relationships and sexual practices to morality and responsibility. The unifying theme is that PLWHA relate the burden of HIV and the law to themselves. Although the data are

striking and diverse, the conspicuous absentee is the ‘other’ in sexual relationships whom the law is meant to protect; there are no mentions of the responsibilities of the partner, in fact, throughout the whole body of responses, there is little mention at all of the other. What is abundantly clear is that even in those who understand little about the actual law, the responsibility to prevent onward transmission is articulated by PLWHA as their own, and not of the uninfected.

Inextricably linked to this ownership are the concepts of blame, morality and responsibility. PLWHA may feel a moral responsibility not to infect sexual partners with HIV, and that legal prosecution is a fair way of addressing the issue of transmission. Other PLWHA feel that the application of the law is discriminatory. These mixed responses demonstrate that the driving factor in a person’s consideration of the law is not simply HIV positivity and the risk of legal prosecution, but considerations that are drawn more widely from concepts of morality and responsibility. These wider concepts are not necessarily associated with the PLWHA’s HIV status, but instead associated with their socially and culturally accepted normative behaviours and expectations. This has major ramifications for the interface between PLWHA, the law and medicine, as medical practice has traditionally considered medical conditions with legal implications as binary questions with binary solutions – epilepsy and driving, for instance.

It was surprising to discover that some respondents did not feel they had ever had the law discussed with them. As mentioned, it sits within the national guidelines that PLWHA should be made aware of legal implications of HIV transmission. Furthermore, it is our clinic policy to discuss legal implications with all new attendees or newly diagnosed people, and this is recorded in the notes. This is not a complex discussion, but simply informs patients that there have been instances of imprisonment when HIV has been transmitted in the absence of disclosure, and this discussion is had in the context of appropriate condom use. We had not anticipated that anyone would feel the law had not been discussed with them, and that many more would not understand the law. Some of the participants revealed that they had never considered the law at all, with a larger group displaying that they had not given it extensive consideration, or possessed inaccurate understanding. This is a concerning discovery: some of our participants may be at risk of prosecution because of their limited understanding, even within a clinic that has an active policy towards enhancing comprehension of the law. It is possible that the data are being given at a point where there is an information overload, and that understanding of the law should be treated more as a process than an event. Interestingly, some participants behave in such a way that would protect them from risk of prosecution even without an in-depth knowledge of the law.

When discussing the law in relation to HIV transmission, clinicians must be mindful that there are differences between Scottish, English and Welsh law. In England and Wales, the deciding factor is transmission of HIV. The advice, therefore, is that prevention of transmission is the best way to avoid prosecution. The correct use of condoms, an undetectable viral load and regular sexually transmitted infection screening will be the best way to meet this aim. Delivery of this advice is part of the role of a clinician in the best interests of their patient and public health. Disclosure to a sexual partner should be encouraged sensitively, as this allows the partner to make decisions related to obtaining post-exposure prophylaxis following a risk-related event. In terms of the law, the prosecution of reckless transmission is far less likely in the event of prior disclosure. These factors are discussed in greater detail in the BASHH/BHIVA position statement,⁸ which provides more detailed advice for clinicians.

From the data considering legal understanding and sexual practices, we were able to construct a 2×2 grid that demonstrates four categories in which PLWHA lie in relation to legal understanding (Table 2). Box 4 shows the ideal as it represents the person who both understands the law well, and is at low risk of prosecution through their behaviours.

CONCLUSIONS

In conclusion, this study has revealed several key themes and concepts that have not been described previously, providing greater knowledge about PLWHA's understanding of the law regarding onward

transmission of HIV. Perhaps most importantly, the data reveal that a person's approach to the law and infection transmission may be influenced by their sociocultural perspective as powerfully as by the prospect of prosecution. This has major bearings on the approach of clinicians when discussing the law with patients, and perhaps explains why many participants did not feel they had had the law discussed with them, despite the fact it is recorded in notes in line with clinic policy. Due to time pressures and a wish not to distress individuals in clinic, the facts relating to prosecution may be presented to PLWHA without reference to their sexual behaviour and their own perception of blame and responsibility. Rather than stating facts and hoping that a person will digest the information, there is a need to take these wider issues into account and to use a process of enabling understanding rather than 'one off' factual events. This research informs our theory that PLWHA need greater resources to help them understand the law in terms of their own sociocultural perspective.

We are able to conclude that many PLWHA are unaware of the law or understand it poorly, and therefore are at risk of prosecution. The primary objective of this research was to reveal the level of understanding amongst PLWHA, and it has demonstrated that understanding is weak and patchy. These data allow us to propose the theory that prosecution for HIV transmission is a poor public health measure, as many PLWHA are not aware of the law or understand it poorly. We are also able to conclude that greater measures must be taken to ensure that PLWHA have a working knowledge of the law, which prevents them from responding either too little or too greatly to the threat of prosecution.

Having constructed the grid to describe an individual's position in terms of their understanding of the law and their sexual behaviours, we have shown that being in Box 1 is very risky (i.e. the participant neither understands the law nor has sexual behaviours that protect them from prosecution), whereas those in Box 4 have both. It is easily demonstrable that within the clinic and within agencies advocating for PLWHA, the aim should be to increase an individual's knowledge sensitively with an awareness of their personal belief framework, until the majority of PLWHA can be sited in Box 4.

Finally, the thematic analysis has shown that when considering onward transmission, important themes for PLWHA are blame, responsibility and morality. Furthermore, PLWHA often take ownership of these issues without reference to the responsibilities of sexual partners. This may propagate feelings of stigmatisation and marginalisation. Medicine may well be fighting the battle with HIV disease, but morals and stigma remain important to people's thinking, and simple answers such as criminalisation of HIV infection will not address the complexities behind sexual behaviour.

Table 2 Behaviours, understanding of the law and risk of prosecution

Understanding of the law	
Low	High
<i>Risk of sexual practices and activity leading to prosecution</i>	
Higher	
Box 1	Box 2
<ul style="list-style-type: none"> ▶ Does not understand the law at all or inaccurately ▶ Does not take active steps to prevent transmission or does not understand the steps needed 	<ul style="list-style-type: none"> ▶ Understands the law well ▶ Does not take active steps to prevent transmission or does not understand the steps needed
Lower	
Box 3	Box 4
<ul style="list-style-type: none"> ▶ Does not understand the law at all or inaccurately ▶ Takes active steps to prevent transmission, shares knowledge with partners or does not participate in high-risk activity 	<ul style="list-style-type: none"> ▶ Understands the law well ▶ Takes active steps to prevent transmission, shares knowledge with partners or does not participate in high-risk activity

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Competing interests Matthew Phillips has received honoraria from BASHH, Janssen Cilag and Gilead to speak about HIV and the law, as well as sponsorship to attend educational meetings and conferences from Gilead, ViiV and MSD. Gabriel Schembri has accepted honoraria to speak for MSD and Gilead and accepted sponsorship from ViiV Healthcare, Janssen Cilag and BMS to attend international HIV conferences.

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