

Blood awareness in hepatitis C prevention

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Blood awareness in hepatitis prevention



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Background to the research

Hepatitis C is a significant public health concern: approximately 200,000 Australians have been exposed to the virus and about 16,000 new infections occur each year across the country, mostly from injecting drug use. Hepatitis C can have serious health outcomes for some, but can have debilitating effects for many more. To date, relatively few people have undertaken hepatitis C treatment.

The hepatitis C virus (HCV) was present in Australian populations from the early 1970s, more than a decade before the advent of HIV resulted in NSPs and educational messages aimed at preventing HIV transmission. HCV is far more infectious than HIV, so although the combination of improved access to new injecting equipment and public health messages advising injecting drug users (IDU) to avoid sharing needles limited HIV transmission in injecting populations, these measures were not sufficient to contain the spread of HCV. Current public health messages aimed at HCV prevention advise that along with needles and syringes, any sharing of injecting equipment—spoons, swabs, tourniquets, filters and even hands, in addition to actual needles and syringes—is a potential source of HCV transmission. The focus of health prevention messages has consequently shifted to ‘blood awareness’, that is, focusing attention beyond needle and syringes to other equipment or surfaces (including hands and fingers) which could have been exposed to blood.

HCV has been the subject of a number of public and academic inquiries into discrimination associated with the virus. It is now generally acknowledged that people with HCV experience discrimination in a range of social settings. This discrimination has been described as resulting primarily from the confounding of HCV with the major risk factor for its transmission—injecting drug use.

Against this backdrop, this research project sought to explore opportunities for innovative HCV prevention education. The researchers were particularly sensitive to the stigma associated with HCV, and to the challenges involved

in researching a stigmatised area, and sought not to contribute to any further stigma for those people living with HCV or those who inject drugs.

Specifically, the researchers were interested in identifying the different ways in which individuals and communities of individuals relate to their own blood and the blood of others. These insights were expected to generate characterisations of blood which could be used for effective health promotion messages.

Research Design

This was a qualitative research project involving interviews with a range of people with different experience and exposure to blood. The researchers interviewed: current and former IDU; people who donated blood; people who had received blood (including those who had acquired HCV through transfusion); people with thalassemia; people with haemophilia; ambulance officers; and people who undertake body modification. In total, 78 people participated in interviews.

Interviews were semi-structured and took about an hour to complete. The process began with a word association prompt, and then situations in which participants encountered blood were explored. These were not limited to drug injecting situations but ranged for example from domestic scenarios to the experience of watching horror movies.

The results of the project were transformed into a range of research publications, all of which are summarised in this report.

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1

Hepatitis C, blood and models of the body: new directions for prevention education

Carla Treloar & Suzanne Fraser

Currently health education aimed at IDU targets the individual user as being responsible for preventing HCV and HIV infection and represent blood as a threat and contaminant to be avoided. Messages produced are typically unidimensional, despite the diversity of injectors. In the literature on HCV where difference among IDU is acknowledged, it focuses on epidemiological categories such as length of time injecting, age at initiation and drug of choice. As the effectiveness of this approach is limited, it was thought useful to find new directions for HCV prevention education using analysis of injectors' perceptions of blood.

Critical Framework

Typically in HCV education material the body is presented as a fortress through which polluting blood can escape (if HCV positive) or enter (if HCV negative). This simplistic inside/outside model echoes the discriminatory perception of IDU as being 'outside' society. It metaphorically reinscribes stigma and may be a barrier to the usefulness of such materials, given the uniquely stigmatised position of IDU. Alternative models need to be considered if we are to produce HCV prevention education materials that are sensitive to difference, and do not reproduce the stigma that rigid inside/outside models can inspire.

Perceptions of blood

Participants described blood in predominantly biomedical terms, but were unclear about its structure or functions within the body. Some believed that blood perceptibly changed by drug use and HCV infection. For example, some stated that people who do not use drugs have 'clear' blood that is bright red, whereas the blood of IDU is compromised:

Raymond: My blood is always dark red, a shade darker than it should be.

Other non-biomedical ways of seeing blood—such as those based on spirituality or kinship—were not readily apparent in this sample.

Accident hypothetical

When presented with a hypothetical scenario of an accident, participants expressed a number of concerns regarding the possibilities of infection alongside a willingness to assist the injured person. These concerns ran both ways: the risk to the injured person and the risk posed by the injured person. The latter concern was expressed by those IDU without HCV who perceived their blood as 'perfect' and 'clean', and also by those with HCV who want to avoid further infections such as HIV or other genotypes of HCV. Some stated that the risk is no different if the injured person is a stranger or a family member or friend. For others, family and friends were presumed to pose a smaller risk: 'You know where they have been'. Different perceptions of risk and degrees of response were reported, depending on whether the injured person 'looked like a junkie'.

Emotions and blood

Strong emotional reactions to blood were not common in the interviews, although some issues evoked more emotions than others. For example, experiences with, or

picturing of, large volumes of blood, different colours of blood, or injury, all produced or incorporated an emotional response. Imagining blood donation produced an emotional response, which was often accompanied by fears of being drained, or 'queasiness' when blood was taken for medical purposes. In addition, having HCV led some participants to see their own blood as 'dirty'.

A life-saving resource

Blood was perceived by participants to be typically life saving rather than life threatening.

Wolfe (IDU participant): Oh no its life sustaining. No matter which way you look at it. Whether it is diseased or not. Without it you are dead. It's as simple as that. Don't get me wrong. I'm diseased at the moment. I've got the virus running through me 24 hours a day. but it's there. Without my blood I wouldn't be here. So as far as I'm concerned it is essential to life no matter whether it's diseased or not.

Alternative models need to be considered if we are to produce HCV prevention education materials that are sensitive to difference, and do not reproduce the stigma that rigid inside/outside models can inspire.

Alternative model for education

Given the overwhelming perception of blood as essentially life-saving, an alternative model to the 'fortress' in current education material may be of the blood bank. The blood bank is deemed to be a valuable institution, and participants were aware that there is a rigorous process for collecting, screening and storing blood to avoid risk of contamination. The blood bank constructs blood as a resource that we all may have to share. It confirms that sharing is a positive human

value, and that donors contribute much to society. In the blood bank model, there are various levels of responsibility (individual through to societal) for ensuring that the blood available is of highest possible quality and lowest possible risk. In essence, society has decided what is good to share, and developed ways of ensuring that this is protected.

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This metaphor can be applied to an injecting context. Various levels of responsibility can be identified in ensuring the safety of injectors *and* society—for example, society can foster an environment in which injecting drug use is treated in an informed, productive way, the government can provide equipment, facilities and support (NSP, information networks, treatment centres, support networks, publicly funded advocates and researchers and medically supervised injecting centres), and IDU can assume a level of individual responsibility for safe injecting practice. Equally, other responsibilities can be acknowledged, such as those some IDU feel around helping others to inject, or sharing drugs with those experiencing withdrawal.

Blood is a resource in which all members of society have a stake, and the role that IDU play in the protection and care for blood could be highlighted. The responsibility for protecting blood rests at all levels. How would HCV prevention material based on a metaphor of the blood bank look?

Conclusion

Approaches to health promotion and education for HCV prevention that utilise the range of injectors' experiences and perceptions are needed and are possible. It is important that such materials and interventions do not further stigmatise this group, and that the diversity of experience, and the structural and societal barriers to safe injecting, are acknowledged. ♦

2

'You sort of switch off': Exploring mindlessness in injecting drug users' accounts of blood

Carla Treloar

Recent research on how IDU think about blood supports the idea of 'mindlessness' in expert injecting drug use. This means that users may be following a kind of 'big picture' safe practice automatically, without paying attention to the particular contextual risks that may be present.

Critical framework

This paper takes up 'mindlessness' theory to explore the practice of injecting drug use and potential for HCV transmission. This theory explains mindless behaviour not as irrational, but as automatic, where an action is performed with little or no conscious awareness of the particularities of a given situation. 'Mindlessness' is the term used to describe the state of mind in which tasks become increasingly inaccessible to consciousness, inhibiting the individual's ability to adapt the action to fit a particular context. This concept has previously been applied in many areas, including needlestick injuries in healthcare workers, but not in injecting drug use.

Evidence of 'mindless' or automatic injecting

Evidence for mindless injecting was found in the reports of some participants who described how they become less aware of the blood present when injecting drugs because it becomes just a part of the process and is taken for granted.

Sue: I don't associate injecting with lots of blood, even though I've sat in pools of my own blood ... And once again it's part of using I suppose, you don't associate. I don't associate it with using but it's a part of using. Does that make sense? Like I don't think, 'geeze I'm going to get a heap of blood over me now I'm going to have a shot'. But if it's there is, it's not even thought about, it's just because it's so much a part of it, you're so used to seeing it when you're using.

David: I've been doing it for so long, it's part of the procedure ... You get desensitised from it all. Most people just think of the whole thing ... When you've been using drugs and that it's something that you do every day, so you sort of switch off.

Other participants echo Sue's and David's descriptions of 'switching off'. Jane describes becoming 'blasé' about blood in injecting and Hannah says that 'sometimes our eyes don't work, eyes don't see what we want to see'.

Related to this, contradictions were evident in injectors' descriptions of the safety of their practices. For example, Lana describes in some detail the lengths to which she goes to inject in a clean environment and to ensure no contamination of her equipment, but later describes injecting a friend:

Lana: ... like I've got a girlfriend where I have to help, you know, shoot it up for her. Each time I jack back sometimes I get pus, sometimes I get very

black jelly blood and it congeals so quick. She's got hep C.

While Lana characterises her own injecting as safe, the discrepancy between how she injects herself and the possibility for blood contact when she injects a friend shows evidence of 'mindlessness'—if she relies on her categorisation of her own injecting as safe when injecting her friend, she may fail to acknowledge the risk of the new situation. By using generic terms like 'safe' to describe one's own injecting, the particular risks of each injecting context is less available to consciousness and in turn, less adaptable to that context.

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Critique of individualist approaches to harm minimisation

Mindlessness theory forms part of individual-focused social cognitive psychology, which has been described as inadequate to address the complex social realities of risk and behavioural intervention. Other authors have argued that the positioning of risk at an individual level (such as with mindless behaviour) ignores the power relations that structure experience and assumes a rationality of choice-making about risk. However, this position ignores the contribution that examinations of risk, risk perceptions, risk constructions and risk

behaviour at the individual level *can* make to a fuller understanding of the spread of blood borne infections through injecting drug use networks. What has been missing from individually-focused, rationalistic models of behaviour—besides the criticism of the void between individual, social and cultural spheres—is understandings of the non-rationalistic, non-volitional behaviours, as predicted by mindlessness theory.

Opportunities for health promotion can emerge from an understanding of the role that mindlessness plays in expert drug injecting behaviour.

Implications for Health Promotion

Opportunities for health promotion can emerge from an understanding of the role that mindlessness plays in expert drug injecting behaviour. Blood can become invisible to the experienced user, and this is significant in terms of HCV transmission. Opportunities for intervention exist within the pre-infection window, between the establishment of skilled injecting and transmission of HCV. Such interventions would focus on ways of learning that are more oriented to mindfulness, and which facilitate learning a task in a way that allows better conscious access to the separate small steps involved in that task. This approach to learning would encourage and facilitate the expert injector to consciously adapt the steps to suit different circumstances.

The application of this theory to injecting drug use health promotion suggests modifications to messages that encourage awareness to particularities of context. Hence, rather than outlining 'the basics' of safe injecting, the emphasis could be on 'certain basics', which is a less rigid and more conditional categorisation. By presenting the ritual of injecting as something that can and should be consciously adapted to each injecting episode, the learner is oriented in the present and encouraged to assess each situation and to make appropriate adjustments to practice. ♦

3

'It's Your Life!': injecting drug users, individual responsibility and HCV prevention

Suzanne Fraser

Taking responsibility for oneself and for others is a pervasive message in health promotion materials on HCV prevention and safe injecting. Through an analysis of health promotion materials on HCV prevention, and interview data gathered from IDU, this apportioning of responsibility to the individual injector is critiqued. Although structural support for HCV prevention is not always adequate, safe injecting is still conceptualised as 'doing the right thing', and injecting practices therefore take on a moral value, which further stigmatises injectors.

The research data

A sample of 30 printed health promotion materials aimed at safe injecting and HCV prevention were examined. This material was analysed to determine whether (and how) it reproduces notions of individual responsibility. Data from interviews with IDU was then used to map the ways in which these notions correspond with the interviewees' comments on HCV and safe injecting.

Critical framework

This paper does not make an argument against current HCV health promotion, nor does it argue that the individual is a notion to be completely avoided. The questions posed in this paper are:

- ♦ how is responsibility (and by implication culpability) distributed in the materials?; and
- ♦ what are the potential social and health effects of this, given that IDU are a uniquely stigmatised group?

Briefly, the following points on the relationship between health, individualism and society are relevant to this analysis:

- i) The modern understanding of the subject as an enterprising individual helps shape the ways in which health promotion materials are produced, in that it identifies the individual rather than social or political structures as the origin of problems and solutions. Thus it is individual behaviour that is most often targeted in health promotion campaigns.
- ii) In targeting individual behaviour in this way, room is created for the identification of the behaviour and state of mind of the subject as centrally culpable for misfortune, illness or other crises. At the same time, potentially more effective or just approaches to health are ignored.

Safe injecting materials

While there is a range of approaches to health promotion, the most common subject matter is information on safe injecting technique, with the emphasis on individual behaviour modification. Most often this is presented in the absence of discussion of the broader societal context that makes safe injecting problematic. The exception to this is magazine-style publications produced by user groups and others which frequently embed health promotion messages in a context of critical rights-focused articles. Such publications acknowledge the structural problems that compound the difficulties of safe injecting. The success of this approach varies, however. In one example from a publication by AIVL, the emphasis on the role of the individual in reducing the spread of HCV contrasts sharply with the critique of the liberal

individual that follows. Incorporating statements into the health promotion messages that acknowledge both broader societal responsibility for HCV and the difficulty of adhering to safe injecting practices might avoid such difficulties.

Vexed issue: sharing fits

The sample materials demonstrated disparate approaches to the issue of cleaning and reusing fits. Using a cleaned fit is an 'unsafe' practice if the goal is super-safe injecting, yet it occurs frequently in some contexts. Super-safe injecting practice involves a range of challenging procedures which are especially difficult to maintain if an individual doesn't live near an NSP. In addition, for regular heroin injectors, physical withdrawal symptoms can make the time needed to ensure safe injecting challenging. Poor housing or homelessness further complicates the procedures.

Despite these obstacles to optimal safe injecting practice, phrases like 'It's your life!', from an article on HCV prevention in *The Hep C Review*, emphatically locate responsibility for preventing infection in the individual. This exhortation, directly following the instruction to 'Use new equipment every time', introduces a moral dimension into the text. This dimension is made even more explicit in an HCV prevention poster that warns the reader there are 'no excuses' for unsafe injecting. While the moral tone here is particularly blatant, the message is present in nearly all the materials in the sample: that the individual is responsible for avoiding (or causing) HCV transmission.

A leaflet published by AIVL (*Cleaning Fits*) partially departs from this approach by acknowledging that that a 'don't share' message is too simple. Instead it constructs a hierarchy of risk management—reusing one's own equipment is safer than someone else's; if using someone else's, specific cleaning techniques can reduce the risk. The focus however remains entirely on individual injecting behaviour. The hierarchy of risk is paralleled by a moral hierarchy described by one interview participant, Sasha, who placed the super safe injector (herself) at the top and the careless user and discarder of dirty equipment at the bottom, with cleaners and bleachers in between.

In some materials, moral responsibility is extended beyond responsibility for oneself to incorporate responsibility for others. Specific responsibility for other users is encouraged in materials that provide advice on disposing of rinsing water so that it can't be reused, and cleaning surfaces that have come into contact with blood. Responsibility is broadened further in a brochure by the NSW Users & AIDS Association (NUAA) and AIVL that concludes: 'What does matter is that you use a new fit EVERY TIME

and actively encourage your friends to do the same!' In this instance, individual injectors are not only held responsible for HCV prevention but also asked to become an informal (and unpaid) health promotion worker.

Relating to the messages

How do IDU read the health promotion materials that address them, and to what extent do the selves constructed in interviews correspond with those offered within health promotion?

The participants in this study generally describe themselves as using safe injecting practices, however in some instances, specific acts—such as injecting others—are described that suggest safety of injecting practices vary. Some participants make specific comparisons between their safe injecting now (as a 'responsible' user) and an irresponsible past:

Daniel: I went into the pub to go to the toilet and take the drugs and the bouncer got me and broke my fit and it was like 11 o'clock at night and I didn't have a cent. There was nowhere to get a fit. I had to get one off the street and clean it out and use it. That's what—heroin addiction's that bad. I mean how stupid is that?

Other participants contrast their own behaviour with an irresponsible other—people who share equipment, who ask for used equipment, or who fail to 'do the right thing' in disposing of equipment. In these comments, both care for others and care for oneself is ascribed a moral value similar to that found in health promotion materials. Care for others is not simply safe disposal of injecting equipment, but also a range of practices including dissuading others from reusing equipment, refusing to lend dirty equipment, advising on safe procedures, and carrying clean equipment for others.

Conclusion

Both health promotion materials and IDU themselves employ individualistic, moralising discourses when discussing injecting safety. This individualisation of responsibility ignores the social context (mutual support and obligation, managing competing interests) and the political context (stigmatisation of injecting, public attitudes toward NSPs) of injecting drug use. Together with an underestimation of the complexity of safe drug injection, this may place an undue burden on individuals for managing the HCV epidemic, and may encourage further stigmatisation of injectors. Messages of individualised responsibility fail to address the daily realities and broader context of injecting drug use, and this has implications for health promotion. ♦

4

'Spoiled identity' in hepatitis C infection

Suzanne Fraser & Carla Treloar

One response to diagnosis with HCV infection—a sense of despair and absolute contamination—sometimes leads to a lack of concern about the contraction of other blood-borne viruses. This suggests not only a disturbing level of distress and damage to self-esteem, but also a public health issue in that those individuals may be at increased risk of co-infection with HIV, superinfection with another strain of HCV, and may participate in practices that lead to onward HCV transmission. One possible way of minimising the likelihood of such despairing responses is to take steps to combat stigma related to HCV diagnosis. This can be attempted partly through consideration of the ways HCV is discussed in health promotion materials.

Critical Framework

Erving Goffman argues that stigma has two aspects: 1) the visible—associated with attributes that are immediately apparent; and 2) the invisible—associated with attributes that are only apparent after close examination or as the result of exposure or disclosure. People with HCV can be seen to fall into both categories. They encounter stigmatising responses from others who are aware of their health status e.g. doctors, nurses and other health professionals, and they also grapple with personal feelings of contamination and illegitimacy related to knowing that their stigmatised attribute may be revealed at any time.

The invisibility of HCV can also lead to situations in which individuals feel they are 'passing' as 'normal'. In this way, they carry a second invisible stigma beyond that related to being HCV positive—appearing to be what they are not (i.e. 'misleading' others). This makes it difficult to feel comfortable associating with other people:

Mona (blood transfusion recipient): It does worry me though, because some near neighbours of mine, they have a farm [...] they took me up there with them a year ago [...] and before we left [one of the neighbours] said to me, 'About your health, is there anything I need to know about you?' So I said, 'Oh everything's under control thanks.' And I felt guilty because I felt I was lying to her [...] I don't like hiding things but I feel I have to.

The binary logic of health and infection

Part of the stigma surrounding HCV emerges from a common view of the HCV-positive body as wholly contaminated or dirty: once HCV has been acquired, cleanliness or purity is lost. This model assumes that once a disease is acquired, the integrity of the entire bodily system is corrupted. This representation of the body emerges from a system of binaries central to Western cultures. In the context of HCV and the body, there are several identifiable binary oppositions: clean/contaminated; closed/open; well/sick; good/bad; before/after infection.

Closely related to this binary approach is an issue not discussed by Goffman—the internalisation of stigma i.e. the *acceptance* of one's health and identity as irredeemably and utterly spoiled (as indicated above), and, in particular, the conviction that acquisition of further discrediting attributes cannot make the stigma any worse. In this case, although the stigmatised person may still employ strategies for 'managing' a spoiled identity, there is no resistance to the notion of spoiled identity itself. In the interviews conducted with HCV-

positive participants, evidence of this approach to stigma was apparent in several cases. For example:

Wolfe (IDU): I look at it like this. I'm sick already, what else can they do to me? Like it can happen, I can get a lot worse than what I am and I can catch a lot more things than what I have. But it doesn't worry me.

Wolfe makes clear that for him, sickness is already present. He is aware of the possibility of acquiring other infections, but his sense of himself as 'sick' of body, and 'spoiled' of identity leaves no room for distinctions between diseases, and between types of risk.

Another participant whose response to contracting HCV can be characterised as 'despairing':

Bugsy (IDU): I didn't think I'd ever get it. I've never shared a needle [...] I didn't think I'd get it until I found out. But when I found out, that's when the care factor went out the window. Morals went out the window. It was like, because it's a terminal disease or virus, you think, 'Oh what's the use?' You've got it; it's not going to go away, what's the use?

Bugsy's diagnosis with HCV infection appears to have caused such a large shift in self-perception and identity that he appears, at least temporarily, to have no concern about further infecting himself, and about infecting others. This ethical shift may be related not just to diagnosis, but also to the effects of stigma, i.e. Bugsy's identity is so 'spoiled' that he no longer understands himself as party to the human ethical economy. This highlights some of the social costs of stigma. Indeed, even where the effect of acquiring HCV results in reduced concern about acquiring other diseases oneself, rather than passing on disease, from a public health perspective, these two issues are to some extent indivisible. Putting oneself at risk of contacting the blood of others often entails putting others at risk of contacting one's own blood.

Health promotion

Infection with HCV does not have to mean passing from clean to dirty, or entering a stable and predictable state of sickness, yet these ideas are sometimes implicit in health promotion literature. This may be the result of a concern that unless HCV is portrayed as a serious, undesirable illness, with predictably negative effects, IDU will not take adequate precautions against it. However, unless HCV is presented accurately, and variations in symptoms and prognosis clarified, despairing responses, and the risks they involve, are likely to continue.

The despairing response described here is the result of (at least) three types of stigma associated with HCV: 1) an infectious, largely incurable disease; 2) a disease understood to be related to the highly stigmatised practice of injecting drug use; and 3) a disease believed to have been acquired through one's own fault i.e. injecting drug use. All these issues need to be considered in health promotion materials, and it may be that broader change, for example around the status of addiction in society, is necessary before this despairing response can be ameliorated.

In the meantime, some suggestions for preparing health promotion materials that minimise the possibility of despair and question the binary thinking in relation to HCV are outlined below:

Binary	Suggested strategies
'health/illness'	Description of HCV and the variability of effects.
'clean/contaminated' (uninfected/infected)	Distinction between diseases. (Greater public awareness of HIV may lead to confusion related to symptoms and prognosis of HCV infection, leading to a sense of hopelessness.)
'well/sick'	Information on the role HCV-positive individuals can play in managing their health.
'good/bad'	Emphasis on shared responsibility for HCV infection between individuals, organisations, governments and society.
'before/after infection'	Inclusion of information on the rights of people with HCV and the need for non-discriminatory treatment in prevention education. (This can contribute to the shaping of public views on HCV, and to the minimisation of despairing attitudes among those infected.)

The stigma associated with infectious disease and injecting drug use has a complex history and set of causes. However, from both ethical and practical points of view, it is crucial that health promotion does not further contribute to this stigma. Where HCV is conceptualised in binary terms such as healthy/sick, clean/contaminated, closed/open, good/bad, before/after, stigma finds fertile ground for growth. ♦

Reference

Goffman, Erving. (1973 [1963]). *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth and Ringwood: Penguin.

5

Citizenship, Identity, Blood donation

Kylie Valentine

Donating blood is imagined to be an act of greater charity than the donation of money or other goods or services (apart from organs). Particular meanings are associated with this act—‘giving a little bit of yourself’. The significance attributed to blood donation constructs the donor as the ‘good citizen’—altruistic, morally superior. By extension, those excluded from blood donation cannot get access to this particular identity category.

The act of receiving donated blood or blood products is connected to the idea of taking that ‘little bit’ of the donor into the body of the recipient; hence blood recipients and donors were revolted by the idea of receiving blood from ‘undesirables’. The imputed moral quality of the donor is extended to the blood itself. Because of the meanings invested in blood donation, the exclusion of certain categories of people is politically significant. The study therefore sought to explore the nature of the citizen who is constituted by the act of donation—and more specifically, who is the citizen excluded from blood donation.

Critical Framework

The giving of blood has been theorised in terms of social obligation and the welfare state, where blood donation can be described as the perfect act of altruism, a transaction free of social indebtedness and economic self-interest (Titmuss, 1971). Such analysis is reliant upon blood being a circulatable substance and its donation not being remunerated. The special qualities of blood itself are largely ignored. Although it is described as a universal, formative substance, Titmuss was nonetheless concerned with the unsuitability of some people as donors. The assumption is that commodification of the blood supply—payment for donation—would result in contamination by unsuitable donors (people with hepatitis, as this writing pre-dates HIV). The anonymity of the donor, the absence of payment, and the honesty of the giver (in disclosing status with regard to hepatitis) were deemed the elements of this unique gift.

Since 1971, scholarship has recognised that the body is a problematic and dynamic constituent, and that blood, by implication, is not an homogenous and universal substance but a vital force in forming and differentiating citizens. Further, the Australian blood supply has been contaminated both by HIV and HCV under the conditions presumed to be safe—volunteer donors who met the appropriate guidelines telling the truth.

‘Healthy donors’

Healthy people aged between 16 and 70 who weigh over 45 kilos are eligible to donate blood, with two provisos according to the Australian Blood Bank website. Firstly, anyone ‘who spent a cumulative period of six months or more in the United Kingdom between 1 January 1980 and 31 December 1996 cannot be accepted as blood donors until further notice’. Second, unspecified ‘guidelines’ also need to be met: these stipulate that people who have ever injected drugs are ineligible to donate, and those who have had sex with

a gay or bisexual man, or a prostitute cannot donate until 12 months have elapsed since that sexual contact. While these exceptions are designed to protect the blood supply from contamination with blood-borne viruses (vCJD, HIV and HCV), they exclude identity categories rather than the precise risk practices (unprotected anal intercourse with a partner of unknown HIV status, sharing injecting equipment and eating beef in the UK in that period). These exclusions are not politically equal.

Lisa (blood recipient): Yeah I would think urg, because it would be like the needle exchange, you’d walk to the, you’d see them all hanging around outside with their cups of methadone and you know, no, it’d be awful. I can just see it now. What it would be like. And I think I’d rather die probably.

Do you really mean that or ...

Lisa: Oh I’d be very unhappy about accepting their blood. I wouldn’t be happy at all.

Politics of exclusion

There is a significant difference between the exclusion of gay men as a group and residents of the UK in a particular time period. One is linked to a social identity strongly, the other weakly. One is politically neutral, the other politically potent, with a pre-existing history of stigma and discrimination attached. The exclusion of UK residents is coded as temporary, that of homosexually active men as permanent.

The exclusion of IDU sits between the two, as injecting drug use does not operate as a social identity in the same manner, nor to the same degree, as homosexuality. Neither IDU nor ex-UK residents protested the exclusion, while homosexually active men did.

The identification of blood donation with altruism inflects the exclusion of identity categories. This is reflected in responses to the notion of payment for blood. Of the 35 people interviewed, only five responded positively to the idea of remuneration. Four gave neutral responses, but the reactions for the most part were hostile. The sharing of self practiced by blood donors becomes, in the context of people getting paid to donate, the presenting of an inappropriate, unwanted self.

Jill (IDU): Because I know that if people were getting paid to give blood you’d get all the dodgy people of society, you know myself included, you would. At least where it is now you only got, you know like, do-gooders, like you know, wanting to do it, but you know.

And why would that matter?

Jill: Because in my eyes do-gooders are cleaner. Do you know what I mean. There’s less, they have a less risky life so there’s less chance of, you know.

Responses singled out drug users as people likely to give dishonestly—i.e. donate blood despite being ineligible to do so—should payment be available.

Carl (blood recipient): You’d get every drug addict in the western suburbs [of Sydney], every drug addict around here that needs a couple of dollars.

Thus the exclusion of IDU operates in three ways. Firstly, at a technical level—their blood cannot be used by blood banks. Secondly, IDU are excluded from the identity categories of altruism and moral superiority—‘good citizenship’. Thirdly, IDU are excluded because their motives are suspect. Their imagined willingness to give dishonestly means they would do harm rather than good if money were involved—they become the inverse of the altruistic donor, a ‘bad citizen’.

Conclusion

Len (IDU): It was in the era when people were getting their licences marked with donations and stuff like that with the organs, I did mine too. I thought that was quite cool. And I’ve felt really awful, now I can’t give blood. I can’t get my little badge and say I’ve done the right thing. I’ve got no status symbol. I feel as though I’ve been cut off in a way. Like I’m now not good enough.

The moral capacity of blood donors should be recognised and valued, but so too should their membership of a particular community. Donors are not morally superior in a kind of generic way—they are located in particular networks of blood collection and processing, and the donating body is possessed of particular characteristics. Non-donors belong to a different set of networks and the non-donating body may be possessed of different characteristics. The convenient fiction that members of the public can and should donate to a public blood bank sits in tension with the recognition that the public is not singular and that donation is not always possible. Persisting with this fiction may reward those who donate, but at some cost to those who are not invited to donate—and to our understandings of the ways private and public are imbricated in blood donation. ♦

Reference

Titmuss, Richard (1998) ‘The Gift of Blood’ *Society* 35 (2): 88–97. (Reprint from 1971)

6

Blood and Bioidentity: Ideas about Self, Boundaries and Risk in Blood Donation

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Bioidentity describes the commonsense understanding of our bodies as 'ours', with the contours of the body forming the limits of self. While real bodies never precisely conformed to this model (the acts of eating, breathing and sex for example blur the boundaries), biotechnology in the 20th and 21st centuries has redefined these limits. It is now not uncommon for a person in a developed nation to have donated or received tissue that originated in someone else's body—for example blood, blood products, organs, ova.

This paper asks how these fragments of other bodies are understood by donors and recipients: to whom are they deemed to 'belong' and to what extent. Is, for example, a trace of original identity retained after donation? Is there a difference between blood and organ donation, and how is this ownership determined? While the similarities and differences between blood and organ donation are discussed, the data is specifically concerned with the bioidentity of blood and its donation and transfusion.

Brief history

Blood was the first bodily tissue to be successfully transferred from person to person, which was made possible by the identification of blood groups in 1991. During World War I anticoagulant was developed and the systems for the mass collection, donation and transfusion of blood were set up during World War II. Organ donation has been practiced since the 1950s, and *in vitro* fertilisation techniques were developed for humans in the 1970s that enabled the transfer of ova, sperm and embryos from donor to recipient.

In addition, bodily fragments that are accorded the status of 'waste'—by-products of surgery, birth, pathology testing or death that are deemed to have no value to the subject—can be transformed into biotechnical commodities such as cell lines and genetic information.

The biomedical ability to detach, transplant and circulate bodily fragments moves faster than the ability to construct appropriate legal and ethical frameworks around these processes. With the relationship (if any) between the donor and the recipient of a bodily fragment imperfectly and inconsistently understood, legal and social scandals have resulted. These have included: instances where hospitals in the UK complied with donor requests for organs to be given only to white people; hospitals in the UK and Australia retaining dead children's organs without parental knowledge or consent; and in the US an African-American family seeking restitution after discovering that their deceased mother's cells were used to make one of biomedicine's most profitable cell lines.

The law

Under UK and Australian law, tissue donors cannot treat tissue as property—they are not deemed to 'own' their tissue and cannot sell it. Once donated, donors are deemed to have abandoned any legal claim. In The UK, USA, Canada and Australia therapeutic tissues are managed as a gift system that must be donated voluntarily and without payment, and distributed according to medical need rather than the ability to pay.

Critical framework

Gift systems, it has been theorised, are different to commodity transaction in that they constitute relationships between people—the generosity of the giver and the indebtedness of the receiver create a relationship of obligation. The donation of blood differs however in that it is an anonymous gift and the ties it establishes are somewhat abstract—ties of citizenship and community. According to this model, the gift of blood helps to construct a sense of social responsibility among strangers and gratitude not to an individual but to the social body as a whole. This theory suggests that rather than ownership of blood being transferred like a commodity, it is inflected by qualities of the donor (the presumed altruism).

Blood donation and organ donation – the differences

There are three significant differences between blood and organ donation. Firstly, donated organs tend to be harvested from young people who have died violent, unexpected deaths unlike blood which is given by live donors and replenishes itself. Secondly, receiving a donated organ is a major process, whereas a blood transfusion is frequently given as a side event—the main event is the surgery or trauma involved in the blood loss. Therefore blood transfusion can be presumed to be less of a focus of attention. Thirdly, donated organs cannot be banked so the temporal relationship between recipient and donor is necessarily proximate.

Perceptions of the interviewees

Most of the interviewees did not regard blood as being highly invested with the identity of the donor, although some did see it as being perpetual self. Generally a proprietary interest was not taken by the donors.

Can you tell me a bit more about your feelings about receiving a blood transfusion? In that situation, how do you think of the blood now that's gone into you. Do you think of it as your blood?

Carl (blood transfusion recipient, but has never donated): Yeah I do class it as mine now yeah. Because you can't get it out of me. It's not as if they can prick my finger and get it back.

For Carl, because donated blood is given away and then readily incorporated into the recipient's body, it ceases to belong to the donor once it leaves his or her body. Other interviewees described transfused blood as being just like another medical product, like a pharmaceutical.

Would you think of it as foreign or just as another medical product?

Murray (IDU, HIV-positive, has donated blood but never received it): Yeah probably more the latter I think ... just another chemical basically ... I

don't have any emotional attachment to it. It's just a fluid and I think it's what you said, it's like getting antibodies in a drip or something, you're getting blood in a drip.

Two of the interviewees with haemophilia described blood as not belonging to anyone, but being a general circulating resource available to those in need. It is arguable that, as the treatment for haemophilia involves the highest degree of intervention with donated blood and pooling from many donors, the relationship to any particular donor becomes extremely tenuous. This concept of blood as a general resource was not limited to haemophiliacs, however.

Interview participants who had HCV perceived their blood as remaining 'theirs' after leaving the body chiefly because it bears the imprint of HCV and is a source of potential infection to others.

You've had some experience of having blood taken, ... when you look at it in that syringe does it become something different or is it always still yours?

Jen (HCV-positive, has never donated blood or been transfused): Um, I think it's still my blood because it's got all my whatevers in it.

Even when it's packed off to the lab and different things, is it still yours?

Jen: Yeah I guess. It's my DNA, isn't it? My viruses.

The contamination of the blood supply in the 1980s with HCV and HIV problematised the 'gift of the altruistic stranger' and affected the legitimacy of blood banks. A wariness of a contaminating stranger replaced the imagined altruistic donor for some, and some participants spoke of not trusting the blood supply. For the 34 interviewees with HCV, however, there was a strong sense that their blood was a potential source of infection. Several of the HCV-positive participants in the study expressed an active sense of responsibility not to donate, to withhold their blood from circulation via the blood bank, just as they must withhold it from other possible routes.

Conclusion

It was found that, generally speaking blood is not strongly imbued with ideas of personal identity, and that interviewees do not regard blood as a personal possession. Qualities of blood itself and the process of its collection and dissemination made it significantly different to organ donation or receipt. However blood was regarded as strongly imbued with 'risk identity'. In particular the HCV positive interviewees regarded their blood as a dangerous personal attribute, one that must be withheld from circulation. ♦