Multiple strategies are required to address the information and support needs of gay and bisexual men with hepatitis C in Australia

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ABSTRACT
Background Hepatitis C virus (HCV) infection is increasingly reported among gay and bisexual men. However, little is known about the personal and social dimensions of HCV-related experience among these men in Australia.

Methods An online survey of 474 Australian gay and bisexual men was conducted from August to December 2013. A subsample of 48 HCV mono-infected and HIV/HCV co-infected men was analysed to explore HCV knowledge, sources of information, unmet information needs and use of HCV-related services.

Results More than half of respondents in the subsample were unaware that HIV infection increases the risk of sexually acquired HCV and most wanted information about how to prevent the sexual transmission of HCV. A majority of respondents requested gay-specific HCV services, and approximately similar proportions of men indicated that they would like these services delivered by a hepatitis organization, a lesbian, gay, bisexual, transgender and intersex (LGBTI) organization and a HIV organization. Men in receipt of HIV antiretroviral treatments were most likely to request that gay-specific HCV information and support services be delivered by a LGBTI or HIV organization (OR = 8.63).

Conclusion These findings suggest that a variety of organizations are required to address the information and support needs of Australian gay and bisexual men with HCV.

Keywords co-infection, hepatitis C, HIV, knowledge, support services

Introduction
At a time when developed nations can—optimistically—imagine ‘ending HIV’,1 hepatitis C virus (HCV) infection has emerged as a complicating factor in the lives of gay and bisexual men and in the delivery of appropriate health, information and support services. HCV is a blood-borne virus most commonly transmitted via the sharing of unsterile injecting equipment.2 Other less common routes of HCV transmission include unsterile body modification practices such as tattooing, unsterile medical procedures and unprotected sexual practices between men.3 Throughout the 1990s, the incidence of HCV infection among HIV-positive gay and bisexual men rose steadily in Europe, the USA and Australia,4,5 with the biggest increase estimated to have occurred after 2002.4 Studies indicate that sexually transmissible infections and high-risk sex and drug use practices among HIV-positive men, including any sexual practice that can result in bleeding or mucosal trauma such as fisting, and sharing equipment for injecting or snorting illicit drugs, increase the likelihood of gay and bisexual men acquiring HCV infection.4 – 8

The estimated number of gay or bisexually identified men in Australia is ~178 000, and around 16 000 of these men are living with HIV.9 HIV-positive gay and bisexual men comprise the most vulnerable group in Australia for co-infection with HCV. Around 9% of HIV-positive gay and bisexual men and
almost 2% of HIV-negative men have HCV. This compares with ∼1% of the Australian population more generally, or ∼230,000 people who report HCV infection. Gay and bisexual men are more vulnerable to HCV infection, in part because the rate of injecting drug use within gay communities is around 10 times higher than among the general Australian population (and even higher still among HIV-positive men). Despite such high rates, exclusionary norms have been identified around the practice of injecting within gay communities in Sydney and Melbourne, which concurs with research from the UK where it is reported that HCV is experienced as more stigmatizing than HIV among men who have sex with men. Injecting and HCV-related stigmatization and discrimination are significant concerns as they can present barriers to people accessing appropriate health, information and social support services.

While the prevalence of HIV and HCV co-infection in Australia is currently low compared with many similarly developed countries, increasing rates of HIV and HCV co-infection, and HCV mono-infection, are a problem for at-risk individuals and for public health systems, because if left undetected and untreated, these infections lead to significant morbidity, mortality and public health costs. Research among illicit drug users shows that HIV/HCV co-infection results in a poorer prognosis than mono-infection with either virus. Co-infected people show decrements on measures of health-related quality of life in the domains of physical functioning, bodily pain, social functioning and emotional health, which translates as limitations in affected people’s capacity to perform their usual life roles. Co-infected people are more likely to report a poorer future outlook, significantly more depression and physical symptoms, and they report a greater use of healthcare services than people with either HIV or HCV. Treatments are not as efficacious in co-infected people, and the cumulative impact of medications for HIV and HCV can lead to liver toxicity in people treated for co-infection.

Gay and bisexual men need access to relevant information and social support services to be tested for HCV, and for mono- and co-infected men to effectively manage the complexity of living with, and being treated for, one or more debilitating chronic conditions. There are suggestions that over time HIV/HCV co-infection may lead to an increase in demand for support and other services provided by government and non-government organizations including lesbian, gay, bisexual, transgender and intersex (LGBTI) and HIV organizations. Meeting the needs of affected gay and bisexual men in Australia and elsewhere will require research, planning and an adequate provision of resources. Among the few studies that have explored gay community awareness and perceptions of HCV, knowledge of key issues such as treatment availability and efficacy is reportedly inconsistent. The aim of this paper therefore is to present findings regarding HCV knowledge, HIV/HCV co-infection, HCV treatments and access to HCV-related information and support services from a recent, exploratory study conducted among gay and bisexual men in Australia.

Method

Participants and procedure

The study received ethical approval from the Human Research Ethics Committee at UNSW Australia, and the research ethics committees of ACON (formerly the AIDS Council of New South Wales) and the Victorian AIDS Council. A cross-sectional, online survey using convenience sampling was conducted nationally from August to December 2013 to examine the social aspects of HCV among gay and bisexual men. Eligible respondents were men aged 18 or more, who identified as gay, bisexual or were homosexually active, and currently lived in Australia. The study was promoted via advertisements placed on Facebook and gay-themed social and sexual networking websites frequented by Australian gay and bisexual men. Banners advertising the study were also placed on the websites of community-based HIV, LGBTI and HCV health organizations, and the study was promoted through their e-mail lists. Study recruitment materials invited men to participate in a confidential and anonymous online survey titled the ‘Gay and bisexual men hepatitis C survey’. An online participant information statement provided details about the study, eligibility criteria, withdrawing from the study, accessing study results and contact numbers for the main institutional ethics committee overseeing the study. Referral information was provided for respondents who wished to seek help for HCV infection and/or drug-related issues. For the final 2 months of the study period, recruitment specifically targeted men living with HIV and/or HCV to increase their representation in the sample. The self-administered survey took around 20 min to complete.

The survey instrument was developed following a review of the literature around HCV among homosexually active men and among the general population. Survey items explored respondents’ socio-demographic characteristics, social engagement with gay men and sense of connection to gay community, general health, illicit drug use history, HIV status and treatment, and co-infection. HCV-related items enquired into barriers to HCV treatment, treatment experiences, unmet information needs, sources of HCV information and respondents’ desire for gay-specific HCV-related services.
Statistical analyses
All statistical analyses were conducted using IBM SPSS Statistics 22. The analyses presented are restricted to respondents who self-reported being HCV positive and are primarily descriptive due to the exploratory nature of the study and the relatively small number of respondents who were living with HCV or HIV/HCV co-infection. Confidence intervals were calculated for all descriptive statistics. Bivariate logistic regression models were used to examine characteristics of respondents who reported a desire for gay-specific HCV support services to be delivered by LGBTI organizations and HIV-related organizations.

Results
Sample characteristics
The survey was completed by 474 respondents, of whom 12% reported being HCV positive. Seven of these men did not complete the survey, resulting in a final subsample of 48 HCV-positive men. Forty-six per cent of these HCV-positive men were recruited via Facebook advertisements, 23% via advertisements on gay-themed websites, 15% via the email lists of community-based HIV and hepatitis organizations, and 4% via word of mouth (12% did not report where they heard about the survey). Table 1 shows that the majority of the 48 respondents with HCV were aged over 40 (66%), identified as gay (94%), were born in Australia (79%), were in paid employment (58%) and lived in a capital city (81%). Most men with HCV reported being co-infected with HIV (75%).

Tables 1 and 2 show the descriptive characteristics of the sample. On average, respondents had been diagnosed with HCV 9 years earlier, and half were treatment naïve. Forty per cent of respondents believed that they had acquired HCV via sharing injecting equipment and 35% felt that they had acquired HCV via sex with a male partner. Around 21% of respondents were unable to account for how they acquired HCV, and one respondent each reported acquiring HCV via...
unsterile tattooing and from a dental surgery. While almost half of respondents reported that most or all of their friends were gay men, the majority did not report a strong sense of connection to a gay community (66%).

**HCV-related knowledge, information needs and treatment**

Overall, respondents’ knowledge of HCV was moderate to good, evidenced by a mean of 5.6 knowledge items correctly identified from a maximum of 7. However, there was some uncertainty in respondents’ beliefs about HCV. While most respondents agreed that ‘HCV can be sexually transmitted between men’ (65%), less than half of respondents agreed that ‘Being HIV positive makes it more likely you will get HCV during sex between men’ (44%).

Table 2 shows respondents’ unmet HCV information needs. The majority of respondents (81%) reported at least one unmet information need. The topics respondents most commonly indicated that they would like information about were how to avoid transmitting HCV to sexual partners (46%), complementary therapies for HCV (42%), how HIV/HCV co-infection affects health (42%) and how HIV and HCV treatments affect each other (40%). Table 2 also shows where respondents said they had accessed HCV information. The majority of men nominated their general practitioner (GP) or specialist (85%) or the Internet (69%) as their primary sources of HCV information, with fewer men reporting they had accessed information via hepatitis organizations (52%), other healthcare workers (38%) and friends (23%).

Half of the respondents had been treated for HCV. Of the respondents who had not been treated for HCV, 88% had discussed treatment with a doctor or other health professional, and 63% indicated that they were willing to attempt HCV treatment. Respondents most commonly reported concern about the side effects of HCV treatment and having heard ‘bad things’ about treatment. Respondents were also concerned about HCV and HIV treatment interactions, and some did not feel unwell enough for treatment, or they wished to postpone treatment until new HCV therapies became available.

**HCV-related support services**

In all, 67% of respondents with HCV reported that they would like gay-specific HCV services such as support groups, a telephone helpline and referral to treatment services. Similar proportions of these men indicated that they would like HCV services delivered by a hepatitis organization (72%), an LGBTI organization (66%) and a HIV organization (59%). Some men also indicated a desire for gay-friendly HCV services to be provided by mainstream health organizations (33%). There were no substantive differences between men according to whether or not they reported a desire for gay-friendly HCV services at mainstream health organizations (analysis not shown).

Table 3 presents bivariate logistic regression analyses examining the characteristics of respondents who reported a desire for gay-specific HCV services to be provided by LGBTI and HIV organizations. Respondents who were on antiretroviral treatments for HIV, who had mostly gay men as friends or who were born overseas were more likely to report a desire for HCV services provided by LGBTI and HIV organizations.

**Discussion**

**Main finding of this study**

The main finding of this study clearly indicates that Australian gay and bisexual men want a choice as to where they can access gay-specific HCV-related information and services. This finding highlights (i) the integral role that both LGBTI...
and HIV organizations perform in catering to the specific needs of gay and bisexual men and (ii) that gay and bisexual men also utilize other services, including mainstream and specialized drug services. Therefore, multiple strategies are required to address the HCV-related information and support needs of gay and bisexual men in Australia.

It is understandable that gay and bisexual men on HIV treatments, or who had mostly gay friends, or were born overseas, reported a preference to access gay-specific information and services from LGBTI and HIV organizations. This preference possibly reflects gay and bisexual men’s satisfaction with the central advocacy role historically performed by Australian gay community organizations around HIV prevention, HIV/AIDS-related health, equality and social support issues.27 Among overseas born men, these organizations’ programmes probably compare favourably to the limited, or non-existent, services available in most regions of the world for homosexually active men. Indeed, more than a decade ago, de Visser and colleagues22 foreshadowed a growing demand for gay community-focussed, HCV-related services for HIV-positive men, and they speculated that these services could be delivered by AIDS councils (i.e. state-based HIV- and LGBTI health-related organizations) throughout Australia. Some of these organizations have begun to address HCV health, information and support issues among gay and bisexual men. Similarly, viral hepatitis organizations in Australia are beginning to provide services such as chronic disease self-management programmes for gay and bisexual men with HCV and HIV/HCV co-infection. However, it appears that gay and bisexual men are often not aware of these existing resources, nor are their specific information and support needs always addressed, or addressed in sufficient detail, within current programmes. In the light of moves towards the greater personalization of health service provision,28–30 which aim to give individuals and communities who need public services greater choice and control over the way in which their needs are provided for and managed, it is consistent that our respondents’ wish for broad access to gay-specific and gay-friendly, HCV-related information, health and support services should be heeded.

Respondents reported a range of unmet information needs such as HCV prevention and the implications of HIV/HCV co-infection. Although most respondents knew that HCV is sexually transmissible between men, they wanted specific information about how to prevent sexual transmission. Presently there is little practical information available about avoiding HCV transmission during sexual activity. The epidemiological evidence regarding the specificity of what constitutes HCV-related risky sexual practice between men is currently equivocal. It has been suggested that any sexual practice that leads to bleeding or mucosal trauma poses a risk.7,31 However, evidence-based recommendations for behaviour modification to reduce sexually acquired HCV in at-risk populations are yet to be determined.32 This uncertainty presents a conundrum for health promotion directed towards HIV-positive gay and bisexual men, many of whom in this study were unaware that HIV infection increased vulnerability to HCV infection.

### Table 3 Bivariate logistic regression analyses examining covariates of desire for HCV support services provided by LGBTI and HIV organizations (n = 48)

<table>
<thead>
<tr>
<th></th>
<th>Want HCV services from LGBTI and HIV organizations</th>
<th>Unadjusted odds ratio (95% CI)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No, n (%)</td>
<td>Yes, n (%)</td>
<td></td>
</tr>
<tr>
<td>Aged &gt;45</td>
<td>12 (55)</td>
<td>12 (46)</td>
<td>1.00 (0.95, 1.06)</td>
</tr>
<tr>
<td>Born outside of Australia</td>
<td>2 (9)</td>
<td>8 (31)</td>
<td>4.44 (0.83, 23.73)</td>
</tr>
<tr>
<td>HIV/HCV co-infected</td>
<td>16 (73)</td>
<td>20 (77)</td>
<td>1.12 (0.58, 2.15)</td>
</tr>
<tr>
<td>Currently on HIV antiretroviral treatment</td>
<td>11 (69)</td>
<td>19 (95)</td>
<td>8.63 (0.89, 83.75)</td>
</tr>
<tr>
<td>HCV treatment experience</td>
<td>12 (55)</td>
<td>12 (46)</td>
<td>0.71 (0.23, 2.23)</td>
</tr>
<tr>
<td>HCV knowledge score (M, SD)</td>
<td>5.3 (2.1)</td>
<td>5.8 (1.0)</td>
<td>1.27 (0.87, 1.86)</td>
</tr>
<tr>
<td>Most or all friends are gay men</td>
<td>8 (36)</td>
<td>15 (58)</td>
<td>2.39 (0.74, 7.66)</td>
</tr>
<tr>
<td>A lot of free time spent with gay men</td>
<td>6 (27)</td>
<td>8 (31)</td>
<td>1.19 (0.34, 4.16)</td>
</tr>
<tr>
<td>Ever injected drugs</td>
<td>17 (77)</td>
<td>22 (85)</td>
<td>1.62 (0.38, 6.96)</td>
</tr>
</tbody>
</table>

CI, confidence interval.
bimodal. HCV-related research among homosexually active men in Australia has been confined to describing HCV-related sex and drug use risks, a brief discussion of the potential impact of HIV/HCV co-infection on gay communities, and assessments of HCV knowledge. Currently, the HCV epidemic among gay and bisexual men remains in the shadow of the HIV epidemic in terms of global gay community awareness, research and health promotion.

What this study adds
This study is the first to investigate gay and bisexual men’s needs and preferences regarding HCV-related information and support services. In addition, this study is the first to signal that mainstream HCV community-based organizations in Australia such as hepatitis councils and illicit drug user organizations should continue to develop gay-specific HCV-related information and services. Because of their extensive experience and expertise in providing HCV-related information and support services to marginalized populations such as people who currently inject drugs, Australian hepatitis and illicit drug user organizations are well suited to help address the information and support needs of gay and bisexual men with HCV.

The findings of this study also add evidence for the utility of integrated HIV and HCV health care and education for gay and bisexual men via general practice. Throughout Australia, HIV-related health care is increasingly delivered by GPs with expertise in HIV medicine who work in inner urban primary healthcare settings where there are high case loads of gay and bisexual men with HIV, and increasingly HCV. The proportion of men in this study, who said a GP was their main source of HCV-related information, and who indicated past or current HCV treatment, provides new evidence that some GPs discuss HCV with HIV-positive men during consultations. GPs can play a crucial role in raising awareness about HCV in this population and by providing referrals to HCV-related information and support services. Treating HCV within HIV general practice is plausible in this era of shorter HCV treatment durations and improved treatment efficacy.

Limitations of this study
Some caution is needed in interpreting and generalizing the results of this study to other gay and bisexual men with HCV, due to the sample size. While a variety of websites were used to target online recruitment, gay and bisexual men with HCV in Australia are relatively few in number and from the experience of this study they may be a difficult population to reach. The wide confidence intervals reflect this study limitation. Despite this, the sample characteristics of the group of gay and bisexual men with HCV (i.e. mostly Australian-born, older, educated, employed, urban gay men) are similar to those reported by men recruited for the Australian Gay Community Periodic Surveys, which are reliable behavioural surveillance studies of mostly HIV-related risk practice.

Given the scarcity of international data available from comparable social research into the HCV information and support needs of gay communities, the findings presented here should be viewed as a basis for further investigation. Future studies are also needed to understand how to support and develop the important HCV-related programmes already in place within some gay community, viral hepatitis and illicit drug user organizations and primary healthcare, so as to improve services for gay and bisexual men with HCV.

References


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