



National Hepatitis C Needs Assessment 2008

Do you C what? C?

Executive Summary

Purpose

The purpose of the National Hepatitis C Needs Assessment (2008) was to identify the education, information and support needs of Australians living with hepatitis C; to inform the development of improved information, education and support services for people with hepatitis C in Australia. This project builds on, and will provide an update to the Needs Assessment conducted by Hepatitis Australia in 2003.¹

Methodology

A triangulation of quantitative (questionnaire) and qualitative (focus groups and semi-structured interviews) were used to characterise the hepatitis C information, education and support needs of people living with hepatitis C in Australia. The questionnaire was informed by the results of an initial three focus groups involving a broad range of people living with hepatitis C. Subsequent focus groups and telephone interviews targeted members of priority populations and explored in greater detail the results of the questionnaire.

Results

In total, 327 people participated in the Needs Assessment. Of these, 261 people responded to the questionnaire, 55 were involved in focus groups and 11 people participated in in-depth interviews.

Questionnaire results

The findings of the questionnaire provide a valuable insight into the information, education and support needs of 261 people living with hepatitis C from diverse backgrounds.

Time of Diagnosis

Diagnosis was a time of concern for questionnaire respondents, primarily because they did not receive adequate information. The majority of respondents were diagnosed by their GP (62%). After diagnosis, only half the respondents (52%) had the impression that hepatitis C was a serious but treatable condition.

Information and education needs

Approximately two thirds of respondents believed they had access to enough information to make informed decisions about their hepatitis C, either all the time, or most of the time. However, the remaining one-third of respondents stated they sometimes, or rarely had enough information to make informed decisions.

The preferred methods of receiving hepatitis C information were face-to-face (67%), printed resources (55%) and internet websites (35%). Hepatitis Organisation print resources and websites were generally considered the best sources of information.

Medical and nursing specialists were highly regarded as sources of information. Other people with hepatitis C and GPs were rated as one of the best *and* one of the worst sources of information, which reflects the diversity in respondents' experiences.

Sixty per cent of respondents indicated they had additional, unmet hepatitis C information and education needs on a range of topics.

Support needs

Only 17% of respondents had always felt supported to manage their hepatitis C, and 39% felt supported most of the time. Once again, face-to-face contact was the preferred method of obtaining support (85%).

Liver specialists (37%) and GPs (42%) were the most frequently mentioned preferred sources of support. Other useful sources of support included the printed resources produced by Hepatitis Organisations (50%) and the personal perspectives of other people living with hepatitis C (34%).

Approximately a quarter of respondents (23%) either belonged to, or had attended a hepatitis C support group, and a further 28% indicated they would like to belong to a support group, but the majority did not know how to access a support group locally. Forty eight percent of respondents had accessed the services offered by a Hepatitis Organisation.

Disclosure of hepatitis C status was noted as an impediment to accessing support and attending support groups; the majority of respondents (58%) indicated they had chosen to tell only a small number of people they trusted.

Focus Group and Interview Results

The following data is presented according to themes that emerged in eight focus groups and 11 individual interviews.

Information needs at diagnosis

Consistent with the questionnaire findings, few participants were knowledgeable about hepatitis C prior to diagnosis. The process of being diagnosed with hepatitis C did not result in significant improvements in knowledge for most participants.

Impact of Hepatitis C-related stigma

Hepatitis C-related stigma and discrimination were identified as significant barriers to openly and freely accessing hepatitis C information and support.

Information and education needs

Participants' information needs evolved as they experienced the spectrum of hepatitis C infection.

Similar to the questionnaire respondents, focus group participants preferred to obtain information through face-to-face contact with professionals and other people living with hepatitis C.

Printed resources and the internet were commonly used for information gathering and the latter had the advantage of providing participants with a means of accessing information confidentially. However, participants expressed concern about trusting information on the internet. Younger participants tended to be less discerning about the trustworthiness of information on the internet. Participants also acknowledged that access to the internet remained limited for many people in Australia.

Many participants emphasised that they preferred to use a variety of methods to gather information, as this assisted them to clarify, retain and understand the information presented.

Valued sources of information

When participants were making hepatitis C management or treatment decisions, they valued the opportunity to interact with other people living with hepatitis C. Hearing other people's stories either face-to-face or through printed resources was highly regarded.

Printed resources produced by Hepatitis Organisations were instrumental to many participants' understanding of hepatitis C and were considered a cornerstone of information and education activities. However, some printed resources presented only a generalised perspective.

Public education forums offered by Hepatitis Organisations were valued sources of information as they provided an opportunity to gather information directly from a range of experts.

Health professionals, specifically liver specialists and liver clinic nurses, were trusted sources of hepatitis C information. General practitioners were frequently identified as lacking hepatitis C knowledge, which supported the questionnaire findings. Nonetheless, GPs remained a preferred source of information for people living with hepatitis C.

Unmet information needs

Participants identified a variety of topics for which they required additional information. Many of these topics were consistent with the needs identified by questionnaire respondents, including anti-viral treatment, coping with non-response or relapse after treatment, self-management strategies and understanding clinical terminology and concepts.

Barriers to accessing information

Key barriers to accessing information included poorly informed health professionals, especially GPs, inappropriately targeted resources and experiences of actual or perceived hepatitis C-related stigma.

Accessing Support

Participants discussed numerous methods of accessing support, including face-to-face, on the telephone and on the internet. Other people living with hepatitis C were a preferred source of support because they demonstrated the greatest empathy.

Peer support

The majority of participants indicated they would appreciate the opportunity to talk to another person living with hepatitis C. Whether the contact was initiated through a support group, telephone service or the internet, depended on the individual's personal preference, however, the supportive impact was equally as significant.

Consideration of, or commencing on, anti-viral treatment were common triggers for participants to seek peer support.

Distribution of information and support through peers was particularly important for people who inject drugs.

Practical support

The need for practical support while on treatment, such as help with meal preparation, shopping and cleaning, was raised regularly by participants.

Unmet support needs

The majority of people involved in the Needs Assessment wanted to receive hepatitis C support from health professionals; most frequently their GP and/or liver specialist and liver clinic nurse if they were on anti-viral treatment. In reality, many participants did not have access to support before they were referred to the liver clinic. However, time constraints were a barrier to accessing support both in the liver clinic and general practice settings.

Ideally, participants wanted to be supported by family and friends, but reported that they often lacked understanding of what it was like to live with hepatitis C.

Information and support needs of priority populations

People who inject drugs

Distribution of information and support through peers was very important for people who inject drugs. Resources developed by Drug User Organisations were particularly useful, because the information was specifically targeted towards people who inject drugs.

Homeless people

Homeless people living with hepatitis C have a range of competing demands that need to be addressed. Based on these findings, there is a need to develop the hepatitis C capacity of the staff of organisations working with homeless people.

Culturally and Linguistically Diverse (CALD) populations

Workers advocated for CALD resources to be developed in the community language to provide specific information about treatment, the practicalities of accessing treatment and the importance of monitoring and health maintenance.

General information about the structure and function of the Australian Health Care System was identified by CALD workers as being equally as important as the provision of hepatitis C information.

People living with hepatitis C in custodial settings

Hepatitis C workers in custodial settings described the proliferation of a variety of custodial specific resources including printed, visual and auditory resources, compulsory training and access to supportive health professionals.

The important role of peer education and support in custodial settings was also emphasised. Face-to-face was the preferred method of obtaining information for confidentiality reasons.

Aboriginal and Torres Strait Islander populations

The importance of having a comprehensive approach to providing hepatitis C information and support to Aboriginal and Torres Strait Islander people was emphasised. A combination of human and printed resources was considered ideal. Participants prioritised the need to build the hepatitis C capacity and infrastructure of Aboriginal and Torres Strait Islander health services concurrently, so information and support could be provided in a familiar and culturally appropriate service.

People living in rural areas

Lack of confidentiality was considered part of the landscape in rural Australia and was a significant barrier to accessing hepatitis C support. Participants explained that while information could be accessed anonymously through the internet or on the telephone, they preferred to access support through direct human contact.

Young people

Generally, young people believed they did not have any particular needs regarding hepatitis C. They considered that because they did not experience symptoms related to hepatitis C, it was not worth worrying about. Most had not sought information or support and the importance attributed to hepatitis C infection was low.

Considerations when using the Needs Assessment

Several issues related to the methodology and findings must be considered when using the Needs Assessment.

Although a broad range of people with hepatitis C were involved in the Needs Assessment, including representatives of the key priority populations, it is acknowledged that the 327 people who were consulted may not be a representative sample of all people living with hepatitis C in Australia. In particular, the needs of people not linked to hepatitis C services may not be accurately reflected in the results, as many participants were accessed through either hepatitis C-related community organisations or hepatitis C clinical services.

Significant barriers were encountered when attempting to consult with people with hepatitis C who come from a range of culturally and linguistically

diverse (CALD) backgrounds and people living with hepatitis C in custodial settings. Therefore, their needs were assessed from the perspective of the hepatitis C professionals working in these areas, which may have biased the results, because they may not have accurately reflected the needs of these priority groups.

People living with hepatitis C were reimbursed for their involvement in the project which may have biased the results.

Limitations associated with the questionnaire design are recognised. Data collection was conducted over a short time frame which may have limited the number of participants and therefore the depth of the findings.

Recommendations

The following recommendations were developed after consultation with Hepatitis Organisations and other professionals working in the sector.

1. Establish a national 'Hepatitis C Time of Diagnosis Project' specifically targeting GPs to develop and implement best practice guidelines around the time of hepatitis C diagnosis.
2. Implement a well-designed hepatitis C public education campaign which dispels the myths and misconceptions around hepatitis C and reduces the negative impact of stigma.
3. Develop effective partnerships with anti-discrimination agencies to guide further action to address hepatitis C-related discrimination.
4. Hepatitis organisations and specialist clinical services consider strategies to increase access to quality interactive information services incorporating hepatitis C peers and health professionals.
5. The National Hepatitis C Resource Network (run by Hepatitis Australia), reviews the results of the National Hepatitis C Needs Assessment as part of their planning process for new consumer resources.
6. Hepatitis-related organisations facilitate timely consumer access to information on new developments in hepatitis C and methods of assessing the quality of international websites.
7. Hepatitis and clinical organisations consider strategies to facilitate improved access to support groups across the country.
8. Hepatitis-related community organisations extend the reach of peer based support programs including treatment-specific programs.
9. Hepatitis-related community organisations promote their support services widely to incorporate family and friends of people living with hepatitis C.
10. Hepatitis Australia consults with Hepatitis Organisations, Hepatitis-related community organisations, clinical services and people living with hepatitis C about the Needs Assessment findings and the strategic development of hepatitis C information, education and support services in Australia.