Evaluation of Health Care Needs and Patient Satisfaction among Hepatitis C Patients Treated at a Hospital-based, Viral Hepatitis Clinic

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ABSTRACT

Objective: To define self-reported hepatitis C knowledge, health care needs, and patient satisfaction in a representative cohort of hepatitis C virus (HCV)-infected adults treated at a university hospital-based viral hepatitis clinic in Canada.

Methods: A questionnaire package evaluating HCV knowledge, health care needs, and patient satisfaction was administered to 111 consecutive consenting HCV patients during their first and 10-month follow-up HCV clinic visits.

Results: At their first HCV clinic visit, 52% of patients rated their current HCV knowledge as "fair" or "poor". Patients identified HCV education, quality medical care, medication coverage, and psychological counselling as important HCV health care needs. Health care satisfaction outcome data at 10-month follow-up indicated that patients felt significantly better informed, more satisfied, and more actively involved in their HCV health care.

Conclusion: A bio-psychosocial framework in which medical, psychological, educational, and social issues are addressed is desirable for optimal HCV health care.

La traduction du résumé se trouve à la fin de l'article.

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In Canada, an estimated 240,000 individuals are HCV-infected.^{1,2} Only a minority has been identified and even fewer have accessed appropriate care for this chronic infection. There is little published information describing hepatitis C knowledge among HCV-infected Canadians. Research from other countries suggests that knowledge about HCV may be particularly inadequate among individuals at high risk for HCV infection, including injection drug users,^{3,4} gay men,⁵ and American ethnic minorities.⁶

The needs of patients living with chronic illnesses, such as HCV, usually involve both physical and psychological components. For example, patients often need help managing recurrent symptoms of physical and emotional fatigue affecting work and family life.⁷ Medical patients for whom such needs are addressed by health care providers report better health care satisfaction.⁸ This is important because satisfied patients attend their medical appointments more regularly and adhere better to their treatments.^{9,10} Patient satisfaction is multi-determined and includes diverse aspects of care such as accessibility of services, quality of medical care, clarity of communication, and the interpersonal style of the health provider.¹¹ Studies repeatedly demonstrate that patients who feel more actively involved in their health care decision-making process are more committed to their care, adhere better to positive health behaviours, and are more satisfied with their health care.¹²⁻¹⁴ To our knowledge, no studies have examined HCV-related health care needs and health care satisfaction among HCV-infected patients. Thus, the present study was designed to evaluate HCV knowledge, determine health care needs, and quantify health care satisfaction in HCV patients before and after receiving care in a hospital-based viral hepatitis clinic.

The Ottawa Hospital Division of Infectious Diseases Viral Hepatitis Clinic was established in June 2000 with a mandate to provide care to adults living with viral hepatitis, to increase patients' knowledge about HCV risk factors and treatment options, and to empower patients to actively participate in their HCV treatment plan. To this end, at HCV patients' first clinic visit, patients receive basic HCV education through discussion with medical staff. Patients are also provided with

HCV-specific educational literature. An evaluation of patients' bio-psychosocial needs is conducted by a clinic nurse and physician, and patients are subsequently referred to psychology, social work, and other allied health care services, as required.

METHODS

This study was a joint effort between the Department of Psychology and Division of Infectious Diseases conducted at The Ottawa Hospital Viral Hepatitis Clinic. All English- or French-speaking adult HCV-seropositive patients attending their initial Viral Hepatitis Clinic visit were approached to participate in this study. Consenting patients completed the questionnaire package in private or with the aid of a family member. Medical staff were not present while the questionnaire was completed but were available to answer queries related to the questionnaire, if requested.

Both the Hepatitis C Needs Assessment Scale (HNAS)¹⁵ and the Hepatitis C Patient Satisfaction Questionnaire (HPSQ) were administered to participants at their first clinic appointment and 10 months following their initial visit. The HNAS is an 11-item self-reported HCV Needs Assessment measure that was developed for the current study. Items were generated from interviews with HCV health care providers, pilot testing with HCV patients, and a review of the HCV literature. Patients are asked to rate the importance of various HCV health care needs on a 5-point scale ranging from "not at all important" to "very important" (Table II). The HPSQ is a 6-item HCV-specific patient satisfaction questionnaire that was modeled on a validated Client Satisfaction Questionnaire (CSQ).¹⁶ Items from the original CSQ were reworded to more accurately reflect HCV-specific health care services (Table III). An overall satisfaction score is calculated by summing across the 6 HPSQ items. Scores on the HPSQ can range from 6 to 24, with higher scores indicating greater health care satisfaction. The original CSQ scale has satisfactory internal consistency (alphas range from .85 to .93).^{16,17} The internal consistency of the HPSQ in the present study was .80. Self-reported HCV knowledge was assessed with the following item: "How would you

TABLE I

Demographic and Psychosocial Characteristics at Initial HCV Clinic Visit

Total Number of Participants	111
Age (years) (Mean $\pm$ SD†)	43.1 $\pm$ 8.4
Male Gender	69%
HIV-HCV Co-infected	12%
Current Alcohol Use	55%
Injection Drug History	59%
Years Since HCV Diagnosis‡	Mean $\pm$ SD 4.7 $\pm$ 4.6 Range 2 wks. – 21 yrs.
Ethnicity	Caucasian 92% African 2% Hispanic 1% Asian 3% Other 2%
ALT (U/L)	Mean $\pm$ SD 97 $\pm$ 75 Range 9 – 453 Below 40 U/L 16% Slightly Elevated (1.1-3 x ULN§) 61% Moderately Elevated (3.1-5 x ULN) 16% Elevated (>5 x ULN) 7%
Liver Fibrosis Stage	Stage 0 7% Stage 1 24% Stage 2 9% Stage 3 3% Stage 4 3% No Biopsy Performed 54%
Employment Status	Full-time 33% Part-time 7% Disability 36% Unemployed 17% Student 6% Retired 2%
Educational Level	Elementary 10% High School 50% College 18% University 23%
Referral Source	Primary Care Physicians 55% Specialists 31% Addictions Counsellors 4% Other Source 5% Self-referred 5%

† Standard deviation

‡ In some cases, patients' initial diagnosis was non-A or non-B hepatitis, which was subsequently identified as HCV

§ Upper limit of normal

describe your overall knowledge of Hepatitis C (e.g., what causes it, what are its symptoms, how it is treated, etc...)" Responses were recorded on a 4-point Likert-type scale ranging from "poor" to "excellent". In an effort to qualitatively determine the severity of symptoms which patients attributed to chronic HCV infection, participants rated their HCV-related symptoms by responding to the following question: "How severe would you say your Hepatitis C symptoms are today?" The five possible responses were "I have no symptoms," "mild," "moderate," "severe," and "extremely severe". Demographic information was captured by questionnaire. Laboratory data were collected from medical chart records.

Data from patients, whose blood sample taken at the initial visit indicated that they had cleared the HCV virus (i.e., they had no detectable serum HCV RNA) (Roche Amplicor, Version 2 assay), were excluded from analysis. In addition to basic descrip-

tive statistics, relationships among health status indicators, psychological measures, and socio-demographic indicators were assessed using Pearson correlations. Paired-samples and independent-samples t-tests were used to compare overall patient satisfaction scores. Responses to individual satisfaction item at initial clinic visit and 10 months follow-up were compared using Wilcoxon signed ranks tests. Statistical significance for all tests was set at $p < 0.05$. All data were analyzed using SPSS (Version 8.0). Patients provided informed consent prior to agreeing to participate in this questionnaire study as per Ottawa Hospital Research Ethics Board guidelines.

RESULTS

Baseline characteristics

Initial questionnaires were administered between June 2000 and February 2002. Of 148 patients meeting eligibility criteria, 122 (82%) agreed to participate. Fourteen

TABLE II

Percentage of HCV Patients Who Rate Each Health Care Need on Degree of Importance (HNAS)

Health Care Need	Not at all Important	Not Important	Somewhat Important	Important	Very Important	Did Not Respond
HCV educational information	0.0	1.8	7.2	35.1	55.9	0.0
Access to pharmacist	6.3	11.7	18.0	26.1	36.9	0.9
Medical treatment for HCV	1.8	4.5	7.2	24.3	58.6	3.6
Psychological counselling	5.4	10.8	16.2	28.8	38.7	0.0
Support for family/partner	8.1	12.6	16.2	22.5	37.8	2.7
Access to support groups	9.9	18.0	22.5	27.9	19.8	1.8
Help finding housing	32.4	18.9	11.7	8.1	18.0	10.8
Alcohol/drug treatment	37.8	15.3	7.2	14.4	21.6	3.6
Access to HCV drug plans	4.5	6.3	10.8	19.8	55.9	2.7
Access to a nutritionist	3.6	9.0	20.7	28.8	36.9	0.9
Involvement in clinical trials	6.3	9.0	19.8	26.1	30.6	8.1

Note: All numbers are in percentages. HCV = Hepatitis C Virus. N=111.

TABLE III

Hepatitis Patient Satisfaction Questionnaire (HPSQ) Results at Initial Clinic Visit

HPSQ Items	Poor	Fair	Good	Excellent
1. How would you rate the quality of services you received for HCV?	23%	27%	42%	9%
2. Did the health care services that were available meet your needs?	All met 21%	Most met 28%	Some met 38%	None met 14%
3. Did the services you received help you to cope better with HCV?	A great deal 16%	Somewhat 42%	Not helpful 33%	Made worse 9%
4. In general, how satisfied are you with the services you have received for your HCV?	Very dissatisfied 9%	Dissatisfied 26%	Satisfied 46%	Very satisfied 19%
5. How often did you feel actively involved in making informed decisions about your HCV care?	Always 11%	Often 20%	Rarely 39%	Never 30%
6. How satisfied were you with access to specialist services (nurse, psychologist, pharmacist, social worker, dietitian)?	Very dissatisfied 8%	Dissatisfied 23%	Satisfied 50%	Very satisfied 19%

Note: Percentages may not sum to 100 due to rounding errors. N=111.

otherwise eligible subjects were unable to participate because of language or disability barriers. Individuals declining participation cited lack of time / interest (n=14) or did not return the questionnaire (n=12). Eleven subjects were subsequently removed from the analysis because blood samples drawn at their initial clinic visit found them to be HCV PCR-negative, leaving a final total of 111 participants. No significant differences were identified between the final cohort of study participants and questionnaire decliners on any socio-demographic variables with the exception of mean age (decliners: 48.0 ± 10.8 years, study participants: 43.1 ± 8.4 years, p<0.05). Twelve percent of patients were HIV-HCV co-infected. No significant differences in baseline demographic characteristics were identified between HCV mono-infected subjects (n=98) and HIV-HCV co-infected patients (n=13), therefore co-infected patients were included in all subsequent analyses.

Patient characteristics are described in Table I. No patient presented with decompensated liver disease, hepatoma, or a history of liver transplant. Mean INR (International Normalized Ratio), albumin, and bilirubin levels were within normal

limits, and mean serum aminotransferase (ALT) levels were approximately two times the upper limit of normal. Liver biopsy results revealed an overall low stage of liver disease. Only one patient of the 111 patients was on interferon-based HCV drug therapy at the time of initial clinic appointment, however, this patient's survey responses did not differ from the mean survey responses of the entire sample. Twenty-four patients initiated interferon-based drug therapy prior to completing the 10-month follow-up questionnaire package.

Patient needs assessment at initial viral hepatitis clinic visit

More than half of patients (52%) rated their current HCV knowledge as being inadequate (i.e., "fair" or "poor"). Percentages of patients who rated the importance of specific HCV health care needs on the HNAS are reported in Table II. Of note, 91% of patients indicated that receiving more education about HCV (e.g., modes of transmission and treatment) was "important" or "very important".

The majority of patients (83%) rated the need for quality HCV medical care as "important" or "very important".

Assistance with obtaining drug coverage plans for HCV antiviral therapy and counselling for psychological issues were also identified as "important" or "very important" needs by most respondents. Interestingly, the need for drug abuse counselling was rated as relatively less important than other health care needs. To understand this finding, the sample was divided between patients with (59%) and without (41%) a self-reported history of injection drug use. Patients without a history of injection drug use were more likely to report the need for drug abuse counselling as "not at all important" compared to patients with some history of injection drug use (OR=2.87, 95% CI 1.27-6.45).

Satisfaction with HCV health care prior to initial viral hepatitis clinic visit

Whereas 51% rated the overall quality of prior HCV health care as "good" or "excellent", 49% rated the quality of care as "fair" or "poor". Sixty-nine percent of patients did not feel encouraged to be actively involved in making informed decisions concerning their HCV health care prior to attending the Viral Hepatitis Clinic. Thirty-one percent of patients were

TABLE IV

Hepatitis Patient Satisfaction Questionnaire (HPSQ) Results at Initial Clinic Visit (Pre) Versus 10 Months Follow-up (Post)

HPSQ Items	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1. How would you rate the quality of services you received for HCV?	Poor 22%	3%	Fair 33%	8%	Good 40%	33%	Excellent 5%	56%
2. Did the health care services that were available meet your needs?	All met 13%	52%	Most met 37%	25%	Some met 44%	19%	None met 6%	3%
3. Did the services you received help you to cope better with HCV?	A great deal 13%	43%	Somewhat 52%	48%	Not helpful 27%	6%	Made worse 8%	3%
4. In general, how satisfied are you with the services you have received for your HCV?	Very dissatisfied 10%	8%	Dissatisfied 25%	5%	Satisfied 49%	41%	Very satisfied 16%	46%
5. How often did you feel actively involved in making informed decisions about your HCV care?	Always 11%	48%	Often 19%	43%	Rarely 41%	8%	Never 29%	2%
6. How satisfied were you with access to specialist services (nurse, psychologist, pharmacist, social worker, dietitian)?	Very dissatisfied 6%	8%	Dissatisfied 24%	6%	Satisfied 56%	56%	Very satisfied 14%	30%

Note: All numbers are in percentages for each question at each administration. HCV = Hepatitis C Virus; n=63.

TABLE V

Correlations Among Health Status Indicators, Psychological Measures, and Socio-demographic Indicators

Variable	1	2	3	4	5	6	7	8
1. ALT serum level	—							
2. Years since HCV diagnosis	-0.09	—						
3. Satisfaction at initial clinic visit	0.08	-0.05	—					
4. Severity of symptoms	0.18	0.11	-0.08	—				
5. HCV knowledge	-0.17	0.26**	0.24*	0.07	—			
6. Education level	-0.09	0.09	-0.03	-0.24*	0.19*	—		
7. Employment status	0.06	-0.27**	0.05	-0.27**	-0.07	0.20*	—	
8. Age	-0.09	-0.19*	-0.08	-0.15	0.01	0.16	-0.16	—

*p<0.05 **p<0.01; N=111.

“dissatisfied” or “very dissatisfied” with not having access to needed specialized multi-disciplinary services (e.g., pharmacy, psychology, social work).

HCV health care satisfaction 10 months following the initial viral hepatitis clinic visit

Sixty-three (57%) of the 111 patients recruited at their initial clinic visit completed the follow-up questionnaire. On average, the follow-up questionnaire was completed 9.8 months (± 5.5) after the baseline questionnaire. Patients not completing the second questionnaire were either lost to follow-up (n=47) or did not wish to complete the questionnaire at their follow-up appointment (n=1). Their baseline characteristics were similar to those who did complete both surveys (data not shown). As well, there were no differences in baseline or follow-up satisfaction scores between patients who initiated interferon-based HCV drug therapy (n=24) and those patients who did not (n=39) (data not shown). Results showed a significant increase in patient satisfaction on the HPSQ from patients' first Viral Hepatitis Clinic visit (14.6 ± 3.6) to 10-month

follow-up (19.7 ± 3.4) ($p<0.001$). In order to address the issue of subjects lost to follow-up, a conservative intent-to-treat approach was used in which baseline satisfaction data were carried forward to 10-month follow-up outcome data for subjects who had no follow-up data. Using this intent-to-treat approach with the entire sample (n=111), there was still a significant increase ($p<0.001$) in mean patient health care satisfaction from baseline (14.3 ± 4.2) to 10-month follow-up (17.2 ± 5.0). Each individual satisfaction item was also compared between baseline and 10-month follow-up. These results revealed that a greater proportion of patients felt satisfied with the quality of HCV care at follow-up ($p<0.001$). Moreover, a greater proportion of patients felt more actively involved in their treatment ($p<0.001$), reported their health care needs were more likely to be met ($p<0.001$), felt better able to cope with their HCV ($p<0.001$), reported a greater sense of satisfaction with their HCV health care ($p<0.001$), and reported greater satisfaction with access to specialized multi-disciplinary services ($p<0.05$) at follow-up compared to at their initial clinic visit. Table IV shows the percentage of patients

responding to each satisfaction item at both initial and 10-month follow-up time points.

Correlations among health status, psychological, and socio-demographic variables

Correlations among health status indicators, psychological measures, and socio-demographic indicators revealed that time since HCV diagnosis was associated with greater self-reported HCV knowledge ($p<0.01$) (Table V). Patients who felt more knowledgeable about HCV also felt more satisfied with HCV services at their initial clinic visit ($p<0.05$). Higher scores for self-reported symptomatology attributed to HCV infection was associated with lower education ($p<0.05$) and lower employment status ($p<0.01$).

DISCUSSION

Results from this study indicate that many HCV patients report that their knowledge about HCV is inadequate. These same patients report that receiving more education about HCV is an important health care need. Previous research has revealed

inadequate knowledge about HCV among specific high-risk groups,³⁻⁵ however, the current study suggests this lack of knowledge about HCV extends to a broad range of HCV patients. In response to these findings, we are developing and validating a short, easy-to-administer paper and pencil HCV Knowledge Scale that could be used as a clinical teaching tool to increase HCV awareness.

The need for more HCV-specific education is consistent with research suggesting that correct health knowledge is a prerequisite for behavioural harm reduction.¹⁸ Furthermore, a lack of knowledge regarding HCV transmission risk factors has been shown to increase rates of HCV infection.³ Although injection drug use and blood transfusion are more common modes of HCV infection, unprotected sex is a risk factor as well.¹⁹ At the time of their first HCV clinic visit, 51% of sexually active HCV patients in the current study reported not using condoms. Our findings have resulted in a more proactive approach toward safer sex education in our Viral Hepatitis Clinic.

The finding that HCV patients with a history of injection drug use report a need for drug abuse counselling as part of their HCV care is not surprising. For individuals with HCV and substance abuse problems, adequate drug abuse counselling is a crucial step towards improved health and successful HCV treatment.

Outcome data collected 10 months following patients' first clinic visit indicate that patients reported being better informed, more satisfied, and more actively involved in their HCV health care. This is an important outcome given that satisfied patients report better medical adherence and tend to engage in healthier behaviours.^{10,20} More complete longitudinal data are needed to draw firmer conclusions on how best to service and satisfy the health care needs of adults living with HCV.

Several methodological limitations may affect the generalizability of findings from the current study. A convenience hospital outpatient sample was used in this study which may not represent all subgroups of individuals living with HCV. Most patients in this study did not have advanced liver disease. Thus, the full range of health care needs for patients with more

severe liver disease progression may have been underestimated. A large proportion of this cohort was HIV-HCV co-infected. This proportion is representative of patient populations typically seen at urban-based Infectious Diseases clinics providing care for HCV infection across Canada; we therefore thought that it was important to include these subjects in our analysis. The health care needs of patients with comorbid illnesses such as HIV are often more complex; for this reason, this population requires further investigations with larger sample sizes. Because measured baseline characteristics of those completing the 10-month follow-up questionnaire were similar to those who did not, it was thought appropriate to compare the study results between baseline and follow-up. Despite this, it is possible that unidentified bias, among subjects who were lost to follow-up, may have affected the strength and direction of the 10-month patient satisfaction outcome data. Finally, this study did not systematically study the impact of HCV medications (e.g., interferon/ribavirin) on patients' health care needs and satisfaction. This merits further exploration.

Overall, the present study provides the first description of HCV health care needs in HCV-infected patients followed in a Canadian, hospital-based viral hepatitis clinic. Our findings demonstrate that medical care alone is not enough to meet the needs of a patient population who require educational and psychosocial support to cope with a long-term and potentially life-

threatening chronic illness. Results from this study highlight the need to develop comprehensive multi-disciplinary HCV clinic teams and advocate for a biopsychosocial model of health care delivery for people living with HCV, perhaps along the lines of those established for HIV care in Canada.

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RÉSUMÉ

Objectif : Définir les connaissances de l'hépatite C, les besoins de soins de santé et le niveau de satisfaction déclarés par les patients au sein d'une cohorte représentative d'adultes infectés par le virus de l'hépatite C (VHC) recevant des soins dans une clinique de traitement de l'hépatite virale d'un hôpital universitaire du Canada.

Méthode : Un ensemble de questionnaires visant à évaluer les connaissances du VHC, les besoins de soins de santé et le niveau de satisfaction des patients a été administré séquentiellement à 111 patients consentants infectés par le virus durant leurs visites de suivi après un mois et après 10 mois à la clinique de traitement.

Résultats : Lors de leur première visite à la clinique de traitement de l'hépatite virale, 52 % des patients ont qualifié de « moyennes » ou « faibles » leurs connaissances actuelles du VHC. Selon ces patients, leurs principaux besoins à l'égard du VHC étaient d'obtenir une éducation au VHC, des soins médicaux de qualité, une assurance médicaments et une aide psychologique de soutien. Selon les résultats du suivi après 10 mois qui concernaient la satisfaction à l'égard des soins de santé, les patients se sentaient beaucoup mieux informés, étaient plus satisfaits et disaient jouer un rôle plus actif dans leur traitement.

Conclusion : Pour un traitement optimal du VHC, il est souhaitable d'avoir un cadre biopsychosocial qui tienne compte des aspects médicaux, psychologiques, éducatifs et sociaux de la maladie.

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Book Review

The Practice of Health Program Evaluation

David Grembowski. Thousand Oaks, CA: Sage Publications, 2001; 344 pp., \$105 US (Cloth), \$58.95 US (Paper)

This book covers the basics of evaluation of health programs from developing the research questions and selecting a design and methods to disseminating findings to the audiences that will use them. The intended audience was first and foremost graduate students in any of the health disciplines. The second audience was larger, being "program administrators, decision makers, and interest groups in public and private organizations, as well as health program evaluators and health services researchers" (p. xv). Chapter one, "Is it Worth It?", is most relevant for the second audience.

The author proposes evaluation as a three-act play: Asking the Question; Answering the Question; and Using the Answers in Decision Making. In addition to the two introductory chapters and an Epilogue, there are eight chapters. Asking the Question and Using the Answers each receive one chapter, while Answering the Question is covered in six chapters, hence, the focus is an overview of methods, principally quantitative. The section on developing research questions is particularly well

developed with an emphasis on articulating the theory of causation and the theory of implementation. The reader is urged to develop immediate, intermediate and ultimate objectives.

The major weakness of the book is an attempt to cover too much for too many audiences. There is a rather simplified conceptualization of the health care system where the population served is part of the "structure" and a bias towards a rational model of decision-making, although there is a nod that evidence is only "part" of what drives policies. A very brief discussion of the "cultural context" takes a cultural sensitivity versus a cultural competence approach. The assumption that the research and dissemination processes leave the political realm "to some degree" (p.16) is also problematic, not just because of the philosophical debates about science, but because the evaluator who believes that she or he can leave power and politics behind is prone to a number of failures. The author never mentions evaluability assessment, a process that seems particularly suited to health program evaluation, although this is essentially covered in Act One. In addition, the evaluation of complex programs and of community interventions is not discussed. Although many of the programs used as examples are what would be categorized as health promotion

in Canada, there seems to be an assumption that health sector change and health promotion are about intervention at the level of individuals. The book almost entirely avoids qualitative methodology (about six pages), an unfortunate oversight given the value of designs such as case study in health program evaluation.

Rather than serve a graduate student audience, I believe this book would be an introductory text for undergraduate students in the health sciences. It would provide an easy read and an introduction to people working in the health sector who know little about evaluation research. Even then, I would caution instructors and readers to supplement this with a text on qualitative evaluation research methods. I would hope that graduate students, who might go on to lead evaluations in the health sector, would take a more in-depth look at many of the issues raised in this book.

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(Book Reviews continued on page 280)