Behavior Modification Following a Diagnosis of Hepatitis C Infection

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***Objectives*: To determine the extent of postdiagnosis counseling and to characterize behavior before and after diagnosis of hepatitis C infection. *Methods*: We interviewed 133 persons diagnosed with hepatitis C in Wyoming from 1999 to 2001. *Results*: Approximately two thirds of cases received counseling at the time of diagnosis. Older and symptomatic patients were more likely to receive counseling. Counseling was significantly associated with increases in condom use, wound covering, and hepatitis A and hepatitis B vaccination, but not with changes in addictive behaviors. *Conclusions*: Counseling was an effective strategy for promoting several desirable behavior changes among persons with hepatitis C infection.**

***Key words*: hepatitis C, counseling, health behaviors, behavior change, STDs**

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Hepatitis C is the most common blood-borne infection in the United States, with an estimated 4 million Americans currently infected. About 15,000 new cases are reported annually in the United States[1] of which roughly 350 occur in Wyoming.[2] Approximately 70% of all acute infections will result in a chronic infection.[3] Among those, an estimated 20% will eventually develop cirrhosis or cancer of the liver.[4,5] The factors that influence viral clearance, severity of disease, and the development of chronic liver disease remain largely unknown.[4] However, available data indicate that alcohol consumption, smoking, and other modifiable factors increase the likelihood of development of chronic liver disease.[6-13]

Behavior modification is a key strategy for decreasing morbidity and mortality from hepatitis C in the United States. Two general categories of desirable behavior modification have been established for hepatitis C patients: changes that will prevent or reduce disease progression in the infected person and those that will reduce the risk of virus transmission to others. Behavior changes recommended to reduce disease progression include decreased alcohol consumption, decreased tobacco use, and vaccination against hepatitis A and B.[1] Decreased injection drug use, decreased sharing of injecting equipment, increased condom use, complete covering of all cuts and sores, and decreased sharing of household or personal care items that might be contaminated with blood are recommended to reduce the risk of disease transmission.[1]

Several studies have evaluated intervention programs for at-risk populations (eg, injecting drug users); however, few

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studies have examined changes in risk behaviors among persons who have been diagnosed with the disease. The limited data available suggest that, in general, fewer than 50% of hepatitis C patients make recommended behavior changes following diagnosis.[14,15] Identification of those persons least likely to be counseled and least likely to make recommended lifestyle changes would allow public health workers to target those individuals and their health care providers for more aggressive intervention. The objectives of this study were to identify demographic and other patient characteristics associated with postdiagnosis counseling, and to evaluate the relationship between postdiagnosis counseling and desired behavior changes.

METHODS

Study Population

The study population consisted of hepatitis C cases reported between 1999 and 2001 in Wyoming. Cases were ascertained through the National Electronic Telecommunications System for Surveillance (NETSS). Attempts were made to locate phone numbers for each case using the NETSS database, phone books, and the Wyoming Department of Motor Vehicles database. Health department staff attempted to contact all cases for whom a telephone number could be identified. A total of 9 attempts (3 calls per day for 3 days with 1 attempt each day after 6 pm) were made to contact each case. No special incentives were offered to encourage participation.

Of the 1005 cases reported to NETSS from 1999-2001, 277 (27.6%) were successfully contacted; failure to contact was primarily due to inability to find a valid telephone number for the individual. Minors and persons who denied ever testing positive for hepatitis C were excluded from the study. Persons under the age of 18 were excluded because hepatitis C is rare in this population. Deceased patients were excluded, since next-of-kin or surrogate respondents were unlikely to accurately report the patient's behaviors and habits during the study period and to be aware of the extent of counseling received by the patient. Of the 277 cases who were contacted, 133 (48.0%) agreed to participate, 23 (8.3%) denied ever testing positive for hepatitis C, 16 (5.8%) were deceased, and 1 (0.4%) was a minor. Participants were interviewed 3 months to 3 years after their diagnosis with hepatitis C.

Data Collection

A standardized questionnaire was developed to collect information regarding demographics, signs and symptoms present at diagnosis, exposure to known risk factors for hepatitis C infection, counseling at diagnosis, and presence of behaviors of interest prior to and following diagnosis. Signs and symptoms that were inquired about included fatigue, anxiety, weight loss, loss of appetite, alcohol intolerance, pain in the liver area, fever, headache, and jaundice. Participants were asked about prior injection-drug use, blood transfusions, receipt of other blood products (eg, clotting factor), sexual contact with a hepatitis C positive individual, patient care in a medical setting, clinical laboratory work with the potential for blood exposure, unintentional needle-stick injuries, dialysis, casual (household) contact with a hepatitis C-positive individual, tattoos, acupuncture therapy, and body piercings. Participants were asked to respond to all questionnaire items, irrespective of their likely route of exposure to hepatitis C virus.

Participants who stated that they had received counseling were asked if they had been advised to refrain from using injection drugs, practice safe sex, refrain from sharing any household items that might be contaminated with blood (such as razors and toothbrushes), refrain from donating blood or other tissues, completely cover all sores and cuts, refrain from drinking alcohol, refrain from smoking cigarettes, get vaccinated against hepatitis A and B, and not take over-the-counter or herbal medicines without first checking with a doctor.

Questions were developed to determine the presence and frequency of each of the behaviors of interest for a typical week before the diagnosis, the month after diagnosis, and at the time of the interview. The original study plan called for an investigation of the temporal course of behavior changes following diagnosis. However, due to sample-size limitations, the analyses were completed using any desired change (either in the month after diagnosis or by the time of the interview) as the outcome of interest. To avoid the recognized problem in survey research of

incomplete disclosure of stigmatized behaviors such as injection drug and other drug use, condom use, and alcohol abuse, confidentiality was ensured and the most sensitive questions were placed late in the interview. Trained interviewers administered all questionnaires by telephone. Informed consent was obtained from all participants according to procedures approved by the institutional review boards of the participating entities.

Data Analysis

Descriptive statistics including age, gender, race, socioeconomic status, insurance status, presence of symptoms, and other variables were summarized for all subjects, using percentages for categorical variables and mean and standard deviation for continuous variables. In order to describe the distribution of known risk factors for hepatitis C among those diagnosed with the disease, each individual was assigned a single exposure using a hierarchy of risk factors derived from that described by Alter et al[16] Patients were assigned to one risk group in the following hierarchical order: blood transfusion/blood products, illegal drug use (sharing of needles or cocaine straws), health care employment with frequent blood contact, hemodialysis, sexual contact with an infected individual, casual contact with an infected individual, and other percutaneous exposures (tattooing, piercing, acupuncture). For example, a patient who had received a blood transfusion but also had a body piercing was assigned to the transfusion exposure category.[16]

To determine whether certain groups of people were more likely to be counseled, patient characteristics were compared between the counseled and noncounseled groups. Discrete variables were grouped when sample sizes were not sufficient and were analyzed in contingency tables using Pearson's chi-square test and Fisher's exact test where appropriate. The only continuous variable under study, age, was normally distributed and was analyzed using a t-test.

The primary objective of this study was to determine whether postdiagnosis counseling was associated with desired behavior modifications. Separate analyses were conducted to investigate the association between each counseling variable and its corresponding behavior change. Success was defined as any desired change in behavior; failure was defined as no change or an undesired change. Behavior change was treated categorically; the degree of change was not measured quantitatively. A participant could have been considered to have made a positive change for one of the behaviors investigated (eg, injection drug use) but not for another (eg, smoking). Only those cases who exhibited the behavior of interest prior to their diagnosis were included in the calculation of the odds ratio for that counseling variable.

Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated using multiple logistic regression analysis to estimate the association between each counseling variable and its corresponding behavior change. Patient characteristics were considered for potential confounding of the association between counseling and behavior changes if they were independently associated with the outcome at $P<0.25$. Potential confounders whose inclusion in the model resulted in a >10% change in the crude odds ratio were kept in the model.[17] The existing literature was insufficient to determine which factors might act as effect modifiers. Therefore, all patient characteristics with plausible biologic relevance were evaluated as potential effect modifiers. Interaction terms were considered significant if the p-value for the term was less than .05 by the Wald test. Statistical analyses were conducted using SAS version 8.1 (SAS Institute Inc, Cary, NC).

RESULTS

The age and gender distribution for study participants was compared to that for nonparticipants; no other data were available for nonparticipants. The mean age for participants (48.2) was significantly higher than that for nonparticipants (42.4) ($P<0.001$). The gender distribution was similar for participants and nonparticipants.

Sociodemographic and other participant characteristics are displayed in Table 1. Of the 133 participants, 60.2% were male. Participants ranged in age from 20 to 79 years with a mean of 48 years. The majority of cases were white (89.5%), had a household income of less than $30,000 a year (51.9%), had health insurance (78.2%), and were symptomatic at the time of their diagnosis (57.9%). Eighty-

nine (66.9%) cases reported prediagnosis exposure to more than one of the known risk factors. When each case was assigned a single risk factor, the largest proportion of cases (39.8%) was attributed to injection drug and other illegal drug use, followed closely by blood transfusions or administration of other blood products (31.6%). Ten (7.5%) of the cases did not report any known risk factors for infection.

Eighty-five of the 133 cases (63.9%) reported at least some counseling about recommended behavior changes at the time of their diagnosis. There were no significant differences between counseled and not-counseled persons for most of the variables evaluated (Table 2). However, the mean age for counseled patients (50.8 years) was significantly higher (P=0.03) than that for patients not counseled (46.8 years). Patients were more likely to have been counseled if they were symptomatic at the time of their diagnosis (P=0.03). Although a larger proportion of the female patients and those who reported liver disease at the time of diagnosis were counseled, these differences were not statistically significant. The following topics were discussed with patients relatively consistently: information about alcohol use (61.7%), blood donation (60.2%), injection drug use (60.9%), condom use (57.9%), and sharing personal care items that might be contaminated with blood (57.1%). However, fewer patients were counseled about wound covering (53.4%), smoking (45.9%), over-the-counter medication use (43.6%), hepatitis B vaccination (39.1%), and hepatitis A vaccination (34.6%).

Table 3 shows the effect of counseling on postdiagnosis behavior, expressed as the odds of having been counseled among those who changed the behavior, compared to those who did not change their behavior. Only those cases that exhibited the behavior of interest prior to their diagnosis were included in each of these analyses. When patient characteristics were tested to determine whether they were confounders of the association between counseling and postdiagnosis behavior, only being symptomatic at the time of diagnosis confounded the association between counseling and decreased alcohol consumption. The effect of counseling on hepatitis B vaccination was dependent upon gender; counseling was

Table 1
Selected Characteristics of 133 Participants With Hepatitis C, 1999-2001

Characteristic	n (% cases)
Gender	
Female	53 (39.8)
Male	80 (60.2)
Age at survey	
20-39	17 (12.9)
40-49	61 (46.2)
50-59	43 (32.6)
60 +	11 (8.3)
Race	
White	119 (89.5)
Other	14 (10.5)
Marital status	
Married	76 (58.5)
Not married	54 (41.5)
Employment status	
Employed	88 (66.7)
Unemployed	44 (33.3)
Education	
High school or less	75 (56.4)
More than high school	58 (43.6)
Household income	
$30,000 or less	64 (48.1)
More than $30,000	59 (51.9)
Health insurance status	
Insured	104 (78.2)
Not insured	29 (21.8)
Risk factor for hepatitis C infection[a]	
Transfusion or exposure to other blood product	42 (31.6)
Illegal drug use[b]	53 (39.8)
Other percutaneous exposures[c]	12 (9.0)
Casual contact with an infected individual	9 (6.8)
Occupational exposure	5 (3.8)
Sexual contact with an infected individual	2 (1.5)
None	10 (7.5)
Symptomatic at time of diagnosis	
Yes	77 (57.9)
No	56 (42.1)

Note.
a Each case was assigned a single risk factor using a hierarchy of risk factors derived from that described by Alter, et al.[16]
b Defined as sharing needles or straws when using drugs.
c Defined as a history of tattoos, piercings, and acupuncture prior to diagnosis.

Table 2
Characteristics of 85 Counseled[a] and 48 Not-counseled Hepatitis C Cases, Wyoming, 1999-2001

	Counseled	Not Counseled	P[b]
Gender			
Male	30	23	0.15
Female	55	25	
Mean age at time of interview (SD)	50.83 (11.1)	46.8 (7.41)	0.03
Race			
Non-Hispanic white	77	42	0.58
Other	8	6	
Marital status			
Single	19	5	0.23
Married	46	30	
Divorced/separated/widowed	20	13	
Education level			
High school and less	45	30	0.29
More than high school	40	18	
Employment status			
Employed	58	30	0.44
Unemployed	26	18	
Household income			
Less than $30,000	40	24	0.54
$30,000 and above	40	19	
Insurance status at time of diagnosis			
Insured	65	39	0.52
Not insured	20	9	
Years since diagnosis			
Less than 1 year	16	13	0.28
1 – 2 years	15	10	
More than 2 years	51	21	
Symptomatic (at diagnosis)			
No	30	26	0.03
Yes	55	22	
Liver damage present (at diagnosis)			
No	49	36	0.11
Yes	29	11	

Note.
a Defined as any postdiagnosis counseling
b Satterthwaite's alternative t test for comparing means with unequal variance.

more likely to result in hepatitis B vaccination among males than among females; OR = 26.6 (95% CI 7.0, 101.4), OR = 4.6 (95% CI 1.2, 17.7), respectively. None of the other patient characteristics modified the effect of counseling on behavior change.

The use of injection drugs prior to the diagnosis of hepatitis C was reported by 50 of the 133 cases (37.6%). All of these patients reported a decrease in injection drug use following diagnosis. Among persons reporting prediagnosis injection drug use, 41 (82%) reported sharing needles, 18 (36%) shared other injecting equipment, and 3 (6%) reported ever using intravenous drugs in a "shooting gallery" prior to their diagnosis. None of the cases reported exposures to any of these risk behaviors following their diagnosis. Donation of blood or other tissues was reported by 49 cases (36.8%) prior to diagnosis. No cases reported donating blood or other tissues after they were diagnosed.

Table 3
Crude Odds Ratios for Recommended Behavior Changes Following Counseling Regarding Specific Behavior[a]

Recommended Behavior	Changed Behavior		Not Changed		OR[b]	95% CI
	Couns	Not Couns	Couns	Not Couns		
Decrease alcohol intake	65	33	6	6	1.97[c]	0.59, 6.58
Decrease tobacco intake	23	29	17	18	0.84	0.36, 1.98
Increase condom use	19	5	22	28	4.84	1.56, 15.01
Decrease i.v. drug use	31	19	0	0	-.-	-.-
Decrease blood donations	32	17	0	0	-.-	-.-
Decrease sharing of personal care items	28	23	3	3	1.22	0.22, 6.62
Increase covering of cuts/sores	25	19	4	16	5.26	1.15, 18.33
Decrease use of over-the-counter medications	27	25	25	40	1.73	0.83, 3.62
Vaccinated against hepatitis A	30	10	12	61	15.25	5.92, 32.28
Vaccinated against hepatitis B	35	11	16	51	10.14	4.21, 24.45

Note.
OR=odds ratio; CI=confidence interval.
a Defined as any desired change in behavior since diagnosis
b Those patients who abided by a recommendation prior to their diagnosis were excluded from the calculation of the odds ratio for that counseling variable
c Adjusted for symptoms present at diagnosis (Adjusted OR=1.60; 95% CI 0.46, 5.54)

Therefore, odds ratios for these outcomes were not calculated.

Counseling was significantly related to increased condom use (crude OR = 4.8; 95% CI 1.6, 15.0), increased covering of cuts and sores (crude OR = 5.3; 95% CI 1.5, 18.3), and vaccination following diagnosis. The crude odds ratio for hepatitis A vaccination following counseling about the vaccination was 15.3 (95% CI 5.9, 32.3). Counseling was also positively associated with decreased alcohol consumption (adjusted OR = 1.6; 95% CI 0.5, 5.5) and decreased over-the-counter medication use (crude OR = 1.7; 95% CI 0.8, 3.6), but these associations were not statistically significant. The confidence intervals around the risk estimates in this study were imprecise, reflecting the relatively small numbers of subjects available for analysis of individual behaviors in the counseled and not-counseled groups.

DISCUSSION

Nationally, injection drug use accounts for approximately 60% of hepatitis C cases.[18] Between 15 and 20% of persons with hepatitis C report sexual exposures in the absence of other risk factors. Other known exposures (occupational, contact, and others) combined account for approximately 10% of infections. No recognized source of infection can be identified in about 10% of those infected.[4,18] Compared to national findings, we found a larger proportion of cases than expected attributable to transfusions in Wyoming, but review of the data showed that nearly all reported transfusions were given prior to 1990 (before donor screening for hepatitis C was implemented). Based on national estimates, we would also have anticipated a higher proportion of cases to be related to injection drug use. Persons who could not be located or refused to participate may have been injection drug users. The proportions of cases attributed to the other risk factors were comparable to those reported nationally.

Counseling regarding behavior changes after diagnosis was reported by only 64% of the participants. Predictors of counseling included age and the presence of symptoms at the time of diagnosis. Among the counseled cases, health care providers communicated relatively consistent counseling about alcohol use,

injection drug use, blood donation, and condom use. However, fewer patients reported receiving counseling about smoking, hepatitis vaccinations, and over-the-counter medication use. Counseling was found to be positively associated with increased condom use, hepatitis A and B vaccination, and increased frequency of wound covering. Not surprisingly, counseling appeared to be less effective for addictive behaviors such as smoking and alcohol consumption.

Several study limitations warrant consideration. We were able to contact only 28% of potentially eligible cases. Among those eligible cases that we were able to contact, only 56% agreed to participate. The resulting small sample size limited our power to find associations between counseling and behavior change. Additionally, selection bias may have been introduced from several sources. The participants in this study were older than the nonparticipants. The basis for this difference in participation rate is not known but may have been due to failure to contact younger subjects due to increased mobility of younger subjects, higher rates of injection drug use among younger subjects and reluctance to participate, or socioeconomic factors. During the recruitment process, eligible cases were told that the Wyoming Department of Health was conducting a follow-up study of hepatitis C patients and wanted to speak with them about their hepatitis C diagnosis and their behaviors and habits. Patients who had not followed prior recommendations may have been less likely to participate. This form of selection bias would be expected to lead to overestimation of the success of counseling and behavioral modification.

Information bias is a frequently encountered issue in retrospective studies like the one reported here. In this study, the potential effect of information bias depends on whether it occurred equally among those counseled and those not-counseled. If inaccuracies in reporting behavioral changes were similar among these groups of respondents then the misclassification was nondifferential, and due to the dichotomous nature of the behavioral variables, the likely effect was to bias the risk estimates (odds ratios), towards the null (1.0). If, on the other hand, counseled patients reported more or less accurately than noncounseled patients, then the misclassification was differential and the estimates may have been biased towards or away from the null.[20] The possibility that counseled persons recalled or reported behavioral change more accurately than did noncounseled persons cannot be excluded. The questionnaire contained items that may have been sensitive to respondents. Therefore, participants may have underreported illegal drug use and overreported condom use because they considered these to be more acceptable responses. Additionally, individuals may have been less inclined to report receiving counseling if they had neglected to comply with the recommendations made during counseling. However, prediagnosis and postdiagnosis behaviors were assessed at the same time to reduce recall bias. In addition, behavioral change was defined as a qualitative, rather than a quantitative, variable to reduce the chance of recall bias. For example, participants were likely able to accurately recall whether they increased or decreased the number of cigarettes they smoked after their diagnosis, rather than the number of cigarettes smoked.

Our understanding of the incidence, patterns, and predictors of desired behavior changes among hepatitis C patients could be enhanced by conducting a prospective cohort study in which patients are assessed at the time of diagnosis and followed for a specific period of time. A prospective design would allow for more complete identification of patients and would result in more accurate and detailed reporting of counseling and behavior change over time. Previous studies of how people intentionally change addictive behaviors have made use of the stages of change model.[19] Incorporation of the stages of change derived from the transtheoretical model may be useful in future studies of addictive behavior change in this population.

In summary, one out of every 3 hepatitis C patients in Wyoming reported not having been counseled about recommended behavior and lifestyle changes. Counseling was found to be an effective measure for implementing some behavior changes, but generally not for the addictive behaviors under investigation. A vaccine to prevent hepatitis C infection is not available, and treatments for chronic hepatitis are of limited efficacy;

therefore, counseling and other interventions designed to elicit behavior changes to prevent the spread and progression of disease are important public health measures. ■

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