ALCOHOL CONSUMPTION WITHIN THE CONTEXT OF HEPATITIS C: A QUALITATIVE STUDY OF NON-PROBLEMATIC DRINKERS

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Abstract — Aims: Little is known about how non-problematic drinkers respond to advice to reduce alcohol consumption as part of disease management. In this article, we examine patient reports of drinking behaviour after being diagnosed with chronic hepatitis C, a condition for which alcohol consumption is contraindicated. Methods: In this qualitative study, we analyzed transcripts of semi-structured interviews with hepatitis C virus+ (HCV+) patients whose level of alcohol consumption would not be considered problematic in the absence of their diagnosis. Results: Most respondents reported some instances of adherence, but only half adhered to the advice to limit drinking consistently over time. Respondents who did not stop drinking often modified their behaviour by changing the type of alcohol consumed or limiting drinking to particular occasions. Conclusion: Most informants understood the risks of drinking after HCV infection, particularly in the presence of symptoms, with the onset of complications, or when undergoing treatment. But some believed they could monitor their bodies for evidence of disease progression or that drinking was acceptable during early, asymptomatic stages of infection. Our results also identified situations in which patients need support in adhering to intentions not to drink, including social pressures, stressful situations, or environmental triggers.

INTRODUCTION

Reducing consumption or abstaining from alcohol is recommended for many medical treatments and non-alcohol-related conditions (e.g. severe diabetes, pancreatitis), but most research on patient responses to medical advice to stop drinking has focused on problem drinkers, whose denial, physical dependence, and withdrawal are major impediments to alcohol reduction (Safdar and Schiff, 2003). Little is known about how non-problematic patients respond to medical advice to reduce drinking as part of management of diseases not related to alcohol consumption. This article explores responses to advice to curtail alcohol consumption after a diagnosis of chronic hepatitis C virus (HCV) infection among non-problematic drinkers, i.e. low-risk drinkers whose consumption is generally within the ‘safe’ limits that are recommended by the National Institute on Alcohol Abuse and Alcoholism.

Although few studies have examined alcohol reduction in medical illness among non-problematic drinkers, researchers have demonstrated that patients are less likely to adhere to recommendations for long-term behavioural change than they are to prescribed medication regimens (Lawton, 2002). Behavioural changes where benefits are not immediately obvious appear especially difficult (Silverman et al., 1999).

We focus on chronic HCV infection for two reasons. First, HCV infection is prototypical of non-alcohol-related conditions for which drinking is contraindicated. Continued use of alcohol after HCV infection, even at relatively low levels, can adversely influence the prognosis for HCV, leading to cirrhosis and/or hepatic cancer/hepatoma (Poynard et al., 1997). Increasing levels of self-reported alcohol consumption prior to chronic hepatitis C diagnosis have been associated with elevations in serum viral titers (Pessone et al., 1998) and hepatic fibrosis scores (Poynard et al., 1997; Pessone et al., 1998; Monto et al., 2004). Despite the somewhat heterogeneous relationship between levels of alcohol consumption and hepatic outcomes among hepatitis C patients (Monto et al., 2004), recommendations for avoidance of alcohol consumption for patients with chronic hepatitis C are frequently made (Oh and Chopra, 2006; NIH, 1997; VA, 2006).

Improving the effectiveness of primary care providers in discouraging even low levels of drinking among these patients provides opportunities to improve health outcomes. Second, HCV constitutes a major public health challenge. An estimated 4 million Americans are currently infected. Costs for medical care and loss of work are estimated to exceed $600 million yearly (DHHS,NIH, 1998).

METHODS

Data

This article reports the results of a 2-year qualitative investigation of post-diagnosis alcohol consumption among non-problematic drinkers diagnosed with HCV. We analyse data generated through semi-structured interviews with 42 HCV patients at an urban teaching hospital in Ohio. Recruitment occurred in two ways. First, HCV+ individuals diagnosed through an emergency department (ED) visit who had not followed up with a doctor were contacted by telephone and invited to contact an interviewer. Second, we implemented in-person recruitment of HCV+ patients at the gastroenterology (GI) clinic. Details regarding our recruitment strategy, which was approved by the hospital’s IRB, are available upon request.

Eligible respondents recruited through both strategies were non-problematic drinkers (defined as a score of 10 or less on...
the Alcohol Use Disorders Identification Test (AUDIT), (Babor et al., 1992). We used a sampling grid designed to ensure variability in gender, race/ethnicity (African–American, Hispanic and White informants), and level of alcohol use (AUDIT scores between 0 and 7, and between 8 and 10) (Bohn et al., 1995; Conigrave and Hall, 1995).

Respondents ranged from 37 to 75 years of age (mean = 50.3 years, SD = 8.1); 69% were men and the mean level of education was 12 years (SD = 2.3). Of these respondents 39% identified themselves as African–American, 27% as Hispanic, and 34% as White. The mean time, since diagnosis, was 7.8 years (SD = 6.6). As specified by our sampling criteria, AUDIT scores ranged from 0 to 10 at recruitment. The mean was 4.8, with an SD of 3.6. Only 10 respondents had been diagnosed within the past 2 years, with a mean time, since diagnosis, of 6.6 years, an SD of 6.8. We did not identify any differences in AUDIT scores at recruitment among respondents by age, gender, education, ethnicity, years of diagnosis, or recruitment source (i.e. GI Clinic versus ED).

The interview protocol (see appendix), which consisted of 12 guiding questions, was developed by a multidisciplinary team and pretested with HCV patients not included in the study sample. The protocol included 12 questions about people’s knowledge, experience, and management of HCV infection. Interviewers used both structured probes and follow-up questions to pursue new themes, encourage respondents to elaborate answers, and explore the context of responses (Weiss, 1994; Rubin and Rubin, 1995). Questions regarding alcohol use were included in the structured probes. Interviews were recorded, transcribed verbatim, and typically lasted 30–90 min. Respondents received a $50 gift card and travel expenses.

Analytic strategy
Analysis began with four researchers open (or line-by-line) coding the interview transcripts, with an emphasis on alcohol consumption and drinking decisions. Our goal in this initial analysis was to identify relevant themes or categories (Esterberg, 2002). Regular meetings were held to discuss emerging themes and coding decisions and to resolve discrepancies. We constructed a coding dictionary that included mutually exclusive definitions for each code. This coding structure was reviewed again after preliminary analysis of a subsample of the transcripts, and the dictionary was refined on the basis of emerging interpretive observations and team discussion (Crabtree and Miller, 1999). The refined codes were applied to the data, with coding decisions recorded electronically using NVivo (QSR International, 2003). The research team then reviewed segments of text attached to each code and further elaborated and categorized the initial coding scheme, generating a typology of post-diagnosis drinking. All transcripts were coded by at least two researchers, and checks of inter-rater consistency using Cohen’s Kappa (Bernard, 2002) were conducted at the beginning, middle, and end of the coding process (Kappa >0.90 for all checks).

Efforts to categorize individual informants according to the typology (i.e. as adherent, tailoring, or non-adherent) revealed that informants often exhibit more than one type of behaviour as they described their post-diagnosis alcohol consumption. We therefore explored sequences of reported drinking behaviours. Five researchers sketched trajectories of post-diagnosis drinking behaviours based on informants’ descriptions, with three researchers examining each description. Any disagreements or questions in sketching trajectories were discussed. After discussion, team members independently made a new decision about categorizing the trajectory. In all instances, the discussion had resolved the disagreement.

Discussion of these sketches generated three trajectory shapes: (i) stable, (ii) monotonic decline, and (iii) fluctuating. In addition, we identified other trajectory properties, including consumption level at diagnosis, timing and nature of any declines in drinking, reasons for change, and pattern of fluctuation. Three members of the team rated each transcript on the trajectory characteristics, with discrepancies resolved through discussion.

RESULTS

Responses to medical advice to quit drinking: a typology of post-diagnosis alcohol consumption
Informants exhibited considerable variation in responding to advice to stop drinking. Some eliminated all alcohol, some modified their drinking behaviour, whereas others continued drinking at pre-diagnosis levels. We label these three behavioural responses as adherence, tailoring, and non-adherence.

Adherence
Adherence involves strict compliance with advice not to drink. We identified two types of adherence.

(i) Quit immediately after diagnosis (N = 15). These informants were drinking when they learned that they were HCV+ and complied immediately with advice to stop drinking. For example, Respondent 84SE explained: ‘It was like, either you drink or you live. If I drink, I’ll die. So I chose life.’

(ii) Quit after a delay (N = 10). Some informants continued drinking after diagnosis but eventually quit, attributing their decision to stop drinking to four factors.

(a) Disease symptoms or complications. Some informants continued drinking until they developed symptoms or complications that they attributed to disease progression. For example, Respondent 49LD did not quit until she ‘got really sick . . . “cause I want to be around a little bit longer”’.

(b) Negative reactions to alcohol. Some informants quit drinking when they began to experience what they interpreted as negative reactions to even small amounts of alcohol. Respondent 49LD reported that unusually intense hangovers discouraged her from drinking, even when she was tempted. She asked herself, ‘So what do you want: to feel good for a few minutes now but to feel like hell for 4 or 5 hours in the morning?’

(c) Treatment-related issues. Other informants expressed concern that alcohol can diminish the effectiveness of medications in eradicating the virus, as illustrated by Respondent 84SE who explained that ‘the treatment wouldn’t work if I had alcohol in my system.’ Others were on waiting lists for liver transplants.
(d) Reasons not linked to HCV. Some informants quit drinking for reasons unrelated to their HCV diagnosis. Religious factors influenced some. As Respondent 64DB explained: ‘I know that I’m sacrificing . . . for a greater cause—salvation of my soul. So that is a motivating factor, an incentive.’ Another Respondent, 816TW, was worried about losing his ‘whole check if I ever got stopped for drunken driving’.

**Tailoring**

Tailoring involves continuing to drink but changing consumption patterns, most often altering the frequency, amount, or type of alcohol consumed. We identified four types of tailoring.

(i) Changing drinking patterns \((N = 31)\). The most frequently reported change involved decreases in frequency or amount. For example, Respondent 19S cut back from 40 ounces of beer a day to ‘maybe a can a day’. Changes in the type of alcohol were usually decisions to eliminate ‘hard liquor’ in exchange for beer or wine coolers. Respondent 145RL now drinks only beer: ‘I used to drink a lot of hard liquor like Jack Daniel’s . . . or homemade moonshine . . . And I stopped all that. Cause I know now that . . . if I keep doing that the liver’s going to burst.’

(ii) Only on special occasions/situations \((N = 17)\). Tailoring also meant limiting drinking to special occasions or specific situations, most frequently holidays and family celebrations. Other informants drink only in certain settings (e.g. stopping at a bar after work) or with certain people (e.g. co-workers, relatives). Drinking can be a way of socializing and fitting in. As Respondent 801OJ explained, ‘Everyone else was doing it so if I want to be cool or in that cool crowd . . . I’ll drink with them.’ Alcohol is also used for stress management. Respondent 19GS reported, ‘Whenever something stresses me out, I go to the store and get me a can of beer.’

(iii) Monitoring the body \((N = 14)\). Some informants continued to drink but watched for evidence of negative effects. Some monitored pain or perceived liver changes: ‘When you drink a lot, your liver won’t filter out certain toxins. And then you begin to get the hardening. The liver . . . shrivels up like a piece of rock.’ [Respondent 35BT]. Others planned to quit when the disease progressed, believing that alcohol would not hurt in the early stages: ‘See if my liver was really in bad shape, cirrhosis or something . . . that would scare me enough to really quit.’ [Respondent 06GM].

(iv) Negotiating for permission to drink \((N = 4)\). Some informants sought justifications to continue drinking. One type of negotiator searched for evidence of ‘safe’ levels. Informants recognized that abstaining reduces risk of complications and that high levels of consumption escalate risk but questioned consumption levels between those end points. Another type of negotiator looked for countermeasures to lessen alcohol’s negative effects. For example, some informants drink large amounts of water or fruit juice to dilute the alcohol; others drink only on a full stomach, dilute beer with ice, or eat mashed potatoes to absorb the alcohol.

**Non-adherence**

Despite recommendations to stop drinking, a number of informants continued to drink at pre-diagnosis levels. We identified four types of non-adherence.

(i) Disregarding medical advice \((N = 10)\). Some informants questioned the rationale of avoiding alcohol to protect the liver. Respondent 824BJ drew a analogy with tobacco use: ‘For instance, when you tell me about smoking, I will tell you . . . that smoking does not cause cancer. Otherwise everyone that smoked would develop cancer. Everyone. So it can’t cause it’. More often informants disregarded recommendations not to drink without challenging medical wisdom. Respondent 802BB explained why he planned to continue drinking despite warnings of medical complications: ‘I’m not going to deprive. Look, I’m poor, I don’t have enough money, I’m not getting the right medical care. A little happiness before I leave here, you’ve got to be joking. No, I’m not going to stop’.

(ii) Discounting the risks \((N = 4)\). Some informants were aware of the risks of alcohol consumption but discounted the likelihood that the risks applied to them. Several reported drinking for some time after acquiring the disease, often before they knew or suspected they had been infected. After they were diagnosed, biopsies found no evidence of liver damage, and clinical tests results did not suggest (at least to the informants) that the disease had progressed. Therefore, they decided that they must be among the exceptions who can drink with minimal negative effects. For example, Respondent 6GM interprets his lifelong pattern of ‘recreational drinking’ and the absence of liver damage as justification for continued drinking. As he explains: ‘I haven’t stopped . . . I’m the kind of person where I might take a couple shots of brandy. I don’t drink until it’s all gone . . . . I’m just a recreational drinker. I don’t drink that much. [The doctor] said, “That’s probably why your liver’s in such good shape.”’ Some pointed to exceptions, people who defied behavioural recommendations without suffering negative outcomes.

(iii) Habitual behaviour \((N = 7)\). Some informants described drinking as a habitual behaviour, a ‘routine that I got myself into’ (Respondent 49LD), that requires little advance planning or awareness. Respondent 6GM explained why he continued to drink: ‘Personal routine that’s just habit forming . . . Something that you do. It’s just something that, I sit back and do it in the evening.’

(iv) No reason to quit \((N = 2)\). Some informants saw few advantages to abstaining. One explained that the disease was so advanced that he had little hope for an extended future. Others were diagnosed during the early stages of HCV awareness and told that no treatment was available. For example, Respondent 111CG asked rhetorically: ‘Why should I not be drinking and have fun? Hepatitis C is still eating my liver. Why not keeping drinking like I was and the hell with it, you know.’

**Trajectories: patterns of post-diagnosis drinking over time**

Although behaviours can be classified as adherence, tailoring, or non-adherence, individual informants often exhibited more than one type of post-diagnosis drinking. For example,
out of the 42 respondents for whom we could infer trajectories, only 52% exhibited evidence of only one type (40% exhibited only adherence, 7% exhibited only tailoring, and 5% exhibiting only non-adherence). A total of 26% exhibited two types, and 22% exhibited all three (see Table 1). Table 1 also indicates the prevalence of specific types of post-diagnosis drinking among our respondents. While 59% reported some behaviour categorized as adherence, 21% reported some behaviour categorized as tailoring, and 24% reported some behaviour categorized as non-adherence.

Reporting more than one type of post-diagnosis drinking sometimes indicated that respondents defined ‘drinking’ by pre-diagnosis levels. For example, some respondents reported that they had ‘quit drinking’ after being diagnosed, but, later in the interview, defined ‘not drinking’ as modifying previous consumption patterns. Reporting multiple types also suggested that alcohol decisions unfolded over time. For example, some people who said they had quit drinking with diagnosis, later reported drinking when stressed. Some initially asymptomatic people continued to drink after diagnosis but quit when alcohol produced intense hangovers.

Our analysis of interview transcripts reaffirmed the dynamic nature of alcohol consumption following HCV diagnosis. We inferred trajectories of post-diagnosis drinking and classified these trajectories into three shapes: stable, monotonic decline, and fluctuation. Stable trajectories involved no change over time, with respondents continuing to drink at pre-diagnosis levels. Monotonic decline describes informants who quit drinking or decreased their level of alcohol consumption after diagnosis, either abruptly or gradually, with respondents sometimes maintaining a particular level of consumption for a period of time. Respondents with fluctuating trajectories reduced their level of alcohol consumption after diagnosis but subsequently began drinking again, a pattern that was sometimes repeated.

**Characteristics of drinking trajectories**

**Level of alcohol consumption at diagnosis.** We identified three levels of reported alcohol consumption at diagnosis. Almost two-thirds reported drinking more than once a week, whereas 36% said they were drinking less than once a week at the time of diagnosis.

**Post-diagnosis changes in drinking behaviour.** Several additional variables characterize trajectories of respondents who changed their drinking behaviour after diagnosis. First, we estimated the ‘timing of the decline’ in alcohol consumption: 42% quit or cut back immediately after diagnosis and another 42% quit or changed after a delay. Others had already quit or cut back at the time of diagnosis. We also classified respondents according to the ‘nature of the change’: 58% quit completely, 18% cut back but did not quit, and 24% decreased gradually and eventually quit.

In explaining ‘reasons for changes’ in drinking behaviour, the majority (58%) cited their HCV diagnosis and 30% mentioned another diagnosis, most often diabetes or HIV/AIDS. The remainder cited family or interpersonal situations or gave no explanation.

Finally, we identified several ‘types of fluctuating trajectories’, including a return to pre-diagnosis levels of drinking, a return to drinking but at a reduced level, episodic or binge drinking, and quitting again after a relapse.

**DISCUSSION**

Few informants completely ignored advice to stop drinking. More than four out of five reported behaviours categorized as adherent, but only half of these reported adherence consistently over time. Some quit drinking immediately after diagnosis, whereas others needed an additional incentive, such as perceptions of disease progression, negative reactions to alcohol, or threats to efficacy of or eligibility for treatment. Others interspersed periods of adherence with episodes of tailoring and/or non-adherence.

Informants who did not stop drinking often modified their alcohol consumption in response to their HCV diagnosis, a response we originally referred to as Modifying Advice but subsequently called ‘tailoring’ to highlight the parallels between our findings and research on adherence to HIV/AIDS medication regimens (Wilson et al., 2002). Wilson and colleagues use the term ‘self-tailoring’ to describe patients who characterized themselves as adherent ‘yet went on to talk in detail about all the ways in which they customized or adapted the prescribed routine.’

Some tailoring behaviours, such as cutting back on the amount of alcohol, trying countermeasures to lessen the...
negative impact of alcohol, or monitoring their bodies for evidence of disease progression, can be seen as compromises between medical advice and individual preferences. Other tailoring behaviours emerged from particular circumstances. For example, some informants limited their drinking to special occasions, like holidays celebrations. Others limited drinking to particular situations, such as those involving stress or anger. Even for these non-problematic drinkers, quitting involves a series of contextualized decisions that unfold over time (Wilson et al., 2002, p. 1313).

In addition to highlighting the dynamic nature of drinking decisions across time and situations, we identified three areas in which we believe our findings support and extend the results of previous research (Matthews, 2005): (i) lay applications of risk–benefit analysis; (ii) lay assessments of personal risk; and (iii) individual attributes and situational constraints.

_Lay applications of risk–benefit analysis_. Although some informants cited medical advice as sufficient motivation to stop drinking, others weighed multiple decision factors and concluded that, in their case, the immediate benefits of drinking, such as alleviating stress, marking celebrations, or enhancing social acceptance, outweighed the risk of complications from HCV infection. Other research supports our conclusion that patients weigh short-term benefits against long-term risks. For example, Pawluch et al. (2000) describe HIV+ informants who decide not to initiate Western drug therapies, even when they recognized that they were compromising long-term survival, because they found medication regimens to be too restrictive. Similarly, Rhodes and Cusick (2000) describe HIV-negative partners in discordant relationships who decided that the risk of infection through unprotected sex was offset by the more immediate benefits of enhanced sexual pleasure and displays of commitment. Other informants may be embracing what Rhodes and Cusick (2002, p. 224) describe as a post-modern fatalism, in which ‘the future is conceived as only partly under human control and the main aim is enjoy the present.’

Some researchers have challenged the assumption that patients incorporate risk–benefit decision-making in thinking about drinking (Lawton, 2002; Lindbladh and Lyttkens, 2002). Drawing on Giddens’ notion of habitual behaviour (which he refers to as ‘habituation’), Williams (1995) suggests that health-related behaviours can become such an ‘unthinking part of daily life that their existence becomes, to some extent, exterior to the people performing them.’ As Bloor (1995, p. 217) explains, ‘behaviours which are habitual do not demand risk assessment or calculation for their doing, they are simply done.’

_Lay assessments of personal risk_. Although aware of the link between alcohol and HCV disease progression, some informants discounted the applicability of these risks to their own situation. For example, informants who had been drinking after infection but prior to diagnosis interpreted the absence of liver damage as evidence that they were less susceptible to HCV complications than the general patient population. This finding parallels Rhodes and Cusick’s (2002) report that people who had engaged in risky behaviours without contracting HIV sometimes begin to think of themselves as having special immunity.

Symptom experience also shapes risk assessments. Some patients found it easier to abstain from alcohol when they were not feeling well. In the absence of symptoms, patients can find it difficult to visualize the bodily changes that characterize early stages of HCV infection (Carricaburu and Pierret, 1995). We also identified instances of people monitoring their bodies for evidence of negative effects of alcohol. When people had been drinking, the absence of such evidence was sometimes interpreted as evidence of diminished personal risk.

Diagnosis of disease is not always sufficient to prompt behavioural change, particularly when behaviours are reinforced by positively valued outcomes. The disease has to become manifest in tangible ways (Lawton, 2002). Our informants filtered information about risk factors through the lenses of their everyday lives and often discounted their relevance ‘unless they fit with one’s lived experience or with the experience of a trusted friend or relative’ (Abrums, 2000, p. 102).

_Individual attributes and situational constraints_. Our results also illustrate the importance of examining interactions between individual traits and situational triggers. Variation within individuals across situations occurred frequently in drinking reports among our informants. A decision to consistently ignore medical recommendations not to drink was relatively uncommon. However, fewer than half consistently followed recommendations to abstain. Most tried to cut back or modify their drinking, but their success was mediated by both situational pressures and personal resources. Our informants’ struggles highlight the importance of recognizing that social locations place some individuals at greater risk for encountering pressures to drink without providing adequate psychological, physical, or material resources to resist these temptations (Schoenberg et al., 2005).

_Limitations_. This phase of our research was designed to understand responses to advice to limit alcohol consumption among non-problematic drinkers diagnosed with HCV. We cannot determine the extent to which our informants reflected the full range of these responses. Indeed, it is unlikely that patients recruited in the urban teaching hospital, either through a gastroenterology clinic or the ED, are representative of the larger population of non-problematic drinkers diagnosed with HCV. Our findings should be considered illustrative rather than representative (Davidson, 2005).

The small size of our sample precludes generalizing our results. We will address these limitations in future research by developing and testing the predictive validity of an instrument assessing drinking behaviour among non-problematic drinkers diagnosed with HCV using a representative sample.

_Practice implications_. Our findings underscore the need for clinicians to be very specific in communicating expectations about drinking behaviour and to be certain that patients understand the rationale for that advice. Most informants understood the negative link between alcohol and HCV infection, particularly in the presence of symptoms, with the onset of complications, or when undergoing treatment. But some believed that they could monitor their body for evidence of disease progression and that drinking was acceptable during the early stages of infection or when they were asymptomatic. Better understanding of the aetiology of HCV infection can
encourage patients who plan to quit ‘down the road’ to stop drinking sooner.

Clinicians must also recognize the possibility of patients’ tailoring. Tailoring is not adherence, although for some patients, limiting the amount or frequency of alcohol, or limiting alcohol consumption to special occasions can represent adherence to medical advice. The range of tailoring strategies provide insights into situations in which patients need special help in adhering to intentions not to drink, including social pressures, managing stress, or environmental triggers.

Finally, drinking behaviours among our informants support and elaborate the conceptualization of adherence developed by Wilson et al. (2002), who categorized patient responses to prescribed medication regimens as adherence, tailoring, and non-adherence. Their trajectory analysis confirms their conclusion (Wilson et al., 2002, p. 1313) that ‘adherence decisions occur in a particular context and in the face of specific conditions.’ Clinicians should expect fluctuations in adherence, which emphasizes the importance of regularly assessing changes in patients’ drinking behaviours and how these changes are shaped by situational forces and shifting perceptions of disease severity. Rather than labelling patients as ‘adherent’ or ‘non-compliant,’ clinicians should recognize that, like medication decisions, drinking choices ‘can change on a day-to-day, if not dose-by-dose, basis’, and post-diagnosis alcohol consumption is a ‘fluctuating phenomenon, not a fixed or static one’ (Wilson et al., 2002, p. 1314).

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REFERENCES


APPENDIX: SEMI-STRUCTURED INTERVIEWS WITH PATIENTS DIAGNOSED WITH HCV

Introductory statement (following informed consent protocol): I am interested in learning more about what it is like to live with a diagnosis of hepatitis C.

Preliminary question 1: Could you tell me how you first came to know that you had hepatitis C?

Preliminary question 2: What is being happening since your diagnosis?

Questions with probes.

First, are you experiencing any symptoms related to the hepatitis C virus at the present time? (Have you experienced any symptoms in the past month?)

IF YES: What symptoms are you experiencing? Are your symptoms pretty much the same everyday, or do you have ‘good days’ and ‘bad days?’ What is a good day like for you? What is a bad day like for you?
Are you doing anything to manage your hepatitis C infection? Anything to treat the virus or to keep you from getting sick? (Anything to keep your symptoms from getting worse?)

Could you tell me a little about hepatitis C? (Did any of your doctors explain what happens to your body once you have been diagnosed with hepatitis C? What does the virus do once it gets into your body? How does it make people sick? How long does hepatitis C last? Does anyone ever recover from hepatitis C?)

Has being diagnosed with the hepatitis C virus changed your life in any way? (Could you tell me about how your life has been different?) What is the hardest thing about living with an HCV diagnosis? Are there any ways that life has gotten better for you?

How important is being diagnosed with the hepatitis C virus to your sense of who you are? Do you think of yourself as a Hep C patient—or does not the diagnosis make much difference in how you think about yourself? How often do you think about the diagnosis? Is it something you’re always aware of—always in the back of your mind? Or do you forget about it completely some of the time?

Do you think other people—your family, your friends—understand what it is like to live with an HCV diagnosis? (What would you like them to understand that they do not seem to get?)

Did the doctors recommend any strategies for managing your HCV infection? (What did they recommend? Did you follow any of those recommendations? Why or why not?)

(i) Did the doctors suggest any changes in your lifestyle—in your everyday behaviours? What did they recommend? Did they explain why these changes are important?

(ii) Did they talk to you about alcohol consumption? What did they say? What happens if you keep drinking?

(iii) Have you tried to change your alcohol consumption patterns? Are you drinking any less than you used to? What is the hardest part of quitting/cutting back on alcohol? What else makes it hard? (IF STILL DRINKS: How frequently do you drink? In what situations or under what circumstances do you drink?) (IF QUIT DRINK-ING: What was the hardest thing about quitting? Is alcohol pretty much behind you or do you still think about drinking? Is it a battle a person fights every day? What is the hardest thing about not drinking anymore?)

(iv) IF STILL DRINKS: What happens if you drink? Do you notice any difference in how you feel? Do you think that alcohol consumption has any long-term risks for people with HCV? What are those risks? How serious do you think they are?

(v) Is there anything you can do to offset the risks of alcohol?

(vi) I would like to move away from talking about HCV to talking about your health in general. What do you do to take care of yourself? To try to stay healthy? (Have these strategies changed at all since you were diagnosed with Hep C? In what ways?)

(vii) Some people say that their sense of the future has changed since diagnosis. Is this the case for you? (In what ways? So how do you see the future now?) What do you think your life will be like 10 years from now? How about 20 years from now? 30 years?

(viii) As I said earlier, we are trying to learn what it’s like to live with an HCV diagnosis. Is there anything else we should have asked? Any other ways in which the diagnosis has affected—or will affect—your life? Anything else we should understand about living with HCV?