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Lay Management of Chronic Disease: A Qualitative Study of Living with Hepatitis C Infection

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Abstract

Objectives—To examine management strategies and goals reported by people diagnosed with chronic hepatitis C.

Methods—We analyzed data from semi-structured interviews (N=42) and from electronic sources [illness narratives (N=79) and Internet threaded discussions (N=264)]. Line-by-line coding, comparisons, and team discussions generated catalogs of lay management strategies and goals. We analyzed code-based files to identify informants' selection of specific strategies for each goal.

Results—We classified lay management strategies into 3 categories: Medical Self-care, Behavior Change, and Coping. These strategies were used selectively in addressing multiple goals, categorized as Fighting the Virus, Strengthening the Body, and Managing Consequences.

Conclusions—Results underscore the diversity of strategies for living with a disease characterized by uncertain prognosis and variable expression of symptoms.

Keywords

self-care; lay management; Hepatitis C

Advances in early diagnosis and treatment of chronic disease have expanded the number of people living in a liminal state between health and illness. Frank¹ characterizes this experiential terrain, comprised of people who are “effectively well but can never be cured,” as “the remission society,” including, for example, people who have had cancer, those with mechanical body regulators such as pacemakers, and those with chronic diseases with uncertain prognoses. We focus on the latter category, examining strategies people with chronic hepatitis C virus (HCV) infection use in learning to live with the disease.

In this article, we explore lay management strategies reported by people living with chronic HCV infection (HCV), examining links between particular strategies and specific treatment goals. We focus on HCV for 2 reasons. First, our research is part of a larger study of alcohol consumption among nondependent/nonabusing drinkers advised to reduce alcohol consumption for medical reasons, and HCV infection is prototypical of conditions for which alcohol is contraindicated. There has been very little research addressing alcohol intake reduction among moderate or occasional drinkers. This has occurred despite an increased interest in the deleterious effects of even modest amounts of alcohol intake among patients with HCV, for whom alcohol consumption is associated with accelerated progression of liver injury, cirrhosis, and hepatocellular carcinoma.^{2–6} Curtailing alcohol intake among these patients is especially challenging, because HCV is generally asymptomatic throughout its course and, unlike alcohol caused illnesses such as pancreatitis, alcohol consumption does not predictably lead to symptoms that might influence subsequent consumption in nonabusing/nondependent patients. Secondly, HCV has been recognized as a major emerging health problem with just over 4 million Americans currently infected⁷ and projected medical costs from 2010 to 2019 of almost \$11 billion, and a societal cost of just over \$54 billion due to years of life lost under age of 65.⁸

Lay management is an essential component of medical management of HCV and other chronic conditions,⁹ incorporating both therapeutic regimens and strategies for containing the impact of disease on everyday life.¹⁰ People with chronic disease are their own principal caregivers, deciding each day “what they are going to eat, whether they will exercise, and to what extent they will consume prescribed medications.”¹¹ In managing a chronic condition, people address multiple goals: minimizing disease progression, treating symptoms, monitoring disease states, alleviating treatment side effects, and improving well-being.^{12,13} In attempting to achieve these goals, they draw on lay management strategies, integrating prescribed and over-the-counter medications, initiating and maintaining behavior changes, and coping with intrusions of disease in everyday life.^{9,12,13} Prescribed treatment regimens can pose challenges for patients as they attempt to maintain social roles and cope with the stresses of potential complications.¹⁴ At times, these treatment regimens become more problematic than the disease itself,¹¹ and patients tailor treatment protocols to better fit their lifestyle.^{15–18}

Our research addresses the need for descriptive studies of patient management strategies, a prerequisite to designing interventions that promote effective lay management.¹⁹ We begin by summarizing goals and strategies for managing HCV infection reported by informants in 3 sets of qualitative data. We then identify specific strategies patients use in attempting to achieve different goals.

METHODS

Our data were gathered in 2003 and 2004 as part of a larger NIH-funded project examining drinking behavior among HCV+ individuals consuming alcohol at rates that would not be considered problematic in the absence of their HCV diagnosis. A major goal in learning to live with chronic HCV is reducing or eliminating alcohol consumption. We describe elsewhere the strategies our informants used to curtail their drinking.¹⁶ In this article, we examine these same informants' descriptions of other strategies for lay management of HCV. We analyze textual data from semi-structured interviews and from electronic sources (illness narratives and Internet threaded discussions). Our qualitative approach is **emic** (elicits meanings from the subject's point of view rather than from that of the researcher), **inductive** (the researcher investigates particular phenomena in order to generate general understanding), and **holistic** (the researcher approaches phenomena of interest by considering and including the underlying values and context associated with the phenomena).²⁰

We conducted 42 semi-structured interviews with HCV+ patients at an urban teaching hospital in the Midwest.¹⁶ In semi-structured interviews, the goal is to explore a topic more openly and to allow interviewees to express their opinions and ideas in their own words. Therefore, respondents were given as much latitude as possible to describe the strategies they used to manage their chronic disease. Semi-structured interviews are an appropriate strategy for learning the vocabulary and discovering the thinking patterns of the target audience as well as for discovering unanticipated findings and explore hidden meanings.

The guiding principle in determining sample size in qualitative research is theoretical saturation. Theoretical saturation is reached when ongoing data collection no longer yields new information or insights.²¹ Our sample size of 42 respondents is within the guidelines of 30–50 respondents recommended by Morse²² for achieving saturation in studies involving semi-structured interviews.

Respondents (R) were recruited from emergency department patients who had not followed up with a doctor after an HCV diagnosis and from patients seeking care at the gastroenterology/liver clinic. Eligible patients were nonabusing drinkers (defined as a score of ten or less on the Alcohol Use Disorders Identification Test [AUDIT]).²³ In recruiting respondents, 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 1 and 7 and between 8 and 10). This sampling strategy was not designed to achieve theoretical saturation for specific demographic categories. For example, we do not claim to have captured the full range of potential responses of African Americans. Rather, our rationale in employing this sampling design was to enhance the potential variation in reported lay management strategies and goals within this group of patients who have HCV.

The interview guide (Appendix A) was developed by a multidisciplinary team (2 sociologists, a psychologist, a nurse and a physician) and pretested with HCV+ patients not included in the study sample. The guide, consisting of guiding questions and structured probes, included 12 questions about people's knowledge, experience, and management of HCV infection.¹⁶ The interview format enabled us to pursue new themes, encourage respondents to elaborate answers, and explore the context of responses.^{24,25} Interviews (conducted at the medical center by AP and NW) were audio-taped, transcribed verbatim, and typically lasted 30–90 minutes. Respondents received a \$50 gift card and travel expenses after completing the interview.

Respondents were 36–74 years of age (mean=49.5, SD=8.1). Sixty-two percent were men, and the mean level of education was 12 years (SD=2.3). Thirty-eight percent identified themselves as African American, 26% as Hispanic, and 36% as White. The mean time since diagnosis was 8.0 years (SD=6.5).

We also sampled 2 types of electronic data sources: illness narratives and threaded discussions from 8 English-language websites (Appendix B for a listing of these websites). These data minimized the reactivity that can emerge from interviews conducted in clinical settings and tapped experiences of people not being treated in a teaching hospital affiliated with a medical center.

We identified 307 HCV-related *electronic illness narratives* (N) from the 8 websites. Line-by-line coding by at least 2 researchers, supplemented by electronic text searching, identified 79 narratives that referred to alcohol consumption, which we analyze in this article. We could infer only limited demographic information about narrators from the posted text. Twenty-two percent were men, 40% were women, and 37% did not provide any indication of gender. We could infer years since diagnosis for 63% of the narratives, among whom 27% were diagnosed within the past year, 47% had been diagnosed 1–4 years earlier, and 27% more than 5 years ago.

We identified HCV-relevant *internet threaded discussions* (D) using 10 alcohol-related search terms synthesized from prior literature and an expedited review of 900 threaded discussions of HCV (Appendix B). In contrast to electronic narratives, which consist of a single post, threaded discussions consist of a series of linked postings that are created over time as people in an electronic discussion group read and respond to an initial post. We collected over 600 HCV-relevant threaded discussions containing at least one of the alcohol-related search terms and selected a systematic sample of every third discussion (264 threads). Discussants rarely revealed information from which personal attributes could be inferred, so we are unable to provide Discussant profiles.

Strategies for Identifying Lay Management Strategies and Goals

Analysis proceeded in 3 stages. We began with line-by-line coding. The qualitative team (CB, AP, ES, NW) independently reviewed each document and coded emergent themes, with an emphasis on lay management of HCV infection. Initial coding decisions and emerging definitions were recorded electronically using NVivo, a program for managing qualitative (text) data. We constructed a coding dictionary that was refined (new codes added, other codes deleted, definitions modified) through comparison, categorization and discussion of team members' interpretation of each code's properties and dimensions.^{26,27} Each document was coded by at least 2 researchers, and all discrepancies were resolved through discussion.

We then retrieved all segments of text attached to particular codes and further elaborated, refined and differentiated the initial codes. Emergent observations were recorded in theoretical memos, which provided the foundations for discussion at team meetings. We repeated this process of engagement with the data and subsequent team discussions until consensus was reached on coding decisions and no new insights emerged. This process generated our typologies of lay management goals and strategies.

Finally, we examined reported use of lay management strategies within the context of specific health goals. To identify these links between strategies and goals, we analyzed code-based files containing all coded text for each lay management strategy and each lay management goal across all respondents. For all strategies, we examined chunks of coded text and surrounding paragraphs to determine if informants linked the strategy with a specific goal. We then repeated this process for all the lay management goals. We counted the number of informants who said they used a specific management strategy for each goal. These counts are lower than the prevalence of specific strategies or particular goals, since respondents sometimes described strategies and goals without linking a specific strategy to a particular goal.

FINDINGS

We classified lay management strategies into 3 categories (Table 1). *Medical Self-care* includes self-administered medications, decisions to refuse or delay conventional medical treatment, and complementary or alternative treatments (CAM).²⁸ *Behavior Change* encompasses dietary strategies, adjusting rest or activity levels, and hygiene practices. *Coping* involves “maintaining a sense of value and meaning in life, in spite of symptoms and their effects”²⁹ and includes cognitive and religious strategies. The counts in Table 1 exceed the number of informants for each data source, because respondents often reported multiple strategies.

Although informants were not asked directly about lay management goals, many provided insights into motivations underlying specific strategies. We classified lay management goals into 3 categories (Table 2). *Fighting the Virus* involves direct efforts to attack or eradicate the virus from the body. Respondents attempt to *Strengthen the Body* by boosting their immunity, staying healthy, fostering “liver health,” and minimizing stress. *Managing Consequences* includes managing symptoms, managing treatment side effects, learning to live with HCV, and minimizing the probability of infecting others. Regulating alcohol consumption is also a disease management goal of HCV+ individuals, which we address elsewhere.¹⁶

Drawing on Lay Repertoires to Achieve Specific Goals

Table 3 and Table 4 summarize the strategies respondents reported using for each goal. Table 3 addresses broader categories of Management Strategies and Goals; Table 4 incorporates subcategories.

Fighting the Virus

Metaphors for fighting HCV conjured images of fighting battles, waging war or slaying dragons, as illustrated by N2030:

The disease still wraps its talons around my life. I intend to fight it until the end and hopefully this beast will breathe its last someday and I will be in remission or maybe even cured!!

Informants drew on all 3 categories of management strategies in fighting HCV.

Medical Self-Care

CAM was the most frequently reported medical self-care strategy. Informants described a range of herbal remedies. Milk thistle was the most prevalent, but informants also mentioned aloe, slippery elm, mustard seed, ginseng, myrrh, chamomile, Echinacea, goldenseal, St. John’s wort, and ginkgo biloba. Some informants had consulted formal CAM providers, including homeopaths, naturalists, practitioners of Chinese medicine, and energy healers.

Behavior Change centered on activity level and diet. Changes in activity levels most often involved exercise, usually walking, as illustrated by R201CP, who reported, “I’m gonna walk this thing out. Circulate my blood system so it can rebuild itself.” Several informants emphasized the importance of getting enough sleep and resting when tired.

The most common dietary strategies were avoiding certain foods or taking supplements. Among foods to avoid were meat or animal products, sugar, salt, caffeine, chocolate or packaged foods with chemicals, dyes or preservatives. Several discussants stressed the importance of avoiding foods high in iron and not cooking in cast iron pots, because, as D5340 explained, iron “can help the virus to reproduce.”

Coping strategies, both cognitive and religious approaches, were also mentioned. Some respondents explained that a “positive outlook accelerates the healing process” (D6017). D5299 described a visualization technique:

Each time I went to the bathroom, I waved “Bye-Bye” to my virus... I told them to keep on trucking, that I didn’t want them in my body, so I flushed them down the toilet.

References to religious healing or “miracles” were relatively rare. Religious strategies for fighting HCV usually involved prayers for medical breakthroughs, as illustrated by N2284, who prayed for “the silver bullet with minimal sides” [side effects]. Others interpreted HCV infection as part of God’s plan, which, for some, included a positive treatment outcome:

God has never let me down... He did not bring me this far to kick me down the stairs (N2039).

Several informants believed that God had chosen them for the fight against HCV, because they had the strength to battle the virus:

I believe that God has chosen the strong ones to fight this war. Some of us may fall but our spirits will stay to make the rest stronger (N2071).

Strengthening the Body

Several strategies attacked HCV indirectly by enhancing the body’s disease-fighting capacity. As N2132 explained:

Allow all your body systems to achieve health in unison, through nutrition, herbs and exercise. You will be strong enough to rid yourself of this thing and keep it away. Weakness is this virus' opportunity.

Efforts to strengthen the body most often incorporated medical self-care and behavior change.

Medical Self-Care

Informants who relied on Medical Self-care for strengthening the body most often described CAM approaches. CAM was used to foster “liver health,” although some mentioned CAM as a resource for boosting immunity and staying healthy. Milk thistle was mentioned most frequently. Informants believed milk thistle protected “against liver damage from alcohol, hepatitis and chemical toxins” (D4002), prevented “further liver damage” (D5268), “boosted liver functioning” (N2187), and helped the liver “regenerate as quickly as the virus destroys it” (D5028).

Some informants had consulted CAM practitioners, most often practitioners of chiropractic, acupuncture and Traditional Chinese Medicine. N2261 relied on a chiropractor, to “relieve pressure on nerves in my spine that corresponded to liver health,” and D5268 used acupuncture to “help my liver regenerate.” N2261 worked with a practitioner of Traditional Chinese medicine:

My liver was suffering from stagnation and could not heal itself... I was given a combination of foul tasting teas and pills to take, complemented with a series of about 5 acupuncture sessions.

Behavior Change

Modifications to activity level and diet were again the most frequently reported Behavior Changes. Informants drew on these strategies for boosting immunity, staying healthy and enhancing liver health.

Changes in activity level usually involved exercise. Walking was the most popular activity, although swimming, yoga and “working out” were also reported. Exercise had been a way of life for some informants, but others began exercising after their diagnosis. For example, D5092 began a weight-lifting regimen after reading that exercise “increased NK cell activity, a constituent of the immune system specifically responsible for fighting viruses and cancers.” Others believed that exercise enhanced liver functioning, like N2202, who has logged “thousands of miles,” because exercise is “my best protection against a deteriorating liver.”

Dietary strategies also figure prominently in efforts to enhance body strength. Informants emphasized the importance of eating properly, following good nutrition, and maintaining a balanced diet. Most often, this meant a diet high in vegetables, low in fat, and, occasionally, high in fruits or protein, although a few respondents mentioned specific dietary philosophies (eg, a macro-biotic diet, the Zone Diet). For some, specific foods were seen as boosting the body’s ability to fight the virus. Informants emphasized the importance of drinking liquids, especially water, but also green tea, milk, chicken broth, or juices (cranberry or tropical fruit). Liquids were believed to have a “cleansing effect” (R35BT), “flushing out toxins and impurities” (R832). Spinach, “greens,” and calf liver were seen as liver-strengthening foods. D5013, who tried to “read up on what foods are good for the liver and eat more of those,” recommended beets and freshly squeezed carrot/beet juice.

Some dietary regimens restricted certain food categories (eg, low fat, low sodium, low protein, additive-free, no sugar, salt or caffeine, no “spicy” foods) or specific foods (eg, chicken, shellfish, pork, red meat, eggs, milk, or chocolate). For example, N2170 has eliminated prepackaged foods; preservatives, meat, caffeine and alcohol. “All of this may sound extreme, but if it stresses out the liver, it is gone from my life.” D5138 recommended avoiding “white foods,” such as white bread or rice, explaining: “These foods are not naturally white. They are denatured, which makes them very rough on the liver.” Several informants were on weight reduction diets, so “my body doesn’t have to work so hard” (R35). Vitamins or supplements were also seen as strengthening the body’s virus-fighting capacity, including multivitamins (especially vitamins without iron), specific vitamins (eg, Vitamins E, C, A and B or B-complex) or supplements (eg, calcium, vegetable protein, lecithin powder and amino acids).

Although not as prevalent as modifications to diet and exercise, some informants described hygiene practices for avoiding exposure to toxins or other disease-causing agents. Sometimes this involved minimizing contact with people who are sick:

I’m always very careful about what I touch, who I touch.... I don’t want any of your germs ‘cause it’s going to hurt me really bad. (R132)

Others avoided touching surfaces in public places:

Like if I go to the bathroom in a public restroom, I will take a paper towel with me. I don’t touch any doorknobs, because I’m so afraid I’m gonna catch some kind of virus.... I can’t afford to be sick with anything. (R132)

Finally, several avoided exposure to environmental toxins, including perfumes, room fresheners, gasoline and cleaning fluids, because “these all place a burden on the liver” (D5346).

Coping Strategies

Few informants described coping strategies for strengthening the body. References to coping focused on “keeping your spirits up,” which, as N2206 explained, “helps to feed and nourish your body.”

Managing the Consequences of HCV Infection

Informants drew on their full repertoire of lay management strategies in managing the consequences of HCV infection. Medical Self Care and Behavior Changes were most often used for managing disease symptoms and treatment side effects. Behavior Changes, specifically hygiene behaviors, were also believed to minimize the likelihood of infecting other people with the virus. Coping strategies were most important for learning to live with HCV.

Medical Self-Care

Informants did not always distinguish between managing symptoms and side effects when they described approaches for alleviating pain, fatigue, nausea, depression, and appetite loss. Once again, CAM was the most prevalent Medical Self-Care approach, particularly herbs, including milk thistle, ginkgo biloba, and St. John's Wort. Acupuncture and Traditional Chinese medicine were seen as effective in combating joint pain, fatigue and nausea. Self-administered medications, particularly analgesics, were occasionally mentioned for pain management, although informants expressed concern about the impact of acetaminophen on liver function.

Some informants delayed or refused conventional treatment because of anticipated side effects, "waiting for a kinder and gentler treatment" (D5248). Decisions to delay treatment were sometimes made within the context of competing demands. For example, R132 was in college when his physician encouraged him to begin a regimen of Interferon. "When I read the paperwork I was like, 'I'm not taking this now, I've got to go to class.'"

Behavior Change

Informants also reported Behavior Changes they believed were effective in combating symptoms and side effects. Modifications in activity levels and diet were mentioned most often.

Both increases and decreases in activity level were used to alleviate fatigue. Some informants, like N2066, "refused to succumb to energy loss and fatigue... generally working out 4 times a week and running at least 15–20 miles each week." Others emphasized the importance of not pushing themselves too hard, like N2061 who "listens to my body. If I need to nap, I nap. If I need to go easy, I go easy."

Dietary strategies for managing symptoms and side effects most often involved avoiding certain foods (eg, animal products, caffeine, sugar and chocolate) believed to exacerbate reactions to the virus or to treatment. For example, D5148 explained that "red meat, when digested, produces ammonia, which a sick liver can't handle, so it ends up in your blood stream causing dizziness, confusion and headaches." Informants also emphasized the importance of drinking water and other liquids "to flush out the toxins from our livers... particularly helpful for night sweats" (D5462).

Some informants reported hygiene practices to avoid infecting others. Safe sex practices were mentioned most frequently, but respondents' awareness of blood as a vector of transmission generated other precautions:

I cut myself the other day and blood was just everywhere. I had to clean that floor up real good and make sure that I didn't drop anywhere where somebody might have contact. (R35)

Several respondents worried that HCV can be transmitted through shared eating utensils. R999 washes her dishes in bleach before allowing other family members to use them. Several others purchased their own eating utensils and never allow anyone to drink from their glass. N2129 no longer "shares tastes" with friends when they are dining together at restaurants.

Coping Strategies

Cognitive strategies were important for learning to live with HCV infection. Some, like N2088, illustrated acceptance: “The cards are down now. I got to play them the best way I can.” Others compartmentalized the diagnosis, trying to contain the impact of HCV, like N2091 who vows not to “allow this crud to take over my persona and lead me around by the nose.” Comparing one’s own situation to that of someone worse off helped some manage stress and stave off despair. R6 illustrated this strategy of downward comparison:

I always keep it in my mind there’s always people in worser shape than I am. That’s what keeps me going.

Finally, some concentrated on the present rather than worrying about an uncertain future:

I’m just dealing with it day by day. I don’t look that far in the future no more man. I be lucky when I wake up the next morning. (R816).

Two themes emerged in religious approaches to living with HCV. Some informants reframed their diagnosis as part of God’s plan. These plans are not always understood by individuals, as illustrated by N2256, who has learned from past experience that “God has never-ever failed me, and He must have a reason for this now.” When the negative aspects of HCV seem overwhelming, others turned the disease over to the Lord, transferring responsibility to a higher power when one can’t handle the disease alone. The result is described as being “at peace with the Lord” (R145) or “finding solace in the Lord” (N2301). As N2169 wrote, “I won’t say I don’t wonder what will happen, but I do feel a certain peace knowing that ultimately it’s in God’s hands. He will take care of me.”

DISCUSSION

Informants reported a broad array of management strategies for addressing multiple goals. Some strategies were believed to attack the virus directly, either killing existing organisms or altering the conditions that enabled the virus to reproduce. Others described strategies for attacking the virus indirectly by enhancing the body’s disease fighting capacity. Some focused on the liver, attempting to mitigate the effects of HCV infection and help the liver regenerate. Informants also tried to manage the consequences of HCV infection on physical and psychosocial functioning.

In addition to managing symptoms and treatment side effects, informants were concerned with what Cartwright³⁰ characterizes as “getting on with life,” exhibiting “a strong sense of continuing despite the difficulties” associated with their diagnosis. They also described hygiene practices designed to protect others from possible HCV infection and cognitive and religious coping strategies to manage stress and minimize despair.

Medical self-care, especially CAM, was reported for all 3 general goals but used most often for fighting HCV and the subgoals of strengthening the liver and managing symptoms. Many informants relied on herbs, especially milk thistle, and some consulted CAM providers, most often practitioners of chiropractic, acupuncture, and traditional Chinese medicine. The increased use of CAM among patients with HCV has been well documented,^{31–32} but our results highlight the ways patients integrate CAM into their lay management protocols. Conditions like HCV with uncertain trajectories place heavy psychosocial demands on patients and their families,¹⁹ and use of CAM can empower patients by encouraging more active involvement in their own health and treatment.^{29,33} In addition, belief in the effectiveness of CAM treatment fosters a sense of control over health and reduces illness-related anxiety.³⁴

Modifications in diet and activity, the most frequently reported behavior changes, were important tools for addressing all 3 goals. Many informants stressed the importance of a healthy

diet, often enhanced by vitamins and supplements. Certain foods were avoided, because they were seen as exacerbating symptoms or side effects or because of alleged negative effects on the liver. Other foods were believed to attack the virus either directly or indirectly through strengthening the body's disease fighting capacity. Walking was the most popular form of physical activity. Others stressed the importance of listening to their bodies and avoiding over-exertion. Like CAM, programs of diet and physical activity can help people cope with illness-related stress and instill a sense of control over the course of a potentially devastating disease. 35–37

Cognitive and religious coping strategies were important tools for managing the consequences of HCV infection and minimizing the disruptive impact of HCV infection on unfolding biographies.^{38,39} Some emphasized cognitive approaches like acceptance, compartmentalization, or downward comparison,³⁰ whereas others employed religious approaches, referencing God's plan or prayers for medical breakthroughs and positive treatment outcomes. Although we anticipated reliance on cognitive coping strategies for managing consequences, they were reported as often for fighting the virus.

Informants often grounded lay management strategies in their understandings of HCV. Almost all understood that HCV is a contagious condition that attacks the liver, and enhancing "liver health" was one of the goals of patient management. Most knew that HCV is transmitted via blood exposure, and informants described hygiene strategies for limiting exposure of others to their blood. Some believed that HCV compromised their own immune system, describing strategies for limiting their exposure to toxins and to people who were ill.

Limitations and Future Research

Our goal in generating the qualitative data was to maximize the range of lay management strategies described by nondependent drinkers diagnosed with chronic Hepatitis C infection. However, the nonprobabilistic design of our sample may have limited the likelihood that our data captured the full range of these strategies. Indeed, it is possible that patients participating in the semi-structured interviews or posting on the Internet are not more than partially representative of the larger population of HCV+ non-abusing drinkers. The semi-structured interviews were conducted in a clinical setting of a single urban teaching hospital. The electronic data were deposited by people who had Internet access, participated in electronic communication forums, and identified themselves as HCV+. The interview format provided opportunities to probe for more complete and nuanced descriptions of lay management strategies. The electronic data minimized the reactivity that can emerge in a clinical setting and tapped experiences of people not being treated in an urban medical center.

Patients consenting to an interview or posting on the Internet may be coping more effectively with their HCV diagnosis than patients not sharing their experiences in these formats. We did not assess the efficacy of these lay management strategies from either clinical or lay perspectives, but patients who employ lay strategies in managing their disease may gain confidence in their ability to minimize or delay negative outcomes. Given these limitations, our findings should be considered illustrative rather than representative.⁴⁰ Estimates of the prevalence and distribution of these lay management strategies will require information from representative samples of patients.

Our cross-sectional data cannot document the dynamic nature of lay management as chronic disease trajectories unfold over time. For example, a longitudinal design would reveal whether clinical evidence of disease progression or the onset of complications undermines patients' confidence that they can manage their health through lay management strategies.

We focus on a single chronic condition, so our results may not generalize to other diagnoses. Comparative studies incorporating patients with other chronic diseases would reveal whether the intersections of strategies and goals we describe are unique to the HCV experience or can be generalized to other chronic diseases.

Despite these limitations, we believe our exploratory study has yielded important new insights regarding lay management goals and strategies among patients living with chronic HCV infection. We encourage other researchers to examine the prevalence, distribution and consequences of lay management among HCV+ nondependent drinkers and other members of Frank's¹ "remission society."

Clinical Implications

Our results underscore the range of personal strategies for managing a chronic disease characterized by uncertain prognosis and variable expression of symptoms. It is possible, nevertheless, to categorize this rich terrain of responses into pragmatic subsets of management strategies with heuristic value for patients, family caregivers and supporters, as well as clinicians. They allow patients to better understand their own approaches to self managing a disease that may be an integral part of their life for years to come and to better communicate and empathize with other patients about their approach, finding communality in the broader category of their management response, if not in the details of how they implement the strategy. The categories also help family and friends to better understand and appreciate the patient's approach to self management, casting it into understandable terms such as self medication, dietary strategies, and exercise.

The categories can also help clinicians understand not only the specific strategies employed by a patient but also the patient's versatility in using multiple categories of management strategies. The categories reduce what may seem an endless number of idiosyncratic self management responses into a usable number of broader categories. When clinicians can ground their recommendations in patients' goals, the chances are greater that patients will implement the therapeutic regimen.¹⁰ Understanding patient goals and the strategies they employ for achieving these goals is central to a holistic approach to chronic disease management, in which treatment of disease is balanced with helping patients approach a desired lifestyle, achieving well-being rather than health.¹⁷

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Table 1
Lay Management Strategies: Number of Informants Mentioning Each Strategy ^a

| | Respondents N = 42 | Narrators N = 79 | Discussants N = 264 | Illustrations from the Data |
|--|-----------------------|---------------------|------------------------|---|
| Medical Self-Care | | | | |
| Self-Administered Medications | 4 | 11 | 25 | <i>I see no way to survive and no quality of life without pain medicine. [N2004]</i> |
| Refuse or Delay Treatment | 4 | 11 | 20 | <i>Since I didn't have any symptoms, my liver enzymes were normal, and the devil you know is better than the devil you don't, I decided to forego Interferon. [N2252]</i> |
| Complementary & Alternative Medicine | 9 | 63 | 93 | <i>I am currently taking Chinese herbs prescribed by a Chinese doctor who came highly recommended to me. It seems that these herbs keep the viral load down and help any symptoms you might have. [D2097]</i> |
| Behavior Change | | | | |
| <u>Dietary Strategies & Supplements</u> | | | | |
| Eating or Avoiding Specific Foods | (16) ^b | (23) ^b | (3) ^b | <i>If you keep a good diet you know it helps keep things stabilized in your body so the liver doesn't break down, you know, like spinach and stuff like that with the iron and all that. Uck, but I eat it. [R49]</i> |
| Good Nutrition | (14) ^b | (23) ^b | (0) ^b | <i>I watch what I eat. I don't eat a lot of fatty stuff. Um, I do eat junk food and that's not good but in between I eat tons of vegetables and I drink a lot of water. [R35]</i> |
| Vitamins/Supplements | (11) ^b | (29) ^b | (57) ^b | <i>Make sure you are not taking more than the daily recommended amount of vitamin A. Try taking a good B complex. [D4008]</i> |
| <u>Adjusting Rest or Activity Level</u> | | | | |
| Exercise | (10) ^b | (20) ^b | (21) ^b | <i>I plan on doing a lot of walking. I'm gonna walk and walk this thing out. Circulate my blood system so it can rebuild itself. [R201]</i> |
| Sleep/Rest, Don't Overdo | (7) ^b | (11) ^b | (15) ^b | <i>When I get tired, I stop. You know, I don't try to go through it or work over it. [R1]</i> |
| <u>Hygiene Practices</u> | | | | |
| Bathing, Monitoring Blood, Not sharing Food/Utensils | (16) ^b | (9) ^b | (6) ^b | <i>One of the best tips I ever got was to take a shower everyday, 2 or 3 event. The hot water makes my aching muscles feel better. [N2211]</i> |
| Avoid Exposure | (4) ^b | (2) ^b | (13) ^b | <i>I mean I couldn't even go around somebody that had a cold or something, 'because I would catch it... A regular person feels better the next day. It took me 3 or 4 weeks to get over a cold. [R132]</i> |
| Coping | | | | |
| Cognitive Strategies | 8 | 11 | 33 | <i>I can't let this thing just dominate my whole life... I can't let the disease dictate how I live. I have to put this disease in one department. [R35]</i> |
| Religious Responses | 10 | 62 | 4 | <i>I am just leaving it all in God's hands. That is all I can do. [N2086]</i> |

¹ We provide counts separately for each data set, although we do not interpret differences among these 3 sources.

² Numbers in parentheses are counts of subcategories, eg, avoiding certain foods is a subcategory of dietary strategies.

Table 2

Lay Management Goals

| | Respondents N = 42 | Narrators N = 79 | Discussants N = 264 | Illustrations from the Data |
|-------------------------------------|-----------------------|---------------------|------------------------|---|
| Fight HCV | 10 | 32 | 51 | <i>The Dr. said there was nothing more they could do for me. It was then and there I decided there was more I could do more me. [N2151]</i> |
| Strengthening the Body | | | | |
| Boost immunity | 5 | 12 | 13 | <i>I started taking Garlicin to help build up my immune system and Ginseng to improve my energy level. [N2008]</i> |
| Stay healthy | 17 | 13 | 66 | <i>I am living healthier than I ever have before. This body that I have abused and ignored is now a temple that I treasure. [D2170]</i> |
| Healthy Liver | 11 | 14 | 51 | <i>Milk thistle is the most helpful thing we can take to give our livers a chance to regenerate and to prevent further damage from occurring. [D5268]</i> |
| Minimize Stress | 2 | 5 | 4 | <i>The doctors did recommend some things, you know, like they gave me folic acid and told me to keep my stress level as low as I can because that can elevate my enzymes. [R35BT]</i> |
| Managing Consequences of HCV | | | | |
| Manage symptoms | 13 | 49 | 64 | <i>I'm scared of not drinking enough fluids. I can never drink water a lot. I hate water but that's something that I needed to learn how to start drinking more of every day. Basically, I'm scared every time my urine is yellow or dark or whatever. [R801OJ]</i> |
| Manage Treatment side effects | 12 | 18 | 18 | <i>They said... the side effects of the treatment will be far less if you drink water and it seems to be true because I've gone days not drinking as much and I don't feel as good. [R61RJ]</i> |
| Learning to live with HCV | 3 | 33 | 17 | <i>I guess the trick is to be sensible and practice moderation in everything. Eat healthy, give yourself some "me" time to relax if/when you need it, and exercise. [D5243]</i> |
| Avoid Infecting Others | 13 | 10 | 3 | <i>I used to go to the bathroom take a leak or whatever, I didn't always wash my hands. Now since I knew I had hepatitis C... I make sure that every time I go to the bathroom I wash my hands. I make sure that everything's pretty neat with me. [R145RL]</i> |

Table 3

Strategies by Goals: General Categories

| STRATEGIES | GOALS | | |
|-------------------|-----------|------------------------|------------------------------|
| | Fight HCV | Strengthening The Body | Managing Consequences of HCV |
| Medical Self-Care | 61 | 80 | 98 |
| Behavior Change | 59 | 95 | 114 |
| Coping | 52 | 21 | 50 |

N = 385 (42 Interview Respondents + 79 Narrators + 264 Discussions).

Table 4

Strategies by Goals: Specific Categories

| GOALS → STRATEGIES ↓ | FIGHT HCV | | | STRENGTHENING THE BODY | | | MANAGING CONSEQUENCES | | |
|--------------------------|-----------|----------------|--------------|------------------------|-------------------|-----------------|-----------------------|---------------------------|------------------------|
| | Fight HCV | Boost Immunity | Stay Healthy | Healthy Liver | Minimizing Stress | Manage Symptoms | Manage Sides | Learning to Live with HCV | Avoid Infecting Others |
| Medical Self Care | | | | | | | | | |
| CAM | 56 | 19 | 15 | 48 | 0 | 59 | 18 | 1 | 0 |
| Refuse / Delay Tx | 11 | 1 | 1 | 4 | 0 | 5 | 24 | 0 | 0 |
| Self-Admin. Meds | 1 | 1 | 1 | 13 | 0 | 15 | 3 | 3 | 0 |
| Behavior Change | | | | | | | | | |
| Adjust Activity Level | 28 | 13 | 20 | 15 | 5 | 40 | 13 | 8 | 0 |
| Hygiene | 0 | 1 | 9 | 13 | 0 | 8 | 1 | 1 | 21 |
| Dietary | 53 | 19 | 30 | 53 | 4 | 66 | 16 | 4 | 1 |
| Coping | | | | | | | | | |
| Cognitive | 30 | 3 | 10 | 6 | 6 | 11 | 5 | 15 | 2 |
| Religious / Spiritual | 24 | 1 | 3 | 0 | 0 | 4 | 6 | 9 | 1 |

Note. N = 385 (42 Interview Respondents + 79 Narrators + 264 Discussions)

For clarity of presentation, we sum counts across the 3 data sources; counts for specific sources are available from the authors.