

Resolute efforts to cure hepatitis C: Understanding patients' reasons for completing antiviral treatment

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Abstract

Antiviral treatment for hepatitis C is usually difficult, demanding, and debilitating and has long offered modest prospects of successful cure. Most people who may need treatment have faced stigma of an illness associated with drug and alcohol misuse and thus may be deemed poor candidates for treatment, while completing a course of treatment typically calls for resolve and responsibility. Patients' efforts and their reasons for completing treatment have received scant attention in hepatitis C clinical policy discourse that instead focuses on problems of adherence and patients' expected failures. Thus, we conducted qualitative interviews with patients who had recently undertaken treatment to explore their reasons for completing antiviral treatment. Analysis of their narrative accounts identified four principal reasons: *cure the infection*, *avoid a bad end*, *demonstrate the virtue of perseverance through a personal trial*, and *achieve personal rehabilitation*. Their reasons reflect moral rationales that mark the social discredit ascribed to the infection and may represent efforts to restore creditable social membership. Their reasons may also reflect the selection processes that render some of the infected as good candidates for treatment, while excluding others. Explication of the moral context of treatment may identify opportunities to support patients' efforts in completing treatment, as well as illuminate the choices people with hepatitis C make about engaging in care.

Keywords

ethnography, health policy, illness behavior

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Hepatitis C (hepatitis C virus (HCV)) is a common chronic viral infection that causes slowly progressive liver damage that can lead to cirrhosis and cancer. Thus, it carries substantial risks for morbidity and mortality. Yet, the virus can be controlled. About half who have undertaken treatment in the past 20 years have achieved a cure, and greater effectiveness is promised by a new, growing array of direct-acting antiviral medications. However, control is in most cases difficult to achieve. Treatment entails long—as long as 48 weeks—complicated medication regimens that cause clinically well described, debilitating side effects, including sometimes severe anemia and immune impairments, fatigue, flu-like symptoms, depression, skin rash, and pain (Ghany et al., 2011). The goal of treatment is elimination of the virus, realized through its prolonged suppression over the course of treatment and indicated by a sustained viral response (SVR) 6 months after completing treatment. Simply put, cure can be accomplished through assiduous and complete self-administration of oft-sickening medications to suppress the virus over a long course of therapy, but treatment failure is common. Hence, patients who undertake antiviral treatment for HCV infection assume substantial responsibilities for completing challenging treatments that offer uncertain benefits.

The responsibilities patients embrace are not well understood. Many patients stop early when told by clinicians that treatment for them is turning out to be ineffective or that the toxicities are seriously threatening their health, while an ill-defined number withdraw for reasons that have not been systematically addressed. Failures to adhere or complete antiviral treatment are expected; they are prominent topics in the clinical and health policy discourse of HCV, albeit with data largely limited to demographic and clinical characteristics of patients that are correlated with failure, that is, risk factors. Early withdrawal has been presumptively ascribed to patients' inability or unwillingness to tolerate the challenges of self-medication and side effects. The substantial *psychosocial* burdens of treatment that could account for patients' failures have been documented (Hopwood and Treloar, 2005; Manos et al., 2013; Treloar and Hopwood, 2009), but patients' own reasoning about these side effects in unsuccessfully completing treatment have not. Moreover, patients' reasons for successfully completing treatment have received very little attention. This is a significant lacuna.

More importantly, the social contexts in which meanings arise—most notably, the moral contexts of HCV practices—have not been taken into account in clinical policy research. Stigma accompanies the diagnosis and often characterizes the lives of people who carry the infection, largely because of the strong association between infection and illicit injection drug use. A growing body of social research has examined the stigma of HCV (Harris et al., 2013; Paterson et al., 2007; Zacks et al., 2006) and moral attributes of the infection and the lives of the infected. Except for the minority who are innocent victims of tainted blood transfusions, people with HCV are typically held responsible for their infections (Duffin, 2005; Orsini and Scala, 2006). However, this work has not yet been well integrated into clinical policy, or penetrated analyses of patients' engagement in antiviral treatment. As a result, patients' efforts in completing antiviral treatment have been left poorly appreciated.

We present a study of patients' reasons for completing antiviral treatment. In a moral context in which people with HCV are presumptively responsible for their infections, and their failure to meet the responsibilities of antiviral treatment is expected, how do

patients construe their efforts? We interviewed patients who had recently attempted a course of antiviral treatment and asked them to describe their experiences. We did not interrogate them directly about completing or stopping treatment. We invited their narrative accounts, expecting they would provide their rationales and their grounds for their actions (Polletta et al., 2011), along with depictions of themselves as reasonable, responsible actors (Riessman, 1993). They provided accounts of their meaningful social actions in embracing *their* responsibilities in completing antiviral treatment. We began this inquiry in order to augment clinical research with a patient-based, sociological explanation of premature patient withdrawal. However, the patients told a different kind of story. As we attended to patients' stories of antiviral treatment, we turned the question around: why did they persist?

Embracing the complex responsibilities of completing treatment in spite of the challenges implies a virtuous pursuit (Williams, 1993). Clinical and moral rationales are often intertwined, as previous studies of chronic illness and adherence to medical regimens have found. In their "metaethnography" of depression self-management, Malpass et al. (2009) described two common lines of reasoning in patients' accounts. Clinical reasons include decisions to start, remain on treatment, manage the regimen, and assess symptoms and adverse events, according to a medical rationale. Moral reasons concern personal identity and social relationships, the social meanings of the disease and its medications, as well as the stigma of the disease. Patients frame their adherence to prescribed clinical tasks, such as self-medication, with respect to claims to respectability, as well as episodes of larger autobiographies (Malpass et al., 2009). In the settings where antiviral treatment for HCV is offered and undertaken by patients whose lives are subject to discredit, respectability is problematic. For patients, completing treatment may support complex counterclaims of personal worth in the demanding contexts of clinical care (Rhodes et al., 2013).

Our analysis of patients' accounts was, therefore, oriented to the contexts in which they were presented. Stories in research interviews are always told and analyzed in manifold contexts. They reflect the socially and culturally situated life-worlds of the tellers, the interests of research interviewers, and the local circumstances of the interviews (Mishler, 1991). They are local productions in manifold contexts. Sociological studies of people with HCV and their medical treatment, as well as the treatment experiences associated with the kindred malady HIV, have shown how patients' accounts of their illnesses reflect attributes of the institutional contexts of health policies and services in which treatments are realized (Mykhalovskiy, 2008; Orsini and Scala, 2006). Hence, in looking for the reasons for completing treatment that they would provide, we were attentive to the discursive context of their HCV care, and indeed the context of our research.

Context of the study

This study was developed within the Veterans Health Administration (VHA) of the US Department of Veterans Affairs in order to address the health policy problem of poor completion of antiviral treatment. Public health policies call for population screening, diagnostic testing, and treatment to prevent suffering and to minimize the costs of treating patients who develop the outcomes of uncontrolled HCV (Institute of Medicine,

2010). These policies are pronounced in the VHA (Department of Veterans Affairs (DVA), 2010), as the prevalence of HCV in the population it serves is three to six times that of the US public at large (Dominitz et al., 2005). Moreover, the VHA assumes long-term responsibility for providing health care to this population, including the consequences of uncontrolled HCV. Yet, less than 30 percent of infected patients served by the VHA have been prescribed antiviral treatment (Butt et al., 2005; Kramer et al., 2012). Adherence is often less than needed for viral suppression and fewer than half complete their planned courses (Beste et al., 2010; Lo Re et al., 2012), compromising the accomplishment of policy goals.

For reasons both biomedical and psychosocial, patients who attempt antiviral treatment are a select group. Clinicians are advised to offer treatment selectively to patients they judge to be good candidates, pursuant to official guidelines (DVA, 2010). Common contraindications for treatment include irretrievably advanced liver disease, physical comorbidities, or mental conditions (e.g. anxiety disorders, depression) that render patients unlikely to benefit from treatment or tolerate its toxicities (Talal et al., 2013). Histories of illicit drug use and alcohol abuse, which are prevalent, etiologically related to infection, and may themselves cause liver damage, are seen as contraindicating treatment. They putatively undermine treatment effectiveness and may signal poor motivation to adhere to the regimen. For treatment, 6 months of abstinence has often been required. Other contraindications include problematic social and economic circumstances that are not conducive to the rigors of treatment. Many patients with HCV lack social support, have unstable domestic or residential circumstances, including homelessness, difficult work situations or unemployment, and financial strains (Harris et al., 2013). These circumstances are associated with irregular engagement with health care, which is taken as foretelling poor adherence (McGowan and Fried, 2012). Moreover, clinicians' evaluations of patients as candidates for treatment are likely complicated by the stereotypes and stigma associated with the infection (Harris et al., 2013; Paterson et al., 2007; Zacks et al., 2006). Clinical determinations of candidacy likely involve moral evaluations, with candidacy-associated perceptions of patients' likelihood of meeting the obligations of treatment.

Patients' decisions to undertake antiviral treatment in the first place have been shown to entail a complex calculus. Beyond curing the infection, the clinical rationale of treatment is to prevent the consequences of uncontrolled HCV: advanced cirrhosis and liver cancer, which occur in 20 and 5 percent, respectively, of infected patients at an average of 20 years after initial infection (Lee et al., 2012). Patients may weigh their perceptions of HCV, the liver disease it can cause, the risk of cirrhosis and other problems in the future, and the effectiveness of treatment against anticipated side effects, along with whether their work, residential, and other life circumstances will support the burdens of treatment (Fraenkel et al., 2010; Fufeld et al., 2013; Osilla et al., 2009). They may consider their personal resources, their willingness and indeed willpower to deal with the side effects, their trust in their doctors, along with the threat of losses if they do not act (Fufeld et al., 2013; Osilla et al., 2009). Some may determine that the potential benefits of treatment are not worth the costs, while for others misgivings may be outweighed by the felt imperative to "do something" in the face of HCV (Fraenkel et al., 2005). Jenner and Scott (2008) highlighted the problematic rationality of antiviral treatment decisions

and the imperative to act against an invasive infection conveyed through patients' narratives of their reasons for pursuing antiviral treatment. Notwithstanding the limited benefits of treatment, they found that patients embraced an irrational "faith in biomedicine," along with its cultural metaphors of combat against invading viruses. In spite of the challenges, patients felt bound to assert control and vanquish an invading virus, while presumably suffering and soldiering through the personal losses (i.e. side effects).

Patients' decisions to start are likely complicated by the challenges they typically encounter with health care providers (Harris et al., 2013). The stigma of HCV entails stereotypes of personalities and ways of living at odds with expectations of reliability, trustworthiness, and commitment to the demands of antiviral treatment. This stigma permeates clinical relationships, with patients reporting communication problems and disrespect in primary care and HCV clinics (Zickmund et al., 2003, 2004). Patients with HCV may encounter harsh judgments by clinicians about who they are and how they live, diminishing the trust that may be needed in pursuing treatment (Harris et al., 2013): a problem akin to that in HIV care (McCoy, 2005).

It is in this context that we explored patients' reasons of completing antiviral treatment for HCV. The implicit presumption of previous research and policy is that well-selected patients will complete the long course as directed, unless thwarted by toxicities. This has been supported with data on demographic and clinical correlates of early termination, largely derived from medical or administrative records. We turned to patients who had been selected and attempted treatment to hear their rationales.

Method

We sought patients who had ended a course of antiviral treatment with pegylated interferon and ribavirin in the past 18 months at one VA hospital. We included any who had either completed the planned course or stopped prematurely because of lack of viral response, excessive toxicity, or their decision to withdraw. All participants were identified with the cooperation of the HCV clinic staff who introduced the study and referred those who were interested to us. Interviews were conducted at times and locations convenient to the study participants, including the hospital, their homes, and various public places. Participants were offered a retail store gift card valued at US\$50. All procedures were approved by the hospital's Institutional Review Board.

The clinic coordinator referred 32 patients to us. Two could not be reached, one could not commit to a time, five declined to be interviewed, and three were deemed ineligible (e.g. were starting a new course of treatment). All but one of the 21 participants were men, aged 49–72 years; 14 Caucasians; 13 unmarried. Histories of injected and inhaled drug use were reported by 14 and 16 participants, respectively; 16 participants reported previous alcohol abuse. Most completed 48 weeks indicated for genotype 1 ($n=13$) or 24 weeks indicated for genotypes 2 or 3 ($n=5$). Three patients had discontinued treatment early; all stopped by their physicians because of severe toxicity. Half (11/21) had achieved SVR when interviewed, while for 7, it was less than 6 months since completion and thus too soon to tell.

The interviews began with an open-ended request for the participant to describe his or her experiences relating to treatment, beginning where he or she saw fit: in most cases

either the initial diagnosis or experiences of initial infection. Subsequent questions focused on topics and narrative threads the patients' introduced, as well as our a priori topics: learning the diagnosis, how the virus had been contracted, decisions to begin treatment, self-medication, side effects, relationships with providers and others, and thoughts about treatment completion or termination. The interviews lasted between 60 and 90 minutes. All were audio recorded and transcribed verbatim for analysis.

A set of codes was developed to represent the content of patients' accounts. It was revised and expanded as transcripts were read and compared. Initially, three analysts read and coded a small set of transcripts, compared codes, discussed differences, revised codes, and reached consensus. This process was repeated with a second set of transcripts, which produced a final codebook with explicit definitions and examples. The remaining transcripts were then coded, and coded extracts were systematically compared with respect to whether or not the patient completed treatment and other distinctions that emerged as analysis progressed, for example, patients with manageable or unmanageable physical side effects. This report focuses on patients' depictions of their expressed motivations for completing treatment and the thoughts they had about stopping while on treatment. Reading each transcript as an analytically coded narrative of antiviral treatment, we discerned these patients' reasons for pursuing treatment. All analyses were implemented using HyperRESEARCH software.

Findings: patients' reasons

The patients' accounts presented four lines of argument that we summarize as reasons for completing antiviral treatment: (1) *cure their HCV infection*, (2) *avoid a bad end*, (3) *demonstrate ability to persevere through an ordeal*, and (4) *accomplish personal rehabilitation, even redemption*.

Cure: I was holding out hope that I would get rid it

Completing treatment in order to cure HCV is consistent with the clinical rationale. Seven patients expressed this reason plainly as to "get rid" of the virus. Their doctors, they said, had offered treatment in these terms. One patient recalled that his doctor left the treatment decision up to him, but "we could try and cure it all completely" (Patient 006). They also appreciated the distinction between effective suppression and complete elimination of the virus, as well as the uncertainty of cure: "if you complete the treatment, there is a good chance that it will show up as not non-existent, but non-traceable" (012). Clinical indications of effectiveness, such as viral levels over the course of treatment, were signs of curative effect that sustained their persistence. One patient's flagging motivation was restored when the clinic nurse showed him his declining viral level:

it showed right on board where she showed it to me. And I saw the progression of it. I saw it from my own eyes. That's one of the things that made me hang in there ... Yeah, I saw it making progress. (017)

Some patients reported that their recent attempt to achieve a cure had not been their first, and might not be their last. If they had not achieved a cure in previous attempts, they

had tried again in pursuit of a cure. One said that although his viral load had not declined enough to indicate cure, the effect was still enough to show it was working and had “done some good.” Another patient who had completed his third course of antiviral treatment was “holding out hope that I would get rid it” (003) as he awaited the 6-month follow-up viral assessment that would indicate whether or not he had successfully achieved a SVR.

Avoid a bad end: You can maybe [get] 25 more years if you take care of it. If I didn't then it would get bad

Most of the patients (14/21) characterized HCV as a progressive disease that would eventually end badly, unless they took timely action. Completing treatment was rendered as seizing a prolonged opportunity in time to forestall the bad end. One recalled he began treatment anticipating the misery it indeed caused, but noted that the alternative was “developing liver cancer and that is no way to go” (012). Some explicitly equated HCV with cancer: “it’s like having cancer ... If you don’t do anything – You have to take action” (011). Moreover, when thoughts of stopping the misery of treatment arose, they were dismissed; stopping could “make things worse” (010). One discussed stopping treatment with his doctor, who pointed out his choice: “either get off of it and let the HEP C kill you and tear your liver apart ... Or live with the agony of the injections” (017). One patient explained that thoughts of stopping were countered by the ominous, proximal threat:

Yeah it occurs to you. Because when you’re sick [from treatment side effects] there’s a way of stopping it. Then again there was a guy who was sick from it, and they took him off of it. And he died six months later of liver cancer or a year later of liver cancer. So that’s something you look at too. People do chemotherapy. I also know this as a paramedic. People do chemotherapy every day and it makes them sick, but there is a goal in mind. (005)

Time framed action. The disease was progressive and remaining time could be short, rendering treatment urgent. Yet, some were sanguine about disease progression. Patients may have known about their diagnosis for a long time, deferring treatment as they watched and waited. One waited until he retired, so he would be unencumbered by his job while he pursued treatment, although he “knew the clock was ticking” and treatment could be delayed no longer. Another watched his disease “hold steady” for “several years,” saying he wanted to avoid needles and the side effects, but chose to act when his virus level “shot up,” feeling that the liver could deteriorate very rapidly, and then it would be too late. Conversely, treatment provided time or the benefits that could come with more time: “... the doctor told me, ‘You could live 25 more years and enjoy your grandchildren’. I’ll never forget his words. That’s why I took care of it. Okay?” (016).

Persevere through personal trial by force of will: my will is stronger than the crappiness

The third line of reasoning presented perseverance as virtuous in its own right. Treatment was a personal ordeal to endure. Whereas *cure* and *avoiding a bad end* were reasons focused on the outcomes of treatment, the perseverance argument focused on the process

of getting through treatment and the willful efforts it required, with attendant claims of virtue though suffering discomforts or misery.

Side effects were acknowledged, but dismissed, beginning with decisions to start treatment. One patient recalled discussing the “pros and cons” with his doctor and how other patients told him things “that would scare you,” but he went on bravely, “I still decided to take it. I said, ‘To hell with it if it is going to cure me’” (Patient 006). While noting the prospect of “cure,” he accented his resolve in spite of the threat of frightening discomforts. Perseverance connoted positive resolve. Another patient, when asked whether he ever wanted to miss a day of the medication, said, “every day,” but he could not: “I don’t want to do this but I have to. ... if I want to try to get healthy, I have to do this. You do what you got to do. If I want to do something, I do it” (003). Completing treatment explicitly meant soldiering through the adversity, as some invoked their past military identity or strength of character they gained in combat. One would do his physically demanding job, ignoring the fatigue and the pain, “but typical me being that way in Nam and stuff. I just didn’t pay no mind to it. Plus I was brought up like that” (017):

Int: Were there ever times when you felt like you wanted to stop the treatment?

Pt: No. There were times when I really got sick. And you think about it a little bit but not serious. But you think, “Come on. Hang tough. You were an Army guy. Gee whiz! Don’t be such a sissy.” (011)

Willful perseverance entailed smart self-discipline. Remaining strong in spite of the side effects was, for some, accompanied by remaining wise and avoiding foolish actions. Two patients described conversations with their doctors who pointed out that they would lose their personal investments if they chose to withdraw because of the substantial discomforts. The wise patient would stay with the treatment in order to protect his or her investment:

I wanted to stop about half way through ... and my wife was on board because she was kind of encouraging me to stop ... [The doctor] kind of spoke to me and basically said, “Look. You want out? You bought a new car. You’ve done half the payments.” He says, “Now you want to get rid of the car. You lose the money you paid in. You lose the car, too. There is still a possibility that this is going to help you.” You know, he broke it down in a real pragmatic way. So I stayed with the treatment. (007)

Willful and wise resolve was contrasted with descriptions by other patients who “fell” in their efforts. With these claims, they parted company with others who, like them, had been drug users or alcoholics, but who lacked resolve and were susceptible to foolish thinking. One patient described the complicated life circumstances of people who have been drug addicts, such unstable residential situations. Those circumstances, he said, can be construed unwisely and made to “justify anything” by patients who make poor decisions and then drop out of treatment. He added that patients might even think they can game the VA system providing their care and avoid its surveillance; that would be foolish as well. This patient pointedly distinguished himself from the unwise

in documenting his perseverance. Asked to say more about these circumstances (“How stable are situations? Do guys change housing a lot?”), he described a possibly autobiographical scenario:

Oh yeah definitely they change housing a lot. I might meet a girl and move in with her and have to get a job to help pitch in for that. And not have time for [HCV treatment]. Or just getting involved in something else. Or find a job and get involved in that. I don't think once you start treatment unless you're just too sick for it I don't see anything as being legitimate in stopping. If I move to another city or another state there are other VAs there. My records could be transferred. So I really don't see anything legitimate— Unless you could fool yourself still. Because a lot of what addicts do or even people is they'll fool their selves. They can justify anything “Well I'm busy at work now so I really don't have time to do this.” But I think you can always find time to get treatment. That's what I think anyways. Other than that other situations can be anything. We all get distracted by things. But I really don't see any excuse unless it's just making yourself sick. And then you're going to be honest. You're going to say “I'm just too sick to do this.” You're going to tell the people. You're not just going to suddenly drop out of sight or drop out of what you're doing. I see the only legitimate thing I can see for something. (005)

Completing treatment could be a proud accomplishment, while quitting would be shameful. One patient depicted the pride of completing treatment, making himself feel better on the inside, and thus presenting a more respectable person on the outside, to himself and others:

Int: Yeah. Did you ever think of quitting treatment, so you can say, “Forget it, I'm not finishing this treatment?”

Pt: Man. I was just too far up into it ... to even try to turn back, to even stop. And actually—I felt like a quitter! I felt like I was quitting. I mean, I said I was off to get some enhancement, and then my motivation was that I was going to get somebody to love me, or have— what you guys are saying, that I was going to feel better about myself. I mean, the price of feeling good was— I don't know what that meant, I mean feel good, and then more as a person, the hepatitis stuff works on your immune system, yadda yadda yadda, and you needed your immune system and stuff like that. So I had to better my insides to begin to feel good on the outside. So it's something to work with. So I began to want to become a little healthier. (014)

Personal rehabilitation: I needed to clean up my life

One-third of the patients explained that completing treatment was part of their efforts to rehabilitate themselves; it was part of a larger personal project. While highlighting the virtue of perseverance, completing treatment was cast in terms of personal changes from a discredited way of life to one that was acceptable. Treatment would not so much eradicate a threat to health as eradicate a stigmatizing vestige of their former lives. HCV was part of their former lives involving drug or alcohol abuse; the new lives were clean and sober.

Completing treatment meant staying on the correct path, chosen at an earlier turning point. As one put it, when she

looked in the mirror, I said to myself “Either I’m going to stop and clean up and do things right in my life, or I’m going to go all the way down the bad road.” And like I said that meant cleaning up. (017)

Pursuing treatment was part of “getting serious” about personal rehabilitation and moving away from a life recollected as ruinous:

I just wanted to get rid of this as possible. Plus I needed to clean up my life. This was the incentive to get away from the drinking. To get away from all of the crap that I was doing to myself. Self-destructive stuff. I said to myself “This is it. This is it. I can’t continue like this anymore.” Killing myself. Literally. Just like that. Especially like that. (020)

In rehabilitation accounts, the bad end to be avoided was not *just* a matter of morbidity, it was a discreditable end:

INT: Where is that determination coming from?

PT: Where does it come from? I’m an old man, I’m a nothing. It’s the only way I can put it—

INT: And you don’t want to die.

PT: Yeah. I don’t know. That might be a consolation [laughter]. I don’t want to die with nothing. I don’t want to die living like a dog. I know how to live on the top shelf, and I know how to live in the gutter. And I have a preference for the top shelf.

INT: And that’s what keeps you going?

PT: It is. I don’t like people looking down on me, which I know they do because of the situation I’m in. But I can change all that. I don’t have to live in that situation.

Completing the treatment was a demonstration that they had changed for the better and would do the right thing. It was explicitly linked with presentations of new clean and sober selves. The sickness attributed to the interferon was likened by one patient to how he felt when he was drinking: “Well I was sick every morning when I woke up from being an alcoholic anyways. So sickness was not a stranger” (005). He had relieved that sickness by drinking, and could relieve the sickness of interferon by stopping, but if he did that, he would lose newly gained self-respect: “but it’s not being true to yourself. It’s not doing the right thing when nobody’s looking. That’s what sobriety to me is about. Doing the right thing when nobody’s looking” (005). Another was proud that he showed up for his work therapy job every day, deliberately denying the sickness of treatment, and proud that he was making some money to meet obligations:

I never missed a day even when I was doing that. Never. So it all depends what—How your mindset is. If you’re used to doing nothing and the medicine is going to emphasize or make it feel more, you don’t want to do that. I had a reason to keep going; I had to pay child support.

So I had to make some money. So I couldn't get behind there. Plus it was my own fault that I ended up that way, so I wanted to get better and get back to where I was. And that worked for me. (013)

Candidacy for treatment was depicted as a positive achievement that completion would reinforce. They had risen to meet personal challenges laid down by skeptical doctors. Doctors had previously treated them poorly, regarding them as unreliable or even unworthy patients, such as one who reluctantly treated this patient when he was hospitalized for an injury and infection after a drinking binge. "First doctor, he said, 'I have to take you'. He says, 'I wouldn't normally take you', he said, 'but I have to'. And he says, 'Once you're discharged, you're discharged from me for good'" (029). Candidacy was presented in their accounts as an opportunity to prove to care providers that they were worthy of treatment, if not care, on the providers' terms. One described his impatience to start treatment as he spent 6 months demonstrating his sobriety, yet accepted that as a trial through which he would prove that he was a "candidate," and would "do what I was supposed to do" (020). Another patient countered the low expectations of his clinicians when treatment was considered. His perseverance in treatment was a prolonged, concerted effort to demonstrate that he was indeed worth the expensive medications. He was clearly proud of proving the clinicians wrong about him:

Now when he looked at me and the first time he seen me he thought I was just going to be one of them people that didn't care even though the medication was very expensive. But I showed him I did care for my health.

Int: What do you mean? Do you think he was sizing you up and thinking you weren't going to care? What do you mean by that?

Pt: Okay. This is what I'm literally getting at. There's so many people that will go in there and try to get help for their HEP C and they can't finish the program. Because either it's too rough for them or "Blah, blah this and that." Or very sick. And he looked at me and told me because me and him basically sit in his office and he goes "Are you sure you want to do this? Because we don't want to waste all this medication and stuff if it isn't going to work out for you." So basically I met him half way. I proved to him that I could literally do it. I've been doing this for two consecutive years. After my two consecutive years I've been done; I'm still clean, haven't smoked, haven't done nothing. So I think I would be a really good example right now to this research that you're doing. (022)

Cure and complex reasons

The four reasons for completing antiviral treatment evince a shared motif: patients' depictions of themselves as responsible agents. Clinicians, if mentioned, were assigned supporting roles as providers of information or witnesses of their resolve. These patients took actions, in time, to forestall the progression of the disease and change behaviors that were leading to a bad end. They presented themselves as strong, smart, and willful, putting aside the miseries of treatment and temptations to think or act foolishly, as they may have at an earlier time.

Most of these patients presented more than one of these reasons. Some expressed both avoiding a bad end and demonstrating perseverance, with efforts to avoid a bad end linked to demonstrations of personal strength and wisdom. While some said “cure” and “rehabilitation,” *rehabilitation* was articulated with *perseverance* by several. Thus, strong, wise perseverance was linked with personal redemption. Patients who said they completed treatment in order to *cure* their virus also sought to avoid the bad end and expressed determined perseverance. Yet, not one said treatment was completed simply to cure the infection. However, *cure* was not with *rehabilitation* in explaining treatment completion. The distribution of reasons was not associated with reported history of substance abuse or how HCV was contracted.

Discussion: displays of responsibility for completing treatment in situ

This study was conducted within the VHA, and thus within a particular institutional context. This context provided opportunities to identify relevant attributes of policies and practices that likely informed the data we collected, as well as the material support for our research. However, the policies that guide treatment for people with HCV in the VHA are akin to and informed by policies promulgated by other agencies for the population at large. While the prevalence of HCV in the population served by the VHA is much greater than in the broader US population, the demographic characteristics of the two populations are quite similar (Dominitz et al., 2005). The patients we interviewed had either completed their treatment or continued until their doctors said they had to stop. None had discontinued treatment on their own account, which may have called for excuses or justifications of *their* decisions. There were no treatment failures for which they could be held personally responsible. Indeed, the absence of failures likely prompted our shift of focus from treatment withdrawal to treatment completion. The reasons for completing treatment expressed by these patients may differ from those who were unsuccessful and withdrew. Yet, we did not discern any differences between those who completed and those whose efforts terminated by the doctor or those who did not achieve the goal of SVR. These patients described their earnest efforts, even when the goal of SVR was not achieved. We should expect their stories to reflect some measure of self-satisfaction. Accounts of personal actions are typically managed with preferences for positive depictions (Riessman, 1993). Indeed, the accounts presented here suggest a rhetoric of self-satisfaction in the complicated context of HCV treatment. Thus, while our data are limited by its size and breadth of the sample, our findings nevertheless raise the question: why these reasons?

These reasons echo the interweaving of *clinical* and *moral* justifications in illness self-management accounts described by Malpass et al. (2009). These accounts of completing antiviral treatment articulated clinical pursuits of disease eradication with transcendent, moral claims of self-worth: meeting challenges and taking responsibility in time to prevent bad outcomes. They highlighted personal resilience, derived from prior experiences in the military or adversity. Moreover, perhaps the strongest moral reason offered, pursuit of redemption, was combined with other reasons in complex arguments, but not with “cure.” These reasons for completing treatment stand in contrast with the image of

patients with HCV typically constructed in the clinical literature: patients at risk of poor adherence or withdrawal because they are unable to cope or too weak to persevere. The patients we interviewed presented themselves as strong and resolute in completing treatment.

Other research has documented how guilt is a common theme in the lives of people with HCV, largely derived from the pervasive association between the infection and discredited intravenous (IV) drug use and alcoholism (Fraser, 2010a; Orsini and Scala, 2006). Although a minority may be innocent victims who contracted the infection through tainted blood transfusions, and thus may enjoy a preferred status in health care, the majority are viewed as guilty; they suffer because of their own misdeeds (Duffin, 2005). This theme is present in popular, self-help, and medical literatures, which also depict antiviral treatment as personal rehabilitation, not just disease eradication (Fraser, 2010b). This cultural context provides ample materials for the accounts we examined. Most of these patients reported histories of drug or alcohol abuse. Their reasons suggest counter-arguments to the presumed deficits of personal capabilities reflected in psychosocial contraindications that are formulated in clinical guidelines for treatment. Moral approbation of unacceptable health habits by health-care providers is not rare, as diverse patients may be compelled to justify or excuse behaviors that can harm themselves or others (Coxhead and Rhodes, 2006). The self-satisfaction expressed in resolute efforts is consistent with constructions of character that may satisfy clinical and broader social definitions of a responsible person, in spite of previous harms and past failings. Responsible efforts, virtuous perseverance, and redemption may reflect attempts to neutralize the guilt ascribed to the etiology of HCV by eradicating the infection.

The participants in this study were members of the select group of patients with HCV: they had been judged to be good candidates and offered antiviral treatment. Pursuant to VHA guidelines (DVA, 2010), their clinicians may have counseled them about the disease and the demands of treatment and determined that they were *ready* to undertake those demands by noting their expressions of readiness. Establishing candidacy may include pretreatment socialization that renders patients ready to undertake treatment (Ho et al., 2008). Counseling may reflect the influences Fraser (2010b) documents, with histories of drug and alcohol misuse highlighted as impediments that must be addressed in order to pursue treatment (Bonner et al., 2012; Butt et al., 2005). For example, Knott et al. found that VHA patients who worked with nurses in preparing for treatment, sometimes over several months of required sobriety, were more likely to be subsequently judged good candidates and go on to complete treatment (Knott et al., 2006). In a related study outside the VHA system, Evon et al. (2011) found that a formal 9-month program of counseling and case management effectively converted risky patients who were then deemed by HCV physicians to be good candidates. The program involved active encouragement to practice recommended abstinence from alcohol, attend substance abuse programs (i.e. 12-step programs), and comply with liver clinic appointments, with counselors using motivational interviewing techniques to change unacceptable behaviors and repeatedly provide opportunities to express readiness for treatment.

The reasons for completing treatment may reflect awareness of having been judged as ready for treatment, especially when the achievement of candidacy itself was recalled as a personal success. The expressions of resolve, rehabilitation, and redemption we

observed echo expressions of treatment readiness in rehabilitation settings, such as those captured in the language used in psychometric scales to measure readiness for drug and alcohol rehabilitation, for example, expressions of guilt and wishes to feel good about oneself that reflect motivations for rehabilitation (Ryan et al., 1995). The reasons are also similar to the rhetoric of personal insight, motivation, and rehabilitation that participants in drug and alcohol rehabilitation programs are expected to perform (Carr, 2011). The resolute efforts we have described are consistent with how patients Rhodes et al. (2013) interviewed depict successful claims to candidacy for antiviral treatment. Treatment, they noted, is not provided simply according to biomedical indication. Personal histories are scrutinized. People who seek antiviral treatment may learn through their interactions with providers how to present themselves as successful recovered from past habits, and are therefore deserving, and to express gratitude, rather than entitlement for the offer of treatment (Rhodes et al., 2013). Thus, the patients we interviewed may have demonstrated their qualifications for candidacy and the success of a socialization process enacted in evaluations of candidacy.

The patients we interviewed appeared to express good faith efforts in depicting antiviral treatment as part of their larger personal rehabilitation. However, their talk could have been in part just that. Carr found that rehabilitation participants can be mindful of the acceptable program conventions in telling artfully scripted personal narratives, suggesting insincerity. Our respondents may have shown that they had learned how to account for themselves in ways they might think acceptable to VHA researchers. However, in settings such as the one studied by Carr, rhetorically correct personal rehabilitation stories are required in order to secure economic benefits: housing and financial assistance contingent on demonstrating sobriety in ways demanded by a rehabilitation program. Many of our study participants had prior experiences in VHA drug and alcohol rehabilitation programs. HCV treatment was the next step in rehabilitation projects, but these interviews were also opportunities to demonstrate what they had learned. Sincere or not, we may have documented the accepted rhetoric of HCV care in the VHA.

Antiviral treatment for HCV continues to evolve, but new and anticipated treatments will continue to present significant challenges. For patients to benefit from these treatments consistently, providers will need deeper understandings of patients' reasons for pursuing control of their diseases. We could offer two suggestions. First, clinicians who care for patients undergoing antiviral treatment could acknowledge their patients' motivations to complete the long difficult course, not in spite of their backgrounds but because of them. Their reasons for completing treatment indicate opportunities to be supportive in the local cultural context of HCV care. Clinicians could frame the clinical tasks of monitoring medication use, viral response, and toxicities with attention to their patients' resolute efforts (Clark and Mishler, 1992). Some patients we interviewed described how physicians and nurses spoke to their personal motivations, effectively encouraging their perseverance. Personal acknowledgement by clinicians may be critical to treatment completion (Beach et al., 2006). We may have identified some of the terms of effective acknowledgement, for those who are deemed acceptable, and accept offers of treatment.

Our findings may also help inform health services research to explain *low* rates of antiviral treatment uptake. We interviewed the select. The reasons we have described, if they are indeed outcomes of previous interactions, may shed light on the processes

through which patients are selected and prepared for treatment, and importantly, the processes through which people with HCV select themselves for treatment. Future research might explore more fully the thinking of veterans who choose not to pursue treatment in light of the rationales for completion we found. *Their calculus* of the costs of treatment may include not only the side effects and inconveniences, but the personal costs of submitting to candidacy and treatment. Some may not be ready for treatment for a variety of reasons that may include being unwilling to embrace the personal discredit that may be a significant part of establishing candidacy. We found little overlap between “cure” and “redemption” in these accounts. Some patients who simply want to eradicate the virus may find the challenges of demonstrating candidacy to be personal, if not moral disincentives.

Declaration of conflicting interests

The views expressed in this article are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the US Government.

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References

- Beach M, Keruly J and Moore R (2006) Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *Journal of General Internal Medicine* 21: 661–665.
- Beste L, Ioannou G, Larson M, et al. (2010) Predictors of early treatment discontinuation among patients with genotype 1 hepatitis C and implications for viral eradication. *Clinical Gastroenterology and Hepatology* 8: 972–978.
- Bonner J, Barritt A, Fried M, et al. (2012) Time to rethink antiviral treatment for hepatitis C in patients with coexisting mental health/substance abuse issues. *Digestive Diseases and Sciences* 57: 1469–1474.
- Butt A, Wagener M, Shakil A, et al. (2005) Reasons for non-treatment of hepatitis C in veterans in care. *Journal of Viral Hepatitis* 12: 81–85.
- Carr ES (2011) *Scripting Addiction: The Politics of Therapeutic Talk and American Sobriety*. Princeton, NJ: Princeton University Press.
- Clark J and Mishler E (1992) Attending to patients’ stories: Reframing the clinical task. *Sociology of Health & Illness* 14: 344–372.
- Coxhead L and Rhodes T (2006) Accounting for risk and responsibility associated with smoking among mothers with respiratory illness. *Sociology of Health & Illness* 28: 98–121.
- Department of Veterans Affairs (DVA) (2010) *The State of Care for Veterans with Chronic Hepatitis C*. Washington, DC: Center for Quality Management in Public Health, Public Health Strategic Health Care Group.
- Dominitz J, Boyko E, Koepsell T, et al.; VA Cooperative Study Group 488 (2005) Elevated prevalence of HCV infection in users of US veterans medical centers. *Hepatology* 41: 88–96.
- Duffin J (2005) *Lovers and Livers: Disease Concepts in History*. Toronto, ON, Canada: University of Toronto Press.

- Evon D, Simpson K, Kixmiller X, et al. (2011) A randomized controlled trial of an integrated care intervention to increase eligibility for chronic hepatitis C treatment. *American Journal of Gastroenterology* 106: 1777–1786.
- Fraenkel L, Chodkowski D, Lim J, et al. (2010) Patients' preferences for treatment of hepatitis C. *Medical Decision Making* 30: 45–57.
- Fraenkel L, McGraw S, Wongcharatrawee S, et al. (2005) What do patients consider when making decisions about treatment for hepatitis C? *American Journal of Medicine* 118: 1387–1391.
- Fraser S (2010a) Hepatitis C and the limits of medicalization and biological citizenship for people who inject drugs. *Addiction Research & Theory* 18: 544–556.
- Fraser S (2010b) More than one and less than many: Materializing hepatitis C and injecting drug use in self-help literature and beyond. *Health Sociology Review* 19: 230–244.
- Fusfeld L, Aggarwal J, Dougher C, et al. (2013) Assessment of motivating factors associated with the initiation and completion of treatment for chronic hepatitis C virus (HCV) infection. *BMC Infectious Diseases* 13: 234.
- Ghany M, Nelson D, Strader D, et al. (2011) An update on treatment of genotype 1 chronic hepatitis C virus infection: 2011 practice guidelines by the American Association for the Study of Liver Diseases. *Hepatology* 54: 1433–1444.
- Harris M, Rhodes T and Martin A (2013) Taming systems to create enabling environments for HCV treatment: Negotiating trust in the drug and alcohol setting. *Social Science & Medicine* 83: 19–26.
- Hopwood M and Treloar C (2005) The experience of interferon-based treatments for hepatitis C infection. *Qualitative Health Research* 15: 635–646.
- Ho S, Groessl E, Dollarhide A, et al. (2008) Management of chronic hepatitis C in veterans: The potential of integrated care models. *American Journal of Gastroenterology* 103: 1810–1823.
- Institute of Medicine (2010) *Hepatitis and Liver Cancer: A National Strategy for Prevention and Control of Hepatitis B and C*. Washington, DC: The National Academies Press.
- Jenner A and Scott A (2008) Circulating beliefs, resilient metaphors and faith in biomedicine: Hepatitis C patients and interferon combination therapy. *Sociology of Health & Illness* 30: 197–216.
- Knott A, Dieperink E, Willenbring M, et al. (2006) Integrated psychiatric/medical care in a chronic hepatitis C clinic: Effect on antiviral treatment evaluation and outcomes. *American Journal of Gastroenterology* 101: 2254–2262.
- Kramer J, Kanwal F, Richardson P, et al. (2012) Gaps in the achievement of effectiveness of HCV treatment in national VA practice. *Journal of Hepatology* 56: 320–325.
- Lee M, Yang H, Lu S, et al. (2012) Chronic hepatitis C virus infection increases mortality from hepatic and extrahepatic diseases: A community-based long-term prospective study. *Journal of Infectious Diseases* 206: 469–477.
- Lo Re V, Teal V, Localio R, et al. (2012) Relationship between adherence to hepatitis C virus therapy and virological outcomes: A cohort study. *Annals of Internal Medicine* 155: 353–360.
- McCoy L (2005) HIV-positive patients and the doctor-patient relationship: Perspectives from the margins. *Qualitative Health Research* 15: 791–806.
- McGowan C and Fried M (2012) Barriers to hepatitis C treatment. *Liver International* 32: 151–156.
- Malpass A, Shaw A, Sharp D, et al. (2009) “Medication career” or “moral career”? The two sides of managing antidepressants: A meta-ethnography of patients' experience of antidepressants. *Social Science & Medicine* 68: 154–168.
- Manos M, Ho C, Murphy R, et al. (2013) Physical, social, and psychological consequences of treatment for hepatitis C. *The Patient* 6: 23–34.

- Mishler E (1991) *Research Interviewing: Context and Narrative*. Cambridge, MA: Harvard University Press.
- Mykhalovskiy E (2008) Beyond decision making: Class, community organizations, and the healthwork of people living with HIV/AIDS. Contributions from institutional ethnographic research. *Medical Anthropology* 27: 136–163.
- Orsini M and Scala F (2006) “Every virus tells a story”: Toward a narrative-centered approach to health policy. *Policy and Society* 25: 109–130.
- Osilla K, Ryan G, Bhatti L, et al. (2009) Factors that influence an HIV coinfecting patient’s decision to start hepatitis C treatment. *AIDS Patient Care and STDs* 23: 993–999.
- Paterson B, Backmund M, Hirsch G, et al. (2007) The depiction of stigmatization in research about hepatitis C. *International Journal of Drug Policy* 18: 364–373.
- Polletta F, Ching P, Chen P, et al. (2011) The sociology of storytelling. *Annual Review of Sociology* 37: 109–130.
- Rhodes T, Harris M and Martin A (2013) Negotiating access to medical treatment and the making of patient citizenship: The case of hepatitis C treatment. *Sociology of Health & Illness* 35: 1023–1044.
- Riessman C (1993) *Narrative Analysis*. Newbury Park, CA: SAGE.
- Ryan R, Plant R and O’Malley S (1995) Initial motivations for alcohol treatment: Relations with patient characteristics, treatment involvement, and dropout. *Addictive Behaviors* 20: 279–297.
- Talal A, LaFleur J, Hoop R, et al. (2013) Absolute and relative contraindications to pegylated-interferon or ribavirin in the US general patient population with chronic hepatitis C: Results from a US database of over 45000 HCV infected, evaluated patients. *Alimentary Pharmacology & Therapeutics* 37: 473–481.
- Treloar C and Hopwood M (2009) The lived experience of hepatitis C and its treatment among injecting drug users: Qualitative synthesis. *Qualitative Health Research* 19: 1321–1334.
- Williams G (1993) Chronic illness and the pursuit of virtue in everyday life. In: Radley A (ed.) *World of Illness: Biographical and Cultural Perspectives on Health and Disease*. London: Routledge, pp. 92–108.
- Zacks S, Beavers K, Theodore D, et al. (2006) Social stigmatization and hepatitis C infection. *Journal of Clinical Gastroenterology* 40: 220–224.
- Zickmund S, Hillis S, Barnett M, et al. (2004) Hepatitis C virus-infected patients report communication problems with physicians. *Hepatology* 39: 999–1007.
- Zickmund S, Ho E, Masuda M, et al. (2003) “They treated me like a leper” stigmatization and the quality of life of patients with hepatitis C. *Journal of General Internal Medicine* 18: 835–844.

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